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Caregivers' Experiences of Nursing Home Restrictions During the COVID-19 Pandemic‡

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Article

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‡The article has been updated since original publication. A notice detailing the change has also been published.

Abstract

Pandemic-related restrictions in nursing homes have undermined the critical role that family and friend caregivers play in enhancing resident quality of life. We examined how family caregiver access restrictions in nursing homes were implemented and how they impacted the mutual well-being of and relationships between residents and their caregivers over time. Between March 2021 and March 2022, 24 'designated caregivers' in Atlantic Canada were interviewed three times. We identified changes in family relationships and activities over time, constricted support networks, the increasing need for advocacy and monitoring, and the generally negative cumulative impacts of restrictions, especially during residents' end-of-life. Subsequent adaptations to access restrictions allowed caregivers to contribute to essential monitoring, care relationships, and advocacy roles. We argue that the role of designated caregivers in nursing homes must be maintained during public health emergencies to ensure resident's supportive family relationships and general well-being.

Résumé

Les restrictions liées à la pandémie mises en œuvre dans les centres d'hébergement et de soins de longue durée (CHSLD) ont affaibli le rôle essentiel des amis et membres de la famille proches aidants dans l'amélioration de la qualité de vie des résidents. Nous avons examiné comment les restrictions d'accès à ces établissements visant les proches aidants familiaux ont été mises en œuvre et leurs répercussions dans le temps sur le bien-être des résidents et de leurs proches aidants et sur les relations entre eux. Des entrevues ont été menées auprès de 24 « proches aidants désignés » dans le Canada Atlantique à trois reprises entre mars 2021 et mars 2022. Nous avons observé des changements dans les relations et activités familiales au cours de cette période, un rétrécissement des réseaux de soutien, un besoin accru de défense des droits et de surveillance, et des effets cumulatifs généralement négatifs des restrictions, notamment pour les résidents en fin de vie et leurs proches aidants. Les ajustements ultérieurs des restrictions d'accès ont permis aux proches aidants de collaborer à une surveillance essentielle, aux relations de soins et aux rôles de défense des droits. Nous estimons que le rôle des proches aidants désignés dans les CHSLD doit être maintenu en périodes d'urgences de santé publique afin de protéger le bien-être général des résidents et de leur assurer un soutien familial suffisant.

Introduction

The COVID-19 pandemic has had a devastating toll for people residing in nursing homes in Canada. In the first 3 months of the pandemic, Canadian nursing homes had the highest resident death rate due to COVID-19 out of all OECD countries (Canadian Institute for Health Information, 2020). To keep nursing home residents and staff safe from COVID-19 early in the pandemic, public health measures were put in place to restrict access to residents in Canada, and many countries banned visitors in early 2020, except for emergency reasons (Healthcare Excellence Canada, 2020). Over time, with various waves of the COVID-19 pandemic, public health officials eased access restrictions in many jurisdictions by allowing on-site visiting, typically in small outdoor contexts, and allowing designated caregivers to assist with care tasks (e.g., Healthcare Excellence Canada, 2022; Nova Scotia Department of Health and Wellness, 2020). While restrictive measures were important to limit the spread of the COVID-19 virus, the resulting prolonged separation from designated caregivers had a tremendous negative impact on the physical and mental well-being and quality of life of residents (Stall et al., 2020), underscoring the critical role that designated caregivers play in enhancing resident well-being. In this paper, we draw on results from a qualitative study to understand how COVID-19-related public health directives that restricted access to family members in nursing homes were implemented, and how these policies impacted the well-being of and relationships between nursing home residents and their designated caregivers over time in Atlantic Canada.

There is great variation in terminology when referring to family members and friend access to nursing home residents during the COVID-19 pandemic. Most Canadian jurisdictions distinguish between those who are: (a) visitors, that is, those who have a casual role in the ongoing care of the nursing home resident and (b) essential care partners or partners in care. That is those designated or identified by the resident or their substitute decision-maker/power of attorney, typically family and friends who provide ongoing physical, psychological, and emotional support as deemed important by the resident (Healthcare Excellence Canada, 2020, 2022; Palubiski et al., 2022; Schlaudecker, 2020; Stall et al., 2020; Zimmerman, 2022). We use the phrase *designated caregivers* to refer to the latter in this article.

Nursing homes (also known as residential long-term care facilities) are residential, rather than community-based, settings where staff, ranging from nurses to support workers, provide 24-hour care and supervision. Most nursing home residents are over 65 and many require assistance with activities of daily living and experiencing physical disabilities, dementia, incontinence, and polypharmacy (Hoben et al., 2019). In Canada, nursing homes can be publicly or privately owned and operated, but most facilities are publicly subsidized, and all facilities are subject to government regulation and standards.

Family members play a critical role in the care and support of nursing home residents, often assisting with direct care responsibilities such as feeding, grooming, and mobility (Barken & Lowndes, 2018; Reid & Chappell, 2017) and in indirect caregiving responsibilities, such as being a manager or overseer of care and being an advocate for residents (Keefe & Fancey, 2000). Linked lives, or strong inter-relationships among residents, family members, and staff, are essential to resident well-being and quality of life (Keefe, Taylor, Irwin, Hande, & Hubley, 2022; Zimmerman et al., 2013). Meaningful family engagement and care provision improves resident well-being and can reduce staff burnout (Zimmerman et al., 2013). Even before the COVID-19 pandemic, high staff turnover rates and shortages of frontline workers in Canada's nursing home sector amplified the importance of family and friends in nursing homes, and their absence during the initial outbreak raised serious concerns about the well-being of residents, their designated caregivers, and staff (Estabrooks et al., 2020; Sloane, 2020).

