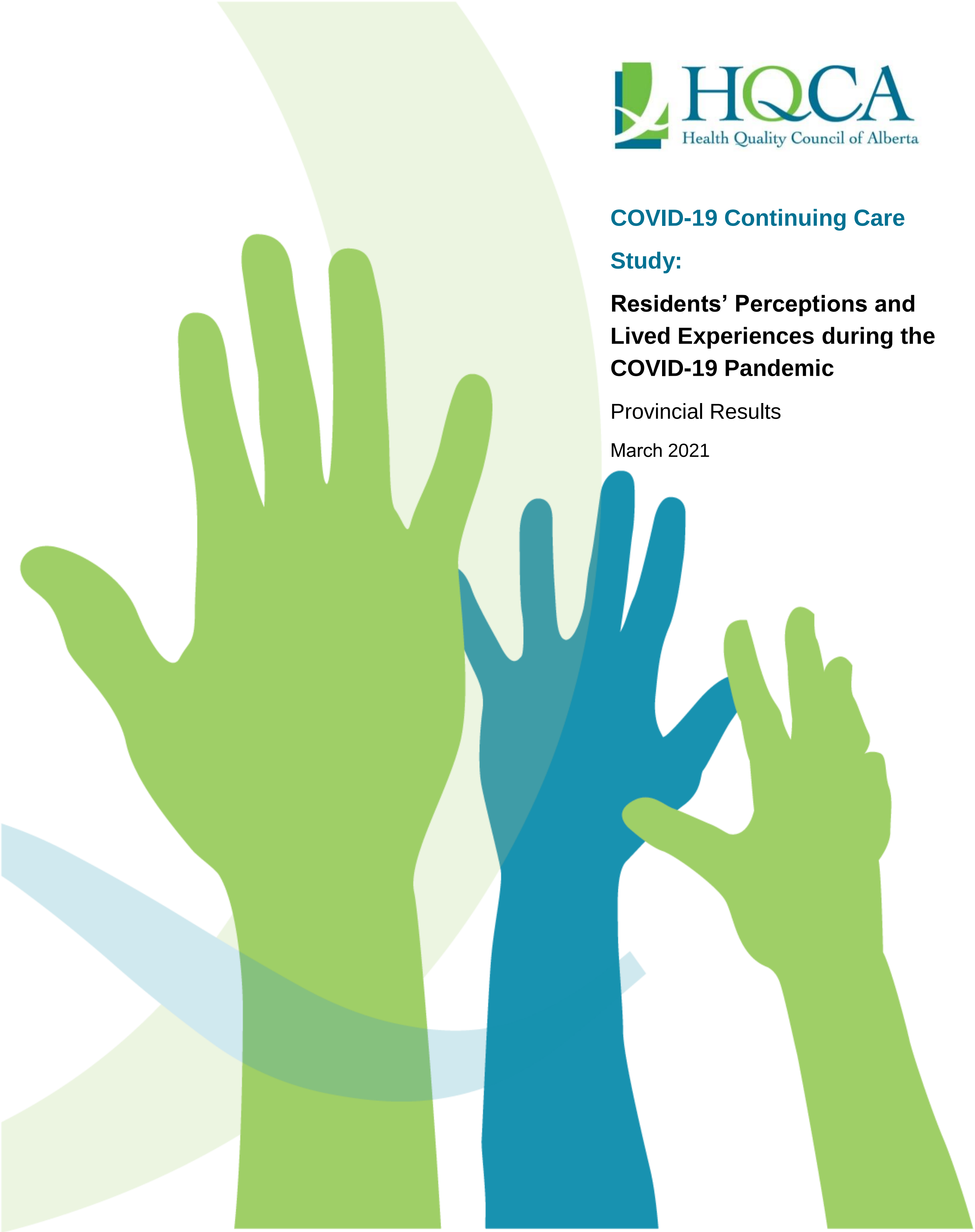
HQCA
Health Quality Council of Alberta

COVID-19 Continuing Care Study:

Residents' Perceptions and Lived Experiences during the COVID-19 Pandemic

Provincial Results

March 2021



Promoting and improving patient safety, person-centred care, and health service quality throughout Alberta

The Health Quality Council of Alberta is a provincial agency that has a legislated mandate to promote and improve patient safety, person-centred care, and health service quality for Albertans. We engage with Albertans to gather information about their experiences and collaborate with Alberta Health, Alberta Health Services, and other stakeholders to identify and drive actionable improvements. Our responsibilities are set forth in the *Health Quality Council of Alberta Act.*

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EXECUTIVE SUMMARY

Introduction

The COVID-19 pandemic presents many challenges 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, early in the pandemic, used a *Restricted Access* approach to limit adverse outcomes among residents. This approach began in March 2020 and included many guidelines about screening, cleaning, hand hygiene, mask wearing, social distancing, use of shared spaces, isolation, visiting, and the assignment of staff to single sites, to name a few. Continuing care sites were expected, at minimum, to follow these orders, but were also able to increase expectations beyond the order based on need.[1] On July 23, 2020, the province shifted to a *Safe Access* approach.[2] This approach allowed more visitors and site-level decision making so that restrictions could respond to the site context and local community. Each of these approaches impacted sites' routines, as well as, the lived experiences of residents in designated supportive living (DSL) and long-term care (LTC) sites and their family members.

Recognizing that restrictions were impacting continuing care residents, the Health Quality Council of Alberta (HQCA) partnered with Alberta Health and Alberta Health Services to conduct the *COVID-19 Continuing Care Study* to achieve a deep understanding of residents' and families' experiences during the COVID-19 pandemic. Using in-depth interviews and a survey, this report explores residents' perceptions about the public health orders and safety protocols and their experiences as sites implemented orders and responded to pandemic-related circumstances, including outbreaks of COVID-19. Information about residents' lived experiences is important as public health officials and continuing care operators try to strike a balance between protecting residents from COVID-19, and the unintended consequences of restrictions to quality of life and the delivery of care and services. Families' experiences were captured in a separate report titled: the *COVID-19 Continuing Care Family Experience Report*.

What did we learn?

> *"In protecting lives, they failed to protect the reasons we would want to live. Sitting in my suite all day, having no social activities, terrible food and nothing to look forward to was just existing - it was not living." (Woman, aged 85-94, survey response)*

Residents' perceptions and experiences with the restrictions varied, but consensus existed that quality of life had been adversely affected by the restrictions

Residents provided rich descriptions about how the pandemic, public health orders, and safety protocols impacted the quality of their lives and the care and services they received. Their perceptions and experiences varied and were polarized, and influenced by many factors, including their health, life

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[1] Chief Medical Officer of Health Order 09-2020. For more information see: https://open.alberta.ca/publications/cmoh-order-09-2020-2020-covid-19-response

[2] Chief Medical Officer of Health Order 29-2020. This order went into effect on July 23, 2020. For more information see: https://open.alberta.ca/publications/cmoh-order-29-2020-which-rescinds-cmoh-order-14-2020-2020-covid-19-response

history, personality, relationships with family, whether they had experienced an outbreak of COVID-19 in their home, or lived in a rural or urban area.

When reflecting on the *Restricted Access* approach:

94 per cent of residents surveyed reported they felt safe.

On the one hand, some residents described feeling safe in their home, that the 'rules'[3] were not too strict, and were coping as well as they could under the circumstances. On the other hand, some residents described feeling unsafe, that the rules were excessive, and struggled to cope. Yet, individual residents' perceptions and feelings could also be contradictory and change depending on the topic being discussed. For example, a resident could feel simultaneously that the rules were too strict/not too strict, safe/unsafe, and be coping/struggling.

When reflecting on the *Restricted Access* approach:

40 per cent of residents surveyed felt the public health restrictions went too far.

Regardless of residents' perceptions about the rules, a dominant finding is that well-intentioned restrictions to protect residents from COVID-19 had harmful consequences on their ability to live their remaining years well. Many residents described feeling "confined," "imprisoned," "depressed," and "lonely." Residents that experienced an outbreak in their home were more likely to feel that the rules were too strict, likely because they lived through stringent restrictions for longer durations. Moreover, feeling safe or unsafe in their home was interlinked to what was happening in residents' local context. As such, residents living in rural areas were more likely to feel safe, because their communities, at the time of interview, had no active cases of COVID-19. However, residents in urban areas expressed an ever-present awareness about the risks that the community around their home presented to them. Residents' perceptions about feeling safe also shifted in response to outbreaks and knowledge of COVID-19 infections in the community.

