



The Golden Ticket: Gaining In-Person Access to Relatives in Long-Term Care Homes During the COVID-19 Pandemic

RESEARCH

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ABSTRACT

Context: Governments made emergency declarations to restrict the presence of family carers in long-term care homes (LTCHs) as part of infection control measures during the pandemic. Within Canada, two visitor statuses were created: ‘essential’ to the health of the resident and ‘non-essential’ or ‘social visitor’, who were subject to additional restrictions.

Objective: This study explored family carers’ experiences navigating in-person access to their relatives in LTCH during the pandemic.

Methods: Using interpretive description, a sample of 14 family carers (nine daughters, five spouses) living in British Columbia, Canada, participated in in-depth interviews via video call about their experiences between March 2020 and June 2021.

Findings: Analyses illustrated variability in carers’ visitor status across families and over time. Two key themes were identified: 1) “Fighting a Losing Battle” describes how reductionist attitudes and policies minimized the role of caregiving and resulted in traumatic disruptions in familial relationships; 2) “Who’s In and Who’s Out” captures inequities in how visitor status policies were applied.

Limitations: Restrictions on conducting research during the pandemic resulted in a smaller sample of family carer participants.

Implications: Findings highlight the patchwork implementation of visitor policies over the initial 17 months of the pandemic and the precarious space family carers continue to occupy within the LTC sector. Future research should focus on formalising support for family presence during public health emergencies.

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BACKGROUND

In March 2020, the SARS-CoV-2 virus (hereafter referred to as COVID-19) was declared a global pandemic by the World Health Organization (2020). Its onset was marked by emergency declarations from governing institutions, allowing officials to undertake actions unavailable to them during non-emergencies and temporarily waive or suspend certain rules or regulations (Tabari et al., 2020). At the start of this unprecedented event, declaring states of active emergency enabled governments to enact lockdown and stay-at-home orders, mask mandates and other restrictions on organisations and individuals in an effort to combat viral transmission (Onyeaka et al., 2021). Internationally, visitation restrictions were executed in congregate residential senior care settings (i.e., assisted living, long-term care homes (LTCHs), retirement communities) to curb the spread of COVID-19 and protect the lives of residents, staff, and families (Daly et al., 2022; Dunning et al., 2020; McMichael et al., 2020).

LTCHs in Canada provide accommodation, 24-hour support with daily activities, and on-site care services for individuals with complex needs who are unable to reside at home or within supportive housing (Government of Canada, 2004). Canada's LTC sector is governed by both provincial and territorial legislation, though homes vary in services provided and manner of administration (Canadian Institute for Health Information, 2021). In addition, LTCHs may fall into not-for-profit, private, and public ownership models, though all service providers receive some public funding for resident care (Daly, 2015). Similar to other countries (e.g., Spain, U.S.), the decentralised nature of Canada's LTC sector and its policies that promoted or restricted meaningful family inclusion varied considerably across jurisdictions, which had serious implications for the essential contributions of families within these care spaces (Grinspun et al., 2023; Keefe et al., 2022). Family carers (including non-biological relations) of people living with serious illness and/or disability play a critical role in supporting their well-being (Williams et al., 2012; Wu & Lu, 2017). Within the LTC context, family caregiving is multifaceted and can include hands-on care, advocacy work, emotional support, identity maintenance, and facilitating opportunities for socialisation with family and friends (Gaugler, 2005; Puurveen et al., 2018; Whitaker, 2009).

The initial policies at the start of the pandemic were guided by recommendations from the Public Health Agency of Canada to restrict visitors and volunteers to "only those essential for basic personal, medical or compassionate resident care" (Public Health Agency of Canada, 2020). Inconsistency and ambiguity in visitation policies were echoed in other nations, including Australia, Austria, France, Germany, Iceland, Ireland, Italy and Slovenia, which did not have specific emergency response guidelines for LTC prior to 2020 (Organization for Economic

Co-operation and Development, 2021) and enacted blanket bans on visitors in homes early in the pandemic (Verbeek et al., 2020). These early policies have been criticised as overly restrictive; family carers of residents in LTCHs were largely classified as social, non-essential visitors, and criteria to determine eligibility for *essential* status were ill-defined and disparately applied (Stall et al., 2020; Yeh et al., 2020). When visiting was permitted to resume, the onus was generally placed on LTCH administrators to ensure safe re-opening and enforce visitation restrictions; significant cross-and-within-country variation in visitation requirements occurred (Low et al., 2021). In some regions, early visitor policies defined all visits as non-essential given the unpaid nature of family caregiving (e.g., Australian Federal and State policies) (Low et al., 2021), while others determined eligibility based on carer's assistance with residents' activities of daily living or compassionate care (e.g., U.S. and U.K. policies) (Department of Health & Human Services, 2020; Department of Health and Social Care, 2022). These visiting restrictions in LTCHs resulted in diminished hours of direct care, social isolation, and reduced well-being among residents and families (Backhaus et al., 2021; Chu et al., 2020; Thirsk et al., 2022; Van der Roest et al., 2020).

