

Family Caregiving 18 months into the COVID-19 Pandemic: *“We need to be truly valued.”*

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Executive Summary and Family Caregiver's Recommendations

Alberta Family Caregivers: Impacts of 18 months of the COVID-19 pandemic is a report on how Alberta's family caregivers are doing a year after our 2020 survey, which examined the impacts of the pandemic after four months of the pandemic.

A total of 556 current family caregivers responded to the survey. The main theme in this survey is diversity of caregivers' lives and their caregiving experiences. Family caregivers, the people they care for, the illnesses, disabilities, and frailties for which they need care, and their socio-economic status, age, relationships to care-receivers, roles beyond caregiving, care locations, and care trajectories are heterogeneous.

The impacts data showed that of the 511 survey respondents who had been caregiving before the pandemic began, 57% reported providing more care, 23% the same amount of care, and 20% less care. Care increased for a greater proportion of those caring in community homes, increasing among 71% of those caring for a care-receiver in the same home and 64% of those caring for someone living in a separate condo, apartment, or single-family home.

In contrast to 2020 when 87% of the family caregivers caring for those in long-term care [LTC] and 70% of the family caregivers caring for people in supportive living said they were providing less care, similar proportions of family caregivers of long-term care and supportive living residents were reporting caring more as were caring less. In long-term care, 40% were caring more and 45% were caring less. Similarly, in supportive living, 39% were caring more and 32% were caring less. Typically, those providing more care were deemed the one or two designated support persons whereas those caring less were designated as visitors.

Some family caregivers were caring for many hours a week. Rates of caregiver distress rise sharply when caregivers provide care for 21 or more hours a week. We found 84% of those caring for a care-receiver living with them were caring for 21 hours a week. The amount of time caregivers dedicated to providing care varied depending on where the care recipient lived, as shown in the table below.

Table 1: Weekly hours of caregiving by care-receiver's residence

Receiver's home.	1-20 hrs/ wk.	21+ hrs/ wk.
Same home (n=205)	16%	84%
Separate home (n=104)	70%	30%
Supportive living (n=83)	87%	13%
Long-term care/group homes (n=126)	78%	22%

Overall, 46% of family caregivers indicated they were experiencing financial hardships. Rates were highest for those caring for a child (60%), followed by 44% of those caring for a parent and 40% of those caring for a spouse. Rates were also higher for younger caregivers (15-34, 78%; 35-54, 73%) than for older caregivers (55-64, 43%; 65-74, 31%; 75+, 36%). Those caring in the

community for a care-receiver who lived with them (61%) or in a separate home (58%) were more likely to worry about finances than those caring for a supportive living (35%) or long-term care (32%) care-receiver.

Very few caregivers were receiving Federal Government COVID-19 relief or federal tax credits. Of the benefits typically available, 8% received the Canada Caregiver Benefit, 3% the Employment Insurance Family Caregiver Benefit, and 3% the Employment Insurance Compassionate Care Benefit. Of the COVID-19 specific benefits, 10% had received the Canada Emergency Response Benefit (CERB) and 3% the Canada Recovery Caregiving Benefit. Most (80%) reported out-of-pocket spending on care supplies during COVID-19.

A third (33.1%) of the caregivers rated their health as moderately frail. Of those, 8.8% reported being inactive and 27.7% were more fatigued and having more trouble obtaining supports. Notably, 2 caregivers rated themselves as very frail.

With increases in care hours per week and financial stress, over half of the caregivers completing the survey reported at least one or more of these symptoms of stress.

- 54% had “not been able to take a break”.
- 60% were always “thinking about all care tasks they had to do”.
- 58% were “feeling more frustrated”.
- 50% were “not sleeping well”.

We need to pay attention to the anxiety and loneliness of family caregivers, as well as Albertans that they care for, because both are a risk to health and premature mortality. Anxiety is the most frequently occurring psychological disorder among family caregivers. Typically, family caregiver anxiety rises as care responsibilities increase and energy levels are depleted. On the valid and reliable Six-Item State Anxiety Scale Anxiety, 73% of participants were moderately to severely anxious.

Loneliness carries the same health risk as smoking 15 cigarettes a day. The risk of premature mortality is like that of alcoholism. Loneliness rates were particularly high. On the widely used DeJong-Gierveld 6-item loneliness scale, 87% of these caregivers were lonely.

We asked family caregivers if their physical and mental health had improved, remained the same, or deteriorated over the last year.

- 69% of family caregivers noticed a deterioration in their mental health.
- 58% of family caregivers observed a deterioration in their physical health.

However, of the family caregivers who reported interacting with healthcare providers in the last 6 months, only 25% had been asked about their caregiving or their health.

In 2020, some family caregivers reported that they were worried that they could not continue caring because they were exhausted and overwhelmed. This year, we asked family caregivers to rate their confidence to provide emotional support, navigate the system, and sustain caring.

- 11% were unsure they could continue caring

- 19% were uncertain of their capability to provide emotional support
- 27% were doubtful of their ability to navigate the health and community care systems

We explicitly asked family caregivers what they needed in the future.

Family caregivers wanted support in two domains: attention to the care-receiver’s overall wellbeing and support for family caregivers to maintain a balance in their life, work, and caregiving roles.

Domain 1: Attend to the care-receiver’s wellbeing

Key themes in caregivers’ recommendations related to attending to the care-receiver’s wellbeing:

1. Respect the care-receiver as a person. They wanted the person they cared for respected, valued, and treated with dignity.
2. Ensure staffing levels meet the care-receiver’s needs. They reported that COVID-19 had exacerbated an underfunded continuing care system. They wanted to ensure that they and healthcare providers had enough time for holistic person-centered care.
3. Support care-receivers emotionally. Family caregivers regarded emotional support as a significant part of their role and of holistic care. They wanted care to explicitly include time to listen, human touch (e.g., holding hands, touching an arm), or reassurance.
4. Ensure care-receivers have opportunities and support to engage in meaningful activities. Caregivers referred to activities like visits with family and friends, physical exercise like walking, or “engaging things to do” (e.g., enjoyable activities, interactions with others).

Domain 2: Supports that enable Family Caregivers to balance their work, life, and family caregiving roles

Key themes related to balancing work, life, and family caregiving roles:

1. Recognize and respect their family caregiver role. They reported that they felt “invisible” and “abandoned”; their care work was considered “failure to work”; and they were treated as an “inconvenient expense” and “expendable.”
2. Communicate in a timely person-centered manner tailored to the caregiver’s roles as partner-in-care, care coordinator, and care advocate. Caregivers used words like truthful, open, clearer, active, and listening to describe the desired communication that would enable them to gather information, determine the best course of action, navigate systems, coordinate care, and solve problems.
3. Ask caregivers about what they need to ensure supports address the caregivers’ and their care-receiver’s needs. These caregivers wanted practical, person-centered support that they could use in their unique situations.
4. Relieve the financial stress of caregiving. About a third of family caregivers wanted government programs or other supports to relieve the financial stress directly related to their caregiving role.

Family Caregiving 18 months into the COVID-19 Pandemic: “We need to be truly valued.”

Alberta’s family caregivers and the people they care for have been hard hit by the COVID-19 pandemic and the public health protocols to control it. The pandemic exacerbated already challenged support systems for children and adults with disabilities and the continuing care system for adults and older adults. Informal support (family, friends) and formal supports (community organizations, healthcare systems) had to close, reduce, or change. Alberta’s caregivers stepped up to care and to coordinate the services and supports that were available. COVID-19 made determining the best course of action, accessing, and coordinating services, and finding solutions to problems even more onerous. It is important to recognize that every caregiver faced unique challenges in trying to balance their caregiving, work, and life roles.

Our goals in this 2021 survey were to

- 1) understand the impacts of 18 months of the COVID-19 pandemic and
- 2) ask family caregivers what they thought Alberta family caregivers need in the future.

A total of 556 current family caregivers responded to the survey. The survey results highlight the diversity of caregivers’ lives and their caregiving experiences. Family caregivers, the people they care for, the illnesses, disabilities, and frailties for which they need care, and their socio-economic status, age, relationships to care-receivers, roles beyond caregiving, care locations, and care trajectories are heterogeneous.

As will be outlined in sections 2 to 8, we heard from different genders (80.4% were women), who predominantly (96%) identified as family members to care-receivers, ranged in age from 15 to 94, and had a variety of formal education levels. These family caregivers were caring for Albertans of all ages and various health statuses. They had been caring for less than one year up to 60 years; cared for 1 to 3 care-receivers; and provided from less than 10 to 168 hours of care per week. They lived and cared in urban, suburban, and rural locations, engaging in varying care tasks for care-receivers living in the same household, separate households, congregate care, and hospice care.

COVID-19 had diverse impacts on weekly care hours, employment security, finances, caregiver stress, and mental and physical health, as well as self-rated confidence to provide emotional support, navigate the system, and continue to care.

This heterogeneity reinforces the need for person-centered care for family caregivers. The Health Innovation Network describes person-centered care as “a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs”.^[1] What family caregivers might find helpful and what they need to support their caregiving and to maintain their own wellbeing will depend on their care situation and where they are in their care trajectory.^[1] Health and community service providers need to know what is most important to family caregivers and the people they care for. Yet, this survey shows most caregivers (75%) were not asked about their health or situation by health care providers. Programs, research, and policy

for caregivers need to recognize the importance of understanding caregivers and their unique needs before pre-supposing solutions.

In what follows we begin with a description of the survey method, then report on the diversity in family caregiver and care-receiver demographics and family caregivers' responses to survey questions. We conclude with what family caregivers suggested they need to better support care-receivers' wellbeing and support their work, life, and caregiving balance.

1. *About this Survey Research*

This online survey was carried out on the University of Alberta REDCap data collection platform from June 21 to August 31, 2021. Conducted with the help of a grant from the Northern Alberta Academic Family Medicine Fund, Department of Family Medicine, University of Alberta, it was done to study the impact of COVID-19 on Alberta family caregivers and the supports they need going forward. A total of 556 current family caregivers responded to the survey.

We define **family caregiver** (carer, care-partner) as any person (family, chosen family, friend, neighbour, community member, church volunteer) who takes on a generally unpaid caring role and provides emotional, physical, or practical support in response to mental or physical illness, disability, or age-related needs.

1.1 Study team

Jasneet Parmar, MBBS, MSc (Project Lead); Bonnie Dobbs, PhD; MBA; Peter Tian, MD, MSc; Jennifer Stickney-Lee, MD; Lesley Charles, MBChB; Suzette Brémault-Phillips, PhD; Lisa Poole, BA (Family Caregiver); and Cindy McCaffrey (Family Caregiver)

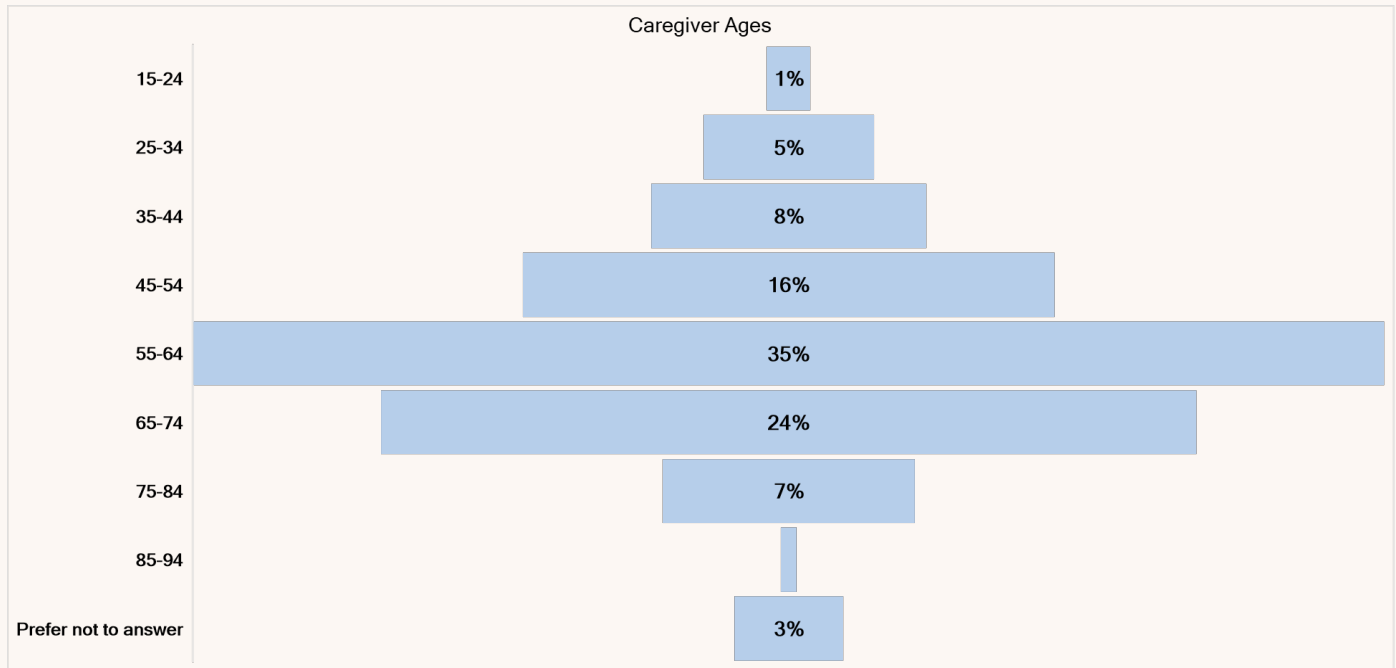
1.2 Ethics

This study, "How has COVID-19 pandemic Affected Family Caregivers in Alberta?" received ethics approval from the University of Alberta Health Ethics Research Board (Pro00097996).

2. *Demographics: Family Caregivers*

Of the 556 family caregivers who completed the survey, 80.4% identified as women, 14.7% as men, 0.2% as transgender, 0.4% as non-binary, 1.1% as other, and 3.2% preferred not to answer. Participants in this study were significantly more likely to be female than in the 2018 Statistics Canada General Social Survey data in which 54% were female and 46% were male.^[2-4] Family caregivers 15 years of age and over completed the survey. Just over one-third (35%) were 55-64 years of age.

Figure 1: Caregivers' ages



2.1 Caregivers' residence location

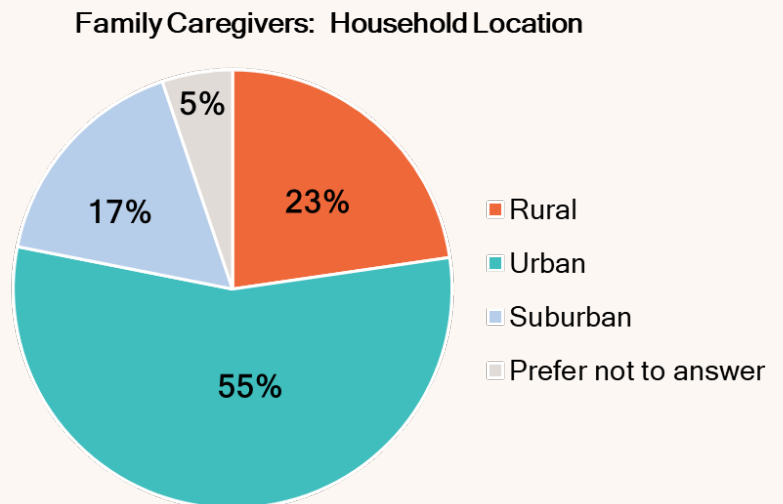
We used the first 3 digits of participants' postal codes to classify location and Alberta Health Services [AHS] Zones where family caregivers lived:

- 55% lived in urban areas
- 17% lived in suburban areas
- 23% lived in rural areas
- 5.2% preferred not to provide their postal code

Alberta Health Services [AHS] Zones

- 9.4% lived in North Zone
- 44.6% lived in Edmonton Zone
- 11.9 % lived in Central Zone
- 21.8% lived in Calgary Zone
- 7.2% lived in South Zone
-

Figure 2: Family caregivers' household location



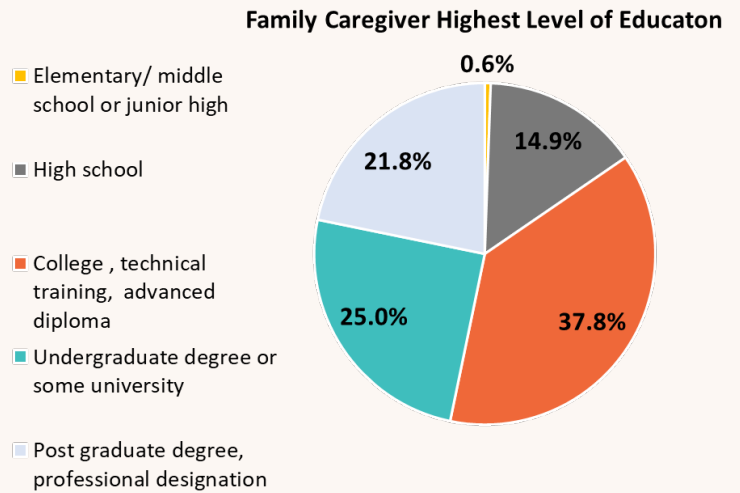
2.2 Number of people cared for:

- 67.8 % for 1 person
- 20.9 % for 2 people
- 7.0 % for 3 people
- 4.3 % preferred not to answer

2.3 Highest level of education

- 14.9% completed high school
- 37.8% had college, technical training, or an advanced diploma
- 25% had some university or an undergraduate degree
- 21.8% had a post-graduate education and/or professional designation

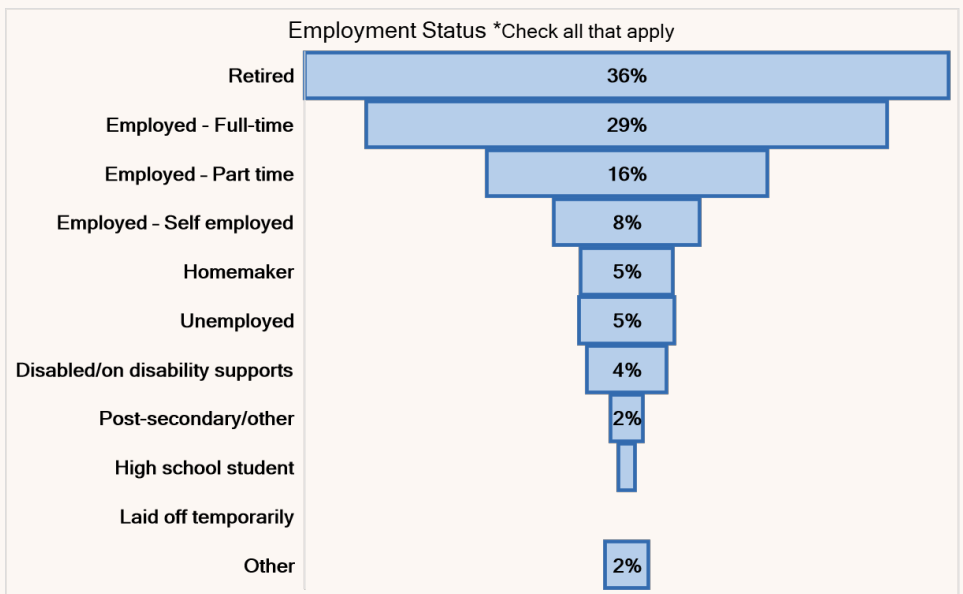
Figure 3: Family caregivers' highest level of education



2.4 Current employment status*

- 36% were retired
- 29% were employed full-time
- 16% were employed part-time
- 8% were self-employed
- 3% were students
- 0% indicated they were temporarily laid off

Figure 4: Family caregivers' current employment



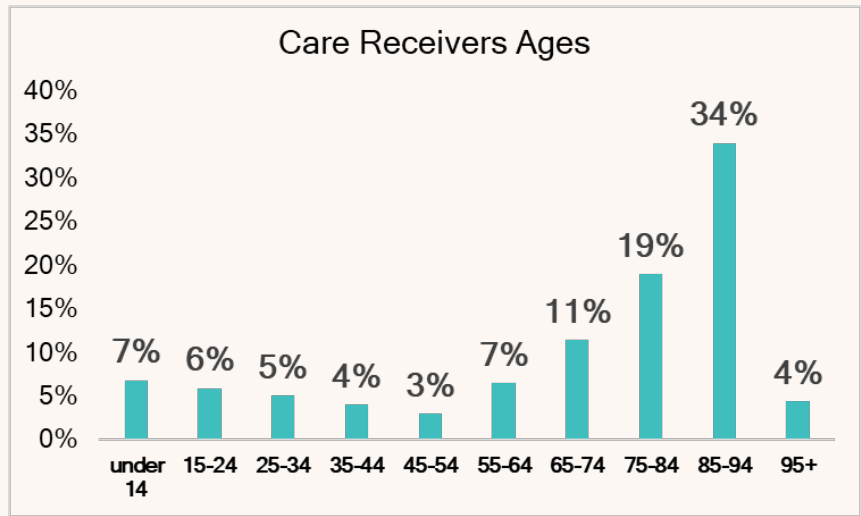
*The percentages add up to more than 100% because respondents were asked to check all that apply.

