

Caring in Canada

Survey insights from caregivers and
care providers across Canada



Canadian Centre for
Caregiving Excellence



Canadian Centre for Caregiving Excellence

The Canadian Centre for Caregiving Excellence is a new initiative incubated and powered by the Azrieli Foundation. The Foundation has long supported innovative initiatives to improve access to quality care. Following a period of building networks and convening stakeholders, the Centre will become a stand-alone organization.



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Land Acknowledgement

The office of the Canadian Centre for Caregiving Excellence (CCCE) is located in Toronto, TKaronto, on the traditional territory of the Anishinaabe, including the Mississaugas of the Credit, Haudenosaunee and Huron-Wendat. This land has been governed by the Dish With One Spoon Wampum Belt for 1,000 years and, in recent times, by the Williams Treaty and Treaty 13.

All people living in Canada are treaty people; we are all part of a relationship based on respect, co-operation, partnership and recognition of Indigenous rights.

CCCE is committed to equity for Indigenous caregivers and care providers and to learning from and working with Indigenous communities.

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Executive summary



Executive summary

Canada is facing a caregiving crisis that will only get worse without real action. A perfect storm is brewing: demand for care is growing, caregivers are aging, the number of available caregivers is shrinking and care needs are becoming more complex due to our aging population and rising rates of disability and mental health conditions. There is an urgent need to make sure that caregivers and care providers have the resources and services to support their caregiving responsibilities.

Better data is needed to further understand the challenges that caregivers and care providers face and the supports they need. That's why we carried out the **National Caregiving Survey, completed by more than 3,000 caregivers and care providers**. This survey fills a significant evidence gap as it is the first time that many of these indicators have been measured in Canada.



Caregivers and care providers: What do these terms mean?

Caregivers

Caregivers are unpaid family members, friends or other support for someone who needs care due to physical, intellectual or developmental disabilities; medical conditions; mental illness; or needs related to aging. Caregivers provide care because of a relationship, not as a job or a career. (This definition does not include parents or guardians caring for a child without a disability, medical condition or illness.)

Care Providers

Care providers are people who are trained and paid to provide care to people who need it due to physical, intellectual or developmental disabilities; medical conditions; mental health conditions; or needs related to aging. This includes direct support professionals, personal support workers, attendants for people with disabilities, and respite workers.

Both caregivers and care providers play crucial roles in Canada's care economy, and both groups need more support. These roles are not mutually exclusive: many care providers are simultaneously unpaid caregivers.

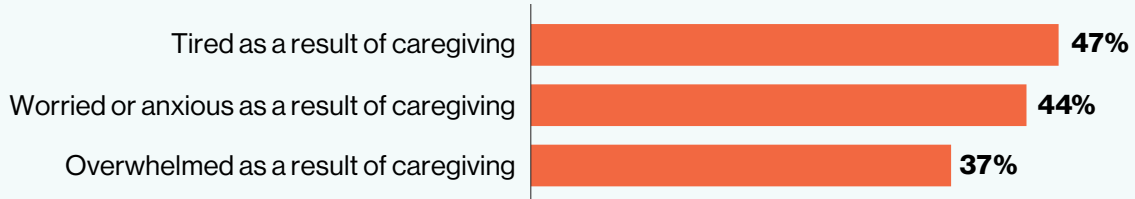
The survey shows that the average caregiver in Canada provides **5.1 hours** of care each day and has been providing care for **4.6 years**. Caregivers are typically **middle-aged** and caring for a **parent who is facing challenges due to aging**.

The data shows us six key stories about the experience of caregiving in Canada and sets the stage for important policy solutions.

1. Caregiving takes a toll on caregivers' well-being

One in four caregivers report fair or poor mental health. The more time spent caregiving, the more tired, overwhelmed and depressed caregivers become.

FIGURE 1 | Caregiving impacts on well-being



Policy implications:

Poor caregiver well-being requires more accessible mental health supports and stronger pathways to help caregivers find support, like within the health-care system.

2. Caregivers are working an extra shift

Nearly two-thirds of caregivers work in addition to caring for someone. It is not easy for them and requires long hours.

Caregivers working full time provide **4.5 hours of care per day, on average**. **In a given week, this could add up to over 30 hours of caregiving**, nearly the equivalent of another full time job.

Working caregivers need help. They are more interested in supports like monthly allowances, free counselling and respite services than their non-working peers. One of the preferred supports among working caregivers is supportive workplace policies, like days off for caregiving or flexible working arrangements.

Policy implications:

The demand on working caregivers stresses the need for caregiver-friendly workplace policies and employment protections, like caregiver-specific leaves and benefits.

3. Caregivers are getting older—and this comes with unique support needs

Nearly 1 in 5 caregivers are over 65 who are most commonly caring for a partner facing challenges related to aging.

Senior caregivers need more support but are receiving less of it. Caregivers aged 65 and older are the only age group that was significantly more likely to have not accessed any services or supports in the past year.

Among senior caregivers attempting to access information and services:

- 70% said it is difficult to hire care providers or paid care. Senior caregivers said improved access to home-care was the most important support.
- 59% said it is difficult to find information about support.
- 55% said it is difficult to get affordable local services.

Policy implications:

A clear priority for improving service access among senior caregivers is making home-care services more accessible. This points to a need for increased funding for home and community care and better integrated systems of care.

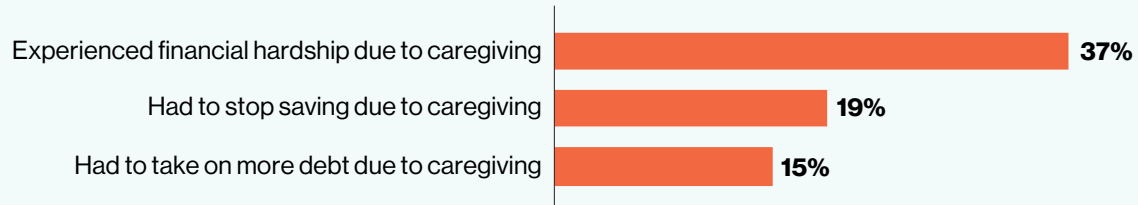
4. Caregiving creates financial stress

Caregivers experience financial hardship at the rate of:

- 56% for caregivers providing five or more hours of care per day
- 55% for caregivers with poor or fair mental health
- 48% for caregivers with household incomes under \$60,000
- 46% for racialized caregivers

Additionally, 22% of caregivers spend at least \$1,000 per month on out-of-pocket caregiving expenses.

FIGURE 2 | Financial stress related to caregiving



Despite the challenges that caregivers face, more than half said they were not familiar with tax credits related to care. At the same time, many said they feel that an income tax credit (87%) or a monthly care allowance (86%) would be helpful. Their access to supports is not good enough.

Policy implications:

Caregivers voiced that financial supports are the most important policy solution—across all supports domains—for meeting their needs. Action is needed to implement direct compensation for caregivers and improve awareness and broader eligibility for tax credits and benefits.

5. Paid care is not working well for care providers, caregivers, or care recipients

Care providers do not stay in the profession for long:

- About one-third of care providers had been working in the profession for less than a year.
- About half of care providers feel that they are not being paid fairly.
- Almost half said that their shifts are inadequately staffed.
- A quarter have experienced discrimination at work or have felt unsafe at work.
- Four in five care providers have considered changing careers.

The care provider system is broken. As a result, almost two-thirds of caregivers have found it difficult to access or hire quality care providers or services. Care providers are most interested in higher pay, flexible scheduling, reasonable working hours and paid sick leave.

Policy implications:

Care providers urgently need increased compensation, support and safety at work. Survey results also reveal a clear need for better working conditions, unionization, access to training and support.

6. Caregiving looks different across identities and communities

The caregiver experience varies across identities and communities. Differences can play out in the day-to-day experience of caregiving, heightened caregiver impacts, and distinct support needs. For example:

- **Racialized caregivers and young caregivers** (aged 18 to 24) are significantly more likely to be caring for a family member who is not a partner, parent, child or sibling when compared to non-racialized caregivers and other age groups.
- **75% of Indigenous caregivers** said it is important that caregiving and supports be delivered in a culturally sensitive manner.
- **LGBTQ2S+ caregivers** are significantly more likely than heterosexual caregivers to be caring for someone with a mental health condition, while sibling caregivers most commonly care for someone with an intellectual or developmental disability.
- **40% of LGBTQ2S+ caregivers** have fair or poor mental health, compared to 22% of heterosexual caregivers.

Policy implications:

Including the voices of diverse caregivers in policy and program discussions is critical to designing effective solutions. Despite a wide range of experiences and impacts, caregivers are united in the supports they are looking for: better financial and mental health supports, where there is even greater interest from caregivers facing heightened impacts of caregiving.

The conversation cannot end with data. Insights from this survey will help set the direction for the future of caregiving policy in Canada. CCCE is excited to take this new evidence, along with caregivers, care providers and stakeholder voices, and put it toward strategic action to strengthen Canada's caregiving landscape.

Introduction



Introduction

Half of Canadians will be a caregiver at some point in their lives.¹ In 2022 alone, 6.4 million Canadians provided unpaid care to dependent adults.² Caregivers and care providers promote the independence of and improve the quality of life of the people in their lives. Caregiving strengthens bonds between friends and families and enriches the lives of caregivers and care recipients.

Caregiving is demanding work that puts a strain on many aspects of life. Providing care can also be rewarding. It can build profound and meaningful connections. It can be an opportunity to make a difference in the lives of others. Care is also crucial to the Canadian economy: caregiving is estimated to contribute \$97.1 billion to Canada's GDP.³

Canada is facing a caregiving crisis: the need for caregiving is already significantly stretched and will only continue to grow.

Canada is facing a caregiving crisis: the need for caregiving is already high and will only continue to grow. As a society, we are getting older. The share of people older than 65 has risen steadily in the last 25 years, reaching almost 19% of the total population in 2022, and projected to reach 23% by 2043.⁴ As baby boomers get older, the ratio of people needing care relative to people who can be caregivers will increase, while older caregivers will have their own age-related challenges and perhaps need care themselves.⁵

At the same time, care needs are becoming increasingly complex. Almost half of Canadians report having a chronic health condition, with one in 12 having three or more co-existing conditions.⁶ Between 2017 and 2022, the prevalence of disability in Canada rose from 22% to 27%, with the largest increase seen in mental-health related disabilities, up 6% over the same period.⁷ People with complex care needs are living longer and fuller lives. This, coupled with the broader shift to more community-based care models (e.g., aging in place, supported independent living) means more care is happening at home.



This is a perfect storm: caregivers are getting older, the number of available caregivers is shrinking, the number of Canadians requiring care is rising and care needs are becoming more challenging. As we look ahead, each year could be a new high-water mark for the number of people who need care.⁸ This puts ever more pressure on caregivers and care providers.

As we look ahead, each year could be a new high-water mark for the number of people who need care.

Caregivers and care providers urgently need resources and supports that consider them and enable their success. The ability to care and be cared for is part of the bedrock of a healthy community and society. Every extra day that caregivers and care providers do not receive adequate support diminishes their physical, mental and economic well-being. It reduces their ability to provide care and leads to worse outcomes for care recipients, caregivers and communities. Without better support, caregivers, care providers and care recipients will face increasingly insurmountable hardship. This will have major consequences for the Canadian health-care system, social supports and services, the labour force and the economy as a whole.

Good data and evidence are essential first steps in understanding the supports that caregivers and care providers need. Unfortunately, reliable and up-to-date data and evidence on this subject are in short supply. For this reason, **CCCE carried out the National Caregiving Survey of more than 3,000 caregivers and care providers in the summer of 2023.** Our survey data fills a significant gap, providing insights into the time that caregivers and care providers spend providing care, their relationships to care recipients, their well-being, their working conditions and more. It also points toward **an urgent need for policy solutions** that can make life easier for caregivers, care providers and people receiving care.

Methodology



Methodology

Findings in this report are drawn from CCCE's first National Caregiving Survey, which was launched in July 2023. The survey is an important step forward in generating evidence on caregivers and care providers. **Many of the survey questions represent the first time that this data about caregiving is being captured in Canada.**

To develop the survey, CCCE worked closely with an advisory group of researchers with expertise in caregiving, as well as market research and analytics firm Leger. The survey collected information on caregiver and care provider demographics, care responsibilities, the impacts of caregiving on different dimensions of well-being and policy priorities. The full set of survey questions is available in the Appendix.

Between July and September 2023, the survey was administered in two ways: as a panel survey by Leger (conducted with caregivers within Leger's existing group of research participants) and as an open-link survey by CCCE (shared across caregiving networks and open to any caregiver) (Table 1). While the surveys included the same question set, they had key differences in how they were conducted. Both surveys were available in English and French.

TABLE 1 | About the panel and open-link surveys



Sharing our survey data

CCCE is making de-identified survey data from the panel and open-link surveys available for further research.

We are making this data available as a part of our commitment to shedding more light on the experiences of caregivers in Canada and to supporting more study and analysis.

Out of respect for participants' expectation of anonymity, we will not be releasing written responses in the publicly available data.

Please contact info@canadiancaregiving.org if you would like to access the dataset used to prepare this report.

	Panel survey	Open-link survey
Eligibility	Response of “yes” to at least one of the following: ⁹ <ul style="list-style-type: none"> ▪ During the past 12 months, have you helped or cared for someone with a medical condition, mental health condition or disability? ▪ During the past 12 months, have you helped or cared for someone who had challenges related to aging? 	
Purpose	To collect nationally representative data on caregivers and care providers in Canada.	To take a deeper dive into the caregiving experiences beyond the representative sample captured in the panel survey.
Sampling method	Leger online panel (a closed, representative group), including targeted outreach to caregiver panelists and an oversample of care providers and Indigenous caregivers.	CCCE online link circulation through newsletter, social media and partner outreach, which is non-representative because anyone can answer it.
Data collection period	July 20 to August 28, 2023	July 20 to September 16, 2023
Language	English and French	English and French
Participants	2,159 participants <ul style="list-style-type: none"> ▪ 1,977 caregivers ▪ 76 care providers ▪ 106 dual caregivers and care providers 	940 participants <ul style="list-style-type: none"> ▪ 771 caregivers ▪ 99 care providers ▪ 70 dual caregivers and care providers

The **panel survey** was shared online with Leger panel members. Leger estimates

that about 20% to 25% of its panel members are caregivers, which is in line with national rates.¹⁰ The panel survey was nationally representative of Canada's caregivers, meaning the distribution of demographic characteristics (e.g., age, gender, race) among the survey sample mirrored the distribution of these characteristics among caregivers in Canada. Leger included an oversample of Indigenous participants (i.e., more than the proportion of Indigenous people in Canada) to reflect CCCE's commitment to understanding the experiences and supporting the needs of Indigenous caregivers. (See the Appendix for more details.)