Limited opportunities among families to care for their relatives during this period have had serious ramifications for residents' quality of care, health outcomes, and the well-being of their family networks (Cooke et al., 2022; Saad et al., 2022). Family carers may gain physical and psychological benefits through providing help, including enhanced positive self-views, feelings of fulfilment, and the development of new skills (Lloyd et al., 2016; Zarit, 2012). Caregiving is a mechanism for the expression of intimacy and love (Hayes et al., 2009) and the maintenance of continuity with one's personal values, identity and relationships with care recipients whose health is declining (Åberg et al., 2004; Jo et al., 2007). Transitions into LTCHs can provoke feelings of grief and guilt among families (Barken & Lowndes, 2018), which may be exacerbated by having little control over the frequency of contact with their relative and the quality of care they receive, as occurred with visitation restrictions during the pandemic (Cooke et al., 2022).

Important global contributions have been made capturing the experiences of LTCH residents and family carers during the pandemic, particularly around how families have historically been positioned within these care contexts (e.g., Kemp, 2021). However, considerable gaps remain in our understanding of the variations of these caregiving experiences over time and across families as they navigated changing policies and processes to gain in-person visitation designations. Thus, the purpose of this study was to explore the experiences of carers navigating public health policies related to in-person access to their relatives living in LTCHs during the pandemic.

METHODS

This study applied Thorne's (2016) interpretive description, which is grounded in naturalistic and constructivist worldviews and aims to generate knowledge that is applicable to applied health disciplines and clinical contexts. Using this approach, the researcher works to create a rich description of a phenomenon to identify associations, themes, patterns and differences among subjective perspectives, with the goal of triggering action related to practice (Hunt, 2009; Teodoro et al., 2018). In this study, this meant moving beyond the simple description of participants' accounts to explore the meanings of the lived experiences of family members navigating public health policies related to visitation throughout the first year of the pandemic.

SETTING

British Columbia (BC), Canada's westernmost province, was the setting. The first case of COVID-19 was identified in late January 2020, followed by a provincial state of emergency starting March 18, 2020 (Office of the Seniors Advocate, 2020). As of March 20th, public health orders closed all LTCHs to visitors. In July 2020, these restrictions were amended to allow two categories of visitors that would remain in place until April 2021 (Mackenzie, 2022): a single essential visitor who could provide hands-on care (e.g., eating assistance, personal care/grooming, ambulation/exercise) was permitted to visit more frequently and for longer periods of time; and a single designated 'social' visitor was permitted for social visits once per week for 30 minutes or less in a designated visiting area while masked and remaining six feet apart under staff observation. The LTCH's operator made the decision as to whether a family member met the threshold for 'essential' status (e.g., critical illness, end-

of-life care, visits paramount to the resident's physical/mental well-being), and if not, would be categorised as 'social' visitor (Mackenzie, 2022).

RECRUITMENT AND PARTICIPANTS

A convenience sample (N = 14) was recruited using social media advertisements (e.g., Facebook, Twitter). Potential participants were screened by HAC and included if they met the criteria: a) carer providing support to an older adult living in a LTCH in BC prior to, and during, the COVID-19 pandemic (i.e., since January 2020), and b) fluent in English. Written informed consent was obtained, after which participants were contacted by email to schedule an interview time.

DATA COLLECTION AND ANALYSIS

Data collection and analysis occurred concurrently, as is the process of interpretive description (Thorne, 2016). Fourteen semi-structured interviews were conducted between May and July 2021. Due to university research restrictions on in-person data collection at the time, HAC conducted 12 interviews over video call (i.e., Zoom); two participants were interviewed by phone per their expressed preference. Interview questions focused on the process of obtaining visitor status, the nature of visits during the pandemic, changes experienced due to pandemic visiting protocols and multi-level contextual factors that impacted the ability to provide care (see Table 1 for sample interview questions). Demographic data were also collected.