The quality of the visiting protocols is poor, and does not reflect residents' preferences or values

When reflecting on the *Restricted Access* approach:

72 per cent of residents surveyed felt the visiting restrictions negatively impacted them.

75 per cent reported feeling stress, anxious, or depressed because they could not visit friends and family.

Residents had different perceptions regarding visiting, but the majority of residents were discontent with the quality of visiting they had experienced, even after the system shifted to the *Safe Access* approach. The majority of residents argued it is was important for them to have improved access to more friends and family, by being more flexible with scheduling, for example. They also desired safe ways to engage in physical touch. However, whether residents were comfortable with more access to friends and family was linked to their perceptions about the rules and whether they felt safe/unsafe due to circumstances in their local context.

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[3] Rules is the colloquial term that most participants used to describe the public health orders, restrictions, and protocols. As such, the term rules is used in the presentation of findings when referring to participants' perceptions and experience.

Residents reported either consistent quality of care or that pandemic-related circumstances were contributing to a decline in quality of care making them feel unsafe, vulnerable, and ignored

Residents also reported varied experiences with staff and the quality of care they received during the pandemic. Some praised staff for their hard work and for continuing to provide consistent quality of care. 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. Further, residents' characterized staff as "stressed," which was changing the atmosphere and morale of their home, and ultimately the quality of care they received. The experience of unpredictable staffing, especially during outbreaks, disrupted residents' confidence in staff and made them feel unsafe, vulnerable, and ignored.

In general, residents felt 'in the dark' and wanted more information about how their home was responding to outbreaks and implementing restrictions

Lastly, residents had different perceptions regarding the quality of communication they experienced with staff and management about their home's response to public health orders, safety protocols, and outbreaks. While some residents were pleased with the information they received, other residents desired increased transparency about what was happening in their homes. Residents wanted more information about outbreak-related issues (e.g., number of cases, location of the outbreak, updates about how residents and staff who were ill were doing, and who had died) and how sites intended to respond to shifts in public health orders, so that they could understand what changes they could expect to routines, activities, and visits in their home.

When reflecting on the *Restricted Access* approach:

72 per cent of residents surveyed said they received information from the site about their response to the pandemic.

39 percent felt they always received enough information

What opportunities exist to balance quality of life with keeping residents safe from COVID-19?

Residents' perceptions of, and experiences with, the *Restricted Access* and *Safe Access* approaches suggest that an opportunity exists for Alberta Health, Alberta Health Services, and continuing care operators to better balance residents' quality of life with protecting residents from COVID-19, as they continue to navigate and respond to the pandemic. Residents expressed concern about the *Restricted Access* approach; they described the harmful consequences these restrictions had on their quality of life, and felt these restrictions did not align with their values and preferences. For these reasons, many residents welcomed the shift to the *Safe Access* approach, which allowed them to see more of their loved ones in-person, for example.

Although residents had concerns about the restrictions, they conveyed that improving quality of life does not mean entirely deprioritizing safety. Rather, they desired that safety protocols protect them from COVID-19 *and* attend to their quality of life. Achieving a better balance between protection from COVID-19 and quality of life involves understanding residents' experiences with the rules as they impact their routines and lives, whether they feel safe or unsafe in their local context and community, and are able to cope under the circumstances of the restrictions. It also involves understanding what quality of life means to residents in the context of the pandemic. For the residents in this study, quality of life was interpreted as ensuring that safety protocols enable them to have purpose in life, relationships with loved ones, human connection through physical touch, access to meaningful activity, emotional and spiritual wellbeing, and physical health.

From the perspective of residents, the opportunities that exist to continue to seek balance between quality of life and keeping residents safe from COVID-19 are detailed below. While many of these elements are present in public health orders that comprise the *Safe Access* approach, residents in this study conveyed that room for improvement exists in how sites implement these orders; particularly when they are perceived to be more restrictive than what most residents' desire.

Engage with residents

Seek to understand residents' concerns about the restrictions and safety protocols, and find ways to address these with residents both individually and as a group. This could involve exploring whether residents feel that the restrictions put in place are too strict or not too strict or are making them feel safe or unsafe. This means recognizing that the perceptions of some individuals may not always align with the feelings of the wider group, and that care and services need to be responsive to personal comfort levels, for example, continuing to serve meals to resident's rooms if they are uncomfortable eating in the dining room. It also means seeking to understand whether residents' perceptions about the rules and how safe they feel are changing as they reflect on what is happening in their home and local community with respect to COVID-19 infections.

Expand access to essential care partners and visitors

Recognize that residents identify family members and friends as essential care partners.[4] This is important because residents perceive family members and friends to be the only people that are able to meet some of the needs they identify as "essential." For operators, this involves understanding, from the perspective of residents, what needs are essential that only these individuals can meet. Residents also want access to visitors (who are not essential care partners), such as friends and family members, for the purpose of socialization and human connection. In-person access to essential care partners and visitors can be expanded by:

- Ensuring continued access to essential care partners (referred to as designated family/support persons in the public health orders) even during outbreaks or periods of isolation.
- Increasing the number of eligible essential care partners that residents can select from.
- Opening up more time slots for visiting.
- Allowing visiting to occur on evenings and weekends.

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[4] For guidance on how to reintegrate essential care partners please see the Policy Guidance for the Reintegration of Caregivers as Essential Care Partners report, located: https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/policy_guidance_en.pdf?sfvrsn=292a980e_4

- Enhancing administrative support for scheduling, so that flexibility and adjustments can occur, even after business hours.
- Expanding or removing time limits on visiting.
- Developing spaces inside sites so that visits can occur during inclement weather and winter months.
- Ensuring that children under the age of 18 are able to safely spend time with their grandparents or great grandparents.
- Developing protocols that allow family members and residents to touch one another safely.

Attend to residents' mental health

Recognize the impact of the pandemic and of the restrictions on residents' mental health and find ways to support them, such as through counselling or providing access to important support persons.

Ensure access to recreation

Ensure recreation programming continues to be available in a way that is safe, but allows residents to socially connect with one another, and fulfills their need to participate in meaningful and purposeful activity. Support residents who are immobile to access recreation.

Inform residents

Ensure residents have information about what is happening in their home due to the pandemic or an outbreak. Let residents know which residents have died; the number of COVID-19 cases among residents and/or staff; the location of the outbreak in their home; and, which restrictions are (or are not) being implemented or eased, and the reasons for this.

Access to fresh air, sunshine, and exercise during periods of resident isolation

Find ways to enable residents to access fresh air and exercise, even during quarantine periods.

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. This is important because residents' lived experience and the atmosphere in their home is interlinked to the emotions of staff, such as whether they are stressed and strained.

1.0 BACKGROUND

The COVID-19 pandemic presents many challenges for Alberta's healthcare system, including continuing care operators, requiring the implementation of public health orders and safety protocols to help control the spread of the virus. Public health orders, early in the pandemic, used a *Restricted Access* approach to limit adverse outcomes among residents. This approach began in March 2020 and included many orders and guidelines about screening, cleaning, hand hygiene, mask wearing, social distancing, use of shared spaces, isolation, visiting, and the assignment of staff to single sites, to name a few. Continuing care sites were expected, at minimum, to follow these orders, but were also able to 'increase expectations' beyond the order based on need.[5] Later in the year, the province shifted to a *Safe Access* approach.[6] This approach allowed more visitors and site-level decision making so that restrictions could respond to site context and the local community. Each of these approaches impacted the site's routines, as well as, the lived experiences of residents in designated supportive living (DSL) and long-term care (LTC) sites and their family members.

Recognizing that restrictions were impacting continuing care residents, the Health Quality Council of Alberta (HQCA) partnered with Alberta Health and Alberta Health Services to conduct the *COVID-19 Continuing Care Study* to achieve a deep understanding of residents' and families' lived experiences during the COVID-19 pandemic. Using in-depth interviews and a survey, this part of the study explores residents' perceptions about the public health orders and safety protocols, and their experiences, as sites implemented orders and responded to pandemic-related circumstances, including outbreaks of COVID-19. Information about residents' experiences is important as public health officials and continuing care operators try to strike a balance between protecting residents from COVID-19, and the unintended consequences of restrictions to resident quality of life and the delivery of care and services. Families' experiences were captured in a separate report titled: the *COVID-19 Continuing Care Study: COVID-19 Continuing Care Family Experience Report*.