The **open-link survey** was circulated online by CCCE through our newsletter and

The panel survey was nationally representative of Canada's caregivers, meaning the distribution of demographic characteristics (e.g., age, gender, race) among the survey sample mirrored the distribution of these characteristics among caregivers in Canada.

social media. Many partner organizations also supported CCCE's survey efforts by distributing the survey to their networks.

Given the distinct purposes and sampling





methods, the panel survey and open-link survey each capture different populations of caregivers (Table 2). **The open-link survey had a greater proportion of women caregivers, older caregivers and caregivers who provide care for more hours a day and over more years.**

These are groups who may face greater impacts of caregiving—on their well-being, employment, finances, and more. This difference is important to consider when interpreting the open-link survey results because it tells us that the findings reflect a specific sub-group of caregivers rather than the general caregiver population. The full set of participant demographics is available in the Appendix.

Throughout this report, we use the panel data as the primary data source and the open-link data as a secondary perspective on the findings. Unless noted otherwise, data cited is from the panel survey. Additionally, use of the terms “caregiver” and “care provider” throughout the report are based on the definitions provided on [page 2](#). Unless noted otherwise, answers from people who are care providers only are not reflected in the data describing caregivers. Results reported as having “significant” differences refer to significance testing with a p-value of ≤ 0.05 .

TABLE 2 | Key differences in the panel and open-link samples

	Panel survey	Open-link survey
Gender		
Woman	57%	88%
Man	42%	11%
Non-binary	1%	1%
Age		
18-24	11%	1%
25-44	35%	18%
45-64	36%	47%
65-74	13%	23%
75+	5%	11%
Average time spent giving care		
Average hours of active care per day	5.1 hours	8.4 hours
Average length of time providing care for main care recipient	4.6 years	8.6 years
The main care recipient is my... (top responses)		
Parent	38%	30%
Partner or spouse	17%	23%
Other family	16%	4%
Child	11%	24%
Friend	7%	2%
Sibling	4%	6%
The primary health issue of my main care recipient is... (top responses)¹¹		
Challenges related to aging	27%	16%
Medical condition	14%	12%
Physical disability	13%	6%
Cognitive decline	12%	23%
Mental health condition	9%	9%
Intellectual or development disability	5%	21%
Main care recipient residing in same home	41%	55%

Snapshot of caregivers in Canada



Snapshot of caregivers in Canada

Data from the National Caregiving Survey tells us about who Canada's caregivers are and what their day-to-day caregiving experiences look like.

Caregivers are most commonly middle-aged women caring for aging parents

FIGURE 3 | Caregiver age

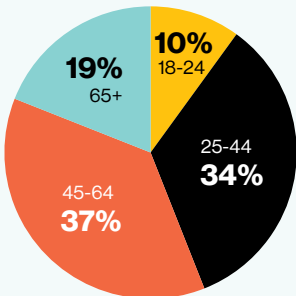


FIGURE 4 | Care recipient age

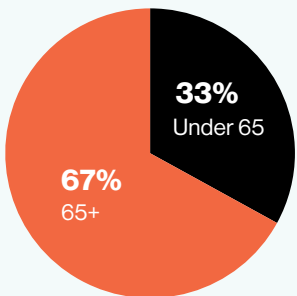


FIGURE 5 | My main care recipient is my...

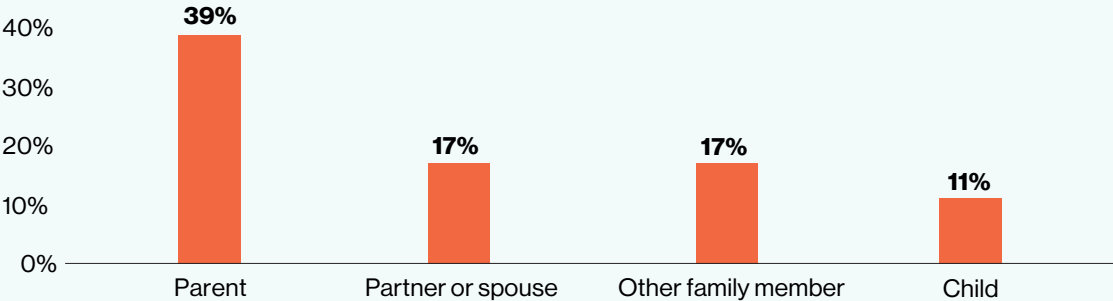
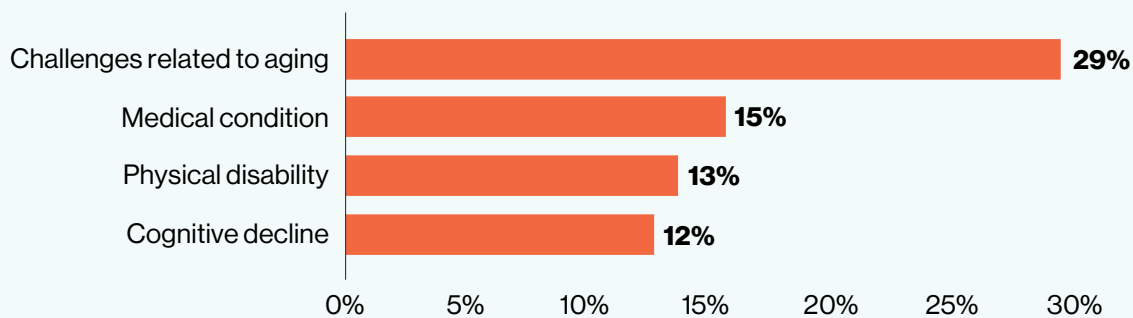


FIGURE 6 | Caregiver gender



- Caregivers reported the primary health issue they provide care for, but we know that many care recipients have multiple complex care needs.
- Combining physical, intellectual or developmental and sensory disabilities makes a disability the second most common care recipient condition (22%).

FIGURE 7 | The primary health issue of my main care recipient is...



Caregivers reflect a diverse set of identities and lived experiences

- **Racialized caregivers** and **young caregivers** (18 to 24) are significantly more likely to be caring for a family member who is not a partner, parent, child or sibling compared to non-racialized caregivers and other age groups.
- **LGBTQ2S+ caregivers** are significantly more likely than heterosexual caregivers to be caring for someone with a mental health condition.
- **Sibling caregivers** are most commonly caring for siblings with disabilities (34%), and 28% of the people they care for are under 18 years old.
- After English and French, the most common languages spoken at home by caregivers are **Chinese languages** (including Cantonese and Mandarin) and **Indian languages** (including Hindi and Gujarati).
- Caregivers live in every province and territory and can have **varied experiences based on their geography**, meaning they receive different supports and face different challenges.

Caregiver profile



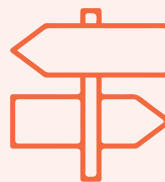
1 in 4
caregivers
are racialized



1 in 4
caregivers
speak French
at home



1 in 4
caregivers have
a household
income < \$40K



1 in 5
caregivers live
in a rural area



1 in 5
caregivers
are single



1 in 5
caregivers were
born outside
of Canada



1 in 10
caregivers are
LGBTQ2S+



1 in 10
caregivers are
18-24 years old

Caregiving is an ongoing responsibility throughout the day and over the years

4.6

average years caring for
main care recipient

5.1

average hours of active
care per day

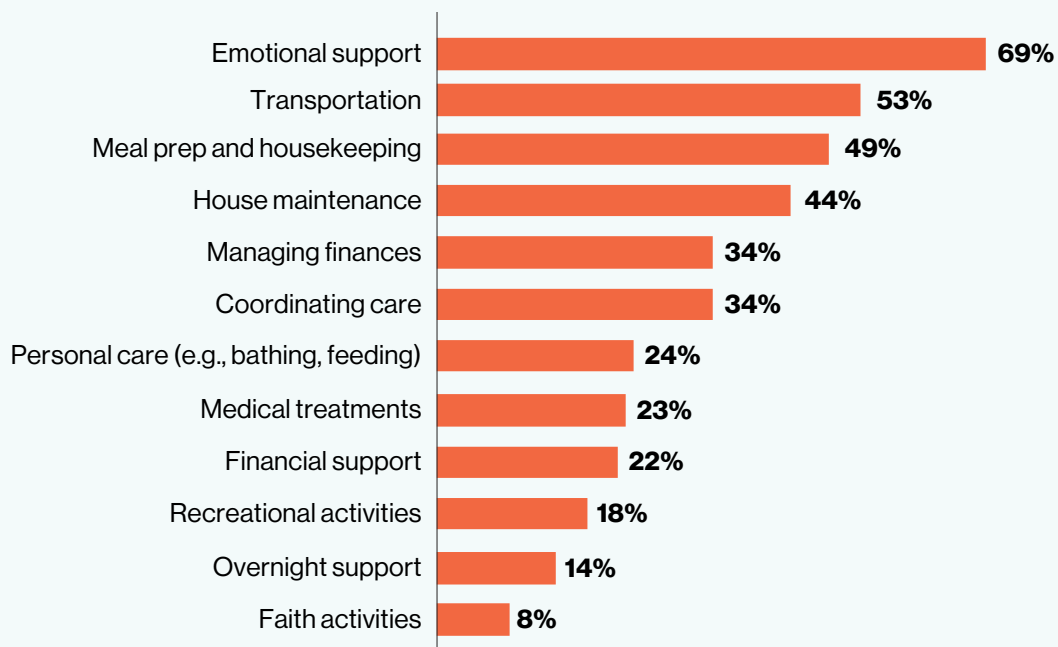
41%

caregivers who live with
main care recipient

Caregivers have a range of duties, providing both emotional and practical support

- The average caregiver helps with **four of 12 common caregiving tasks** (adapted from the Canadian Social Survey).
- Caregivers for **people with intellectual or developmental disabilities** have higher rates of providing personal care (45%) and financial support (43%).
- **Women** are significantly more likely than men to provide **emotional support, meal prep and housekeeping** and care coordination.

FIGURE 8 | Caregiving duties

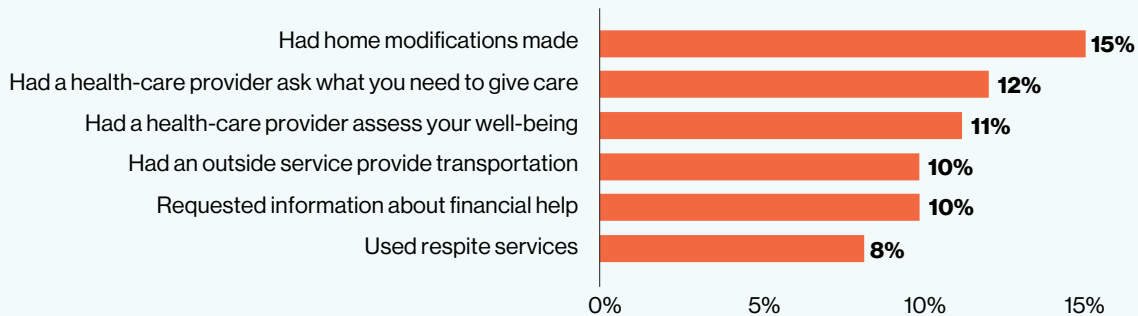


Caregivers are not accessing support and services and find it difficult to do so

In the past year:

- 25% of caregivers sought out information about caregiver support, services or benefits.
- 24% received support or services for their main care recipient.
- 21% attempted to access caregiver support, services or benefits.
- 11% received financial benefits for caregivers.

FIGURE 9 | In the past 12 months, I have...



- **Sibling caregivers** had lower rates of seeking information (21%) and attempting to access support (18%).
- 59% of caregivers spend time each week **researching supports and navigating systems**.
 - Racialized caregivers spending 3+ hours: 20%
 - Non-racialized caregivers spending 3+ hours: 10%
- 50% of caregivers find it difficult to get **information and advice about caregiver support**.
 - Women finding it difficult: 58%
 - Men finding it difficult: 40%
- **Caregivers in rural areas** are significantly more likely to have never used any of these services.

When caregivers do access information, they typically get it from:



41%

family
doctors



38%

online



28%

social
workers



22%

hospital



21%

family



19%

caregiving
organizations

Open-link survey participants report more caregiving responsibilities

Caregivers who completed the open-link survey are more likely to be connected to organizations working in this field. Their experiences tell the story of those facing an even greater impact of caregiving than the panel data presents.

8.4

average hours of active
care per day

10.5

average years caring for
main care recipient

58%

share of care recipients
aged 65 or older

The average caregiver helps with 7 of 12 common caregiving tasks (adapted from the Canadian Social Survey):

- 90% of caregivers provide emotional support.
- 48% of caregivers provide personal care.
- More than 70% of caregivers help with transportation, care coordination, meal prep and housekeeping and managing finances.

Data shows caregivers need more support



Data shows caregivers need more support

The survey data highlight six key stories about the realities of caregiving in Canada:

- **Caregiving takes a toll on caregivers**
Caregiving can be a rewarding experience, but it impacts many dimensions of caregiver well-being. As caregivers provide more hours of care in a day, or provide care over many years, they report greater impacts on their well-being.
- **The extra shift for working caregivers**
The largest group of caregivers are of working age and most caregivers are working. It is no surprise that working caregivers are calling for supportive workplace policies and more support services.
- **Today's caregivers, tomorrow's care recipients**
Caregivers are aging and many may soon be care recipients themselves. Senior caregivers have the lowest uptake of supports and services among all age groups, signalling an upcoming wave of need for a population that is disconnected from systems of care.
- **The costs of caregiving**
Caregiving takes a significant toll on financial security. Caregivers are facing several financial stressors—with long term financial consequences—and see targeted financial supports as the way to help.
- **Improving paid care for care providers *and* caregivers**
The paid care landscape is not working well for care providers, caregivers or care recipients. Paid care services are often inaccessible and unaffordable, while care provider wages are too low, working conditions are too stressful and many care providers have considered leaving the care workforce.
- **Diverse experiences, shared needs: the diversity of Canada's caregivers**
The caregiver experience varies across identities and communities, in both the day-to-day experience of caregiving and heightened impacts of providing care. Despite differences, caregivers are united in the supports that they seek.



