



“Be Their Advocate”: Families’ Experience with a Relative in LTC during the COVID-19 Pandemic

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Article

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Résumé

Peu de temps après la déclaration de la pandémie, de strictes restrictions ont été imposées aux visiteurs dans les centres de soins de longue durée (CSLD). Un an plus tard, ces restrictions demeurent en vigueur et continuent d’affecter les membres de la famille qui, encore aujourd’hui, n’ont que peu ou pas de contacts en personne avec leurs proches dans les CSLD. Le but de cette ethnographie longitudinale qualitative était de comprendre l’expérience des membres de la famille dont le proche est hébergé dans un CSLD où les visites ont été restreintes pendant la pandémie. Dix-sept (n = 17) membres de la famille ont participé à deux entrevues à six mois d’intervalle. L’analyse des données a mis en évidence cinq facteurs clés, soit la main-d’œuvre, les déficits de communication, les caractéristiques des soins, les directives de santé publique et l’autonomie du proche, qui à leur tour, ont mené à trois thèmes principaux : la détresse psychologique, la surveillance et les défis liés aux visites. Cette étude dresse un portrait critique des expériences des familles dont un proche réside dans un CSLD au Nouveau-Brunswick.

Abstract

Shortly after the COVID-19 pandemic was declared, strict visitor restrictions were issued for long-term care facilities (LTCFs). A year later, restrictions are still in place and they continue to impact family members who have limited or no in-person contact with their relative in LTCFs. The goal of this qualitative longitudinal focused ethnography was to understand the experience of family members who have a relative in a LTCF where visiting has been restricted during the pandemic. Seventeen family members participated in two interviews that were 6 months apart. Data analysis highlighted five key drivers, defined as the workforce, communication deficits, characteristics of care, public health directives, and autonomy of relative which in turn resulted in three main themes: psychological distress, surveillance, and visiting challenges. This study provides a glimpse into the difficult experiences of families with a relative residing in a LTCF in the province of New Brunswick.

Do you remember where you were or what you were doing on March 11, 2020, when the World Health Organization (WHO) declared the global coronavirus disease (COVID-19) pandemic (World Health Organization, 2021)? Did any of us understand how our way of life was going to change?

It is a period in time that families¹ with relatives in a long-term care facility (LTCF) will not soon forget. Family members immediately learned that they would be separated from their relative because of visits being *temporarily* suspended; however, more than a year after the pandemic was declared, restrictions are still in place. Some people will argue that older adults in long-term care facilities (LTCFs) are vulnerable and need to be protected from the virus no matter what it takes, whereas others deem that the strict guidelines on family visiting have created more harm than good especially relating to ignored mental and physical health needs of older adults (Levere, Rowan, & Wysocki, 2021; Tupper, Ward, & Parmar, 2020). No matter the line of argument on the matter, what is certain is that there are detrimental consequences to depriving families of having physical contact with their relative. Families are more than visitors when they walk into a LTCF (Canadian Foundation for Healthcare Improvement, 2020). They participate in the life of the facility by providing multidimensional personalized care to their relative, hence supporting employees in their role (Ting-Chun et al., 2020; Tupper et al., 2020).

¹Although we use the terms “relative” and “family” throughout, we recognize that in some instances these caregivers can be close family-like friends, or neighbours (Change Foundation, 2019).

Families not only tend to their relative but also often extend a helping hand to other residents. With a clear understanding of the role of families in LTCFs, it was obvious that visitor restrictions were going to have consequences, even in one of the Canadian provinces with the fewest infections and deaths. New Brunswick has one of the highest proportions of adults over the age of 65 years in Canada and although the province has been spared the many effects of the pandemic, the experience is nonetheless significant to understand. Therefore, the goal of this qualitative longitudinal focused ethnography study was to understand the experience of family members who have a relative in an LTCF in the province of New Brunswick, where visiting has been restricted during the COVID-19 pandemic.

Context of the Study

In the province of New Brunswick, there are currently 70 licensed LTCFs of which 88 per cent are owned by private not-for-profit organizations and 12 per cent are owned by private for-profit organizations (Canadian Foundation for Healthcare Improvement, 2020) representing almost 4800 residents, or 4 per cent of adults over the age of 65 years in the province (Government of New Brunswick, 2017; New Brunswick Association of Nursing Homes, 2021). They are located throughout the province from urban centres to rural villages, with language designations of English, French, or bilingual, and are independently owned by a board of directors and formed under the province's Companies Act as non-profit organizations (Government of New Brunswick, 2021a).

With the news of COVID-19 spreading in other provinces in early 2020, several LTCF administrators in New Brunswick decided to restrict visits to people who had been away on vacation or outside the province as of the end of February or very early in March 2020 (G. Hache, personal communication, May 20, 2020). On March 9, 2020, 2 days before the official WHO pandemic declaration, a provincial news release (Government of New Brunswick, 2020d) informed the public that keeping the new virus out of LTCFs was a priority and that staff members, family, and friends who had any respiratory infection symptoms were to avoid going into LTCFs. This message kept being repeated until an official guidance was provided on March 13, 2020, from the chief medical officer of health for the province declaring that all visits in LTCFs were being halted (J. Hall, personal communication, March 2, 2021). Four days later, some older adults waiting in hospital to transition into LTCFs were urgently moved to prepare space in hospitals for COVID-19 isolation units (Government of New Brunswick, 2020c). A month later, on April 13, 2020, the provinces' premier announced during a press conference that many steps had been taken to protect residents in LTCFs such as: not allowing visitors, advance screening for staff, avoiding unnecessary transfers to hospital, and ongoing training for employees on the proper use of personal protective equipment (PPE) (Government of New Brunswick, 2020b).

