



Two Solitudes of Caregiving: The Impacts of COVID-19 Pandemic on Alberta's Family Caregivers

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**Family Caregiver Wellness Virtual Event
Norquest College and Caregivers Alberta
November 17, 2020**



Based on a survey: June 21 to July 31, 2020.

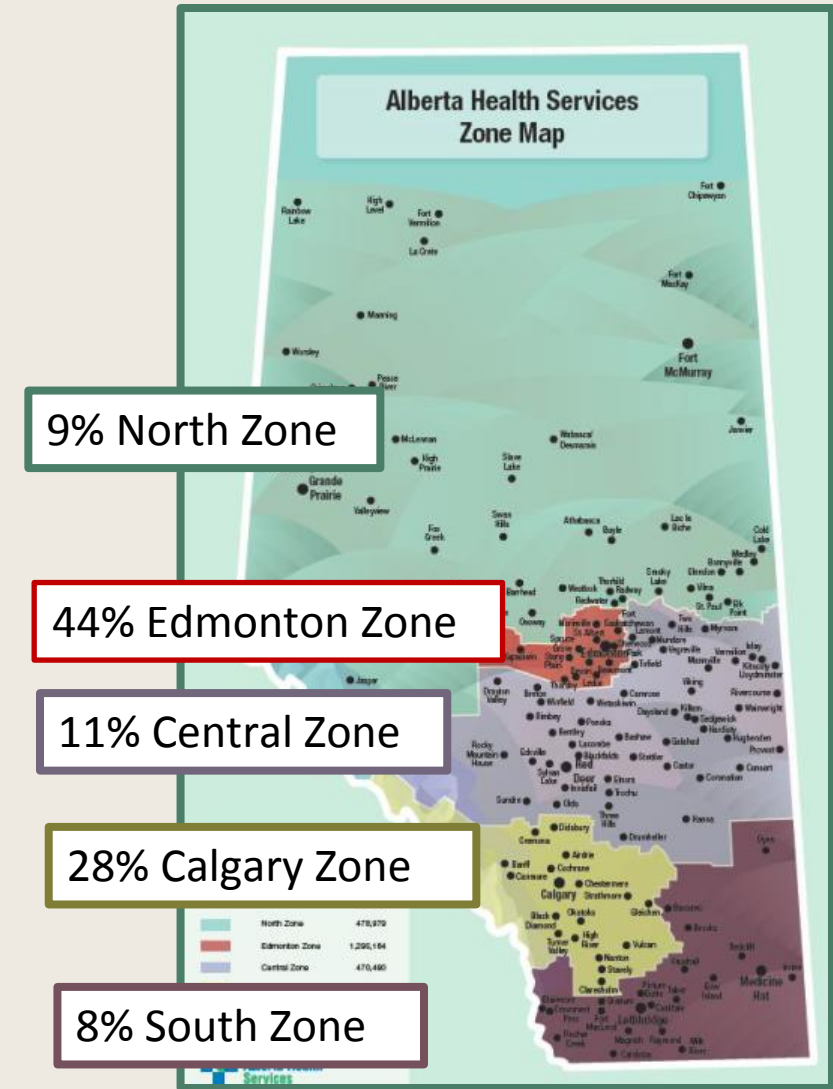
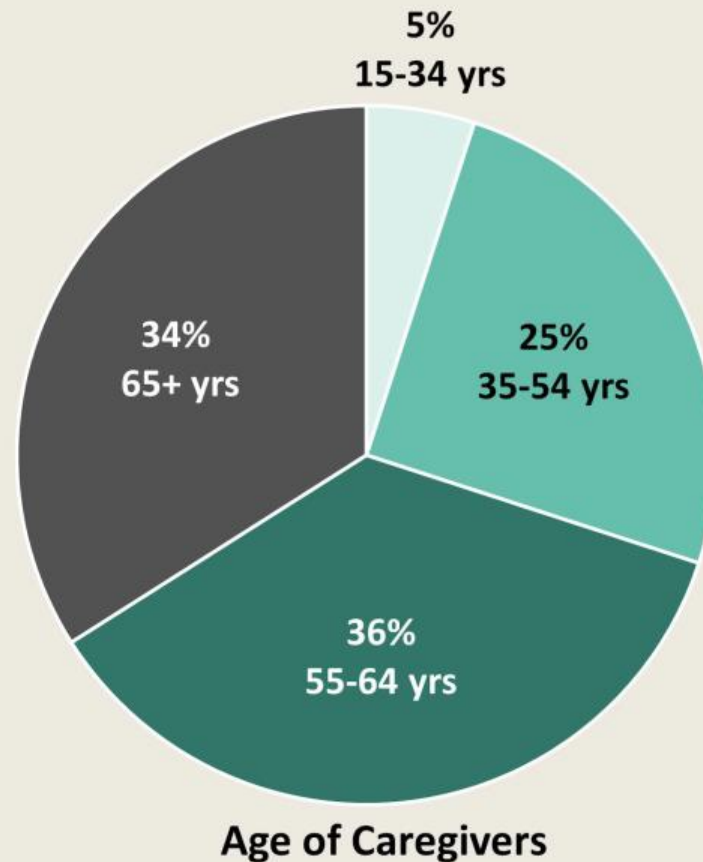
604 Family Caregivers participated

