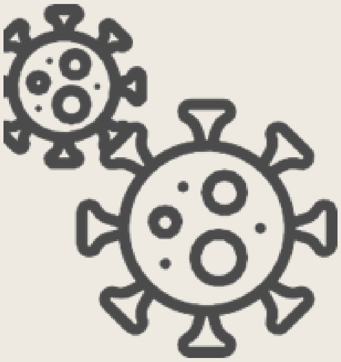

A Tale of Two Solitudes
Experienced by Alberta Family Caregivers during the COVID-19 Pandemic

Caregivers overwhelmed by additional care in private homes; and Caregivers excluded from caring in congregate living

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Executive Summary and Recommendations

The COVID-19 pandemic created two solitudes for family caregivers. Solitude emphasizes the quality of being detached or separated from others. Family caregivers of Albertans living in private homes were overwhelmed with caregiving needs and those caring for Albertans living in congregate settings were restricted from caregiving.

- 73% of family caregivers caring for Albertans living with them in the same home and 56% living separately were providing significantly more care after the COVID-19 pandemic began.
- After the onset of the COVID-19 pandemic, 87% of those caring for those long-term care [LTC] and 70% of those caring in supportive living said they were providing less care.

Both solitudes increased family caregiver distress, anxiety, and loneliness. The COVID-19 pandemic and both caregiving solitudes, that is being overloaded with providing care and being unable to care triggered distress. The risk of family caregiver anxiety, stress, and burnout significantly increase with more hours per week. Those who were providing more care reported that as the COVID-19 pandemic continued, they were the person designated as the "essential family caregiver". The majority reported that a single family member was doing all the care formerly provided by two or three family members.

Over half of the caregivers completing the survey reported at least one or more of these symptoms of stress.

- 57% of family caregivers agreed that since the COVID-19 pandemic they have "not been able to take a break".
- 68% of family caregivers agreed that since the COVID-19 pandemic they were always "thinking about all care tasks they had to do".
- 79% of family caregivers agreed that since the COVID-19 pandemic, they have been "feeling more frustrated".
- 62% of family caregivers stated that since the COVID-19 pandemic they were "not sleeping well".

Anxiety rose significantly during the COVID-19 pandemic regardless of where the caregiver was providing care—in a private home or in a congregate living setting. In addition, loneliness rates were particularly high. We need to pay attention to loneliness and anxiety of family caregivers as well as Albertans that they care for. Loneliness carries the same health risk as smoking 15 cigarettes a day. It is twice as harmful to health as obesity and the risk of premature mortality is like that of alcoholism. A recent study noted that anxiety and depression increase premature mortality rates by 76% or more compared to mortality rates of those who never had anxiety and/or depression. 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.

- 78% of family caregivers reported anxiety.
- 85% of family caregivers reported loneliness.

Family caregiver's health deteriorated. Higher intensity care (care overload/ worry) has a negative impact on the caregiver's health. Since the outbreak of COVID-19:

- 58% of family caregivers noted a deterioration in their mental health.
- 48% of family caregivers noted a deterioration in their physical health.

Family caregivers noted that since the COVID-19 pandemic, reductions in homecare, respite or closure of community and day programs occurred resulting in an increase in the care intensity as well as the hours spent providing care without a break. Almost half (48%) of those who received homecare services before the COVID-19 pandemic reported that services were reduced after the pandemic struck. Many of the new protocols increased family caregivers' responsibilities. They were also distressed by the lockdown and not being able to provide care. Many reported that the congregate care resident's health deteriorated without their socio-emotional support and practical assistance with care.

Before COVID-19, 40% of the family caregivers had been asked about family caregiving or how they were doing as a caregiver. Since the COVID-19 pandemic began, only 32% of our sample of Alberta's family caregivers surveyed had a health or social care provider ask about their caregiving situation. Of the 26% of family caregivers who cared for Albertans receiving homecare services, 73% reported their homecare case manager had checked in with them or the person they were caring for. The caregivers providing the most intensive care noted that respite and homecare gave them a much needed break. Participants appreciated the homecare services and reported that without that assistance sustaining caregiving was difficult.

Recommendations: How to Move Ahead to Support Alberta Family Caregivers in the COVID-19 Pandemic and Beyond

Now is the opportunity to build a better system to support family caregiver's health and wellbeing during their caregiving journey. Moving ahead we recommend that Alberta policy makers:

1. Recognize family caregivers as partners- in- care in need of support to maintain their own health and wellbeing, not just to sustain care.
2. Ensure that person-centered care for family caregivers is foundational to practice and policy in all settings throughout Alberta.
3. Recognize the essential role of family caregivers who provide physical care as well as emotional and social support in all health and social care settings.
4. Consider the risks and benefits to family caregivers as well as the care-receiving patient/ client/congregate care resident in health and social care planning in this COVID-19 pandemic and beyond.
5. Educate healthcare providers and community social care providers to identify and support family caregivers and mandate this education.
6. Acknowledge the necessity of assessing family caregivers' strengths, risks, support needs, and preferences regularly throughout the care trajectory. Use an approach that assesses caregivers needs from their lens such as Carer Support Needs Assessment Approach.

7. Evolution of homecare supports should include partnering with family caregivers to provide client and caregiver-centered care.
8. Continue to work with researchers, health and social care providers, community organizations and advocates, and family caregivers to co-design coordinated supports for family caregivers.

1. *About this Survey Research: The Impacts of the COVID-19 Pandemic on Alberta Family Caregivers (June-July 2020)*

This online survey was carried out on the University of Alberta REDCap data collection platform during the months of June and July 2020. 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. A total of 604 current family caregivers responded to the survey.

We define **family caregiver** (carer, care-partner) as any person 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); Jennifer Stickney-Lee, MD; Lesley Charles, MBChB; Suzette Brémault-Phillips, PhD; Bonnie Dobbs, PhD; Anwar Haq, PhD, MBA; Peter Tian, MD, MSc; Catherine Thornberry, MN; Lisa Poole, BA (Family Caregiver); and Cindy McCaffrey (Family Caregiver) Acknowledgement: Catherine Thornberry, MN for support and editing assistance.

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 604 family caregivers who completed the survey, 85% identified as female, 14.6% as male and 0.4% as other. 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. [21-23] Family caregivers 15 years and over completed the survey.

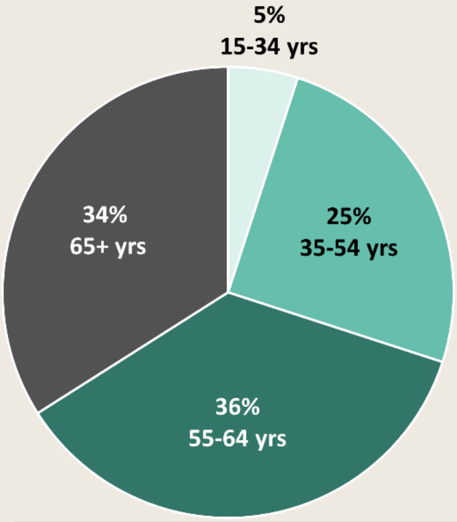

Figure 1: Caregivers' Age

2.1 Alberta Health Services [AHS] Zones

Zone where family caregivers lived:

9% North Zone
44% Edmonton Zone
11% Central Zone
28% Calgary Zone
8% South Zone

2.2 Number of people cared for:

72.5% for 1 person
20.2% for 2 people
5.1% for 3 people
2.2% for 4 or more people

3. *Demographics: Care-Receivers*

3.1 Ages: Care-receivers

68% of care-receivers were 65 years or older.

3.2 Living Situation

The majority of care-receivers (44.3%) lived with family caregivers, 15.5% lived in LTC, 14.2% in supportive living, 10.1% in a private home separately from the caregiver, and 1.7% lived with other family member or a friend. The remaining 14.2% lived in a variety of living situations.

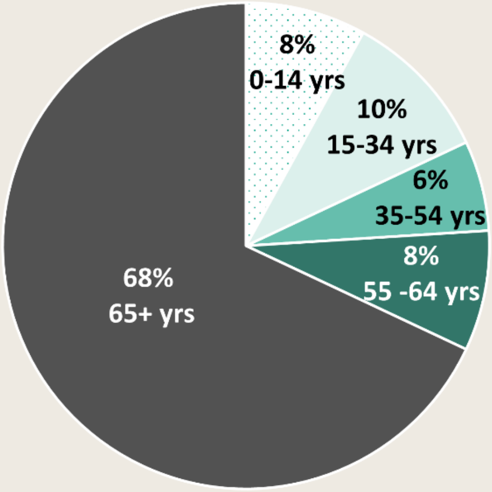

Figure 2: Care Receivers' Age

Some family caregivers were caring for two or more people who lived separately (e.g., mother in own home, father in supportive living). Some were caring for one person whose residence changed during care to, for example, the caregiver's residence, the hospital, or LTC.

Table 1: Living Situation of Care-receivers

Living Situation (n=592)	Frequency	Percent
Same home with caregiver	262	44.3
Long-term care	92	15.5
Supportive living	84	14.2
Lives separately	60	10.1
Supportive living & LTC	12	2.0
Lives with other family/friend	10	1.7
Same home & LTC	10	1.7
Hospital	8	1.4
Same home & Separately	8	1.4
Same home & Supportive living	7	1.2
Separate & Supportive living	6	1.0
Same home & Hospital	5	0.8
Separate & LTC	5	0.8
Separate & Other	4	0.7
Hospice	3	0.5
Same home & With Other family or friends	3	0.5
Same home, Separate & Supportive	3	0.5
Same home, Separate, & LTC	3	0.5
Supportive living & Hospital	3	0.5
Group home	1	0.2
LTC & Hospital	1	0.2
Same home, Hospital, & LTC	1	0.2
Same home, Separate, Supportive, LTC, Hospital	1	0.2

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

4.1 Care-Receivers' Health

4.1.1 Health Conditions

The conditions of receivers are shown in Figure 3. As can be seen dementia (46%), chronic conditions [diabetes, arthritis, asthma, Crohn's disease, cystic fibrosis, COPD] (36%) and sensory impairments (25%) were most reported. See Appendix 1 Methods for condition groupings and other conditions.

