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# Experiences of long-term care and supportive living residents and families during the COVID-19 pandemic: “It’s a lot different for us than it is for the average Joe”

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## ABSTRACT

Long-term care and supportive living (LTC/SL) residents are among the most at risk for severe outcomes of COVID-19. As such, early public health measures focused on this population. This study examined the experiences and perspectives of residents and family members of residents living in LTC/SL centres in Alberta, Canada during the COVID-19 pandemic. Between July and October 2020, we conducted semi-structured interviews with 14 residents and 18 family members of residents from 10 centres. Interviews were audio-recorded and analyzed using qualitative content analysis. Analysis revealed 5 categories from resident interviews (Living with Rules and Restrictions; COVID-19 Knowledge and Information; Wellbeing; Centre Operational Response; Criticisms and Suggestions for Improvement) and 6 categories from family interviews (Family Role; Navigating the New Normal; COVID-19 Knowledge and Information; Policy Limitations; Policy Impact; Centre Response). The results highlight the importance of engaging residents and families during pandemic preparation, response, and follow-up evaluation.

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## Introduction

The COVID-19 pandemic has significantly impacted Canada’s continuing care sector. Between March 1, 2020 and February 15, 2021 more than 2,500 care homes across Canada reported a COVID-19 outbreak, resulting in the deaths of over 14,000 residents.<sup>1</sup> These deaths represent more than two-thirds of Canada’s COVID-19 deaths.<sup>1</sup> Due to the significant risk of COVID-19 to older adults living in congregate living settings, such as long-term care (LTC) and supportive living (SL), severe public health restrictions were enacted in these settings by provincial governments across Canada. In Alberta, this included restrictions on entrance into centres, as well as restrictions on the type and location of allowable visits with residents, the number of visitors permitted, and the use of personal protective equipment (PPE) by visitors.<sup>2–4</sup> Resident life within LTC and SL changed significantly with the introduction of public health restrictions. Residents were no longer able to participate in typical recreation, dining, and social activities, endured enhanced cleaning and testing protocols, and encountered staff wearing masks and other protective equipment during the day.<sup>5,6</sup> These swift changes were unprecedented for residents, families, and care providers. The restrictions imposed were aimed at protecting residents from the physical risk of contracting COVID-19.

Commentaries on the potential impact of public health measures on the quality of life and wellbeing of residents were swiftly published in the early months of the pandemic,<sup>7–10</sup> however research directly with residents and family of residents living in LTC or SL was not readily available given the challenges with accessing these groups. Researchers are beginning to publish empirical studies on resident and family experiences. Paananen et al.<sup>11</sup> explored the impact of visiting restrictions on the wellbeing of nursing home residents and their family members in Finland, through family member interviews. Family members described feeling frustrated and worried themselves, and spoke of apathetic, lonely, and medicated loved ones living in the nursing homes.<sup>11</sup> Family members in that study also spoke of their relationships with staff as a result of the visitation restrictions, with some identifying improved cooperation and others experiencing strained relationships.<sup>11</sup> Avidor and Ayalon<sup>12</sup> explored the experiences of family members of residents in LTC in Israel during Israel’s first COVID-19 wave. Family members in that study described a decline in their trust and satisfaction with the LTC home in general, with some reporting a discontinuation of necessary care for their loved one.<sup>12</sup> In New Brunswick, Canada, Dupuis-Blanchard et al.<sup>13</sup> examined the experiences of family members with a relative in LTC. That study identified three themes: psychological distress, surveillance of their loved one in LTC, and visitation challenges.<sup>13</sup> Family members described anxiety, stress, depression, and grief during the pandemic, and spoke of using visitation as an opportunity to check

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up on their loved one, resulting in a heightened sense of observation and surveillance.<sup>13</sup>

Fewer studies directly with residents have been published. Quantitative analyses using administrative data to explore the impact of the COVID-19 pandemic on LTC resident outcomes are available. McArthur et al.<sup>14</sup> evaluated the impact of the pandemic on the mental health of LTC residents in New Brunswick, Canada. They found that the visitation restrictions in New Brunswick did not result in a significant decline in depression, delirium, or behavioral problems of LTC residents during the initial months of the pandemic.<sup>14</sup> A similar approach using administrative data was used to examine the wellbeing of residents living in Connecticut nursing homes.<sup>15</sup> That study found a significant increase in depressive symptoms and incidence of incontinence among residents, and a significant decrease in weight and cognitive function.<sup>15</sup>

These studies begin to shed light on the experiences and impact of COVID-19 public health restrictions on residents in congregate living settings, however there is little literature looking at the qualitative experiences of residents or examining how they compare to the family experience to provide a fuller look at the impact of COVID-19 in continuing care. This study contributes to that growing body of literature by examining the perspective and experiences of residents and families regarding the public health restrictions enacted in LTC and SL during the COVID-19 pandemic. Resident and family experiences are presented together because, jointly, these perspectives represent the realities of congregate living settings where care providers have complex, overlapping relationships with residents and their families. It is difficult for care providers to consider one group without also considering the other, particularly for residents with dementia for whom family often represents advocate and voice. We share these resident and family experiences so ongoing and future pandemic planning can be shaped by the voices of the individuals they most impact.