Caregiving takes a toll on caregivers

While caregiving is valuable and rewarding, it is difficult work that requires a broad range of skills. To make things easier, caregivers need effective supports. Varying levels of care intensity reveal an alarming pattern: caregivers who provide more hours of care each day or who have been providing care for longer are struggling the most. As caregiving demands rise over time, more and more caregivers will find themselves in this situation.

Many caregivers associate their care responsibilities with positive feelings, like making a difference (47%), a sense of importance (32%) and appreciation (30%).

But caregiving also has negative impacts on well-being. For instance, caregivers report feeling tired (47%), worried or anxious (44%) or overwhelmed (37%) as a result of caregiving, while **one in four caregivers report fair or poor mental health**.

"We are beyond burnt out but we have no choice but to keep going 24/7."

– Panel survey participant

"Honestly, I'm so exhausted that I don't even have the brain capacity to figure out what would be helpful."

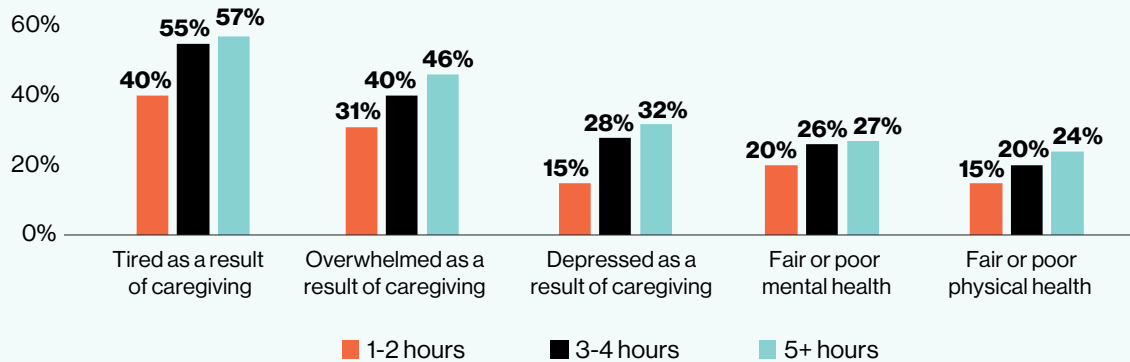
– Open-link survey participant

"[Caregiving has] caused deterioration of my already poor physical health [and c]aused mental health needs I might not have otherwise had."

– Open-link survey participant

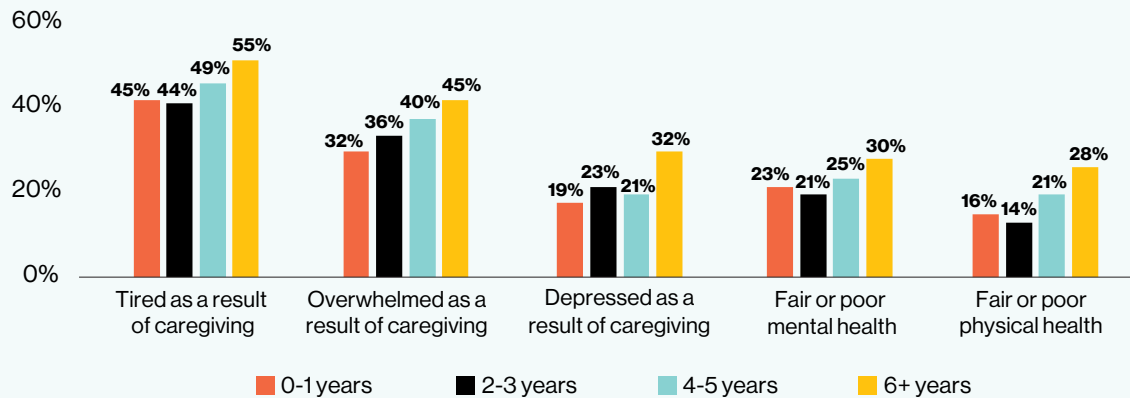
These effects on caregivers' well-being become even more concerning when we factor in the number of hours or years that a caregiver has spent providing care. **The more hours of care they have provided, the more likely caregivers were to report fair or poor physical and mental health** and being fatigued, overwhelmed or depressed as a result of caregiving (Figure 10).

FIGURE 10 | Impacts of caregiving on well-being by typical active hours of care per day



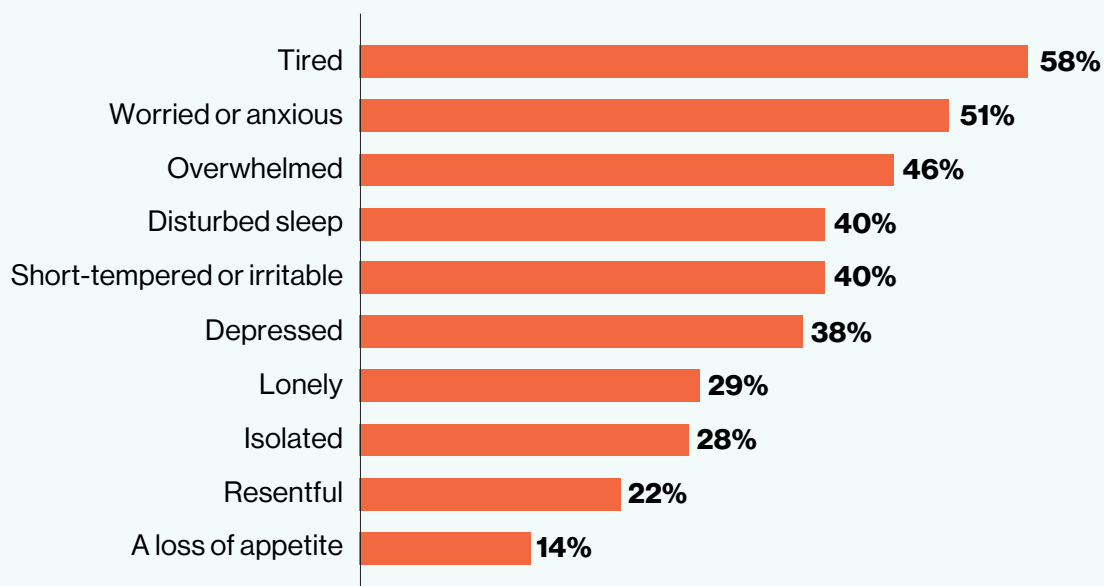
A similar pattern emerged based on how long a caregiver has been caring for their main care recipient. Caregiver well-being—in terms of feeling tired, overwhelmed and depressed—is most impacted for those who have been providing care for six or more years (Figure 11).

FIGURE 11 | Impacts of caregiving on well-being by years of providing care



The effect of caregiving intensity is most stark when we look at the well-being of caregivers who have been providing a lot of care for a long time. Among caregivers who provide five or more hours of active care per day *and* have been providing care for six or more years, **a majority said that caregiving has led them to feel tired or worried or anxious**, and almost half said the same about feeling overwhelmed (Figure 12).

FIGURE 12 | In the past year, my caregiving responsibilities have caused me to feel...



Another group of caregivers who reported struggling with mental health was **LGBTQ2S+ caregivers**. Forty percent rated their mental health as fair or poor, significantly higher than heterosexual caregivers at 22%. Similarly, compared to their heterosexual counterparts, LGBTQ2S+ caregivers had significantly higher rates of being overwhelmed (45% vs. 36%), depressed (29% vs. 22%), lonely (22% vs. 15%) and isolated (22% vs. 14%) as a result of caregiving. LGBTQ2S+ caregivers may report worse mental health as a result of simultaneously navigating discrimination alongside their caregiving responsibilities.

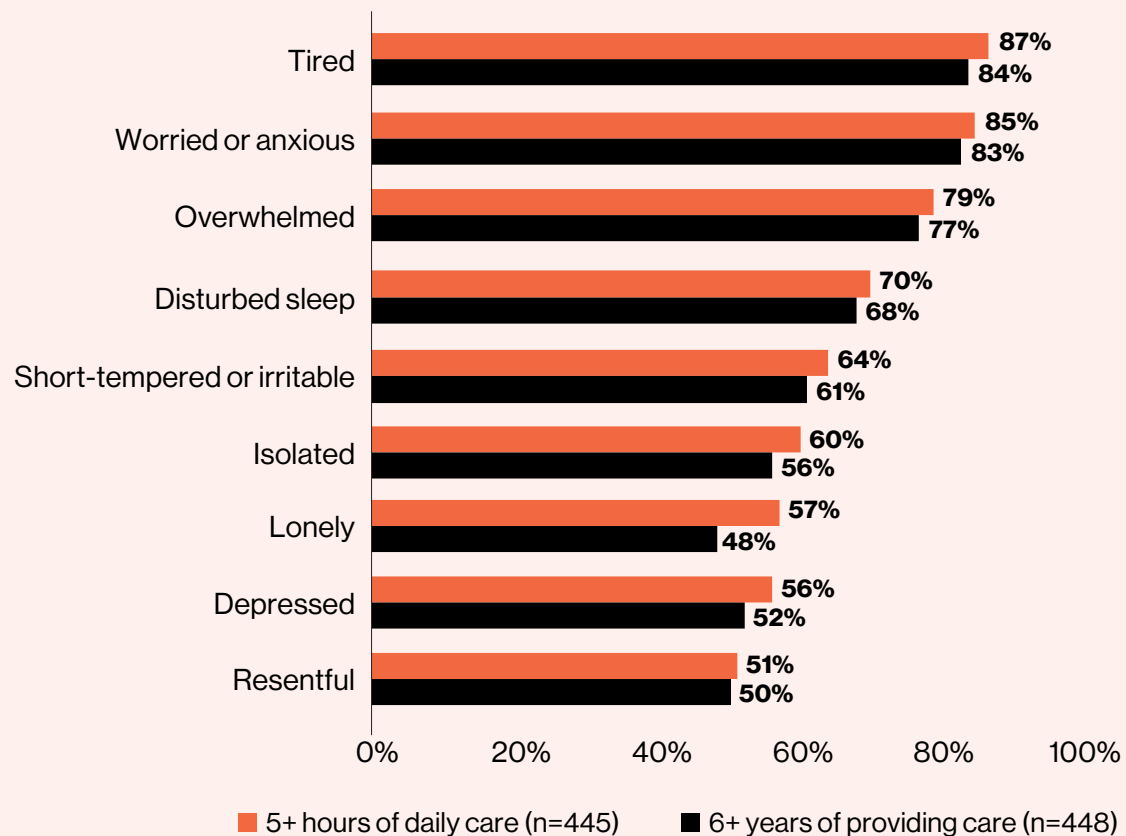
Women also face greater well-being challenges as a result of caregiving: 28% of women reported fair or poor mental health, significantly higher than the 20% of men who reported the same. Compared to men, women were significantly more likely to report feeling tired (51% vs. 41%), worried (50% vs. 34%) or overwhelmed (42% vs. 29%). This may be because of the types of caregiving roles that women perform more often than men (such as meal preparation, emotional support and care coordination). In particular, the labour associated with providing emotional support can be mentally taxing. Women caregivers may find their contributions accorded less value and respect than their male counterparts, because of harmful stereotypes and gendered expectations about caregiving being “women’s work”. LGBTQ2S+ caregivers may report worse mental health as a result of simultaneously navigating discrimination alongside their caregiving responsibilities.



Caregivers in the open-link sample report worse well-being

The majority of caregivers in the open-link survey have felt tired (80%), worried or anxious (79%), overwhelmed (73%), sleep disturbed (61%) or short-tempered or irritable (60%) as a result of caregiving. Similarly, 40% reported fair or poor mental health and 33% said they have fair or poor physical health. These numbers are alarming even before diving into caregiving intensity.

FIGURE 13 | In the past year, my caregiving responsibilities have caused me to feel...



Note: These are not mutually exclusive groups.

The picture gets worse when considering hours and years of care. Caregivers providing five or more hours of active care per day report higher rates of fair or poor mental and physical health (49% and 41% respectively). This pattern is paralleled among caregivers who have been providing care for six years or more (46% with poor or fair mental health and 40% with poor or fair physical health).

We also see very high rates of caregiving impacts on other well-being indicators for both these groups, with each impact experienced by at least half (and in some cases as high as 87%) of caregivers (Figure 13).

Outcomes are worse for caregivers with the greatest intensity in both hours and years of care. Half of these caregivers are in fair or poor mental health, 44% are in fair or poor physical health and more than 80% reported fatigue, worry or being overwhelmed as a result of caregiving.

What caregivers need

Four of five caregivers said free counselling and mental health supports are important to address the toll on their well-being. In particular, women and caregivers aged 25 to 44 were significantly more likely to find this helpful (compared to men and all other age groups), while Indigenous caregivers said culturally appropriate counselling or therapy services would be one of the most beneficial supports for them. A large majority of caregivers (77%) also said it would be important to have a health-care practitioner assess and track their well-being, with women significantly more likely than men to rate this as important (79% vs. 73%).

On the policy agenda

Developing policy solutions for caregiving is not only about supporting care recipients; it's also about supporting caregiver health and well-being. Caregivers are looking for **improved access to mental health supports** and see the **health-care system as an entry point** for assessing and addressing their well-being needs.



Voices of Care



**Jennifer
Johannesen**

In the mid-'90s, Jennifer Johannesen embarked on a career in an emerging industry that she loved: website development. When Jennifer and her partner decided to start a family, her plan was to take a maximum of four months of maternity leave before returning to work.