Three months after visitor restrictions were implemented, on June 5, 2020, outdoor visits between residents in LTCFs and families were permitted with strict guidelines of physical distancing and no touching (J. Hall, personal communication, March 2, 2021). Although announced in early June, LTCFs necessitated time to organize and put in place requirements for outdoor visits. Some LTCFs were only able to accommodate a small number of visits every day, thus leaving an interim of 2 weeks between visits for each resident and that person's family, whereas other facilities delayed outdoor visits considerably because of a lack of resources. Finally, on August 28, 2020, 5.5 months into the pandemic, provincial

authorities introduced changes to LTCF visitations. LTCFs were given leeway to introduce designated support people, permitting families to identify a member who would be allowed into the LTCF to provide care for their relative (Government of New Brunswick, 2020a). Off-site visits were also introduced with strict guidelines and dependent on the COVID-19 alert level. In New Brunswick, as in many other provinces, the public health alert levels were colour coded: red indicated strict controls, orange indicated a balance for some reopening, yellow meant allowing a loosening of restrictions, and finally, green implied full opening and public health restrictions lifted. Again, although allowed within public health guidelines, LTCFs implemented these new guidelines differently and with inconsistencies among facilities.

Families and LTC

In wanting to protect the residents of LTCFs with changing public health directives throughout the course of the evolving global pandemic, the needs of family members with a relative in an LTCF were at the forefront of many discussions and online public opinions. Many arguments can be made that the directives could have been different (Stall et al., 2020). Years of theorizing and study about aging and family life relationships (Silverstein & Giarrusso, 2010), family as care partners (Canadian Foundation for Healthcare Improvement, 2020; Government of the United Kingdom, 2021; Tupper et al., 2020), person-centred care (Bouchoucha & Bloomer, 2021; Canadian Foundation for Healthcare Improvement, 2020), the role of families in LTCFs given the shortage of care providers (Gwyther, 2001; Ting-Chun et al., 2020) seem to have completely been ignored in the face of this pandemic. Empirical research confirms the need to consider family caregivers as extended clients of LTCFs (Gwyther, 2001) given the emotional burden that usually accompanies having a family member in a LTCF (Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006; Ting-Chun et al., 2020). Families often feel isolated (Gwyther, 2001) while worrying about the health and well-being of their relative (Strang et al., 2006). Given what is known about the importance of family members visiting a relative in LTCFs and the imposed restrictions in the context of COVID-19, understanding the experience of family members who have a relative in a LTCF in the province of New Brunswick where visiting has been restricted during the COVID-19 pandemic seemed essential.

Methods

Given that extensive prior research on the study topic was lacking, a qualitative longitudinal focused ethnographic approach (Roper & Shapira, 2000) was used to describe families' ongoing experiences with visitor restrictions in LTCFs. Focused ethnographies are time-limited studies that gather data from multiple sources (LeCompte & Schensul, 1999) such as context data on the evolution of the pandemic. This approach is useful in gaining a better understanding of the experiences of people in specific situations or ways of life (Cruz & Higginbottom, 2013) and consists of an iterative data collection and data analysis process up to data saturation (Roper & Shapira, 2000).

Data Collection

Following research ethics board (REB) approval from the Université de Moncton, the care manager at a selected large LTCF in

Southeastern New Brunswick sent an e-mail to family members whose e-mail addresses were on file. The recruitment message included the study description and an explanation on how to participate by directly contacting the research team. The inclusion criteria were: (1) having a relative in a New Brunswick LTCF where visitor restrictions had been implemented, (2) being able to speak French or English, and (3) being 18 years of age or older. Exclusion criteria included: (1) having a relative in a LTCF outside the province of New Brunswick, and (2) refusal to give informed verbal consent.

Data collection consisted of semi-structured telephone interviews at phase I (May/June 2020) and again at phase II (December 2020) with the same participants. Consent was obtained verbally by reviewing previously sent information on the study at time of recruitment. The interviews lasted between 30 and 60 minutes and with participant consent were audio recorded and later transcribed verbatim for analysis. Guiding questions encouraged participants to share their experience about not being able to visit their relative in a LTCF, while focusing on how they were managing the situation and what not being able to visit represented to them. Phase II interviews consisted of the same questions with slight revisions to capture the 6 months time span. Guiding questions encouraged participants to discuss their experiences while prompts such as “tell me more about that” allowed for more in depth understanding (Roper & Shapira, 2000). Data saturation was achieved when no new information emerged from the interviews. Sociodemographic data were also collected at the beginning of each interview at phase I. At the end of each interview, the telephone number of a provincial support service was provided verbally to the participants and they were informed that they could speak with the nurse manager at the LTCF if they needed support. Provincial government press releases were also scanned for contextual information such as the number of COVID-19 cases, the number of deaths, and public health directives. Media interest and interviews with the principal investigator (PI) resulted in eight spontaneous contacts (e-mails or telephone conversations) from the general public who wanted to share their own experiences having a relative in a LTCF during the pandemic.

Data Analysis

Verbatim transcriptions were analyzed line by line using open coding, and as more data were added, clusters of information were examined for similarities and differences and then gathered into categories. Both phase I and phase II data were analyzed separately up to the forming categories stage of analysis and then compared with each other and grouped into larger categories. This sifting process (Morse, 1994) left the most significant data to form the results of this study. In keeping with the focused ethnography approach (Roper & Shapira, 2000), the larger categories were examined for relationships and moved into two larger conceptualized categories of patterns: key drivers and manifestations. Data analysis was conducted by the same research team member supported by NVivo12. All members of the research team were involved in reviewing and discussing the results. Analysis was conducted by keeping transcripts and codes in French and English as long as possible and then having them translated into English by the bilingual research team members. Rigour was established through field notes, team discussions, and member checking (Lincoln & Guba, 1985). Data from provincial government press releases were analyzed one by one to establish the contextual timeline of the pandemic during the study phases.