Interviews ranged in length from 68 to 117 minutes (mean = 89 minutes). All interviews were digitally recorded and transcribed verbatim. Participants' body language and reactions were noted in field jottings and then expanded into more detailed notes to contextualise participants' narratives during analysis (Silverman,

ITEM	INTERVIEW QUESTION
1	We know very little about what it's like to be a family care partner during a pandemic. Can you tell me what it's been like to be the care partner/family member of someone living in a long-term care home during the pandemic?
2	Do you have essential visitor status? If so, for how long have you had it? Can you walk me through the process of obtaining essential visitor status?
3	What changed for you as a care partner during the pandemic?
4	What changed for your relative living in a long-term care home during the pandemic?
5	What stayed the same for you as a care partner during the pandemic?
6	What stayed the same for your relative living in a long-term care home during the pandemic?
7	What have been the most difficult aspect(s) for you as a care partner during the pandemic? Why?
8	What aspect(s) have made things easier for you as a care partner during the pandemic?
9	What would you have liked the people working in the long-term care home to do during the pandemic to support you as a care partner?
10	What would you have liked the government to do during the pandemic to better support you as a care partner?
11	If there was one thing you would like people to know about being a care partner during a pandemic, what would it be?

Table 1 Sample Interview Guide Questions.

2015). Field notes were also used as a reflexive diary to process emerging patterns and researcher responses to data (Teodoro et al., 2018). Data collection stopped when no new patterns were noted that would warrant additional interviews. Transcripts were de-identified, and participants were assigned codes. Participants' experiences attempting to gain in-person access to their relatives were captured in an Excel file and analysed for patterns and differences across time.

Data analysis was iterative and applied an inductive process to identify patterns or "conceptual links" to generate a commonly understood reality of a phenomenon (Teodoro et al., 2018; Thorne, 2016). Transcripts and field notes were entered into the qualitative software programme NVivo12 to support analysis. Each interview recording and transcript was listened to/watched by authors HAC and SAW, and transcripts and field notes were read several times as a process of on-going reflexivity: "What is going on here?", "What might this mean?", "What am I learning about this?" and "How else might I understand this aspect of the data?" (Thorne et al., 2004; Thorne, 2016). Concept mapping was used to describe the relationship between codes, categories and broader themes. In doing so, the researchers engaged in broadening rather than tapering conceptual linkages to develop a coherent, rich interpretation that challenged *a priori* assumptions (Thorne et al., 2004). Biweekly team meetings facilitated the examination and constant comparison of patterns between participants and the extraction of exemplars that best reflected specific aspects of family carers' experiences. Data collection concluded by assessing the sufficiency of information power within the dataset and whether the data were relevant and rich enough to provide meaningful insights to inform practice (Malterud et al., 2016).

Credibility was enhanced through documentation of the analytic process through an analytic log, the use of thick descriptions and verbatim accounts from study participants (Thorne, 2016). The research team members also engaged in reflexivity on their own positionality within this study. Underpinned by a constructivist worldview and intersectional lens, research team members approached this study from 'outsider' perspectives as they worked to gain a deeper understanding of the multiple realities of family carers' experiences. Co-authors LK, HAC, GP, AB and JB are of European decent, and first author, SAW, is a racialized minority scholar, which likely influenced the interpretation of varying levels of access garnered by family carers depending on their social location, in particular ethnoracial backgrounds, gender and socioeconomic status. HAC, who has a deep knowledge of conducting qualitative interviews, incorporated reflexive accounts via memos that examined the power imbalances produced through the different social

positions held between her and the research participants. Authors SAW, LK (PhD Candidate), HAC and GP are PhD-prepared social gerontologists with experience conducting LTC research with staff, residents and family carers (e.g., Cooke et al., 2022; Puurveen et al., 2018). Authors JB and AB are PhD-prepared nursing faculty who have extensive experience conducting research in LTCHs as well as the impact of COVID-19 on older adults and their family carers (e.g., Baumbusch et al., 2022; Bourbonnais et al., 2023). Previous intersectional research examining the nature and gendered aspects of family caregiving within LTC contexts prompted the current investigation. To reinforce the shared truth claims reported in our findings, we demonstrated interpretive authority through the presentation of methods, transparency of participant recruitment and data collection processes and analysis (Thorne, 2016). Investigator triangulation during data analysis (HAC and SAW) and interpretation (all authors) helped to reduce bias and assumptions and enhance the internal validity and reliability of our study findings (Thurmond, 2001).

FINDINGS

Fourteen carers participated in the study (n = 13 women, n = 1 man), nine of whom were daughters and five were spouses. Three participants were carers to more than one relative living in LTCHs. Our sample was relatively affluent and well-educated: all participants had completed college or obtained a university degree; six were retired, five were employed full-time, two worked part-time and one was between employment. Seven participants had a 2020 household gross income of or over \$81,000. All but one participant (East Asian) was of European decent. Participants' ages ranged between 38 and 87 years (mean 64.2 years) (see Table 2).