Number of people cared for:

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

Sex

- 85% Female
- 14.6% Male
- 0.4% Other



Demographics: Care-receivers

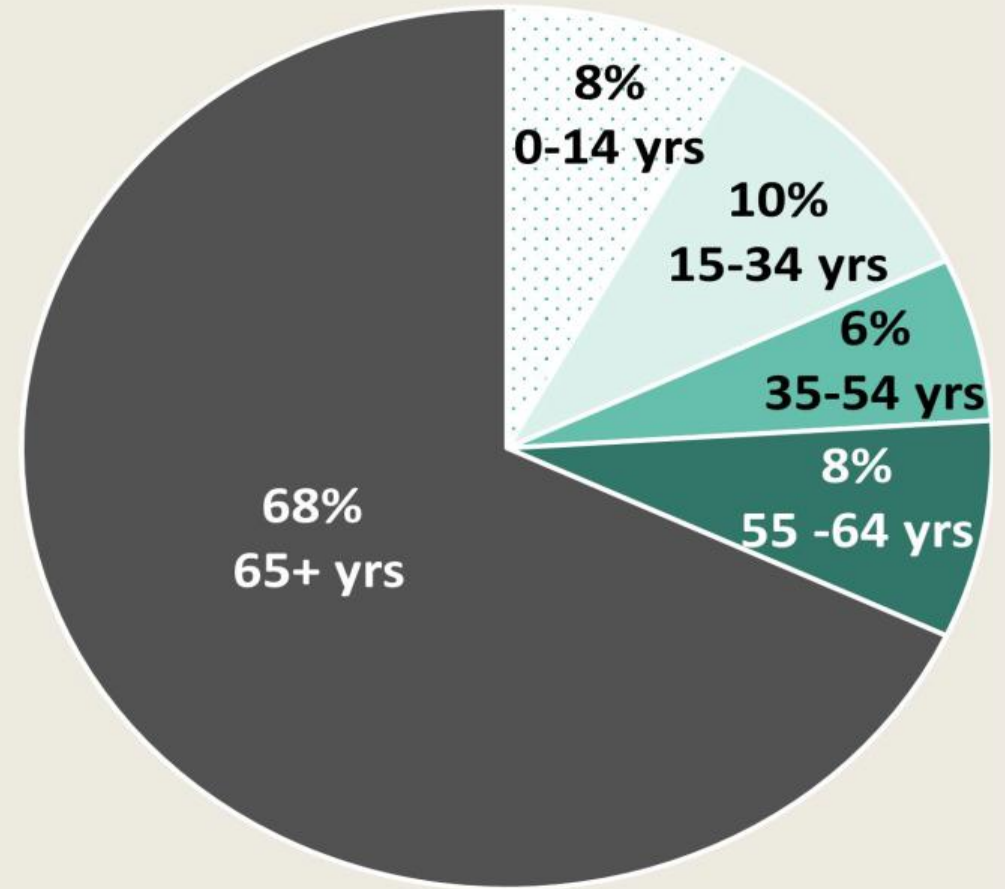
Living Situation



44.3% with family caregivers
10.1% private home separately
1.7% with other family/friend



14.2% in supportive living,
15.5% lived in LTC
14.2% lived in a variety of living
situations.