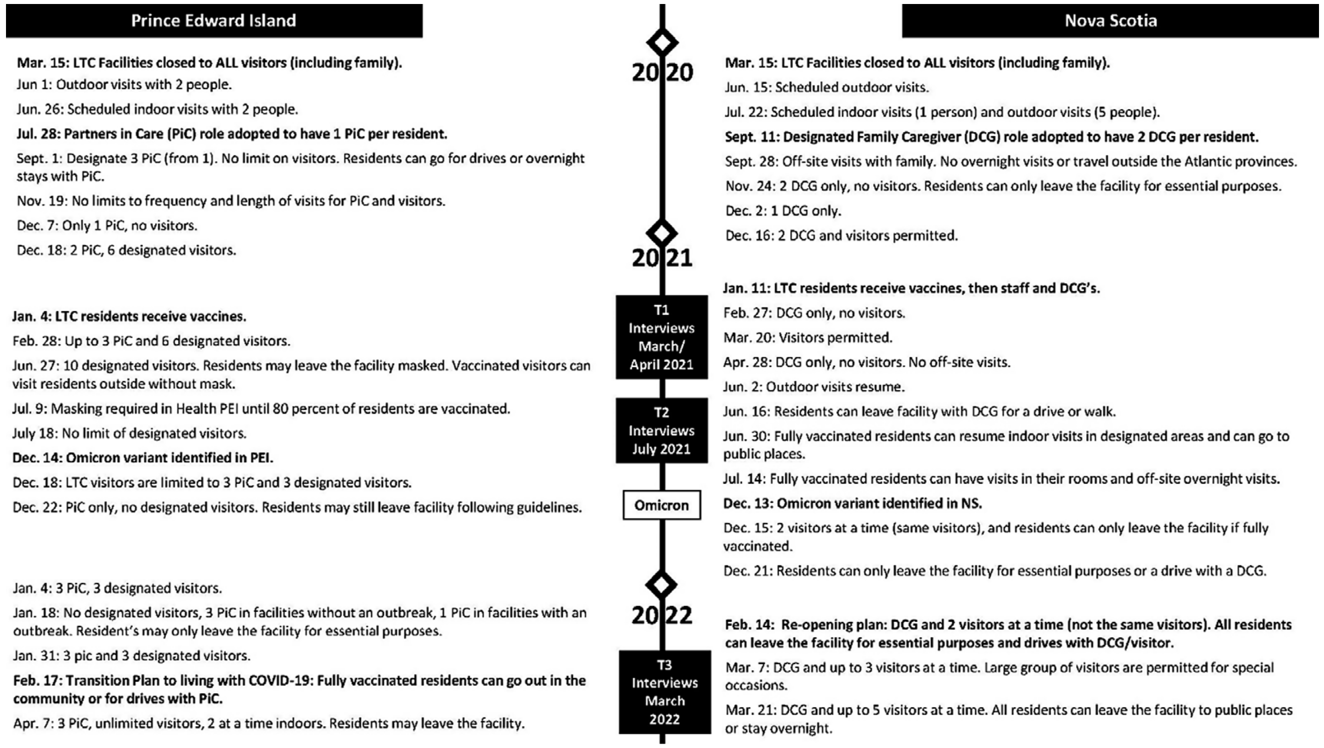
There is some emerging empirical evidence about the harmful impact of restrictions in access on designated caregivers during the early waves of the pandemic. Cornally et al. (2022) conducted a web-based survey in Ireland in June 2020 and identified that during the first wave of the COVID-19 pandemic, the sudden withdrawal of family visitors caused potential harm to both visitors and residents through disrupting resident-family centered care. Chu, Yee, and Stamatopoulos (2022, 2023) conducted virtual focus groups with essential family caregivers in early 2021 and identified that they experienced trauma in various ways during lockdowns due to prolonged separation and the inability to provide care, feeling powerlessness and helplessness, and uncompassionate interactions with nursing home staff and administrators. Similarly, Lane et al. (2022) identified that designated caregivers reported significant personal and caregiving-related stresses during the first wave of the pandemic. Thirsk, Stahlke, Perry, and Gordon (2022) analysed Canadian news articles, blog postings, and tweets published from March 2020 to April 2021 and found a negative impact of restricted access to residents on the emotional and physical well-being of residents and families.

It is critical to understand the experiences of designated caregivers' access in nursing homes over time to appreciate the *cumulative* effects of prolonged, and sometimes rapidly shifting restrictions. In a prior phase of our study, we examined data collected from the perspective of nursing home administrators and direct care staff about access policies, and these results are reported elsewhere (Chamberlain et al., 2023). The focus of this article is an analysis of the impact of access policies on family relationships and resident/caregiver well-being using data collected from designated caregivers across three time points including after the Omicron variant reached the region of study. Other Canadian COVID-19 studies have highlighted the cumulative impact of restricted access policies in nursing homes during the early stages of the COVID-19 pandemic, focusing on residents (e.g., De Witte et al., 2024) and 'family visitors' (e.g., Dupuis-Blanchard, Maillet, Thériault, LeBlanc, & Bigonnesse, 2021). There were notable variations in family access restrictions in nursing homes across Canadian provinces related to differential cultural and political contexts, COVID-19 rates, and province-specific nursing home regulatory frameworks (Stall et al., 2020). For example, Ontario and Quebec had the highest rates of COVID-19 outbreaks in nursing homes in the first few waves of the pandemic and are notable for dramatic staffing shortages (Bourbonnais et al., 2024; Garnett et al., 2024). Nevertheless, numerous studies highlighted the significant negative impact of such restrictions on both resident and caregiver well-being (Anderson, Parmar, Dobbs, & Tian, 2021; Boamah et al., 2024; Bourbonnais et al., 2024; Garnett et al., 2024). Significant changes to residents' relationships with family have also been noted (Boamah et al., 2024; Cooke, Wu, Bourbonnais, & Baumbusch, 2023; Garnett et al., 2024).

Our study contributes a qualitative longitudinal analysis of how such restrictions were implemented and how they impacted the relationships between *designated* caregivers and nursing home residents over three time points from March 2021 to March 2022. Moreover, our research is unique in its focus on the Atlantic region of Canada, which was somewhat insulated COVID-19 outbreaks until the Omicron variant wave in 2022.