## Materials and methods

We used purposive and convenience sampling methods to recruit residents and family members for semi-structured interviews from 10 LTC and SL centres in Alberta's Edmonton Zone. In Alberta, residents in LTC centres are individuals with complex or unpredictable medical care needs who require 24 h access to a Registered Nurse on site.<sup>16</sup> Designated supportive living centres in Alberta have three defined levels which correspond to progressively increased levels of care: SL-3, SL-4 and SL-4D.<sup>16</sup> All SL centres in this study were either SL-4 or SL-4D. Residents in SL-4 or SL-4D centres may have complex care needs but are typically stable and require 24 h access to a Licensed Practical Nurse on site, with a Registered Nurse available by telephone.<sup>16</sup> SL-4D centres support residents with moderate to severe cognitive impairment who also have complex but stable care needs.<sup>16</sup> Residents living in any designated continuing care centre in Alberta have had an assessment completed by a case manager who has deemed them appropriate for their level of care.<sup>16</sup> For the remainder of this paper, we use LTC to represent the centres in this study.

## Sample

Residents were eligible to participate if they moved into a participating LTC centre before March 1st, 2020, were their own decision maker, and were physically able to participate in a Zoom or phone interview. Family members of residents were eligible if their loved one moved into a participating LTC centre before March 1st, 2020. Eligible residents were identified by centre staff, who approached residents to determine interest. Residents who agreed to take part were then telephoned or emailed by a research team member. A total of 19 residents were approached by centre staff. All residents agreed to speak with the researchers. Four residents did not respond when the

researchers tried to contact them for scheduling. Fifteen residents agreed to participate, but one did not answer the phone to conduct their interview, leaving 14 residents who consented and participated. To recruit family members, a notice was placed in centre email newsletters. A total of 34 family members responded to the notice expressing interest in participating. Of those, 10 family members did not respond when the researcher tried to contact them for scheduling, 3 were ineligible, and 3 declined to participate after follow up, leaving 18 family members who consented and participated. Family and resident interviewees were not matched or related.

## Interviews

Due to COVID-19 restrictions, all interviews took place over Zoom or telephone. Resident interviews were conducted by JL, a researcher with 12 years of experience conducting research with residents in continuing care. Family interviews were co-conducted by RS, a public health master's student, and CI, a masters-prepared qualitative researcher with 12 years of research experience in continuing care. Interviews, ranging from 24 to 95 minutes, were conducted between July and October 2020. Separate interview guides were prepared for residents and family members (Table 1). The focus of questions for both groups was to explore the impact of the COVID-19 pandemic on daily life, reflect on changes resulting from both the pandemic and from public health policies, explore how they stay informed about the pandemic, and understand how they stay connected with others. The family interview guide included questions for participants to provide their own insights, but also asked them to reflect on their loved one's experience living in LTC. Interview guides were piloted and question order was revised following the first interview. All participants were also asked closed-ended questions regarding demographic characteristics. All interviews were recorded and transcribed verbatim. All participants provided verbal consent prior to the interview. This research was approved by the Health Research Ethics Board at the University of Alberta (Pro00101906).

## Analysis

Data was analyzed using a conventional content analysis.<sup>17</sup> Codes were derived inductively from the transcript data. Coding, using Nvivo, and interviewing was completed concurrently. Family and resident interviews were coded and analyzed separately, to ensure that unique experiences within the two groups were appropriately represented. JL completed coding for resident interviews; RS completed coding for family interviews. For both sets of analyses, the first interview was coded, then reviewed by CI and the codebook was discussed and refined. The next three completed and transcribed interviews were coded, then reviewed again by CI and the codebook was further discussed and refined. Additionally, one interview from both the resident and family participants was double-coded by CI; the codes were reviewed for consistency and refined after discussion. Saturation was reached when no new codes emerged from the data. A similar process was followed for categorization; JL and RS developed preliminary categories for 20% of their respective codes; CI developed preliminary categories for the same 20%. Team members then met to review and establish preliminary categories with definitions. These preliminary categories were applied to the full set of codes, and then were further reviewed and refined by the team. Descriptions of the categories were developed and provided to individual participants for review and feedback. No changes resulted from participant review. Trustworthiness and rigor were addressed by having experienced interviewers conduct all interviews, piloting the interview guides, ensuring independent coding, having discussion and consensus-building with the team at both the coding and categorization stages, reviewing categories and definitions with

**Table 1**  
Resident and family interview guides.

Resident Interview Guide	Family Interview Guide
1. Start by telling me a bit about yourself.	1. Start by telling me a bit about yourself and your loved one in long-term care.
2. What do you think about the public health measures that have been taken to protect residents in long term care?	2. What do you think about the public health measures that have been put in place to protect residents in long term care?
3. How do you find out what is happening with the pandemic? How have policies and changes been communicated to you?	a. Is your family member aware of the pandemic? What do they think about the public health measures?
4. How did you find out about the visitor restrictions that were put in place in March?	3. What do you think about the visitor restrictions that were put in place in March? How has that impacted you? How has that impacted your loved one?
5. What do you think about the visitor restrictions that were put in place in March? How has that impacted you?	4. How did you find out about the visitation restrictions put in place in March?
6. Can you tell me about what the pandemic has been like for you, living in a long-term care facility?	5. How do you find out what is happening with the pandemic? How have policies and changes at the long-term care home been communicated to you?
7. How have you been able to stay connected to friends and family during the pandemic?	a. How do you find out how your loved one is doing?
8. How has your quality of life been impacted by the pandemic?	6. Can you tell me about what the pandemic has been like for you, with a loved one living in a long-term care facility?
9. What could long-term care organizations do in the future to improve the response to the pandemic?	7. How have you been able to stay connected to your loved one in long-term care during the pandemic?
10. What could long-term care organizations do in the future to improve resident quality of life during the pandemic?	8. How has your quality of life been impacted by the pandemic?
	a. How has your loved one's quality of life been impacted?
	9. What could long-term care organizations do in the future to improve the response to the pandemic?

participants, and providing a full description of the data analysis process above.<sup>18,19</sup>