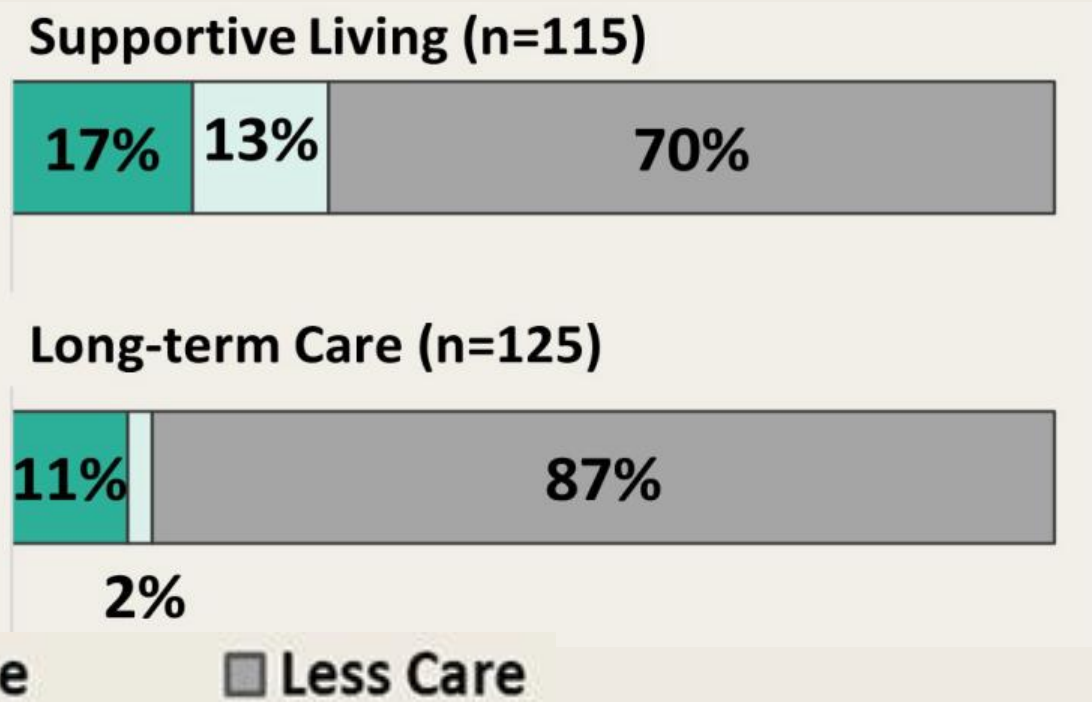
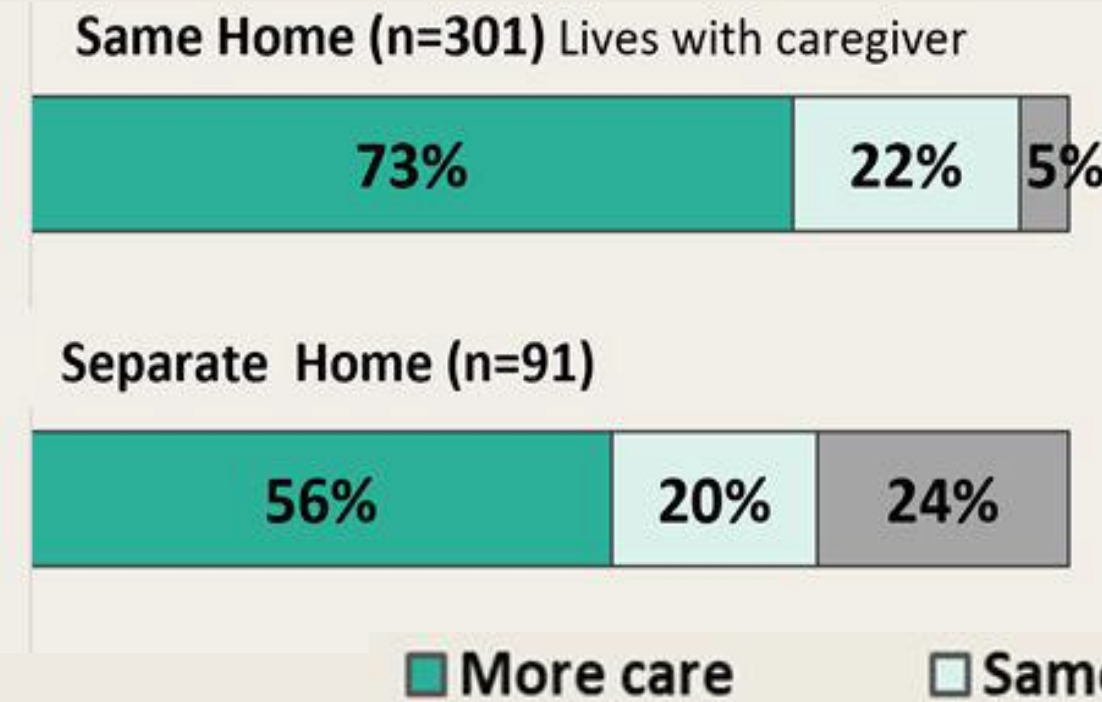
Family caregiving during the Pandemic: the Two Solitudes



Private homes:
Overwhelmed by providing care



Congregate Care: Unable to provide care

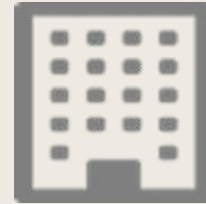


Family Caregiving during the Pandemic: the Two Solitudes



**Private homes: Overwhelmed
by providing care**

“I have become a 24 hour a day care provider with no breaks. It is exhausting to always be needed. I cannot finish a thought without being interrupted. I am sleeping poorly and feel anxious most of the time. My hyper vigilance is high.”