Methods

This study is part of a larger mixed-method study that examined the implementation of COVID-19 family restriction policies in Atlantic Canada (Chamberlain et al., 2023). A rapid qualitative longitudinal approach was developed to examine family caregivers' experiences of time. This qualitative approach (Hsieh & Shannon, 2005) enabled us to descriptively examine the subjective and shifting experiences of family caregivers in close and sustained relationships with nursing home residents, giving us a more nuanced and distinctive family caregiver lens to our understanding of family caregiving in nursing homes during the pandemic. This study was approved by the Research Ethics Boards of Mount Saint Vincent University (REB # 2020-129), Dalhousie University (REB #2021-5456), University of Alberta (REB # Pro00108265), University of Victoria (REB # 21-0003), and Prince Edward Island Health Authority (no number).



Prince Edward Island

Mar. 15: LTC Facilities closed to ALL visitors (including family).
Jun 1: Outdoor visits with 2 people.
Jun. 26: Scheduled indoor visits with 2 people.
Jul. 28: Partners in Care (PiC) role adopted to have 1 PiC per resident.
Sept. 1: Designate 3 PiC (from 1). No limit on visitors. Residents can go for drives or overnight stays with PiC.
Nov. 19: No limits to frequency and length of visits for PiC and visitors.
Dec. 7: Only 1 PiC, no visitors.
Dec. 18: 2 PiC, 6 designated visitors.

Jan. 4: LTC residents receive vaccines.
Feb. 28: Up to 3 PiC and 6 designated visitors.
Jun. 27: 10 designated visitors. Residents may leave the facility masked. Vaccinated visitors can visit residents outside without mask.
Jul. 9: Masking required in Health PEI until 80 percent of residents are vaccinated.
July 18: No limit of designated visitors.
Dec. 14: Omicron variant identified in PEI.
Dec. 18: LTC visitors are limited to 3 PiC and 3 designated visitors.
Dec. 22: PiC only, no designated visitors. Residents may still leave facility following guidelines.

Jan. 4: 3 PiC, 3 designated visitors.
Jan. 18: No designated visitors, 3 PiC in facilities without an outbreak, 1 PiC in facilities with an outbreak. Resident's may only leave the facility for essential purposes.
Jan. 31: 3 pic and 3 designated visitors.
Feb. 17: Transition Plan to living with COVID-19: Fully vaccinated residents can go out in the community or for drives with PiC.
Apr. 7: 3 PiC, unlimited visitors, 2 at a time indoors. Residents may leave the facility.

Nova Scotia

Mar. 15: LTC Facilities closed to ALL visitors (including family).
Jun. 15: Scheduled outdoor visits.
Jul. 22: Scheduled indoor visits (1 person) and outdoor visits (5 people).
Sept. 11: Designated Family Caregiver (DCG) role adopted to have 2 DCG per resident.
Sept. 28: Off-site visits with family. No overnight visits or travel outside the Atlantic provinces.
Nov. 24: 2 DCG only, no visitors. Residents can only leave the facility for essential purposes.
Dec. 2: 1 DCG only.
Dec. 16: 2 DCG and visitors permitted.

Jan. 11: LTC residents receive vaccines, then staff and DCG's.
Feb. 27: DCG only, no visitors.
Mar. 20: Visitors permitted.
Apr. 28: DCG only, no visitors. No off-site visits.
Jun. 2: Outdoor visits resume.
Jun. 16: Residents can leave facility with DCG for a drive or walk.
Jun. 30: Fully vaccinated residents can resume indoor visits in designated areas and can go to public places.
Jul. 14: Fully vaccinated residents can have visits in their rooms and off-site overnight visits.
Dec. 13: Omicron variant identified in NS.
Dec. 15: 2 visitors at a time (same visitors), and residents can only leave the facility if fully vaccinated.
Dec. 21: Residents can only leave the facility for essential purposes or a drive with a DCG.

Feb. 14: Re-opening plan: DCG and 2 visitors at a time (not the same visitors). All residents can leave the facility for essential purposes and drives with DCG/visitor.
Mar. 7: DCG and up to 3 visitors at a time. Large group of visitors are permitted for special occasions.
Mar. 21: DCG and up to 5 visitors at a time. All residents can leave the facility to public places or stay overnight.

Figure 1. Timeline of access policy changes by province and timeline of interviews. *Notes:* In PEI, the term partners in care (PIC) was used to refer to family caregivers, and in Nova Scotia, the term designated caregiver (DCG) was used. In both provinces, additional visitors were specified who did not contribute to caregiving tasks. These were termed designated visitors in PEI and visitors in NS.

All participants provided verbal informed consent prior to participating and all study data were de-identified. Participants were assigned a research identification number that was linked to their name and contact information in a separate password-protected file.

Study context

Our study was conducted in the Eastern Canadian provinces of Nova Scotia (NS), and Prince Edward Island (PEI). We selected these two provinces due to their similarities in the experiences of COVID-19 in the community and in nursing homes, and high rates of COVID-19 vaccination once this became available. These two provinces were part of a regional effort in Atlantic Canada to contain the spread of the COVID-19 virus that included strict lockdowns early in the pandemic and an 'Atlantic bubble' that was in place for many months, allowing travel between four provinces, with a 14-day quarantine for visitors from outside the region (MacDonald, 2021). Six nursing homes were included in our study (NS, n = 4; PEI, n = 2) that varied in ownership model, layout design, facility age, and number of beds. Partners in this study included family caregiver representatives, administrators from partner nursing homes, and knowledge users.