Participants' navigation of the process to obtain essential or designated visitor status was highly variable. Only one participant carer (P04) and a participant's relative (P10's mother) were granted essential visitor status at the outset of the pandemic in March 2020 and maintained that status until the end of data collection in June 2021. One participant obtained designated visitor status almost one year after the start of the pandemic (P02). The other 11 participants experienced between two and four essential visitor status changes between March 2020 and June 2021. Variations in essential visitor status among participants were often ascribed to their relative's oscillation between fair and very poor physical health. No participants were granted essential visitor status due to concerns for the residents' emotional well-being or cognitive health. Table 3 provides an overview of participants obtaining visitor status for their relative in LTC over the course of data collection.

DESCRIPTIVE CHARACTERISTICS	n	%
Family Caregiver Participants (N = 14)		
Age (years)		
Mean	64.2	-
Range	38-87	-
Gender		
Female	13	93.0
Male	1	7.0
Relation to resident		
Spousea	5	35.7
Daughter	9	64.3
Marital status		
Married/Common-law partner	11	79.0
Separated/Divorced	1	7.0
Widowed	1	7.0
Single	1	7.0
Highest level of education attained		
High school	0	0.0
College	3	21.5
University - Undergraduate	3	21.5
University - Graduate	8	57.0
Employment outside the home		
Full-time	5	35.7
Part-time	2	14.3
Retired	6	42.9
Other	1	7.0
Ethnic origin		
European	13	93.0
East Asian	1	7.0
Household gross income in 2020b		
<=\$40,000	0	0.0
\$41,000-\$60,000	2	14.3
\$61,000-\$80,000	1	7.0
\$81,000-\$100,000	2	14.3
\$101,000-\$150,000	1	7.0
>\$151,000	4	28.6
Resident Characteristics (n = 17)c		
Age (years)		
Mean	83.1	-
Range	66-97	-
Gender		
Female	7	41.2
Male	10	58.8
Primary language spoken		
English	15	88.2
Other (Taiwanese, German)	2	11.8
Primary health challenge		
Cognitive impairment (i.e., dementia)	15	88.2
Physical impairment (no dementia)	2	11.8

Table 2 Participant Demographics.

a = One family caregiver participant had both their husband and mother in long-term care homes; however, this participant was only counted once as a caregiving daughter.

b = Missing data (n = 4).

c = Three of the 14 family caregiver participants each had two relatives living in long-term care (residents n = 17).

	2020										2021					
	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	JAN	FEB	MAR	APR	MAY	JUN
P01										EV ^a	EV ^a	EV ^a	EV ^a	EV ^a	EV ^a	EV ^a
P02													SV	SV	SV	SV
P03					EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV
P04			EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV
P05											EV	EV	EV	EV	EV	EV
P06			EV/R	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV
P07					EV ^b			EV ^c	EV ^c	EV ^c	EV ^c	EV ^c	EV ^c	EV ^c	EV ^c	EV ^c
P08											EV	EV	EV	EV	EV	EV
P09																EV ^d
P10				EV ^d	EV ^d	EV ^d	EV ^d	EV ^d	EV ^d	EV ^d	EV ^d	EV ^d	EV ^d	EV ^d	EV ^d	EV ^d
P11												EV	EV	EV	EV	EV
P12					EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV	EV
P13							EV	EV	EV	R	EV	EV	EV	EV	EV	EV
P14				EV	EV	EV	EV	EV	R	EV	EV	EV	EV	EV	EV	EV

Table 3 Timeline of participants obtaining visitor status for relative in long-term care home between March 2020 and June 2021.

Legend

- EV = participant obtains essential visitor status.
- SV = participant obtains designated ‘social’ visitor status.
- R = participant essential visitor status revoked.
- a = participant obtains status, in addition to adult son and adult daughter.
- b = participant obtains status for father; father dies shortly thereafter.
- c = participant obtains status for mother.
- d = other family caregiver (i.e., not participant) granted essential visitor status.

Two themes underpinned participants’ experiences of gaining in-person access to their relatives in LTCHs during the pandemic. The first theme, “Fighting a Losing Battle,” demonstrates how reductionist attitudes and policies towards carers minimised the role and resulted in traumatic disruptions in family relationships. The second theme, “Who’s In and Who’s Out,” highlights the inequities that existed both within the visitor status policies created by public health officials as well as the inconsistent application of those policies by LTCH operators.