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[5] Chief Medical Officer of Health Order 09-2020. For more information see: https://open.alberta.ca/publications/cmoh-order-09-2020-2020-covid-19-response

[6] Chief Medical Officer of Health Order 29-2020. This order went into effect on July 23, 2020. For more information see: https://open.alberta.ca/publications/cmoh-order-29-2020-which-rescinds-cmoh-order-14-2020-2020-covid-19-response

2.0 METHODOLOGY

2.1 Interviews

2.1.1 Participants and recruitment

In-depth qualitative interviews were conducted with 43 residents from 19 different continuing care sites across Alberta between **August 12** and **October 28th, 2020**.[7] Participants were recruited from sites that were selected to ensure diversity with respect to Alberta Health Services (AHS) zones, ownership type, and geography (e.g., rural, urban).[8] Twenty-seven residents lived at sites located in three AHS zones that had undergone a COVID-19 outbreak[9] and 16 residents lived at sites located in four AHS zones that had not undergone an outbreak at the time of participant recruitment.[10] Residents interviewed in August reflected more on their experience with the *Restricted Access* approach, whereas residents interviewed in September and October most often provided their reflections on the *Safe Access* approach, which began on July 23, 2020.

Residents were recruited using an information letter that sites distributed to eligible residents, who contacted the HQCA directly to schedule an interview. Residents were deemed eligible if they lived in a LTC or DSL site, were their own decision-maker, and had sufficient ability to participate in an interview (i.e., were cognitively well and not severely hearing impaired).

Most participants were women, regardless of whether they lived in a rural or urban area or at a site that had undergone, or not undergone, an outbreak. A detailed summary of participant demographics and participating site's characteristics are presented in Table's 1 and 2.

Table 1: Participant demographics

Participants who lived in an outbreak site (N=27)	Participants who lived in a non-outbreak site (N=16)
78% female (N=21)	75% female (N=12)
Average age 81 (range 48 to 97)	Average age 76 (range 52 to 96)
Average length of stay 36 months	Average length of stay 42 months
78% (N=21) lived in an urban area; 22% (N=6) lived in a rural area	69% (N=11) lived in an rural area; 31% (N=5) lived in an urban area

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[7] Two residents requested that a family member be present during their interview. In these interviews, the family member helped facilitate the conversation, and at times, provided their own insights in response to the interview questions. However, only residents' insights are considered in this report.

[8] In addition, when selecting sites that had undergone an outbreak, two other factors were considered. This included the length of the COVID-19 outbreak and the number of COVID-19 cases.

[9] 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.

[10] For the purposes of this study, a site was identified as a 'non-outbreak site' if there were zero confirmed cases of COVID-19 at the time of data collection.

Table 2: Site characteristics

Outbreak sites (N=9)	Non-outbreak sites (N=10)
1 DSL; 4 DSL/LTC; 4 LTC	6 DSL; 4 LTC
7 Urban; 2 Rural	3 Urban; 7 Rural
7 sites with outbreaks greater than 21 days; 2 sites with outbreaks less than 21 days	No outbreaks and 0 confirmed COVID-19 cases
4 sites with zero COVID-19 related resident deaths; 5 sites with COVID-19 resident deaths	No resident deaths linked to COVID-19
1 AHS, 1 Not-for-Profit, 7 Private	3 AHS, 4 Not-for-Profit, 1 Private, 2 Volunteer

2.1.2 Data collection

Interviews took on average 70 minutes to complete by telephone with residents that had experienced an outbreak and 50 minutes with residents that had not experienced an outbreak. In the interviews, participants were able to reflect on their experience since the pandemic began and their life at present. They were not restricted to discussing only the *Restricted Access* or *Safe Access* approaches, which enabled them to discuss what was most important and meaningful based on their experience.

A semi-structured interview guide (see Appendix VI, Figure 2) was used which was developed in consultation with stakeholders from Alberta Health – Continuing Care Branch and the HQCA Patient and Family Advisory Committee. The interview guide consisted of open-ended questions that asked participants to describe what their life had been like during the pandemic and how it compared to life before the pandemic. Residents were also asked to reflect on how safe they felt living in their home and how the pandemic and restrictions impacted how they spent their time, connected with family, relationships with staff, and the quality of care and services they received. They were also asked to identify opportunities for improvement. More details about the methodology can be found in the *COVID-19 Continuing Care Study: Appendices.*

2.2 Survey

2.2.1 Survey development

A survey was also conducted and sent to all residents who had a valid email address and lived in a continuing care site (DSL or LTC) in Alberta, to provide as many residents as possible with the opportunity to share their perceptions and experiences. A survey was developed by the HQCA in consultation with the HQCA's Patient and Family Advisory Committee and external partners, which included (1) Alberta Health – Continuing Care Branch; (2) Alberta Seniors and Housing; (3) Alberta Seniors Communities & Housing Association; and (4) Alberta Health Services Quality Management

Teams and Zone Leaders. The survey was built using questions from existing HQCA surveys to leverage established question reliability and validity.[11]

From these surveys, questions were selected and then modified to fit the context of the study and align with topics important to stakeholders and included: (1) visiting restrictions, (2) communication by sites, (3) perceived adequacy of care and staffing, (4) trust in the provision of care, (5) perceptions about resident safety and infection control, and (6) opportunities to connect residents with family members, and how sites supported or enabled this (e.g., virtual visits).

In addition, questions were written to assess resident's perceptions about the *Restricted Access* approach to the pandemic (from March 20 to July 23, 2020) and to assess their perceptions about the lifting of these restrictions. The latter was important given that the system's response was shifting to the *Safe Access* approach during survey development.

An open-ended question was also included in the survey for residents to answer.

> *Do you have any suggestions for how the province, Alberta Health Services, or [your site] could improve their response to the pandemic? If so, please explain.*

2.2.2 Survey protocol, sampling, and response rate

In collaboration with AHS, publicly funded DSL and LTC sites were contacted and informed about the study. Resident email addresses were requested from sites so that a web-based online survey could be delivered to respondents. Data collection for the online-only survey occurred from August 24 to October 30, 2020. In total, 387 residents completed and returned the survey. Of these, 271 residents (70 per cent) provided feedback in response to the open-ended question. To address a low response rate, designated family members of residents were asked to encourage residents to take part in the survey. Residents were asked to complete the survey on their own, but family members were urged to provide support if it was needed. To determine if this occurred, the survey included a question that asked the respondent to indicate whether the resident had received support completing the survey and who supported them.

In response to the open-ended survey question, residents provided suggestions for improvement in addition to describing their concerns with the system's response to the pandemic. Their feedback provides rich reflections about their experiences during the pandemic. Given that the survey was in the field from August 24 to October 30, 2020, it is important to note that residents may have reported on their experiences at any time during the pandemic, including after July 23.

2.3 Analysis

Resident interviews and responses to the open-ended comment question in the survey were analyzed for themes. There was consistency in how residents described their experiences, and as a result, the themes are a combined reflection of those identified in the interviews and open-ended comments.

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[11] The following HQCA surveys were considered: (1) Long-term Care Family Experience Survey; (2) Designated Supportive Living Resident Experience Survey; (3) Designated Supportive Living Family Experience Survey, and (4) COVID-19 Experiences and Impacts Survey.

In addition, interviews were analyzed to identify whether residents' perceptions and experiences differed based on whether they lived at a site that experienced an outbreak or not, a severe outbreak (i.e., high number of cases and/or resident deaths), or lived in a rural or urban area. Such differences are explained, where they exist, in the descriptions of the themes below.

Survey questions that aligned with the themes identified in the interviews, and further contextualized the interview findings, were reported as they related to the themes. Due to a low response rate, caution must be taken in interpreting survey results independent of interview findings. For more information on methodology, including analytical details and a complete summary of resident survey results, see the *COVID-19 Continuing Care Study: Appendices.*

3.0 FINDINGS

3.1 Residents' perceptions and lived experiences during the COVID-19 pandemic

Residents provided rich descriptions about how the pandemic, public health orders, and safety protocols impacted the quality of their lives and the care and services they received. Their perceptions and experiences varied and were polarized, and influenced by many factors, including: their health, life history, personality, relationships with family, whether they had experienced an outbreak of COVID-19 in their home, or lived in a rural or urban area.