## Results

Of the 14 residents, 50% were female, the average length of stay was 4.3 years, and most (79%) had children (Table 2). Of the 18 family members, 89% were female, most (67%) were a child of the resident, and most of their loved ones living in LTC had dementia (82%) (Table 2). Five categories emerged from the resident data, while six

**Table 2**  
Resident and family member participant characteristics.

Resident Participants (n = 14)	
Gender, % (n)	
Male	50% (7)
Female	50% (7)
Marital Status, % (n)	
Married	21% (3)
Divorced	21% (3)
Widowed	29% (4)
Single	29% (4)
Has Children? % (n)	
Yes	79% (11)
No	21% (3)
Age in Years, Mean (SD)	68.1 (10.2)
Length of Time Living in Centre in Years, Mean (SD)	4.3 (3.9)
Site on Outbreak During Interview	
Yes	29% (4)
No	71% (10)
Family Member Participants (n = 18)	
Gender % (n)	
Male	11% (2)
Female	89% (16)
Age in Years, Mean (SD)	63.8 (8.3)
Relationship to Resident % (n)	
Son/Daughter	67% (12)
Spouse	11% (2)
Son-in-law/Daughter-in-law	11% (2)
Parent	6% (1)
Sibling	6% (1)
Does Resident Have Dementia? <sup>1</sup> % (n)	
Yes	82% (14)
No	18% (3)
Length of Time Resident Living in Centre in Years, Mean (SD)	4.1 (2.1)

SD = Standard Deviation

<sup>1</sup> Two family member participants were related to the same resident. That resident's characteristics are only captured once.

categories emerged from the family data. Results are presented below separately for each group of participants.

### Resident results

A total of 1,586 statements were coded into 595 codes. Following the categorization process detailed in the Analysis section above, 5 categories were developed: COVID-19 Knowledge and Information (95 codes), Centre Operational Response (112 codes), Living with Rules and Restrictions (117 codes), Wellbeing (135 codes), and Criticism and Suggestions for Improvement (136 codes).

### COVID-19 knowledge and information

Residents accessed information about COVID-19 and changes to public health rules in a variety of ways, with some residents describing family members or centre staff as their primary source of information, while others described reading or watching the news, public health official teleconferences, and government websites, including R 14 who noted that "I keep up through the media and friends." Two residents acknowledged that the information on COVID-19 was sometimes hard to understand, including R 03 who commented "But I can't take a lot of that info in because scientifically, that part, I don't understand." When it came to centre-specific information, such as details about whether their own centre was on outbreak, or changes to centre-level policies, most residents described verbally asking staff questions to gain information: "Usually I'll ask the nurse if she knows anything" (R 07) and "[I] have to go to the front desk and ask what's going on" (R 04). At some centres, this process was efficient, as R 05 explained: "It goes from our, usually from our care manager to the staff. And then from the staff on to us. And I have to say it's done in a timely manner." At other centres, residents described gaps or inefficiencies in the sharing of information, with one resident observing that "they don't tell you anything around here" (R 08), and another noting that "the only time they answer you is when you ask questions. Otherwise, they are not forthcoming" (R 01). One resident was asked how he found out that his centre was on outbreak, and he responded "Actually my son told me" (R 08).

Although none of the resident participants had dementia, many were keenly aware of the challenges related to pandemic information sharing with fellow residents who had dementia. Participants provided insights about residents across their centre. Several described observing residents waiting for family member visits that were not going to happen, noting "They don't get it, they don't understand.

They wait a week, a week for their families to show up. Every day you know. Very sad, it's sad" (R 03). Similarly, R 09 observed "Sure I miss the visits from family, but I'm capable of understanding why it's necessary versus some residents here who are incapable of understanding why this has to be. And then there is some that you can explain it over and over and over to them and half an hour later they're gone." Other participants described staff trying to explain the visitation restrictions to residents with dementia, only to result in responsive behaviors: "They get agitated and they don't understand and they quite often will verbally lash out at some, at staff" (R 05).

#### *Centre operational response*

Residents spoke at length about the operationalization of public health polices at their individual centres. Residents described various site logistics that were enacted, related to things such as PPE use, visit procedures, and COVID-19 testing procedures. A common observation that residents described was increased staff hand hygiene and PPE use, for example: "The staff was very diligent about washing their hands, wearing the gloves and their masks" (R 12). Residents were typically happy with the increased PPE use, with one noting "I want [the staff] protected to the very best of the system's availability" (R 10) while others simply commented that "the masks was a good idea" (R 08) and "I don't mind. It's just to protect everyone" (R 02). Many residents also discussed experiences with COVID-19 testing at the centre, which occurred regularly due to either developing COVID-19 symptoms, or as part of a centre-wide scheduled testing scheme resulting from an outbreak. Most residents described the testing as unpleasant but necessary given the ongoing threat of COVID-19 in their centre, including R 13 who commented "I've had two COVID tests and I don't really enjoy them" and R 12 who joked, "[laugh] Well, I wouldn't repeat it for anybody."

Several residents spoke of the role that staff play in the centre's response to COVID-19, such as enforcing the public health guidelines. During visits, for instance, staff were "kind of there babysitting you or, like, watching you, so you don't get closer than 6 feet away" (R 11). R 08 had a similar experience at his centre, commenting "I don't like the idea of having a chaperone there. I don't want a chaperone to overhear what I think of the chaperone." Even in the building with other residents, staff were reported as "bugging me because I happen to be sitting 5 feet from, away from somebody instead of 6 feet away" (R 08), while another resident observed that "the social distancing is very very strict" (R 05). Residents were also cognizant of the impact of the public health guidelines on centre staffing. In Alberta, a single-site order was issued that forbade staff from working at multiple continuing care homes. Several residents observed that this order appeared to reduce the number of available staff at their centre, and that in general, staff appeared busier. One resident noted "Staff changed by the way. Less staff. I don't like that at all" (R 03) while another commented that "the staff are run off their feet" (R 06).