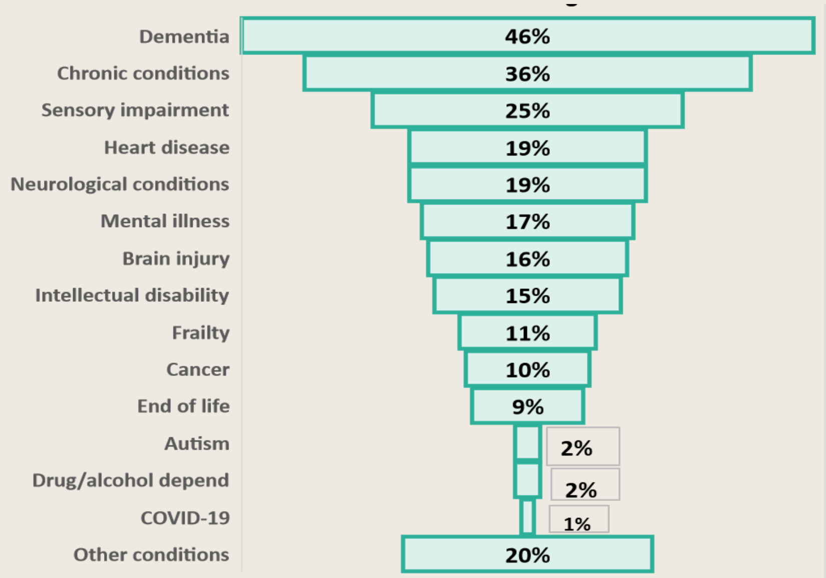

Figure 3: Conditions of Care Receivers' Necessitating Care

4.2 Severity of the Care-Receiver's Health Condition

92% of family caregivers rated the severity of the first care-receivers' health (illness, frailty or impairments) as moderate to severe with 70% of those caring for a second care-receiver rating the second care-receivers' condition as moderate to severe.

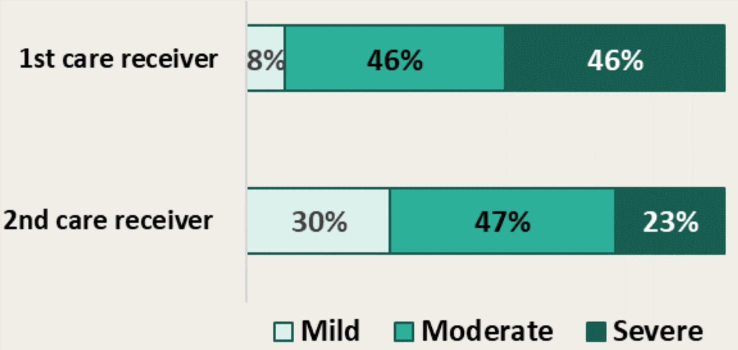

Figure 4: Severity of Receivers' Condition (Would you say the care receiver's condition is..?)

4.3 Length of time care-receiver could be left alone

Close to one-half of caregivers (45%) reported that the care-receivers could be left alone for a for a few hours with one-third indicating the care-receiver could not be left alone for any length of time.

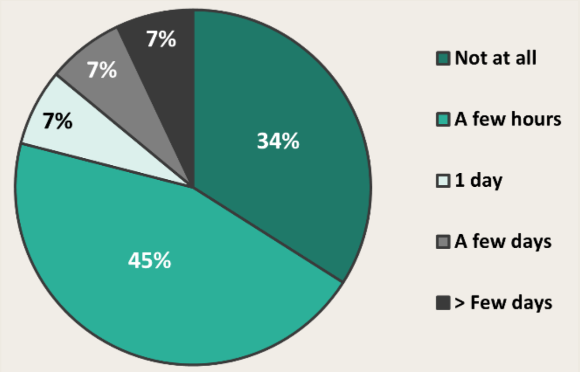

Figure 5: Length of Time Receiver can be Left Alone (n= 585)

4.4 Changes in Care-Receiver’s Health During the COVID-19 Pandemic

More than half (60%) of the family caregivers reported that the health of the persons they cared for declined during the first four months of the COVID-19 pandemic.

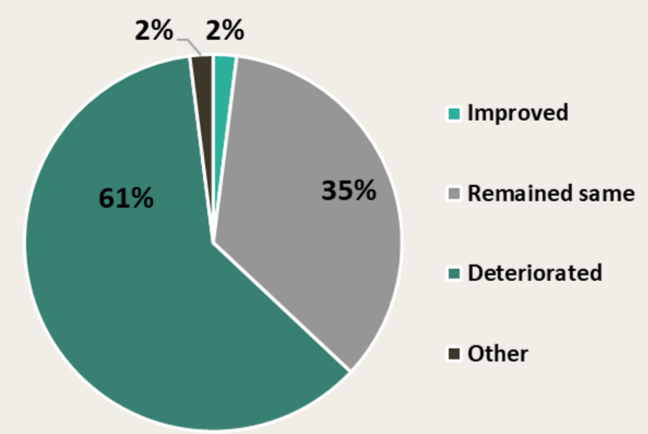

Figure 6: Changes in Health of the First Care-Receiver (n= 565)

> *Anxiety has increased at least four-fold. Two of three [care-receivers that I care for] refuse to leave the house at all, even to go to the backyard.*
>
> *She doesn't say much but she feels isolated, it may not be noticed by those caring for her since she went into care [at] the end of March. Beginning to see less energy in her and she says she is always tired.*
>
> *Although my daughter's health has remained the same, her rages and outbursts have returned, and her mental health is suffering. She is always worried and focusing on things that she cannot change.*

5. *Family Caregiving Crisis with Two Solitudes*

The COVID-19 pandemic created two solitudes for family caregivers. Solitude emphasizes the quality of being detached or separated from others. Family caregivers of Albertans living in private homes were overwhelmed with caregiving needs and those caring for Albertans living in congregate settings were restricted from caregiving. Both solitudes increased family caregiver distress, anxiety, and loneliness.

> *"While the caregiving for my institutionalized parent has gone down, the care for my independent parent has gone up."*

5.1. Solitude 1: Family caregivers in private homes provided significantly more care.

73% of family caregivers caring for Albertans living with them in the same home and 56% living separately were providing significantly more care after the COVID-19 pandemic began.

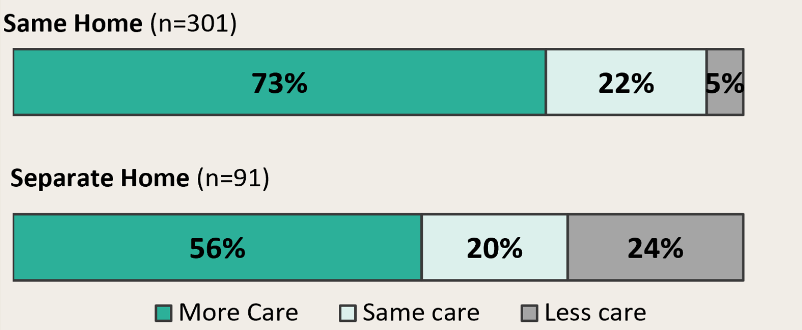

Figure 7: Changes in Care Since COVID-19 Pandemic in Private Homes

- 47% of caregivers to Albertans living in the same home were providing care for an additional 21 to 40+, hours a week after COVID-19 began.
- 18% of caregivers to an Albertan who lives in a separate home added 21 to 40+, hours of care work per week.

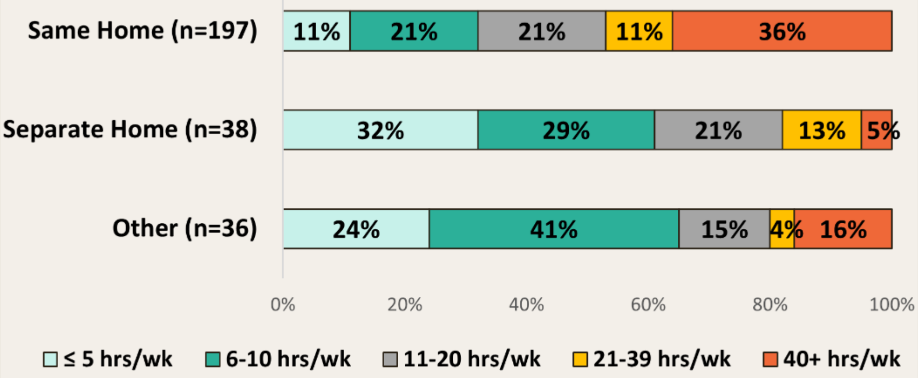

Figure 8: Additional Hours of Care Provided in Private Homes and Other Multiple Locations Since COVID-19

Thirty-seven caregivers were providing care in more than one location. Reasons included: providing care for more than one person, moving the care-receiver from home to hospital and/or congregate care, and removing the receiver from congregate care.

- 20% of the caregivers providing care in more than one location added 21 to 40+ hours of care work per week.

> *"I or my sister had visited mom or taken her out to the park 6 days out of 7 before lockdown….As they had an outbreak we had taken her out of the facility and isolated at*

> *another sister's acreage for 3 weeks. …. During the time we had her, we did activities. Her improvement was quite notable. Taking her back and having her isolated in her room for 2 weeks seemed to have her decline quite quickly. Now being an essential caregiver, I find that staff leans on me more for her care. I am unable to look for work as I seem to be on call for the times, they can't get her to eat, take her meds, or calm her down. It has been extremely hard."* [16]

How valuable is family caregivers work? Dr. Janet Fast conservatively estimated that Alberta family caregivers care work saves the Alberta's health system $5.8 billion yearly. [16]

5.2. Solitude 2: Family caregivers for Albertans living in congregate living were unable to provide care.

The family caregivers of residents in supportive living (lodges, assisted living, seniors' apartments) and long-term care were providing significantly less care as soon as the COVID-19 pandemic was declared.

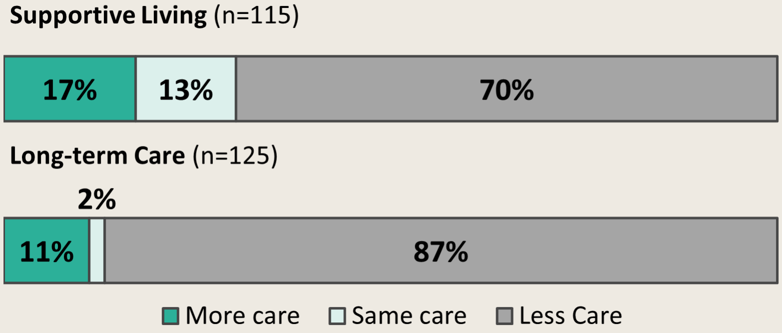

Figure 9: Changes in Care Since COVID-19 Pandemic in Congregate Living

After the onset of the COVID-19 pandemic, 87% of those caring for those LTC and 70% of those caring in supportive living said they were providing less care.

The family caregivers for Albertans living in congregate living were providing less personal and emotional care. In supportive living, some family caregivers were able to continue to support extended activities of daily living, such as grocery shopping, laundry, or transportation to medical appointments. At the time of the survey (July 2020), a few caregivers of LTC residents had been declared essential and were able to resume some personal care.