See Figure 1 for a timeline of the implementation of access policies in nursing homes in NS and PEI throughout the COVID-19 pandemic from March 2021 to March 2022. During the first several waves of the COVID-19 pandemic, there were relatively few cases of COVID-19 in nursing homes and little community spread, other than an outbreak at one NS nursing home during the first wave that resulted in 53 resident deaths (Gorman, 2021). Various restrictions were imposed on access by visitors and designated caregivers (e.g., length of visits, number of visits in a specific period, number of different visitors, and visiting hours). Notably, following initial uncompromising restrictions to enter nursing homes in mid-March 2020, outdoor visits were first implemented, followed by indoor visits and then finally residents being allowed to leave the nursing home. Vaccines were available for residents by January 2021, and gradually fewer restrictions were imposed until the Omicron variant reached the region by early December 2021 when there were increased COVID-19 cases among nursing home residents (Nova Scotia Department of Health and Wellness, 2022; Prince Edward Island Department of Health and Wellness, 2022). At that time, more nursing homes were in an active outbreak (i.e., 39 in NS; 7 in PEI; Patil, 2022; Prince Edward Island Department of Health and Wellness, 2022), and there were increased resident deaths due to COVID-19 (i.e., 23 in NS; 9 in PEI; Campbell, 2022; Nova Scotia Department of Health and Wellness, 2022). Many homes reported staff shortages and increased resident and visitor restrictions, but designated caregivers did have limited face-to-face access, in contrast to early in the pandemic.

Participant Recruitment

Senior administrators and managers (variously titled 'facility administrators', 'site managers', 'directors of care', or 'nursing managers' across facilities) at nursing homes assisted with participant recruitment by identifying individuals assigned as the designated caregivers who met the study inclusion criteria (i.e., had at least two support visits before T1 to ensure experience with the related policies). They asked designated caregivers for permission to forward their contact information to the research staff. We do not have details of the various means that administrators used to identify and contact potential participants. After receiving the list of potential participants, research staff contacted these individuals directly by e-mail or telephone to provide more information about the project and to discuss their potential participation. Research staff communicated that participation in the study was voluntary and that senior administrators would not be made aware of their decision to participate or not. Research staff then sent the informed consent form to participants who indicated an interest in being interviewed. The interviewer reviewed the informed consent form with prospective participants and answered all participant's questions prior to the start of the interview. Verbal informed consent was documented by audio recording at the start of each interview.

Data Collection

The interview guides for the three time points were developed by study investigators: T1 (March/April 2021), T2 (July/August 2021), and T3 (March 2022). The questions were informed by a health equity lens (e.g., race, gender, employment status, social location, and geography), and sought to understand the designated caregivers' experiences of the restrictions in terms of the physical, mental, and emotional well-being of both caregivers themselves and the residents they care for.

The T1 interview guide was piloted with the four family caregiver representatives and revised based on the pilot interviews. The pilot data was not used in the analysis. The final guide included questions about designated caregiver characteristics and characteristics of the nursing home resident; experience with the process of becoming a designated caregiver; experiences in the role; the relational, psychological, emotional, and physical impact of visiting restrictions on themselves and the nursing home resident and staff; and implementation issues related to equity, diversity, and inclusion. Interview questions varied slightly in T2 and T3 interviews, where the primary purpose was asking for up-dates on information from the previous interview (T1 or T2) and introducing new questions on the Omicron context in T3. Interviews were semi-structured whereby a set of questions were followed with opportunity for probing and follow-up questions. A summary of the content of the interview guides for the three time points is included in Table 1.

Video or telephone interviews were conducted by trained research assistants with designated caregivers in six nursing homes in NS and PEI at three points in time (see Figure 1): T1 ($n = 38$), T2 ($n = 33$), and T3 ($n = 24$). This approach allowed us to examine the experiences of designated caregivers before (T1 and T2) and during (T3) COVID-19 outbreaks and community spread in the region. Our results focused on interviews with 24 designated caregivers who participated in an interview at T3 and a minimum of one prior interview; 21 were interviewed at all three points and three were interviewed at T2 and T3 only. Reasons, why designated caregivers did not participate in all data collection points, included that the

Table 1. Summary of interview guide content across time points

T1	T2	T3
Section 1: Background Relationship to resident, resident physical and mental health status, description of access prior to and since the onset of the pandemic *Section 2: Becoming a DC* Learning about the role of a DC, motivations for this role, processes and experiences of becoming an approved DC, any involvement in the DC program, suggestions for change about the DC program/ approval process *Section 3: Experience as a DC* Length of time, process involved in planning access, what happens during visits, any restrictions, level of support from staff and how this is perceived, who provides support with problems encountered, level of safety perceived during visits, factors affecting experiences of DC, feedback requested, recommendations for change *Section 4: Impact/outcome* Impact of access on resident physical and mental health, impact on relationships with staff or managers, meaning of the visits, and impact on DC	*Any change in DC experiences* Any changes since the last interview (e.g., resident's physical or mental status)? Impact of any changes in the role for DC. Any changes in the role of a DC in the facility? How were any changes communicated? Why were these changes made? Who was responsible for the changes? How did changes impact the role of DC and for residents? What could be done differently to make the experience for DC better?	*Any change in DC experiences* Any changes since the last interview (e.g., resident's physical or mental health status, changes since the Omicron variant emerged in the area)? Impact of any changes in the role for DC. Any changes in the role of a DC in the facility (e.g., during reopening in the Fall and since the Omicron Variant)? How were any changes communicated? Was this communication effective? Why were these changes made (e.g., the presence of COVID-19 in the community/ facility)? Who was responsible for the changes? Have they been invited to be involved in changes? How did changes impact the role of DC and for residents? What could be done differently to make the experience for DC better?
Section 5: Demographic questions and wrap up Age, gender, education, country of birth, ethnicity, and languages spoken Anything else you would like to add in terms of the fairness of the policy implementation or how it might impact different groups of people differently (e.g., age, gender, sexuality, financial resources, ethnicity/culture, language, and family dynamics)? Anything missed or anything else you would like to add?	Anything else you'd like to add in terms of the fairness of the policy implementation or how it might impact different groups of people differently (e.g., age, gender, sexuality, financial resources, ethnicity/culture, language, and family dynamics)? Anything missed or anything else you would like to add?	Anything else you would like to add in terms the fairness of the policy implementation or how it might impact different groups of people differently (e.g., age, gender, sexuality, financial resources, ethnicity/culture, language, and family dynamics)? Anything missed or anything else you would like to add?