#### *Living with rules and restrictions*

The COVID-19 public health polices implemented in LTC significantly changed day-to-day life for residents. Several residents noted the reduced activities as a result of reduced group sizes. One resident was asked by a new roommate "What do you do here during the day?" to which she responded "Well, nothing, because we don't do anything anymore. We used to have [...] a recreation program" (R 06). Similarly, R 04 observed that there are "no activities, they're scared to do anything," while another noted "You have to make your own fun" (R 01). In reflecting on the impact of the restrictions on her day-to-day life, one resident observed that "you can't do anything spontaneous" (R 06) due to the isolation requirements when leaving the building. Pre-pandemic, she would go on spontaneous outings with family

members to a mall or restaurant but doing so during the pandemic would mean isolating in her room after returning to the centre.

Another commonly observed change in day-to-day life for residents during the pandemic was the dining experience. R 07 noted that "only two people [are] allowed at the tables, which were 6 feet apart. So the rest of the people that couldn't... or numbers couldn't fit them into the dining rooms, they ended up eating at the bedside." R 09 had the same experience at his centre: "Well they've had to space everybody out in the dining room. So that limits the number of people that they can have in the dining room." For him, the solution was to "go into the TV room and they bring me my food there and come and help me eat" (R 09). This change to the dining experience impacted residents' ability to socialize: "When they used to sit people together, we'd chat about what's going on and, you know, the group and all, but now... none of that" (R 07). Likewise, R 06 observed: "Four months we've spent in our rooms, and the dining room was about the only place we could go. That was also a thing; we had to sit two to a table, they broke up our table. We had four people sitting there and then we had two." These comments indicated that however necessary the COVID-19 rules and restrictions were, the effect was that "socializing was really hard" (R 06).

For some residents, living with rules and restrictions involved adaptation. For instance, R 06 "couldn't go to physio for about 4 months" and in an effort to stop her physical decline, noted "I'm working on improving on my own" by exercising alone in her room. In other instances, residents found ways to abide by rules but adapt important activities. For example, some residents described sitting outside the door to chat with a fellow resident who was in their room self-isolating, including R 02 whose friend was "on precautions because she just got back from the hospital. She has two more weeks, two or something, y'know? I'm not sure how long she has, but I go close to her door and we just chat and sit that way." For some residents, living with rules and restrictions also involved circumventing the rules. This could involve prohibited touching, as in the case of R 05 who noted "We're sitting so far apart and my daughter on the last visit for her, she's leaving me [laugh] I mean, we snuck a hug but [laugh] I mean I-I don't care if I'm quarantined forever, I'm getting a hug from you before you go." For R 14, circumventing the rules meant visiting on his own terms, rather than having visitors at the centre where there were time and visitor limits. As he described: "When I wanted to visit with someone, right, a friend? I went to a nearby park where there's a bench. And we maintained our physical distance and, uh, my doc said that's perfectly safe. So I did it!"

#### *Wellbeing*

Residents described the myriad impacts of the pandemic on their wellbeing. A small number of residents discussed the impact on their physical wellbeing, such as reduced movement leading to functional decline or lost weight. For example, R 03 observed "I've lost weight." However, residents' discussion of wellbeing predominately focused on their psychosocial wellbeing. Common feelings described by residents were sadness, loneliness, fear, and frustration. As one noted "I'm lonely. It's lonely here and sad" (R 03), while another said that "as time goes on, it's becoming, like there's a lot more people that's depressed, and I cry at night" (R 06). When asked about their observations of other residents, such as those living with dementia, there were similar comments: "For the rest of the residents, they sat in their chairs and just kind of looked lost" (R 07) and "you can just see it, the mood of the people" (R 10).

Several residents noted that the public health rules impacted their wellbeing more than those living outside continuing care, such as R 11 who observed "When you're in here, you're not like other people. They go out and do things. We're stuck here. So all the little things we do, for enjoyment, well, you take them away. So it's a lot different

for us than it is for the average Joe.” R 10, when discussing allowing volunteers back into the building, commented “Let ‘em come back at least, you know, half time or something. Because they were quite an important part of our happiness. I think they represented an outdoor— they could tell you what was going on in the world outside of the place.”

Some residents observed that the impact on residents with dementia was greater than on themselves. R 11 remarked “They can’t use their arms, they can’t use their fingers. . . they don’t have the mental capacity to make a phone call.” Similarly R 12 said that she was relatively fortunate, noting that “it didn’t impact me as much as maybe for the others,” while R 05 commented that they “feel really, really sorry for them. . . for a dementia patient I can imagine how frightening that would be. . . When you were at the hospital you got used to your routines. . . then all of a sudden you’re in a completely new environment. And you can’t have family visiting you on a regular basis.”

It is important to note that not all residents described a deterioration in their wellbeing. For example, one resident whose children did not live locally observed that his social relationships remained relatively stable during the pandemic, as they largely took place using technology pre-pandemic. He commented that his mood and energy had “virtually no change” (R 14), which was an observation made by a handful of other residents as well. In addition, most residents we spoke to stated that they had not experienced a decline in their physical health, such as R 05 who commented “My physical health has been fine.” Three residents actually noted improvements in their physical health during the pandemic, including R 06 who was “working on improving on my own” after her physiotherapy was cancelled due to COVID-19 restrictions and R 12 who was “starting to relearn how to stand. Eventually, hopefully, how to walk.”