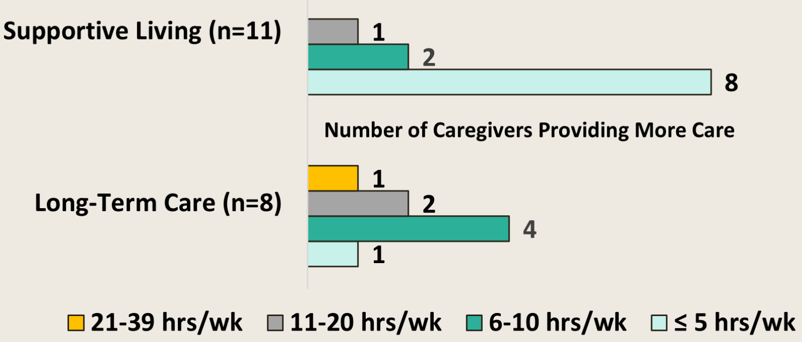

Figure 10: Additional Hours of Care Provided in Congregate Living Since COVID-19

The Regional Geriatric Programs of Ontario and the Canadian Geriatrics Society recognized "The prolonged absence of Family Caregivers during the COVID19 pandemic has been devastating to residents of congregate settings and older adult patients and deeply felt by organizations and health care professionals." [17]

6. *Caregiving Hours Before & During the COVID-19 Pandemic: Care Location Matters*

In this section, we take a closer look at the hours of care provided by family caregivers

Before the COVID-19 pandemic. The Alberta family caregivers who completed this survey were already providing many hours of care per week before the onset of the COVID-19 pandemic. Survey participants provided an average of 16.8 hours of care weekly (SD= 13.67) before the COVID-19 pandemic.

The impact of the care location. The amount of time family caregivers spent caregiving depended on the residence of the care-receiver, both before and after the onset of the COVID-19 pandemic.

What does the research say about care by location? Typically pre-pandemic, family caregivers provided 75* to 90% of the care to people with frailty, complex chronic conditions, and impairments living in private homes [22-25] and approximately 30% of the care to residents in congregate living (lodges, supportive living, and long-term care). [12-14]

6.1 Care-Receiver Lives with the Family Caregiver

Before COVID-19 pandemic:

- 37% of caregivers provided 40+ hours of care a week,
- 14% of caregivers provided 21-39 hours of care a week.

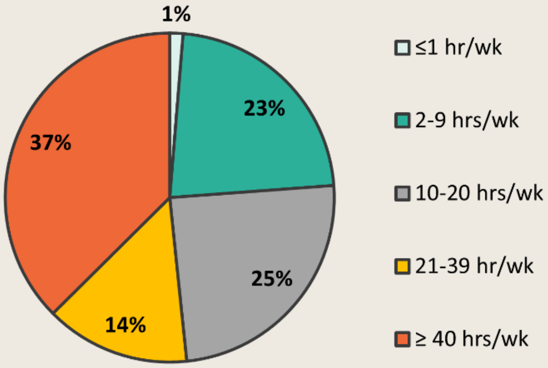

Figure 11: Hours of Care Work Pre COVID-19 Same Home (n=302)

The additional hours of care provided since the COVID-19 pandemic began were substantial:

- 47% were caring for an additional 21 to 40+ more hours a week
- 21% were caring for additional 11 to 20 more hours a week.

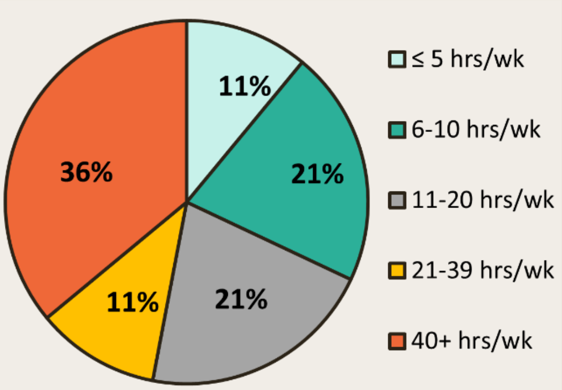

Figure 12: Additional Hours of Care Provided in the Same Home Since COVID-19 (n=197)

Why do hours of care matter? The risk of family caregiver anxiety, stress, and burnout significantly increase with 21 or more hours per week.[1, 2] Other factors that increase the risk of family caregiver distress include: (i) the client lives with the primary caregiver; (ii) the client has dementia, cognitive impairment, and/or depression; and (iii) the client demonstrates anger or responsive behaviours.[1, 2]

Family caregivers caring for an Albertan who lived with them reported caring “alone behind closed doors” and “on my own”. Those providing more care reported reduced availability of homecare and respite, senior social and day program closures, as well as reduced assistance from other family members and friends. The 5% of family caregivers who reported providing less care revealed that the care-receiver needed less care, recovered, or had died.

More Care: Services were reduced; Less help from others
"As my father lives with me and I'm now working remotely I find I'm having to navigate more of his frustrations. I'm not able to get the breaks I had before due to me being at home and I find I've needed to explain things more often to calm his fears." *"Because all programs have been cancelled or put on hold, my husband had nothing to go to to stimulate him. Both his physical and mental conditions got worse. The one thing that I would like is respite and that is the thing that the health system will not cover. I can do many of the chores (bathing, medication) but I cannot go out for a day or lunch and leave him."*
Less Care: Care treatments stopped; Care-receiver’s health improved.
“My husband previously attended numerous appointments for his cancer treatment. He has not had treatment since March and his expected treatment, which should have started in June, has been delayed indefinitely due to lack of ethics approval for phase 1 trials.” *“This person has healed somewhat from multiple surgeries and taken back caring for themselves.”*

6.2 Care-Receiver Lives in a Separate Home than Family Caregiver

Before the COVID-19 pandemic:

- 20% of caregivers were providing care for 10 to 20 hours a week.
- 19% of caregivers were providing care for 21 to 40+ hours a week.

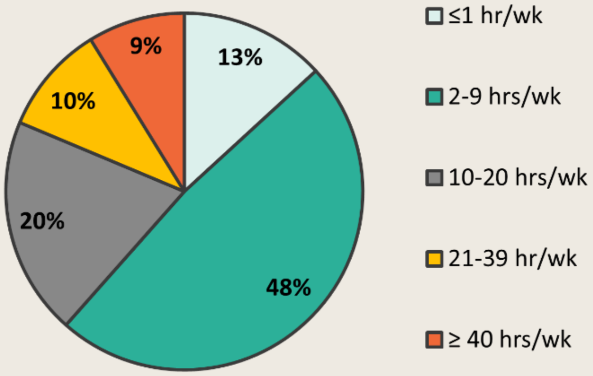

Figure 13: Hours of Care Work Pre COVID-19 Separate Home (n=91)

Additional hours of care provided since the COVID-19 pandemic began:

- 21% of caregivers were providing 11 to 20, more hours of care a week,
- 18% of caregivers were providing an additional 21 to 40+, more hours of care a week.

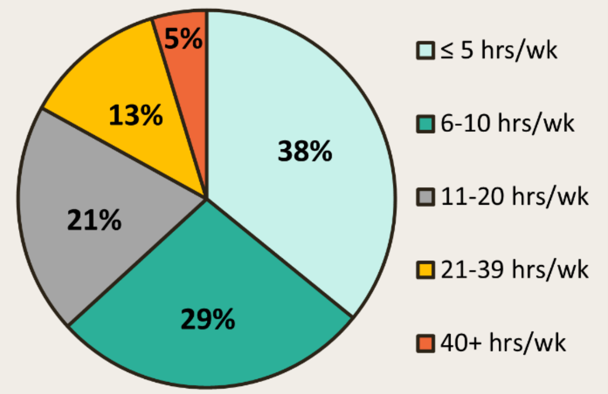

Figure 14: Additional Hours of Care Provided in the Separate Home Since COVID-19 (n=38)

What do we know about caring for those in separate homes? Statistics Canada reports care hours by relationship rather than location. In 2012, the median number of hours family caregivers spent caring for their father or mother was 4 hours per week. The median for a parent-in-law or other relative was 3 hours. In comparison, caring for a child required 10 hours of commitment per week, and caring for a spouse, 14 hours. [15]

Family caregivers who lived separately from the care-receiver reported that services that enabled the care-receiver to remain independent such as homecare and/or interactions with family and friends decreased compared to interactions before the COVID-19 pandemic. Typically, one designated family caregiver stepped in to fill the void.

Those reporting decreased care hours noted that they did so to reduce the risk of contracting the COVID-19 infection for them or for the care-receiver. Others reported providing more care by phone or by dropping groceries or supplies at the door to keep the care-receiver from contracting COVID-19. A few family caregivers reported that another family member had to take over all the care because their own health was at risk.

More Care: Worried about the COVID-19 infection; Relying on 1 family caregiver; Less help from other family members
"My father's cognitive abilities have gone way downhill. His young friends never call because of it. Family can't travel to help. AHS has given us only 3 hours a week help. Eight different caregivers come and go so I am afraid to introduce more privately hired people to help with him and cleaning, laundry, etc. My friends are often afraid to socialize with me. I can't do the volunteer work I am used to because of COVID-19 pandemic restrictions. Cannot do my usual exercise" *"Brother in U.S; so support and visits from him gone. Had to take on grocery shopping initially. As pandemic continues, see their ability and interest to do anything declining. Dementia progressing, hygiene decreasing, and anxiety or depression being isolated at home. …. Homecare inadequate and stopped for a while so all falling on my shoulders. Virtual phone calls*

from family physician short, less than ideal for seniors and requires my coordination as my father can not see and my mother cannot hear."
Less Care: Social distancing; Support by phone or Internet rather than in-person
"I have a rare health condition that caused me to have to stop doing what I was doing for my grandparents. My aunt had to move here from out of province." *"My father in law has dementia and lives in another town. We would visit twice a month for groceries, house keeping and company and have not been able to visit for the first part of the pandemic. Caring is mostly through phone calls."*

6.3 Care-Receiver Resides in Supportive Living

Family caregivers of individuals who live in lodges and other supportive living settings are responsible for a wide range of activities that sustain daily living, including (but not limited to) laundry, shopping, transportation, managing medical appointments and finances.

Before the COVID-19 pandemic:

- 32% were providing 10 to 40+ hours a week.

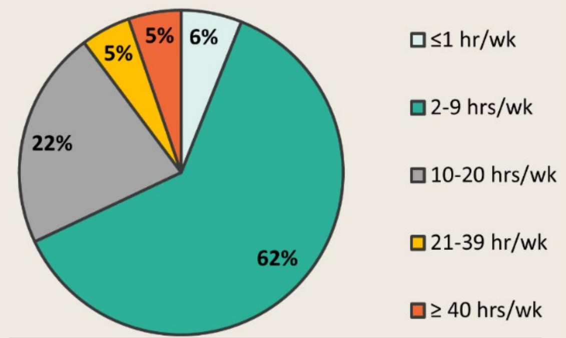

Figure 15: Hours of Care Work Pre COVID-19 Supportive Living (n=114)

Since the COVID-19 pandemic, eleven family caregivers said their care hours had increased.

