



HIGHLIGHTS: COVID-19 Continuing Care Study

The Health Quality Council of Alberta (HQCA) conducted the *COVID-19 Continuing Care Study* in **long-term care (LTC)** and **designated supportive living (DSL)** to gain a better understanding about resident and family member experiences and perceptions regarding public health orders and their implementation by sites during the COVID-19 pandemic.



RESIDENTS interviewed:

43 residents from **19** LTC and DSL sites across Alberta

387 residents completed the online survey

"People my age need human contact. I was confined to my room for 8 weeks. This was less than ideal. I have no idea how to Zoom or Skype. I was totally isolated and very depressed."

(resident)

FAMILY MEMBERS responded:

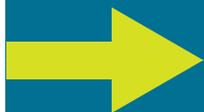
9,625 to an email survey from **308** LTC and DSL sites across Alberta

"I feel that [the site] did very well in their response to the pandemic. I don't see what more they could have done. I have been satisfied that my family member in care has received good care."

(family member)

Context:

The COVID-19 pandemic presented many challenges for residents, their family members, and for Alberta's healthcare system and continuing care operators, requiring the implementation of public health orders and safety protocols to help control the spread of the virus. Public health orders started early in the pandemic and evolved from including guidelines about things like isolation, visiting, and the assignment of staff to single sites, to an approach that allowed more visitors and site-level decision making so that restrictions could reflect the site context and local community.



These experiences were collected from August to October 2020 and are presented in two reports, the *Residents' Perceptions and Lived Experiences during the COVID-19 Pandemic* report and the *Family Experience Survey Report*, available at: www.hqca.ca/covid-19-continuing-care



Key Findings

From **both** residents and family members it was clear that:

- ➔ **Perceptions were polarized** and experiences varied.
- ➔ Restrictions had **harmful consequences** on residents' quality of life and sometimes quality of care.
- ➔ There needs to be a **balance** between infection prevention and associated restrictions, and quality of life.

"In protecting lives, they failed to protect the reason we would want to live."
(resident)

***Quality of life** for residents meant having purpose in life, relationships with loved ones, human connection through physical touch, access to meaningful activity, emotional and spiritual wellbeing.*



Opportunities for improvement

Residents and family members highlighted the following opportunities for improvement:

- ➔ **Seek to understand** residents and families' concerns about the restrictions and safety protocols.
- ➔ **Engage** family members as **essential care partners** and **expand access** to families, support persons, and other visitors.
- ➔ **Improve the visiting experience.**
- ➔ **Improve communication** with residents and family members.
- ➔ Attend to residents' **quality of life** and not just their physical health. For example:
 - Address residents' **mental health.**
 - Ensure access to **recreation.**
 - Provide access to **fresh air, sunshine, and exercise** during periods of resident isolation.
- ➔ **Support staff.** Recognize the impact of the pandemic on the mental well-being of staff, and find ways to support them, for example by **increasing the number** of staff.



"[Residents] believe that their dignity is at stake and they feel capable of playing a part in a decision that so profoundly involves them. [...] They are not children and have managed a century of war, depression, etc., and profound change. [...] I wish those making all these challenging decisions all the best and appreciate all the efforts to date."
(family member)