**Congregate Care: Unable
to provide care**

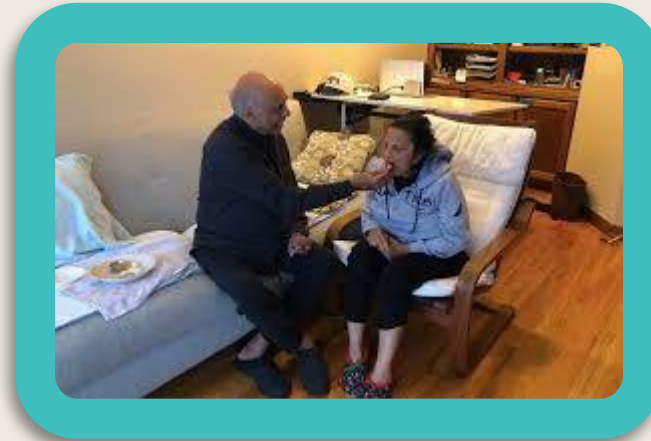
“My Mother is in Long Term care and since COVID there have been huge visiting restrictions. I could not visit her for many months. Once the restrictions to visitors opened I am able to see her for 35 minutes once a week. We sit at a table that keeps us 8M apart. We cannot hug, kiss or touch each other; I cannot give her a new blanket or a special treat like a latte coffee.”

Solitude 1: Additional care - Family caregivers in Private homes

Providing many hours of care before COVID-19

Same Home

37% cared for 40+ hrs/wk,
14% cared for 21-39 hrs/wk.



Added more hours of care after COVID-19 began.

Same Home

47% added 21 to 40+ hrs/wk

Separate Home

19% 21 to 40+ hrs/wk.

20% 10 to 20 hrs/wk



Separate Home

18% added 21 to 40+, hrs/wk

Solitude 1: *More Care. Services were reduced; Less help from others*



"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."

"My 90- year- old mother has become anxious and has not left the house since March. She is afraid to see family and friends and has become quite isolated. Her affect continues to decline, and she is increasingly sedentary. Her health as a result has been impacted by all of the above. She has been unable to see her physician during this time but has had some calls from AHS providers. This has caused me anxiety as well as I observe her decline."

Solitude 2: Family caregivers for Albertans living in Congregate living.

Providing many hours of care before COVID-19

Supportive Living

22% 10 to 20 hrs/wk

16% 21 to 40+ hrs/wk

Long-Term Care

34% 10 to 20 hrs/wk

13% 21 to 40+ hrs/wk



Unable to care after COVID-19 began.

Supportive Living

70% were providing less care

Long-Term Care

87% were providing less care



Solitude 2: Family caregivers for Albertans living in congregate living.