But seven months into her pregnancy, Jennifer's midwife grew concerned about the sudden buildup of fluid in her abdomen and urged her to seek care. "I walked out of the office to have an ultrasound, and I never went back," she says.

Her son, Owen, required surgery in utero and was born prematurely with unique needs that would require 24/7 care. Along with having cerebral palsy, Owen was Deaf, non-ambulatory, G-tube fed and required support for all aspects of daily living.

Suddenly, Jennifer's path had diverted from a fulfilling career to "extreme caregiving."

Determined to continue with their family plans, Jennifer and her partner had another son two years later. While her partner's career remained uninterrupted, Jennifer's new caregiving role constrained her opportunities. "I didn't see how I could continue to work, or how my partner and I could switch roles because I was so invested in caring for my sons and providing extra support to Owen. I felt I didn't have options. I started to feel like a wilted flower," she says. Their relationship eventually ended. While the boys' father remained actively involved, Jennifer carried the responsibility for managing Owen's care.

"It took a lot of finagling," she says, referring to the necessity of toggling between several government ministries to get services for Owen, and then having to justify each new request in writing—and often on little sleep. "Whether or not I was given support always came down to Owen's medical diagnosis, and never my own needs as his caregiver," she says.

To maintain her skills and work toward financial independence, Jennifer began building websites for freelance writers in between home care visits. She completed 50 sites in two years and found it fulfilling on a creative level. Now, almost 20 years later, Jennifer is a successful self-employed web developer and communications strategist. She is also using her lived experience to raise awareness about what needs to change for caregivers on a national level.

Caring for Owen—who passed away 14 years ago at the age of 12—was both joyful and challenging, and allowed Jennifer to learn and grow as a person.

Even though Jennifer feels fortunate to have landed on her feet, it is a far cry from where she expected to be at this point in her life. While providing "extreme care" for Owen was necessary and important, she is aware of the opportunity cost.

"I never saw Owen as a tragedy," she says. "It was an immense privilege and rare experience to care for my son for his entire life. I am also grateful that I have been able to pick up my own life again. Every caregiver should have options that allow them to flourish."



The extra shift for working caregivers

Many of Canada's caregivers are balancing care responsibilities with paid work. This amounts to taking on an "extra shift" after the workday, leaving working caregivers with little time outside of their caregiving and employment duties. There are both time and financial pressures to being a working caregiver. Caregiving responsibilities can interfere with work responsibilities, but maintaining full time employment is often needed to meet the costs of caregiving.

Sixty-two percent of caregivers reported working, whether full time, part time or in a self-employment or freelance capacity. Working full time was the most common employment status among caregivers, with 46% having full time jobs.

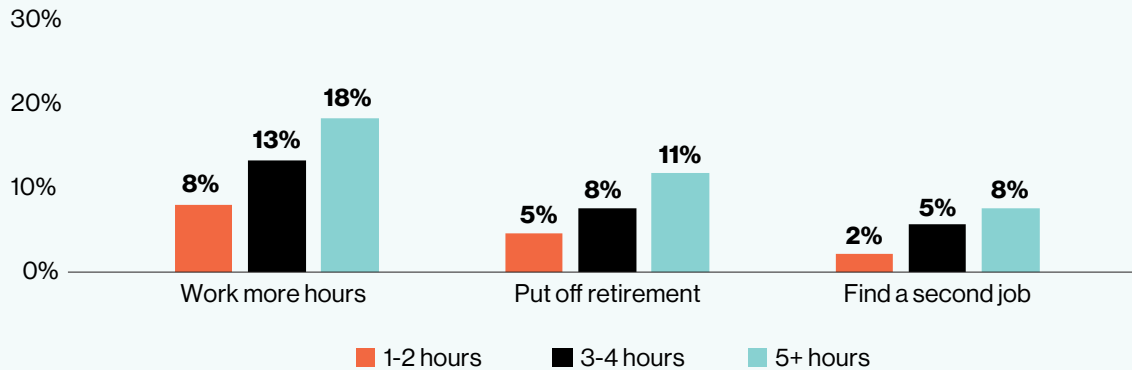
The highest rates of employment are among caregivers **aged 25 to 44, where more than two-thirds of caregivers (68%) are working full time.** Working full time does not seem to result in providing much less care: full time workers still average 4.5 hours of active care per day, not far off from the survey average of 5.1 hours. **In a given week, this could add up to over 30 hours of caregiving—almost the equivalent of a second full time job.**

Balancing work and care has direct impacts on caregivers' employment. Among working caregivers, 16% have had to work more hours, 10% have had to put off retirement and 6% have had to find a second job because of their caregiving responsibilities. This tells us **some caregivers likely need to work more to cover the costs associated with caring** for someone.

"I have considered finding a better paying job, but I'm so burnt out I don't have the hustle needed to secure that. I have considered taking on freelance, but have little extra time or focus."

– Open-link survey participant

FIGURE 14 | Impacts of caregiving on employment among working caregivers



These figures change for the worse when we look at employment impacts by caregiving hours (Figure 14). Paradoxically, those who spend more time caregiving are more likely to take on a second job or increase hours at an existing one. This means **caregivers with more care responsibilities also have growing employment responsibilities seemingly as a result of caregiving**—a distressing cycle in which providing more care corresponds to needing to meet higher caregiving costs.



Working caregivers in the open-link sample are facing more employment impacts of caregiving

The open-link survey captured fewer working caregivers than the panel survey, with 49% of caregivers aged 25 to 44 working full time. However, this group of working caregivers more commonly experienced employment impacts of caregiving. Among working caregivers, 25% put off retirement, 20% worked more hours and 9% had to take on a second job due to their caregiving responsibilities. Almost half of these caregivers (47%) reported that it would be helpful to have better support from their workplace, and nearly all saw financial benefit in caregiving days off work (94%) and paid leave for caregiving (91%).

What caregivers need

The survey asked participants what supports and public policy changes would help them most. The results make it clear that **caregivers are looking for supportive workplace policies** that help them fulfill their care duties. Almost one in three working caregivers told us that support from their workplace, like days off or flexible working arrangements, would be helpful. Most working caregivers also said that **days off work** (86%) and **paid leaves of absence** (84%) specifically for caregiving would be **financially helpful**.

"[I] lost my job partly because of caregiving; [it] would be nice if caregiving would be included in labour laws."

– Open-link survey participant

Working caregivers also need supports outside the workplace. The **most important support** for working caregivers was improved access to **home-care** services, and about **four of five working caregivers said it would be important to have:**

- Monthly allowances to help with costs associated with caregiving (see [page 46](#))
- Free counselling and mental health supports
- Respite services available to relieve caregiving duties
- Formal training on care responsibilities
- Mandatory caregiver assessments by health-care providers

"Working full time and providing care full time seems impossible. In other countries, there are programs that pay the family caregiver. I wish that was an option [here]."

– Open-link survey participant

On the policy agenda

Caregivers need caregiver-friendly workplace policies to effectively balance paid work and care work. Support priorities expressed by caregivers include **expanding leaves and benefits for caregiving**. These priorities emphasize the need for a multi-faceted approach to supporting working caregivers, where policies and programs promote both flexibility at work to attend to care commitments and service accessibility to attend to work commitments.



Voices of Care



Susan
Palijan

Susan Palijan is hesitant to evaluate the cost of caregiving because, she asks, how do you quantify love for a parent? Still, having provided end-of-life care to her late mother, and now currently caring for her father, Susan says the financial costs and impact on her career have been considerable.

Susan was raised by immigrant parents who encouraged her and her older sister to be ambitious. She had always been curious about human behaviour and decided she would pursue an academic path in psychology.

Just as she was entering a PhD program in psychology, Susan's mother fell ill and had care needs that led Susan to pause her education in order to care for her. "The implicit rule growing up was that you help your family. I was the younger one, so I took on that role," she says.

Her mother eventually succumbed to colon cancer in 2013, mere weeks after Susan had secured a senior advisory role in the provincial government. "I had just made her proud, and then she was gone. I lost my drive to succeed for a few years after that," she says.

After his wife's death, Susan's father struggled with chronic major depression, and was later diagnosed with dementia. He endured multiple hospitalizations. Looking for help, Susan and her sister discovered the system was not set up for his or their needs; they had to pay out of pocket for private caregivers and a temporary stay in a retirement home. "Both my sister and I are working full time but not getting far. We have no reprieve, no respite or time off to care for him or to care for us," she says.

All of her vacation time and personal days are used for medical appointments. There are very few free or affordable counselling supports available to her, and she can't take family caregiver leave because it is unpaid.

Susan wants to see real change: recognition and support of caregivers in the workplace, and financial supports so caregivers don't have to choose. She says her family would benefit from funding for the many unpaid services that caregivers provide such as personal support work, medication management, appointment management and care coordination.

Now, Susan has returned to school part time, working to complete a PhD in health systems research with a focus on caregiving.

"There has to be a reason that I have gone through all of these caregiving experiences. I have a strong need to advocate for people," she says.



Today's caregivers, tomorrow's care recipients

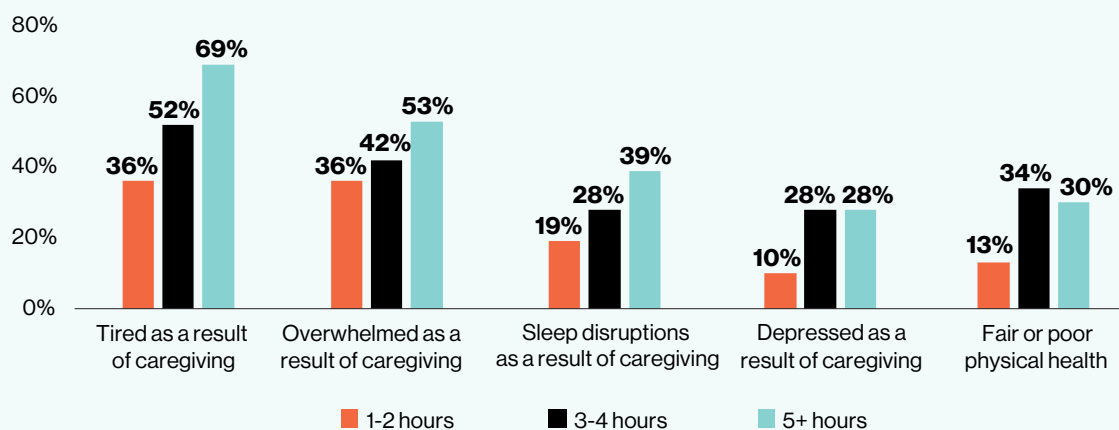
Canada's aging population will lead to more people needing care in the years ahead. But this misses the other side of the equation: the people currently providing care are aging as well. About one in five caregivers is 65 or older. Many of Canada's caregivers are just one diagnosis or accident away from a sudden crisis. Senior caregivers report effects on their well-being due to caregiving; at the same time, they are the age group least connected to the supports that can help them face new and changing care needs.

There are many senior caregivers: about **one-fifth of caregivers (18%) are over 65**, with 13% being 65 to 74 and 5% being 75 or older. These caregivers are most commonly caring for partners or spouses (40%) due to challenges related to aging (28%). The next most common care scenarios are those caring for a parent (21%) or a friend (10%) with either a medical condition (16%) or physical disability (16%). Almost half of these caregivers (47%) are living with their main care recipient; 83% of their care recipients are 65 or older themselves.

Senior caregivers are experiencing the impact of caregiving on their well-being. Nearly half (46%) said that they were tired as a result of caregiving, while 25% reported sleep disruptions and 18% reported depression. As senior caregivers provide more hours of daily care, they are more likely to have poorer physical health and experience more fatigue, worry, sleep disruptions and depression due to caregiving (Figure 15). Despite these challenges, **senior caregivers are not accessing supports**.

Caregivers 65 and older were the only age group that was significantly more likely to have not accessed any services or supports—such as home modifications, respite services or transportation services—in the past year. During that same time period, only a quarter of senior caregivers sought out information about caregiver supports, and even fewer (21%) attempted to access them. Similarly, only a quarter of senior caregivers have received support for their care recipient.

FIGURE 15 | Impacts of caregiving on well-being for senior caregivers (65+) by active hours of care per day



This aligns with the service access challenges expressed by senior caregivers:

- 59% said it was difficult to find information about caregiver support.
- 55% who attempted to access affordable local services found it difficult to do so.
- 70% who attempted to hire quality care providers or paid care services found it difficult to do so.

“People mention resources, but an organization that would sit down with you and go over items helping to access would be more beneficial as we elderly are not always technical[ly] [in]clined”

– Open-link survey participant



Senior caregivers in the open-link sample are not doing well and report greater use of supports

Participants in the open-link survey are generally older, with 34% aged 65 and older. Findings from these caregivers tell a different but complementary story.

In the open-link survey, the largest group of senior caregivers are caring for a partner or spouse (47%), the average age of their care recipient is 73 years old and the most common condition they are caring for is cognitive decline (31%). Fifty-eight percent of these caregivers live with their main care recipient.

Senior caregivers reported lower well-being in the open-link data: fair or poor physical health and mental health were each reported by a third of the sample. Other impacts of caregiving are very common, with 77% experiencing fatigue, 75% reporting being worried or anxious, 56% having sleep disturbances and 45% reporting being depressed as a result of caregiving.

Senior caregivers in the open-link survey reported accessing supports more often. Sixty-five percent have sought out information about caregiver supports and 62% have attempted to access them. Over half (58%) have received supports or services for their main care recipient. This may reflect the fact that the open-link sample is likely to be participants who are already connected to the caregiver community.

Senior caregivers' top sources for seeking information are family doctors, online, social workers and care organizations. This information complements the panel data to help identify opportunities and pathways for better connecting senior caregivers to support systems and resources.

What caregivers need

Senior caregivers reported that the **most helpful supports** would be accessible and generous **tax credits**, improved access to **home-care** services and a **monthly allowance** to help with caregiving costs. In particular, **improved access to home-care was rated the most important support for senior caregivers (87%)**. Almost all senior caregivers (88%) said that an income tax credit for care would help them make ends meet.

“There is need for increased staffing and positions, like outreach services. [...] I am also a social worker so know systems fairly well. I know this is a huge barrier for other folks, especially older caregivers.”