3. Demographics: Care-Receivers

3.1 Care-receivers ages

Family caregivers were caring for care-receivers of all ages. Two were infants and two were 100 years of age. Most care-receivers (68%) were 65 years or older. The average age was 68 years.

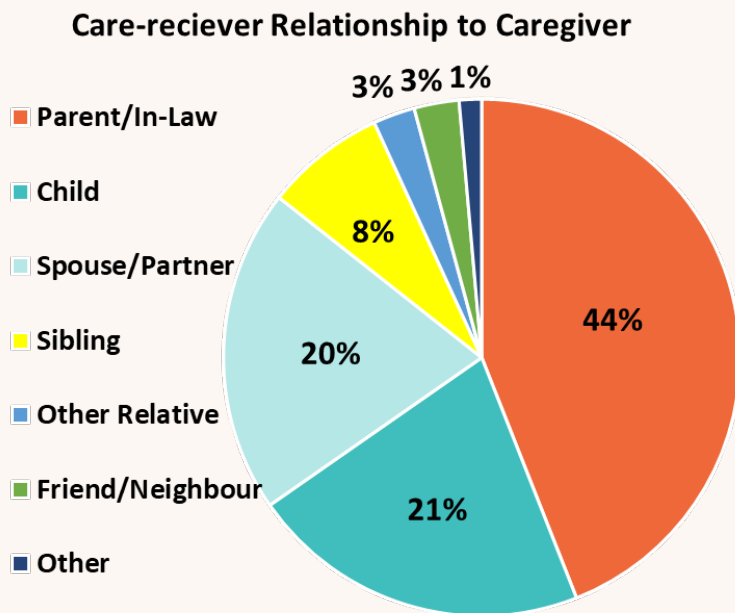
Figure 5: Care receivers' ages



3.2 Relationship to caregiver

- 44% Parents or parents-in-law
- 21% Children of caregiver
- 20% Spouses
- 8% Siblings
- 3% Other relatives (e.g., aunt, uncle, cousin)
- 3% Friends/ neighbours
- 1% other relationship

Figure 6: Care-receivers' relationship to family caregiver

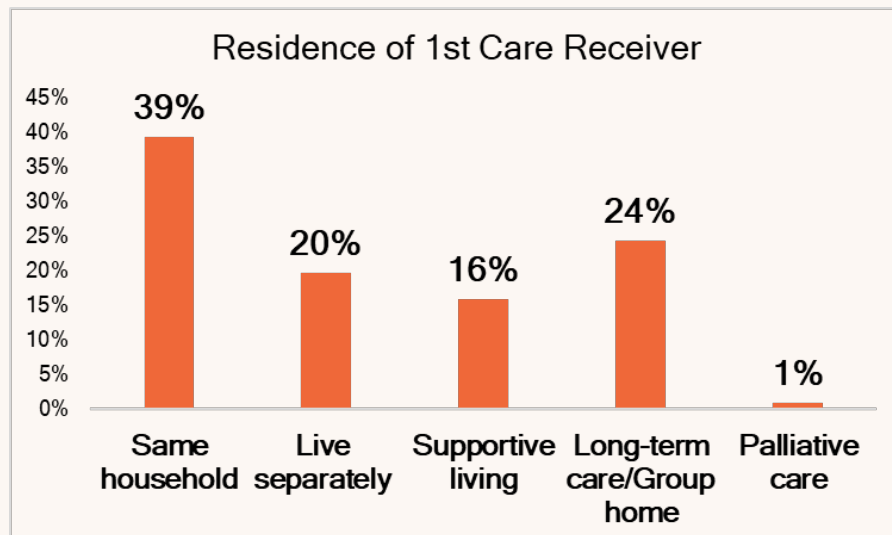


3.3 Living situation

We asked caregivers where the person they provided the most care to lived most of the time.

- 39% in the same household as family caregivers
- 20% in a private home separately from the caregiver
- 16% in supportive living
- 24% in LTC
- 1% in palliative care

Figure 7: Care-receivers' residence

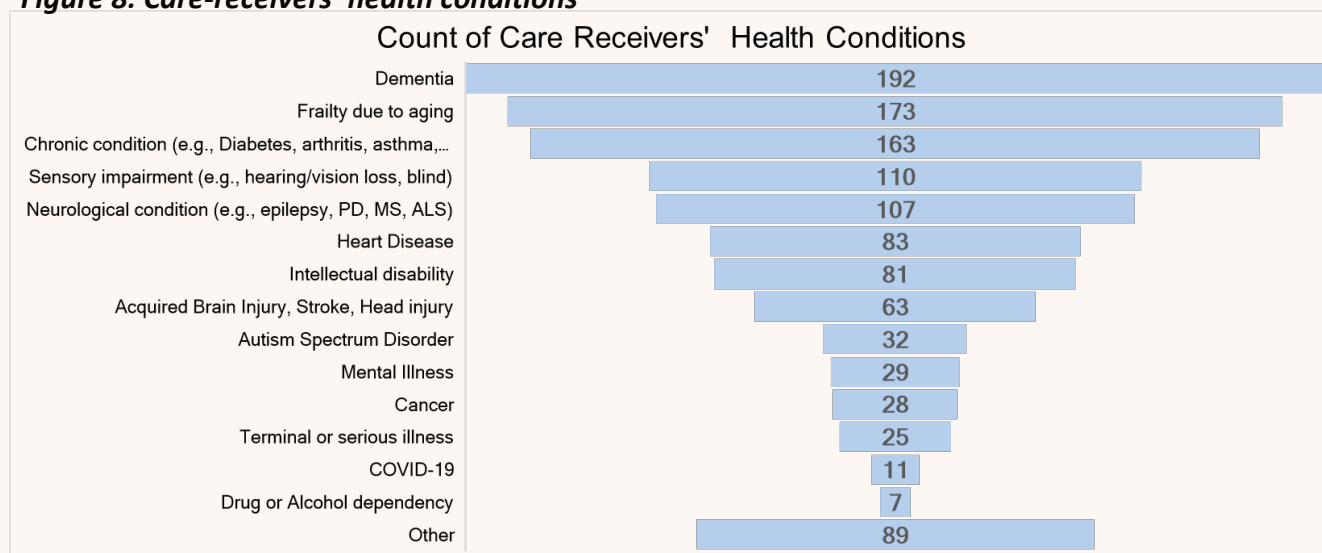


4. Care-Receiver's Health and Changes in Health

4.1 Care-receivers' health conditions

We asked caregivers what conditions, disabilities, or illnesses the person they provided the most care for had. They were asked to check all that applied. Caregivers reported that care-receivers had 1 to 12 conditions. Aligned with the higher proportion of older adults receiving care, dementia, frailty, chronic conditions [diabetes, arthritis, asthma, Crohn's disease, cystic fibrosis, COPD], and sensory impairments were most frequently reported. See Appendix 1 Methods for condition groupings and other conditions.

Figure 8: Care-receivers' health conditions

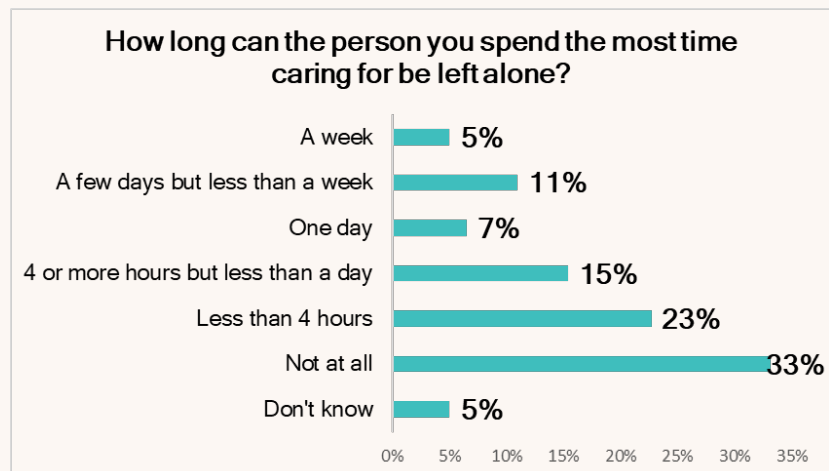


4.2 Length of time primary care-receiver could be left alone

Caregivers who are unable to leave the care-receiver alone either must be there to care or arrange for someone else to care. Caregivers reported the following about whether and how long care-receivers could be left alone:

- 17% for a few days
- 45% for a few hours
- 33% could not be left alone

Figure 9: Length of time care-receivers can be left alone



Caregivers' perceptions of the length of time a care-receiver can be left on their own is an indication of the care-receiver's frailty. There was a strong positive correlation between caregiver's ratings of frailty and how long the care-receiver could be left alone, $r = .51$, $n=463$, $p < .001$. There was also a small, positive correlation between caregiver's perceptions of the time care-receivers could be left alone and caregivers' weekly caregiving hours, $r = .27$, $n=460$, $p < .001$.

4.3 Care-Recipients' frailty

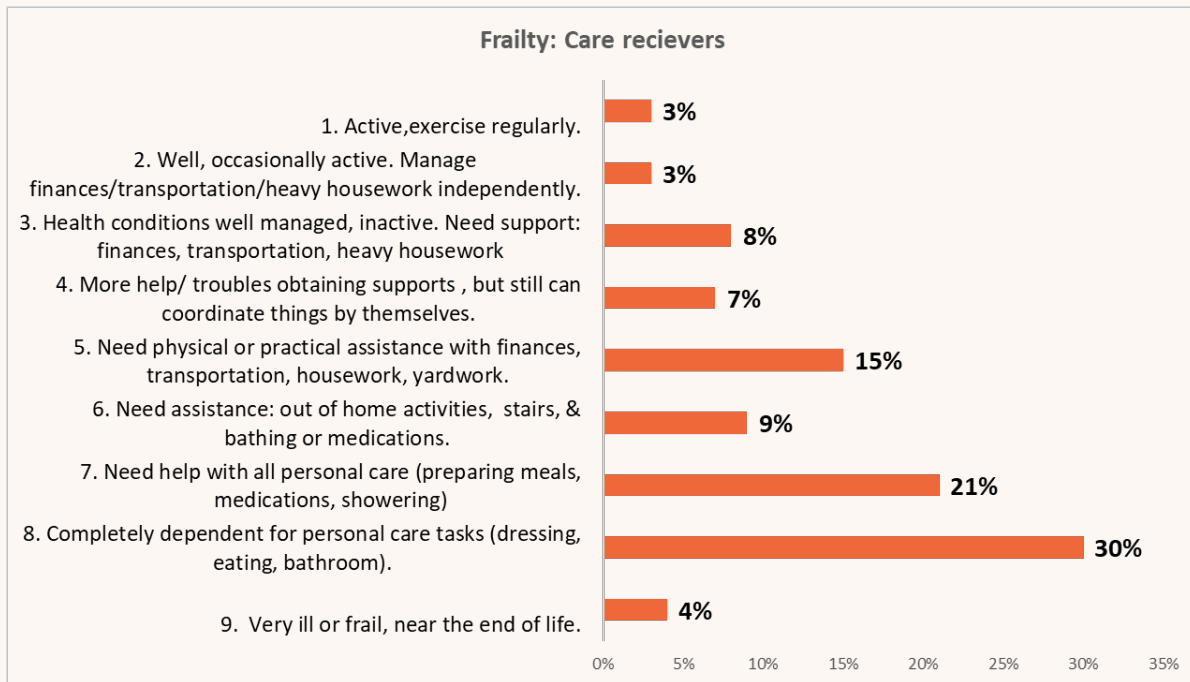
We used a community version of the Clinical Frailty Scale to assess care-receivers' frailty.^[5 6] The 9-point screening tool broadly identifies the level of frailty in a series of 9 questions about how the person can manage in their daily life. The ratings range from 1 (very fit) to 9 (terminally ill). In the 492 completed family caregiver ratings,

- 14% were relatively physically fit (Scores of 1-3),
- 31% were moderately frail (Scores of 4-6),
- 51% were severely frail (Scores of 6-8),
- 4% were very frail/at the end of life. (Score of 9)

Several caregivers noted that this community version of the frail scale was missing the impact of cognition, mental health, or impulsive behaviours. Many caregivers who reported that the care-receivers were physically active and healthy, indicated that they needed caregiver support because cognitive impairments, dementia, mental illness, or brain injuries made it difficult for them to manage their affairs independently:

This person doesn't need physical support with activities outside the house but needs support with social interactions, how to behave, etc.

Figure 10: Family caregivers' perceptions of care-receiver frailty



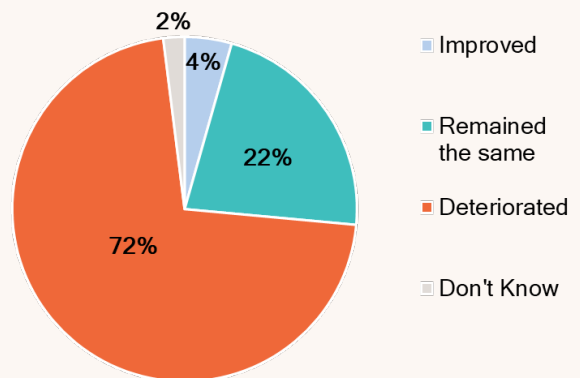
4.4 Changes in care-receiver's health during the COVID-19 pandemic

In our survey last year (July 2020), 60% of the family caregivers reported that the health of the persons they cared for declined.

In this 2021 survey, almost three-quarters (72%) of caregivers thought the care-receiver's health had deteriorated in the 18 months since the COVID-19 pandemic began.

Figure 11: Changes in care-receivers' health during the pandemic

During the COVID-19 pandemic, the health of the person I care the most for has:



Caregivers of care-receivers living with them in the same home were more likely to report that the receiver's health remained the same or improved.

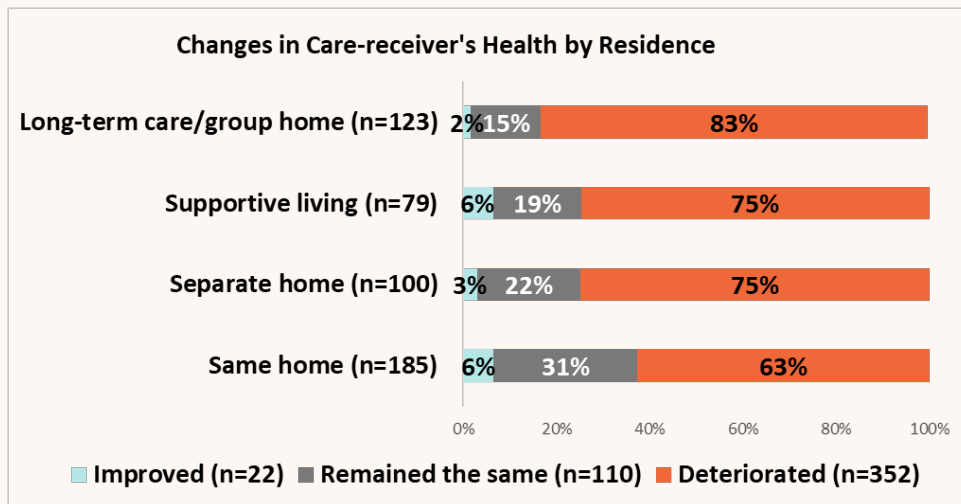
Family caregivers' qualitative comments connected deterioration in receivers' health to social isolation:

Being part of a gym boxing program designed especially for

Parkinson's patients was such a wonderful thing for my husband. The physical and social benefits were phenomenal! He really missed it and I noticed his mood and motivation deteriorated. Moving to Zoom classes helped somewhat. Hope to get back soon!

Social isolation during the pandemic was extremely hard on this person who is a social butterfly. Huge decline in health during the pandemic. Also, a big negative impact on mental state and ability to communicate due to lack of interaction with loved ones.

Figure 12: Changes in care-receivers' health by residence



5. Changes in Care in COVID-19 and Weekly Hours of Caregiving

Before the COVID-19 pandemic, family caregivers provided 75–90% of the care to persons living with frailty, complex chronic conditions, and impairments in the community^[7-9], and assisted with 10 to 30% of the care for congregate care residents^[10 11]. Without disaggregating caregiver diversity, Statistics Canada reported 41% of caregivers provided 1 to 3 hours of care weekly, 23% provided 4 to 9 hours, 15% provided 10 to 19 hours, and 21% provided 20 or more hours a week in 2018.^[12]

In this survey and our July 2020 survey,^[13 14] we delved into the changes in care by care-receivers' residences. In 2020, four months into the COVID-19 pandemic, we found 73% of those caring for a receiver living with them in the same home and 56% living separately were providing significantly more care after the COVID-19 pandemic began. The situation was reversed for family caregivers of congregate care residents: 87% of those caring for long-term care residents and 70% of those caring in supportive living were providing less care.

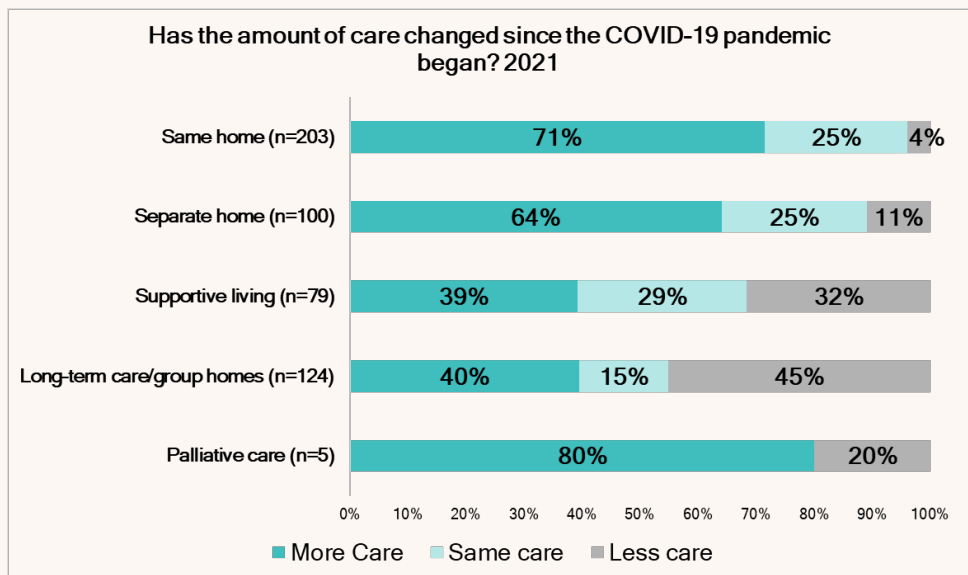
5.1 Family caregivers: Changes in care

There were 511 survey respondents who had been caring before the COVID-19 pandemic began. Of those, 57% reported providing more care, 23% the same amount of care, and 20% less care during the COVID-19 pandemic.