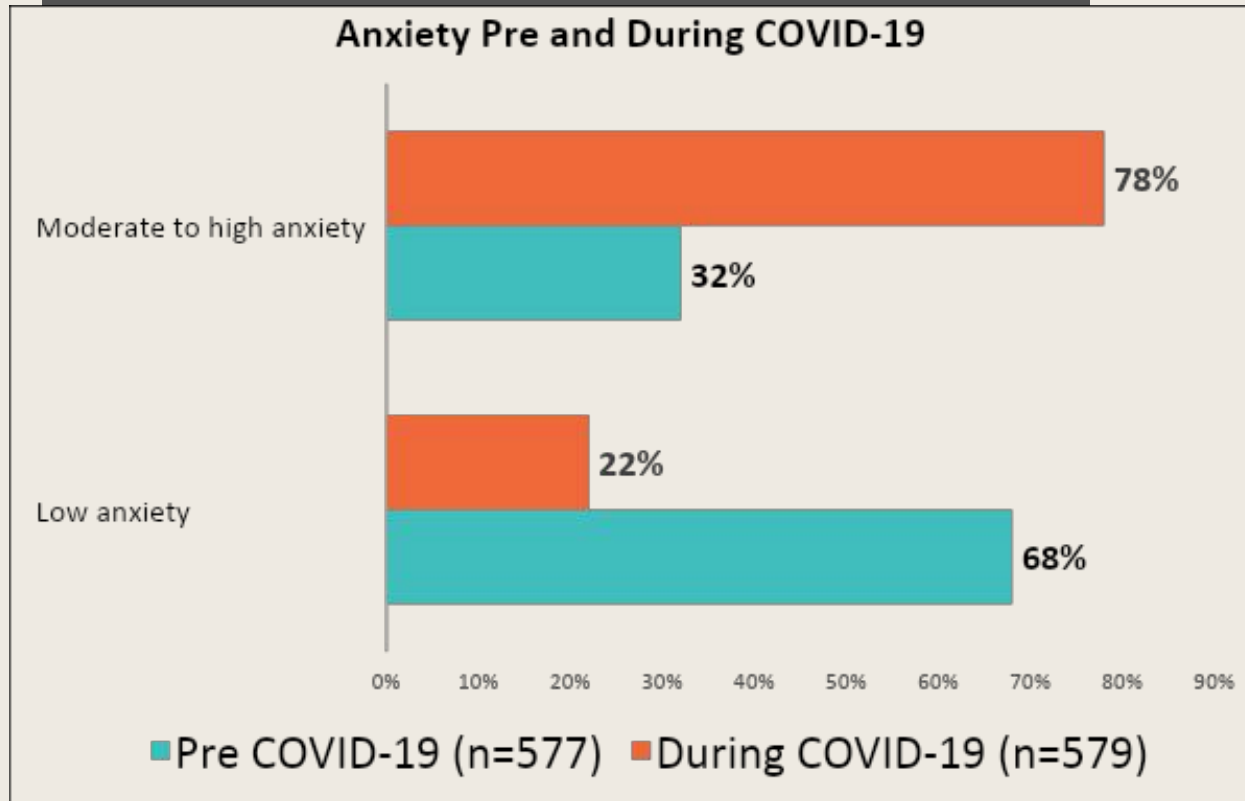


“My Mother is in LTC and I am not allowed in to do the things that I did before. This includes, companionship, checking her well being and notifying the staff about what I am seeing, replenishing needed supplies, doing laundry, taking her to events at the facility and out in the community, and going to eye appointments. I also am unable to help the others living there by helping with activities etc.”

Anxiety* Increased During the Pandemic

32% Before (January 2020)

78% During (July 2020)