resident they cared for died (n = 7), the participant could not be contacted (n = 5), the participant declined a follow-up interview (n = 3), or the participant no longer met inclusion criteria (n = 3; e.g., resident moved to a different nursing home). Trained research assistants interviewed designated caregivers primarily over the phone or via MS Teams videoconference (two participants at T1). In the case of phone interviews, hand-held audio recorders were placed near a speaker to record the interview. Interviewers used a spreadsheet to organize their notes during the interview. Interviews ranged in length from 24 to 92 minutes (mean = 50 minutes) for initial interviews (T1 and new at T2) and from 13 to 53 minutes (mean = 27 minutes) for follow-up T2 interviews, and from 19 to 65 minutes (mean = 35 minutes) for T3 interviews. All participants interviewed received a $5 gift card for each interview.

Data analysis

We analysed the designated caregiver interview data using the rapid data analysis approach (Beebe, 2001). This is an intensive, team-based approach to qualitative data analysis that uses triangulation, iterative data collection, and iterative data analysis to quickly gain the insider's perspective. This approach enabled us to expedite the sorting of data that could be useful to non-academic project partners (such as policy-makers and implementation teams; Nevedal et al., 2021), while other data could be explored in more depth for other project outcomes such as academic articles. A prior article published by our team provides further details about the rapid analysis process we followed (Chamberlain et al., 2023).

While full transcripts were not prepared, very detailed summaries of the content of the interviews were created for each interview. These summaries were written both during and immediately after each interview. The research assistants listened to the audio recordings to capture nuances/context and added some verbatim quotes in the summaries. The data were added to an Excel spreadsheet organized by the topics in our interview guides. A second research assistant and one investigator participated in a review process for each interview to ensure rigour, consistency, and usability of the Excel document.

Themes pertaining to the experiences of designated caregivers over the three time points were then identified inductively (Hsieh & Shannon, 2005). A narrative summary of each theme was developed with exemplary quotes added to illustrate participant responses. The second author reviewed the detailed summaries and identified places where excerpts of the interview recording, or 'quotes', should be transcribed for further analysis. Quotes were transcribed verbatim by research assistants from the audio recordings. Each transcribed interview quote featured in this article has a participant identification number, time point, and province. Themes were discussed and verified by the research team.

Results

We first describe the characteristics of the designated caregivers and then the five inductive themes identified that illustrated how restrictions in access to designated caregivers were experienced over time: changes in visiting experiences and activities; a constricted network of support; health impacts of visiting restrictions; the increased importance of an advocacy and monitoring role; and navigating end-of-life experiences.

Table 2. Participant characteristics

Characteristic	N = 24	%
Province		
NS	15	62.5
PEI	9	37.5
Relationship with the resident		
Adult child	12	50
Spouse	5	21
Sibling	3	12.5
Parent	1	4
Other family relationship	3	12.5
Age		
64 or younger	7	29
65–74	13	54
75+	4	17
Gender		
Women	18	75
Men	6	25
Highest level of education		
High school	4	17
Some post-secondary, diploma, or bachelor's degree	15	62
Graduate degree	5	21
Languages spoken other than English		
French	4	17
Other	2	8

Participant characteristics

The characteristics of the 24 participants are summarized in Table 2. Half of the participants were an adult child of a resident followed by spouses, siblings, parents, and other relatives. All participants, but one, were born in Canada, one-quarter spoke languages other than English, such as French, and were currently residing in NS (n = 15) or PEI (n = 9). All identified as white, three-quarters identified as female, and their average age was 67 years old (range = 50–84 years). Over 80% had completed education beyond high school.

Theme 1: Changes in family relationships and activities

Throughout the three data collection points, interactions between designated caregivers and residents were modified in various ways that influenced their experience of visiting and what they could do with residents. Some key issues identified across the time points were alternatives to face-to-face communication, restrictions on residents leaving the nursing home, and restrictions on supporting the social and recreational needs of residents.

Over time points, methods of communication were altered. While outdoor or window visits were possible for some designated caregivers early in the pandemic, caregivers did not feel that these were useful in maintaining family relationships due to factors, such as sensory impairments and the cognitive status of the resident. As identified in a T1 interview, one designated caregiver described:

> I did window visits and they were very frustrating because I would have to call the desk to get someone to come and help her with the phone because she was n't managing the phone and she put it on her most deaf ear and of course I'd be screaming at the window, 'put it on the other side' she enjoyed seeing my face but we were n't allowed to open the window … and then we were allowed to start outdoor visits and again six feet away, compulsory masks even though they were outdoors and somebody who's confused by this and hard of hearing and can only see my eyes and I was yelling at her and you know … she was just very frustrated by the way visits were structured. (005-02 T1 NS)

Other than the telephones, there was little evidence that various forms of other technology (e.g., video calls) were effective alternatives to face-to-face communication, except when designated caregivers were able to operate the technology. For example, at T3, one designated caregiver and her mother would Facetime with family members all over the world, and this helped with 'a lot of positive connections with lots of people' (061-05 T3 NS). Many designated caregivers indicated relief when face-to-face visits were reinstated.

Restrictions on taking residents out of the facility when desired was a concern identified by many participants. During T1 interviews, designated caregivers described total bans on this, and appreciation was expressed during T2 when residents could leave the facility. While there continued to be restrictions, such as not leaving the vehicle or not encountering other people, reinstating taking residents out of the facility was important for resident's sense of freedom and the enhancement of visits with family.