Care increased the most for those caring in palliative care hospices or community homes.

- 80% Palliative care
- 71% Same home
- 64% Separate home
- 39% Supportive living
- 40% Long-term care

Figure 13: Changes in amount of care by receivers' residence



For the most part, the family caregivers providing more care in supportive living or long-term care were *designated support persons*¹ defined as “individuals identified by the patient as a needed support and who the patient wants to be involved in their health matters (e.g., family members, close friends, or informal/hired caregivers).”

Because my husband is in a secure unit- most of the caregiving I do is during my daily visits (when we were allowed into the home of course). I do some special meals, all the laundry for him at home as well as looking after our home now. I do as much (all) personal care as I can for him during my time there. Personal care includes toileting, massage, exercise dental care, and foot care. I am tired when I get home, but more than happy to be the one helping him and getting to see him now that the unit is open. I just need a few more hours in the day ...and really a bit more family support.

Those providing less care reported that family caregivers were still restricted from congregate care settings. They could have been *visitors*¹ defined as “anyone not identified as designated support persons.” Access for visitors varied depending on COVID-19 prevalence, care location, and care-receiver’s situation. Visitors could schedule appointments to see care-receivers at the end of life, visit outdoors, or sometimes a scheduled visit one person at a time in the resident’s room.

*I need to be able to see my mother regularly to support her emotionally as well as to ease my anxiety about how she is doing in her care home.
Need to be able to freely visit and get back to life pre-COVID. Too much control from govt and medical workers. My mother agrees with this as well.*

¹ Alberta Health Services, Family/Designated Support Persons & Visitors of Patients
<https://www.albertahealthservices.ca/topics/Page17001.aspx>

5.2 Weekly hours of care

We asked caregivers to estimate the time they spent providing care in an average week:

- 37% 10 or fewer hours weekly
- 16% 11-20 hours weekly
- 14% 21-40 hours weekly
- 20% 41-120 hours weekly
- 12% 121- 168 hours weekly

The amount of time family caregivers devoted to providing care depended on the residence of the care-receiver. The caregivers caring for receivers living in the same home were caring for significantly more hours per week than caring for Albertans living in separate homes, supportive living, or long-term care. 84% of the caregivers caring in their own homes were caring for more than 21 hours a week compared to 30% of those caring for a receiver living in a separate home, 13% of those in supportive living, and 22% of those caring for long-term care or group home residents.

Figure 14: Weekly hours of care

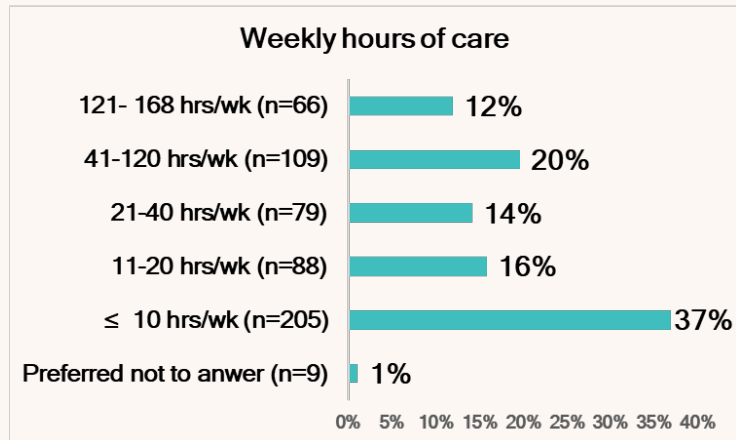
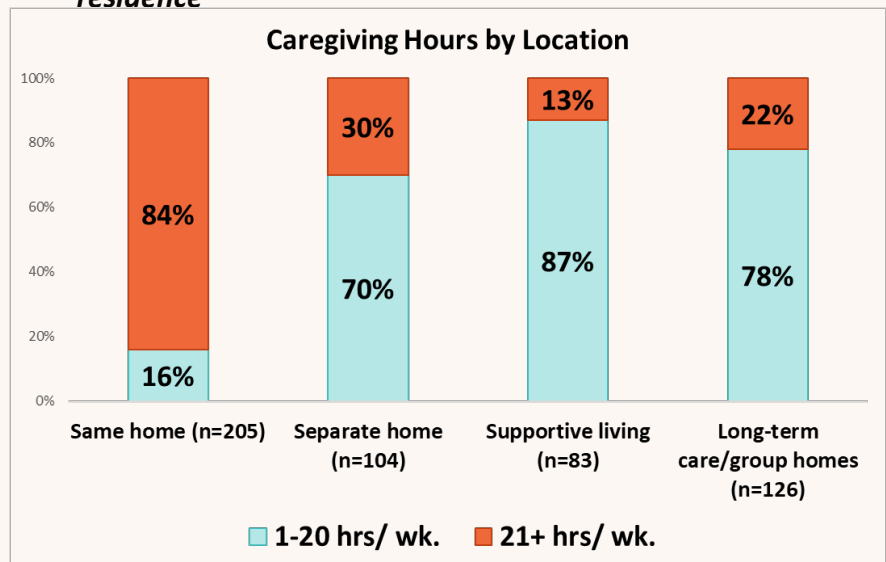


Figure 15: Weekly hours of care dichotomized by receivers' residence



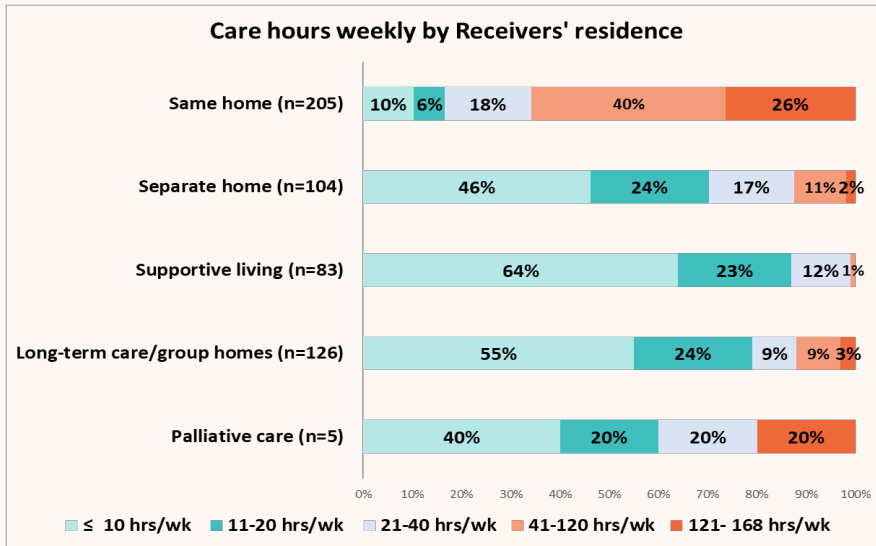
The qualitative quotes highlight the diversity and challenge assumptions that caregivers spend less time caring for someone in long-term care,

"I take care of both my parents; one is at home and the other is in long-term care. I care for both equally."

Many family caregivers caring for someone in their own home were caring for significantly more than a 40-hour week.

- 40% were caring for 41- 120 hours a week
- 26% were caring for 121- 168 hours a week

Figure 16: Weekly hours of care by receivers' residence



With care hours dichotomized to over and under 21 hours a week, there were significant differences in care hours by caregiver's age. More caregivers aged 35 to 54 and 75 and over were caring for over 21 hours a week ($\chi^2(4, n=529) = 29.3, p < .001$ Cramer's $V = < .001$).

The caregivers caring for younger care-receivers were more likely to care for more than 21 hours a week ($\chi^2(9, n=468) = 69.6, p < .001$ Cramer's $V = < .001$).

Figure 17: Weekly hours of care by caregivers' age

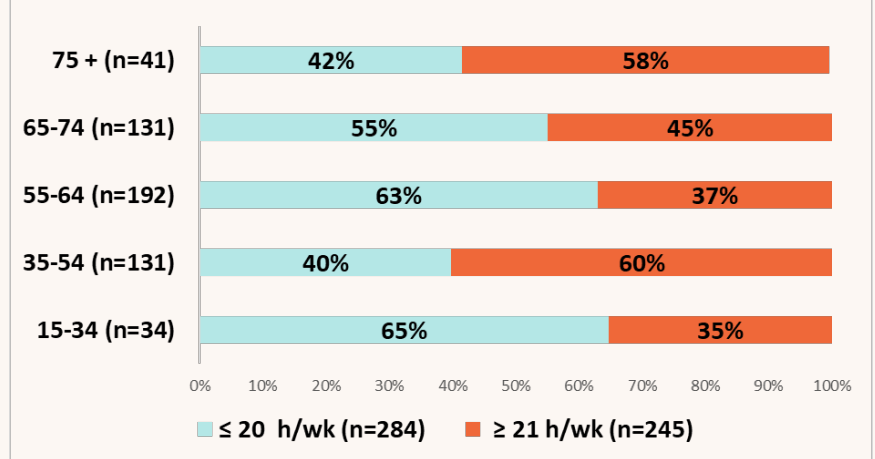
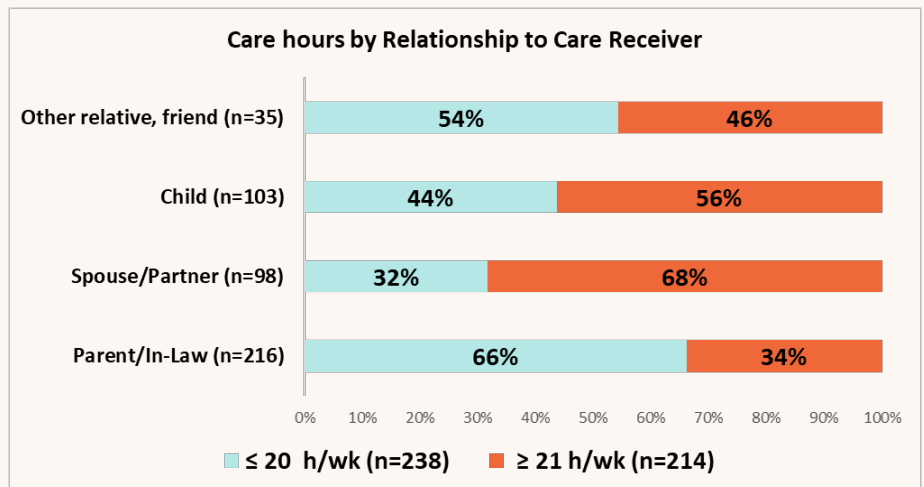


Figure 18: Weekly hours of care by relationship



Those over 75, tended to be caring for a spouse. Those caring for a spouse or child were more likely to care for 21+ hours a week. ($\chi^2(3, n=452) = 36.6, p < .001$ Cramer's $V = < .001$).

The differences in care hours between rural, urban, and suburban care locations were not significantly different. *Graph not shown.

Qualitatively, however, rural caregivers reported that when added to other work, caregiving was taxing,

My Parents moved into Continuing Care during the pandemic. My mother passed away and I contribute to the lack of social and emotional support as a huge factor. Facilities need to remain open to visitors. Limitation on the number of visitors allowed was a huge strain to everyone - parents, other family members, and myself who was down as essential family caregiver to both parents and my son who is also in a group home. Working full-time, farming, and trying to support parents (same facility, but different floors) was very taxing both physically and mentally.

5.3. Caregiver’s care tasks by care location

We asked family caregivers to check off all the types of care and support they provided. To get a more accurate view of the tasks in each care setting, we report the percentages for family caregivers caring for one person. The p-values indicate that significant differences were found for the care provided by receivers’ residence.

Those living with the care-receiver were more likely to engage in more intensive care tasks such as assistance with activities of daily living, intimate care, and medical care. In addition to being most likely to check off all the listed care tasks, family caregivers caring for a receiver living in the same home added school and homework support; training, supervising, and hiring staff; assisting with rehabilitation (physio, OT, SLT); and complex medical care tasks (airway suctioning, tube feeding, seizure monitoring/intervention, oxygen monitoring, breathing machine delivery/maintenance).

Table 2: Type of care work by receiver’s residence

Care work	Same home (n=128)	Separate home (n=49)	Supportive living (n=49)	Long-term care/group homes (n=184)
Emotional and social support	94%	88%	96%	96%
Managing care such as making appointments ($p = .01$)	87%	69%	76%	71 %
Shopping for or delivering food/supplies ($p <.001$)	84%	71%	76%	56%
Help with home maintenance or outdoor work ($p <.001$)	62%	61%	16%	14%
Transportation, including trips to the doctor, social visits, or for shopping ($p <.001$)	90%	76%	80%	63%
Help with preparing food, housekeeping, laundry ($p <.001$)	91%	59%	27%	30%
Handling finances ($p <.001$)	81%	50%	78%	80%
Assistance with eating, dressing, managing medications ($p <.001$)	68%	27%	18%	45%
Intimate care such as bathing, showering, toileting, managing incontinence ($p <.001$)	52%	16%	8%	14%
Medical care such as help with nursing care (e.g., wound care/bandage changes, foot care managing medical equipment) ($p <.001$)	52%	18%	6%	22%

The family caregivers caring for a care-receiver living in a separate home were less likely to assist with basic activities of daily living (eating, dressing, managing medications), personal care (bathing, toileting, managing incontinence), and medical care than those caring for someone who lived with them. Other tasks included finding social activities, exercises to maintain physical and mental capability, coordinating additional supports/caregivers, and monitoring safety and security (e.g., phone sales, scam calls).

There needs to be assistance for elders who want to stay in their homes. They are not able to remember routines, but they do know where home is. It isolates caregivers and is very hard to find staff capable of 24 hr care.

Family caregivers of supportive or assisted living residents were less likely to prepare food, do housekeeping and laundry, assist with eating, dressing, and managing medication, or assist with intimate care or medical care. Other tasks included tech support, shopping for clothing and other supplies, substitute decision-making/assisting with decision-making, and monitoring safety and security (e.g., phone sales, scam calls).

I maintain contact with my parents' friends and relatives. This is usually done via telephone, so I place the call and they talk to the person(s).

Contrary to the assumption that family caregivers provide less assistance with activities of daily living, intimate care, and medical care when receivers become long-term care residents, almost half (45%) of the caregivers caring for long-term care residents were assisting activities of daily living such as eating and dressing and 14% were assisting with intimate care like managing incontinence. Other tasks included tech support, substitute decision-making/assisting with decision-making, dialysis companion, and monitoring and advocacy.

Parent has Alzheimer's/Dementia and is in long-term care. I come and see her, toilet her, and do other care basically 7 Days A Week. I also provide care for my autism spectrum disorder son 7 days a week.

6. Employment, Financial Hardships, Federal Benefits, Out-of-Pocket Costs

We asked family caregivers three questions about their employment. The first two were closed-end questions with a predefined list of answer options, 1) their current employment status (refer to section 2.4) and 2) changes in their employment because of their caregiving work. The third was an open-ended question, "Is there anything else you would like to tell us about the impact of caregiving on your employment during the pandemic?"

6.1 Changes in Employment Status Because of Your Caregiving

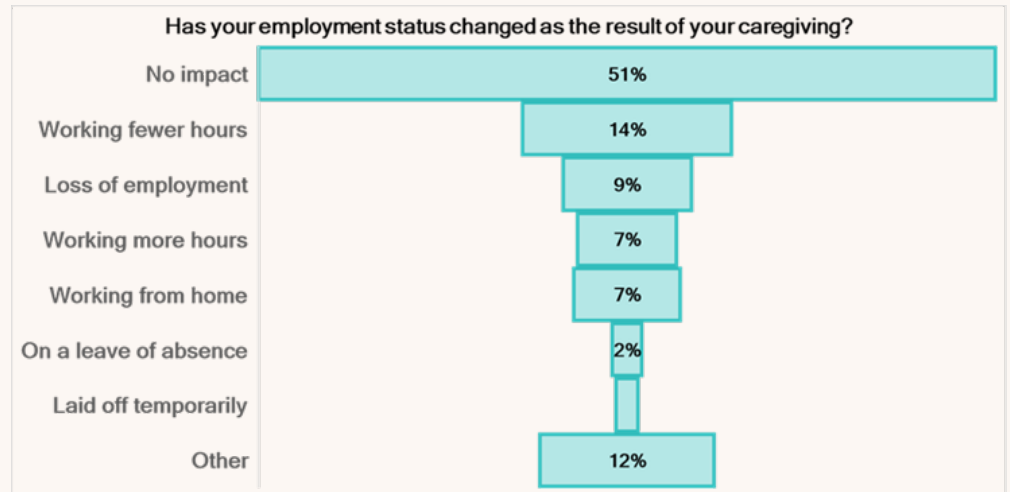
When asked if employment had changed as the result of their caregiving role:

- 51% reported caregiving had not changed their employment status
- 14% were working fewer hours
- 9% had lost employment

- 7% were working more hours
- 2% were on leave of absence
- 1% were laid off temporarily
- 12% reported other

*Percentages add up to more than 100% because they checked off all that applied.

Figure 19: Employment status changes due to caregiving role.



No Impact on employment. Of those who reported employment had not changed, 72% (199/276) were retired and/or homemakers. Several of those who were retired reported they had taken early retirement or lost their job due to their care work before the pandemic.

We have the "luxury" of living on pensions. I took early retirement to be a full-time caregiver. My fixed income is a definite concern as prices rise because we are barely above water right now. 7 years ago, I worked part-time. Employer told me they needed full-time or I'm out of my job.

Would not have been able to manage full-time employment with 2 elderly parents and 2 teens. Sandwich generation sucks.

No, I already lost my job. Back in 2013, my ward was hospitalized for 30 days. I thought if I went to work at 4 in the morning and left at noon, I could visit him for the rest of the day (only visitor) My employer found out and fired me.

Others reported that their employer or employment situation was flexible enough to accommodate their caregiving work.

No major impact. I am free to take off the necessary time from work to visit my mother in the Manor when the need arises.

While employment did not change, there were many comments about increased fatigue, stress, and anxiety of trying to manage caregiving and employment.

I have continued to work full-time and have not asked my employer for special consideration; however, it has led to some exhaustion and stress-related issues as a result of doing it all.

Working fewer hours. Family caregivers who reported working fewer hours did so because caregiving was taking more time. The care-receivers health declined, or respite was not available (school or day program closed, respite short-staffed).

At one point I was not able to work and look after my son. So, work has been sporadic because of this.

A few family caregivers reported taking early retirement and others worked part-time or casually to accommodate caregiving. Some reported that their work hours had been reduced due to work availability during COVID-19.

I took early retirement in order to provide a higher level of support for my mother. Also, her dementia symptoms escalated during covid, and I needed more time to deal with her dementia issues and manage to find her a facility that provided a higher level of care.

With less paid work, I had more time for caregiving.

Finally, caregivers reduced work due to stress and anxiety.

The absolute despair, anxiety, depression, worry & sleepless nights due to being LOCKED OUT of my mother's long-term care facility left me in a state where I felt unable to do my job efficiently. She had given up – a sense of abandonment, very dehydrated, loss of weight, & broken heart all contributed to our family almost losing her.

Lost employment. As in working fewer hours, those who lost their employment reported care responsibilities increased and they had difficulty securing paid care staff.

Employment although I would like it is not feasible for me right now with 2 high needs elderly parents with declining, rapidly changing health conditions and changing, sometimes urgent emotional, social, and clinical health needs.

I absolutely could not leave my 16-year-old who is a complex care case. I was offered two jobs during the pandemic and because of trouble securing respite I had to turn down the first offer and quit the second job.

Others left employment because they were concerned about the risk of bringing COVID-19 infection from work to the care-receiver.

It was terrifying to be redeployed in a healthcare setting. I first had an LOA then I was on stress leave and then I had to go back to work so I quit.

Working more hours. The main theme with more hours was that COVID-19 increased employment demands.