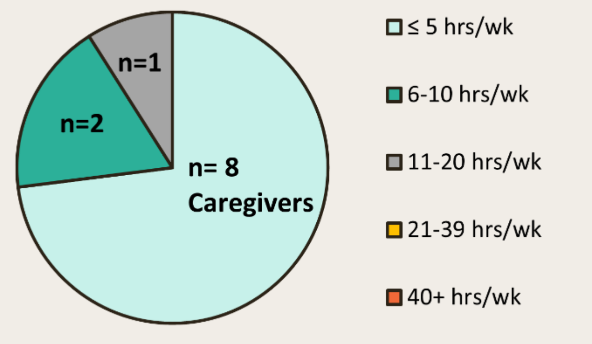

Figure 16: Additional Hours of Care Provided in Supportive Living Since COVID-19 (n=11)

What is supportive living? Alberta has a range of supportive residential options including senior's apartments and lodges, group homes, mental health, and designated supportive living accommodations. These settings can be operated by private for -profit, private not-for-profit or public operators. [18 19]

Those who were providing more care reported that as the COVID-19 pandemic continued, they were the person designated as the "essential family caregiver". The majority reported that a single family member was doing all of the care formerly provided by two or three family members.

More Care: Becoming an "essential family caregiver" allowed the caregiver to enter a supportive living venue to care for a resident.
"Mine is unique situation, my husband is in a private level 4 care. They don't offer the certain therapy he needs for his stimulation or exercise he needs on a weekly basis. I would spend 5 to 8 hours a week providing this for him." *"I am the sole family member who is allowed to go in and help my mother in her suite. This means any shopping, extra housework, medical needs, financial help all fall on my shoulders."*
Less Care: Support from outside the building, by phone or Internet rather than in-person; Dropping off the laundry or the shopping at the building door.
"As my Mom was in an Independent Living Facility, the Lodge was on lock down and I was not able to enter to assist her." *"I haven't been allowed to see my father, I can only drop off medications and groceries."* *"Mother is in [Name of facility]. And it has been in lock down. I now call mother 2 to 3 times a day providing support. I provide laundry service weekly, pickup mother's requests. I monitor [Name of facility] care and their changing policies. And provide them with regular input."* *"The reason care is taking less time is because my mom passed away. She was so used to having me visiting almost daily, and my sisters weekly. She struggled with dementia, although [she] knew all of her family members. She lived in a senior's lodge, and we believe that because of no visitation that she took a turn for the worse. … COVID-19 has had a very negative impact on us and affected our mental health."*

6.4 Care-Receiver Resides in LTC

Before the COVID-19 pandemic, family caregivers of LTC residents were providing an average of 11.5 hours of care a week (SD= 8.8).

- 34% of caregivers were providing care for 10 to 20 hours a week.
- 13% of caregivers were providing 21 to 40+ hours a week.

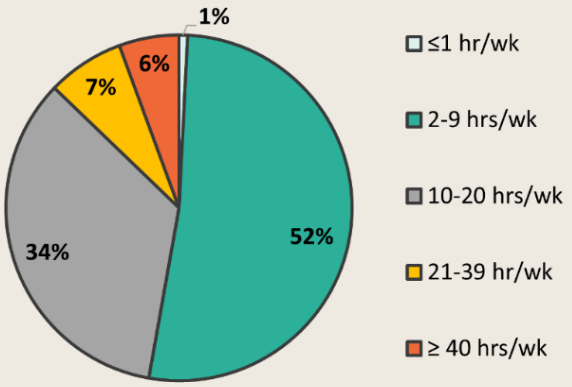

Figure 17: Hours of Care Work Pre COVID-19 Long-term Care (n=125)

At the start of the COVID-19 pandemic, family caregivers were not able to provide any care. However, at the time of the survey, some family caregivers (n=8) had been designated "essential family caregivers" and were able to provide care such as one-on-one direction or time-intensive hand feedings in the LTC resident's room.

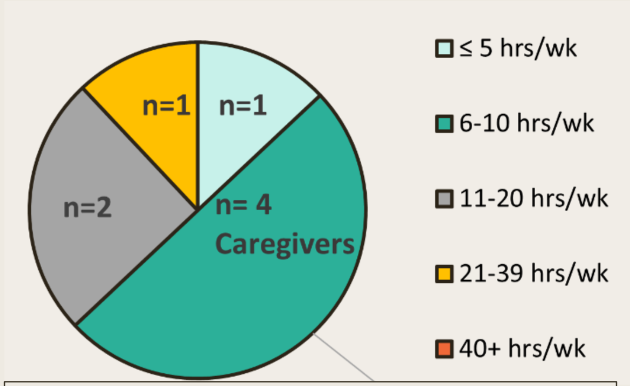

Figure 18: Additional Hours of Care Provided in Long-term Care During COVID-19 (n=8)

What do we know about family caregiving in LTC? Family caregiving does not stop when people are admitted to long-term care. Pre-COVID19, family caregivers were providing about 30% of the care in long-term care.[9-11] In addition to emotional and social support,[20] family caregivers monitor, manage care and assist with meals, and 40% assist with personal care tasks. [9-11]

Increased caregiving in LTC settings was typically related to one or two designated family caregivers assuming the care tasks previously done by several family members.

More Care: Relying on one essential family caregiver to improve a resident's wellbeing and quality of life
"I have always been the essential caregiver, however, [I] was asked to stay away on the third week of March, 1 week after my grandmother fell and broke her hip. I was not permitted to re-enter due to COVID and not permitted to help care for my 99-year-old grandmother until 6 weeks ago. That's just wrong. When I finally returned, she was emaciated and near end of life. Since my return I feed her supper everyday, ensuring that she eats, drinks adequately and takes her vitamin supplements (that were NOT provided in my absence). …. Of course, I did not have help from family.... they were not permitted to come. It's been beyond difficult trying to manage her care and stay employed. I drive one hour per day to see her and stay 2 hours. That is 3 hours of my day everyday preventing me from earning an income. Now I am suffering financially, and I am absolutely exhausted. My grandmother is doing very well now and gaining weight, good health and brain function."
Less Care: Caregiving restricted; Support provided only by phone or Internet
"Caring is taking less time because my loved one is in a nursing home, we only FaceTime once a week." *"My mother had a stroke in Sept 2019, and I moved in with her to provide care after her discharge from [Rehab] at the end of October. She made a wonderful recovery and then the second stroke happened. She was admitted to a LTC facility on the very day they were shut down to visitors. It was devastating to 'hand over' my aphasic mother to 'strangers' in LTC*

facility to which I had NO access. I could not speak to her on the phone as she cannot speak. More info than you asked for, but..... venting feels good!

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

7.1 Caregiver Stress: Increased During the COVID-19 Pandemic

Caregiver stress was triggered by being overloaded with care provided for people living in private homes, and by being unable to provide care for congregate care residents. Common signs of caregiver stress are trouble concentrating; difficulty sleeping; inability to stop worrying; feeling tired or rundown; irritability; anxiety; and depression. Notably, over half of the caregivers completing the survey reported at least one or more of these symptoms of stress.

- 57% of family caregivers agreed that since the COVID-19 pandemic they have "not been able to take a break".
- 68% of family caregivers agreed that since the COVID-19 pandemic they were always "thinking about all care tasks they had to do".
- 79% of family caregivers agreed that since the COVID-19 pandemic, they have been "feeling more frustrated".
- 62% of family caregivers stated that since the COVID-19 pandemic they were "not sleeping well".

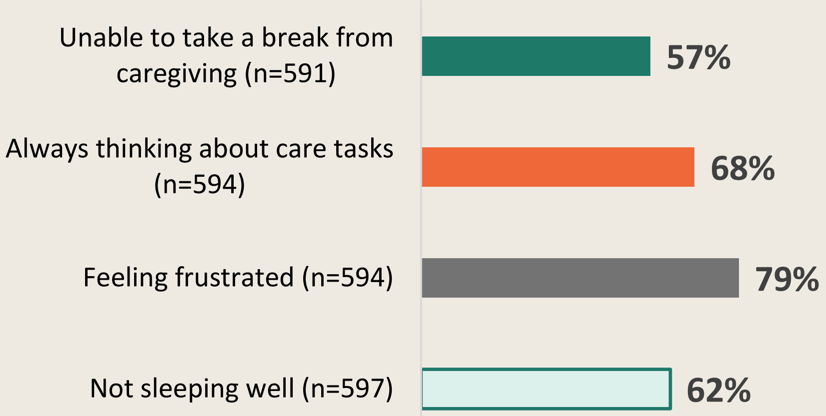

Figure 19: Signs of Stress Since the COVID-19 Pandemic

7.2 Caregiver Self-Rated Mental and Physical Health Deteriorated During the COVID-19 Pandemic

Since the outbreak of COVID-19:

- 58% of family caregivers noted a deterioration in their mental health.
- 48% of family caregivers noted a deterioration in their physical health. (Not shown with graph).
  "Respite closed and my one day a week from 10:00 a.m. to 4:00 p.m. was closed to me. Sure, mentally it's much worse for caregiving because there is no break, for him or me."

However, there were a small percentage that reported their health had improved.

- 4% of family caregivers reported an improvement in their physical health
- 2% of family caregivers reported an improvement in their mental health (Data not shown with graph)

> *“When my husband was living at home in January, I provided care 24/7 all year long. Homecare allowed me 6 hrs a week of respite. When my husband was first placed in [Name of LTC home] on Feb 4th I travelled an hour each way to see him 5 days a week. I was terribly burned out but wanted to ensure he settled into his temporary home and felt safe. When the COVID pandemic arrived, it forced me to stay at home and regain my strength. Although physically I regained my strength, it was mentally challenging not to be able to see my husband. Although I had peace of mind the staff where doing an awesome job at looking after my husband, it was difficult not knowing where my husband was mentally. Did he think I just abandoned him? Would he understand what was happening?”*

What about family caregiving impacts health? Higher intensity care (care overload/ worry) has a negative impact on the caregiver’s health. *[15]*

Care Location and Health

Again, care location mattered to family caregivers’ assessments of their mental and physical health. Significantly more family caregivers, whether caring in private homes or in congregate care homes, felt their physical health had declined, possibly because they were doing more hours of care and hands-on labour.