E-mails and notes from calls with the members of the public were looked at for similarities and differences with study participants' experiences and as a means of data triangulation allowing for multiple sources of data to complement each other and enhance credibility (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014).

Findings

The following section presents the characteristics of the study participants and the context in which the study was conducted, along with the key drivers or influencers of the family members' manifestations of visitor restrictions. The context, the drivers, and the manifestations intertwine to represent the experience of family members with a relative in an LTCF.

Study Participants

Seventeen family members participated in this study for a total of 34 interviews (phase I and phase II). The average age of study participants was 63 years, while the mean age of their relative in a LTCF was 85 years. The majority of participants were female (71%) with most being married or in a common-law relationship (65%). Participants in this study were highly educated, with 71 per cent having a post-secondary degree. Participants shared that their relative had been in the LTCF for an average period of 18 months. All participants had other family members who would also normally visit their relative in the LTCF. All participants stated that they visited their relative at least once a week, with some visiting daily, before the pandemic. Table 1 highlights the socio-demographic characteristics of the participants in this study.

Context

There were few cases in New Brunswick during the first month of the pandemic, and these were mostly travel related and outside of LTCFs. In fact, during the spring of 2020, the province had little to no active cases of COVID-19, prompting the Atlantic provinces to form a bubble on July 2, 2020. According to provincial statistics released during press conferences (Government of New Brunswick, 2021b), the age group with the most diagnosed cases of COVID-19 has been those 50–59 years of age, but 80 per cent of people who have died were over the age of 70, and half of all deaths were in people over 80 years of age. Thirteen LTCFs had reported cases, with only about half declaring an outbreak. In fact, the first provincial outbreak in a LTCF was declared on June 4, 2020, the same date that New Brunswick reported its first death.

To provide some context of the COVID-19 scenario during times of data collection, during phase I interviews (May/June 2020), there had only been a handful of positive cases, none of which were in a LTCF. The context changed drastically for phase II interviews (December 2020) when there had been outbreaks and deaths in LTCFs, public health directives were restricting travel between provincial health zones, and the daily positive cases of exposure to COVID-19 averaged four people each day. Two outbreaks in LTCFs had been declared at the end of November and this continued to have impact on residents, families, and staff well into the month of December. The first dose of the vaccine was available to some LTCF residents and staff on December 19, 2020.

Table 1. Socio-demographic characteristics of participants

Characteristics (n = 17)	n	%
Age of participants		
≤ 54	1	6
55-59	5	29
60-64	4	24
65-69	6	35
≥ 70 or over	1	6
Gender		
Female	12	71
Male	5	29
Marital status		
Single	3	18
Married/partnered	11	65
Divorced/widowed	3	18
Highest education		
High school	5	29
College or university	12	71
Age of relative		
60-69	2	12
70-79	2	12
80-89	7	41
90-99	6	35
Months in an LTCF		
1-12	7	41
13-24	2	12
25-36	7	41
≥ 37	1	6
Number of visitors to LTCF pre-COVID-19		
1-4	14	82
5-9	2	12
≥10	1	6

Key Drivers

Family members described five key drivers that were determining factors of their experiences: workforce, communication deficits, characteristics of care, public health directives, and the autonomy of the person in the LTCF. These drivers influenced all aspects of family caregivers' experience and intertwine with each other to impact families' experiences. Figure 1 depicts how the key drivers were dominant features of the family members' manifestations of visitor restrictions in LTCFs, with the intensity of the experience increasing between phase I and phase II.

Workforce

Workforce or human resource issues were a dominant component in all interviews. The main subthemes involved the lack of staff or staff turnover, the consequences of not having sufficient staff, training, and language issues. Participants shared their

concerns and frustrations with the lack of staff and/or staff turnover (new staff) at the LTCF in both phase I and phase II. All participants had similar observation to those of this one who explained:

The employees are overworked, they don't have the time to talk with residents, they don't have the time, the time to do their job correctly, they only have time to do certain tasks, they run all the time and it's even worse now with the pandemic.

(DF4 – 67 year old female)

One participant explained: "In the last three weeks, they were missing staff, one was injured, and it put everyone behind, so they couldn't answer the phone or offer activities" (F10 – 65 year old male). Another family member shared: "They hired for activities, for Facetime, and still that, well they went through three of them, so I don't even know who it is anymore" (F2 – 59 year old female). Another participant who was a designated care person and could visit shared:

Maybe it's just me, but I find that there are fewer employees or fewer people, I don't know. I find that her room is not clean or not well maintained. I also wonder about how much time they have to care for her.

(DF11 – 55 year old female)

Similarly, another participant wondered about the overtime staff were completing: "It means that they are short, I like to know, but sometimes no, because I wonder if they are ok to work" (DF2 – 58 year old male).

Lack of staff also impacted contact with LTCF residents. One participant explained: "We had problems entering to visit Mother because they did not have enough human resources for the demand. We could only Facetime for 15 minutes, sometimes only 10 minutes" (F10 – 65 year old male).

Additionally, some participants mentioned that staff lacked training to care for older people. One family member shared:

I don't understand why, with the training that they are supposed to have, the education, the career they have, that they could not determine that before I suggested it to them. They should see it themselves. It, it really, blew me away! Because I tell myself, they are the ones who are there, it's their job, and they didn't see the care that was needed until I told them.

(DF11 – 55 year old female)

Another participant explained: "The new staff, the young, they hire anyone, they hire anyone to work there but they don't have the qualifications" (DF3 – 57 year old female).

The other element related to the workforce was language. An important number of participants voiced concerns about their relative not being able to understand the staff who didn't speak their mother tongue or who had an accent. One concerned participant described it well.