> When they changed the restrictions again that we can actually take him out, well I took my dad out in the car and he said '… feels kind of funny, being in a car again you know' … just to go for a drive and to see other things other than the walls in the building right, and he's quite happy. (091-05 T2 NS)

Throughout all time points, the participants spoke about the lack of physical and social activities residents experienced due to being isolated in their rooms for long periods of time. Without family support, staff had little time to assist with socialization. This was combined with concerns about the reduced amount and quality of care provided by staff due to staff shortages and staff turnover exacerbated by COVID-19. In addition to there being fewer or no activities organized by recreational staff, volunteers were also restricted from their usual activities with residents, and designated caregivers were largely restricted from interacting with other residents while they were visiting. For example, at T1, one designated caregiver explained:

> I can walk him, well in his wheelchair, just push him along the corridors and we can't go into anyone else's unit … if I'm helping him with lunch or dinner, we have to stay in his room because you can't be handy to other residents. (074-01, T1 PEI)

Even at our last data collection point (T3), there continued to be restrictions on residents' activities with designated caregivers if outbreaks occurred.

> When restrictions are loosened a little bit and we're back where we were … we can accompany them to bingo or help them with that … they have music and all those things … but not right now, so I think when that all comes back it will be better. (074-01 T3 PEI)

Theme 2: A constricted network of support

Throughout the three time points, there were varying restrictions on which family members could interact with residents that affected the maintenance of family relationships over time, especially in larger families. Once the designated caregivers were chosen, they were often unable to swap with others for many months, such as replacing a son with a daughter. This placed stress on some designated caregivers who were either the sole person or one of a very small group, responsible for supporting their relative in a nursing home.

> They seem to think I understand her better so that kind of puts more onus on me to visit her more often … it would be nice if one of them would go because I don't like [the resident] to go a week without seeing somebody, so that does put a little bit more pressure on me. (001-02 T3 NS)

At different times during the pandemic (e.g., when initial lockdowns were eased in July 2020), only one designated caregiver was permitted to visit at a time and just one visit per day was allowed (see Figure 1). These parameters affected the dynamics of the visit, as recounted during T1 interviews.

> The other designated caregiver can't go up the same day as me, I don't understand the logic … me and my sister can't do the visits the same day, it's just one per day … we're both able to go in … so what's the difference if I go 11:00-1:00 and she goes 4:00-6:00 in the evening … they're only allowing one per day. (063-05 T1 NS)

By T2, some participants noted that they were allowed to visit at the same time as another designated caregiver, but they often carefully choreographed their visits to allow the resident to have visitors more days in the week, even if it was a visit by one person at a time. Even at T3, participants noted that due to the Omicron wave, some facilities reverted to allowing one designated caregiver at a time.

The participants also identified the importance of access for the broader group of family and friends and not just for those selected as designated caregivers. There were challenges noted in maintaining relationships with multiple generations over the three time points. Restrictions on both the number and age of family visitors resulted in many residents not having face-to-face contact with other members of their family for long periods of time. During the T2 interviews, participants identified that residents were happy to see grandchildren again, but these visits were restricted again during the Omicron wave that started in late 2021 and included the Christmas season. 'In the last two years … she doesn't see her grandchildren and she basically doesn't really know any of them anymore and so I think that affects [the resident's] mental health' (001-02 T3 NS).

Theme 3: Increased importance of an advocacy and monitoring role

Restrictions during the pandemic altered the ability of designated caregivers to fulfil an advocacy and monitoring role to ensure that residents received personalized and thorough care.

At T1, one designated caregiver (005-02 T1) with a medical background felt that there was no ability to interface with medical staff in the nursing home or to troubleshoot and resolve problems early. At T1, one participant whose access was reinstated after their relative had stroke felt that without reinstatement of access, the resident would have died without their ability to monitor and advocate for care (003-02-T1).

As the various waves of the pandemic occurred, staffing shortages continued to strain nursing facilities. Many participants spoke about the ongoing and increasing importance of caregiver advocacy and monitoring 'I felt like I've had to advocate more and more on my mother's behalf' (071-03 T3 NS). Another designated caregiver reflected a similar sentiment at T3.

> I had to be there as long as I could because they [staff] were just so stretched … my mom could not communicate her needs and as her body was changing, just all the things that happen as people are moving towards the end of life … I had to be a voice for her. (061-05 T3 NS)

Theme 4: Impacts of visiting restrictions

Many designated caregivers discussed the importance of access on the physical and mental health of residents. Several participants described the initial lockdown period as contributing to declining resident mental health and this improved when face-to-face contact was reinstated.

> The visits are what keep her going. As soon as I get up there, I don't even have my butt in the chair and she has the deck of cards and tells me 'sit down, we're playing cards' and you know we have laughs … the visits, I mean that's a saviour, like I said, I'm just grateful, I mean they're only two hours, but I'm grateful just to get that. (063-05 T1 NS).

At T2 and T3, some designated caregivers spoke about access as a right versus a privilege and emphasized that there should not be a ban on face-to-face visits early in the pandemic. It was difficult for residents to adapt to increased visitor restrictions again when the Omicron variant emerged in late 2021. 'Everyone was starting to brighten up when restrictions were easing and then boom, shut down, and it was upsetting right before Christmas, you can really tell when you go in there … just very sombre' (063-05 T3 NS).

Given the high level of frailty of nursing home residents, it is not surprising that many caregivers discussed changes in residents' physical health status in this study. However, some participants attributed declining health, or the acceleration of declining health, to family access restrictions and the resulting social isolation experienced by residents. During a T1 interview, one designated caregiver attributed her mother's post-op infection to a lack of staff time to provide care. At T3, she attributed isolation as contributing to her mother's increased rate of decline in her health status.