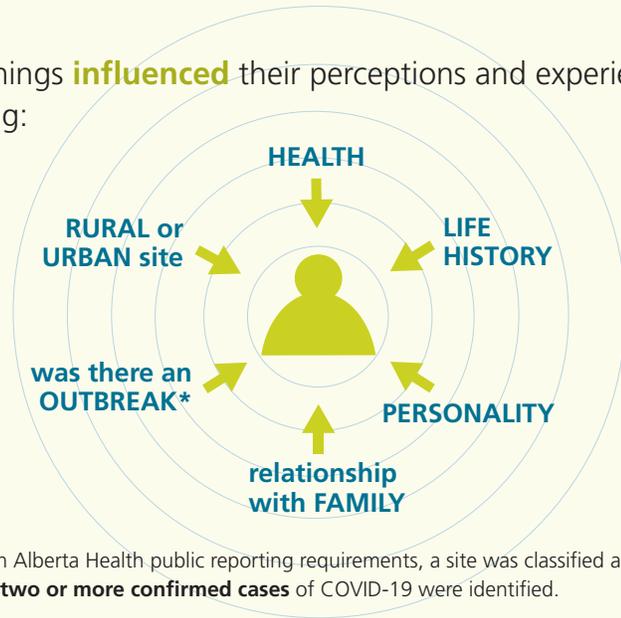


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RESIDENT Perceptions

Perceptions and experiences varied and were often on **both ends of a spectrum**; but could change for a resident depending on the situation (e.g., they could feel safe when reflecting on a topic, and unsafe when reflecting on another).

Many things **influenced** their perceptions and experiences, including:



*In line with Alberta Health public reporting requirements, a site was classified as having an outbreak if **two or more confirmed cases** of COVID-19 were identified.

What we heard:

SAFE



Residents described feeling **safe** and protected against COVID-19 because of policies, protocols, and the behaviours of staff.

"I feel that they're doing the most ... that they can. ... I really don't expect them to do anything more than what they are doing."

NOT SAFE

Other residents described circumstances where they **did not feel safe** because of risks being introduced into their lives that they could not control (e.g., staff behaviours, other residents, or visitors to the site).

"I know that some of the [residents] don't abide completely with the rules. Some of them have gone out and said... they... have a doctor's appointment, but they come back with their hair cut, so you know they've been out, which I would not do."

RULES are NOT too strict



Some residents felt the rules helped to **protect** them and others, and **reduced their worry**.

"Just the two people that you're allowed, and that's most important, because if you get all these people coming in... you would worry about that."

RULES are too STRICT

For many others, they felt that rules resulted in **extremely poor quality of life** because the rules limited access to human touch, fresh air, sunshine, and everyday comforts.

"I feel like I'm in a prisoner of war camp. I have no quality of life and I'm trapped in my room. I miss my family – this is no life."



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I am COPING

Some residents were coping with the pandemic and restrictions, and **found ways to keep busy** during periods of isolation.

"So, it was a really long time. It really was. But as I say, I'm independent. I don't mind being alone."



I am STRUGGLING

Many other residents said that well-intentioned restrictions had **harmful consequences** on their ability to live their remaining years well. They described feeling "confined," "depressed," and "lonely," and explained that the restrictions resulted in loss in strength, memory, and social skills.

"They do all these things to keep us safe, but we lose out on the things that [give] us a reason for living. ... If I don't have a purpose for living, I'm not going to keep going."

The quality of CARE is consistent

Some residents **praised staff** for their hard work and for continuing to provide consistent quality of care.

"They're really good workers, considering they're putting themselves in danger. You never heard them complain about anything."



The quality of CARE declined

Others felt factors beyond staffs' control like insufficient staffing levels and turnover of staff contributed to a **decline in the quality of care** they received during the pandemic.

"They didn't even barely have the staff to look after the people that were here. ... What they should have done, was at least come in and check in on me to make sure that I was okay... because I do fall."

I am AWARE of what's going on

Some residents were **pleased** with the amount and type of information they received about how sites were responding to restrictions and outbreaks.

"We're certainly informed about everything... [about] all reasonable precautions to prevent the occurrence or spread in our site."



I'm in the DARK

Other residents felt the site was **not transparent** about what was happening. They wanted **more information** about outbreaks and how sites were responding to changes in restrictions, so that they could understand **what changes they could expect** to routines, activities, and visits.

"Communicating changes as soon as possible is essential and informing resident of the extent of relaxation of restrictions would be appreciated."