Work hours were longer so fitting in the caregiving responsibilities was sometimes a challenge (but always got done). I work for AHS and have also had a stressful 16 months as I work with home care clients too.

I am always "on". I can't put in fewer hours. The circumstances of my job are that it is busier now and more demanding and stressful than in regular times. I'm concerned and have thought about taking some kind of leave, but I am over 65 so not eligible for long-term disability. It would be a hard thing for me to admit as well - that I can't handle things. I've always handled everything that has been thrown at me.

Working from home. Several caregivers reported that they were able to continue working because they worked from their home,

My employment status hasn't changed during the pandemic, I've been working from home for many years to provide the flexibility for caregiving.

However, caregivers frequently reported the constant interruptions while working were challenging. Some wondered how they were going to juggle caregiving and work when they had to return to their workplace. Others were considering leaving paid employment.

I was able to work from home during the pandemic. This is the only reason we survived.

I was able to ramp up my caregiving at the cost of my work productivity. Thankfully, we don't have kids, and others with kids were missing work all the time for homeschooling. My employer has been VERY understanding. I am very concerned about what will happen when we are sent back to work. If the mental health programming is still not back, we are going to really struggle. It's been especially stressful trying to balance working from home while providing care at the same time.

I am constantly interrupted by the needs of care I provide. It seems no one except my husband respects my time. I try to get work done but it is done under duress stress and not done as well.

On leave of absence, Laid off temporarily. In these two categories, caregivers sometimes asked for leave or were temporarily laid off due to caregiving responsibilities.

As a casual worker, I requested fewer hours from my boss for the first year of COVID closures, then had to request a leave of absence when another family member died in 2021. Still off on leave and don't know yet when/if I can return to work.

The increased caregiving demands left me unable to manage the demands of my job even after cutting back on hours. It was eventually decided that it was everyone's best interest if I were to take a leave of absence. While my employer has been very understanding and supportive, it still leaves my family without the financial support of my income. I also do not have any real confidence that when my 2 months leave is up, I will be in a position to resume my duties. Every day has become an act of will to complete what needs to be done for the physical and mental health of my family, leaving me with nothing.

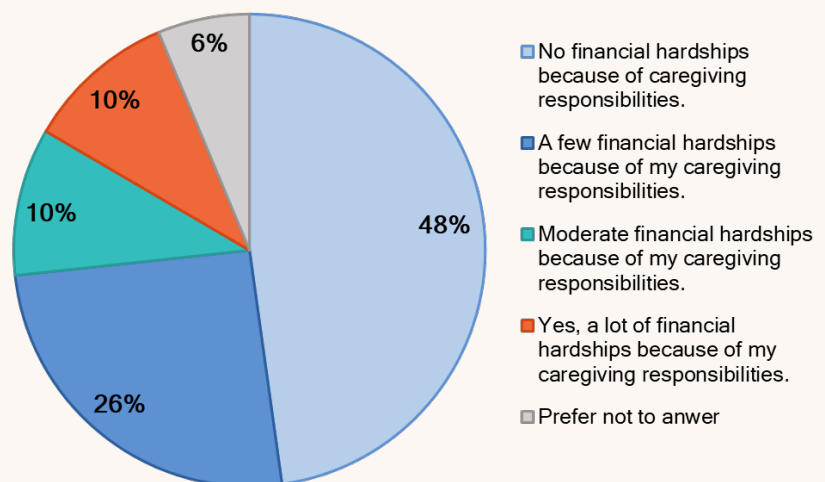
6.2 Financial hardships due to caregiving responsibilities

Almost half (46%) of the family caregivers indicated they were experiencing financial hardships due to caregiving.

- 26% experienced a few financial hardships
- 10% experienced moderate financial hardships
- 10% experienced a lot of financial hardships

Figure 20: Financial hardship because of care responsibilities

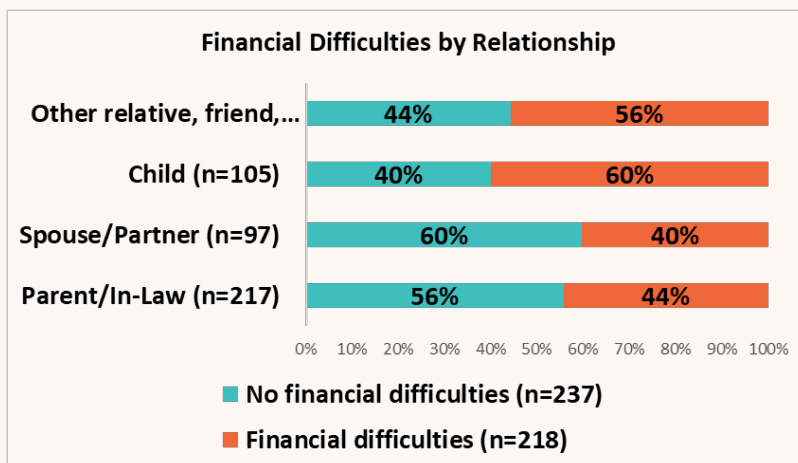
During the pandemic, have you experienced financial hardship because of your caregiving responsibilities?



6.2.1 Financial hardships and caring for children

60% of family caregivers who provided care for children had financial hardships compared to 40% of those caring for a spouse or 44% for a parent. ($\chi^2(3, n=455)=10.5, p < .015$ Cramer's $V = < .001$).

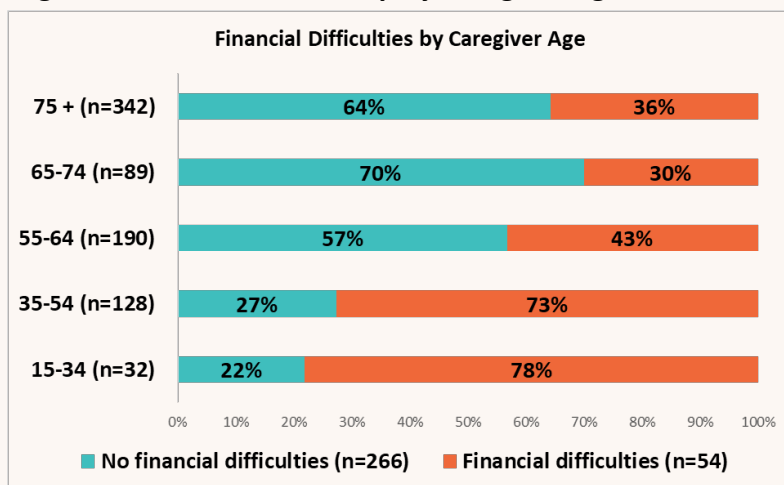
Figure 21: Financial hardship by relationship



6.2.2 Financial hardships and caregiver age

Younger caregivers were more likely to experience financial hardships compared to older caregivers ($\chi^2(4, 520) = 36.62, p < .001, \text{Cramer's } V = < .001$)

Figure 22: Financial hardship by caregiver age



6.2.3 Financial hardships and care location

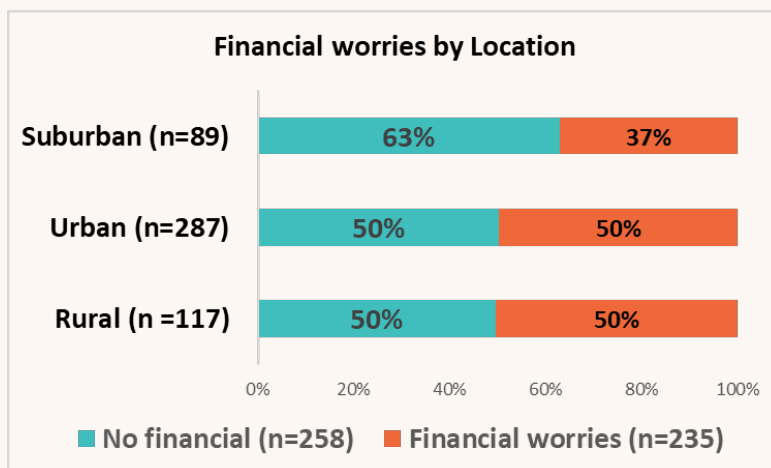
Rural, suburban, urban

Half of urban (50%) and rural (50%) participants indicated that they were experiencing some financial difficulty. In contrast, 37% of suburban caregivers reported financial difficulties. ($\chi^2(3, 493)=10.9, p < .012$ Cramer's $V = < .012$)

Healthcare Zone

Financial worries by Healthcare Zone were not significantly different. *Not shown in the graph.

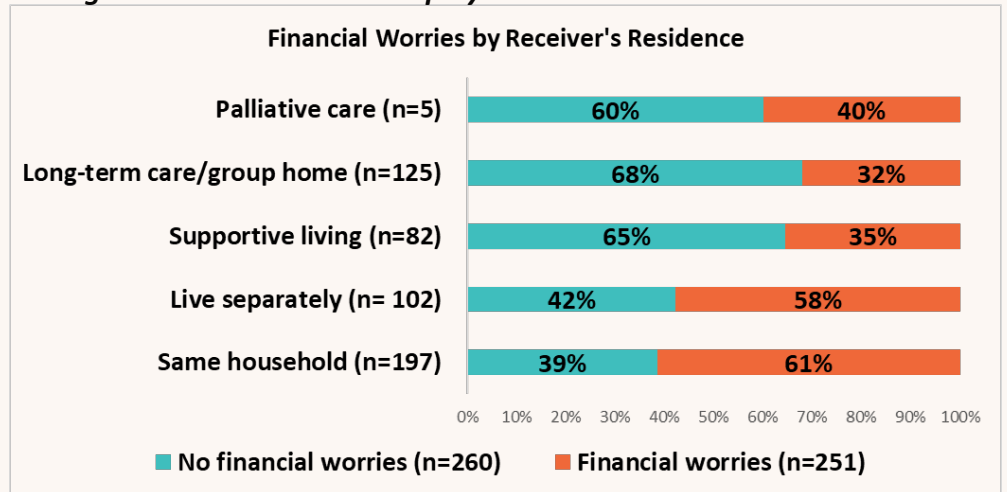
Figure 23: Financial hardship by rural, suburban, urban



Care-receiver's residence

Notably, those caring in the community, for a care-receiver who lived with them (61%) or in a separate home (58%) were more likely to worry about finances than those caring for a supportive living (35%) or long-term care (32%) resident. ($\chi^2(4, n=511)=36.1, p < .001$ Cramer's V = $< .001$).

Figure 24: Financial hardship by care receivers' residence



Family caregivers' comments revealed that reduced incomes, increased costs of living, and out-of-pocket costs for care caused financial hardships.

Since COVID started the increase in monthly bills has skyrocketed. Our insurance [went] up 36 percent over the past 2 years, groceries have tripled, utilities doubled, gas for transport has made it so we miss many things. We used to provide a very balanced meal. We can't do this anymore. We are already 24-7 caregiving, trying to look after our own families, school, lost wages from missing work, and now stressed to the max with increased everything.

Financially it is also challenging as I am also providing financial support due to the increased needs of the person I am supporting.

I need the option of bringing a sibling to an appointment if I cannot find childcare or cannot afford it that month. Emergency visits and required routine appointments are very difficult when no siblings are allowed (breastfed children for example) and childcare gets very expensive. Better outside supports for my son, he needs more financial support from AISH and AADL, quicker access to specialized healthcare, and more access to recreation.

A few caregivers indicated that they needed to return to work,

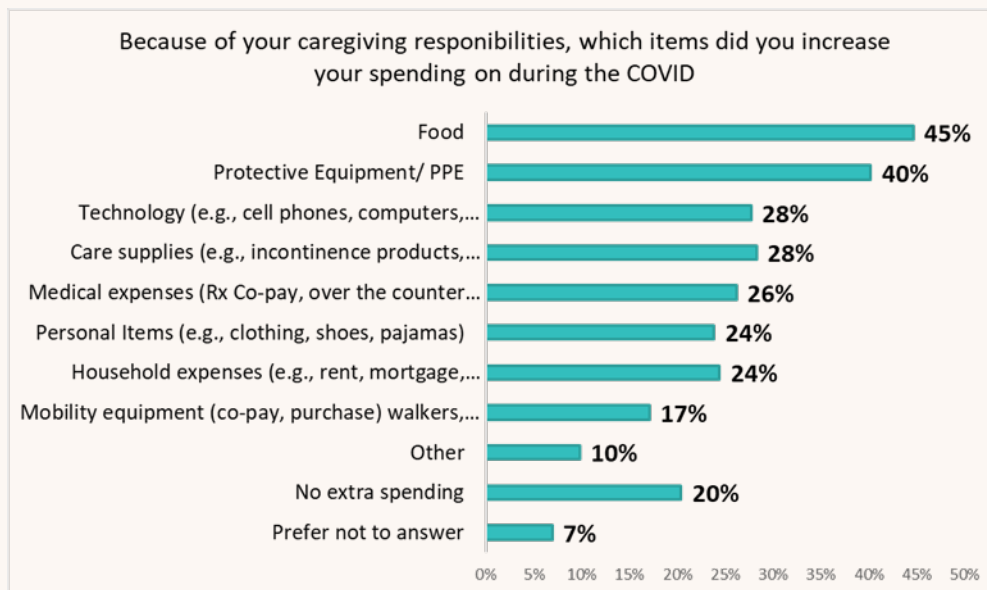
I need to return to work part-time or 20 hours a week or I cannot afford my home mortgage."

6.3 Increased spending on care supplies due to caregiving responsibilities during COVID-19

We asked caregivers what items they increased spending because of their care responsibilities during the COVID-19 pandemic.

- 20% did not increase spending
- 45% increased spending on food
- 40% on protective equipment
- 28% on technology
- 28% on care supplies
- 26% on medical expenses
- 24% on personal items
- 17% on mobility equipment
- 10% on other items

Figure 25: Increased spending on care supplies



While we expected spending on personal protective equipment and technology would have increased, family caregivers noted that as care-receivers were at home more, their spending on many other items (food, care supplies mobility equipment, and medical expenses) increased.

Hopefully, caregiving expenses will decrease as the schools provide more supports but there are still not enough supports for kids with special needs, especially for mental health.

The increase in living costs for my loved one during the lockdown was hard, as all my own expenses had gone up. I was faced with increased costs for food, insurance, mortgage, power, and gas to heat my own home.

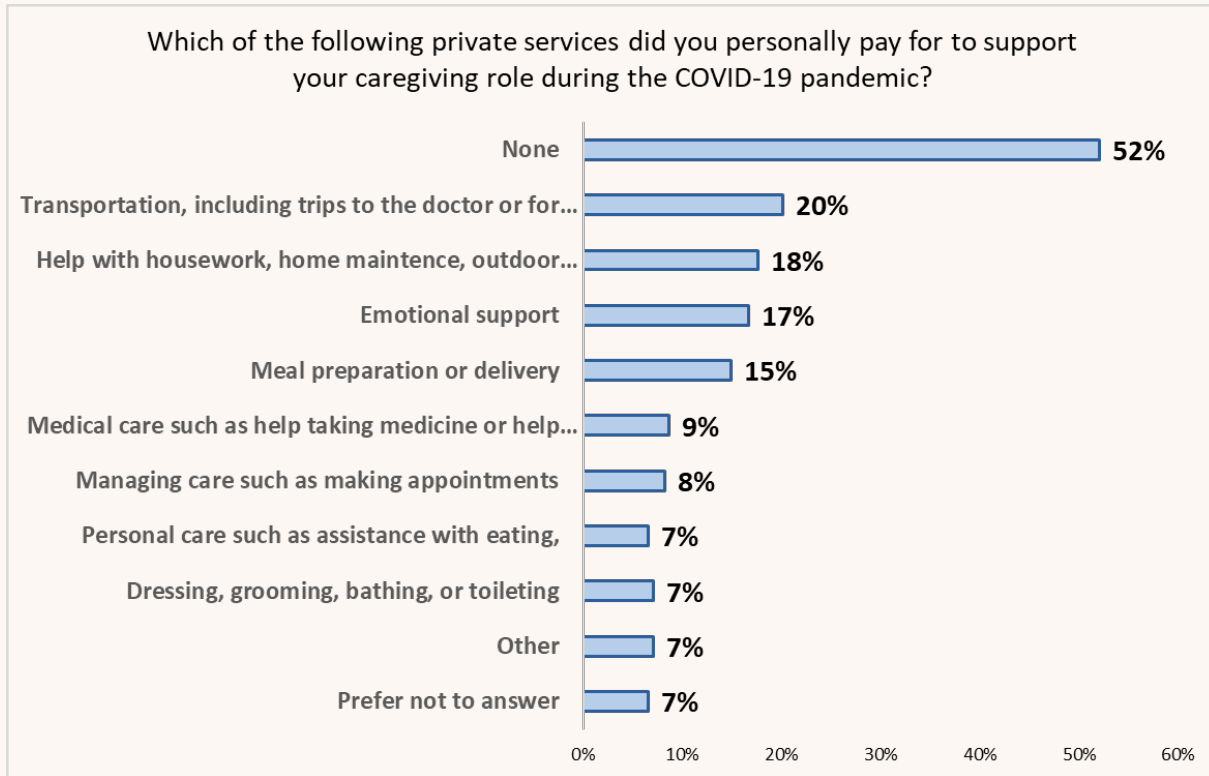
I provide care for a low-income senior. As a result, I've had to pick up additional costs to ensure she has all of the supplies, and support that she needs. It would be beneficial if for example, a note from the patient's family physician would qualify for some sort of caregiver relief to cover the additional cost that I have had to incur to provide appropriate care.

6.4 Increased out-of-pocket expenditures on services to assist with caregiving responsibilities during COVID-19

We wanted to understand the types of services family caregivers paid for privately to support their caregiving in the COVID-19 pandemic. Just over half of the family caregivers (52%) did not purchase private services. For those who did purchase services out-of-pocket, the most frequently purchased items were:

- 20% transportation
- 18% help with housework, home maintenance, or outdoor work
- 17% emotional support (e.g., friendly visitor or support worker in congregate care)
- 15% meal preparation/delivery

Figure 26: Private pay for services to support caregiving role.



The qualitative comments reinforced the spending on travel.

It would be nice to qualify for some assistance, being I travel hours every time I go into caregivers.

We are self-employed so therefore I do not qualify for any help.

Having my husband in long-term care plus maintaining a residence for myself has doubled my cost of living. I also have the cost of driving for an hour when I visit him. My income has not increased to cover that.

Comments from the 17% of caregivers who spent funds on emotional support and stimulation for the care-receiver revealed they did so to maintain the receiver’s wellbeing. Many prefaced their comments by noting the physical care was excellent, but emotional support and meaningful activities had been sparse.

My mother is in a care facility and her basic needs are taken care of. However, prior to COVID, we provided her with extra care - outside personal care support. This does not speak to a need for financial supports - however, speaks to the need to be able to resume this important support again.