FIGHTING A LOSING BATTLE

Participants expressed confusion and exasperation over the complexity of obtaining visitation status from LTCHs to gain in-person access to their relatives. Biomedical underpinnings entrenched in Canada’s LTC system were exposed by the reductionist approach used to assess the residents’ health and rationalise granting or denying essential visitor status. This had significant ramifications for the well-being of residents and families.

Participants described their frustration with the restrictive approach used to monitor and assess

residents’ health and well-being throughout the pandemic. Residents were eligible for an essential visitor if care support for their activities of daily living was beyond staff’s capacities.

Residents’ emotional and mental well-being were not part of this assessment. This meant that if residents had significant emotional needs, their carers would not be eligible for essential visitor status. Such constrained definitions of (inter)dependence also implied that the specialised care provided by carers was interchangeable with staff. P06 (62-year-old wife) obtained essential visitor status for her husband only to have it rescinded three weeks later, on the grounds that her husband was physically stable.

I just want to maintain essential. And I want the role of an essential visitor to be more clearly defined. I think everybody needs at least one, if not two, because it really is a hard task to fall to one person. Somebody who can come in and help, somebody who can be there for them, a familiar face so it’s not just us. Care staff are not family. They’re wonderful, they do a great job, they work their tails off, absolutely, but they’re not family. And family was completely negated. (P06)

Here P06 draws the clear distinction between staff and the unique care provided by families. This rationale for granting or revoking essential visitor status poses a risk to those residents whose improvements can be attributed to family care (e.g., weight gain supported by family eating assistance) and whose health may become subsequently compromised after family access is restricted.

The experience of seeing their relatives decompensating (e.g., significant weight loss, increased confusion) via video calls and window visits while being denied physical access to the LTCH was incredibly distressing. Family members were desperate to provide care and support but were unable to do so until their relative's health had deteriorated to a critical level. P05 (60-year-old daughter) explained that she was finally able to obtain essential visitor status after being rejected multiple times over a 10-month period.

The difficulty for me was not being allowed in until my father was either palliative or showed significant decline. And we all felt this way... what a reactive shameful statement to make that someone has to decline beyond certain conditions before you bring in the care that's there chomping at the bit. (P05)

A point of contention for many carers was the confusing and contradictory nature of the essential visitor definition, which explicitly included "visits paramount to the resident's physical care *and mental well-being*" (italics added by author; [Public Health Physicians of Canada, 2020](#)). Yet, for residents who did not present with distress and/or physical deterioration based on the LTCH operator's interpretation of the Ministry's criteria, there was little hope that a family member would be granted essential visitor status. All participants emphasised the reactive nature of pandemic policies set out by B.C.'s public health office and how poorly they served residents and families. Eleven months after the onset of the pandemic, P07 (47-year-old daughter) was able to obtain essential visitor status after undertaking considerable advocacy efforts.

I basically demanded to be given access to my mother through essential visit. And I said, "I understand that she doesn't qualify. And I don't care. I don't care that she doesn't qualify. I have some serious concerns about what's going on... Even your own [depression scale] scores indicate that she's deteriorating. She's lost her husband, she's been locked up in your facility for God knows how long, she's been cut off from her family, I want in through the emotional support clause – whatever that is. That's what I want." (P07)

Participants described a network of family and friends who supported their relative's support needs pre-

pandemic, including physical care and socialization. Yet, visitation guidelines stipulated that only one person per family could hold essential visitor status; the care once provided by several people was now the responsibility of a sole family member. This responsibility weighed heavily on essential visitors: "I am the single point person. The responsibility...the burden. It's so not good to say burden because it's my mother but it's a big responsibility. It's huge." (P03, 66-year-old daughter). Participants acknowledged either the need to offload the caregiving to others or the compassion they had for others who were forced to take on this role.

They had to choose which one came in. And you know it's such a burden to see the husbands in there, the wife who's in her 80's or 90's having to come in and toe the line and be the only allowed person in there, and either getting heart issues or anxiety issues or stress issues or just fatigue issues by being the only one allowed in. And the daughter and the son are like, a knock on the door, you know. I'm that person too. Why can't I be there as well? (P05)

Truncating a caregiving network to a single person also had implications for the identity work normally reinforced by the many kinship roles a resident plays within their family, such as spouse, parent, sibling, grandparent, friend or companion. Limiting essential status to a single person forced residents and families to prioritise which relationships would be reinforced and which would potentially be compromised due to limited communication and to make value judgements as to which family member was more 'essential'; this devalued others' roles within their family and friend network.