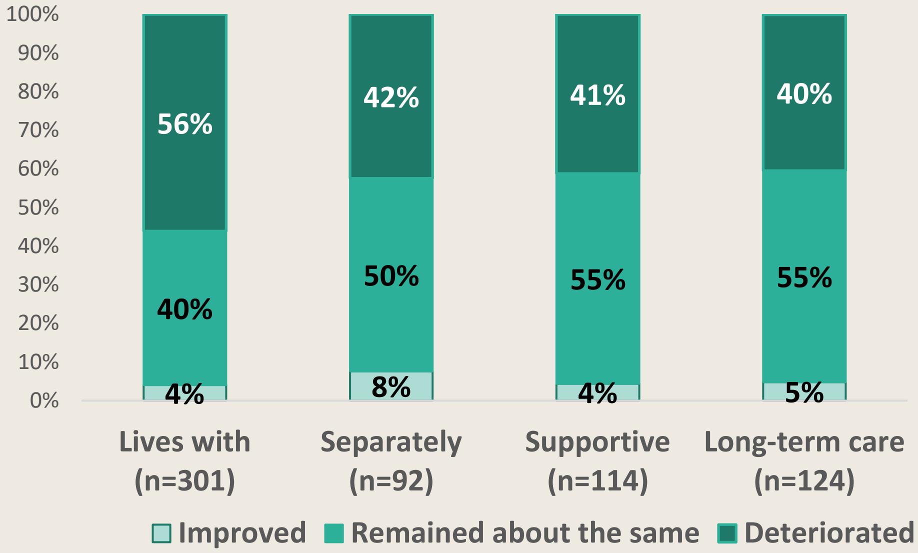

Figure 20: Changes in Caregivers’ Physical Health Since the COVID-19 Pandemic

Mental health ratings of family caregivers did not differ significantly by care location.

> *"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."*

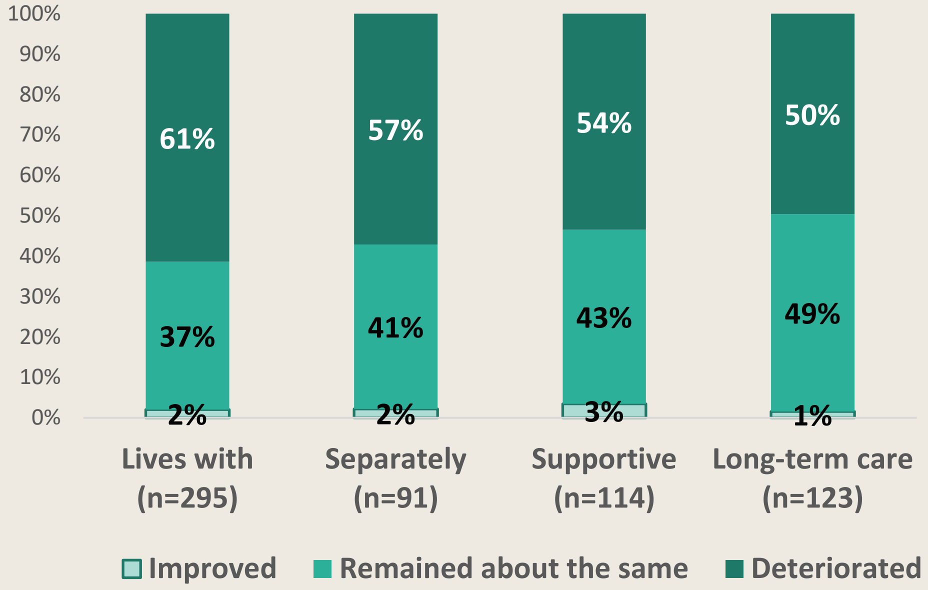

Figure 21: Changes in Caregivers' Mental Health Since the COVID-19 Pandemic

> *"Day Support services were put on hold, 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 weekend care back twice a day."*

7.3 Caregiver Anxiety Increased During the COVID-19 Pandemic

Anxiety rose significantly during the COVID-19 pandemic regardless of where the caregiver was providing care—in a private home or in a congregate living setting.

Why measure anxiety? Anxiety is the most frequently occurring psychological disorder among family caregivers.[7] Anxiety typically rises as care responsibilities increase and energy is depleted.[3-8]

We used the Six-Item State Anxiety Scale[1] to assess family caregiver anxiety before the COVID-19 pandemic retrospectively (January 1, 2020) and family caregiver anxiety at the time of the survey (June 21-July 31, 2020). We asked family caregivers how they would have answered the six questions on January 1, 2020 and then at the time of the survey June-July 2020 (see Appendix 1 for methods).

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[1] The Six-Item State Anxiety Scale [24] is a reliable short-form of the widely used Spielberger State-Trait Anxiety Inventory (STAI).24. Tluczek A, Henriques JB, Brown RL. Support for the reliability and validity of a six-item state anxiety scale derived from the State-Trait Anxiety Inventory. Journal of Nursing Measurement 2009;**17**(1):19-28 doi: 10.1891/1061-3749.17.1.19.

Anxiety rose significantly from the pre-COVID-19 time to the time of the survey. On January 1, 2020, according to the Six-Item State Anxiety Scale, approximately a third (32%) of the family caregivers completing the survey indicated they were anxious.

During COVID-19, the Six-Item State Anxiety Scale indicated that more than three-quarters (78%) of the family caregivers were anxious. (see Appendix 1: Methods).

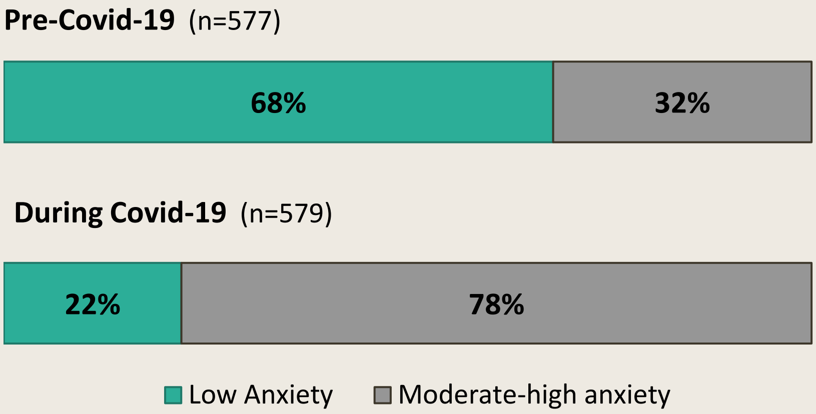

Figure 22: Proportions of Anxious Family Caregivers Before & During the COVID-19 Pandemic (Six-Item State Anxiety Scale)

Almost half (42%) of the caregivers who were providing care for a care-receiver who lived with them were experiencing moderate to severe anxiety before the COVID-19 pandemic. Approximately a quarter of those caring for those living separately in their own private home (29%), supportive living (27%), and LTC (25%), were experiencing anxiety.

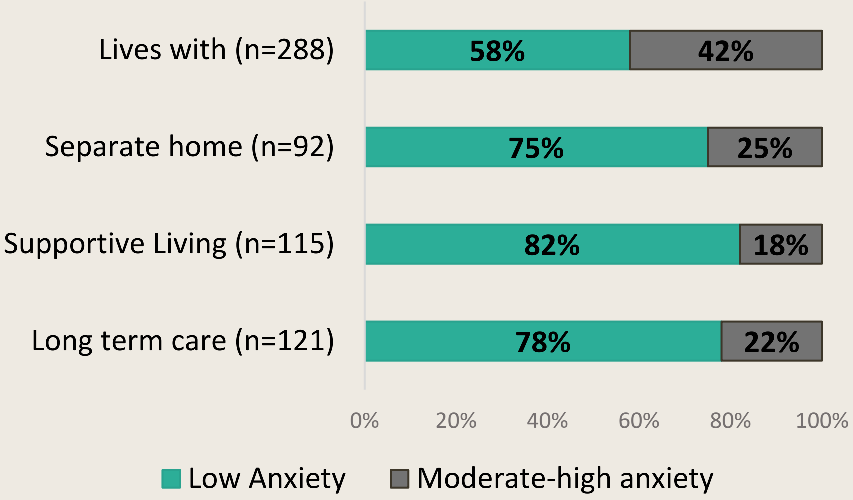

Figure 23: Proportions of Anxious Family Caregivers Pre-COVID-19 Pandemic by Receivers' Residence (Six-Item State Anxiety Scale)

During the COVID-19 pandemic, about three-quarters of caregivers to people living in separate homes, supportive living and LTC were anxious compared to 84% of the caregivers to Albertans who lived in the same home.

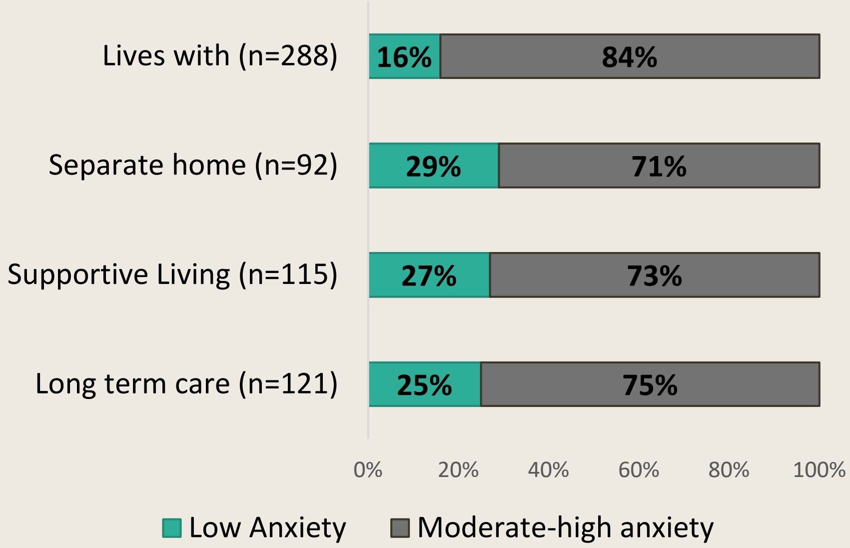

Figure 24: Proportions of Anxious Family Caregivers During COVID-19 Pandemic by Receivers' Residence (Six-Item State Anxiety Scale)

> *"Family and friends are less available. Homecare is felt to not be an option as services have been ceased in a number of cases. Ongoing personal anxiety and bouts of feeling low and overwhelmed."*

> *"Access to homecare rehabilitation services stopped during the pandemic for approximately a month. It became more challenging to try to incorporate virtual health visits with my daughter's team members. My daughter was greatly benefiting from weekly in-home visits from a therapist assistant before the pandemic. There is now more of a burden on me and my husband for her therapy. We are experiencing more stress and anxiety about this lack of support and caregiver burn out."*

7.4 Caregiver Loneliness Increased During the COVID-19 Pandemic

Loneliness was high pre-COVID-19 and increased significantly after the onset of the COVID-19 pandemic.

Why measure loneliness? Family caregivers are particularly at risk of isolation and loneliness. [33-36] Feeling lonely is linked to the risk of depression, dementia, poor self-rated health, and premature mortality. [27-32] Loneliness carries the same health risk as smoking 15 cigarettes a day. It is twice as harmful to health as obesity and the risk of premature mortality is as lethal as alcoholism.[8]

We used the Six-Item DeJong-Gierveld Loneliness Scale[2] to assess family caregiver loneliness retrospectively before the COVID-19 pandemic (January 1, 2020) and family caregiver loneliness at the time of the survey (June 21-July 31, 2020). (See Appendix: Methods).