– Open-link survey participant

“I will soon need extra help as we get older.”

– Panel survey participant

“In [the] future, I would like to have info about how to get help with aging in place for myself.”

– Open-link survey participant

On the policy agenda

This portrait of senior caregivers illustrates a serious disconnect. Senior caregivers are facing the difficulties of caregiving and are quickly approaching a time when they may need care themselves, but they are not accessing supports and services for themselves or their care recipients. **A clear priority for improving service access among senior caregivers is making home-care services more accessible.** This points to a need for increased funding for home and community care and better integrated systems of care.



Voices of Care



Margaret
Bayer

Margaret and Andy were in their mid-60s when they met online. Their first date was a two-hour lunch, which was followed by a second date of dinner and dancing to the music of the Beatles. Over the next five years, they would get married and travel across Europe, where Andy was respected for his academic research.

Then Andy began to experience falls and decreased mobility. He was diagnosed with early Alzheimer's disease and other health challenges that eventually required full time care.

For the next several years, Margaret and Andy adjusted their lives to allow for Andy to remain at home. But his health continued to decline—and with it, his independence.

After an eight-week hospital stay in August 2023 after Andy broke his arm, he was assessed as needing a long term care placement.

Throughout the years of caring for Andy, Margaret's own health has frayed. She suffers from arthritis in her spine and experiences back spasms. She also has an autoimmune condition that is exacerbated by stress. Caring for her partner while managing her own needs as she ages has been very challenging; the supports she needs are not always there. Her lowering energy levels impede her visits to see Andy or transport him. "We have an agreement—if he falls, I call for help. I do not try to get him up," she says.

Margaret would like to see a health-care system in which caregivers feel seen and valued instead of feeling, as she says, "invisible unless [they make themselves] visible." She notes that "in the past five years, not one doctor or nurse has asked me how [how she is] doing, and it has contributed to [her] feeling isolated."

Margaret has joined a support group for caregivers which has proven vital to her. Together they discuss their own mental, physical and spiritual needs. She sees an opportunity within the caregiver organization to offer meditation and exercise classes, and counselling to help caregivers deal with the loss of the life they imagined living with their partners, in Margaret's case, travel, music and theatre.

Still, Andy is at the centre of her world. "Love carries you through. It is the thread that binds, and it is an important piece to keep alive," she says. "I am lucky that Andy can still express gratitude for what I do. That makes it all worthwhile."



The costs of caregiving

Caregiving touches all aspects of caregivers' lives, in both rewarding and challenging ways. One of the places in which caregivers face the most challenges is their finances. Caregiving comes with a direct financial cost, which can be exacerbated by there being few and insufficient financial supports. Even in cases of clear financial need, the financial supports that are available still come with barriers to access and eligibility.

One in five caregivers (22%) provide financial support to their main care recipient. In reporting how much they spend, **22% of caregivers spend at least \$1,000 per month on out-of-pocket caregiving expenses**, including 10% whose out-of-pocket caregiving costs are at least \$3,000 per month. This is separate from additional money care recipients contribute, although this becomes blurrier in cases of caregiving between spouses.

Spending at least \$1,000 per month on out-of-pocket expenses was significantly more likely among racialized caregivers (35% vs. 18% of non-racialized caregivers), working caregivers (28% vs. 15% of non-working caregivers), caregivers born outside of Canada (24% vs. 20% of caregivers born in Canada), and caregivers in urban areas (25% vs. 17% in rural areas).

Unsurprisingly, many caregivers are facing serious financial strain. About 65% of caregivers indicated some form of financial strain in the survey. **More than a third of caregivers (37%) have experienced “a little” or “a lot” of financial hardship in the past year due to caregiving.** There are clear patterns between financial hardship and caregiver socio-demographics.

Experiences of financial hardship happen across all income levels but were most common among caregivers with lower household incomes. Almost half of caregivers with **a household income below \$60,000** have experienced financial hardship due to caregiving responsibilities, compared to 36% of those with a household income of \$60,000 to \$100,000 and 30% of those with a household income of \$100,000.

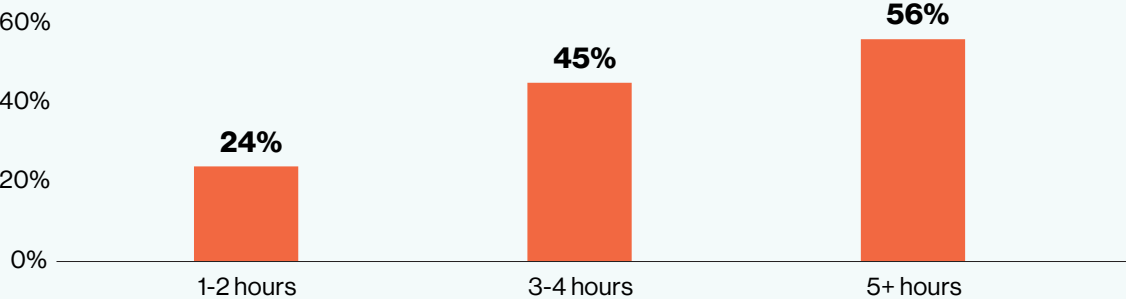
Almost half of **racialized caregivers** (46%) have experienced financial hardship due to caregiving, compared to 34% of non-racialized caregivers.

Nineteen percent of **caregivers for people with intellectual or developmental disabilities** have experienced **a lot of financial hardship** due to caregiving, compared to 10% among the full sample. Almost half (43%) of these caregivers provide direct financial support to their care recipient, compared to 21% of all caregivers.

Financial hardship was connected to mental health. More than half of **caregivers with poor or fair mental health** (55%) have experienced financial difficulties due to caregiving in the past year, compared to 28% among caregivers with very good or excellent mental health.

Financial hardship due to caregiving was also more common among caregivers providing more hours of care each day (Figure 16).

FIGURE 16 | Caregivers who have experienced “a little” or “a lot of” financial hardship by hours of active care per day



“[I] had to get 24/7 private care due to a sudden health change in [my] mother. [It] cost me over \$1,000/day, [which is] not sustainable as [it] cost over \$15,000 for two weeks [of] help. [...] [I] had to borrow money to pay for unexpected care needs.”

– Open-link survey participant

“Simply having caregivers be able to access financial supports would be helpful. [...] There is no help or compensation if you do it yourself, but [there are] often many financial difficulties because of it.”

– Panel survey participant

Half of caregivers have experienced financial stress in some form over the past year because of caregiving. Some caregivers have had to stop saving (19%), while others have turned to using their personal short-term savings (17%) or taking on more debt (15%) because of their caregiving roles. About one in ten caregivers had to leave bills unpaid or paid late, use their own long term savings or borrow money from family or friends to meet financial needs because of caregiving. These are all immediate financial impacts that can have **long term financial consequences** for caregivers.

Women and caregivers with a household income of less than \$60,000 were also significantly more likely to have experienced more financial stressors when compared to men and higher household incomes.

“For 23 years of my best working years, I could not work due to caregiving 24/7 at home. Lost wages and no tax reflection of my contribution makes me angry still.”

– Open-link survey participant

“I had to leave the workforce and put my career on hold. My obligation was to look after my mother and I had to quit my job.”

– Open-link survey participant

Young caregivers, who may have less financial stability and face more difficulty with the rising cost of living, are experiencing financial strain. About **one in four young caregivers (aged 18 to 24) had to work more hours due to the costs of caregiving**, while 14% had to use personal short-term savings and 13% had to stop saving altogether.



Making ends meet as a double-duty caregiver

Participants who have the “double duty” of being both a caregiver and care provider (based on the definitions on [page 2](#)) may face the worst financial impacts. Almost a quarter of this group (23%) has experienced a lot of financial hardship in the past year. This group is also significantly more likely to have higher out-of-pocket caregiving expenses, with 42% spending \$1,000 or more each month.

Caregivers with fair or poor mental or physical health (compared to those reporting good, very good or excellent health), working caregivers (compared to non-working caregivers) and caregivers aged 25 to 44 (compared to those 45 and older) were all more likely to experience most forms of financial stress. These intersections may create a trade-off for caregivers between reducing work hours to meet care demands or losing access to employment-related supports or benefits that can help their well-being.

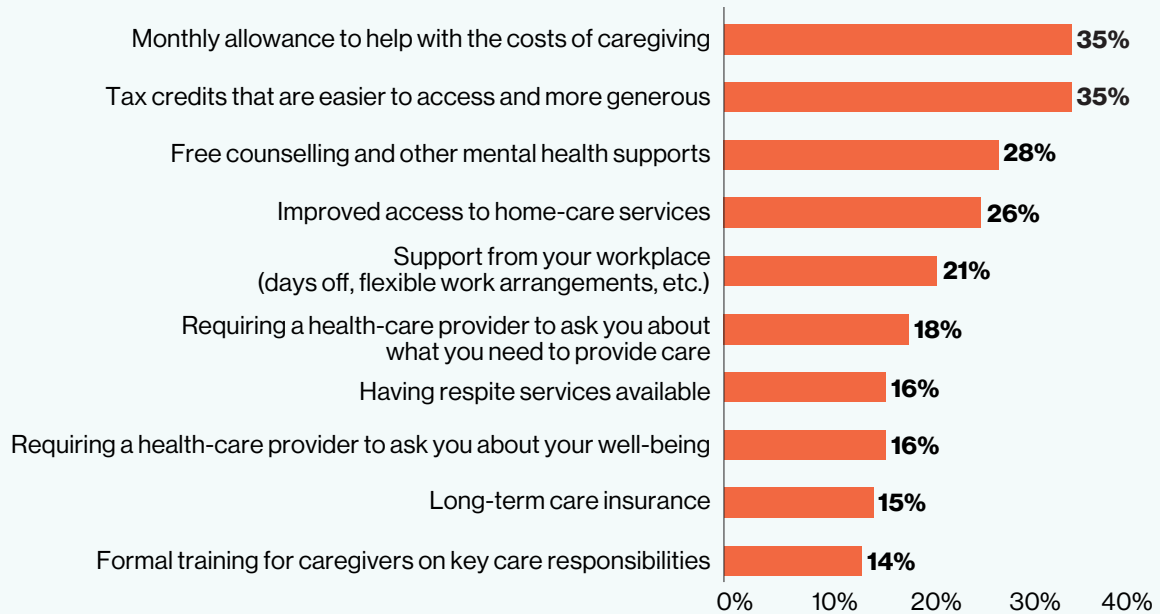
“[There should be] financial supports for unpaid caregivers that would allow us to not have to choose between our well-being and the well-being of the person in our care and our financial survival.”

– Panel survey participant

What caregivers need

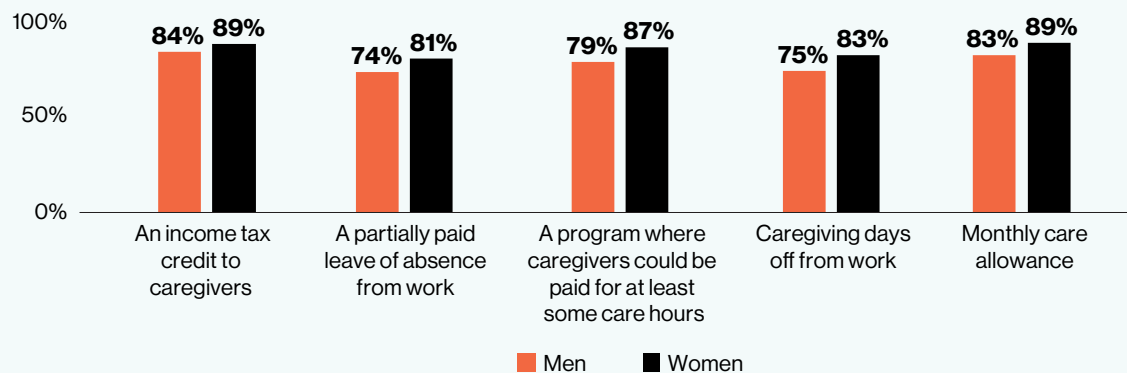
Caregivers told us about the supports they would find helpful, across different support domains like finances, health-care and well-being. The **top two selections both target financial security: a monthly allowance to help with caregiving costs and tax credits that are easier to access and more generous**, each of which are desired by about one in three caregivers (Figure 17).

FIGURE 17 | % of caregivers who would find supports helpful



A large majority of caregivers also said that financial supports—like an income tax credit (87%), a monthly care allowance (86%) and a program to pay caregivers for at least some care hours (84%)—would help their financial situation. Women were significantly more likely than men to report potential financial benefit from income tax credits, monthly allowances and a program to pay caregivers (Figure 18). Additionally, Indigenous caregivers said the most beneficial caregiver support would be financial assistance programs.

Figure 18 | Percentage of caregivers who would find supports financially helpful



While some financial supports for caregivers and care recipients are available, many still reported limited familiarity and uptake of these benefits. Only 12% of caregivers said their care recipients have received financial supports and only 11% have received caregiver benefits themselves. This is consistent with the finding that **more than half of caregivers (52%) are not familiar with tax credits related to care**, and that only one in 10 caregivers has sought out information about financial help.

The use of financial supports varies by some socio-demographic characteristics. Caregiver benefits were significantly more likely be received by men, racialized caregivers, working caregivers and caregivers born outside of Canada. Relatedly, women were significantly more likely than men to be unfamiliar with tax credits related to care.

Eligibility and access may also play a role in the low uptake of financial supports among caregivers. Among the 39% of caregivers who are familiar with tax credits, 21% said they are not eligible for them and only 9% have received them. More than one in three caregivers said more accessible and generous tax credits would be helpful to them, while **income tax credits to offset the cost of care were seen as the most helpful financial support for caregivers**, reported as financially helpful by 87% of caregivers.

“Caregivers spend an obscene amount of time figuring out how to navigate the system and who to call—time that should be spent on caregiving and rest!”

– Open-link survey participant



The time cost of caregiving

Caregiving has a time cost and financial cost. Beyond the “hands-on” time spent caring directly for a person, caregivers also spend time dealing with administrative tasks. More than a third of caregivers help with scheduling appointments or managing care recipients’ finances, while 31% spend one or more hours per week on system navigation tasks. Half of caregivers say that finding information and advice about caregiver resources is difficult.