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What we heard – continued



The quality of visiting protocols is POOR

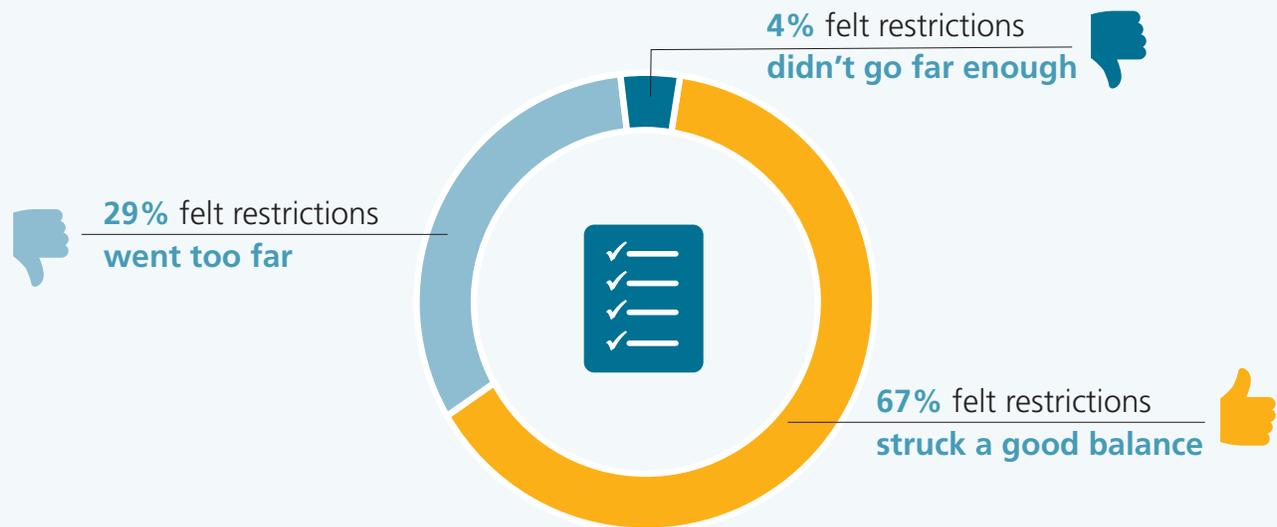
The majority of residents were **not happy** with the quality of visits they had. Most residents felt it was important to have **improved access** to more family, more visits, and more flexibility with scheduling, for example.

"It's been hard, absolutely hard. ... [The family member] has to book ahead. And that really creates difficulty... because [the family member] works odd hours, and as a result of this booking nonsense, [the family member] doesn't come, either, very often."

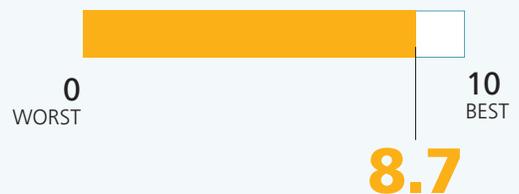
FAMILY MEMBER Perceptions

We asked family members about their experiences from **March to July 2020** at the site where their loved one resided.

Overall site RESPONSE to the pandemic



Where 0 is the worst and 10 is the best, **family members** rated their site's **overall response** to the pandemic at **8.7 out of 10**.





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Worsening HEALTH



41% of family members reported their loved one's **physical health worsened**

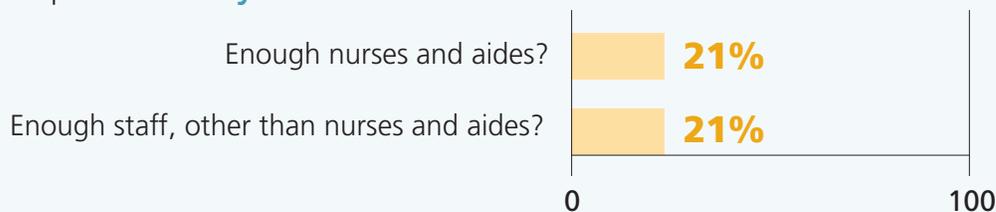


57% reported their loved one's **mental health worsened**

"Let residents enjoy quality of life rather than quantity. ... Her mental and spiritual health has declined leading to a physical decline with less stimulation. ... I'm very disappointed in her quality of life."