#### *Criticisms and suggestions for improvement*

Residents’ opinions about the public health measures and restrictions varied. Many residents agreed broadly with the restrictions, including R 10 who commented “I thought all the protocols were justifiable” and R 03 who observed “I agree that we should be kept from harm’s way.” Many also noted their agreement with specific measures, such as staff wearing masks or the single site order requiring staff work at only one LTC centre. For instance, R 12 commented on the single site order: “I think that it is an excellent idea because that was what, people working at different sites, is what caused all the problems in Ontario and Quebec.” Several residents mentioned seeing news about outbreaks at other LTC centres and feeling glad about their centre’s response.

Most residents understood the reason for the restrictions, with comments such as: “It was strict, but again, I know why it had to be done” (R 07). Some residents, even if they understood the cause for the restrictions, were critical of the measures. For example, one public health order limited the number of visitors to two people per resident. Several residents felt this was too low, such as R 11 who commented “They didn’t open it up enough, Only two. . . like, we’re allowed two family members [. . .] I have a lot of friends who want to come and see me but I can’t do it.” Over half the residents interviewed described other residents in the centres as being unhappy with the restrictions, even when they understood them. R 01 said that “some are fed up with it,” while R 08 described other residents’ response: “Some of them say ‘Well, I’m not happy about it,’ . . . They are a little bit different, like I say. They’re tired of it.”

The residents had a variety of suggestions for improving life during the pandemic. These ranged from improvements to communication, to changes in visitation policies and even suggestions about staffing. Regarding communication, several residents recommended door-to-door communication directly with residents, either via “some kind of a notice for each resident about new. . . new

regulations or new restrictions” that were specifically “pieces of paper at each door” (R 14) or verbally “to come and tell me what’s going on” (R 08). Many residents had recommendations regarding visitation, with the most common suggestions including: increasing the number of visitors allowed, for example “I would like two more visitors” (R 14); increasing the time or days allotted for visits, for example “I’d like to see holidays open to let the families in” (R 02); or changing the visit location, for example “I would have preferred to give the residents and the, and the, their families an option to meet outside in the sunshine” (R 14).

Most residents had specific suggestions about staffing at their centre. Several residents commented that more staff were needed, including R 05 who commented that “we need more staff” and R 06 who noted “You’ve gotta get some more staff, or they’ll burn out the ones that they got here.” R 11 specifically suggested hiring more staff to assist with visitation booking: “They’ve gotta hire more people to answer the phone and book these things,” while R 12 recommended more staff at night: “The overnight shift, which I always find that they’re running around, like crazy and I feel like they could use a few more people.” In addition to more staff, some residents noted that “you gotta give ‘em more money” (R 11) and “they need a raise” (R 06).

#### *Family member results*

In total, 1831 statements were coded into 667 codes. Following the categorization process detailed in the Analysis section, there were 6 categories developed: Family Role (57 codes), Navigating the New Normal (192 codes), Policy Limitations (62 codes), Policy Impact (102 codes), Centre Response (214 codes), and COVID-19 Knowledge and Information (40 codes).

#### *Family role*

Family members discussed the numerous ways their roles were impacted by the pandemic, and the central role they felt they should play in both resident lives and policy decisions. The public health restrictions established family roles in ways that several family members disagreed with. As FM 18 commented “These new visit restrictions don’t allow us to go back to being the caregivers.” Some family members described their belief that their presence was essential to the residents’ care or mental wellbeing. As FM 03 noted “We do everything. We legitimately do everything. So we are essential, we are helping everybody in that home.” As such, many family members discussed how they sought to be deemed “essential” under the existing public health policy, with varying success. For example, FM 02 described an unsuccessful attempt at being classified essential: “I did contact and say ‘You know, I think that there are some essential things that are not going to be done, well [manager of the unit] didn’t agree that my sense of essential was the same as his.”

Some family members believed that policy makers should have engaged families in decision making due to family’s essential role. As noted by one family member, “There should have been warning if not consultation. There should have been warning and discussion and information. . . I do feel that family need to be involved” (FM 12). Other family members spent time engaging politicians and policy makers in an attempt to influence the public health restrictions. FM 11 commented that “the first time when the outdoor visits were announced I emailed Mr. Kenney [Alberta’s Premier] and Dr. Hinshaw [Alberta’s Chief Medical Officer of Health] my concerns,” as had FM 18, who stated “I’ve written many politicians.”

Family members shared how they also tried to uphold their previous roles during the pandemic, including completing chores and laundry for the resident, providing supplies, and advocating for the resident’s wellbeing remotely. One family member shared that he would visit his mom’s terrace daily to water her outdoor plants and



look in the window to “see inside her place” (FM 04) as a way to continue to check on her wellbeing. Other family members called the nursing station to discuss the resident’s care and wellbeing. For example, FM 02 described “a couple occasions lately where I have called about appointments or procedures that were being considered for [resident’s name]”. Multiple family members described actively managing their loved ones’ responsive behaviors over the phone with staff. For example, FM 01 described situations where “if I have spoken to her and she’s not, she’s expressing a concern or she is very upset sometimes with hallucinations I will phone and let [the staff] know that she’s called and saying ‘xyz’ and maybe they would, you know, go down and check on her and please give me a call back.”