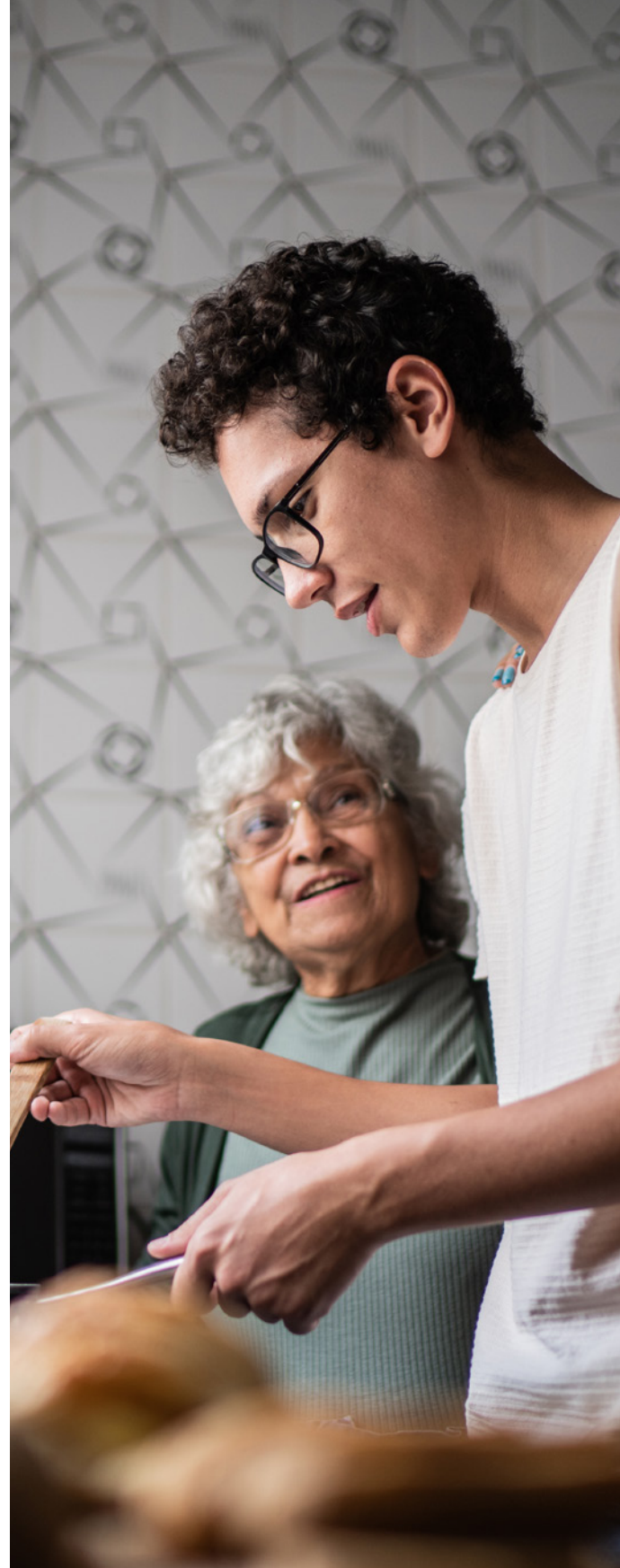
Caregivers for people with disabilities have a higher degree of familiarity with and a greater uptake of tax credits related to care. More than half (55%) of caregivers for people with intellectual or developmental disabilities are familiar with tax credits, along with half of caregivers for people with sensory disabilities and 44% of caregivers for people with physical disabilities. More than a quarter (27%) of caregivers for people with intellectual or developmental disabilities have used care-related tax credits.

“Caregiving when family members are disabled [and] poor is extremely difficult and expensive. Everything is all on you. Plus, I already gave up my full time job to be a caregiver, so it’s extra hard. I think we need to talk more about caregiving and poverty.”

– Open-link survey participant

“[It would be helpful to have] better financial support for adults with disabilities who require adaptive equipment and vehicle and home adaptation.”

– Panel survey participant



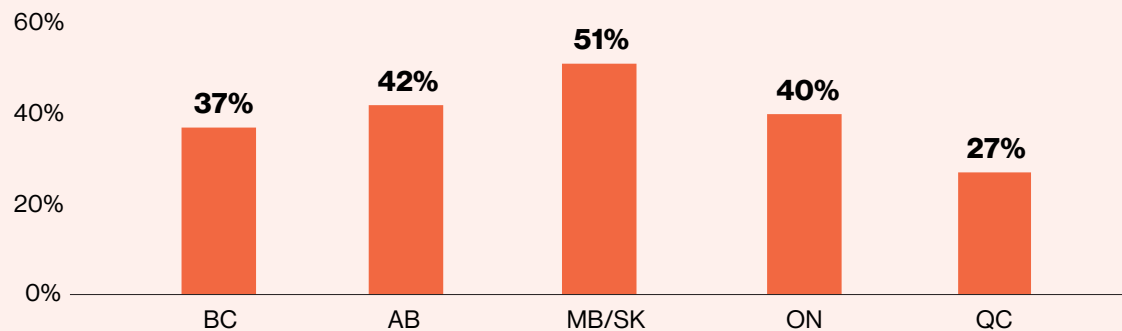


A regional picture of financial impacts and benefits

Financial supports for caregivers vary between provinces, as do social service systems where benefits are accessed. These differences mean it is important to consider how caregivers in different regions may be facing distinct financial challenges.

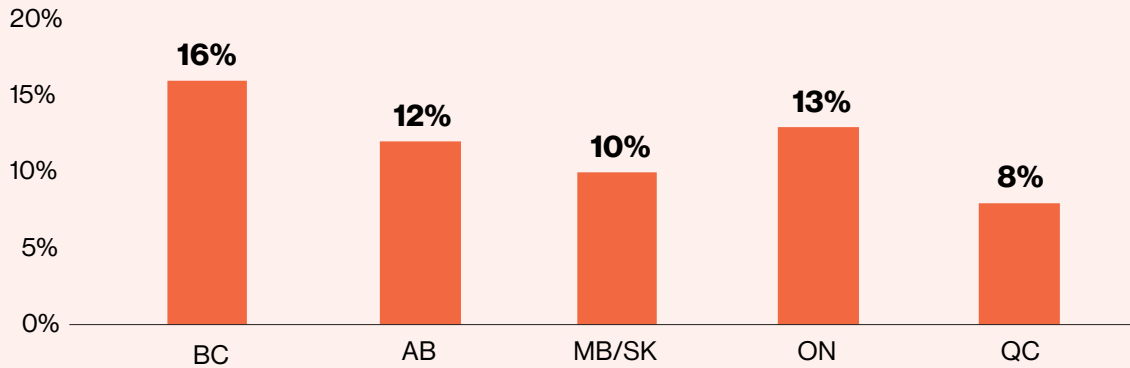
Experiences of financial hardship are not uniform across the country (Figure 19). Financial hardship is least experienced in Quebec, where 27% report “a little” or “a lot” of hardship in the past year, and most experienced in Manitoba and Saskatchewan, where one in two caregivers have experienced financial hardship. Similarly, caregivers outside of Quebec are significantly more likely to spend \$1,000 per month on out-of-pocket caregiving expenses compared to those in Quebec (24% vs. 18%).

FIGURE 19 | Percentage of caregivers experiencing ‘a little’ or ‘a lot’ of financial hardship in the past year (in selected provinces)



Rates of caregiver benefit uptake range from 9% in Alberta to 16% in Manitoba and Saskatchewan. There is slightly more regional variation for care-related tax credits, ranging from 6% of caregivers in British Columbia having accessed them to 16% of caregivers in Manitoba and Saskatchewan. There are also some regional differences in the time caregivers spend each week on researching supports and system navigation. The most time spent is in British Columbia, where 16% of caregivers spend three or more hours per week researching supports and navigating the system (Figure 20).

FIGURE 20 | Percentage of caregivers who spend three or more hours per week on supports research and system navigation



Notably, Quebec is unique among Canadian provinces and territories in having a respite credit. It is also one of only a handful of provinces with a refundable caregiver credit. As shown above, caregivers in Quebec face the lowest levels of financial hardship and out-of-pocket caregiving costs. The relationship between experiences of financial stress and the availability, amount and refundability of tax credits for caregivers is worth further investigation, but the evidence in Quebec suggests that more generous financial support would help address the financial concerns of caregivers across Canada.



The financial impact of caregiving is greater among the open-link sample

Fifty-eight percent of caregivers in the open-link sample reported experiencing financial hardship in the past year, including more than one in four (26%) who have experienced “a lot” of hardship. They reported high rates of financially supporting care recipients (39%) and high out-of-pocket expenses. Thirty-seven percent of these caregivers spend at least \$1,000 per month, among which 18% have monthly caregiving expenses of \$3,000 or more.

Financial stressors were also more common in this group. As a result of caregiving duties, 35% have used their own short-term savings and 22% have used their own long term savings, while 32% have stopped saving altogether. Twenty-six percent of open-link caregivers have taken on more debt and 17% have had to leave bills unpaid or paid late.

The use of financial supports was more common. This is unsurprising given that this sample is composed of people who accessed the survey either directly or indirectly through networks of caregivers. Twenty-six percent of caregivers in this sample have had their care recipient receive benefits, while 29% have received caregiver benefits themselves. Still, 35% of caregivers said they are not familiar with tax credits related to care.

The perceived helpfulness of financial supports is also greater among this group, with more than half of caregivers having said that they see value in a monthly caregiving allowance (59%) and more accessible and generous tax credits (57%).

On the policy agenda

With high financial strain and low financial support, caregivers are facing an uphill battle against the costs of caregiving. Caregivers clearly voiced that **financial supports are the most important policy solution** for meeting their needs. Action is needed to implement **direct compensation** for caregivers and improve awareness and broader eligibility for **tax credits and benefits**.

Improving paid care for care providers and caregivers

Paid care services are essential to meeting Canada's care needs. Yet the paid care system is not working well for its users or its workers. Care providers are enduring difficult working conditions and low wages, and the majority are relatively new to the profession. There are retention issues in the care workforce while care needs are on the rise. Meanwhile, most caregivers are not seeking out care providers or paid care services, and to those who are trying to are struggling to find affordable and reliable options.

Paid care: the care provider experience

The survey sample of paid care providers reflects a variety of roles, settings and care recipients. Care providers identified themselves as personal support workers (33%), direct support professionals (21%), attendants for people with disabilities (12%), nurses or registered nurses (7%) and respite workers (5%). These professionals work in a range of settings: about one in four work in residential care facilities (e.g., group homes), about one in five work in the care recipient's home and about one in seven work in each of nursing homes or seniors' residences, long-term care homes or hospitals. Care providers average about seven hours of active care per day, and about half (49%) said they associate their care responsibilities with making a difference.



Understanding the care provider experience

Fewer care providers participated in the survey than caregivers. Care providers have not received enough attention in research and policy conversations on caregiving. CCCE is dedicated to growing Canada's knowledge and attention on care provider experiences and solutions.

As part of this commitment, CCCE is working with researchers at University of Toronto to conduct a qualitative follow-up on caregiver and care provider experiences, including interviews with care providers from the survey.



The majority of care providers reported having worked in the field for a short duration of time. Sixty-four percent have been working as care providers for five years or less, of which **about one in three care providers (29%) has been working in the profession for less than a year.** Care providers working in the field for less than a year were significantly more likely to be men, be racialized, be born outside of Canada and have a household income of less than \$60,000. In contrast, care providers who have been working in the field for at least 11 years are significantly more likely to be women, be white, be born in Canada and have a household income of \$100,000 or more.

Some care providers reported serious problems with their working conditions. **About half of care providers do not feel they are being paid fairly (48%) or have adequate staffing on their shifts (47%).** Thirty percent said they do not feel supported at work, including about one in 10 care providers who reported not feeling supported *at all*.

“[I would feel supported by] more pay. We are doing so much in the health-care system and not being recognized financially for it. It says that health-care staff are not valued or important in a public health system.”

– Open-link survey participant

Care providers also reported safety issues. **One in four care providers said they do not feel safe at work. The same proportion of care providers have experienced discrimination at work, while 21% have experienced abuse.**

There is a clear relationship between feeling unsafe or supported at work and reporting fair or poor mental health (Figure 21).