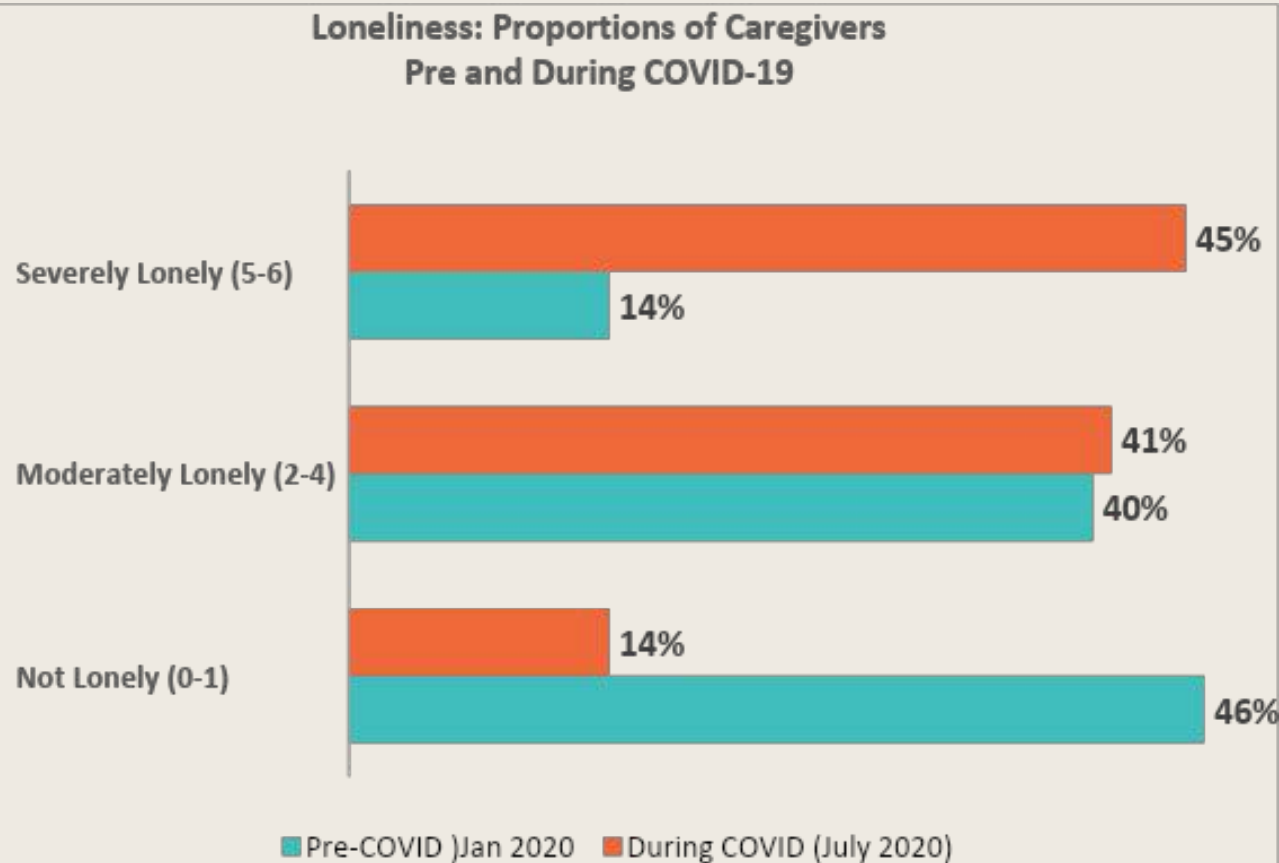


“Government financial supports do not work. I have personally supported this person at a cost of \$1000 per month..., plus the cost of food/lodging. Every time I try to access government programs, my own anxiety and stress increase exponentially as I waste time and energy applying for programs that do not produce benefits.”

*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.

Loneliness* Increased During the Pandemic

44% were lonely before COVID-19
86% are lonely during COVID-19

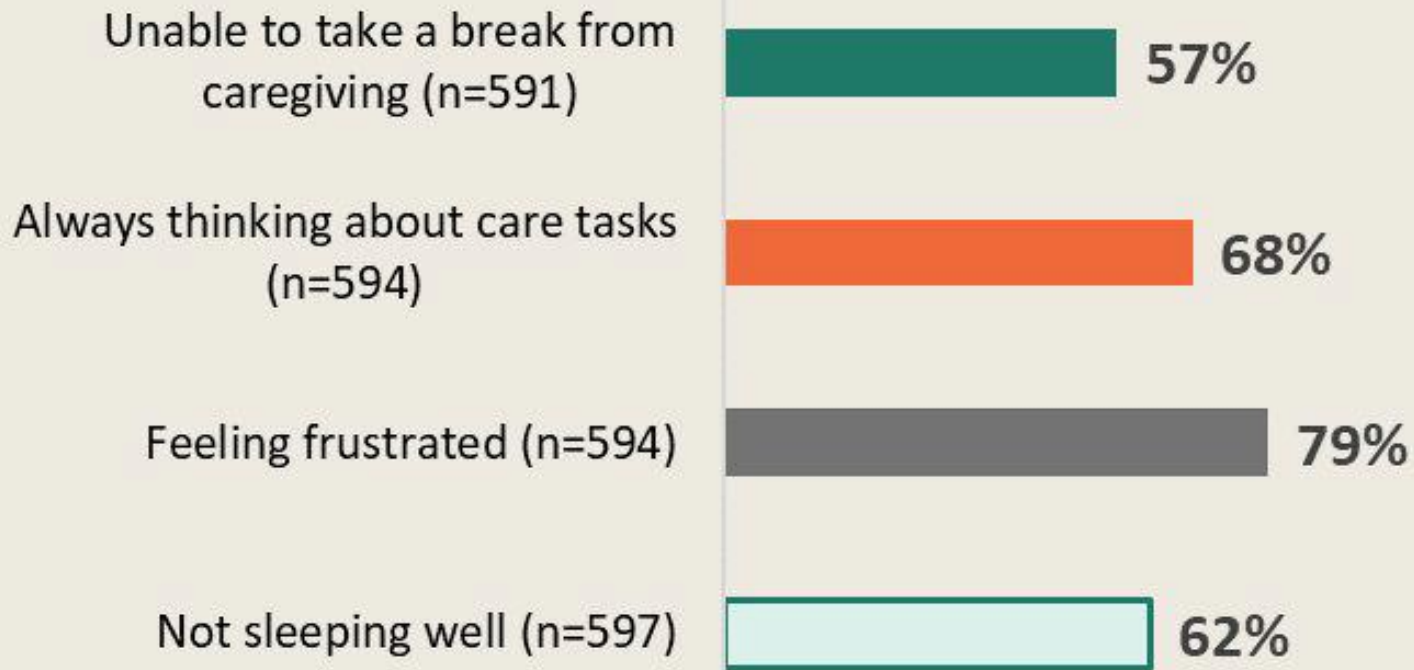


“COVID 19 has made this an even more lonely, isolating and defeating position to be in as a single parent who was already struggling to access the right resources for my son. Just as we were on the right path to care everything got shut, he started to get pushed off further and further, appts dropped to zoom or phone call and I have never felt more alone or more afraid in my life about ending up homeless or being unable to hep my son.”

*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’.