### *Navigating the new normal*

With the introduction of the COVID-19 provincial policies, families and residents had to learn a new way of living within policy constraints. Families described navigating new systems of scheduling, visitation and communication that arose from the COVID-19 restrictions placed on continuing care homes. As noted by one family member, “With this COVID stuff you just have to be patient and try different things, you know if it doesn’t work well, you just got to change what you’re doing and try to make it work” (FM 04). The most commonly explored new experience for families was visitation. Families described the numerous ways that they were navigating connections with their loved one, with varying levels of success. One resident “couldn’t understand why she was being forced to go outside” (FM 01) for a visit, during a time when only outdoor visits were allowed, while another family member described his concern that his father would think “I’m being mean or I’m playing a game on him” (FM 16) by meeting through a fence.

Some family members revised their approach to visitation, given the restrictions, to try and optimize the times they had available to connect with their loved one. For FM 02, that meant reflecting on the topics discussed with her loved one during their limited connections: “When we do get together we don’t want to be talking about the frustrations he’s having [...] we used to talk about that and figure out you know how better he could communicate, and negotiate and all these kinds of things, and so it became clearer to both of us that we didn’t want to spend our time doing that.” FM 06 described how she “learned how to, what to do with the time we have in the 30 minutes” including starting each 30 minute outdoor visit with 5–10 minutes of chair exercise, which, she explained “Within five or ten minutes of the exercises starting [her mom is] brightening up, she’s more aware, she’s more alert.” After her mom is more alert, FM 06 described how during “the last 15 visit minutes of the visit, I reminisce about family events and history” as a way to focus the visit on topics that were important and meaningful to her mother.

Family members described having to now navigate new decisions related to the care and wellbeing of their loved one. Three family members described the difficulties of deciding whether to remove their loved one from the centre, including FM 03 who explained: “So my sister phones and says ‘Mom’s coming to your place’ and we were going to pull her.” But after discussion with the centre staff and with her other family members, FM 03 reflected that the “[centre] will at least be able to make her peaceful for whatever the situation is. If she comes here, I don’t have that experience.” Another family member discussed with her mother’s family physician the possibility of moving her mother out. The physician asked the family member to consider “If you have your mom away from [centre] long enough, when she’s able to go back, cognitively will she reconnect and settle in well again or will she be significantly confused? And then in the long run have you really done her a favor?” (FM 06). FM 06 ultimately decided to keep her mother in the centre, but pointed out that “those were

difficult decisions to contemplate as a family, and as an individual, as a daughter.”

### *Policy limitations*

Family members identified numerous issues with the COVID-19 provincial public health policies. This included noting weaknesses and implications of the policy, for example isolation requirements applied to residents with dementia. FM 18 noted this issue with her mother, who lived in a secure dementia unit: “You’ve got a lady who can’t read or write and you’re going to sit her in her room with nothing to do [...] if you’re going to have to isolate these people you have to come up with a better way to isolate them.” Nearly all family members described limitations of the continuous masking and physical distancing policies, including FM 10 whose mother is deaf: “She doesn’t sign so she reads lips so that’s why actually masks make it difficult. So those outdoor visits where you have to wear a mask, I don’t think that would work for us so well”. Similarly, FM 04 noted about her family member in the centre: “She couldn’t hear us and somebody with dementia, and hearing aids, that mask is a problem.” Regarding physical distancing, FM 16 observed “They don’t understand. They wanna touch and you back away and they think you’re teasing them or you’re mean and something’s wrong.”

Many family members also commented on the challenge of blanket rules applied across diverse LTC centres: “I don’t believe it should be a flat out “this is how it’s gonna work in every single facility” because there’s differences in every facility” (FM 03). Similarly, when discussing visitation policies, FM 08 observed that “I think they should have taken each care center and looked to see if there was any issues, or if there was any outbreaks, or if they had any cases and take them individually.” Others were not only critical of a blanket policy approach, but also commented that other domains of health beyond the physical were not considered in the creation of the public health policies. FM 12 was critical that policies focused solely on physical health: “The rules are one size fit all. And my mom has dementia and she’s in a secure dementia unit, she is a very small subset of that large group and there are no rules that take into account her health aside from COVID.” This limitation was echoed by other family members, who observed that COVID-19 public health policy was focusing on quantity of life only: “For her it’s very important to have her family and for us to be able to be there for her ... I think that’s more important to her than the length of her life” (FM 01).

### *Policy impact*

The public health policies impacted family members and their loved ones living in LTC in a variety of ways. Family members experienced emotions such as loss, sadness, frustration, grief, and stress because of the inability to visit, with some noting “For us, it’s stressful” (FM 08) and “Sometimes it’s a little bit frustrating” (FM 01). Pre-COVID, when his mother was distressed on the phone, FM 04 would “go ‘Yeah I’ll be there in about 10 minutes,’ like it was no big deal.” During the pandemic, with the visitor restrictions, the situation was different: “Sometimes when she gets that frustration, if she can’t get past it you gotta end the call because it just makes things worse. You know, and that’s tough to do, it’s tough to just say ‘Y’know Mom, it’ll work out, I’ll talk to you later,’ and that’s tough to do, it just ... you’re cutting your parents short.” Family members observed many of these same emotional impacts on their loved ones living in LTC, for instance commenting “He’s frustrated too of course” (FM 07) and “She said she’s lonesome” (FM 01). FM 18 described how “my mom started to cry” the day a nurse at the centre explained to the resident that FM 18 couldn’t come inside to visit.

Family members also described other impacts the COVID-19 policies had on residents. For example, the lack of family presence for

one resident meant that advocating for his own needs had to be done alone: “It’s just hard for him to know that he’s basically on his own to fight for whatever he needs, that’s the hardest part” (FM 02). Several family members also noted declines in the physical or mental health of their loved one resulting from the lack of regular family contact. For instance, pre-pandemic, one family member took her mother for daily walks, and observed that “her mobility, her strength has gone downhill in this because she hasn’t had those afternoon walks seven afternoons a week” (FM 06). Conversely, some family members observed that it was difficult to distinguish between deterioration resulting from the COVID-19 restrictions, and deterioration resulting from the progression of dementia. FM 12 commented “Some of that [change] is dementia and over the course of three months, would she have deteriorated to that extent? I don’t know.”

