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Navigating (Long-Term) Care in Crisis: A Critical Ethnography of Care Partners in a Pandemic

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Article

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Abstract

The COVID-19 pandemic highlighted significant vulnerabilities in long-term care (LTC) homes, severely impacting residents and care partners. This study investigates how care partners of older adults living in Ontario LTC homes perceived residents' experiences during the COVID-19 pandemic, and how those perceptions shaped their own caregiving experiences. Using critical ethnography, we identified four key themes: (a) masks and miscommunication, (b) loneliness and loss, (c) from interaction to isolation, and (d) loss of the advocacy role. Supportive actions included transparent masks, increased allied health professionals, and enriching daily programs. These findings emphasize the need for policies that balance infection control with the emotional and social needs of LTC residents, addressing power imbalances, ageism, and systemic inequities.

Résumé

La pandémie de COVID-19 a mis en évidence d'importantes vulnérabilités dans les foyers de soins de longue durée (SLD), affectant gravement les résidents et les partenaires de soins. Cette étude examine la façon dont les partenaires de soins des personnes âgées vivant dans les foyers de SLD de l'Ontario ont perçu les expériences des résidents pendant la pandémie de COVID-19, et comment ces perceptions ont influencé leurs propres expériences en tant que soignants. En utilisant l'ethnographie critique, nous avons identifié quatre thèmes clés: (a) les masques et la mauvaise communication, (b) la solitude et la perte, (c) la rupture des liens sociaux, et (d) la perte du rôle de porte-parole. Les mesures de soutien comprenaient des masques transparents, l'augmentation du nombre de professionnels paramédicaux et l'enrichissement des programmes quotidiens. Ces résultats soulignent la nécessité de mettre en place des politiques qui concilient la lutte contre les infections et les besoins émotionnels et sociaux des résidents des établissements de soins de longue durée, en s'attaquant aux déséquilibres de pouvoir, à l'âgisme et aux inégalités systémiques.

Introduction

Long-term care (LTC) homes, also known as nursing homes, care homes, and residential care facilities, were disproportionately impacted by the COVID-19 pandemic (Kuy et al., 2020). Older adults in these settings faced an elevated risk of contracting the virus and experiencing severe adverse outcomes, including hospitalization and death, due to pre-existing conditions such as frailty (Resciniti et al., 2021). During the first wave of the pandemic (i.e., March to June 2020), LTC residents and staff accounted for over 80% of the total Canadian deaths and infections (Canadian Institute for Health Information, 2021). Overall, people aged 65 and older comprised 93% of deaths in Canada between March 2020 and May 2021 (Government of Canada, 2021).

Due to COVID-19 being spread through airborne particles and droplets released during exhale, it was believed that visitors to LTC were the vectors introducing SARS-CoV-2 into this setting (McMichael et al., 2020). Despite limited evidence to this effect, provincial governments swiftly enacted strict public health measures to mitigate infection risks in LTC (Hsu & Lane, 2020). Many provinces limited LTC visits to only essential visitors, defined as those visiting residents who were palliative (Government of Ontario M. of H. and L.-T. C., n.d.). Protocols were implemented to require COVID-19 testing, procedural mask use, and restrictions on certain physical contact, such as directly facing residents (Stall et al., 2020).

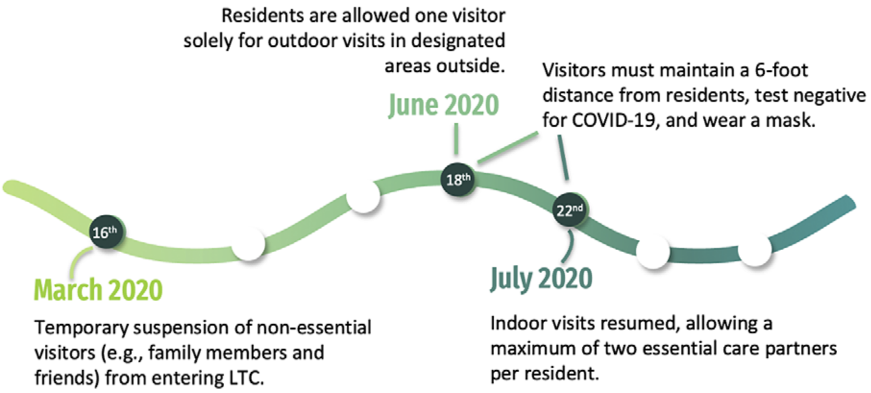

Figure 1. Visitor restrictions in Ontario LTC homes during the COVID-19 pandemic.