Both Solitudes have Negative Impacts on Family Caregiver's Health and Wellness

Signs of Stress since the COVID-19 Pandemic



Physical Health Deteriorated

48%



Mental Health Deteriorated

58%

Health Deteriorated

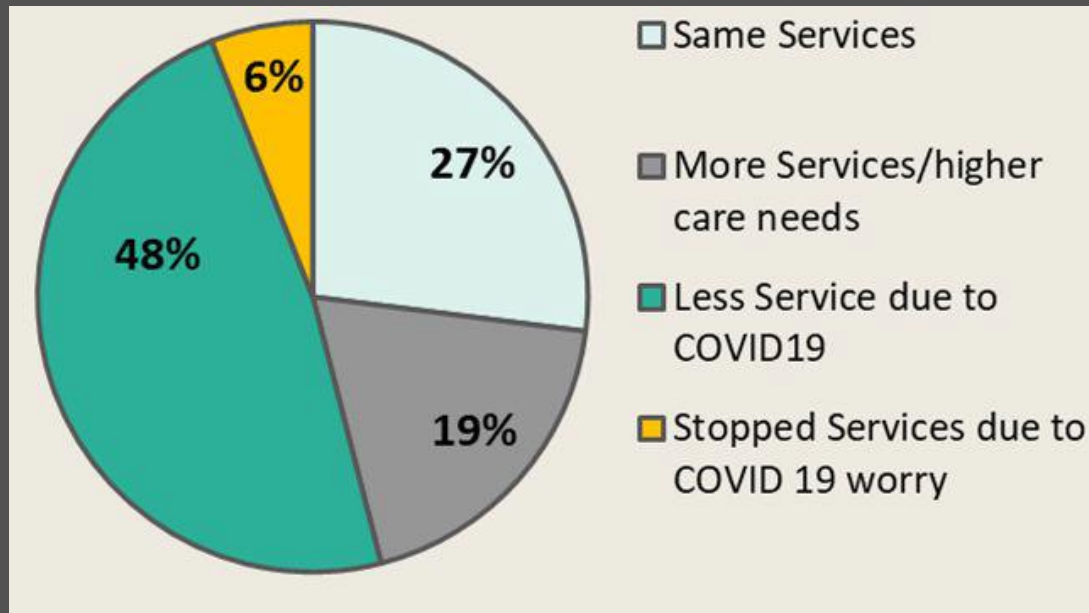
“Respite closed and my one day a week from 10:00 a.m. to 4:00 p.m. was closed to me. Sure, mentally it's much worse for caregiving because there is no break, for him or me.”

“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.”

Health Improved; worried about care receiver

“When my husband was first placed in LTC 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?”

Changes to Homecare Services



“I was coping with my husband going to day programs which have now been cancelled. Zoom gatherings for 1 hour 3 times a week have minimal value. He looks at it like a TV that occasionally talks to him.”

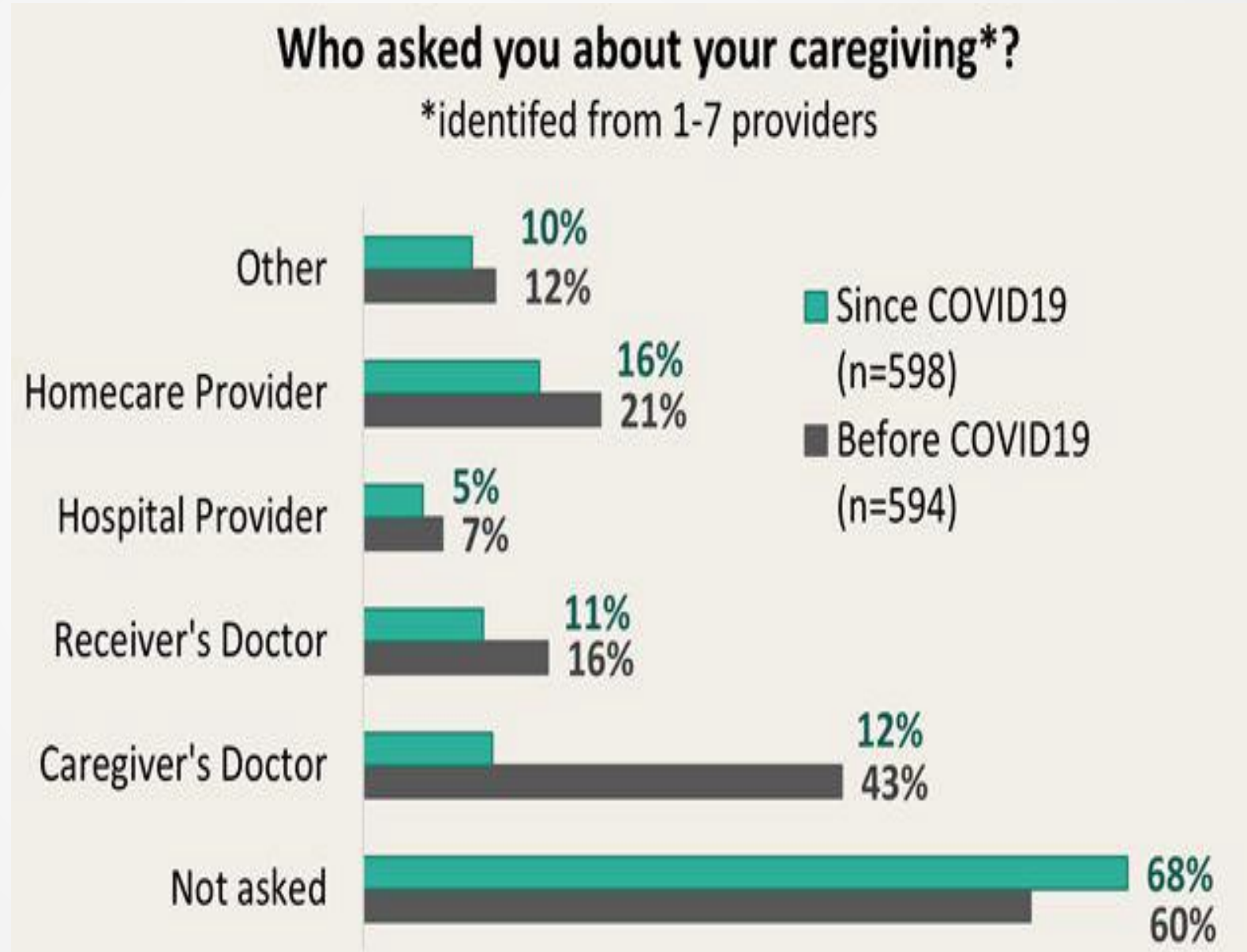
“Respite and ADP's were very valuable to me. I was able to do necessary chores without concerns for spouses care.”