FIGURE 21 | Care provider feelings of safety and support at work by mental health status

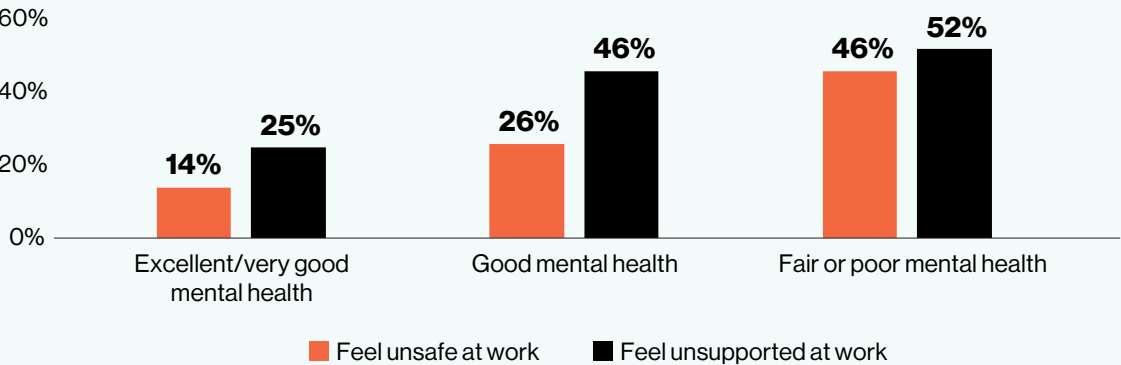
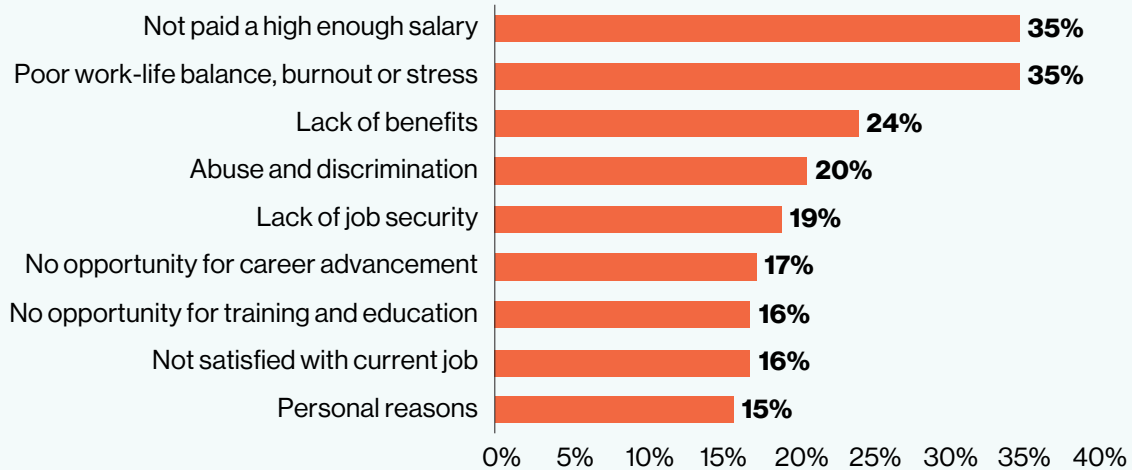


FIGURE 22 | Reasons care providers have considered changing careers



Issues around pay, staffing and safety all point to risks in the sustainability of the care provider workforce. **Eighty percent of care providers have considered changing careers.** The top reasons they have done so are because they are not being paid a high enough salary (35%), they are experiencing poor work-life balance, burnout or stress (35%) and they do not have benefits (24%) (Figure 22).

The majority of care providers are women (54%), and women reported challenges with their working conditions more often than men. Significantly fewer women reported feeling supported at work (58% vs. 76%), and more women said they are not being paid fairly (56% vs. 36%). Women were also significantly more likely to report poor work-life balance, burnout and stress as a reason they have considered changing careers (42% vs. 26%).

What care providers need

Care providers identified several supports that would make their jobs easier. Many of the top supports discussed were related to **employment policies and practices**: higher pay (42%), flexible scheduling (36%), reasonable working hours/good work-life balance (33%) and access to paid sick leave (30%) (Figure 23).

FIGURE 23 | Factors that would make care providers' jobs easier



Care providers told us about system-wide changes that would improve their working conditions. For example, 54% of care providers said that being in a union would make them feel more supported at work. Care providers also saw a role for the government, with 57% reporting that they do not feel supported by the government in their work.

"[I would feel supported by] real action. The failing health-care system can't be bandaged together anymore by nurses and care workers! We have done this for years and just can't keep up anymore. [...] There is lots of talk and no action. Or there is action that literally solves no problems."

– Panel survey participant



While care providers in the open-link sample work in different roles and settings, difficult working conditions persist

Care providers who responded to the open-link survey most often worked as personal support workers (38%) in care recipients' homes (31%). This was followed by direct support professionals as the second most common role (14%) and a nursing home or seniors' residence as the second most common work location (18%).

Care providers in the open-link survey have been working in the field for longer, for an average of about 14 years. These care providers average 7.5 hours of active care per day. About three-quarters (76%) care for more than one person.

Experiences in the care workforce in this sample were mixed:

- 94% of care providers said they feel appreciated by care recipients and 71% feel supported at work.
- Rates of workplace discrimination and abuse were lower (17% and 16%, respectively) than they were for the panel survey group.
- Many care providers said they would find their job easier to do if they had higher pay (64%), reasonable working hours (50%), flexible scheduling (44%) and access to paid sick leave (41%).
- 72% of care providers have considered changing careers, with poor work-life balance, stress and burnout and low pay topping the list of reasons.

Caregivers in the open-link survey generally used more paid care services than panel survey participants:

- 30% said the person they care for has used home-care in the past year and 24% of caregivers have used respite services.
- 67% of caregivers have tried to hire care providers and 77% of caregivers are satisfied with the supports and services their main care recipient has received.

However, this group seems to have more difficulty with finding support. Among caregivers who have tried to access paid care providers, 87% had difficulty doing so, and seven in 10 caregivers who attempted to find affordable local services found it challenging.

Paid care: the caregiver perspective

We can also learn about the state of paid care in Canada by looking at caregivers' use of and access to existing systems. Caregivers' use of paid care services is generally low: **42% of caregivers have never attempted to access paid care** for their care recipient. Only 16% of caregivers said the person they are caring for has used home-care services in the past year, while use of respite services is even lower (8%).

Women, caregivers in rural areas and senior caregivers (65+) were significantly more likely to have never attempted accessing any paid care services. Forty-four percent of women, 47% of rural caregivers and 55% of senior caregivers have never tried to access or hire paid care services in their area.

"[It would be useful to have a] list of recognized, registered respite providers in my area without my having to go out and find one."

– Open-link survey participant

Widespread difficulties in service access may be driving low uptake of paid care. For **caregivers who have sought out paid care, 63% found it difficult to access or hire quality care providers or services in their area**, including 20% who said it was "very difficult" to do so. When asked about affordable services more broadly, **almost two-thirds of caregivers (63%) who have looked for affordable services said it was difficult to find them in their communities.**

"I can't work because I can't find enough [care providers] to support me, but I still need to provide for my family financially. Also we desperately need more care aides and nurses willing to work nights in community care."

– Open-link survey participant



Those who do receive services report positive experiences: 84% of caregivers who have received support or services to assist their main care recipient were satisfied with them.

“When we started getting help from a PSW, she was very helpful in informing me about personal care.”

– Open-link survey participant

On the policy agenda

Care providers urgently need increased compensation and increased support and safety at work. Regulators and employers need to improve care provider working conditions in order to ensure that care providers who are new to the field are incentivized to stay and that current care providers are retained long term to meet care demands. Clear interest from care providers in better working conditions, unionization, training and access to supports suggest some form of professional development and coordination for care providers.



Voices of Care



Juanita Forde

Juanita Forde is passionate about her work. She is a direct support professional, supporting people with developmental disabilities, and a union leader. She views the residents of the group home where she works as family and often includes them in her own holiday celebrations.

Juanita says her propensity to care about others was modelled for her by her parents and grandparents early on. “The message was ‘If you need something, we are here. We are the village.’” she says. She loves her job but also says there are barriers for her and other care providers that must be broken down.

Juanita is familiar with many of the challenges faced by care providers in Canada and has experienced many of the same difficulties she assists her union members with, including income disparity, systemic racism and sub-par working conditions. She has some solutions to bring to the table.

The first issue she would like to see addressed is low pay. “Some people are going into debt to show up at work. Others are sleeping in their cars or in shelters. To think that those [who] care for others are paid the least is sad,” she says.

Next are working conditions, which Juanita says are often unsupportive when it comes to a care provider needing to care for themselves or their own families. Time off work can result in a frontline care worker missing needed pay or being docked shifts. Paid sick days and adequate health-care benefits should be a given.

Juanita wants to see the voices of frontline care workers at the centre of conversations about systemic change. What is needed, she says, is a diversity of voices to make proposed solutions stronger. “If you don’t have someone who is living the experience that you are overseeing, then what benefit do you have of knowing what people really need?” she asks.

There is much more work to do, and Juanita looks forward to continuing to advocate for the type of changes that will ultimately result in a healthier care sector overall. It won’t be easy, she says, but with respect for each other’s positions, it can be done.

“As a human being I always say, ‘Be empathic and find grace—whether you are giving it or receiving it, allow it.’ With grace we can find common ground and begin to make positive changes together.”



Diverse experiences, shared needs: The diversity of Canada's caregivers

The findings presented in this report speak to many of the shared caregiving experiences reported by survey participants. But we know that the caregiver experience varies across identities and communities. It is vitally important to understand how caregivers' intersecting identities impact their experiences.

Caregiving differences can play out in what the day-to-day care experiences of caregivers look like. For example, when it comes to their **relationship to care recipients**, racialized caregivers and young caregivers (aged 18 to 24) are significantly more likely to be caring for a family member who is not a partner, parent, child or sibling compared to non-racialized caregivers and other age groups. These groups may be providing care to grandparents, aunts or uncles or other relatives in multi-generational households—and this can make their care experiences and needs distinct from the more common experience of caring for a parent.

The **health conditions of care recipients** also vary among different groups of caregivers. LGBTQ2S+ caregivers are significantly more likely than non-LGBTQ2S+ caregivers to be caring for someone with a mental health condition, while sibling caregivers most commonly care for someone with a medical condition or intellectual or developmental disability. Again, this creates different challenges and support needs than the more common experience of caring for someone with challenges related to aging.

There are also caregiver groups who are facing **heightened impacts of caregiving**. As seen in the sections above, whether it is racialized caregivers experiencing financial hardship, LGBTQ2S+ caregivers experiencing poor mental health or young caregivers needing to work more hours to cover caregiving costs, it is clear that the impacts of caregiving are not uniform.



Caregiver groups who are facing heightened impacts of caregiving

Caregivers for people with disabilities

- Caregivers for people with disabilities care for people with physical disabilities (13%), intellectual or developmental disabilities (5%) and sensory disabilities (4%).
- Caregivers for people with disabilities have good familiarity with and uptake of tax credits related to care. About half (47%) of these caregivers are familiar with care-related tax credits, including 16% who have used them and 19% who have received caregiver benefits.
- Caregivers for people with intellectual or developmental disabilities have higher rates of managing care recipient finances (49%), providing direct financial support (48%) and providing personal care (41%). They also have higher rates of financial hardship, with 48% of caregivers experiencing some level of financial hardship in the past year, including 23% who have experienced “a lot” of financial hardship.

Racialized caregivers

- Racialized caregivers most commonly care for a parent (42%), but their second most common care recipient is a family member other than a partner, parent, child or sibling (19%).
- Racialized caregivers spend more time navigating supports compared to non-racialized caregivers: 19% spent three or more hours per week on supports research and navigation.
- Racialized caregivers were more likely to do certain caregiving tasks online, such as watch videos to learn about care, have virtual health-care visits, create an online calendar for caregiving activities and help care recipients use rideshare services.
- In the past year, 47% of racialized caregivers have experienced financial hardship due to caregiving.

Caregivers in rural communities

- Rural caregivers are significantly more likely to have not used common caregiving supports and services, like home modifications, health-care provider assessments or transportation or respite services. Almost half (47%) of rural caregivers have never attempted to access or hire paid care providers and 41% have never attempted to access affordable local caregiving services more broadly.

LGBTQ2S+ caregivers

- LGBTQ2S+ caregivers' most common care recipients are those whose primary health issue is challenges related to aging (24%)—in line with the full sample—but the second most common care recipient condition among LGBTQ2S+ caregivers is a mental health condition (14%).
- LGBTQ2S+ caregivers reported struggling with mental health at higher rates. Forty percent rated their mental health as fair or poor; 31% said they have felt depressed in the past year due to their caregiving responsibilities.

Young caregivers

- Young caregivers (aged 18 to 24) are most commonly caring for family members who are not their partners, parents, children or siblings (40%).
- On average, young caregivers spend no less time on caregiving than the full sample, providing about five hours per day of active care.
- More than one in three young caregivers (36%) said their mental health is fair or poor.
- Young caregivers have experienced financial strain as a result of caregiving. For example, 23% have had to work more hours, 14% have stopped saving altogether and 13% have had to use their personal short-term savings.

Sibling caregivers

- Caregivers are caring for siblings ranging from 10 to 90 years old, with a median age of 64. Care recipients' most common primary health conditions are medical conditions and intellectual or developmental disabilities (18% each).
- Three-quarters of sibling caregivers do not live with their main care recipient.
- Only about 20% of sibling caregivers have sought out information about caregiver supports and benefits in the past year or attempted to access them.

What caregivers need

While caregivers across the board are interested in most caregiver supports, some groups of caregivers expressed higher interest in certain supports. **Free counselling and other mental health supports had the greatest differences:** women, low-income caregivers, Indigenous caregivers, LGBTQ2S+ caregivers and caregivers outside of Quebec were all more likely to find these supports helpful when compared to caregivers not in these groups (i.e., the rest of the sample without them).

Additionally, **racialized caregivers and those born outside of Canada were significantly more likely to find it helpful when health-care providers asked about what they needed to fulfill their caregiving duties.** They were also more interested in long-term care insurance than non-racialized caregivers and caregivers born in Canada.

These increased levels of interest suggest that mental health and financial supports can meet both targeted and broad caregiver support needs.

We also know that including the voices of diverse caregivers in policy and program discussions is critical to designing effective solutions. Many of the caregivers in the survey shared written responses that highlight the intersections of identity and caregiving:

“Translation service is hard to find. My parents don’t speak English—when they go to hospitals or go to see doctors, they need translation service.”

– Panel survey participant

My wife passed away a few months ago. It has been impossible to find a safe space to get support in a group setting (online or otherwise) for the loss in a lesbian relationship. There are some groups advertised online, but they are funded through U.S. services and not open to me. Grieving as a lesbian is outside the realm of grief support services.

– Open-link survey participant



"[I would find it useful to] hire someone who can cook Eastern meals for my parents a few times [a] week."

– Panel survey participant

Supports for both those with mental health and addictions and their caregivers are really lacking. While my spouse does have 1:1 counselling services, once he has been sober for a certain period he can no longer access those services. Eventually he relapses and we start over. The cycle is exhausting and no[t] at all prevention- or recovery-focused.

– Open-link survey participant

On the policy agenda

Despite caregivers' wide range of experiences and impacts, they are united in what they want: better financial and mental health supports. Action on these supports—and ensuring they are inclusive to diverse groups of caregivers—has the potential to help the caregivers who are both struggling the most and would find these supports the most helpful.