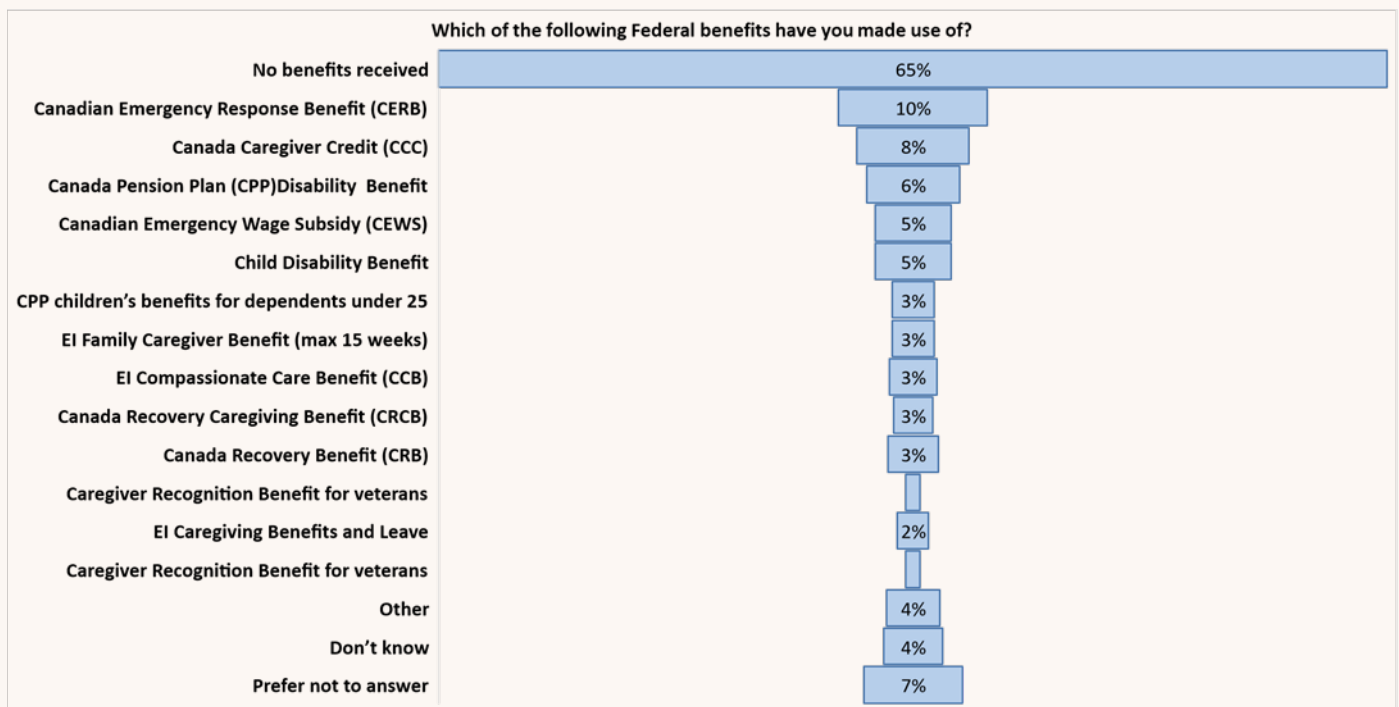
During nonpandemic times we employ various support people to supplement nursing home care which is too sparse. For example, paid companion during the work week, massage therapists, speech-language pathologists for swallowing therapy, a music therapist in the past.

6.5 Federal benefits

We asked family caregivers to indicate all of the federal financial benefits they received. Receipt of financial benefits by survey respondents was the exception. Of the benefits typically available, 8% received the Canada Caregiver Benefit, 3% received the Employment Insurance Family Caregiver Benefit, and 3% received the Employment Insurance Compassionate Care Benefit. Of the COVID-19 specific benefits, 10% had received the Canada Emergency Response Benefit (CERB) and 3% received the Canada Recovery Caregiving Benefit.

In comparison to the Alberta survey respondents, the 2018 Statistics Canada General Social Survey—Caregiving and Care Receiving reported that 8% of their survey respondents received federal tax credits, and 6% received funds from a government program. ^[31]

Figure 27: Federal family caregiver benefits



Many caregivers referred to being fortunate they were retired or had sufficient income.

Fortunately, I do not anticipate needing financial support, I am managing without as best as possible.

Many caregivers had never heard of any of the federal supports listed.

I have never heard of any of these government programs. Who should let me know about these and if I am eligible?

I did not even know of any of these programs that were available. So we need a very easy one-stop mechanism to access them depending on set criteria. And hopefully having this financial assistance is not so restrictive in their criteria as individual needs vary considerably between people and over time.

Governments at all levels make obtaining additional financial supports too onerous and time-consuming.

Knowledge about what supports are available to me, easy access, and assistance with completing forms.

I need more awareness of all the Federal benefits that could be applicable.

I work contract (paid for the hours I work). I work less because I need to spend more time caregiving. I don't know what benefits I could apply for.

I'm self-employed and there was no support that I know of.

I didn't know financial help was available for caregivers. More info has to be made available to people so they can get help.

Others found it was difficult to qualify for the programs available.

I have been investigating the Disability Tax Credit application with CRA.

I was told I didn't qualify for Federal Government financial support as my Dad is not terminal. He has dementia and is not able to live on his own.

Had family members pass away and weren't able to get any CERB or other benefits. The cost of basic utilities and groceries/ gas makes it so hard to make ends meet.

It seems like we don't qualify for any caregiving benefit before and after I quit my [name of profession] job.

As I am not eligible for EI. I am not eligible for any of the financial support that was available. So, any financial support would have been welcome.

Any help would be great, but I seem to fall thru the cracks since I work full-time and do not meet the qualifications for any programs. Although I am taking care of my aging mom, my chronically ill roommate, and backup babysitter for my grandchild there are no supports for me.

A few pointed out that COVID-19 programs were only available for those who had been employed prior to the pandemic, not those who left work to care.

I have lost the remaining years of my employment. It will impact my years ahead in many ways.

I would also like to mention that the pandemic affected me by depleting my savings as I had to cover additional expenses that resulted from it. For caregivers that were already a caregiver when the pandemic started and were not employed, the Federal Government provided no caregiver assistance payout. Caregiver payout was given only to people who took time away from their employment

In the qualitative comments, most caregivers talked about caregiver benefits not being available to those who needed financial supports, however, there was one caregiver who thought too much had been spent on support during the COVID-19 pandemic.

Fortunately for my husband and myself, we were able to keep working while caregiving. But, for many caregivers, they are not. Government Caregiver Benefits for those who have to give up their employment to take care of their care recipients would make a significant impact on our caregiver community.

Currently, financial assistance for a person who becomes ill is provided if the illness is permanent or if the person was working before becoming ill. If a person finishes school and is then diagnosed with cancer, there is no income support for them. Their caregiver is not eligible for caregiver support unless they are terminal. We could afford grocery delivery and other small things that make the demands of caregiving less intense if my partner had income assistance. If a person is medically unable to work, they should be eligible for income assistance. It does not make sense that a person who worked for a year gets assistance but that a person who works for 5 years, goes to school for a few years, and is then ill and unable to work receives no assistance. It makes more sense for my partner to receive income assistance than to create a difficult-to-understand web of individualized supports that require professional-level understanding to find, apply for, and receive.

None - the public system (taxpayers) has paid for enough through the COVID response. The system needs to scale back supports now or we will be setting future generations up for failure.

7. Caregiver Stress, Self-Rated Mental & Physical Health, Frailty, Anxiety, and Loneliness during the COVID-19 Pandemic

Even before COVID-19, family caregivers' circumstances varied widely, however, the factors associated with stress are being overloaded with care work and worry: 1) caregiving over 21 hours a week, 2) caring for someone with depression, responsive behaviours, dementia, anger, and or severe disability, and 3) living with the care-receiver.^[15 16] Financial strain is another well-known risk factor for stress, sleep disturbances, and depression.^[17-19]

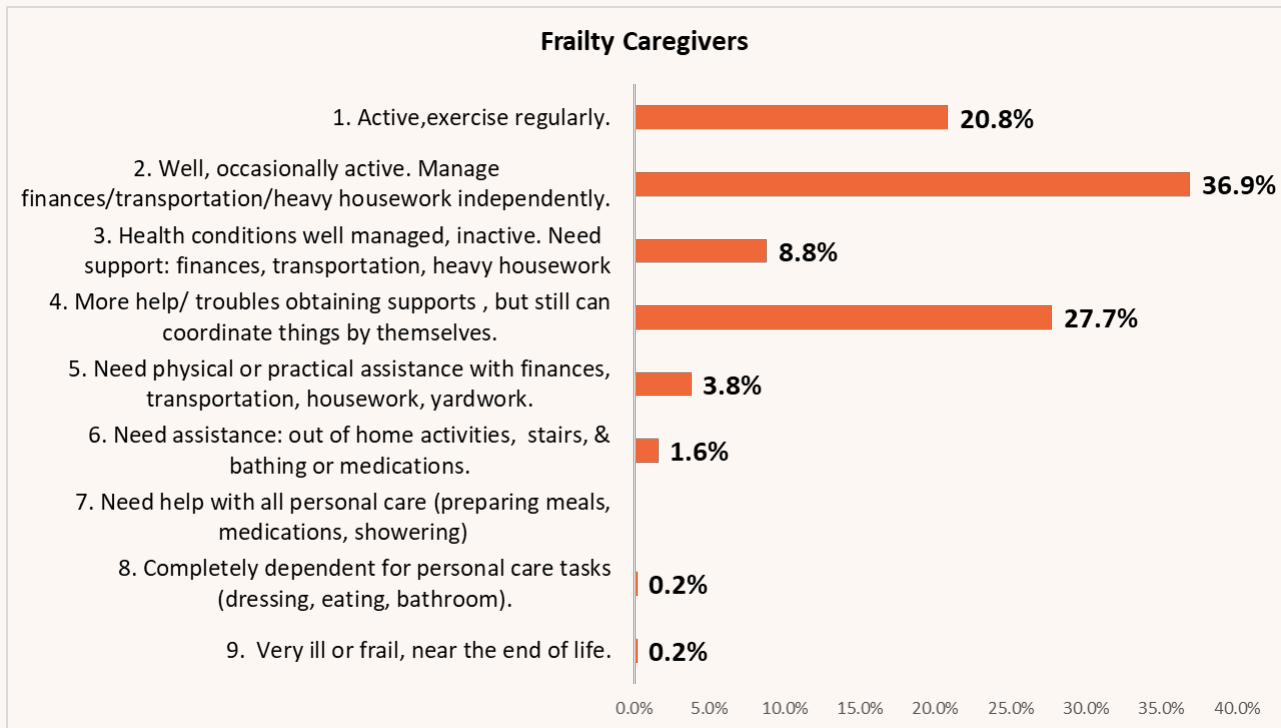
7.1 Caregiver's ratings of frailty

We used a community version of the Clinical Frailty Scale to assess family caregivers' perceptions of frailty.^[5 6] The 9-point screening tool broadly identifies the level of frailty in a series of 9 questions about how the person can manage in their daily life. The score ranges from 1 (very fit) to 9 (terminally ill) with the scores of 4 to 6 corresponding to moderately frail. There were 499 completed scores.

- 66.5% rated themselves managing well (Ratings 1-3)
- 33.1% rated themselves as moderately frail (Ratings 4-6)
- Two caregivers rated themselves as very frail or near the end of life

Those with frailty scores of 4 to 6 would benefit from health providers asking them what would help them to maintain their own wellbeing as well as to support their access to and navigation of those resources.

Figure 28: Frailty: family caregivers' ratings of how they were managing



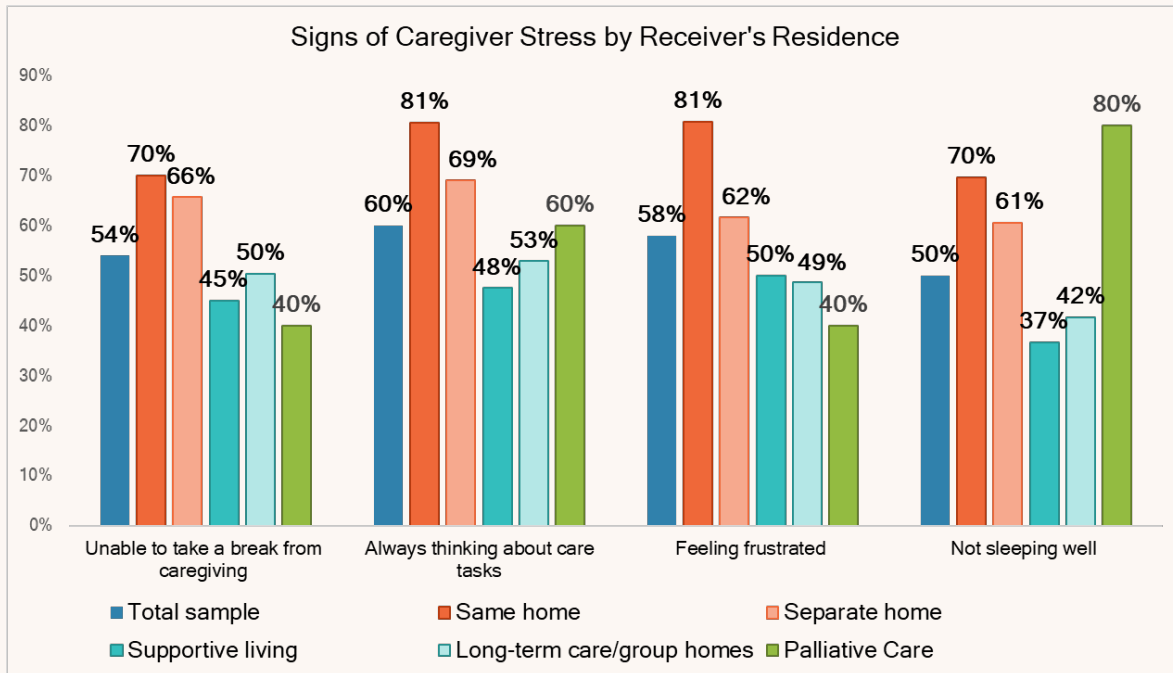
7.2 Caregiver stress: Increased during the COVID-19 pandemic

Signs of caregiver stress are physical, mental, and emotional exhaustion. Typically feeling overwhelmed by care tasks, constantly worried, frustrated, getting irritated or angry easily, and having trouble sleeping are signs of caregiver stress.^[20 21] Notably, over half of the caregivers completing the survey reported at least one or more of these symptoms of stress. Since the COVID-19 pandemic:

- 54% of family caregivers agreed that in the past month, “I have not been able to take a break.”
- 60 % of family caregivers agreed that in the past month they were always “thinking about all care tasks they had to do.”
- 58% of family caregivers agreed that in the past month, they have been “feeling more frustrated.”
- 50% of family caregivers stated that since the COVID-19 pandemic they were “not sleeping well.” See Total sample in Figure 27.

As would be expected, the caregivers caring for a care-receiver in a community home (same home or separate home) were significantly more likely to report being unable to take a break from caregiving, always thinking about care tasks, feeling frustrated, and not sleeping well.

Figure 29: Signs of stress by care receivers' residence

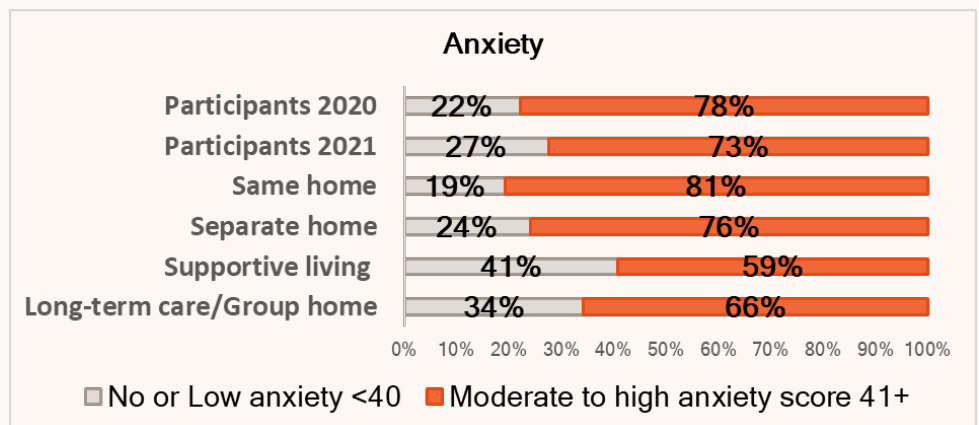


7.3 Caregiver anxiety

Anxiety is the most frequently occurring psychological disorder among family caregivers. It typically rises as care responsibilities increase and energy is depleted.^[22-27] Measured on valid and reliable Six-Item State Anxiety Scale,^[28] 73% of the family caregivers had moderate to high levels of anxiety. See Appendix 1 for methods.

The proportion of family caregivers who were anxious in 2021 (73%) was slightly less than in our 2020 survey (78%). The proportion of the caregivers caring for community-dwelling residents either living in the same home (81%) or separate homes (76%) who rated as moderate or high for anxiety was significantly higher than for those caring for congregate care residents (supportive living 59%; LTC/ group homes, 66%).

Figure 30: Proportions of family caregiver anxiety by receivers' home



Some family caregivers added succinct comments, “Tired, Anxiety, Depression.” Others explained that not being able to care for supportive living or long-term care residents increased

their anxiety. Others connected to lack of sleep, work overload, and stressful situations to anxiety. One caregiver noted how virtual healthcare visits significantly reduced anxiety.

I need to be able to see my mother on a regular basis to support her emotionally as well as to ease my anxiety about how she is doing in her care home.

When I'm feeling rested, I can take on the world but when the anxiety gets high it brings me down. Should we be putting our name in supportive living as we're different levels of care? I want to see more in-home supports available for individuals who have difficulty leaving the home - respite, work-related childcare, nursing, physical therapy, occupational therapy, speech-language pathology. - I think virtual services should continue. There was a time where we had weekly appointments - and would need to pack up my son's things and then wait for an hour or so for each appointment. It was exhausting and gave me intense anxiety as my son can have severe seizures at any moment. I, myself am traumatized by seeing his seizures and have significant anxiety about them in general, let alone in public. Virtual services have been amazing - no need to pack up, wait at the clinic, or worry about managing things in public by myself.

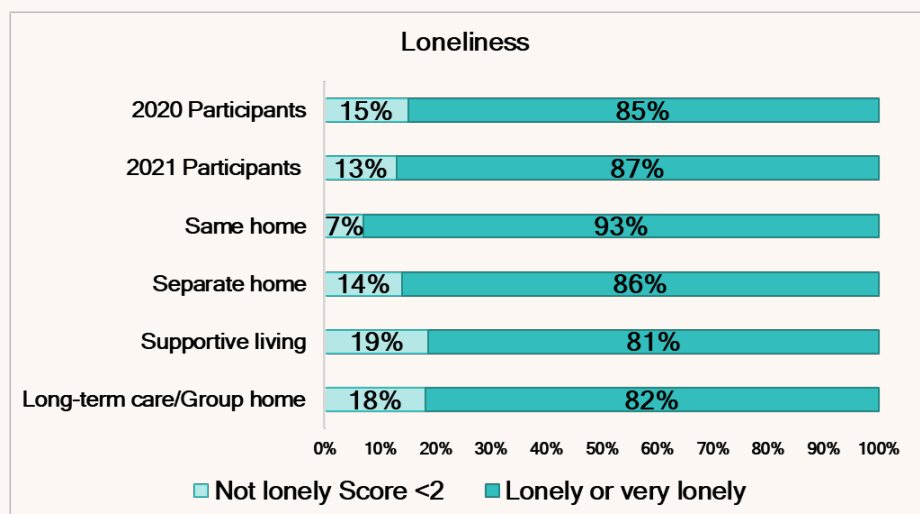
7.4 Caregiver loneliness increased during the COVID-19 pandemic

Family caregivers are particularly at risk of isolation and loneliness.^[29-32] Feeling lonely is linked to the risk of depression, dementia, poor self-rated health, and premature mortality.^[29-32]

Loneliness carries the same health risk as smoking 15 cigarettes a day. The risk of premature mortality is as lethal as alcoholism.^[30] We used the Six-Item DeJong-Gierveld Loneliness Scale to assess family caregiver loneliness.^[33] (See Appendix 1: Methods).

In 2021 the percentage of family caregivers who were lonely was high (87%) and statically similar to the proportions we reported in 2020 (85%). A slightly higher proportion of family caregivers caring in community homes (same home 93%; separate home 86 %) were lonely compared to those caring for congregate care residents (supportive living 81%, long-term care 82%).

Figure 31: Proportions of family caregiver loneliness by receivers' home



In their qualitative comments, family caregivers wrote more about the care-receiver's loneliness than about their feelings.

Her mental health takes a hit when she is isolated, but the burden is much greater on me as she calls me upset and lonely regularly.