“We used to receive 8 hours of respite service in addition to the 2 hours of personal care that my mother in law needed. We were reduced to 1 hour of personal care for a bath once a week since mid-March....we are most concerned that my mother in law lack social interaction with her home care staff person.”

Recognizing the Caregiver Role: Just asking is therapeutic

40% Before
COVID-19

32% Since
COVID-19
began



Key Points

- Alberta family caregivers, their care situations, and trajectories are diverse.
- Alberta family caregivers completing this survey were already providing substantial care before the pandemic.
- Care intensity and hours spent providing care increased for family caregivers caring in private homes.



Key Points

Family caregivers caring for congregate living residents also experienced loneliness and anxiety

About half of the Family Caregivers reported their physical (48%) and mental (58%) deteriorated.

Family caregiving per se does not cause distress or burnout. When providing care becomes overwhelming—too much to do in too little time—family caregiving becomes stressful

(Schulz et al., 2020, Pauley et al., 2018).

Recommendations

1. Ensure that person-centered care for family caregivers is foundational to practice and policy in all settings throughout Alberta.

2. 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.

3. Consider the risks and benefits to family caregivers as well as the residents in congregate settings in health/social care planning.

<https://www.albertahealthservices.ca/assets/info/ppih/if-ppih-covid-19-dfsp-know-your-role.pdf>



Recommendations



4. Mandate education of healthcare and community social care providers to identify and support family caregivers.

5. Assess family caregivers' strengths, risks, support needs, and preferences regularly throughout the care trajectory from their lens

6. Evolution of homecare supports should include partnering with family caregivers to provide client and caregiver-centered care.

7. Researchers, health/ social care providers, community organizations and advocates, and family caregivers need to co-design supports for family caregivers.

Now is the opportunity to build a better system to support family caregivers to care and for their wellbeing during their caregiving journey.

Alberta-- working together to build a better system to support family caregivers.



Participate in Research

Health providers who work with Family Caregivers: Foundational Caregiver-Centered Care Health Workforce Education. Free online. The education will take about an hour of your time. www.caregivercare.ca

Caregivers of Supportive Living Residents: Are you a family member or friend of an older adult in assisted/supportive living? We invite you to voice your [#COVID19](#) experiences through the COVCARES-AB/BC Survey: <https://bit.ly/36bVdDE> Study website: <https://bit.ly/38dB4jc>

Family caregivers for people living with dementia. We are looking for participants to participate in a study to evaluate the effectiveness of the [#seepainmoreclearly](#) social media initiative to mobilize knowledge about pain in dementia <https://www.seepainmoreclearly.org/participate-in-our-study>

Questions?

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Report: <https://bit.ly/3kiu873>

Fact Sheet: <https://bit.ly/2UpjBfS>

Website: Caregivercare.ca