WHO'S IN AND WHO'S OUT

While many participants expressed similar frustrations in gaining in-person access to their relatives during the pandemic, experiential variation reflected the influence of social locations and power dynamics among family members, staff, and administrators. Regardless of whether they were granted essential visitor status, every participant reflected on the privileges and inequities surfacing through the designation process.

Information sharing among families via online platforms (e.g., Facebook groups) revealed significant inconsistencies in the interpretation of visitor guidelines across LTCHs. The changing public health orders and contradictory ways in which in-person access was permitted both between regional health authorities and within LTCHs, along with poor communication to carers, left participants feeling desperate, helpless and mistrustful of those in leadership positions. As P13

(64-year-old daughter) recounts, “We were powerless. But they make us powerless because they don’t want us in there.” Inconsistencies in how and when essential visitor status was granted were posited as an aspect of ‘power games’ between specific families and administrative gatekeepers.

Not everyone went through the same person and even through that same person, it depended what side of the fence you sat on with [the administrator]. She said I was either favourable or not favourable in her granting the pass, the golden ticket of the essential visitor... (P14, 49-year-old daughter)

In addition to power relations, participants noted how their social locations (e.g., gender, class, race) shaped their experiences of obtaining in-person access to their relatives. For example, P04 (78-year-old husband), the only male carer in our study, said staff at the private, for-profit LTCH where his wife lived assumed he was behaving himself by following precautions both within the LTCH and in his personal life during the pandemic. As a result of these assumptions and traditionally privileged social locations (European descent, cisgender-identifying man, highly educated) occupied by P04, he had comparatively unfettered access to his wife almost immediately after the initial restrictions introduced in March 2020. The situation was similar for P01, an 84-year-old wife; both she and her two adult children were granted essential visitor status by her husband’s for-profit home, where he lived as a private-pay resident. Further, P01’s two grandchildren were given designated visitor status: “We bring different people. So that there’s some change for [husband]. I mean it’s quite boring to see the same person every day.” In contrast, P02, whose father lived in an owned-and-operated home, made the astute observation: “... if you were in private system, it seems to me that you can get those visitation designations a lot easier...”. P14 described other ways in which some families were ‘in’ and others were kept ‘out’ during the initial months of the pandemic. This included the rationale to deny essential visitor status to families of residents with cognitive impairment, claiming that “[residents living with dementia] can’t tell the difference if a family member’s there or not.”

Other participants felt that their concerns about the rights of residents were largely undermined by the government’s pandemic response: “And that was clear from September [2020] on that the measures taken were more drastic and were causing more damage than the threat of COVID” (P14). Residents’ lack of autonomy and a general disregard for their mental health due to mandated restrictions were likened to those of prisoners of war who endured torture by being locked in their rooms with little to no contact with staff or families.

In response to being kept out of LTCHs, several participants described their shift into advocacy: “I don’t think I realized how hard I could fight” (P06). When asked what changed for participants as a carer over the pandemic, P03 (66-year-old daughter) explained how her experiences altered the way she viewed herself as not only advocating for the rights of her own relatives in care, but also supporting other families in the process.

...because I was an essential visitor, it had changed me where I knew there were so many people out there in [relative’s long-term care home], residents that didn’t have anyone that could be their eyes or their ears inside. I wasn’t spying, wasn’t trying... I just wanted others...to have what I had. So it changed me in that I became more of an advocate...advocate for residents in long-term care homes. And how I became so strong with my insistence and fighting for it.

Participants explained the lengths they went to support other disenfranchised families by providing status updates on the well-being of residents and advising on strategies to obtain essential visitor status. Speaking to the media and forming advocacy groups were approaches participants felt would be effective in bringing attention to the reductionist elements of the pandemic policies. Unfortunately, these efforts were often met with condemnation by LTCH operators who tried to quash organising efforts amongst families. P14, a strong advocate for residents’ rights, went to great lengths to support other families and residents who were struggling to maintain connections with one another.

We organized an advocacy group and we were told they will not recognize us as a Family Council even though we went through everything... The only way I was able to build our group was through word of mouth. (P14)

DISCUSSION

Our study provides unique insights into the complex and deeply harmful processes carers navigated as they attempted to gain in-person access to their relatives living in LTCHs over the course of the pandemic. While initial responses by governments and public health officials were intended to manage these anomalous circumstances, ultimately the continued enactment of the reductionist visitation policies gave way to concerning disparities in familial in-person access tied to individual social locations, institutional factors (e.g., LTCH ownership) and power dynamics. Research examining carers’ experiences during this period to date has relayed consistent messages of family trauma, resident cognitive

and physical deconditioning, inconsistent application of visitation policies, and a general failure to recognise families as integral members of LTCH communities (Hartigan et al., 2021; Kemp, 2021). This study further expands on this work by illuminating the inconsistent and, at times, contradictory nature of the visitation policies that families were compelled to navigate.