She calls me often and she cries that they hired someone new, staff, and that they only speak English. She does not understand one word of English and it bothers her a lot. She says to me, 'I don't know what's going to happen when I want something, and I can't tell them'. Yesterday I called the manager, to tell them that Mother is French and that she doesn't understand the English-speaking staff. I was told the staff was learning French. But is it the responsibility of our parents to teach them French? They already have problems themselves with dementia and other things that make it difficult to even speak French.

(DF5 – 66 year old female)



Figure 1. Families experience with a relative in LTC during the COVID-19 pandemic

Similarly, another participant shared:

Just recently, they hired new people, but a lot of them don't speak French. But, I'll take them as long as they want to work I guess. Mother can ask for water, it still works. You know, it's just not good. It's a challenge. It's really bad, but I mean, there's not enough staff.

(F2 – 59 year old female)

Another participant explained: “She could speak English but since she was diagnosed with dementia, she lost her ability to speak English” (F1 – 65 year old female).

Communication deficits

All participants described difficulties communicating with staff at the LTCF in phase I and phase II of the study. With visiting restrictions, family members were seeking other means by which to get news about their relative, but this proved to be a difficult endeavour especially during phase I interviews. “You call and no one answers. People want news of their relatives who are there. We want news, we want to know how it's going, did they eat, are they sleeping, are the medications the same?” (DF3 – 57 year old female). This same participant clearly explains what others also shared,

The other day I called several times and there was not one time when I was able to talk with someone. The receptionist says ‘I'll transfer you’ but someone picks up the phone and hangs up again or put on hold and no one comes back. I find that very difficult.

(DF3 – 57 year old female)

A different participant explained:

Whenever I was calling them, I wasn't getting the answers about her care. The nurses, they said they didn't know about it, the PSW that had taken care of her was unavailable for the call so we were not getting any information about her condition, about what she ate, how many times she was changed or whether she was changed or not, the information was not available at all.

(F1 – 65 year old female)

Another participant shared the same concern during phase II: “You can't speak to anyone who knows her, who knows her file” (F9 – 43 year old male). And related to the workforce, this same participant explained that when staff change, they don't know whom to contact for information: “We were used to dealing with someone and then they change and we no longer have a reference point on who to communicate with” (F9 – 43 year old male).

Similarly, another participant shared:

When you call, they never answer. There's a lack of communication between the home and I'm the power of attorney and I had mentioned at two staff that I feel that my mom is sliding in a depression, but I don't know if she's being treated. No one has contacted me to let me know if they put her on medication, so I figure it's untreated right now.

(F2 – 59 year old female)

One participant shared during phase II:

I find that lately, there is less communication between the team and us than just a few months ago, if there was a change, they would call us right away and if Mom wanted something, we would know right away. Now, that doesn't happen.

(F12 – 63 year old female)

Characteristics of care

Participants shared their concerns about the care that their relative was receiving, specifically the quality and quantity of care, and more during phase II of the study. “Three times I went to visit him outside, he had no teeth in his mouth, the top teeth, and there is a big sign on his wall stating when you brush his teeth, put them back in” (F3 – 63 year old female). Another participant shared concerns about medication administration: “Her chart indicates in red that everything has to be crushed. If Mom would have choked, and died a worst-case scenario, would it have been just a mistake?” (F2 – 59 year old female). For others, it's the little things as this participant explained: “We had to bring up some little things to the attention of management, and still today, there are other things. It's frustrating” (DF2 – 58 year old male).

Characteristics of care had some overlap with *workforce* by participants voicing concerns about the impact of workforce issues on the care of their relative. One family member explained: “For the room to be clean or her personal care she should receive, I’m worried about those things. The quality of care is just not there, and even the quantity” (DF11 – 55 year old female). Another participant shared: “Someone was supposed to cut his nails, the person didn’t. It was the day to change the bed, it wasn’t done either” (DF3 – 57 year old female). Concerns were also shared by this participant.

Because she is not able to express anything on her own, that’s why one of us had to be in the nursing home with her. To let the caregivers know what her needs are, to change her or if she’s hungry. Because she is not able to express herself, we have to offer it and being her children, we know what she’s like. And because of the pandemic, otherwise she was starting to settle down, but since we couldn’t visit, she is lost completely.

(F1 – 65 year old female)

As a result, over half of all participants considered taking their relative out of the LTCF during phase I. Despite thinking about this, only one participant went through with the relocation.

She had language problems, it was getting to be difficult, so I brought her home, at least until the pandemic is over, otherwise it was getting to be too much for her. We have the peace of mind that she is in front of us, that we can feed her, put her in the wheelchair and take her around the house. I think she is happier.

(F1 – 65 year old female)

Other participants didn’t have the resources to care for their relative at home. One participant explained: “If I had a better place, yes. If I would have been capable, I still work, and even if I didn’t work it demands a lot” (DF11- 55 year old female). Another participant said: “Oh my God, yes, we think of it often, but, you know, no one of us can accommodate her in our houses, the way our houses are made and she needs so much care. All kinds of things have gone through our heads, I’ll be honest” (DF2 – 58 year old male). Another participant shared the same sentiment: “Oh my God, yes! I even thought about it yesterday. When you call there and it’s impossible to reach someone because they don’t answer the phone, you know, you ask yourself questions” (DF3 – 57 year old female). Despite the challenges of care, one participant shared what many also explained to us: “Many many many times I thought of getting him out of there, I don’t like the care at all, but it’s not there, it’s everywhere” (F3 – 63 year old female).

Public health directives

As the pandemic evolved and measures were put in place to protect the public, it became confusing for everyone to keep track of the phases and the impact of public health directives on LTCFs. Many participants shared the confusion explained by this participant.

With the rules for my Mother and the rules for my father, and then the rules for us, it’s like, it changes so crazily quick. Then it’s, no we can’t do that, then it’s ok, ok, they have changed, we can do that, but I can’t because they didn’t change. It’s breathtaking!