However, these public health measures largely overlooked the essential caregiving roles of family members and friends, treating them as merely visitors rather than as integral components of resident care and as relational care providers (Chu et al., 2022, 2023). Figure 1 illustrates the progression of visitor restrictions in Ontario's LTC homes during this period.

LTC homes confronted a combination of resident-level, facility-level and policy-level challenges that compounded into a crisis (Carbone et al., 2023). At the resident level, congregate living and underlying health conditions increased outbreak risk, while visitor restrictions further contributed to isolation (Stall et al., 2020). Efforts to enforce physical distancing were constrained by overcrowding and limited space for isolation (Li et al., 2023). For residents living with dementia, infection control measures posed additional challenges, as they often struggled to remember the rationale behind wearing masks or maintaining physical distance (Kirkham et al., 2022).

At the facility level, pre-existing resource limitations were exacerbated by the pandemic. Many LTC homes faced severe shortages of personal protective equipment (PPE), such as masks, gowns, goggles, gloves, and hand sanitizer, forcing staff to reuse PPE and increasing the risk of transmission (McGarry et al., 2020). Staffing shortages, already a major issue in LTC, worsened due to high rates of burnout and illness, leading to increased absenteeism (McGarry et al., 2020). Many LTC homes also lacked dedicated, trained infection control personnel to implement effective pandemic management strategies.

At the policy level, inconsistent and unclear guidelines across jurisdictions on infection control, PPE usage, and visitation policies created confusion and hindered effective pandemic response (Peters et al., 2020). Many LTC homes were also inadequately prepared for a large-scale pandemic due to the absence of comprehensive emergency plans or disaster response protocols (Estabrooks et al., 2020).

Prior to the COVID-19 pandemic, many LTC residents received daily or weekly visits from a care partner, typically a family member or friend, who played a vital role in their care (Bethell et al., 2021). In Ontario, the implementation of stringent visitor restrictions, from the complete prohibition of visitors in mid-March 2020 to the gradual introduction of scheduled outdoor visits in June and limited indoor visits in July, illustrated the drastic measures taken to curb the spread of the virus (Government of Ontario, M. of H. and L.-T. C., n.d.). Data from 30 family care partners in Ontario and British Columbia revealed a decline in both the frequency and duration of visits to LTC homes during the COVID-19 pandemic (Chu et al., 2023). Before the pandemic, 33.3% visited 4-7 times per week, and 23.3% visited more than seven times per week, with the average visit lasting 135 minutes (SD = 72.4, range = 0-360 minutes). During the pandemic, average visit duration dropped to 81 minutes (SD = 75.6, range = 0-300 minutes), reflecting significant restrictions on in-person contact (Chu et al., 2023). As such, the prolonged separation of residents from care partners had measurable physical, cognitive, and emotional consequences for residents and families alike (Chu et al., 2023). Public health measures thus severely disrupted the crucial roles played by care partners in LTC homes (Bourbonnais et al., 2024).

The introduction of visitor restrictions sparked critiques and controversies as it threatened the relationship- or family-centred care philosophy (Dupuis-Blanchard et al., 2021). Care partners play a crucial role in maintaining the social and health outcomes of residents (Dupuis-Blanchard et al., 2021). Their responsibilities range from basic daily care, such as helping with mealtimes and personal hygiene, to communication, assistance with functional and cognitive needs, and decision making (Chu et al., 2023).

Yet, as Conklin et al. (2024) argue, the exclusion of care partners from LTC settings during COVID-19 was a form of structural violence, one that exacerbated existing inequities and overlooked the relational nature of care. Several studies have shown that the pandemic and its related policies caused significant changes, with psychological distress being a common outcome (Bourbonnais et al., 2024; Cooke et al., 2022; Dupuis-Blanchard et al., 2021). The inability to provide in-person care and limited access to alternative remote communication methods left care partners feeling socially isolated and emotionally strained, leading to a reduced quality of life for both residents and care partners (Chu et al., 2023; Dupuis-Blanchard et al., 2021).