Central to ethical public health policy development is the harm principle, which in certain circumstances may warrant governments to limit certain individual freedoms as a means of protecting communities from harm. In this case, it meant implementing visitor restrictions to reduce viral transmission in LTCHs (Chase, 2020). The immediate public health response to a poorly understood viral threat generated a standardised approach, one the public conceded was necessary to prioritise residents' safety (Frank, 2021; Nash et al., 2021). Yet, as described by participants, this same rationale continued to be used even after evidence demonstrated that family presence posed little risk to residents and staff. Findings from recent research indicate limited empirical evidence to suggest that visiting restrictions prevented transmission of the virus (Sims et al., 2022), while the re-introduction of family carers into LTC homes yielded positive emotional impacts for both residents and staff (Verbeek et al., 2020). Similarly, less than one percent of outbreaks in LTCHs in BC, Canada, during the first and second waves were attributed to a visitor (Office of the Seniors Advocate, 2021). In their study exploring the trauma experienced by family members being locked out of LTCHs in Ontario, Canada, Chu and colleagues (2022) report that carers believed administrators prevented access to their relatives to avoid poor residential conditions being reported to the media and authorities. Unsurprisingly, recent evidence identifies the iatrogenic outcomes that resulted from such decision-making: residents who had no personal contact with family or friends experienced a 35 percent greater excess mortality compared to those who had access to their network of care (Savage et al., 2022). The 'us-versus-them' sentiment between families and administrators described in Chu et al., (2022) parallels the experiences of our participants, whereby the threat of the COVID-19 virus was conflated with the potential risk of caregiving within LTCHs by public policymakers and LTCH operators.

The reductionist tensions and inequities in families gaining in-person access reported here reflect the historical friction that persists between biomedical and social models of care within LTC systems, standpoints that have important implications for those receiving care and those providing care (Armstrong, 2018; Banerjee & Armstrong, 2015; Barken & Armstrong, 2019). This friction, exacerbated by the pandemic, reconfigured what was deemed a priority (task-focused efficiency) and what was relegated from the foreground, namely the socio-emotional well-being of residents and families, and resulted in stressful and, at times, traumatising working

conditions for LTC staff (Palacios-Ceña et al., 2021). This reprioritisation has further undermined the already precarious position that family involvement occupies within these care spaces (Baumbusch & Phinney, 2014; Puurveen et al., 2018; Robinson, 2016).

Despite their integral contribution to the capacity of formal care systems, family carers report experiences of being devalued, dismissed, unheard and unsupported (Groenvynck et al., 2022). Social models of care, many of which include a palliative approach, have emerged, positioning residents and family members at the 'centre' of the care team; however, their implementation has garnered little sustained success (Dellenborg et al., 2019). These barriers may be promoted by formal care providers' beliefs that family carers lack sufficient expertise to contribute meaningfully to resident care and that familial preferences cannot be prioritised given constrained staff time and resources (Bell, 2013; MacKean et al., 2005). Yet, within fragmented health care systems, family carers are commonly the most familiar with residents' health history and illness trajectory and well-positioned to be key partners in care and supplement staff (Levine et al., 2010). The policies crafted by public health officials during the pandemic reinforced the family-as-visitor narrative and deepened the schism between families and the LTC system (Avidor & Ayalon, 2022; Kemp, 2021).

Whilst our study's aim was to understand visitation policies from the perspectives of families, it must be acknowledged that healthcare professionals were also faced with the dilemma of protecting vulnerable resident populations within rapidly evolving and highly stressful working conditions during this period. Reports of insufficient access to personal protective equipment (McGarry et al., 2020), high staff turnover (Frogner et al., 2022), fear of contracting the virus (Hung et al., 2022) and managing burnout while balancing resident safety and quality of life, particularly end-of-life care (Peter et al., 2023), exacerbated an already strained LTC system (Estabrooks et al., 2020). Similar to family carer experiences reported in our study, LTC staff were also tasked with navigating frequently changing and sometimes contradictory guidance from multiple government and public health bodies (White et al., 2021). The long-term impact of the pandemic on this workforce will likely result in further staff turnover and shortages, making it critical that all stakeholders, including staff, residents and family members, are included in policy reforms related to pandemic preparedness and other emergency situations (Boettcher et al., 2023).