On the one hand, some residents described feeling safe in their home, that the 'rules'[12] were not too strict, and that they were coping as well as they could under the circumstances. On the other hand, some residents described feeling unsafe, that the rules were excessive, and they struggled to cope. Individual resident's perceptions and feelings could also be contradictory and change depending on the topic being discussed. Residents could feel simultaneously that the rules were too strict/not too strict, safe/unsafe, and be coping/struggling. Residents had different perceptions regarding visiting by family members, but the majority of residents were discontent with the quality of visiting they had experienced, even after the system shifted to the *Safe Access* approach. Their comfort with visiting was linked to their perceptions about the rules and whether they felt safe/unsafe. Lastly, residents had different perceptions regarding quality of care and the quality of information provided to them in their homes. If the quality of care and information they received was perceived to be good, residents were more likely to feel safe and to be coping.

The findings below are organized into themes that reflect the polarized perceptions and varied experiences of residents living in continuing care sites during the COVID-19 pandemic. Verbatim quotes from the interviews and open-ended comments are used to illustrate these themes.

3.2 I feel safe/I don't feel safe

When reflecting on the *Restricted Access* approach:

Residents were asked to rate their confidence in the site and site staff to help keep them and other residents safe from contracting COVID-19, from 0 (not confident at all) to 10 (completely confident). On average, residents rated their confidence as **8.6** out of **10**.

94 per cent reported they felt safe.

This theme describes residents' feelings about whether they felt safe and protected from COVID-19 and illustrates the factors contributing to whether residents' felt safe or unsafe in their home.

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[12] Rules is the colloquial term that most participants used to describe the public health orders, restrictions, and safety protocols. As such, the term rules is used in the presentation of findings when referring to participant's perceptions and experience.

I feel safe

Most residents reported feeling safe and protected against COVID-19 because of policies and protocols and the efforts of staff. As examples, residents referenced policies that limited visitors and ensured staff work at only one site, as well as increased cleaning, frequent temperature checks, use of masks and shields, quarantine requirements, and physical and social distancing. In particular, screening for COVID-19 symptoms made residents feel confident and that safety was a priority. This was important to them as sites moved into the *Safe Access* approach, which eased visitor restrictions and allowed more designated family/support persons and visitors into the building. They observed that staff's efforts were integral to ensuring their safety, and expressed appreciation for staff in doing so.

> *"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." (Man, 88, outbreak site)*

> *"Just [gives me] more confidence that they're making sure that everybody that comes in here is COVID-free and not been exposed to anything, and that sort of thing." (Woman, 56, non-outbreak site)*

> *"It's good that they screen the visitors and keep track of who comes in, so that if there were a problem and somebody phoned and said, "Okay, I was there a few weeks ago or two weeks ago and I've got symptoms now," that's good to know." (Woman, 52, non-outbreak site)*

I feel unsafe

Even though most residents generally felt safe, they also felt unsafe because of various risks being introduced into their lives. They recognized that staff work in their homes but also live in and interact with the wider community (e.g., grocery shopping), thereby making it difficult to establish a "firewall" that prevents COVID-19 from coming into their home. They also expressed concerns about residents and visitors not adhering to protocols, staff not enforcing the rules or experiencing challenges in doing so, residents living with dementia not being able to comprehend the protocols, and their risk of exposure to COVID-19 increasing as the *Safe Access* approach enabled more visitors into their home. All of these reasons were concerning for residents, because they were unable to control the people and environment around them.

> *"[Y]ou have to have a firewall. You have to keep it out, to keep us safe. And they just weren't doing that. That's why I knew, I was … getting [COVID-19] myself, because I knew there was no way I could keep it from coming into the place." (Man, 69, outbreak site)*

> *"I know that some of the [residents] don't abide completely with the rules. [S]ome 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." (Woman, 90, outbreak site)*

> *"But a lot of the residents, because of their mental state, they're not wearing masks properly, or they're forgetting to have it on. The staff will occasionally notice and get them to put it on, but it's really hard, babysitting them." (Man, 69, outbreak site)*

> *"[T]hey have let some visitors in to visit. And my concern is just the testing, the temperature tests and questionnaire. Is it enough to … keep COVID out of the building? Because we hear on the news and stuff, how some people are not taking the virus seriously and they might not answer the questions properly when they come in to visit." (Woman, 89, non-outbreak site)*

Perceptions about safety were contingent on what was happening in residents' local context. Residents felt safe if they perceived that their community was safe. Most often, residents in rural areas described feeling safe because there were no reported COVID-19 cases in their area. They felt safe not necessarily because of the actions of sites, but because their home was located in an "isolated" community that had not been impacted by COVID-19. Their geographic location lessened worry about staff and visitors bringing the virus into their home, making them feel safe both in their home and in interactions with family and the wider community. Yet, residents living in rural areas were not exempt from feeling unsafe. They expressed that if COVID-19 cases became present in their community or in a neighbouring community, they would no longer feel safe and would expect rules to become more restrictive.

> *"[I]f there was a case in [city] or in [other city], right in the close community where everybody's mixing [visitors would be restricted], because the help have to go home at night, too, and they could bring stuff into the home without even knowing it." (Man, 82, non-outbreak site)*

By comparison, residents in urban centers expressed an ever-present awareness about the risks that the community around their home presented to them. As such, these residents were more likely to feel safe and at ease in their home, and were eager for members of their community to do their part and follow protocols, so they "wouldn't have to worry." Residents, especially those that had experienced an outbreak at a site, described how their home suddenly became a place that felt unsafe. Retreating to and isolating themselves in their room was a way to control their environment and feel safe. The quotes below illustrate the interrelationships that exist between feeling safe/unsafe and local context:

> *"Unfortunately [staff] are coming in from all over the city and no one knows if they are carrying the virus or not until they become very ill." (Woman, 75-84 years old, survey response)*

> *"…if everybody… wore a mask, then you wouldn't have to worry. But you notice a lot of people that don't abide by those rules. And that's how the infection gets transferred from person to person pretty easy... And that's why I feel safer just staying in and not getting out there, because it affects older people a heck of a lot faster than young people." (Man, 88, non-outbreak site)*

> *"Once I stayed in my room, I felt safe that way… because I felt that no one was—and I think, which was an advantage for me, I did not have to have people attend to me." (Woman, 90, outbreak site)*

3.3 The rules are not too strict/The rules are too strict

When reflecting on the *Restricted Access* approach:

34 per cent of residents felt the site rules were always reasonable and **42 per cent** felt they were sometimes reasonable.

This theme represents residents' contrasting perceptions regarding the rules and safety protocols intended to protect them from COVID-19. Some experienced all or some of the rules to be "not too strict" and others as "too strict."

The rules are not too strict

Residents who described the rules as "not too strict" felt the rules were necessary and helped to protect them and other residents from COVID-19. Residents who viewed the rules as "not too strict" often expressed anxiety about the pandemic and found comfort in the rules and new routines incited by public health orders or guidelines (e.g., mask wearing, isolation). One resident explained that while the restrictions resulted in lack of "company," he understood they were keeping him safe because his preference was not to die of COVID-19.

> *"[W]e find it restrictive. … I think some other buildings that my friends are in have more freedom than we do, but maybe that's not a good thing." (Woman, 91, outbreak site)*

> *"I know there was a big demonstration in the cities where people—older people—saying they'd rather die of COVID than be lonely. You know, I don't quite feel that way. Like, I'd like to have the company, but I understand." (Man, 69, non-outbreak site)*

Other residents appreciated it when site management decided to exceed public health orders and implement even more stringent rules, if they felt that doing so was responsive to local context. Residents expressed respect for the rules, understanding they were intended to control their environment, and ultimately, limit their "worry." As such, residents followed the rules and safety protocols to keep their home and other residents safe when on an outing or medical appointment, for example.

> *"[I]f the government says as of the first of the month, everybody will be able to have their relatives, friends to come upstairs to visit, and if [site] says, "No, we're not ready for that," then we wouldn't do it." (Woman, 83, outbreak site)*

> *"Just the two people that you're allowed, and that's most important, because if you get all these people coming in, you have no idea where they've been or who they've been associating with, and you would worry about that." (Woman, 90, outbreak site)*

> *"I'm afraid, if I do something wrong, it might come in here. … So, like I went to a meeting of some friends the other day. I wore a mask through the whole thing, because it was not a very big living room." (Woman, 79, non-outbreak)*

Other residents expressed ambivalence about the rules, particularly those residing in rural areas and at sites that had not experienced an outbreak. These residents did not evaluate them as being too strict. This may be because they experienced minimal disruption to their day-to-day life, even when reflecting on their experience with the *Restricted Access* approach. More often, these residents reported being able to eat in the dining room and participate in recreation activities, with modification (e.g., physical distancing at tables). Yet, some residents that had experienced an outbreak also explained that pandemic-related precautions and routines had not dramatically changed their personal routines and habits. Such residents did not feel they were being restricted as engaging in solitary activities was their preference and already part of their everyday life.