(F12 – 63 year old female)

What became clear for the participants is that public health directives were isolating them from their relative. One participant

explained the difficulties associated with changing public health directives.

We have the privilege with Facetime to tell her that it’s not going to last long. It’s not going to be six months like the last time. It encourages her, but like the last time, with was two or three weeks without seeing her. It’s heavy, when we change colours, it becomes heavy. They are the ones affected.

(DF4 – 67 year old female)

Another participant shared: “That’s what I find frustrating when it changes from yellow to orange. For me, family caregivers should be able to continue to go in” (F10 – 65 year old male). Not going in to visit means not helping out, as one participant described. “It’s something that needs to be dealt with, sooner or later, and now because of the orange phase, I can’t visit her at all, I can’t offer any services, so I’m without her” (F2 – 59 year old female). Yet another participant explains the consequences of the public health directives: “It’s really difficult with COVID, it’s a lot of missed time and opportunities to make her daily life happy” (DF11 – 55 year old female). This same participant continues with:

She will look at me and say, ‘I don’t hear anything’. Then I bring my mask down so she can look at my lips, but I distance myself. You know, I’m sitting far from her and she’s in her chair. She doesn’t understand as much...I found that the last time, it was a bit sad because I think it made her sad.

(DF11 – 55 year old female)

Some participants share their concern about what they have observed. For example, one participant shared:

My mom has started to scream, she never did that before. She screams because she is no longer mobile, she can’t blow her nose, can’t do anything. She depends 100% on others, so when she needs something, either physically or needing to feel in security, because she is an anxious person, she’ll scream. So that’s one thing that’s happened since the beginning. It’s very difficult for us.

(DF2 – 58 year old male)

Another participant explained

It’s difficult to see all those seniors there, all alone, they are sad. Before, you would enter the nursing home and there was life, everybody would laugh, everybody would talk. We would speak to the residents. Now it’s like, oh my God, it’s sad. The atmosphere in the nursing home is not at all what it was before the pandemic.

(DF4 – 67 year old female)

Similarly, this participant shared:

When I went there to take care of her, usually I’d walk down the hall at 6:30PM, and all of the residents would be in their rooms and I’d wave and say hi, now, I walk by and they’re all in their beds at 6:30 at night, like this is foolish. I don’t know if they went in by themselves or they were put to bed, but there’s just no life whatsoever. You can tell people are depressed.

(F2 – 59 year old female)

Some participants made their concerns about the restrictive measures known but without any results. A participant shared:

I wrote letters to the minister of Health and asked, ‘what are you doing, there are no cases and they are losing’. All those letters, all those comments, all without a response. They never told us why they had to be kept confined when everyone else was resuming their lives and there

were no cases in New Brunswick...you know what I mean, very little cases.

(DF4 – 67 year old female)

Autonomy of relative

Another key driver influencing family members' experiences was the level of autonomy of their relative in the LTCF. In phase I of the study, one participant explained: "My mom is smart enough, she can still use a phone, she has access to her telephone, we talk to her every day, but she's missing those hugs, she's missing those visits, she's missing those grandkids" (F2 – 59 year old female). When relatives had access to a phone, participants seemed to have a different experience: "I call her every day, in the morning, in the afternoon, and in the evening when she goes to bed" (DF5 – 66 year old female) (phase II). Another participant shares the joy of their mom being able to use FaceTime: "We survived, thank God for my Mother who had a tablet and that we were able to Facetime every day" (DF4 – 67 year old female) (phase II).

Manifestations

As a result of visitor restrictions and the influence of the key drivers described, family members experienced three consequences or manifestations from the pandemic: psychological distress, surveillance of their relative, and visiting challenges.

Psychological distress

The psychological impact on families was a feeling of distress that intensified with the duration of visitor restrictions and the pandemic. Psychological health of family members was also impacted by all drivers previously described. During phase I interviews, the common theme was "it will be over shortly" with little description of psychological distress other than worry for the safety of residents in a LTCF. Family members' experiences in the span of 6 months was greatly intensified. One participant described it clearly: "Since the last time we spoke, honestly, I am very anxious. Very very anxious, I am depressed, I am always concerned for Mother" (DF5 – 66 year old female). This same participant explained: "She calls me crying. It destroys me. It stresses me, it stressed me so much, I actually saw my doctor yesterday...I feel so depressed and so she gave me antidepressants and all that" (DF5 – 66 year old female). Similarly, another participant described: "It's the worry, the fear... I'm always on the edge, I'm always scared" (DF2 – 58 year old male). The worry is constant as another participant explained: "I worry all the time that it gets in that nursing home. It's hard, it's really, really hard" (F3 – 63 year old female). One participant described:

When everything started, the restrictions and the shut down and so on, you know, we just assumed that it would be over shortly. We went through the initial one, and then it shut down again, it's depressing, I have to, I have a hard time when I can't go there to be with her, I think in the morning, 'what am I getting up this morning for'.

(DF10 – 81 year old male)

Feelings of depression were certainly the most described, as another participant reflected.

There are days when I'm ok, but there are other days that are really not good. A couple of weeks ago when putting up the Christmas tree, out of the blue, I had a meltdown. I didn't know where it was coming from, but

we are a close family and we always have family gatherings and I think it hit me that it wouldn't happen this year.

(DF9 – 55 year old female)

Another participant described living with grief.

I'm grieving that I can't visit like I used to, I can't bring her to the hairdresser like we used to do and visits with the little kids. I mean, we have been obligated to go through a grief process. It's a series of little things. It used to bring her so much pleasure, that's what makes me sad.