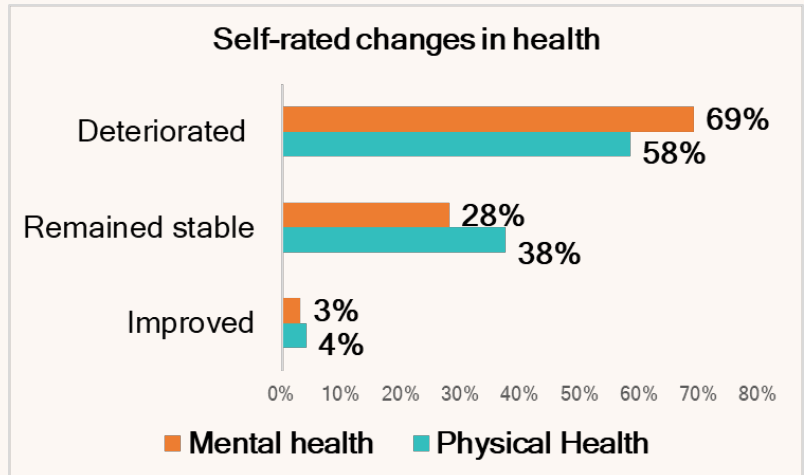
Our elderly in care, are suffering mentally and emotionally due to COVID- 19. They are lonely they miss their families. Of all of the demographics impacted by COVID, I believe older people have suffered the most and lost the most. It's just sad.

7.5 Caregiver self-rated mental and physical health deteriorated during the COVID-19 pandemic

We asked family caregivers if their physical and mental health had improved, remained stable, or deteriorated in the last year.

- 69% of family caregivers noted a deterioration in their mental health.
- 58% of family caregivers noted a deterioration in their physical health.

Figure 32: Changes in family caregiver's health



In their qualitative comments, family caregivers recognized that they needed time for themselves and to socialize with others to be able to maintain or regain their health.

Time to make doctor's appointments for myself. Someone who could make sure that I have accessed all supports needed for my family member.

The reopening of senior centers for social and physical interaction. Yes, I consider senior centers as health care services.

There was a small percentage that reported their health had improved.

- 4% of family caregivers reported an improvement in their physical health
- 3% of family caregivers reported an improvement in their mental health

Caregivers related their improved health to having time to devote to caregiving, respite care, a receiver who was admitted to congregate care, and feeling like the care-receiver was well cared for in long-term care.

Being retired enables me the flexibility to care at my leisure.

Day Support services were put on hold, an exercise program was stopped, weekend care was stopped but have that back as was too hard to do everything and family doctor deemed it essential so now have respite care back twice a day.

As mentioned, it became too much to do it all by myself and difficult to reintroduce caseworkers once the restrictions lifted a little. I was burned out, and my mental health suffered greatly. This is why I opted to transfer my mother to a private facility assisted living 3 weeks ago.

Just knowing mom and dad are receiving the best care possible, alleviates any concerns I ever had. The staff are amazing!

8. Caregiver’s Self-Rated Confidence to Provide Emotional Support, Navigate the System, and Continue Caring.

In our July 2020 survey of family caregivers, some family caregivers reported qualitatively that they did not think they could continue caregiving at home or that their health may break down from the worry about the care-receiver’s quality of life. In this survey, we asked family caregivers to assess their ability to provide emotional support and to navigate health and community systems. Then we asked if they felt they could continue caregiving.

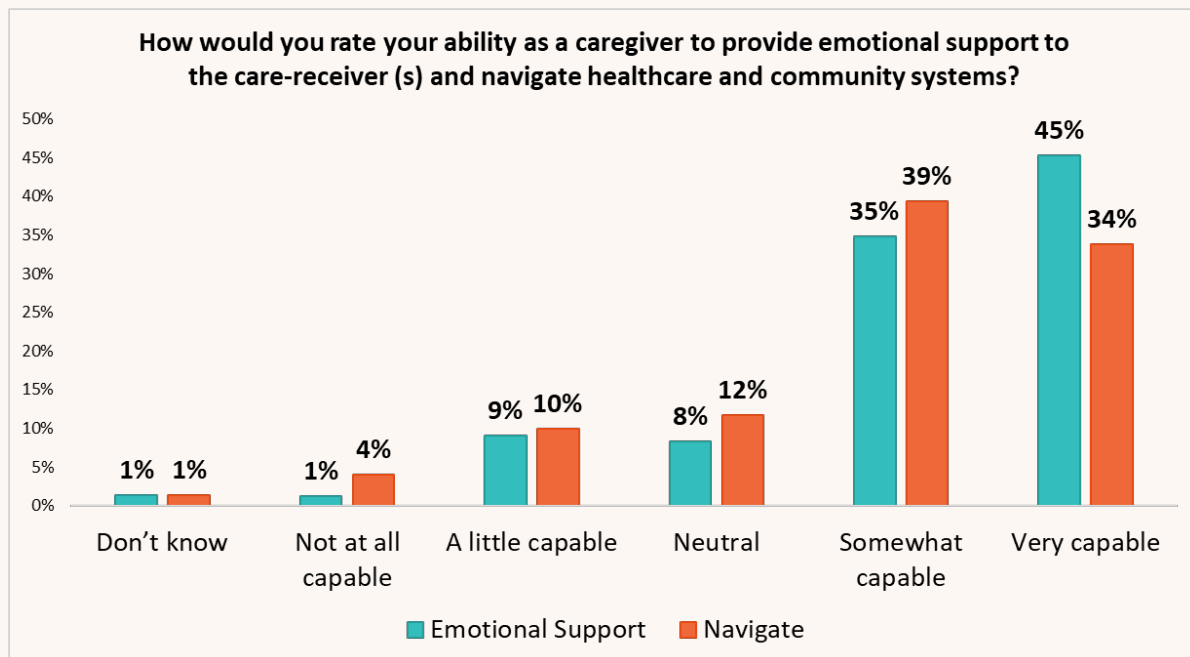
8.1 How would you rate your ability to provide emotional support and navigate the system?

Despite the impacts of caregiving mentioned above, 80% of caregivers indicated they were capable or very capable to provide emotional support and 73% felt they were capable or very capable to navigate health and community systems.

19% of caregivers were unsure of their ability to provide emotional support and 27% of family caregivers would likely benefit from assistance to navigate the healthcare and community systems. Navigation assistance is available through home care, of which 36% of the caregiver reported currently having access or services were pending (Data not displayed in a graph).

The person I care for needs emotional support at times I am not there and more than I possibly can give. She is far more depressed than I have the skills to manage, and it is taking its toll on me. I feel her sadness and frustrations.

Figure 33: Caregivers’ ratings of their ability to provide emotional support & navigate



Aligned with caregivers’ rating of the ability to navigate health and community systems, in their comments a few caregivers thought that caregivers themselves needed to be more proactive in asking for supports, while most commented on the difficulty of accessing the systems and the delay in finding supports.

The resources are there if you reach out for them. Too many people think they can deal with everything themselves, and don't reach out.

The biggest source of stress for the caregiver is trying to navigate the various systems. There is no way my parents could do these things on their own. A prime example is the assumption that seniors are tech-savvy, have access to tech, or can see/hear or understand what is being asked/required so they can access services/programs. As a caregiver, you are frequently denied helping on their behalf due to privacy issues. There are often ridiculous barriers that seniors can not comply with. For example, my mother was denied acceptance to a subsidized lodge for low-income seniors because she did not earn enough income!

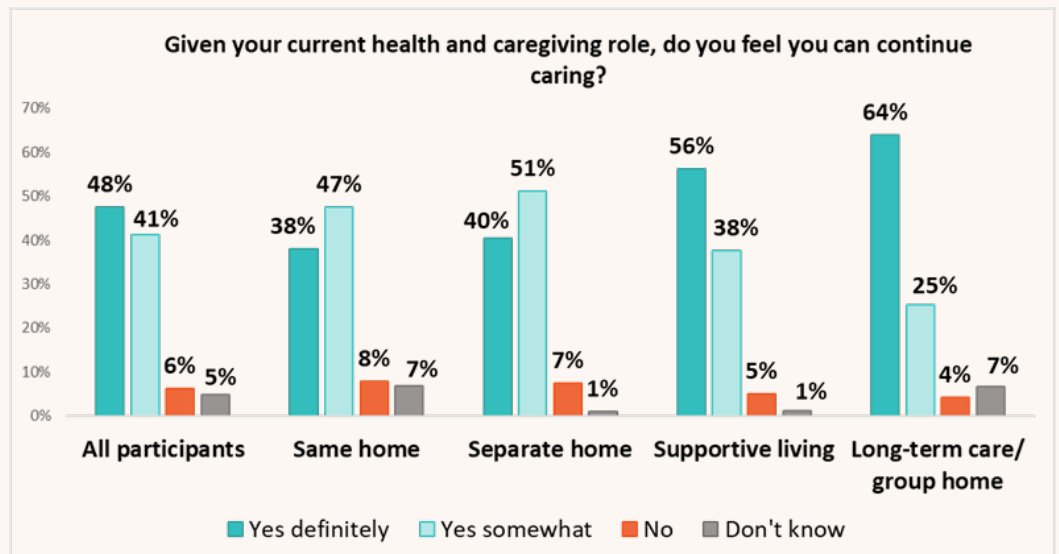
Transition to LTC was very difficult and lacked the proper emotional supports and the appropriate information for what services were available. For example, I was struggling to find the proper clothing for a newly disabled daughter not knowing there are some online adaptive clothing companies in Canada. We had to wait for almost 2 years for her own wheelchair which finally allowed us to use DATS or adapted taxis. This delay meant no community health care visits to dentist or optometrist for example which were both very badly required. We somehow discovered the Glenrose Dental Clinic on our own. The additional caregivers we gathered have gotten to know our daughter well and in turn, this has been of tremendous personal support. The SLP's treatment reports were instrumental in having the RAI coordinator correctly change the persistent vegetative state diagnosis to consciousness - this official change lagged by many years. To be honest I am worn down by the bureaucracy of LTC. There must be an absolutely iron-clad assurance that family caregivers are NEVER locked out again.

8.2 Caregiver's self-rated ability to continue caring.

We asked caregivers, "Given your current health and caregiving role, do you feel you can continue caring for your family member or friend?" Overall, 11% of caregivers responded "no" or "don't know" if they could continue caregiving. The proportions were slightly different by care location:

- 15% lived in the same home
- 8% lived in separate homes
- 6% lived in supportive living
- 11% lived in long-term care or group homes

Figure 34: Caregivers' ratings of their ability continue caring



9. Support for Family Caregivers from Healthcare Providers

The COVID-19 pandemic has stressed the healthcare system and healthcare providers. It also increased family caregivers' responsibilities and stress. We asked family caregivers if any health care provider has asked them about their needs as family caregiver. Just asking can be therapeutic. [34]

In 2021, only 25% had been asked about their needs as a family caregiver.

In comparison, 32% of family caregivers had been asked about their needs in our 2020 survey, four months into the COVID-19 pandemic. [13]

Slightly more of those caring for an Albertan living in the same home or at the end of life were asked about their needs.

Figure 35: Proportion of caregivers asked about caregiving or health
In the last 6 months, has ANY healthcare professional asked you about your caregiving or your health ?

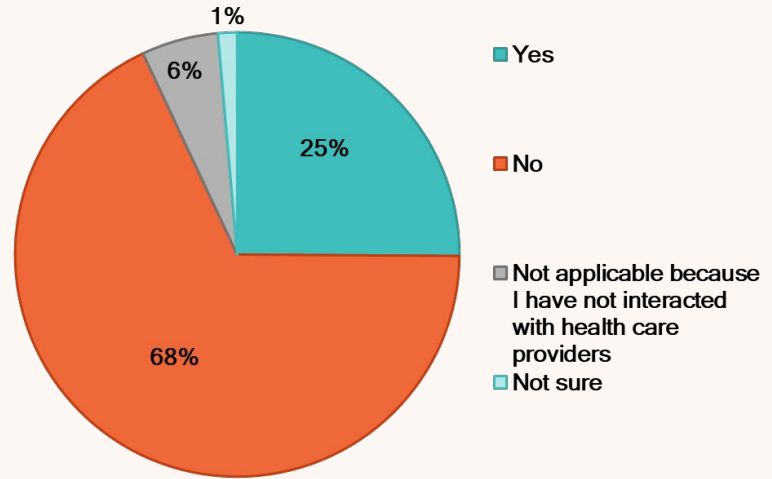
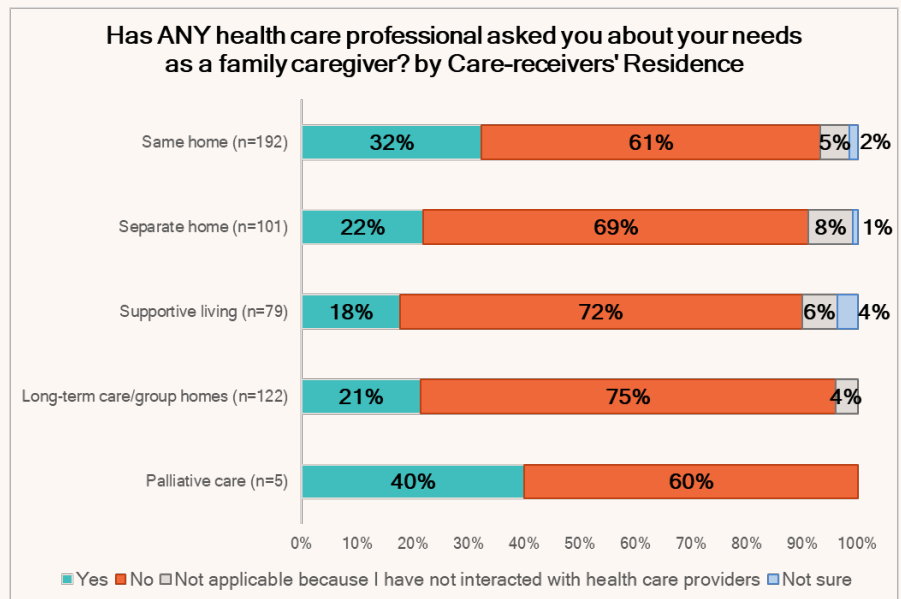


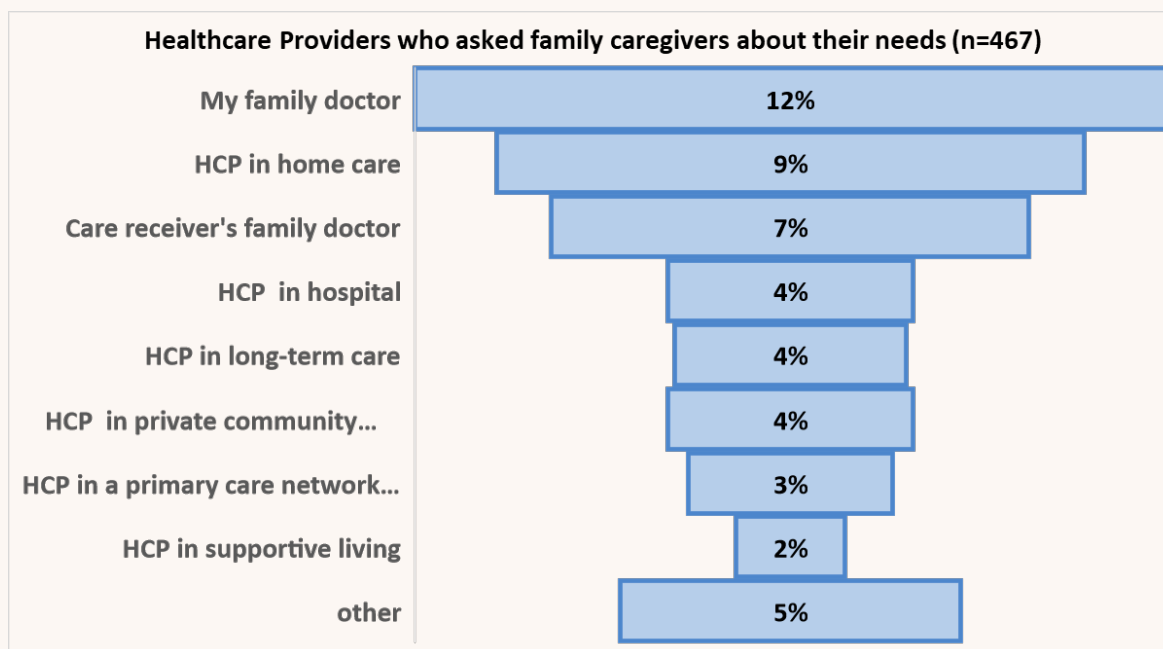
Figure 36: Caregivers asked about caregiving or health by receivers' residence



9.1 Health Professionals who asked about family caregivers about their health or situation

The caregiver's own family doctor (12%), home care providers (9%), and the care-receivers family physician (7%) were the providers whose caregivers reported asking them about their situation.

Figure 37: Health providers who aske caregivers about caregiving or health



In their comments, family caregivers were concerned about the loss of primary care physicians,
*Primary care is most important yet seems to be overlooked by the Ministry of Health.
 More doctors in Southern Alberta. Ours is retiring and we are not currently able to get a new one.
 Keep our GP from leaving Alberta*

Family caregivers valued health providers' affirmation of a job well done.

*The homecare nurse checks in once a month but says our son is looked after better than any of their clients. My husband and I work together to provide for our son. He is a quadriplegic.
 The geriatric nurse [Name] and Dr [Name] in Red Deer. [Name] with recreation I am very lucky to have a supportive town and community that is dementia aware in my town.
 Support from the social worker at the Alzheimer's Society has been very helpful. I will continue to be in contact with them.*

A few family caregivers protested the lack of support and having to ask for assistance,
I need the case manager to check-in or someone to check to see if I need anything. I have to do all the calling, all the research, no one tells me anything.

10. What do family caregivers suggest they need in the future?

We asked family caregivers about what they believe needs to be done to support family caregivers caring for Albertans living in community homes, supportive living, or long-term care. See Appendix 3 for our qualitative analysis methods. They wanted:

1. attention to the care-receiver's overall wellbeing, and
2. support for family caregivers to maintain a balance in their life, work, and caregiving roles.

10.1 Supporting the care-receiver's wellbeing

Ensuring the care-receivers wellbeing was foremost in family caregivers' qualitative comments. The Oxford English dictionary defines wellbeing as "the state of being comfortable, healthy, or happy." It encompasses the person's physical, psychological, emotional, and spiritual health along with notions of "living well" with mental and physical illness, disabilities, frailty, and dementia.

The key themes related to care-receivers wellbeing were:

- 1) Respect the care-receiver as a person,
- 2) Ensure staffing levels to meet the care-receiver's care needs,
- 3) Make certain care-receivers are supported emotionally, and
- 4) Ensure care-receivers have personally meaningful activities.

For the most part, family caregivers noted that their care-receivers' physical care was good quality, however, they wanted care-receivers' mental and emotional health supported. They considered respect and participation in personally meaningful activities to be critical elements in mental and emotional health.

10.1.1 Respect the care-receiver as a person

Caregivers used terms such as "respected", "valued", and "treated with dignity" to indicate the importance of recognizing the care-receiver as a person.

Where is the mechanism that values our intellectually disabled and infirm and values their life and contribution to the community? Our population has been disproportionately left out during the COVID19 pandemic. Left with no physical supports, no financial supports, no health supports especially since virtual technology is not an appropriate means of intervention.

I think that when we agree to have our loved ones placed in LTC, it is under the impression that their last days will be filled with quality, dignity, and respect for their wishes.

The immigrant population has cultural and language barriers. Need to educate medical staff to be more inclusive, to treat all people with respect and equality.

10.1.2 Ensure staffing levels meet care-receiver's needs

Aligned with recognizing the care-receiver as a person, family caregivers recognized that having adequate care time was important to the care-receiver's overall wellbeing. They regarded "care" holistically as practical care tasks as well as socio-emotional care that provides care-receivers with meaningful things to do. Overwhelmingly, caregivers wanted to ensure that they, family caregivers, and healthcare providers have enough time for holistic person-centered care.