Several family members discussed the impact of the COVID-19 policies on the ability of the resident to engage in recreation and leisure. Regarding her mother, FM 06 explained “The church that she attended for years, we found out when she moved to [centre] they had done a weekly sing song at [centre] and she loved that. And so you know what the loss of those kind of things in terms of quality of life, yeah they would be very significant.” FM 05 noted that “the one thing that mom talks about constantly is not being able to play bingo” while FM 07 observed that “he really looked forward to always being able to go out, and go out for a coffee or whatever so that’s impacted him.”

#### Centre response

Family members shared opinions about the ways that their individual centres enacted the provincial public health policies. Family members’ discussion of the centre response focused on two areas: visitation and communication. Common issues participants noted in relation to visitation included challenges with visit scheduling, location, timing, frequency, and resident preparation. For instance, FM 13 commented that “the first time we had a window visit they forgot her hearing aid all together [...] they should train the girls that are going to the window visits better.” To manage public health visitation policies, all of the centres in this study required advanced scheduling for visits. Some family members observed that the restrictions placed on frequency of visits was frustrating, when open visit slots were available, such as FM 03 who commented “If you only have four people visiting in a day, let me come three times! I live five minutes away, I’ll drive, if I’m off, I’ll go.” Other family members found the available visit slots too restrictive, such as at one centre that did not offer evening or weekend visit slots. FM 01 recommended adding evening and weekend slots to accommodate more visitors: “It would allow people flexibility for people who are working in the daytime to have an evening time, and people working in the week, during the week to have a weekend, you know and so you could go more often.”

Communication from the centre played a major role in family member experiences. Family members described a diverse range of positive and negative experiences with centre communication. One spouse, who described herself and fellow family members during the pandemic as “outsiders, the ones on the outside” (FM 16), commented that a lack of regular communication about her spouse’s wellbeing was difficult. She recognized that individual families could not feasibly be contacted daily with updates by staff, but also noted “Once a week, somebody that knows what their health is like, what their eating is like, what their personal care is like and what their personality is like, phone and say ‘He’s having a great week,’ or ‘He had a couple of blips but he’s okay,’ because all we do is imagine, out here on the outside.” When asked what LTC centres could do in the future to improve their pandemic response, FM 05’s answer was: “The big thing is to have more communication on the residents to the family members.” Similarly, when asked if she had anything else to share,

FM 10’s final comment was “they could communicate; they could take the time to communicate better.” Other family members described positive experiences with ongoing communication. For example FM 06 commented that his mother’s centre “set the standard for clear, open, honest communications” and that they “responded, from what I can see, very effectively and promptly to the directives of the medical officer of health.”

#### COVID-19 knowledge and Information

Family members described their personal knowledge and understanding of COVID-19, and discussed the various sources of information they drew on to learn about public health policy changes. Some family members, like FM 18, watched the Chief Medical Officer of Health’s (CMOH) updates on television, and read the published CMOH public health orders: “I watch Hinshaw when she’s on and... read that Dr. Hinshaw’s order from back to front, the whole order.” Other family participants obtained information online from the provincial health body, or from news sites.

Family members also described the level of knowledge and awareness that their loved one in LTC had about the pandemic and public health policies. The majority of family members we spoke to did try to share information about the pandemic with their loved one. Most family members whose loved one had dementia reported that the resident had minimal understanding of the pandemic or public health restrictions. This varied from no knowledge at all, such as FM 08’s mother who “doesn’t have that cognitive ability to understand that anything is going on” to other’s such as FM 01 whose mother-in-law was able to understand the basic concept of a “sickness”: “And I know that [the resident] doesn’t totally grasp what’s going on [...] She’ll still say ‘Is this sickness happening?’ and thankfully my husband is pretty gifted and so he explained it to her like polio... which she does remember.” Some family members described how their loved one was aware of the need for restrictions without understanding the broader concept of a pandemic, such as FM 07’s father: “When I go for my open visits he says ‘Oh yeah we got to put that mask on,’ or ‘Oh yeah you can’t, you gotta keep 6 feet away,’ so he is aware of it, sometimes I need to remind him about it. But yeah, its, so he is kind of aware of it.”

#### Discussion

Residents and family members of residents in LTC facilities experienced a unique, once in a lifetime event during the COVID-19 pandemic. The sector was hit particularly hard by COVID-19, and public health policies enacted worldwide were especially restrictive in this setting.<sup>20</sup> Given the relatively few remaining years of life those living in these settings have,<sup>21</sup> it was important to capture the experiences and perspectives of those who lived through the initial months of the pandemic. This study explored the dual perspectives of residents and family members, collected at the same time during the pandemic and across the same centres, providing a fulsome depiction of the COVID-19 LTC experiences in Alberta during the first months of the pandemic. These experiences can be used to shape future pandemic response and planning.