> *"Honestly, it wasn't any different than what I'm doing right now, just sitting here, talking to you." (Man, 80, outbreak site)*

> *"I have [meals] in my room anyway, because of my [medical condition]." (Woman, 90, outbreak site)*

The rules are too strict

When reflecting on the *Restricted Access* approach:

40 per cent of residents felt the public health restrictions went too far.

Other residents perceived and experienced the rules in their home to be "too strict." These residents stated that rules intended to protect them resulted in "persecution" and extremely poor quality of life, such that "we just don't want to keep going." They felt "dehumanized" and like "prisoners" because the rules limited access to human touch, fresh air, sunshine, and everyday comforts (e.g., magazines). Residents who felt this way often experienced a lengthy outbreak that resulted in isolation to their rooms for long periods of time, which influenced their perception about the rules.

> *"This was NOT protection. It was persecution. Our families, when they can visit, are treated like unwanted guests at best and lepers at worst. Honestly, it was existence. Not life. Ask yourself, is this how YOU would choose to spend the final years of your life?" (Woman, aged 75-84, survey response)*

> *"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." (Man, aged 85-94, survey response)*

> *"[W]ith all these restrictions that they put on us, I understand it was to keep us safe. But the effect of it was to make us all feel more isolated and less like we belong, and more dehumanizing. We're just things. And if we live in those kind of conditions for months or any kind of length of time, what happens is we start to believe them. And we just don't want to keep going." (Man, 69, outbreak site)*

The rules were also perceived to be unjust because they were not applied fairly to both residents and staff. Specifically, residents felt it was unfair that they had to isolate for 14 days after leaving their home, even though they acted responsibly, when staff was not expected to do the same. They also felt it was unreasonable for staff to monitor for strict adherence to the rules, when staff did not always adhere to them, and that application of the rules and protocols felt like staff were protecting themselves from residents (rather than the other way around).

> *"I came back the day after [event] and I had to go into isolation for two weeks … I was doing everything right that I should be doing … [T]he workers here … they just get tested with temperature. They've been gone overnight. They don't have to go into isolation." (Woman, 84, outbreak site)*

> *"Well, for a while they walked around with their six-foot stick, making sure we weren't too close…And then they'll harp on you if you're visiting another person at a table. It's just, "You're not supposed to be that close," and not nicely. It's really irritating. And then they will do it themselves!" (Woman, 79, non-outbreak site)*

> *"[W]hen they come to us, they treat us like, "Whoa...COVID." … [I]t's like they're protecting themselves from us." (Woman, 66, outbreak site)*

Other residents experienced the rules to be especially strict because of the ways public health orders and safety protocols were implemented by sites. Some residents felt sites implemented orders in ways that protected the interests of management, rather than the needs of residents, so that they "stayed out of trouble." They also felt that sites and nursing staff were "overzealous in their approach" to safety, such as when residents were isolated to their rooms when they had an illness with symptoms similar to COVID-19 symptoms, but tested negative for COVID-19. Residents advised that the quality of their lives would improve if the orders and guidelines allowed staff to use critical thinking and flexibility, as they implemented guidelines about things like isolation, visiting, and recreation.

> *"[On the town hall] call, they explained that at this nursing home … the rules seemed too obsessive, too overbearing. And [the Chief Medical Officer] said there's recommended recommendations, and then there's required recommendations. … [A] lot of the stuff that they told the people to do here, I think a lot of them were suggested, but not required… [The site is] thinking what's best for them, so they stay out of trouble or whatever else." (Man, 69, outbreak site)*

> *"They don't want you to go out. They [say] … "We're worried about your safety." No, you're worried about being sued, is more I think what the issue is." (Woman, 84, outbreak site)*

> *"I was given a COVID diagnosis and a 14 day isolation in our suite. … I was not only negative but misdiagnosed. I had a reaction … [and] symptoms similar to COVID symptoms. The nursing staff is overzealous in their approach. They 'don't care' how this is affecting the person, only to isolate every person who shows any symptoms at all. … I realize this is a tough one. However, before they slap on the 14 day restriction if nursing would take the time to listen and question the person they might find a different answer." (Woman, aged 85-94, survey response)*

Residents also reflected that the rules and their implementation lead them to question their overall effectiveness, purpose, and whether other risks were present because they were too strict. For example, residents wondered whether strict rules about physical distancing made sense inside their home, when they were living and interacting together as a large cohort, and observed inconsistent physical distancing rules across similar types of interactions (e.g., eating, recreation). They reflected that the rules were strict inside their homes, but less strict in their community. This discrepancy compelled them to pursue opportunities outside their home to meet their needs (e.g., visit with family, shopping), which made them ultimately question the value of the rules and whether risk was being introduced into their lives because of the strictness of the rules inside their home. Finally, they also questioned the effectiveness of the rules, when they were out of sync with their values, preferences, and health and wellbeing needs. Specifically, they wondered why services they required, such as foot care and physiotherapy, were 'non-essential,' when lack of access to these services, they felt, resulted in adverse health consequences.

> *"Well, I think it's silly inside here. I mean, we're all talking to each other. We're visiting each other." (Woman, 90, outbreak site)*

> *"They want us to distance, but if you go play bingo, they'll put four at a table. .... [If you're] going to eat, they're only allowed two per table. So, I can't understand why, and I have asked them, but nobody will tell me, so I just let it go." (Woman, 73, outbreak site)*

> *"When we were allowed to leave the property we could go anywhere, even meet in a restaurant, yet we could not meet family without scheduling a visit on the premises. It had to be done behind their back, and it was." (Man, aged 85-94, survey response)*

> *"[T]hey [staff] came into your room. They're allowed. So why can't they do your physiotherapy in your room?" (Woman, 78, outbreak site)*

In general, residents were excited about restrictions easing, as their home adapted to the *Safe Access* approach or emerged from a lengthy outbreak. Residents, even if they had experienced an outbreak in their home, felt that it was important for sites to lift some rules and change routines because they "have to continue living." Residents expressed a willingness to "take chances" and introduce risk into their lives, especially if this meant they could see their family:

> *"I listen to all the news… and I think they're sounding more lenient than the people here. And what they're saying is – what I get told is, "Well, we have no cases here. We want to keep it that way." Okay, and I can understand that. But I have to continue living, whether I like it or not." (Woman, 84, outbreak site)*

> *"I think we've got to slowly start opening up and living normal, what I consider normal life again. And I guess that means taking on a few chances, and I know it's going to be uncomfortable for us… I don't see that keeping us under lockdown for the rest of our lives is going to help." (Woman, 69, non-outbreak site)*

> *"I would sooner die of COVID then be so cut off from my family and friends like I am now. I'm old and I lived my life. Just let me see my family and take my chances." (Man, aged 85-94, survey response)*

3.4 I am coping/I am struggling

This theme conveys the range of residents' thoughts and emotional experiences as they encountered uncertainty, changing routines and environments, and restrictions that limited their access to common spaces, in-person visits, recreation activities, and freedom to leave their room. Here, the differing experiences are explained along with their contributing factors.

I am coping

Some residents reported they were coping well, given the circumstances. These residents credited their mental and physical capability, which enabled them to keep busy during periods of isolation, and/or a preference for solitary activity. Such residents also characterized themselves as having a positive attitude, in spite of the circumstances, because they found comfort in faith, or a unique perspective on the situation due to their advanced age and poor health making them less fearful of the situation.

> *"I practically wore the phone right out." (Woman, 82, non-outbreak site)*

> *"So, it was a really long time. It really was. But as I say, I'm independent. I don't mind being alone. And I'm fitted out with all these electronic gadgets. And I do love to read, so I read a lot of books. I watched a lot of movies. I listened to a lot of music. I did all sorts of things. Oh, and I started to knit!" (Woman, 90, outbreak site)*

> *"I'm 84 years old, too. And if I get it, it's God's willing. He wants me." (Woman, 84, outbreak site)*

These residents missed in person visits with family and other residents, but used technology (e.g., FaceTime) and other approaches (e.g., window visits), at times supported by sites, to facilitate safe interactions with others.