Caregivers of long-term care residents reported residents' care needs were complex. They indicated that ensuring caring for the care-receiver's basic activities of daily living such as dressing, bathing, mealtime assistance, and bladder and bowel care required more time than health care aides were allotted for care. Thus, staff had little time for emotional support, assistance to engage in meaningful activities, or support physical activity. Many family caregivers felt obligated to spend significant time supplementing paid care.

[Where] my dad is, they have some really great staff and a few not so great. Part of the issue is the staff/resident ratio is not meeting the requirements necessary for the quality of care and dignity of the residents. The nurses and healthcare aides have far too many patients that require a lot of care.

My mom is fortunate to have enough remaining equity from her home sale to pay for additional private care in her [long-term] care facility, but it's very expensive. If the province paid for a higher ratio of staffing, I could let go of the private care. During the lockdown last year, my mom's weight dropped to 88 pounds-- she is 5 feet tall. Her private caregivers can spend the hour or longer she needs to feed her at each meal where the facility staff cannot. The extra help also keeps her hydrated and more alert, so she can stay awake long enough to eat. I am retired, but also a senior awaiting a second hip replacement. I'm fortunate to be retired but ensuing my mom's quality of care takes significant mental and emotional effort as well as physical time.

While caregivers of long-term care residents were the most outspoken about insufficient care time, caregivers also thought homecare, the family and child support system, and adults with disabilities systems were underfunded. All family caregivers reported their anxiety and distress increased if they were worried that the care-receiver was neglected or disengaged.

10.1.3 Support care-receivers emotionally

Family caregivers regarded supporting care-receivers emotionally was a significant part of their caregiver role and of holistic care. Emotional support included terms such as time to listen and human touch (e.g., being able to hold hands or provide reassurance through touch).

I provide ongoing emotional support to my husband and medical care intermittently when his congenital, chronic medical condition requires more intensive care in a relapse.

The pandemic has increased the amount of emotional support that I need to give my mom, she is so isolated.

The times when there were no visitors allowed in long-term care, the person for whom I provide care's condition deteriorated significantly. They have cognitive changes and it was difficult for them to understand why I and others were not visiting. They stopped eating at times etc. The person had a private room and we would have come in hazmat suits if necessary, but I could not understand why ONE person could not visit.

Some mental health support for my father. He is losing ground to Parkinson's, grieving for the loss of his wife, and is having a tough time coping. Dealing with his sadness tears me apart and wears me down. Homecare deals with physical things but mental health gets left behind.

10.1.4 Support for care-receivers to engage in meaningful activities and exercise

While care was important, family caregivers thought that opportunities for care-receivers to engage in meaningful activities had been overlooked in the COVID-19 pandemic. Caregivers referred to activities as “enjoyable activities”, “stimulation”, “engaging things to do”, “interactions”, “visits with family and friends”, and physical exercise. Many caregivers reported that care-receivers became anxious, depressed, and disengaged when lacked stimulating activities or were isolated from family and friends by COVID-19 protocols.

We don't need healthcare services, but it would be wonderful to have more social activities for my mother-in-law. If she was able to get out with a skilled service provider during the day, we would get a break for ourselves. We haven't been able to go out together during the day either for errands or social activities for the past 16 months and it's discouraging knowing that this situation is not likely going to change.

Keeping community-supportive churches and gyms open is essential to maintain health and wellbeing, including morale and social wellness.

Due to a lack of outside resources, he began drinking so had to move back here to be helped.

Several caregivers lauded the importance of community programs for both exercise and socio-emotional support.

My mother used to be able to engage in regular group exercise at a community facility. It was also a place where she met and became friends with people in her group. She is not only losing the exercise component but also a social component to her weekly activities as the result of having to stay away from others physically due to COVID.

When he is not active with the vocational program, he will spend most of the day with the TV. I would like to know how to access more (better) care for my parents regarding recreation and social-emotional interactions for them. I am generally satisfied with the physical care they are currently receiving.

10.2 Work, Life, and Caregiving Balance for Family caregivers

Family caregivers wanted a better balance between their work, life, and caregiving roles. There were four main themes related to balance in caregiver roles: 1) recognize the caregiver role, 2) timely personalized communication, 3) ensure supports address caregiver needs, and 4) relieve the financial stress of caregiving.

10.2.1 Recognize the caregiver role as “Invisible and abandoned.”

Family caregivers are the ongoing source of considerable care and support for care-receivers, and they wanted their role recognized and valued. They noted that family caregivers were essential to supporting the overstretched health systems, yet top-down decisions were made without including input from family caregivers or patients/residents.

We're real people with real feelings. The governments treat us like we're an inconvenient expense and that we're expendable. We need to be truly valued and the people receiving the care need 100% support from the health care system. If there is support that can help the caregiver and or the person living at home, we need the information in a clear easy to access manner. I feel that we don't get all the help available because some form hasn't been filled out or we just don't know about the availability. Caregivers need help in accessing everything that is needed. It's so fragmented and separated. Why does the place that helps seniors get their taxes

done have no parking available or be easily accessible? Downtown is not easily accessible. And I don't feel safe on any transit anymore. Why isn't there a 1-800-caregiver phone number that could help with anything and everything? It needs to be more centralized and streamlined. The whole system seems so fractured and broken.

I need the government to recognize the impact on the disability sector that COVID or any pandemic has moving forward. To recognize the sacrifices parents of neurotypical parents had to make but absolutely identify the additional impact it had on families who cared for loved ones with disabilities. I hit a wall, managing home, working full-time, and trying to ensure my son had the best care I could give him was done by sheer mental strength and, I question my mental strength often. I don't know what the answer is, but I do know many families like mine have felt invisible and abandoned.

I would like care roles to be considered useful unpaid work, not a failure to work. It is the unpaid labour force that anchors the economy and keeps formal health care and social work costs down. It is very unfair to consider those who do it having dropped out of paid labour force.

Recognition, caregiver support day, links to free info sessions.

10.2.2 Timely personalized communication

Family caregivers wanted timely communication tailored to their caregiver roles as a partner-in-care, care coordinator, and care advocate. They used words like truthful, open, ongoing, clearer, active, and listening to describe communication that enabled them to gather information, determine the best course of action, navigate systems, find solutions to problems, and coordinate care.

My husband and I advocate and provide care for my mother. I cannot fully explain the complexities involved in my mother's care and I could literally "write" a book about the intricacies of the AHS healthcare system from the patient's and caregiver's point of view. There is not only disorganization in the way care is delivered to seniors (and the disabled), but also a severe lack of communication at all levels.

There needs to be open and ongoing communication with family members, and family members must be seen as a resource for supporting residents.

We need to be at the table having conversations when policies etc. are made.

As both my parents are in assisted living, ongoing communication which has been excellent in my situation is key. During the pandemic, it was very important to communicate with my parents daily when I was unable to enter the facility. I could sense loneliness, depression, and just bad days. I was able to talk at length with them and also able to share with their caregivers who were amazing in filling the void. Going forward in my case, I would advise those in my position to be very involved in open communication with their facility who went above and beyond in my opinion. If you do this you will know when things are not right.

Better communications, more frequent meetings, and more active involvement by the professional care teams. Movement from facility to facility needs improvement as very apparent no communication/information sharing and fell to the caregiver to continually advise the new team and usually met with skepticism.

We needed regular communication from the LTC facility about our loved one's status. Regular email updates, personal phone calls, more than one facetime once every 2 weeks. family needs to be recognized as part of the care team.

Proper and timely communication from care home #1 - Ability to communicate with other caregiver families at the care home, without the involvement of administration

10.2.3 Ensure supports to address the caregiver's and care-receiver's needs: Ask caregivers about what they need

These caregivers need person-centered supports that meet their unique caregiving situation. As one would expect, when family caregivers, the persons they care for, the conditions requiring care, living situations, and place on care trajectory are all diverse, there were a wide variety of needs going forward. Family caregivers reported they didn't know what they didn't know, what might be available to support them, or to whom they should talk. Several caregivers suggested that health and social care providers should ask family caregivers about their needs.

I would appreciate being asked about my role as a caregiver and given supports/resources that may help me.

I find I often don't even know what questions to be asking so more information on what is available for support, who to talk to about supports, clearer lines of communication with staff would all be helpful.

No needs. Almost half of the family caregivers reported having “no” needs or that they had already found what they needed.

Personally, I don't think that there is anything that needs to be done for us, but I recognize and appreciate that not all caregiving families are in our position. For many caregivers, there is a need for assistance in day-to-day care as well as financial and emotional support.

No, just more contact outside of the LTC where my spouse is. I volunteer at a food bank 3 times a week. I visit friends and family a couple of times a week.

Just knowing mom and dad are receiving the best care possible, alleviates any concerns I ever had. The staff are amazing!!

Many were asking for supports that should be easily addressed, for example, time with a mother before she dies, seeing a spouse who is a resident in long-term care, learning more about dementia, a peer support group, or skills education.

It's not necessarily a service, but the recognition that supporting multiple family members with high needs is taxing.

Strategies for encouraging someone who is reluctant to exercise/move during the day and seems to not care about their personal health.

I want more time to spend with her before she dies. I need to prepare myself for her passing. I would like to be able to see my spouse more often at the nursing home.

Asking for supports that are available. Others were asking for supports that are available in Alberta, e.g., dementia education (Alzheimer Society Alberta, Dementia Network Calgary, Dementia Advocacy Canada), caregiver peer support (Caregivers Alberta, Family Caregiver Centre), or caregiver skills training (Norquest College, Family Caregiver Wellness Workshops).

I want to know more about dementia, especially about how I can help my mother and what services I can advocate for her in her senior's residence and elsewhere.

I would benefit from a group that meets, maybe every other week, for an hour or so. I'd like to know that I'm not alone in this. I joined a U.S.-based online group for caregivers of veterans because there's nothing similar available here.

I would be very grateful if I was given practical education from medical professionals. When I am asked if I have any questions, I don't always know what questions I should be asking. I definitely don't know what symptoms might manifest in the future. However, if I have some practical knowledge I would be better prepared as a caregiver and that alone would lower my own stress level. I feel that having to rely on the internet for medical information is quite unsettling. It gives me hope that medical professionals are getting better at hearing the voices of caregivers. Not all are receptive though.

Respite. Across all the diverse caregivers completing this survey, the respite was the most frequently mentioned unmet need. Caregivers wanted respite to 1) carry out tasks like grocery shopping, banking, medical appointments, or rehabilitation to maintain their own health; 2) maintain other roles e.g., work, parent/ grandparent; or 3) have breaks from long caregiving hours.

There is no additional support giving me a break in caring for my husband who has early-onset Alzheimer's, and I was diagnosed with cancer.

Time for myself. Everyone tells me that I need to take care of myself first, but it has been very challenging to do this during the pandemic. The pandemic isn't over for compromised people either.

The respite was nonexistent in the beginning stages of the pandemic. I found it very difficult being cooped up for so long and not being able to go places and see people or step out of my caregiver role at all. The individual that I care for is nonverbal with extreme aggressive behaviour when frustrated. It was very difficult for him to understand why all of his activities stopped, and why his routine changed so drastically which was expressed with an increase in behaviours and compounded by not having respite available for me to recharge and stay calm and positive

RESPITE, actual hours for a PDD contract, either staff for FMS for PDD, or actual programming within a community.

We need more external supports. In particular, we need respite so that we can go away for a weekend as an entire family. We have 3 children under 6 and my 86-year-old mother-in-law in our home.

We need a break. The cumulative effects of constant care have left me exhausted and our family finances strained. During COVID, our provider agency continued to receive funding for our son, however, they didn't provide care. We were left providing full-time care. The constant strain has resulted in a loss of employment and a significant mental health crisis.

A few people said they were able to pay for respite, they just needed help finding the care.

Because of the risk of falls, I do not feel confident leaving my husband overnight by himself so that I can meet some of my social and recreational needs. I would like to find someone who would stay with him overnight and someone he feels comfortable with. I was wondering about a nursing student who might be able to do that and earn some extra money.

Another small group of caregivers only wanted occasional respite such as someone to step in during an emergency.

Would benefit if I could reach out to someone when I feel tired and need a break. I need the option of bringing a sibling to an appointment if I cannot find childcare or cannot afford it that month. Emergency visits and required routine appointments are very difficult when no siblings are allowed (breastfed children for example) and childcare gets very expensive.

A few reported they had not received respite or the time they received for respite was inadequate. For example, two hours of respite care in a rural area used much of the time for travel.

My husband's health is deteriorating and actually, COVID didn't make that much difference. I would have wanted to stay home and make sure he was safe, and I don't think we would have travelled although that would be harder for my husband to expect. We started with home care in the fall of 2020 and provide help with showering and I get respite care--2 hours every other week. We live at least a half-hour away from the closest larger community, so I actually get 1 hour each time home care comes. My concerns going forward will be what happens when I need to go to appointments and my husband can't come with me - I would be very reluctant to leave him especially when most specialists are in Calgary. With all my own pursuits I have been able to Zoom and what will happen when Zoom is not an option? I will not be attending social or educational events. We have been struggling with finances as well.

My parents live in a village with very little support to keep them in their own homes. I am providing healthy meals, house cleaning, along with trips for appointments, shopping, etc. I guess the largest need for them is helpful in their home and companionship. I need a break. I still work, have my own family, and feel like I am falling apart trying to keep everything and everyone going

I would appreciate access to rural counselling in-person within 50km of where I live. I know there are several telephone and virtual mental health services where volunteers and students listen. This is not the same, and I am tired of everyone acting like COVID is worse than my mental health condition. If we are actually taking caregiver mental health seriously, then we need someone willing to provide even one day of outreach per week to either rural hospitals or FCSSs.

Mental Health. About two-thirds (69%) thought their mental health had deteriorated in the last year. Prior to the COVID-19 pandemic, family caregivers are a group with higher levels of adverse mental health symptoms.^[35 36] During the pandemic, worry about COVID-19 infections, reduced practical and emotional support from family and friends, feeling isolated, and intense caregiving further challenged caregivers' mental health. Family caregivers wanted improved access to mental health care resources for themselves, the care-receiver, or both.

Post-COVID PTSD support (dealing with the anxiety of covid returning and how it affects supporting family).

Support for my own mental health with the stresses from this and help from a professional to understand the best way to deal with his illness.

Not sure the COVID is the cause - but in general the emotional strain of being a caregiver can be overwhelming some days.

Someone that understands - we talk about mental health and support is there, but have you tried to access mental health supports? This is a very sad situation. Caregivers and parents are falling apart, with limited support.

Several caregivers contended that mental health supports were available only in a crisis. They wanted access to support earlier.

Mental health supports. Waiting lists are so long when you reach out for help. There are not enough resources for the need. Unless a person is in crisis and suicidal they do not have resources to help keep you from getting to that point.

There needs to be better access for caregivers to get mental support. There needs to be groups that are more diverse and are open to the LGBTQ2 Community.

Mental health services have been so hard to access. I could use help with that. I also find it hard when I have a therapist that I have a relationship with now, and no support to see them. I started seeing the therapist because no one at the hospital would call us back and referrals took so long. I don't want to have to start again with a new therapist.

Others pointed out that mental health supports were costly

I have access to psychological services through my benefits. If I didn't, I would like to see coverage for such services, specific to caregivers.

Psychological services being covered and not where it's funded at 75.00 as psychologists are 200.00 per hour do funding at 75.00 does not help.

Therapy professionals are costly & we have a limit of \$500yr for their services. At +\$100/appt, that \$ doesn't go far.

The stress of caregiving without relief from the day program (and the resultant costs) has caused me to require therapy, which I cannot afford as often as my therapist wants me to attend.

Rural caregivers reported there were fewer mental health supports in rural areas,
You have cancelled Canadian Mental Health supports in rural remote Alberta.

10.2.4 Relieve the financial stress of caregiving.

Many caregivers recommended financial relief, such as tax breaks or credits, monthly allowances, and a guaranteed annual income,

Any type of financial support! My family struggles every day due to the loss of my employment and with having to renovate my home in order to have my quadriplegic daughter move back in. Income supports for parents who have to stay home with children over the age of 12 with severe needs!!!!

A tax system that recognizes the homemaker role as fully equal to the earner, that allows income splitting, that provides EI benefits the same as if the work was paid, and that provides a pension for the care years not just a dropout provision to have the care years forgiven in the calculation. I believe a universal basic income is an invaluable tool in supporting equitable finances in times of societal and personal upheaval.

The government should be putting in more financial supports for caregivers who are often overworked, overburdened, and overlooked. Caregivers are akin to nurses except without any pay or any time off.

Pay family members to care for loved ones no matter the age of the person you are providing care for. Or maybe provide things like house cleaning or meal prep so we aren't exhausted from caring for loved ones AND trying to maintain our home and do our daily household jobs.

Others suggested policy that enabled time off work for caregiving would be useful,

Time off of work. Really, I should have taken a leave of absence. I didn't as I felt compelled to work but I'm worried they could get rid of my position.

Assistance to help with time off work for caregiving duties like taking elders to appointments. I'd be happy with no cuts to my wages really.

A protected leave that covers supporting an elderly parent. In my case, I needed to take unpaid leave to coordinate getting a medical diagnosis for my father, an inter-provincial move, and the selling of a house. It was not possible to continue working, even remotely, while trying to coordinate a medical diagnosis of dementia, moving to a new facility, and selling a primary residence. The amount of travel that I have had to undertake is staggering, not to mention the emotional and financial stresses that come with a parent's life-changing medical diagnosis.

Two suggested pension credits for caregiving,

Financially, we do alright. However, in five years I'm going to feel the hit because I left my job at 50 to care for my spouse. Previous to that, I was paying the maximum into CPP every year. I can have years of no contributions taken off for raising children, but not for caregiving a spouse. My CPP will be less because of this and seems somewhat unfair.

Since we Caregivers are saving the Government millions by keeping our loved ones at home...some kind of monthly pension in addition to old age security.

11. Discussion and Next Steps

This survey is a snapshot of the impacts of the COVID-19 pandemic on Alberta family caregivers 18 months after the World Health Organization declared the SARS-COVID-19 was a pandemic. It highlights the diversity of both caregivers' experiences and their needs for supports. Canadian researchers^[37 38] charge that research and policy have failed to acknowledge the diversity in caregivers' experiences or what diversity might mean for supports and services. To illustrate, research often reports that anxiety is higher in female caregivers, however, the woman's health, difficulty with finances or employment, rural residence, and/or access to respite or support services may also contribute to female caregivers' higher anxiety.

Diversity

Diversity means that one size will not fit all; caregivers need to be asked about their caregiving situation, needs, goals and supports personalized to their situation.^[37-40] As one caregiver said, *I would appreciate being asked about my role as a caregiver and given supports and resources that may help me.* However family economist, Dr. Janet Fast and colleagues^[39] contend caregiver diversity is largely ignored, *“Family caregivers are diverse, with dynamic, enduring, and variable life course care trajectories that are largely ignored.”*

When asked what they needed in the future, these family caregivers wanted to shine on light both on supporting the care-receiver’s overall wellbeing and their need for a balance in their life, work, and caregiving roles. First, they were concerned about the care-receiver’s holistic wellbeing. They wanted the care-receivers to be treated with dignity as well as to ensure there was adequate time to care for the receivers’ physical needs as well as to support them emotionally. They asserted that engagement in meaningful activities was a critical element in care-receiver’s wellbeing.

In the early 1970s Norman Kirk, then Prime Minister of New Zealand said, “People do not want much. They want someone to love, somewhere to live, somewhere to work, and something to hope for.”^[41] Similarly, O’Rourke and colleagues meta-synthesis of factors related to the quality of life in dementia cited four factors, 1) relationships with family, friends, and paid staff characterized by kindness, love, or respect; 2) agency in a life characterized by participation in desired activities; 3) a sense of place (feeling settled), and 4) a wellness perspective in which illness did not dominate other aspects of life. Notably, the recent MNP report commissioned by Alberta Health to identify changes to modernize facility-based continuing care, *Improving Quality of Life for Residents in Facility-Based Continuing Care Alberta Facility-Based Continuing Care Report*^[43] also advocates for policies to improve care-receiver’s quality of life.