Spotlight on Indigenous caregivers

Indigenous caregivers were oversampled in the survey and had a unique set of questions about their caregiving experiences and support priorities. We learned that:

- The primary health issues among Indigenous caregivers' care recipients are challenges related to aging (19%), a medical condition (17%) or a physical disability (15%).
- Indigenous caregivers reported that the services and resources they would find most beneficial are financial assistance programs (59%), education and training opportunities (37%) and culturally appropriate counselling or therapy services (35%).
- Three-quarters of Indigenous caregivers said it is important that caregiving and supports be delivered in a culturally sensitive manner.
- 44% of Indigenous caregivers said there is inadequate representation and inclusion of Indigenous voices and perspectives in caregiver supports and policy discussions.

We recognize the unique experiences of Indigenous caregivers in Canada as they navigate the complex dimensions of cultural, historical and systemic factors that shape their caregiving experiences. Indigenous caregiving is interconnected to communal values, which often view the responsibility of caring for Elders and community members as a sacred duty. However, these experiences are also heavily influenced by the ongoing legacies of colonization, including the intergenerational trauma resulting from residential schools, forced assimilation policies and systemic marginalization.

Indigenous caregivers often face significant barriers in accessing culturally appropriate resources and support services, leading to feelings of isolation and frustration as they attempt to balance their traditional caregiving roles with the demands of contemporary society.

While this report is an important initial step in understanding the experiences of Indigenous caregivers, it cannot fully represent the complex perspectives and experiences of Indigenous caregiving. We know there is a pressing need for further research that centres Indigenous voices and perspectives, ensuring that the experiences and priorities of Indigenous caregivers are accurately captured and represented. This involves fostering collaborative research partnerships with Indigenous communities, employing methodologies that respect Indigenous ways of knowing and being and prioritizing the principles of reciprocity and mutual benefit.

Additionally, research should focus on understanding the unique challenges and strengths of Indigenous caregiving, including the impacts of colonialism, intergenerational trauma and cultural resilience. We are committed to supporting Indigenous-led efforts to meaningfully explore the realities of Indigenous caregiving.



Voices of Care



**Gerrilynn
Buffalo**

Gerrilynn (Gerri) Buffalo is the main support for her 13-year-old son, Cassius, who has autism. Getting a diagnosis for Cassius was an ordeal. It didn't take long for Gerrilynn to notice that Cassius exhibited some behaviours that seemed unusual to her, like stimming, hand gestures and having a difficult time with food textures. But seeking advice from medical professionals was complicated. "When talking to doctors, I worry that they won't believe me—that I'm making everything up," she says. "There is a lot of judgement because I am Native."

Nevertheless, Gerri wants the best for her son, and so she advocated for a diagnosis. During that time—and even before it—Gerri can't remember a single time a health-care professional asked her about her cultural preferences for receiving care. But, she notes, the first questions often asked to both her and Cassius were whether they were under the influence of drugs or alcohol.

Realizing the extra attention needed to care for Cassius, Gerrilynn, like many other caregivers, quit her job. "I want to work, but I worry about leaving him alone. He likes to open and close doors and sometimes wanders. I don't have access to additional support, and I can't leave him alone," she says.

Cassius—who loves trains, drawing and playing with his uncle's cats and hamsters - is taking a break from school because his local school could not appropriately support his needs, leaving Gerri worried about his learning, care and safety. During this time of transition, Gerri is helping Cassius develop independence skills, like cooking simple meals and developing good personal habits—typical lessons for any new teenager.

Gerri is grateful to organizations, like Autism Society of Edmonton, for the support and resources that have helped her understand her son's diagnosis and navigate the system of specialists and programs to help with Cassius' development.

When asked about what kind of support she wished there was more of, Gerri noted the need for more culturally appropriate resources and care, free of judgement and racism.

"Everything I do now is for Cassius," she says. "It's hard, but I have to be patient. I want him to be in a good school, pursuing drawing and a better life. I hope that things for both of us get a little bit easier."

Conclusion and next steps



Conclusion and next steps

Caregivers and care providers play an essential role in Canadian society. As our population continues to age and the rate of complex health conditions continues to grow, most people will find themselves providing care to others and/or needing care themselves.

To effectively support caregivers and care providers, we need good data about their experiences and policy solutions to address these issues. The National Caregiving Survey **fills a significant evidence gap** by capturing insights about the roles and responsibilities, well-being, access to supports and needs of caregivers.. This is the first time that much of this data has been collected in Canada. It has also charted a course for understanding more about Canada's care providers and their work experiences.

From the survey, we can see that care responsibilities encompass a range of emotional and practical supports that take up on average five hours per day. This is only the beginning: caregivers and care providers will likely have to provide care for longer hours and more years as our population ages, care needs become more complex and the number of available caregivers diminishes (both because of aging and family units getting smaller).

The data highlights key stories about the realities of caregiving in Canada. Caregiving takes a significant toll on **caregiver well-being**. There are **distinct challenges facing working caregivers and senior caregivers**, who need more support for their unique care contexts and the balancing acts between individual needs and care responsibilities. We see the serious **financial impacts of caregiving**, with many caregivers facing financial hardship and stressors as a result of their care duties. We also see the **cracks in Canada's paid care landscape**, with care providers facing difficult working conditions and at risk of leaving the profession, and caregivers facing barriers to service access.

To understand Canada's caregiving landscape further, there is still work ahead to unpack the needs of different caregiver demographic groups, like young caregivers, LGBTQ2S+ caregivers and Indigenous caregivers. Despite their differences, there is **strong shared interest** in the need for improved caregiver supports, especially around financial and mental health supports.

The conversation does not end with data. Insights from the National Caregiving Survey will set the direction for the future of caregiving policy in Canada.

- Poor caregiver well-being calls for more accessible **mental health supports** and stronger pathways into caregivers finding support, like the health-care system.
- The demand on working caregivers stresses the need for **caregiver-friendly workplace policies** and employment laws, like caregiver-specific leaves and benefits.
- The disconnect between an aging caregiver population and limited uptake of paid care services points to a need for **better service integration and navigation**, along with **improved access to home-care services**.
- The financial toll of caregiving needs to be met with **direct compensation for caregivers** and improved awareness of and access to **tax credits and benefits**.
- Barriers to care provider retention—like low pay and burnout—underscore the importance of improving conditions for the care workforce, through reforms like **increased compensation** and **professionalization of care providers**, as a priority for preparing for the care needs of tomorrow.

These findings are the foundation for future work towards a National Caregiving Strategy that commits to clear, collaborative and evidence-informed actions to prioritize the needs of caregivers across the country.

CCCE is excited to take this new evidence, along with caregiver and stakeholder voices, and put it toward strategic activities to strengthen Canada's caregiving landscape. These findings are the foundation for future work towards a National Caregiving Strategy that commits to clear, collaborative and evidence-informed actions to prioritize the needs of caregivers across the country.

Appendix

Research with Indigenous participants

The panel survey oversampled Indigenous participants to reflect CCCE's commitment to understanding the experiences and supporting the needs of Indigenous caregivers. Still, we recognize that survey research may not be the best fit for reaching some Indigenous caregivers, as it is largely rooted in colonial histories of using research as a means of control and dispossession.¹² We know that more research, using more inclusive data collection methods, is needed, and we are committed to doing this work in collaboration with Indigenous researchers.

In working with data from Indigenous participants, we are mindful of OCAP principles (ownership, control, access and possession)¹³ in how we use and share the data. Applying OCAP principles is challenging when working with pan-Canadian surveys. There is not one community that stands as a clear partner or data steward when Indigenous research participants come from many communities across the country. Data control and ownership is also complicated by the fact that our dataset has a mix of Indigenous and non-Indigenous participant data.

Because of this, CCCE is focusing its application of OCAP on the principle of **access** and **applying good practices in how Indigenous participants can access data and information** collected in the surveys. We will develop an active outreach approach that seeks to share survey findings and publicly available data with Indigenous participants. As we further our work with Indigenous caregivers, we will look to improve our application of OCAP principles and work collaboratively with Indigenous communities to design research in line with them.

TABLE 3 | Participant demographics

	Panel survey	Open-link survey
Gender		
Woman	57%	88%
Man	42%	11%
Non-binary	1%	1%

	Panel survey	Open-link survey
Age		
18-24	11%	1%
25-44	35%	18%
45-64	36%	47%
65+	18%	34%
Household income		
<\$60,000	32%	33%
\$60,000-100,000	29%	24%
\$100,000+	28%	24%
Geography		
Urban	44%	46%
Suburban	38%	30%
Rural	17%	22%
Province or territory		
British Columbia	14%	16%
Alberta	11%	11%
Saskatchewan	3%	1%
Manitoba	3%	2%
Ontario	38%	41%
Quebec	24%	19%
New Brunswick	2%	2%
Nova Scotia	3%	6%
Prince Edward Island	<1%	<1%
Newfoundland and Labrador	1%	<1%
Northwest Territories	<1%	<1%
Nunavut	<1%	N/A
Yukon	N/A	<1%

	Panel survey	Open-link survey
Ethnicity		
White (European descent)	76%	80%
South Asian	7%	3%
East Asian	6%	4%
Black	4%	3%
Middle Eastern	3%	1%
Latino	2%	1%
Southeast Asian	2%	4%
Other	2%	
Indigenous		
Yes–First Nations	2%	2%
Yes–Métis	2%	2%
Yes–Inuk (Inuit)	<1%	<1%
No	96%	96%
Born in Canada		
Yes	79%	79%
No	20%	19%
Years in Canada		
Less than 1 year	7%	1%
1 year to less than 5 years	18%	9%
5 years to less than 11 years	17%	10%
11 years to less than 21 years	14%	10%
21 years or more	41%	63%
Immigration status		
Canadian citizen	90%	93%
Permanent resident	5%	4%
Temporary resident	3%	1%
Refugee	<1%	<1%
Asylum seeker	<1%	<1%

	Panel survey	Open-link survey
Sexual orientation		
Heterosexual or straight	85%	83%
Bisexual	4%	2%
Gay	2%	<1%
Asexual	1%	1%
Lesbian	1%	1%
Uncertain or questioning	1%	<1%
Pansexual	1%	1%
Queer	1%	1%
Two-Spirit	<1%	<1%
Other	<1%	<1%
Marital status		
Single	28%	14%
Married or living common law	61%	69%
Widowed/divorced/separated	10%	15%
Education		
High school or less	18%	11%
College or technical/trades training	29%	28%
University	52%	59%
Employment status		
Working full time	46%	30%
Working part time	10%	12%
Self-employed/freelance work	6%	9%
Student	5%	1%
Homemaker	4%	6%
Unemployed	5%	7%
Retired	22%	33%

	Panel survey	Open-link survey
Language		
English	75%	83%
French	27%	22%
First Nation/Indigenous	<1%	N/A
Arabic	1%	1%
Chinese, Cantonese, Mandarin	3%	2%
Filipino/Tagalog	1%	3%
German	1%	1%
Indian, Hindi, Gujarati	3%	1%
Italian	1%	2%
Korean	<1%	N/A
Pakistani, Punjabi, Urdu	1%	1%
Persian, Farsi	<1%	N/A
Russian	<1%	N/A
Spanish	2%	1%
Tamil	1%	N/A
Vietnamese	<1%	N/A
Other	3%	N/A

References

- 1 Canadian Centre for Caregiving Excellence. (2022). *Giving care: an approach to a better caregiving landscape in Canada*. https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE_Giving-Care.pdf
- 2 Statistics Canada. (2024). "Sandwiched" between unpaid care for children and care-dependent adults: a gender-based study. <https://www150.statcan.gc.ca/n1/en/pub/89-652-x/89-652-x2024002-eng.pdf?st=s3z1Q0Ug>
- 3 Fast J. (2022). *Family Day imagery neglects family caregivers' care work; it needs to be valued*. The Conversation. <https://theconversation.com/family-day-imagery-neglects-family-caregivers-care-work-it-needs-to-be-valued-175801>.
- 4 Statistics Canada. (2022). *Population projections for Canada, provinces and territories, 2021 to 2068, 2022*. <https://www150.statcan.gc.ca/n1/daily-quotidien/220822/dq220822b-eng.htm>
- 5 Redfoot, D., Feinberg, L., Houser, A. (2013). *The aging of the baby boom and the growing care gap: a look at future declines in the availability of family caregivers*. AARP Public Policy Institute. <https://www.caregiver.org/uploads/2023/02/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf>; Deloitte. (2021). *Canada's elder care crisis: addressing the doubling demand*. Canadian Medical Association. <https://www.cma.ca/about-us/what-we-do/press-room/new-study-cost-and-demand-elder-care-double-next-10-years>; Statistics Canada. (2020). *The experiences and needs of older caregivers in Canada*. <https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00007-eng.htm>
- 6 Statistics Canada. (2023). *Health of Canadians*. <https://www150.statcan.gc.ca/n1/pub/82-570-x/82-570-x2023001-eng.htm>
- 7 Statistics Canada. (2023). *Canadian Survey on Disability, 2017 to 2022*. <https://www150.statcan.gc.ca/n1/daily-quotidien/231201/dq231201b-eng.htm>
- 8 Stall, N. (2019). We should care more about caregivers. *Canadian Medical Association Journal*, 191(9), E245-E246.
- 9 The survey does not include parents who are caring for their children (i.e., childcare) unless they have a medical condition, mental health condition or disability.
- 10 Statistics Canada. (2022). *More than half of women provide care to children and care-dependent adults in Canada, 2022*. The Daily. <https://www150.statcan.gc.ca/n1/daily-quotidien/221108/dq221108b-eng.htm>
- 11 Participants were asked to select the primary health issue that they were providing care for, but many care recipients may have multiple conditions that impact their care.
- 12 Goodman, A., Morgan, R., Kuehlke, R., Kastor, S., Fleming, K., Boyd, J., Western Aboriginal Harm Reduction Society (2018). "We've Been Researched to Death": Exploring the Research Experiences of Urban Indigenous Peoples in Vancouver, Canada. *International Indigenous Policy Journal*, 9(2).
- 13 First Nations Information Governance Centre. (n.d.) *The First Nations Principles of OCAP*. <https://fnigc.ca/ocap-training/#:~:text=The%20First%20Nations%20principles%20of%20ownership%2C%20control%2C%20access%2C%20and,this%20information%20can%20be%20used>.



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