> I don't think you can stick old people in their rooms for two years and expect anything but decline and death … This has been the worst kind of social experiment we could ever have conducted. I mean an ethics board would never take people and isolate them in their rooms for two years and see what the outcomes are. (005-02 T3 NS)

Several designated caregivers spoke about their importance in providing nutritional support to residents, including bringing food the resident would eat or being present at mealtimes to encourage food intake. Restrictions related to supporting resident's nutritional intake varied across nursing homes and over time, and this combined with less capacity of staff to provide support during mealtimes was identified as resulting in poorer nutritional intake.

> We try to ensure that somebody is there every day to make sure that she eats. She doesn't do that very well on her own, so we make sure that somebody's there once a day to ensure she eats at least one meal. (045-05 T2 NS)

Some designated caregivers felt that resident health did not decline over our data collection points. Residents described as introverts may have coped better than those who were more extroverted. For example, one participant reported that her introverted mother's physical and mental health was quite stable over the three time points (018-03 T1-T3). Also, some residents wanted to spend more time alone to reduce their risk of contracting COVID-19. These are examples of how various contextual factors, such as personality traits and personal preferences could moderate the impact of visitor restrictions.

Our interview guide did not prompt designated caregivers to reflect on how restrictions directly impacted their own well-being. Nevertheless, participants were sometimes emotionally distressed during interviews (e.g., crying or quivering voices) as they described the toll of the restrictions, particularly in the second and third interviews. For example, one spouse described being emotionally 'torn apart' in the first interview. In the second interview, he found it was increasingly difficult for him to manage his emotions.

> I continue to go on a consistent basis, if daily, but it's catching up to me. I thought I had my emotions under control, but I find that every aspect of this creates different emotions. So, yeah. It's harder for me … I think that she would rather be, you know, if she could pass away, it'd be the best thing for her. (071-03-T2)

Over time we noted a shift in emotional responses to prolonged restrictions. At T1, many participants expressed an excited willingness to comply in any way requested. At T3, however, mounting grief and frustration were evident in the emotional accounts provided. In our first round of interviews, one woman shared that she would do anything to see her mom, even 'dye my hair purple' (015-04-T1). However, at T3, she commented how the continued restrictions prevented her from visiting for up to a month at a time. When she did see her mother, the restrictions felt 'unnatural', and sometimes 'ruined' their time together (015-04-T1). Such accounts underscore the negative impact of these long-term restrictions on family caregiver–resident relationships.

Theme 5: Navigating end-of-life experiences

A small number of designated caregivers spoke about their experiences of having access to the residents at the end of their lives. Early in the pandemic, strict visiting restrictions could even apply to residents at the end of life. Several designated caregivers who identified end-of-life care access as an issue highlighted feelings of frustration and guilt about residents not having the opportunity for connections with family and friends during the last months of life. These feelings were repeated across all time points, suggesting that expectations for growing leniency around end-of-life caregiving restrictions were not realized. Restrictions at the end of life were often very difficult for both designated caregivers and residents to comprehend or rationalize. Staffing shortages throughout the three time points may have contributed to some resident and family preferences not being carried out at the end of life, such as prompt communication with families. Other participants described that by T3, visiting policies had been modified to allow for access if a resident was nearing the end of life and/or was identified as palliative. One participant described a very positive experience at the end of life where she was present when her mother died in the nursing home early in 2022.

> It was just so beautiful and peaceful, I was able to sit on the bed with her, hold her hand, and bend down and talk to her in her ear, and rub her hair and her forehead, and just talk to her and be there, I told her it was ok to

> go, I would say things to her in Polish … a tear formed in her right eye … her last breath was at 5:52 … it was so peaceful, it was just so peaceful … They [staff] said you take your mask off and you be with her, just be with her, keep her door closed … that was like so huge, I get to be with her without a mask. (061-05 T3 NS)

Discussion

Most designated caregivers in our study identified challenges related to restrictions in access to nursing home residents during various phases of the COVID-19 pandemic, and over time this often strained relationships between residents and their family caregivers and negatively impacted their perceived well-being. This analysis supports pre-pandemic arguments that safety regulations are often overemphasized in comparison to other equally important dimensions of resident quality of life, such as maintaining meaningful family relations and family-supported activities (Keefe et al., 2022). Our analysis also shows how resident and family well-being is often inextricably linked. Restrictions on family visiting were perceived by designated caregivers as having numerous and varied impacts that rippled out from resident health status to designated caregiver well-being, broader family dynamics, and the ability to monitor care and be an advocate for the resident. It is imperative that these cumulative impacts be considered, and proactive measures are put in place to ensure that caregiver access to nursing home residents is recognized as essential and thus maintained, regardless of outbreaks of infectious disease or other emergencies. This access must extend not only to designated caregivers but a wider number of people in a resident's social network, such as grandchildren. Stall et al. have recommended that *at least* one designated caregiver be permitted at all times and that safety protocols become increasingly flexible as residents near death.

While designated caregivers had some level of access to residents, at least after initial lockdowns that began in March 2020, the number of designated caregivers allowed varied over time between one and three, depending on the level of risk (see Figure 1). In addition, those without designated caregiver status sometimes did not have any access (Chamberlain et al., 2023). This resulted in many residents having little access to a variety of people in their social network who bring joy, such as friends, grandchildren, and other loved ones. Over time, these restrictions were widely experienced as distressing and even unjust and undermined the well-being of both residents and family members.

It is hard to pinpoint states or provinces whose COVID-19 protocols were wholly 'successful' for family caregivers in nursing homes (Stall et al., 2020; Van Houtven et al., 2021). Van Houtven et al. (2021) noted that restrictions on family visitors were 'ubiquitous, though based on a slim evidence-base' (p. 264). While Canadian provinces varied in their family caregiver restriction policies, all provinces severely curtailed family caregiver access for prolonged periods of time (Stall et al., 2020). Our study supports mounting evidence that top-down blanket restrictions on family access in nursing homes have long-term detrimental impacts on both caregivers and residents and that policy recommendations to support safe access (Schlaudecker, 2020) for essential family caregivers were sometimes not implemented – even in later waves of the pandemic when life outside of nursing homes was slowly returning to 'normal'.