(DF4 – 67 year old female)

There were also feelings of mistrust towards the staff at the LTCF. One participant shared: "I think they take advantage of us not being there. To neglect people, to not wash them, not feed them. I know that personally, I worry about the care" (DF3 – 57 year old female). Similarly, another participant shared that: "I feel scared, I don't know if those people...I know she eats well, but we're not there, we don't know what is happening, we don't know. I have fears about that." (F10 – 65 year old male). One participant summed it up as: "You have to stay on them...Ask a lot of questions, demand answers and even if they answer you, some of it is just to get rid of you so you won't bother them again, but you have to be their advocate" (F2 – 59 year old female).

The number of residents infected in other LTCFs also had an impact on participants' psychological health. One participant explained: "It causes some worry you know, but we have to have faith in the corporations running these nursing homes, but it causes worry" (DF10 – 81 year old male). Similarly, another participant explained: "I'm always in fear that it will happen where Mother is." (F10 – 65 year old male). Feelings of anger were also shared, as explained by this participant: "I'm mad. It gets me so mad" (DF3 – 57 year old female). Reacting to a local LTCF outbreak, one participant explained: "Those cases, they affected me. It affected me deeply" (DF9 – 55 year old female). As a result, many participants described limiting their outings and social interactions out of fear of transmitting the virus during limited visits with their relative, as explained by this participant: "You just have to stay safe, for ourselves and for our mother because we have to keep her safe too" (F1 – 65 year old female). Another participant emotionally described: "As caregivers, we chose to limit ourselves, not going to certain places that otherwise we would have if Mother wasn't in the picture...I minimize my outings to the grocery store, the essentials only" (DF9 – 55 year old female).

Surveillance

As a result of visitor restrictions and the time span between visits, family members described a heightened sense of observation of their relative during contacts and clearly expressed this during phase II of data collection. This manifestation was mostly influenced by the *characteristics of care* drivers but was also impacted by *workforce* and *lack of communication*. One participant explained: "I find that she has diminished, her appearance, and all" (DF11 – 55 year old female). Another participant similarly shared: "She hasn't been completely isolated from her family because of the iPad but I see the negative effects" (DF4 – 67 year old female). Similarly, another participant explained: "When there's an outbreak and they close and then open up again, we found an enormous deterioration. We found a big physical and cognitive deterioration in her" (DF2 – 58 year old male). Another participant explained the cognitive changes in their mother: "She doesn't remember anymore, she mixes up her children" (DF5 – 66 year

old female) while another participant also shared: “I find that lately, she doesn’t remember anymore, she thinks I’m my brother, I think it’s because we’re not there often but lately her memory is really going down” (F10 – 65 year old male).

Participants also described observing physical changes in their relative. A participant explained: “She can’t call anymore, she can’t use her fingers to call, it’s not easy...and she has trouble eating. When she undresses, before she could do it, now she can’t do anything herself” (DF5 – 66 year old female). Another participant shared a similar experience: “Physically, she can’t feed herself anymore. The consequences are due to what exactly?” (DF9 – 55 year old female). Still related to meals, another participant explained: “She wasn’t eating, even before the pandemic. I was going in to feed her, but now, she is just refusing” (F1 – 65 year old female). Another participant observed: “She has lost some weight; her appetite isn’t what it used to be” (F2 – 59 year old female). Some participants also described their observations in regard to the mobility of their relative. One participant shared: “I find her mobility has changed quite a bit, but again, they don’t have any activities, so there is no need for her to get out of her room, she’s always sitting” (F2 – 59 year old female) while another explained: “She is completely bed ridden now. She couldn’t get any exercise at the nursing home, when we went, we used to make her walk, so she has lost the ability to walk completely” (F1 – 65 year old female).

Family members are also recognizing the emotional toll of the pandemic on their relative. One participant shared:

He was in a daze, like shy. Yes, yes, I absolutely noticed that. It was as if he wasn’t comfortable with us. Usually he would laugh, he laughs all the time, and now he was serious, very serious, the words weren’t there. He couldn’t have a discussion. Something had changed.

(DF3 – 57 year old female)

Another participant shared: “Mother is very depressed” (DF5 – 66 year old female). Similarly, another participant explained:

My main concern right now is her mental health because it has deteriorated...everyday she cries over something, and that’s not something she used to do...she’s just depressed, there’s nothing to live for, they don’t even have activities anymore and she can’t see us.

(F2 – 59 year old female)

Visiting challenges

Early in the pandemic, participants were grateful to have the opportunity to speak with their relative by phone or to have a virtual visit with the use of a tablet. One participant shared: “They were really quick, they didn’t wait for the government funding, they got iPads and hired someone right away” (DF1 – 63 year old female) (phase I). And although Facetime became a means by which to visit, some participants shared the experience of this family member: “She couldn’t understand why we weren’t visiting, and we had to explain that every time” (DF7 – 67 year old female). However, as weeks became months without face-to-face visits, many participants expressed frustrations. One participant shared: “We had the Atlantic bubble, people were able to move around, but we still didn’t have access to the people we love in nursing homes. It was only at the end of June when we were able to visit outside” (DF3 – 57 year old female).

Outdoor visits were implemented as a low-risk option to have family members spend time with their relative, but it had its challenges. One participant shared: “Mother doesn’t like going outside

anymore. If it’s cool or windy, she really doesn’t like it. And she doesn’t speak loud now, so we have difficulty hearing her so I’m only a little satisfied with outdoor visiting” (DF2 – 58 year old male). Another participant explained: “The only thing I didn’t appreciate was that older adults, the residents, were basking in the sun, and it was really, really hot this summer. They could have had umbrellas or something” (DF3 – 57 year old female). Another participant shared a similar experience: “It was difficult for her, the wind, the sun in her eyes and we couldn’t finish the full allotted time because it was too much for her” (DF9 – 55 year old female). Some families didn’t get to visit outside as this participant explains.

My Mother refused to see us outside, she didn’t want to go outdoors because that meant she would have been sitting in a wheelchair to get her outside but it also meant that she would likely have to stay in that wheelchair the rest of the day.