During the initial months of the COVID-19 pandemic, public health policies were enacted rapidly, and with little consultation with continuing care stakeholders.<sup>22</sup> Residents and family members in this study had a wide range of observations regarding limitations of public health policy and provided numerous suggestions for improvement, both at the centre-level and at the policy-level. Some participants explicitly called for active consultation. This approach aligns with the spirit and practice of person-centred care, which has a guiding principle the incorporation of the resident perspective and encourages integrating resident experience and expertise into



decision-making.<sup>23</sup> Additionally, the two groups shed light on the perspectives of a third group: cognitively impaired residents. Both resident and family participants discussed residents with cognitive impairment, either extemporaneously or in response to interviewer probes. Resident participants in particular often highlighted the ways those individuals' experiences differed from their own, reinforcing the importance of integrating the experiences and perspectives of all key stakeholders during policy planning. In Alberta, there was recognition from the CMOH, following the initial months of the pandemic, that more consultation with residents and their families was needed to address the impact of severe public health restrictions on resident quality of life. Resident and family consultation was built into later public health orders to try and balance resident physical safety with their quality of life and psychosocial wellbeing.<sup>4</sup>

Consultation with LTC stakeholders should not only be undertaken during future pandemic-planning, but plans for consultation should be incorporated into pandemic plans to ensure that the perspectives and experiences of stakeholders are considered when public health policies are developed and implemented. Our results suggest that care needs to be taken when planning based on consultation, because while the feedback from the residents and families in this study often overlapped, there were important differences. For instance, many residents and family members shared dissatisfaction with the communication they were receiving. However, there were observable differences in how these two groups received centre information. Family members received newsletters from the centre, which they would sometimes relay to their loved one in care. This same information had to be sought out by our resident participants by directly asking staff, or in some cases signing up for the newsletter themselves. Both residents and family members provided feedback that communication from LTC centres needs to be improved in a pandemic, though the communication approaches to address this need might differ in practice. When planning future LTC policies and frameworks we must carefully consider shared perspectives and experiences, as well as differing needs.

Although the model of care in continuing care has shifted over the past decades from a strict biomedical focus to a more holistic person-centred or relationship-centred approach,<sup>24</sup> the COVID-19 pandemic saw a rapid shift back to a biomedical focus in LTC. Numerous family members and residents made this observation, noting that there was no space in current public health policies for psychosocial wellbeing. Interestingly, discussion of physical health was largely absent from our resident interviews. While most resident participants understood and recognized the risk of contracting COVID-19, this was not a dominating theme. Instead, when discussing the impacts of the pandemic, residents described the effect of the restrictive policies on their mental health and their desire for improved access to family and friends, as well as challenges unique to more cognitively impaired residents. In particular they noted residents with dementia looking lost, frightened, and sad. Family members echoed these descriptions of their loved ones with dementia, commenting that they were frustrated, lonely, and sad. These results are consistent with the experiences of community-dwelling older adults during the COVID-19 pandemic, as identified in a recent scoping review.<sup>25</sup> Increased social isolation and worsening neuropsychiatric symptoms, such as anxiety and depression, were key themes identified.<sup>25</sup> The finding that there was a lack of psychosocial consideration for residents in LTC during the COVID-19 pandemic highlights the importance of planning for psychosocial and mental health supports, in addition to infection control measures, in future pandemic responses.

In Alberta, during the initial wave of the COVID-19 pandemic, a CMOH order was released that allowed for 'essential' visitors to enter LTC centres to attend to unmet needs of residents.<sup>2</sup> The use of the word 'essential' was problematic to our family participants, many of whom felt their role in the lives of their loved one was essential but

did not fall under the order's definition. Previous studies have outlined the variety of roles that families take on, on behalf of their loved ones in LTC, including: decision-making, advocacy, grooming, shopping, housekeeping, decorating, mealtime assistance, and supporting leisure and recreation.<sup>26,27</sup> These activities serve not only to provide physical support to residents, but, importantly, function to preserve the identity of the individual in residential care.<sup>27</sup> By defining some visitors as 'essential' and others not, the CMOH order effectively created two tiers of visitors and placed higher value on visitors providing 'essential' physical care by giving them access to their loved one. Of note, our resident participants did not criticize 'essential' visitor policies to the same degree as family participants. This is likely a result of our sampling strategy, which included only residents without cognitive impairments. The residents who participated in this study were capable of communicating their needs and advocating directly to staff. Although family and friends undoubtedly play an important role in the lives of these residents, the loss of visitor presence within the centre was likely not as immediately impactful as it was for those individuals with dementia. This important difference between residents and families in our study again serves to highlight the need to consider multiple stakeholder perspectives when planning pandemic public health policy.

This study has limitations that must be considered. The severity of the pandemic, and the public health policies enacted in response, varied worldwide and are thus location-specific. The experiences of the residents and family members in this study may differ from those in other areas of Canada or around the world. In addition, the interviews took place in the time between the 1st and 2nd COVID-19 waves in Alberta; the results are thus also time-bound. It is possible that resident and family perspectives may have changed following the 2nd and 3rd waves of the pandemic, as well as following increased vaccination rates within this population. Follow-up studies on changes in perspectives may be warranted to compare initial experiences with later ones. Lastly, this study did not capture the direct experiences and perspectives of residents with dementia. Due to restrictions in accessing the resident populations, phone interviews were necessary. This limited our sample to individuals capable of maintaining a 30 minute to one-hour long telephone call. While resident and family participants were able to provide secondhand information on the experiences and feelings of residents with dementia, those individuals' direct experiences are not captured in this study.

## Conclusion

This study explored the experiences of LTC residents and family members while living with the public health restrictions imposed due to the COVID-19 pandemic. The results emphasize the importance of engaging LTC residents and families in decision-making during pandemic preparation and response, and of considering the psychosocial impact of restrictions in LTC. This knowledge can help shape ongoing or future pandemic planning to ensure that residents and families are consulted and their needs and preferences considered. Overall, this study shares the opinions of the individuals who LTC policies impact the most, so future LTC pandemic planning can be shaped by the voices of the individuals most affected.

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## Declaration of Competing Interest

None.

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