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[2] The Six Item DeJong-Gierveld Loneliness Scale is a widely used, valid, and reliable measure of social and emotional loneliness. The scale authors consider scores of 0 to 1 as 'not lonely', 2-4 as 'moderately lonely', and 5-6 as 'severely lonely'.

Retrospectively (January 2020), before people were aware of the COVID-19 virus), almost half (46%) of the family caregivers completing the survey were not lonely (Scores of 0-1).

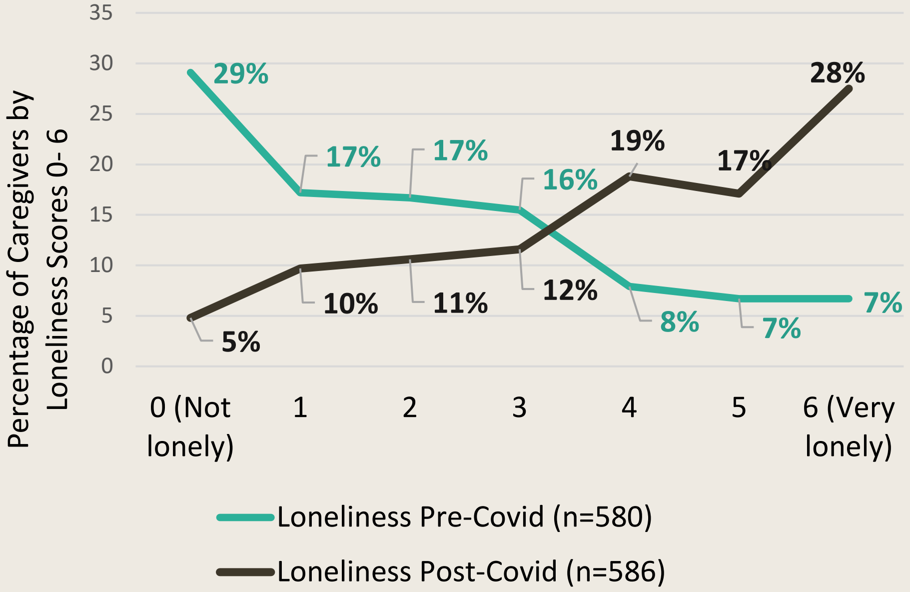

Figure 25: Comparisons of Family Caregivers Pre and During COVID-19 Loneliness Scores (Six-Item DeJong-Gierveld Loneliness Scale Scores 0 to 6)

More caregivers (58%) were emotionally lonely, than were socially lonely (40%). According to the scale authors this would be interpreted as more family caregivers perceived they had other people in their social networks that could support them, but 58% were missing emotionally "intimate relationships"

Caregiver loneliness increased after the onset of COVID-19:

- 85% were lonely during the COVID-19 pandemic versus 54% pre-COVID-19 (Total Scale)
- 89% were emotionally lonely during the COVID-19 pandemic versus 42% pre-COVID-19 (Emotional Loneliness Subscale)
- 81% were socially lonely during the COVID-19 pandemic versus 60% pre-COVID-19 (Social Loneliness Subscale)

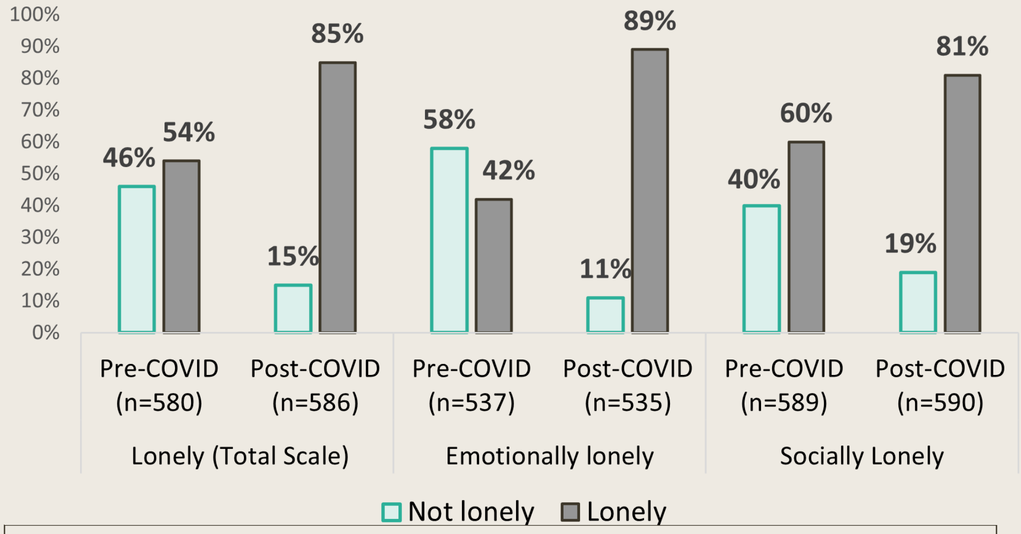

Figure 26: Comparison of Proportions of Family Caregivers Experiencing Loneliness Before and During COVID-19 (Six-Item DeJong-Gierveld Loneliness Scale)

Notably, in our survey the differences in caregiver loneliness were significantly different depending on where the care-receiver resided (private homes, congregate living, or private and congregate living). Those living in the same home as the care-receiver were most likely to be lonely during the COVID-19 pandemic.

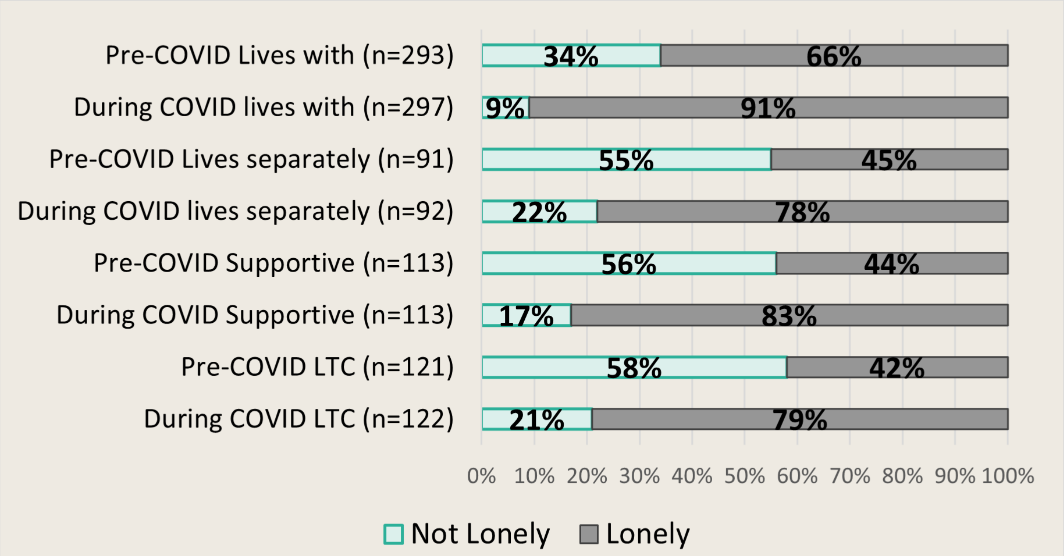

Figure 27: Comparison of Proportions of Family Caregivers Experiencing Loneliness Before and During COVID-19 by Care Receiver's Residence (Six-Item DeJong-Gierveld Loneliness Scale)

8. *Support for Family Caregivers from Healthcare Providers*

As the COVID-19 pandemic took hold, the health and community care systems were asked to adopt policies/practices to prevent COVID-19 transmission, increase testing for COVID-19, and safeguard acute care capacity to treat the people contracting COVID-19. Many of these new protocols increased family caregivers' responsibilities.

8.1 Healthcare Providers Asking Family Caregivers About their Situations

Before COVID-19, 40% of the family caregivers had been asked about family caregiving or how they were doing as a caregiver (January 2020). Since the COVID-19 pandemic began, only 32% of our sample of Alberta's family caregivers surveyed had a health or social care provider ask about their caregiving situation.

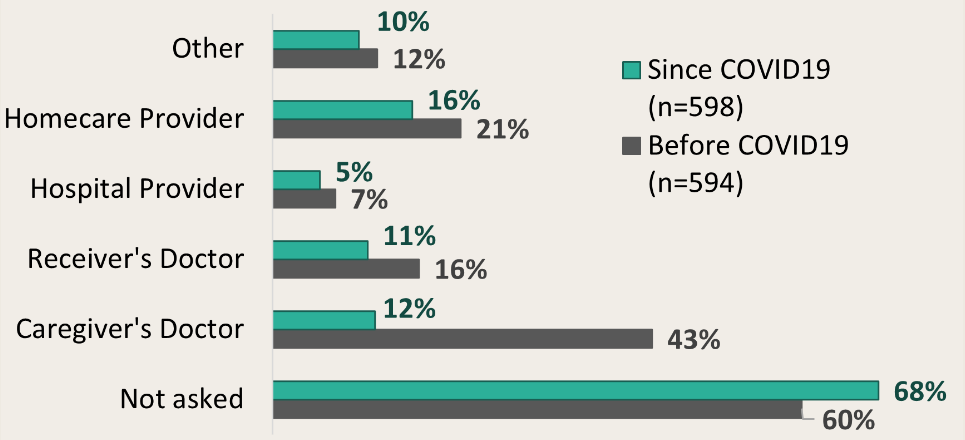

Figure 28: Health Providers Who Asked Family Caregivers About Caregiving (*Identify all that apply*. Caregivers identified 1 to 7 providers)

Before the COVID-19 pandemic almost half (43%) of the caregivers' family physicians [FP], three in 20 (16%) of care-receivers' FP, 21% homecare providers, and 7% of hospital providers asked family caregivers about their caregiving experience.

Other agents who asked family caregivers about their caregiving experience, in order of frequency, were social workers; Day Program and CHOICE[3] staff; LTC staff; physician specialists; Alberta Caregivers staff'; chaplains or pastors; Alzheimer's Society staff; psychologists on a dementia team; nurses; homecare staff; pharmacists, Persons with Developmental Disabilities caseworkers; recreation therapists; occupational therapists; private agency home support staff; speech therapists; palliative care team staff; chiropractors; acupuncturists; and school teachers.

8.2 Homecare Supports During the COVID-19 Pandemic

Homecare services are provided to qualifying people living in the community or in seniors' apartments, lodges, and supportive living.

Of the 599 family caregivers who replied to the question, "Do you currently have homecare services for you or the person you care for?" 152 (26%) answered 'yes'.