(DF4 – 67 year old female)

Another participant shared their frustration: “I was pretty pissed off that somebody not using their heads and thinking that those elderly people would sit out in that hot sun” (F3 – 63 year old female). Still another participant shared: “With a mask, two metres apart, she wanted to hug us. It broke our hearts, for the love of God.” (F10 – 65 year old male). And lastly, some participants, like this one, had regrets about visiting outside.

It was 30 minutes. Thirty minutes you only have time, and sometimes they would be late, so you just had time to sit and then it was time to leave. It would break my heart. It was very, very difficult, sometimes, sincerely, I would have preferred not going at all because I felt like I was abandoning her.

(DF5 – 66 year old female)

To be allowed to visit inside the LTCF, families could identify two people to be the designated support person and although this allowed many families to have a member visit their relative, others questioned how it was described. One participant explained:

I questioned the whole thing because you could go in twice a week, on consistent days every week, but you had to provide some kind of service to the person, like bath them, give them care. I told myself, wait a minute! You are paid to do this, you have the training, and now you’re asking me to do this so I can visit? I’m not ready to try and do that. Yes, there are things I can do, but when I go visit, it’s for mental support, you know, talk with her.

(DF11 – 55 year old female)

And although able to enter the LTCF, another participant shared:

My sister and I are the designated caregivers. We could go for an hour, the mask, six feet apart, we couldn’t touch, and then the visits became longer but we had to offer personal care, help her eat but we could touch her, hug her.

(DF2 – 58 year old male)

Participants also expressed frustrations with the process of getting a visit arranged. One participant explained:

The appointments are really difficult to get. I don’t know if it’s their booking system or what, but it’s difficult. You really have to get at it one or two weeks ahead of time, and my other sister works, so she can only go weekends, it’s like a puzzle.

(DF4 – 67 year old female)

And similar to outdoor visits, some participants found the limited indoor visits difficult, as explained by this participant:

It's very, very difficult. When we leave, just the fact that we are leaving, it's so difficult, it's like leaving your kids when they are little and they cry, she doesn't cry, but she says 'stay, stay, stay' and she doesn't understand the concept of why we can only stay for one hour.

(F10 – 65 year old male)

Intensity of experiences

Participants also shared different intensities or impacts of the pandemic on their experiences based on time. There are subtle but important differences in experiences between phase I and phase II. During phase I of the study, a number of study participants recognized pre-existing challenges in LTCFs which had an impact on them or their relative. One participant observed: "It just doesn't work, in nursing homes, I mean, even before the pandemic, there are not enough staff, not enough good care and not enough people to give proper care to our seniors" (F6 - 69 year old female). Another participant explained: "It's difficult because I know some people had worries before the pandemic, and now, we just have to have faith in them" (DF8 - 59 year old female). One participant summed it up by saying: "Since Mother has been at the nursing home, we've noticed that if the family isn't there to look after her, all kinds of things would happen or rather not happen" (DF4 - 67 year old female). Although participants had concerns based on their experiences with LTCFs before the pandemic, their worry remained manageable during the early stage of the pandemic. Actually, participants commented on the lighter side of things such as cleanliness of the rooms, as one participant explained: "She told me I'd be upset if I visited because her room was not clean" (DF4 - 67 year old female). The majority of participants had hoped that things would get better soon and as explained by this participant, felt reassured by the measures taken by the LTCF: "It was hard accepting that they were cutting off all visits, but in the long run, it may be the safest thing to do" (F2 - 59 year old female). Psychological distress in phase I was mostly around their relative's mental health, with one participant sharing "it's mostly difficult for my mother, I'm doing ok" (F9 - 43 year old male). Others, like this participant, shared: "I was going to visit daily, so it's hard on my mental health, not being able to go and wondering how she is doing" (DF5 - 66 year old female). Although all key drivers and manifestations were present during phase I of the study, they were less intense and had less impact on families compared with 6 months later.

During phase II of the study, the tone of the interviews was unlike in the previous contacts with study participants. Participants shared much more emotion and concerns for their relative and expressed considerably more impact on their own mental health. The root causes of these differences between phase I and phase II interviews was the passing of time and the continued ban or limitations on visitation. One study participant encapsulates what many others shared during their second interview by saying: "With the passage of time, honestly, I'm feeling very anxious, even depressed, because I'm always thinking about Mother" (DF5 - 66 year old female). Another participant shared: "These changes in phases make deterioration worse" (F12 - 63 year old female). In fact, with families not able to tend to their relative, participants worried about the level of care being provided, given their role when visiting. One participant shared the sentiment of many.

She's deteriorating every day, more so than before. I think because we can no longer visit. We used to go in, talk with her, bring her for a walk, you know, stimulate her. We're not there every day and it makes a difference.

(F2 - 59 year old female)

Discussion

There is no question that the consequences of public health measures meant to protect residents of LTCFs have had irreconcilable consequences for the families of those older adults. Most striking is the intensity of the experience for families in a province with little COVID-19 diagnosis or death when compared with other Canadian jurisdictions. This study confirms that isolating family members from their relative in a LTCF has had a detrimental effect. Five key drivers influenced families' experiences: workforce, communication deficits, characteristics of care, public health directives, and autonomy of their relative. These key drivers manifested themselves in family members by means of psychological distress, constant surveillance of their relative, and continued visiting challenges. The intensity of the experience was amplified by time. In phase I interviews, family members believed that visitor restrictions were temporary, and although displeased, the experience was very different 6 months later in phase II of data collection. When interviewed for the second time, families described a very different and intense experience which will undeniably have long-lasting consequences.