> *"[T]hey did make a phone list for us of all the residents here. So we were able to contact different [residents] by phone, which was fun, and nice. And then they did start some concerts and things like bingo, that we could do from our suites—which was really quite cool." (Woman, 79, outbreak site)*

Although these residents felt as if they had been coping well, the pandemic was whittling away their resilience. A few residents noted an emergent feeling of irritability about the restrictions and being "not as cautious" as they were in the early months of the pandemic.

> *"You can stand something that's abbreviated, but when it goes on and on and on, and we don't know how long it's going to go more, it is, I guess, sort of mentally challenging at times." (Woman, 91, outbreak site)*

> *"Well, I'm cautious, but not as cautious as I was in the beginning…I used to wear gloves to go to do my laundry and I couldn't touch any buttons unless I had my gloves on. … I'm still washing my hands with disinfectant, all the time.... I think you get tired of this continuous, "I can't do this, I can't do that." (Woman, 84, outbreak site)*

I am struggling

When reflecting on the *Restricted Access* approach:

47 per cent of residents rated their mental health as worsened during the pandemic.

By comparison, many other residents struggled to cope, even those that had not experienced an outbreak in their home. Such residents described their mental state using terms such as "depressed," "lonely," "sad," "mad," "stir crazy," and "bored." One resident felt it would be better to die than go through another COVID-19 lockdown, and other residents contemplated self-harm. Residents felt the impact of restrictions and isolation on their bodies and lives, feeling losses in physical strength, "memory," and social skills. Residents that characterized themselves as "social" beings emphasized it was particularly challenging for them, because the rules prevented them doing activities with other people (e.g., singing, playing cards).

> *"I was going to bed thinking, "Well, is it all worth it?" Like, you feel like—I don't know how to say it. I feel very isolated…and then you're wondering is it worth it? Shall I continue or shall I stop eating? Shall I do something? And even now, I'm not completely myself. It seems like I'm losing my memory because of lack of use." (Woman, 78, outbreak site)*

> *"I just don't feel socially adept anymore… we do chitchat back and forth and on the phone or whatever. But I don't know, it's just not the same as when you have a face on face meeting with them…I tend to visit very well, person on person. But I am not a very good talker on the phone." (Woman, 69, non-outbreak site)*

> *"I'm a people person and I really, really missed contact with others." (Woman, 79, outbreak site)*

Residents also conveyed they felt "depressed" and "lonely" because they were unable to connect in-person with their loved ones and encountered difficulties using technology to facilitate connections. They conveyed that human touch is necessary for expressing one's self and for feeling loved and valued, but that physical distancing requirements prevented this form of human connection. One resident also explained that separation from family was especially impactful and resulting in "anxiety and depression," because it was difficult for their family to provide essential "comfort" and support virtually. This resident needed family to help them interpret and understand the situation, given their impairments.

When reflecting on the *Restricted Access* approach:

72 per cent of residents felt the visiting restrictions negatively impacted them.

75 per cent reported feeling stress, anxious, or depressed because they could not visit friends and family.

> *"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." (Woman, aged 75-84, survey response)*

> *"During the pandemic I struggled with anxiety and depression when inside visits were not permitted. I don't understand fully what's going on. I just know that I needed more in-person contact with my family. It's very difficult for me to communicate by phone, talk at the window or visit outside. Because of my situation I need the comfort of being in the same room as my family." (Woman, aged 85 to 94, survey response)*

Residents also struggled because recreation activities were much less available, and at times unavailable, making it difficult for them to take part in activities that were meaningful to them.[13] Residents perceived recreation staff to be essential, because the activities they organized kept their bodies physically and mentally stimulated. However, the emphasis on safety, and cancelation of recreation, had costs—"extreme boredom," "losing out on the things that give a reason for living," and poorer quality of life.

When reflecting on the *Restricted Access* approach:

16 per cent of residents always had enough to do at their site.

> *"[K]eeping recreation may not sound like much to somebody that sits in an office, but to us, it's a major part of the day…to not have it, you get extremely bored … Recreation keeps your mind stimulated, but it also is social contact." (Woman, 52, non-outbreak site)*

> *"They do all these things to "keep us safe," but then we lose out on the things that [give] us a reason for living. Because to me, the more important people around here are …. the recreation staff, it's the social workers, and the staff that are really friendly with the patients, and they develop a relationship with the patients. … [I]f I don't have a purpose for living, I'm not going to keep going." (Man, 69, outbreak site)*

> *"They used to take us out for recreation visits and to restaurants or just to drive around to get out of the place, and those have stopped, because you can't socially distance yourself. But there's a lot of—the quality of life comes at a cost. And sometimes, the cost isn't necessarily to the benefit of the residents." (Woman, 48, outbreak site)*

3.5 The quality of the visiting protocols is poor

This theme explains that although residents were grateful to see friends and family in person under the circumstances allowed by public health orders during the *Restricted Access* and *Safe Access* approaches, they experienced visits to be dissatisfactory because of the way protocols were implemented by sites due to how they limited and changed interactions with friends and family in their home.

Residents felt that visits had become regimented, institutionalized, and prescriptive. Visits were uncomfortable because they lacked privacy. They also had to be scheduled, but times were in short supply and unavailable in the evenings and weekends, which was challenging for working families. The requirement to book an "appointment" also did not align with the realities of daily life for residents and families, whereby much meaningful human interaction is unplanned and spontaneous. As such, residents were frustrated that they did not have control over how often and how long they saw their family members and where they could visit.

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[13] During the *Restricted Access* approach, group activities were reduced to five or fewer residents, and sites were encouraged to engage residents in one-on-one activities. However, sites could implement more strict restrictions, if they perceived this to be necessary. Residents indicated in interviews that during the restricted period some sites may have offered one-on-one activities, while other sites paused both one-on-one and group activities. With the shift to the *Safe Access* approach, recreational and group activities for non-isolated residents were permitted and encouraged (i.e., group sizes could be increased to no more than 15 people with appropriate physical distancing). For more information, see Chief Medical Officer of Health Order-23: https://open.alberta.ca/publications/cmoh-order-23-2020-2020-covid-19-response

> *"Some privacy would be nice during visits. Staff coming into my room every 5 minutes is disturbing." (Woman, aged 85-94, survey response)*

> *"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." (Woman, 80, non-outbreak site)*

> *"We're so regimented that we have to schedule anything that we do. Our [family members] … can come in a couple of times a week, I think it is. But you just have to plan things, and there's a lot of things in life that you can't plan. … [T]here's got to be an easier way to make our home a little bit more friendly." (Woman, 79, non-outbreak site)*

They felt the emphasis on scheduling and safety was making their home "less friendly" and created "bad feelings" for them as they observed family members become uncomfortable in their home. They also desired ways for in-person visits to be more comfortable, given the challenges of visiting outside, (e.g., weather, noise), mask wearing, and physical distancing, which interfered with their ability to communicate with their loved ones.

> *"[My relative] doesn't really go in anymore, because [my relative] doesn't think [my relative] is supposed to walk around. … I just ignore it. But [my relative] doesn't. …But you're asking of my feelings, and that's a bad feeling for me." (Woman, 84, outbreak site)*

> *"The last time I went out with my [family member], we got sat down … [and] they started jackhammering the sidewalk … for 15 minutes … [and then] they came and said, "Oh, there's a storm coming. You've got to go in." (Woman, 85, outbreak site)*

Some residents, at the time of interview, conveyed that minors were not allowed into their home. This was difficult for them because they felt window and telephone visits did not work well for young children, and they wanted to be involved in their grandchildren and great-grandchildren's lives. Not being able to see and interact with their grandchildren created worries about being forgotten.

> *"It was torture…I couldn't see my family, couldn't see my [family members]… And I mean, coming to the window—kids at this age, where they're playful and that, they don't like to come to a window and look at you and that, so my [family members] never came…It was very, very lonely." (Woman, 73, outbreak site)*

> *"The thing that's been hard is just not getting to see them, and I don't know if [my grandchildren] even remember me anymore." (Woman, 88, non-outbreak site)*

Most residents argued it was important for them to be able to see "more" friends and family. They wanted protocols and perceptions to shift from "controlling access" and seeing families as a vector for the spread of COVID-19, to instead be more flexible and allow residents to draw from a pool of eligible visitors. Sites, they argued, should instead help families "prevent" the spread of COVID-19 through use of personal protective equipment and trust that families will be "diligent about not catching it" since they felt their families have their best interests in mind. Such shifts in protocols would help to mitigate risks to their overall health and wellbeing and address fears of feeling disconnected from family, being forgotten, and dying alone. Further, they felt if family and friends were able to help meet their social and emotional needs, the load would be lightened on staff who are "much too busy."