8.3 Changes to Homecare Services

Almost half (48%) of those who received homecare services before the COVID-19 pandemic reported that services were reduced after the pandemic struck.

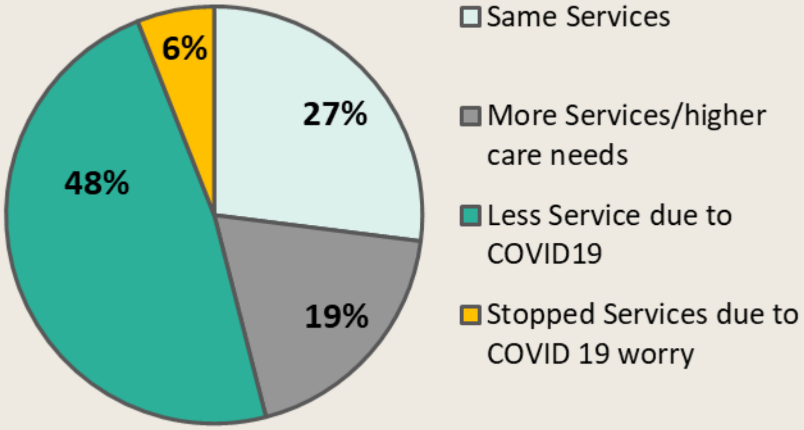

Figure 29: Changes to Home Care Services since the COVID-19 Pandemic (n=148)

> *"They stopped my mother's showers. She did not get a shower or a hair shampoo for six weeks! Then they were able to reinstate them every two weeks and recently they are back to being weekly."*

> *"My husband receives care from AHS Palliative Care, but of course, the nurses cannot visit and help with caring for my husband and respite is not possible because he is so vulnerable. The AHS nurse does call approximately once a month, but there is nothing she can do so we are just here waiting for it to end."*

> *"I had to do tasks normally done by homecare. I have no medical training but had to take care of foot ulcers for my 83 year old husband. I could not attend foot clinic session due to restrictions and husband is not able to understand or pass on info. Husband admitted to hospital with chest infection; no visitors allowed unless he was palliative. He has dementia and was in extreme distress in the hospital without me. Everything was very difficult;it felt like we were thrown to the wolves."*

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[3] Comprehensive Home Option of Integrated Care for the Elderly

8.3.1 Family caregivers appreciated homecare services.

Twenty-seven percent of family caregivers reported services remained the same and 19% received more services due to higher care needs. They appreciated the ongoing services.

> *"We were so grateful for the level of support provided by home care. They did not hesitate to increase the level of support as needed even during the pandemic. My mother has since passed away In her home. It was a wonderful experience for everyone to palliate at home."*

> *"I have been very impressed with homecare. But more so with the Transition Coordinator. Her care and help has been amazing."*

> *"Because of COVID-19, our daughter was admitted to homecare, so we didn't have to take her to the hospital for pick-line maintenance. Homecare providers are more careful."*

> *"My mom is receiving more services from home care as we were not able to go to her room to provide the service."*

> *"My Mom fractured her hip in May. She was Discharged home to her independent supportive living residence and required new homecare services to assist with exercises and personal care post surgery."*

> *"My husbands condition deteriorated considerably during this time but it was nothing to do with the pandemic. I now have more home care."*

8.3.2 Family caregivers stopped homecare services

Six percent of family caregivers reduced or stopped providing homecare services because they worried about getting the COVID-19 infection from homecare staff.

> *"I stopped services at the start of the Pandemic and did all care myself. This is not sustainable. I needed to risk having staff back in our home for both of our mental and physical health."*

> *"Had to stop homecare because we had a different person each time and we're not assured that they followed safe protocol procedures. Homecare workers had to buy their own booties and masks etc."*

8.3.3 Staffing difficulty

Several caregivers reported getting consistent staff was more difficult in the pandemic.

> *"We were so grateful for the level of support provided by homecare. They did not hesitate to increase the level of support as needed even during the pandemic. My mother has since passed away in her own home. It was a wonderful experience for everyone to palliate at home."*

"It is difficult to get consistent, trained staff on week ends or vacation of the regular weekday staff. We have reduced homecare to one hour in the mornings because my husband gets so frustrated with staff who do not know his routine, are not well trained, or are simply reticent to do a proper job."

8.4 Case Managers in Contact with Family Caregivers/Clients

Of the 26% of family caregivers who cared for Albertans receiving homecare services, 73% reported their homecare case manager had checked in with them or the person they were caring for.

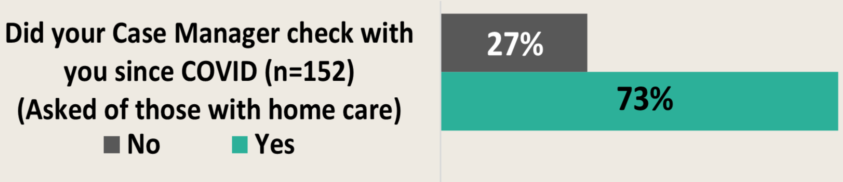

Figure 30: Contact with Home Care Case Managers Since COVID-19 Pandemic Began

"LO's Recreation Therapist contacted me and sensed the overwhelm in my voice over increased caregiving. He previously went to adult day support two times a week. I asked his homecare nurse for more respite hours as things opened up so I could attend my own medical appointments."

"He is concerned with germs being transferred by homecare caregivers, so refuses most visits."

"I stopped some of the services due to the number of different health care aides and the increased risk of exposure. The health care aide did not always follow protocol for continuous masking, hand cleaning, gloves. My confidence level dropped dramatically during/after COVID. I filled in sometimes spending 40 plus hours including driving and caring for my parent."

9. *Discussion and Next Steps*

The COVID-19 pandemic has significantly increased the challenge for Alberta family caregivers. Overall, those providing care in private homes were providing much more care as homecare services were reduced, people were discharged from hospitals as quickly as possible, day programs closed, respite was reduced, and residential care admissions were reduced. Face-to-face family caregiving to congregate care residents was limited. When the pandemic was initially declared, family caregivers were restricted from physically entering congregate care and hospitals to provide personal care (e.g., feeding, grooming) and support (e.g., monitoring care, advocating for the resident, maintaining the resident's continuity and connectivity with other family members and friends). Only support by phone, over the Internet, or by mail was possible. Window visits, then outdoor visits, and later one or two designated family caregivers could enter some congregate care residences or hospitals. The COVID-19 pandemic and both caregiving solitudes, that is being overloaded with providing care and being unable to care triggered distress. Anxiety and loneliness amongst the family caregivers increased significantly.

Alberta family caregivers completing this survey were already providing substantial care before the COVID-19 pandemic. Family caregivers who resided with the care-receiver were providing the most care before the COVID-19 pandemic and after it took hold. In fact, 51% of these caregivers were providing more than 21 hours of care weekly before the COVID-19 pandemic and almost half (47%) added an additional 21 hours a week following the onset of the COVID-19 pandemic. These caregivers noted that since the COVID-19 pandemic, reductions in homecare, respite or closure of community and day programs occurred resulting in an increase in the care intensity as well as the hours spent providing care without a break. About two-thirds (61%) of caregivers who resided with the care-receiver reported care hours increased by 10 or less hours a week and 18% added 21 or more hours a week. As caregiving scholars note, caregivers' circumstances vary widely thus following the research on successful interventions they recommend beginning with an assessment of caregivers' strengths, risks, support needs, and preferences.·[26 27]

Our study also concurs with findings that family caregivers continue to provide significant care after admission to supportive living and LTC. [14 28] Before the COVID-19 pandemic, 34% of the survey participants were providing 10 to 20 hours of care, and 13% were providing 21 to 40+ hours of week of care in LTC. In supportive living, 10% were providing care for 21 or more hours a week before COVID-19. Caregivers acknowledged that congregate care staff worked hard during the COVID-19 pandemic. However, they were distressed by the lockdown and not being able to provide care. Many reported that the congregate care resident's health deteriorated without their socio-emotional support and practical assistance with care.

Aligned with the longer hours, heavier care workloads, and longer care trajectories detailed above, signs of stress including the inability to take a break, thinking about caregiving, feeling frustrated, and not sleeping were prevalent (57-79% of study participants). Family caregiving per se does not cause distress or burnout. In fact, 88% of those who care for older parents say their care work is rewarding.[28] However, when providing care becomes overwhelming—too much to do in too little time—the work becomes stressful.[26 29] Family caregiving usually becomes more onerous as illness, frailty, and impairments become more severe. Caregiver distress was rising even before the COVID-19 pandemic. For example, in 2016, one-third (33.3%) of family caregivers to homecare-receivers in Ontario and British Columbia were stressed and distressed,[30 31] up from 15.6% in 2010. [32] In the last two decades, medical advances, increased longevity, shorter hospital stays, and a push for community care have made caregiving more complex and longer lasting. [29 33] At the same time, there are fewer family caregivers available as more men and women are working full time and families are smaller.

In our study, the rates of anxiety and loneliness were high and increased during the COVID-19 pandemic. Three-quarters (78%) of study participants were anxious. In addition, loneliness rates were particularly high (85%). Loneliness carries the same health risk as smoking 15 cigarettes a day. It is twice as harmful to health as obesity and the risk of premature mortality is as lethal as alcoholism.[8] As such, we need to pay attention to loneliness and anxiety of family caregivers as well as Albertans that they care for. A recent study noted that anxiety and depression increase premature mortality rates by 76% or more compared to mortality rates of those who never had anxiety and/or depression.[34] Anxiety is the most frequently occurring psychological disorder among family caregivers.[7] Typically family caregiver anxiety rises as care responsibilities increase and energy are depleted.[3-8] Based on this evidence, some caregiving scholars regard anxiety as a good measure on which to base the effect of interventions..[5 28]

Many family caregivers were providing more than 21 hours of care a week, with 42% assessing they could not leave the person they cared for alone for an hour or less. Being overwhelmed with long hours of care, onerous care tasks, stress, anxiety, and loneliness can take a toll on family caregivers throughout the care trajectory. [29 35 36] Compared to non-caregivers, family caregivers have higher rates of depressive symptoms, anxiety, stress, and emotional difficulties.[29 36-38] There is evidence that family caregivers have lower self-rated physical and mental health, elevated levels of stress hormones, higher rates of chronic disease, and impaired health behaviours.[1 29 39 40] In fact, the primary reason for LTC admission is that the family caregiver's health is failing. [1 2] Although only four months had elapsed since the COVID-19 pandemic began, about half of the participants reported that their physical health (48%) and mental health (58%) had declined.