It is unimaginable that a year and some months have passed since visitor restrictions were introduced in LTCFs and that they remain in place despite the notorious effect on families and residents. It would be easy to try to assign blame, but the truth is that the issues at the root of families' experiences have existed for years; however, the pandemic has aggravated what had previously been regarded as problematic in LTCFs. Essentially, gerontologists, health professionals, and community organizations have been advocating for changes in the LTC sector for the last two decades (Estabrooks *et al.*, 2020; Registered Nurses Association of Ontario, 2020). Magnified by the COVID-19 pandemic, the realities of Canadian LTC have become widely known; however, despite the acknowledgement, change has been stagnant. Several voices have referred to what is happening as a tragedy (Holroyd-Leduc & Laupacis, 2020; Meisner *et al.*, 2020; Registered Nurses Association of Ontario, 2020). The findings of this study are a result of these systemic failings.

The common denominator in this study, accountable for family members' experiences, was workforce-related concerns such as staff shortages and turnover. Human resources concerns are not new in LTC and have been at the forefront of a number of reports (Estabrooks *et al.*, 2020; Registered Nurses Association of Ontario, 2020), strategies on aging (Government of New Brunswick, 2017), human resource plans (Government of New Brunswick, 2019; Government of Ontario, 2020) and most recently COVID-19 (McGilton *et al.*, 2020; Meisner *et al.*, 2020). Foremost, human resources issues had a profound impact on the lack of communication between the LTCFs and family members. Communication challenges during COVID-19 were especially prominent as families sought information about their relative (Leaman & Azios, 2021; Ting-Chun *et al.*, 2020; Tupper *et al.*, 2020). Interestingly, McArthur *et al.* (2021) reported that quick deployment of communication strategies in LTCFs in New Brunswick resulted in residents being protected from the mental health consequences

of lockdown. Based on our participants *surveillance of their relative*, our study does not support these positive outcomes, and in fact, shows that not only did residents not fully benefit from these communication strategies but that family members remained concerned and anxious. Family members' psychological distress was intensified as a result, given that workforce issues resulted in limited video-chats or visits and the need to be super-vigilant of the health of their relative.

Second, the consequences of social isolation as shown in this study are distinctive. Before the pandemic, families had seldom been forced to separate for such a duration as they have since March 2020, and this brings a uniqueness to our study findings. First, the psychological anguish experienced by families in this study is tremendous. Most of the participants experienced new feelings of worry, anxiety, and/or depression that were not present during the beginning of the pandemic, but which are common manifestations of social isolation (Santini et al., 2020). Contrary to Ting-Chun et al.'s (2020) findings of family members' high satisfaction with quality of care during the pandemic, our study found that family members worried about the quality of care that their relative was receiving because of visitor restrictions and isolation. More so, given the *surveillance of their relative* by family members, one can conclude that the impact of restrictions on residents was also having consequences on their physical and cognitive health. This is not surprising, because the presence of family members not only improves the quality of life of residents in LTC (Leveré et al., 2021; Stall et al., 2020; Tupper et al., 2020) but also supports the role of staff (Bouchoucha & Bloomer, 2021). Based on our comparison of phase I and phase II results, our study clearly illustrates the positive influence of families' continued presence in LTCFs on multiple aspects of older adults' health and that they are essential members of the care team. Length of time between visiting, or lack of visiting, seems to be an important factor in older adults' well-being as well as family members' mental health.

Lastly, combined with workforce issues and social isolation, visitor restrictions were a source of concern. Visits, both virtual and in person, were difficult to schedule and were time limited. But, of deeper concern is the failure of the LTC system to recognize that family members are not visitors. The rapidity with which restrictions were implemented showed the fragility of patient-centred policies and practice in LTCFs (Canadian Foundation for Healthcare Improvement, 2020; Fancott et al., 2021). Families are care partners along with the staff in LTCFs (Bouchoucha & Bloomer, 2021; Gwyther, 2001; Meisner et al., 2020; Tupper et al., 2020) and unpaid carers are essential to supporting residents (Government of the United Kingdom, 2021). Although the designated support person role was introduced, to visit indoors, family members had to agree to provide care which could include bathing and other personal care for which they have not received training or did not feel comfortable providing to their relative. More flexible policies with fewer restrictions would have benefited both the family members and the LTCF residents (Stall et al., 2020; Tupper et al., 2020). More so, evidence is lacking on the benefits of visitor restrictions, as it is believed that it is more harmful than good in certain settings (Munshi, Evans, & Razak, 2021; Stall et al., 2020).

Limitations and Future Directions

One possible limitation of this study includes the recruitment of family members who were possibly the most vocal and wanted to voice their experiences. The fluidity of the pandemic also presented

challenges in keeping updated with public health directives and how these would impact participants' experiences. For the purpose of capturing the full experience of visitor restrictions in LTCFs, future research should include residents as well as the staff of LTCFs. In fact, we know very little about social isolation in LTC, but factors such as those seen in this study, such as communication barriers, cognitive impairment, disconnect from existing social connections, staff shortages, and structural factors of the LTCFs have all been found to contribute to residents' social isolation in LTC (Boamah, Weldrick, Lee, & Taylor, 2021). What has happened in the LTC space since the beginning of the pandemic requires immediate policy review so that families are never isolated from each other again for such a long period of time. Safe visitation protocols should have been activated, educating family members on infection control protocols, and empowering them to report their symptoms accurately and honestly (Bouchoucha & Bloomer, 2021; Fancott et al., 2021; Munshi et al., 2021).

Conclusion

This study provides a difficult glimpse into the experiences of families with a relative residing in LTCFs in New Brunswick. The study identified five key drivers to families' experiences along with three manifestations of which mental health will likely have lingering effects. Given the findings of this study with family members, residents and staff in LTCFs likely have distinct experiences as a result of visitor restrictions that would be interesting to study. It is hoped that findings from this study will support LTC policy review. Would we have accepted the experience described by participants in this study if it were children instead of older adults? Reform of LTC is overdue!

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