Second, caregivers wanted attention to their wellbeing through support to balance their caregiving, work, and life roles. Included in this were: recognition of, and respect for, the caregiving role; timely communication tailored to their needs and roles; supports to enable them to balance their care, work, and other roles; and relief from the financial stress of caregiving. Over the last three decades, caregiving researchers have argued that policymakers, health, and social care providers regard family caregivers primarily as resources to provide care, carry out providers’ treatment plans, and sustain the healthcare system.^[44-48] Indeed, well before the COVID-19 pandemic American caregiving scholars Richard Schulz^[15] and Stephen Zarit^[49] both argued that “Fundamental changes are needed in the way we identify, assess, and support caregivers.” COVID-19 has further reinforced the need for researchers’ requests for changes to policies and practices that respond to caregivers’ needs as partners in care and to maintain their own wellbeing.^[39 50]

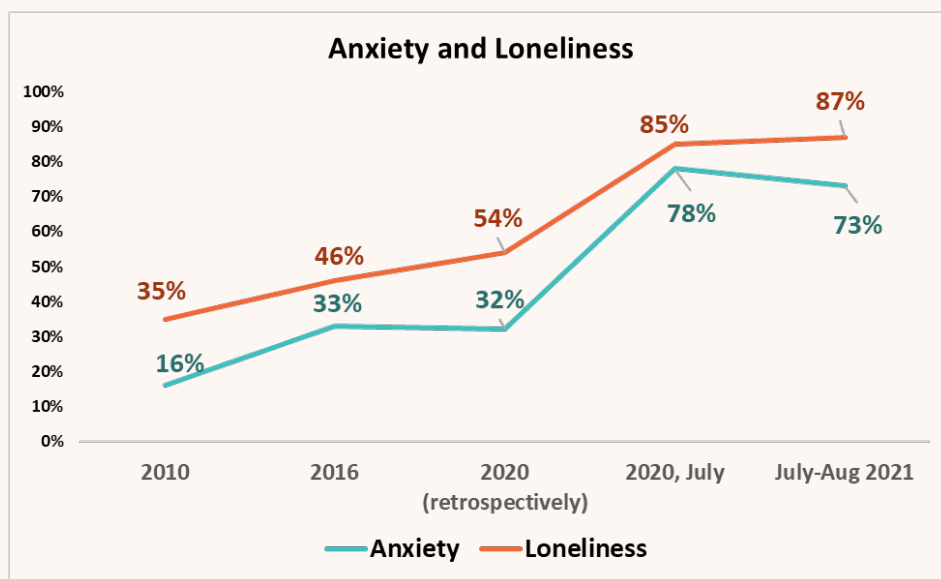
Anxiety and Loneliness

Anxiety and loneliness are very common in family caregivers. Eighteen months into the COVID-19 pandemic, the family caregivers completing this survey were as anxious (73%) and lonely (85%) as they had been four months into the COVID-19 pandemic in July 2020 (anxiety, 78%; loneliness, 87%).^[13 14] It is important to note that the proportions of caregivers who were anxious and lonely had been rising before the pandemic. In 2016, Health Quality Ontario

reported that, on average, 33.3% of caregivers were anxious and distressed,^[51] while the British Columbia Senior’s Advocate found that figure to be 31% in 2017.^[52] While important to track, these averages do not capture the diversity of caregivers’ experiences. The proportion of caregivers with distress was significantly higher for severe cognitively impaired (54.5%), functionally disabled (48.7%), and frail (56.1%) clients. See Figure 38 for changes in anxiety and loneliness.

Anderson and Thayer^[53] reported that the prevalence of loneliness was 42% in an American population-based sample of caregivers, while Victor^[54] found 61.4% of the UK caregivers participating in the Dementia and Enhancing Active Life study (2014–2016) were lonely. Long before the stress of the COVID-19 pandemic, population health researchers^[30 55] and family caregiving scholars^[20] were advising that prolonged anxiety, physically demanding caregiving, and ongoing loneliness could compromise caregiver’s physiological functioning and increase their risk for health problems.^[20 49 56]

Figure 38: Comparison of rates anxiety and loneliness



Anxiety and Weekly Hours of Caregiving

Anxiety typically rises as care responsibilities increase and energy is depleted.^[22-27] The COVID-19 pandemic and the public health measures to control it further restricted the family caregivers’ access to formal and informal resources that might have reduced anxiety and loneliness.^[57-59] The risk of anxiety rises sharply at 21 hours of care a week as well as if the care-receiver lives with the caregiver.^[16 60] In this survey, anxiety was significantly higher for those caring in community homes. The majority of those caring for a care-receiver who lived with them (84%) were caring for 21 or more hours a week compared to 30% of those caring in a separate home, 13% for supportive living residents, and 22% for long-term care residents.

Even before COVID-19, family caregivers caring in community homes were caring for many hours. In 2019, the Health Quality Council of Alberta reported that on average family caregivers of homecare clients were caring for 115 hours per week.^[61] For three decades, researchers have pointed out that shifting care from hospitals and long-term care to communities has increased family caregivers’ responsibilities and that we need to build a better system to support family caregivers, not just expect them to support the healthcare system.^[45 62-65]

Financial Hardships due to Caregiving Responsibilities

Family caregiving often brings additional costs.^[37 66 67] In this survey almost half of the family caregivers (46%) were experiencing financial hardships due to their caregiving responsibilities. While there is much more analysis that can be done to explore the factors associated with financial hardship, younger caregivers, the caregivers of children, and those caring in community homes (same home or living separately) were more likely to report financial hardships. Many of these caregivers are caring for the most hours per week. Family caregivers overall attributed the financial difficulty to reduced incomes, out-of-pocket caregiving expenses, and increased costs of living. Giesbrecht and colleagues^[37] contend that patterns in vulnerability and inequity are often overlooked because caregiver diversity is not explored. Just under half of the participants in this study reported that their employment changed because of their caregiving role. They took early retirement, were working fewer hours, had lost employment, had taken leave of absence, or had to return to work or work more hours to cover the costs of their caregiving. The unpredictability and demands of caregiving can impede caregivers' ability to maintain their work role.^[37 68] In a study of African American caregivers of cancer patients, almost three-quarters of employed caregivers made similar changes in employment to accommodate their caregiving.^[69] Equitable access to respite and support services for the care-receiver are needed to assist family caregivers to manage employment and care responsibilities.^[70-72]

Despite the changes in employment and financial hardships from caregiving expenses, very few participants received Federal Government benefits. This aligns with findings in the national Statistics Canada, 2018 General Social Survey.^[3 12] A study of the availability of Canada's Compassionate Care Benefit, which provides job security and some income assistance to caregivers for Canadians at the end of life, reveals inequitable access.^[37] The authors reported cultural barriers (e.g., non-English or non-French speakers), gender (e.g., women were ineligible due to employment circumstances), geography (e.g., costs for travel not included), age (e.g., young families, retired adults), and material resources (e.g., high cost of supplies). Work impacts, out-of-pocket caregiving expenses, and financial hardships are associated with increased caregiver anxiety^[69 73] and the work impacts on caregiving may contribute to anxiety and depression among caregivers.^[69]

Recognition of the Caregiver Role

These caregivers wanted their role and their contributions recognized. Family caregivers did not think their role or their work have been recognized by the health system. In addition, only 25% of the caregivers who interacted with a health provider had been asked about their caregiving by a healthcare professional in the last six months. That was down from the 32% of family caregivers who had been asked about their situation in the first four months of the COVID-19 pandemic.^[13]

Roy Romanow's 2002 The Future of Healthcare in Canada Report,^[46] and a plethora of subsequent reports^[45 74-76] and research studies^[50 77] refer to family caregivers as "invisible" or "hidden" workforce. Alberta's family caregivers have been essential in the COVID-19 pandemic. COVID-19 disproportionately affected people with chronic conditions and in later life. Family caregivers were at the forefront of care for Canadians needing care and thereby played an

essential role in assisting our healthcare system cope with this emergency. They should be recognized and supported.

We are heartened that the MNP, *Improving Quality of Life for Residents in Facility-Based Continuing Care Alberta Facility-Based Continuing Care Review Report*^[43] recommends recognition of family caregivers as partners in care as well as a person who may need support to maintain their own wellbeing, “Recommendation #5: Include primary caregiver(s) of FBCC residents as essential members of the Care Team and provide them with supports to reduce burnout.” Policy recognition is another step towards building a better system to support Alberta’s family caregivers.

No single person or organization is likely to meet the diverse family caregivers’ needs over varied care trajectories. A collective impact approach in which many organizations intentionally share information and work together to find solutions to complex problems. Again, this year we would like to highlight some of the work towards building systematic supports for Alberta’s family caregivers:

1. Alberta has a Cross-ministerial Caregiver Supports Working Group.
2. The MNP Report^[43] recommends including primary caregivers of congregate care residents be included as essential members of the care team.
3. The Alberta Caregiver Focused Coalition made up of Researchers, Not-for-profit Organizations, Health and Social Care providers, and family caregivers meet bimonthly to share knowledge.
4. Caregivers Alberta and the Family Caregiver Centre in Calgary offer support to family caregivers.
5. The Alberta Caregivers College and Norquest College (Family Caregiver Wellness Workshops) offer skills training.
6. Alberta’s not-for-profit organizations offer knowledge and support (Alzheimer’s Society, Parkinson’s Society Early-Onset Dementia Foundation, The Dementia Network Calgary, Schizophrenia Society of Alberta, ALS Society, and many others).
7. Dr. Wendy Duggleby and Dr. Barb Pesut’s NavCare (NavCare.ca) is training NavCare volunteers to provide companionship and emotional support to family caregivers and seniors in their community as well as support to access resources and services.
8. Dr. Janet Fast and Dr. Norah Keating from the Research on Aging, Policies, and Practice [RAPP] Department of Human Ecology, University of Alberta are nationally/internationally renowned caregiving research experts.
9. Dr. Jasneet Parmar and a team of over 100 multi-level, interdisciplinary stakeholders have co-designed competency-based education for healthcare providers who work with family caregivers. It is offered free, online at Caregivercare.ca

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13. Appendix 1 Methods

13.1 Survey methods

The Survey of the Impacts of COVID-19 on Alberta Family Caregivers, June 21-August 31, 2021, received ethics approval from the University of Alberta Health Research Ethics Board. By August 31, 686 people clicked on the survey, 130 did not complete any questions on survey. People were asked two questions to qualify for the survey: “Do you look after someone (or help to look after someone) who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, needs care due to frailty and aging, and/or COVID-19” and “Do you live in Alberta?”

Links to the survey were sent out to not-for-profit associations, seniors centers, Family and Community Support Services program representatives, health care providers, and on social media (Facebook, Twitter, Instagram). A margin of error is not applicable in this study due to the online methodology. Dr. Janet Fast, University of Alberta, estimated that there are 965,000 caregivers in Alberta (based on growth in the Alberta population since the General Social Survey[GSS], 2012, a national survey in which 28% of Canadians age 15+ was a caregiver). The Health Quality Council of Alberta suggests 400,000 informal caregivers provide support to seniors. There is also a more recent GSS (2018) that indicates 25% of Canadians 15 years of age and older are family caregivers; presumably this is the same in Alberta.

All statistical analyses were conducted using the Statistical Package for the Social Sciences (v.26) (SPSS IBM). Descriptive analyses were first conducted to describe the study sample (i.e., frequencies, age of caregiver/care-receiver, the underlying condition of the primary care recipient, number of people providing care for others, and hours of care provision. Bivariate analyses (chi-square test) of men/women, care location (own private home, separate home, supportive living, LTC) were conducted to gain a deeper understanding of caregiving in Alberta.

Conditions of the care-receivers were grouped as follows:

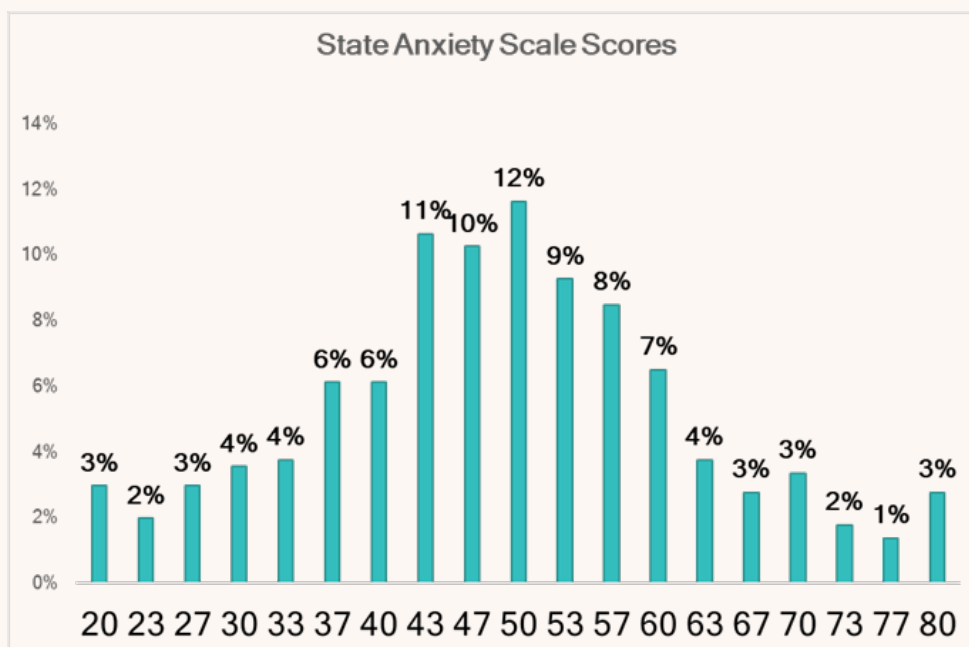
- Autism (n=32),
- Brain injury/ stroke [Acquired brain injury, aneurysm, head injury, stroke] (n=63),
- Cancer (n=58),
- Chronic health conditions [diabetes, arthritis, asthma, Crohns, cystic fibrosis, COPD] (n=163),
- COVID-19 (n=11),
- Dementia (n=192),
- Drug/alcohol dependency (n=7),
- Frailty (n=173),
- Heart disease (n=83),
- Intellectual disability (n=91),
- Mental illness (n=29),
- Neurological conditions [epilepsy, Parkinson’s, multiple sclerosis, ALS] (n=107),
- Palliative care/end of life (n=25),
- Sensory impairment [hearing loss, vision loss, blindness, deafness] (n=110),

13.2 Anxiety: Six-Item State Anxiety Scale

We assessed anxiety with the Six-Item State Anxiety Scale.^[28] The Six-Item State Anxiety Scale is a validated short-form of the State-Trait Anxiety Inventory [STAI]. Both are designed to measure feelings of apprehension, tension, nervousness, and worry. Participants respond to each of the items on a four-choice Likert scale with options ranging from “not at all” to “very much.” Items 1, 3, and 6 are positively worded (absence of anxiety are reverse scored). The final score was obtained by adding the scores for each item, then multiplying the total score by 20/6. STAI scores range from 20-80, with higher scores indicating more severe symptoms. The 6 item versions are as reliable and valid as the original 20 item version.^[28 78 79] Cronbach alphas range from .74 to .82.^[28] In this survey, the Cronbach’s alpha pre-COVID-19 was .853 standardized. To permit comparability with previous studies we dichotomized the STAI scores using cut-point scores of < 40 to indicate no symptoms or minimal symptoms and ≥ 41 to indicate the presence of moderate or severe symptoms.

Table 3: Six-Item State Anxiety Descriptive Statistics

Six-Item State Anxiety Scale (Range 20 to 80)		
	July 2020 (n=595)	July/ August 2021 (n=507)
Mean	53.7	48.9
Median	53.3	50.0
Mode	46.7	50
Standard Deviation	14.5	13.7



13.3 Loneliness: Six-Item DeJong-Gierveld Loneliness Scale

We used the Six-Item DeJong-Gierveld Loneliness Scale^[33] to assess loneliness.^[28] The Six-Item DeJong-Gierveld Loneliness Scale can measure social and emotional loneliness.^[80 81] Social loneliness indicates the extent that the person misses wider social networks (people one can

trust, enough people to feel close to, people that can be relied on to help solve problems) and emotional loneliness indicates the lack of an emotional relationship with other people (feelings of emptiness, miss having people around, feeling rejected). While it was designed for use with older people, the Six-Item DeJong-Gierveld Loneliness Scale^[33] has been tested with large survey samples of adults 18 and over.

There are three response categories in the Six-Item DeJong-Gierveld Loneliness Scale^[33]: Yes, More or Less, and No. The mix of positive, negative, and neutral responses avoids automatic answers and socially desirable responses. On the negatively worded items, the neutral (More or Less) and positive answer (Yes) are each scored as 1 and No is scored as 0. The positive questions are reverse scored. The scale is reliable and valid, with Cronbach alphas ranging from .64[80] to .74.^[33] In this survey, the Cronbach’s alpha was 0.74 (standardized) which is acceptable reliability. As previous studies have done, we dichotomized the total loneliness scores using cut-point scores of < 2 to indicate no or minimal loneliness and ≥ 2 to indicate the presence of loneliness.^[82]

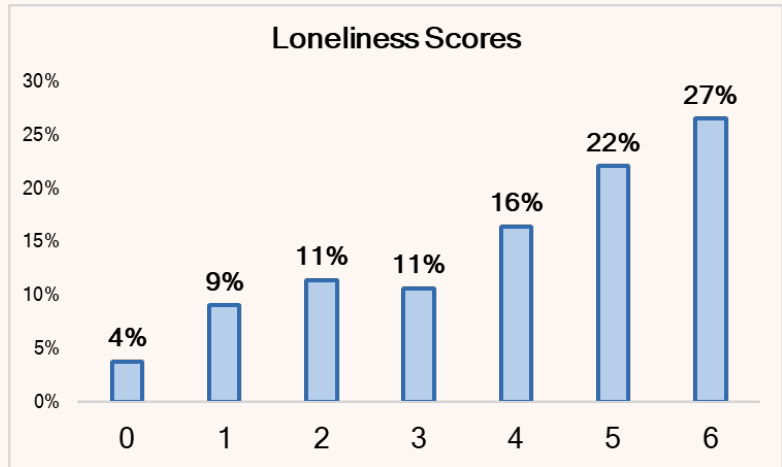


Table 4: Six-Item DeJong-Gierveld Loneliness Scale Descriptive Statistics

Six-Item DeJong-Gierveld Loneliness Scale (Range 0 -6)		
	July 2020 (n=595)	July/ August 2021 (n=498)
Mean	3.91	3.99
Median	4.00	4.00
Standard Deviation	1.86	1.81

13.4 Qualitative analysis

The qualitative comments were analyzed the data thematically [83]. Thematic analysis is a flexible qualitative method used to explore the different perspectives held by research participants; it highlights the similarities and divergences in their viewpoints and generates thematic insights[84]. We methodically followed Braun and Clarke’s (2006, 2021) six stages of analysis.

We imported the comments into separate MS Word documents (133 pages) then read through the comments to become familiar with the data and generate first impressions of meaning (stage one). We made notes of our impressions on MS Word transcripts and discussed the initial impressions. The Word documents were imported into NVivo for data management. In stage two, one member of the research team worked separately to inductively generate initial open codes. In stage three, two team members then worked together to generate categories. Patterns within the open codes were identified and codes with similar attributes and meanings

were grouped. The categories were then refined into preliminary themes (stage four). At stage four, we discussed how health providers applied knowledge from the education in their work with family caregivers. We then reread the Word documents to name and confirm the final themes (stage five). The report was generated (stage six) and edited by the team.