> *"I'd like some more—I'd like to see my family. That's number one with nearly everybody who has family. We hardly ever see them." (Woman, 91, outbreak site)*

> *"I can understand … we have to have limited number of people who come in contact with us. But my concern is that the number that we can have is only two and that, for most people in here with families, is not big enough. It's not a large enough pool." (Woman, 69, non-outbreak site)*

> *"[A]bout this visiting with the families. To me, it's still bonkers, because just about every family or friend of a resident that I've known here, they're super, super diligent about not catching it, with everything they do at their homes, you know?... It's just like it's—to me, if they focused on the PPE and prevention that way, and not be so obsessed about trying to control access, it would work a lot better." (Man, 69, outbreak site)*

> *"Without my normal visitors who performed the small duties I now rely totally on staff for their help, and the staff are much too busy." (Woman, aged 75-84, survey response)*

> *"The biggest fear I have right now is dying alone." (Woman, 66, outbreak site)*

3.6 The staff are dealing with the pandemic and the quality of care is consistent/the staff are stressed because of the pandemic and the quality of care declined

This theme reflects residents' varied experiences with staff and the quality of care they received during the pandemic. Descriptions ranged from characterizing staff as working hard and being able to ensure consistency in quality of care, to drawing attention to multiple factors, such as stressed staff, insufficient staffing levels, and changes in the staff caring for them, to illustrate how the quality of care they received, during the pandemic, had worsened.

The staff are dealing with the pandemic and the quality of care is consistent

Most residents appreciated staff, stating they were "really good workers" doing the best they could, everything considered. They commented on their "very happy attitude" and acknowledged the things they had done to lift their spirits, such as bring them a special treat or engage them in conversation.

> *"They're really good workers, considering they're putting themselves in danger. You never heard them complain about anything." (Woman, 76, outbreak site)*

> *"They've always had a very happy attitude here. The staff is always smiling and friendly and is available to help you in any way." (Woman, 89, outbreak site)*

Residents praised staff and their efforts because they understood that the pandemic had shifted profoundly the context in which staff were providing care. They described staff's increased workload, difficulties providing timely care due to the use of personal protective equipment, and the need to interpret and adapt swiftly to changing information.

> *"[H]aving to … gown up every time you walked into a person's room. So if you're allotted ten minutes in a room, per patient, now you're taking 20. You know, you're getting behind and building up work behind you." (Woman, 56, non-outbreak site)*

> *"They had so many people on [isolation and needed meal] trays [delivered]… I felt quite bad for them… [Y]ou didn't like to ask them to help you or do anything for you, because it seemed like it would take away from somebody else's time—you know, I can make my own bed." (Woman, 84, non-outbreak site)*

> *"[T]hey get 46 papers here and 46 papers there that they've got to go through and try and figure out how it fits with us. … Like from Dr. Hinshaw or from AHS, telling them that they have to incorporate these things, and usually it gives them a couple of weeks to do it. And you can just tell they're just mind-boggled. It's so much work." (Woman, 79, non-outbreak site)*

However, in light of these observations, some residents, even at sites undergoing an outbreak, identified that staff were dealing with the pandemic and ensuring consistency in quality of care. As evidence, they characterized staff as available and able to continue to provide help with necessary care tasks, such as eating, and with new tasks emerging because of the restrictions, such as getting bus tickets (a task they were previously able to do when they were able to go on outings to shop).

> *"[T]he staff are very helpful in making sure that somebody is there to give me my meals. I could handle it myself, but it takes a lot of determination and a lot of patience, and I find that having somebody feed the meals to me makes the meal far more enjoyable." (Man, 88, outbreak site)*

> *"[D]uring the quarantine I couldn't get things I needed from outside, getting money, for example—no ATM machine here. But the manager … [has] been very good … phoning and organizing things for me, getting me bus tickets, you know. They're just very kind." (Woman, 90, outbreak site)*

The staff are stressed because of the pandemic and the quality of care declined

When reflecting on the *Restricted Access* approach:

23 per cent of residents felt there were always enough nurses and aides available at their site.

Although some residents experienced staff as dealing well with the pandemic and ensuring consistency in quality of care, there were other residents with a different experience. Residents' characterized staff as "stressed," with a few even witnessing unprofessional behavior (e.g., staff yelling at other staff). Some residents reflected that the pervasiveness of emotional stress among staff due to COVID-19 had changed the atmosphere and morale of the home they were living in and ultimately the quality of care they received.

> *"I was concerned for the staff who were all so dedicated, and worried about taking it home to their families. Stress was very obvious." (Man, aged 75-84, survey response)*

> *"I can go out of my room and walk in the building, but the atmosphere in here is the pits. If you do that, you walk out, and you see somebody, and there's not a happy atmosphere that we had before the COVID came, so the COVID has really disturbed a lot going on here." (Woman, 73, outbreak site)*

Residents explained that they "felt ignored" because staff shortages were occurring for pandemic-related reasons.[14,15] In general, though, residents felt that the pandemic had "compounded" pre-existing conditions of "short staff."

> *"COVID contributed to it in the fact that if the staff answered any of the questions, they're not feeling well or whatever, then they were sent home for ten days or 14 days. So then that compounded the short staff. They're working more hours per shift." (Woman, 52, non-outbreak site)*

> *"Because they were short-staffed, or at least not enough staff covering, period, particularly for this ward... And so, the COVID just added to that problem. We felt ignored." (Woman, 85, outbreak site)*

Concerns about staffing eroded residents' confidence that staff could proactively identify the need for help or attend to an emergent need in a timely manner. As such, residents felt more vulnerable as they worried alone in their rooms about whether help would be available if they needed it. For this reason, one resident felt it was "safer" to have a roommate who could act on his behalf.

> *"I've called them and told them I'm finished with the bedpan or whatever. And then I wait and wait and wait and then ten, fifteen minutes later I go back and go, "How much longer?" And they go, "Oh god, [resident]. … [T]here has been more of those type of lapses since the pandemic, than there was before." (Woman, 69, non-outbreak)*

> *"And during the COVID, they didn't even barely have the staff to look after the people that were here. … [W]hat they should have done, was at least come in and check in on me to make sure that I was okay, if nothing else. Because I could have been on the floor—because I do fall—or I could have had an accident." (Woman, 66, outbreak site)*

> *"It's also really safer, being in a room with another roommate. It's sort of functional, because if I ever got into distress, which happened a few times, a lot of times, it's been really hard to get the attention of the nurses or the staff or anybody, and the other person in the room can go and grab them for me." (Man, 69, outbreak site)*

Residents also had concerns about how pandemic-related circumstances (e.g., the expectation that staff stay home when symptomatic with COVID-19 symptoms) were changing the staff that cared for them and this was impacting the quality of care they received. Specifically, they found it "awkward" and tiring to have to inform new staff about their needs and preferences. They also missed the personal relationships they had developed with familiar staff, who they had gotten to know over time.

> *"I had a [staff member] who's never been here before that doesn't know anything about me, and so you have to tell them everything. And it just makes it awkward." (Woman, 90, outbreak site)*

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[14] Residents illustrated that the policy limiting staff to one site, staff's familial obligations to care for children, and the requirement that staff stay home when they are sick, were pandemic-related reasons that were contributing to staffing shortages.

[15] Some residents that had lived through an outbreak in their home described that additional staff were available at the onset of the outbreak, but that staffing levels decreased over time, while other residents described persistent unpredictability in staffing, even after the outbreak ended.

> *"[W]e've had a lot of new staff. … [T]he new staff take a few months to get used to all the routines and the residents and what each resident requires for assistance." (Woman, 52, non-outbreak site)*

3.7 I know what's going on here/I'm in the dark

When reflecting on the *Restricted Access* approach:

72 per cent of residents said they received information from the site about their response to the pandemic.

39 per cent felt they always received enough information

This theme captures residents' varied experiences regarding the quality of communication they experienced with staff and management about their home's response to public health orders, safety protocols, and outbreaks. Variation existed in the content and amount of information they received, and the mechanism by which it was delivered.

I know what's going on here

Residents, particularly at non-outbreak sites, were pleased about the information they received about how their home had responded to public health orders and other pandemic-related circumstances. Residents described the ways they received information, which included letters, memos, newsletters, speaker announcements, videos, and town halls. Residents appreciated learning about how to prevent the spread of COVID-19, and what was required of them and their families, as sites implemented and then eased restrictions as the pandemic unfolded.