STAFFING

% who responded **always...**



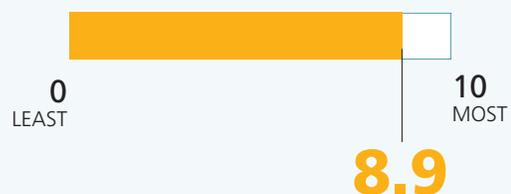
"Most of the roadblocks to visitation or assistance with meals, etc. have been due to insufficient dedicated staffing being devoted to those activities, including scheduling, controlling movement within the facility, etc. Existing staff, whom were already fully engaged and at times short staffed, were stretched with additional requirements due to COVID-19 protocols and are hard pressed to take on an additional coordinating role."

CONFIDENCE in preventing spread of COVID-19

Where 0 is the least confident and 10 is the most confident, **family members** rated their **confidence...**



8.8 out of 10 in preventing **visitors and designated support persons** from contracting COVID-19



8.9 out of 10 in preventing **residents** from contracting COVID-19

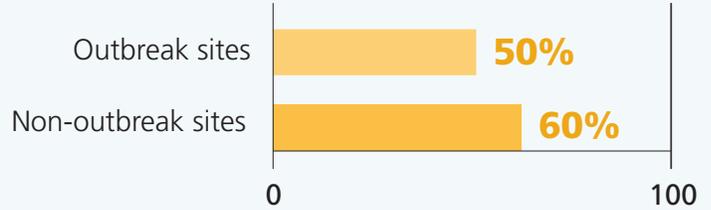


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Feeling SAFE at the site



58% felt their loved one was **always safe** at the site.



A site was defined as under **“outbreak”** if it had **two or more confirmed cases** of COVID-19 between **March and July 2020**.

“I know that it is very difficult to enforce masking requirements with visitors but I have noted more than a few visitors with masks worn incorrectly or who frequently remove them when speaking with loved ones.”

Visiting and virtual VISITS

Satisfaction with the ways your site **assisted you to connect or visit** with your family member.



Virtual visits

Family members reported challenges with technology, and that there was a lack of options, or **not enough options and support** to connect virtually that also considered resident’s ability (e.g., hearing, vision, and cognitive impairments).



24% reported having some **difficulty in connecting** with their loved one virtually.



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COMMUNICATION



45% were **always satisfied** with the information received about their loved ones

34% felt the information received about site actions was **very easy to understand**

40% felt they **always received enough** information about their loved ones

"The communication we did receive was very general and felt like the person that called was not really aware of how our loved one was doing."

IMPACT of restrictions on family members



69% of family members felt **negatively impacted** by visiting restrictions

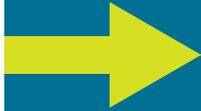
75% felt **stress, anxiety, or depression** related to not being able to visit

"Before the pandemic, I was with [the resident] every day. After the pandemic hit I suddenly was not able to see him at all... This is extremely cruel... [My family member] and I cry ourselves to sleep many a night."





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The *Residents' Perceptions and Lived Experiences during the COVID-19 Pandemic* report focuses on what was heard in in-depth interviews and surveys with residents who live in designated supportive living or long-term care. Some of these sites experienced a COVID-19 outbreak and some did not.

The *Family Experience Survey Report* focuses on survey results from family members with a loved one living in designated supportive living or long-term care.



Thank you for sharing your voice

The HQCA would like to thank the residents and family members who took to the time to share their experiences. These reports provide a voice for residents and family members and an **opportunity for that voice to be heard and shared across the health system.**



Working together

The HQCA worked in partnership with **Alberta Health, Alberta Health Services, and continuing care operators** on this study and ensured timely information was shared. **Individualized site-level results** were provided to those designated supportive living and long-term care sites that participated in the family experience survey.

Feedback and questions

are welcome at info@hqca.ca or by mail:

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About the HQCA

The Health Quality Council of Alberta (HQCA) is a provincial agency that brings an objective perspective to Alberta's health system, pursuing opportunities to improve person-centred care, patient safety, and health service quality for Albertans.