COIVD-19 has exposed just how undefined the family caregiver role is. While importance of family presence has previously been endorsed by many health care organizations, there is growing recognition of how essential family caregivers are. There is, however, inconsistency in the application of family caregiver policy on the ground. Family caregivers' work, both in private homes and in congregate living, has always been invisible; it is nonetheless crucial to sustain the formal care system.[30 32 41] The caregivers providing the most intensive care noted that respite and homecare gave them a much needed break. Without that assistance, participants reported that sustaining caregiving was difficult. The provision of care has been all the more critical as a result of the COVID-19 pandemic, but the impact of the pandemic on family caregivers caring at home and in congregate care, and their related needs, have been largely ignored in the health system's pandemic responses to date.

A plethora of policy and practice documents[42-48] including Roy Romanow in *Building on our values: The future of healthcare in Canada*[49] note that our health system is not sustainable without the unpaid labour of family caregivers and recommended support for family caregivers. Despite the recommendations, the current landscape of caregiver policy and support is a patchwork of small uncoordinated programs that do not yet meet the needs of the diverse population of family caregivers. [26 27 29 50-52] In addition, family caregivers are often marginalized rather than supported by providers in the healthcare system. [26 30 53] Our 2020 Survey of the Impacts of COVID-19 on Alberta Family Caregivers clearly indicates the stress, anxiety, and loneliness family caregivers are experiencing. As this caregiver recounted, *"I did not have any services for 3 months. No one has ever asked how I am. Truth is, I am disposable according to the system."* Family caregivers did not think their role, or their work has been recognized by the health system. In addition, less than a third (32%) had been asked about their care situation since the COVID-19 pandemic began in March.

A decade ago, researchers recommended that healthcare providers recognize family caregivers as partners in the client's care as well as clients in need of support to maintain their own wellbeing. [54-56] To support these efforts, researchers proposed training to enhance the competencies of healthcare providers to work effectively with family caregivers. [54-56] In 2018, American caregiving scholars reiterated that, “educational and workforce development reforms are needed to enhance the competencies of healthcare and LTC service providers to effectively engage [family] caregivers.” [16 p. S36] Despite these recommendations, the focus of healthcare education is left to family caregivers, as health providers receive little or no education or training that can help them support family caregivers. [26 57] Mandating health and community providers to identify, partner with, and support ALL family caregivers throughout the care trajectory requires minor changes in practice. For example, the United Kingdom enacted caregiver support policies in 2004 and in the United States in 2018, the U.S. President signed the Recognize, Assist, Include, Support, and Engage [RAISE] Act directing the Secretary of the Department of Health and Human Services to develop and maintain a strategy for healthcare providers to recognize and support FCGs.[58]

There is ongoing work in Alberta to build a better system to support family caregivers. In addition to Caregivers Alberta, the Alberta Caregivers College, the Family Caregiver Centre, and support through condition specific not-for-profit organizations (e.g., ALS, Alzheimer’s, Mental Health, Parkinson’s), there are several collaborative efforts that recognize caregiver diversity and changing needs along the trajectory. Dr. Janet Fast and Dr. Norah Keating from the Research on Aging, Policies, and Practice [RAPP] program at the University of Alberta are nationally/internationally renowned caregiving research experts. At the policy level, a Cross-ministerial Caregiver Supports Working Group has been established and recently the pan Alberta Caregiver Focused Coalition is also joining forces to ensure collaboration on the broad range of resources that diverse family caregivers need. Norquest College has developed a range of skills training education for family caregivers that are now offered online.

Dr. Jasneet Parmar from the University of Alberta with healthcare and community organizations, researchers and policy makers consulted with over 400 multi-level interdisciplinary stakeholders including family caregivers. [59-64] Based on these consultations, they have developed and validated the Caregiver Centered Competencies for the health workforce. [62 65] Currently, over 100 multi-disciplinary stakeholders are developing and testing the Foundational Caregiver- Centered Competency based education to train the health workforce to support family caregivers. A website to support Family caregivers in Healthcare has been launched (caregivercare.ca) with the support of Dept. of Family Medicine, University of Alberta.

Since the COVID-19 pandemic began, many not-for-profit organizations (e.g., Caregivers Alberta, Alzheimer’s Society, Parkinson’s Society) have moved support online. Congregate living staff have also worked to connect families and residents. The Dementia Network Calgary and the Canadian Red Cross are training family caregivers in the use of personal protective equipment and managing infection control. There is increasing acknowledgement of the necessity of assessing family caregivers’ strengths, risks, support needs, and preferences regularly throughout the care trajectory. The Carer Support Needs Assessment Tool [CSNAT] is included in CONNECT Care and has been used in an Edmonton Zone Home Living Clients and Caregivers Supports pilot project. Over 60 Alberta providers were trained to use the CSNAT by the study authors September 9-11, 2019. Caregivers and their care situations are diverse and change as the care-receiver’s needs shift. Edmonton Zone Home Living Clients and Caregivers Supports pilot project (Jan 2019-March 2020) showed reduction in caregiver distress and gave clients and caregivers a real choice to stay at home.

Hopefully, the results of this *Survey of the Impacts of COVID-19 on Alberta Family Caregivers* will shine a light on the need for consistent support for family caregivers throughout the care trajectory. Caregivers are doing their part to provide care, but the stress is increasing. It is not good enough to return to the pre-COVID status quo. Now is the opportunity to build a better system to support family caregiver’s health and wellbeing during their caregiving journey. Educating and mandating health and community social care providers to identify and support family caregivers is one of the next critical steps. It is also critical for policy makers, researchers, health and social care providers, community organizations and advocates, and family caregivers to work together to co-design the approach and supports needed during the rest of this pandemic and beyond.

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Appendix 1 Methods

Survey Methods

The Survey of the Impacts of COVID-19 on Alberta Family Caregivers, June 21-July 31, 2020, received ethics approval from the University of Alberta Health Research Ethics Board. In July 2020, 1225 people clicked on the survey, 504 did not complete any questions on the survey, and 117 completed 5 questions or fewer. 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 centres, 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 there are 400,000 informal caregivers who 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, underlying condition of 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=12),
- Brain injury/ stroke [Acquired brain injury, aneurysm, head injury, stroke] (n=97),
- Cancer (n=58),
- Chronic health conditions [diabetes, arthritis, asthma, Crohns, cystic fibrosis, COPD] (n=216),
- COVID-19 (n=3),
- Dementia (n=280),
- Drug/alcohol dependency (n=12),
- Frailty (n=66),
- Heart disease (n=116),
- Intellectual disability (n=91),
- Mental illness (n=101),
- Neurological conditions [epilepsy, Parkinson’s, multiple sclerosis, ALS] (n=115),
- Palliative care/end of life (n=55),
- Sensory impairment [hearing loss, vision loss, blindness, deafness] (n=151),

- Other health conditions (n=123). Anorexia; Attention Deficit Hyperactive Disorder; Cerebral palsy; Complex needs; Deletion syndrome; Double organ transplant recipient; Huntington Disease/Juvenile Huntington Disease; Learning disabilities; Lyme disease; Meniere's disease; Multi-system atrophy; Neurodegenerative condition; Obsessive compulsive disorder; Post-traumatic stress disorder; Spinal osteoporosis; Spinal stenosis/severe secondary scoliosis; Surgical complications/awaiting surgery; and vertigo.

Anxiety: Six-Item State Anxiety Scale

We assessed anxiety with the Six-Item State Anxiety Scale. [24] 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 have been found to be as reliable and valid as the original 20 item version.[24 66 67] Cronbach alphas range from.74 to 82.[24] In this survey, the Cronbach's alpha pre-COVID-19 was.845 standardized and the during COVID-19 Cronbach's alpha was. 891 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 2: Six-Item State Anxiety Descriptive Statistics

Six-Item State Anxiety Scale (Range 20 to 80)		
	Pre-COVID	During COVID
Mean	35.9	53.7
Median	36.7	53.3
Mode	20	46.7
Standard Deviation	12.4	14.5

We used a paired samples t-test to evaluate the difference between the pre-COVID-19 retrospective anxiety ratings (January 1, 2020) and at the time of the survey (June21- July 31, 2020). The increase in anxiety scores between 01 January 2020 and June/July 2020 on the Six-Item State Anxiety Scale[24] was statistically significant: Pre (M=35.77, SD=12.42) Post (M=53.57, SD 14.47) t (560) = 27.45, p<.0005 (two tailed). The eta squared statistic (.57) indicated a moderate effect size.[4]

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[4] Effect size tells you the magnitude of the difference, and thus what is clinically meaningful. Cohen proposed values for interpreting eta squared are: <0.2= trivial effect; 0.2-0.5 = small effect; 0.5-0.8 = moderate effect; > 0.8= large effect. Cohen's effect sizes may be positive or negative.30. Cohen J. Statistical power analysis for the behavioral sciences. 2nd ed. ed. New Jersey: Lawrence Eribaum, 1988.

Loneliness: Six-Item DeJong-Gierveld Loneliness Scale

We used the Six-Item DeJong-Gierveld Loneliness Scale[68] to assess loneliness retrospectively before the COVID-19 pandemic (January 1, 2020) and in June-July 2020.[24] The Six-Item DeJong-Gierveld Loneliness Scale can measure social and emotional loneliness.[69 70] 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[68] 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[68]: 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[69] to.74.[68] In this survey, the Cronbach's alpha before the COVID-19 pandemic was.77 (.77 standardized) and during the COVID-19 pandemic it was.76 (.76 standardized). 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.[71]

We used the paired samples t-test to evaluate the difference between loneliness rated retrospectively before any hint of COVID-19 (January 2020) and as the COVID-19 pandemic evolved (July 2020). The increase in loneliness scores on the 6 Item DeJong-Gierveld Loneliness Scale was statistically significant: Pre (M=2.01, SD=1.87) Post (M=3.91, SD 1.85) t (569)= -23.98, p<.0005 (two tailed). The eta squared statistic (.50)[72 73] indicated a moderate effect size.

The Chi-square test for independence indicated significant associations between loneliness and care location. Before the COVID-19 pandemic χ2(2, n=570) =23.96, p=.0005, Cramer's V=.205; During the COVID-19 pandemic, χ2(2, n=576) =8.55, p=.0014, Cramer's V=.122.

Table 2: Six-Item DeJong-Gierveld Loneliness Scale Descriptive Statistics

Six-Item DeJong-Gierveld Loneliness Scale (Range 0 -6)		
	Pre-COVID-19 (n=587)	During COVID-19 (n=595)
Mean	2.03	3.91
Median	2.00	4.00
Standard Deviation	1.87	1.86
Emotional Loneliness Subscale (0-3)		
	Pre-COVID-19 (n=589)	During COVID-19 (n=590)
Mean	.75	1.89
Median	.00	2.00
Standard Deviation	1.03	1.01
Social Loneliness Subscale (0-3)		

	Pre-COVID-19 (n=589)	During COVID-19 (n=590)
Mean	1.28	2.02
Median	1.00	3.00
Standard Deviation	1.22	1.18