> *"The president of our—[site] sends memorandums to us every month, at least one. … [W]e're certainly informed about everything and precautionary measures and all reasonable precautions to prevent the occurrence or spread in our site." (Woman, 91, outbreak site)*

> *"Oh, we get a newsletter once a month, and probably once a week, there's a memo that goes out about COVID and the new rules or if things are changing or whatever. But the monthly newsletter fills us in on everything that's been going on." (Woman, 56, non-outbreak site)*

I'm in the dark

Most residents, especially those who underwent a severe and lengthy outbreak, felt the quality of information provided to them was poor. In fact, many residents expressed that sites were not transparent about what was happening at their home. They had to seek out information by asking questions of staff, and when doing so, encountered staff that stated privacy rules preventing them from relaying information. Instead, they were more likely to receive information, by chance, from other residents or indirectly from family members. Moreover, some residents felt "in the dark" because staff had forgotten to consider their cognitive ability to understand information.

> *"[O]ne or two of the patients find out, and then I hear it from them … I keep asking the nurses … I'd like to know what's going on, so I know." (Man, 75 year, outbreak site)*

> *"We couldn't find anything out, because they always come around and say, "Well, it's confidential. I'm not allowed to say." (Man, 66, outbreak site)*

> *"[T]hey won't tell me directly because I'm a resident. They would rather tell my family and have my family tell me." (Woman, 52, non-outbreak site)*

> *"[T]hey haven't made a distinction between the residents that are nonfunctional and have a family that has their guardianships … And residents that don't … So I was in the dark during most of the pandemic." (Woman, 69, outbreak site)*

Overall, residents wished to be better informed. Residents that lived through an outbreak stated that it was important to have knowledge about the number of COVID-19 cases among residents and staff, the location of the outbreak in their home (e.g., floor number), how residents and staff that were ill were doing, and which residents had died. Even residents that had not experienced an outbreak in their home, reflected that information about whether someone had tested positive for COVID-19 would be important to know, along with whether other staff were being tested or isolated as a precaution. Residents explained that because the quality of the information they received was poor, it was "hard," difficult to manage expectations, and resulted in them encountering situations that made them feel "terrible."

> *"I'd love if the head manager … or the nurses … say, "[Resident], we have an outbreak on the first floor…" Well, that's fine. I know it, and I know what to expect, and that we're going to be quarantined again and can't get around. … [I]f you don't know what's going on, that makes it hard." (Man, 75, outbreak site)*

> *"I would care and want to know if anybody got it. You know, are [they] staff or residents? … [W]e should be told that, or be told that there's two staff that are at home because … they haven't been confirmed yet, you know?" (Woman, 52, non-outbreak site)*

> *"[S]ome friends die, and you don't know they're dead! I went to visit a friend one day, and [the friend] had died. I didn't know. And I walked in and sat there. I felt terrible." (Woman, 90, outbreak site)*

Finally, residents also expressed that more information was needed about what changes they could expect to routines, activities, and visits in their home, as the site responds to shifts in the public health orders. Residents wanted to know "what was going to happen" and such information to be provided "as soon as possible," so that they aren't "kept in the dark."

> *"[I]f we could be notified that these things [easing of restrictions] are happening or going to happen, you know, down the road… Like, when are we going to have breakfast in the dining room? You know, let us know roughly when or what, why not. Just keep us all informed." (Woman, 79, outbreak site)*

> *"Communicating changes as soon as possible is essential and informing resident of the extent of relaxation of restrictions would be appreciated." (Man, aged 95 to 104, survey response)*

> *"Make sure that managers explain the new rules and regulations about visiting and other matters. We are being kept in the dark here" (Man, aged 65-74, survey response).*

4.0 CONCLUSION & LEARNINGS

This study reveals residents' perceptions and experiences about the restrictions and safety protocols intended to keep them safe and protected from COVID-19 during the *Restricted Access* period and as their homes transitioned into and implemented the *Safe Access* approach. Residents had different perceptions about the rules, and varied experiences about whether they felt safe or unsafe that were influenced by a mix of individual, social, and contextual factors.

Residents' perceptions of, and experiences with, the *Restricted Access* and *Safe Access* approaches suggest that an opportunity exists for Alberta Health, Alberta Health Services, and continuing care operators to better balance residents' quality of life with protecting residents from COVID-19, as they continue to navigate and respond to the pandemic. Residents expressed concern about the *Restricted Access* approach; they described the harmful consequences these restrictions had on their quality of life, and felt these restrictions did not align with their values and preferences. For these reasons, many residents welcomed the shift to the *Safe Access* approach, which allowed them to see more of their loved ones in-person, for example.

Although residents had concerns about the restrictions, they conveyed that improving quality of life does not mean entirely deprioritizing safety. Rather, they desired that safety protocols protect them from COVID-19 *and* attend to their quality of life. Achieving a better balance between protection from COVID-19 and quality of life involves understanding residents' experiences with the rules as they impact their routines and lives, whether they feel safe or unsafe in their local context and community, and are able to cope under the circumstances of the restrictions. It also involves understanding what quality of life means to residents in the context of the pandemic. For the residents in this study, quality of life was interpreted as ensuring that safety protocols enable them to have purpose in life, relationships with loved ones, human connection through physical touch, access to meaningful activity, emotional and spiritual wellbeing, and physical health.

From the perspective of residents, the opportunities that exist to continue to seek balance between quality of life and keeping residents safe from COVID-19 are detailed below. While many of these elements are present in public health orders that comprise the *Safe Access* approach, residents in this study conveyed that room for improvement exists in how sites implement these orders; particularly when they are perceived to be more restrictive than what most residents' desire.

Engage with residents

Seek to understand residents' concerns about the restrictions and safety protocols, and find ways to address these with residents both individually and as a group. This could involve exploring whether residents feel that the restrictions put in place are too strict or not too strict or are making them feel safe or unsafe. This means recognizing that the perceptions of some individuals may not always align with the feelings of the wider group, and that care and services need to be responsive to personal comfort levels, for example, continuing to serve meals to resident's rooms if they are uncomfortable eating in the dining room. It also means seeking to understand whether residents' perceptions about the rules and how safe they feel are changing as they reflect on what is happening in their home and local community with respect to COVID-19 infections.

Expand access to essential care partners and visitors

Recognize that residents identify family members and friends as essential care partners.[16] This is important because residents perceive family members and friends to be the only people that are able to meet some of the needs they identify as "essential." For operators, this involves understanding, from the perspective of residents, what needs are essential that only these individuals can meet. Residents also want access to visitors (who are not essential care partners), such as friends and family members, for the purpose of socialization and human connection. In-person access to essential care partners and visitors can be expanded by:

- Ensuring continued access to essential care partners (referred to as designated family/support persons in the public health orders) even during outbreaks or periods of isolation.
- Increasing the number of eligible essential care partners that residents can select from.
- Opening up more time slots for visiting.
- Allowing visiting to occur on evenings and weekends.
- Enhancing administrative support for scheduling, so that flexibility and adjustments can occur, even after business hours.
- Expanding or removing time limits on visiting.
- Developing spaces inside sites so that visits can occur during inclement weather and winter months.
- Ensuring that children under the age of 18 are able to safely spend time with their grandparents or great grandparents.
- Developing protocols that allow family members and residents to touch one another safely.

Attend to residents' mental health

Recognize the impact of the pandemic and of the restrictions on residents' mental health and find ways to support them, such as through counselling or providing access to important support persons.

Ensure access to recreation

Ensure recreation programming continues to be available in a way that is safe, but allows residents to socially connect with one another, and fulfills their need to participate in meaningful and purposeful activity. Support residents who are immobile to access recreation.

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[16] For guidance on how to reintegrate essential care partners please see the Policy Guidance for the Reintegration of Caregivers as Essential Care Partners report, located: https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/policy_guidance_en.pdf?sfvrsn=292a980e_4

Inform residents

Ensure residents have information about what is happening in their home due to the pandemic or an outbreak. Let residents know which residents have died; the number of COVID-19 cases among residents and/or staff; the location of the outbreak in their home; and, which restrictions are (or are not) being implemented or eased, and the reasons for this.

Access to fresh air, sunshine, and exercise during periods of resident isolation

Find ways to enable residents to access fresh air and exercise, even during quarantine periods.

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. This is important because residents' lived experience and the atmosphere in their home is interlinked to the emotions of staff, such as whether they are stressed and strained.

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