Feelings of powerlessness and the erosion of trust were recurrently expressed by participants. Our findings bring to the forefront the understanding that trust is relational and constructed through interactions (Calnan et al., 2006). As the pandemic progressed, participants recounted their growing disenchantment and loss of trust as poor communication and variation in who did and did not receive essential visitor status exacerbated

existing tensions. While our study did not investigate the experiences of LTCH administrators, findings from Savage et al. (2022) indicate the awareness of LTCH leaders that inconsistent messaging and restrictive policies during this period compromised longstanding, trusting relationships with families. Ensuring that LTC staff and health care providers have the training and resources to support the repositioning of families as valued members of palliative care teams will be important and has been identified as an area for further investigation (Bolt et al., 2019). In addition, more research is needed to understand the relationship between public health policy, institutional trust and the social context of families and residents in LTCHs during pandemics and other similar situations, such as influenza outbreaks. The creation of visitor policies also reinforces the informal, liminal role of families in LTCH settings. These policies were developed and adopted without consultation with residents or families (Frank, 2021), reflecting both the epistemic privilege of political institutions and the long-standing management of LTC as analogous to that of acute care settings (i.e., LTC is a 'home' vs. hospital is temporary) (Chase, 2020; Saad et al., 2022).

Our findings provide important implications for policy and practice, with the objective of acknowledging families as central to the care and well-being of residents. Steps to achieve this goal include: 1) positioning families as central to the care team; 2) creating formalised and accessible processes for families to voice their needs and concerns (e.g., family councils); 3) developing education and training for staff and administrators to support meaningful family involvement and 4) implementing policies to undergird and guide family-inclusive practices. Certain organisational processes of responsibility are necessary to achieve these steps, including the avoidance of authoritative approaches and placing greater emphasis on the relationships between reciprocal trust and accountability between residents, families and staff (Robinson, 2016). Schwartz (2009) offers an 'agent-centred model' to policy development, focusing on the repair of relationships and decision-making dynamics in situations featuring potential distrust among those who are disadvantaged or vulnerable. In this model, those traditionally deemed experts are in equal partnership and are "one source of knowledge among many" so that unilateral decision-making is avoided. Policies are negotiated, and responsibilities are shared among stakeholders (Schwartz, 2009). An agent-centred approach towards public health policy reinforces the idea that "trusting another requires the belief that goals and values of the one we trust are similar to our own" (Schwartz, 2009, p.122). The traumatic effects of visitation policies enforced by public health officials have resulted in shattered trust between families, residents and home staff and administrators. Concerted efforts need to be made to regain trust relationship by relationship (Robinson, 2016). Based on the findings of our study, along with those of other studies, we suggest

that an agent-centred model guide decision-making processes in LTCHs in the event of and beyond future public health crises resulting in visitation restrictions.

LIMITATIONS

Although this study provides novel insights into the experiences of carers as they navigated visitation policies during the pandemic, there are limitations that should be considered. First, given the challenges associated with conducting research during the pandemic, a convenience sample was recruited via social media. This resulted in a participant sample whose experiences as carers may differ from those who interact less with social media. Second, although our participant sample reflects the gendered nature of caregiving for a relative in LTC (i.e., the majority are women), men's perspectives were limited in our study. Lastly, participants were relatively well-educated, affluent and English-speaking, with only one participant who identified as an ethnocultural minority. Limitations related to recruitment and sample diversity are common in qualitative studies examining family carers' experiences in the early phases of the pandemic (Chirico et al., 2022; Chu et al., 2022; Dupuis-Blanchard et al., 2021). Given the disparity in COVID-19-related deaths that were identified between white, Black and Latinx nursing home residents in the US (e.g., Garcia et al., 2021), it is critical that future LTC research include strategies to ensure diversity in participant groups (e.g., translating recruitment material, translation services) so as to capture the intersectional nature of varying social locations of carer experiences. In addition, research is needed to examine how pandemic public health directives were interpreted and enacted based on the LTCH ownership model to help identify and address organisational and systemic processes that perpetuated inequities in families accessing relatives in care.

CONCLUSION

Our findings provide novel and unique insights into the experiences of carers during the first 17 months of the pandemic and point to future directions for research, policy, and practice. Inconsistencies and inequities in gaining in-person access to relatives point to the dissonance between public health policies and their application in practice. Using an agent-centred model for the development of such policies could help address many of the issues we raise here and mitigate the negative outcomes experienced by residents and carers. Further, consistent with pre-pandemic research, there continues to be a need to formalise family presence in LTC to ensure that the restrictions that occurred during COVID-19 are not repeated in future public health emergencies.

ETHICS AND CONSENT

Ethics approval was obtained from the University of British Columbia Research Ethics Board (H21-00176). All participants provided written informed consent.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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