Given the enormous contributions of family caregivers in nursing homes (Barken & Lowndes, 2018; Keefe & Fancey, 2000; Reid & Chappell, 2017), it is unfortunate that in the context of a plethora of staffing issues in nursing homes during the COVID-19 pandemic (Bourbonnais et al., 2024; Cooke et al., 2023; Dupuis-Blanchard et al., 2021; Hindmarch, McGhan, Flemons, & McCaughey, 2021), a vital source of support to the residents was cut off through initial and then continuing restrictions of designated caregivers and other visitors. In contrast to evidence about policymakers disregarding the key role that family caregivers fulfil in nursing homes (Thirsk et al., 2022), our results contribute to the argument that caregivers' essential care contributions are essential to resident wellbeing (Bourbonnais et al., 2024; Hindmarch et al., 2021), and often soften the impact of the current workforce crisis in nursing homes (Zimmerman, 2022) in ways that may have critical outcomes for residents. In addition to providing supportive exchanges to their relatives or friends in a nursing home, our results provide evidence that social exchanges with other residents that would have occurred prior to the COVID-19 pandemic were also restricted over time. Thus, an important source of support was curtailed when it was greatly needed.

The international literature does not support blanket bans on face-to-face access in nursing homes (Cornally et al., 2022). Our results suggest that while this lack of face-to-face access was imposed early in the pandemic, there are numerous ways to safely accommodate caregiver access, and this is especially important for residents who are near death. Structural barriers should not be imposed that impede supportive relationships between family members in any setting, especially when supporting frail older adults in nursing homes. Continued social contact is key to overall quality of life (Barken & Lowndes, 2018; Keefe et al., 2022; Reid & Chappell, 2017).

To protect residents and staff during public health emergencies, family caregivers might follow similar safety protocols as staff (e.g., undergo screening, wear appropriate PPE, etc.) when attending to their loved ones in nursing homes (Schlaudecker, 2020). Supporting safe access for family and friend caregivers during a public health emergency may require dedicated staffing (Bourbonnais et al., 2024) and additional government investments (Collingridge Moore, Garner, Cotterell, et al., 2024). Notably, many of the designated caregivers we interviewed felt shut out of the policy planning and implantation process. Instead, we recommend that they be actively engaged in protocol implementation (Chamberlain et al., 2023).

Given that our participants did not represent a great deal of diversity in terms of ethnicity, place of birth, or language, further inquiry is needed to focus on ensuring that the needs of diverse residents and their families are met during times of infectious disease outbreak (Palubiski et al., 2022). The role of designated caregivers is particularly important to ensure that residents receive culturally safe and appropriate care, especially for LGBTQ2S+, Indigenous residents, and those with language barriers (Stall et al., 2020). Restrictive visiting times may exclude some designated caregivers due to other demands in their lives (e.g., employment, education, caring for others). The participants in this study were not unusual in that women comprised most of the designated caregivers. Women are over-represented among those who provide higher intensity care in terms of number of hours of care per week (Chappell, Penning, Kadlec, & Browning, 2023). Restrictions on access, such as specific hours and days, may have a greater impact on women who are juggling various paid and unpaid roles. Diverse designated caregivers need to be empowered to be involved in health policy decision-making affecting access, such as through individual and family consultation, direct family engagement in decision-making process and policymaking (Gaugler & Mitchell, 2022) and ensuring adequate technological and staff resources to support bi-directional communications between designated caregivers and staff.

While some designated caregivers spoke poignantly about the challenges around visiting a relative in a nursing home at the end of life, others had positive experiences where nursing homes enacted palliative processes which involved fewer visitor restrictions. Others have suggested that visiting policies should be flexible during the end of life in a nursing home (Schlaudecker, 2020; Stall et al., 2020). Additional inquiry is needed about family and friend involvement at the end of life in nursing homes during times of infectious disease outbreaks, especially within the context of limited staff resources in nursing homes (Bolt et al., 2021).

Our approach was unique in the ways it was able to trace changes in caregiver access restrictions throughout the second year of the COVID-19 pandemic. It also revealed the cumulative negative impacts of restrictions for designated caregivers during a prolonged pandemic COVID-19 pandemic. Our research reveals the need for policymakers to consider the long-term impacts of 'emergency' policy responses. We acknowledge that this is easier in hindsight; however, our hope is that policies and practices will be developed to prioritize the essential role of designated caregivers in nursing homes. It is essential that procedures are in place to maintain supportive exchanges between residents and their family members in future infectious disease outbreaks. Said simply, designated caregivers should never be locked out again.

While there were many strengths inherent in this qualitative study, we also acknowledge some limitations. In other phases of our research, we collected data from additional stakeholders (e.g., visitors without designated caregiver status, and staff). At the same time, in this article, we focused on the perspective of designated caregivers. A primary reason for this is that only designated caregivers were interviewed across all three points of time, because of their sustained and intensive one-on-one relationships with residents. We did not include data from staff interviews because they did not provide insights on caregivers' perceptions and experiences of restrictions. We could not collect data from residents in this research undertaken during the COVID-19 pandemic; garnering their perspective on visiting is also important. Finally, there is a need to continue examining how policies related to access are implemented and how a family-centered perspective is utilized.

Conclusions

Restrictions to access generally had a cumulative negative perceived impact on both resident and family physical and mental health underscoring the essential role that designated caregivers in nursing homes. Overall, our findings reveal the multiple ways in which designated caregivers are more than 'just visitors' in nursing homes; rather, their supportive exchanges are crucial in maintaining the health and well-being of residents, their relations with family and social networks (including with staff), and the operation of nursing homes. These essential roles should be protected and considered rights, rather than privileges that can be revoked or obligations that can be exploited in times of emergency (Kusmaul, Miller, & Cheon, 2022).

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