Even before the pandemic, high levels of burden associated with caregiving were widely reported (Huang, 2022). Despite this, care partners' advocacy during this period also illuminated the urgent need to formally recognize their roles as essential, not optional, components of the LTC workforce (Chu et al., 2023). While several studies have examined the experiences of care partners during COVID-19 across Canada, including in Ontario (Chu et al., 2023), further research is needed to deepen our understanding of how these policies affected care partners' perceptions of residents' well-being and to elicit actionable recommendations for future infectious disease outbreaks and crises.

Focusing on Ontario allowed for a contextually grounded analysis of pandemic-era visitor restriction policies in a province that experienced one of the highest COVID-19 death rates in LTC in

Canada (CIHI, 2021), and where care partner advocacy led to the creation of the Essential Caregiver role in 2021 (Conklin et al., 2024). This research provides an in-depth examination of Ontario's LTC-specific public health directives and their implications for relational care to contribute a nuanced understanding of care partners' experiences in Ontario's policy landscape and offer transferable insights for future crisis response. Previous studies in the provinces of Quebec (Bourbonnais et al., 2024) and British Columbia (Cooke et al., 2022) highlighted unique demographic, infrastructural, and health care dynamics that influenced the outcomes of such policies. A focused study on Ontario can provide insights into mitigating these effects in future health crises.

Building on this existing literature, the aim of this study was to explore the experiences of care partners of older adults living in Ontario LTC homes during the COVID-19 pandemic, with a focus on how their perceptions of residents' experiences shaped their own caregiving roles and emotional well-being. Using critical ethnography, we examined how care partners interpreted the pandemic's impact on residents' physical, psychological, and sociocultural well-being. Additionally, we sought their recommendations for policies and practices to support resident and care partner well-being in future public health emergencies.

Methods

Study design

Critical ethnography is a qualitative research method and theoretical framework that seeks to examine cultural discourses in an effort to recommend actions to address power inequities (Ross et al., 2016). James Spradley's ethnography aims to investigate dialectical relationships between structural constraints on human actors and its impact on human agency (Spradley, 1979). This research method allows researchers to study how people are influenced by sources of domination and repression within their culture and to give them a voice (Spradley, 1979). For this study, human actors were the care partners of residents in LTC in Ontario, while the culture was the LTC context amid the COVID-19 pandemic. Although residents were not directly involved as participants due to COVID-19-related restrictions, they remained central to the study as care partners reflected on and interpreted residents' experiences during this period. Using a critical ethnography, we aimed to describe care partner acculturation during the COVID-19 pandemic by critically examining and addressing the power dynamics, social injustices, and norms, values, and institutional practices that shaped care partners' marginalization within the culture of LTC homes (Spradley, 1979). The project was approved by the Bruyère Health Research Ethics Board (Protocol #M16–21-023). For the present study, we re-engaged participants from a prior survey study examining patterns of caregiving in LTC (Ménard et al., 2025), in which they had indicated willingness to be contacted for future research. We reiterated the study's purpose, explained how the data would be used, and obtained additional oral informed consent for participation in the interview phase. Ethics approval covered both the original survey and the interview components.

Setting and participants

We recruited care partners of residents living in LTC homes in Ontario, Canada, using a combination of snowball and purposive sampling. Participants were primarily recruited through a related survey-based study (Ménard et al., 2025) involving care partners to residents in LTC, who had consented to be contacted for follow-up studies. In addition, we reached out to several organizations, including Family Councils Ontario, *Réseau francophone des Conseils de familles Ontario*, and LTC homes in the province, who kindly agreed to circulate our recruitment flyer through their monthly newsletters to families and friends of residents. Interested individuals were invited to e-mail the research team for more information on the study and provided oral consent to participate in an interview. To be included in the study, participants had to provide care to an individual over the age of 65 residing in LTC in Ontario and be able to communicate in French or English. All participants received $30.00 compensation for their involvement in the study.

Positionality

The research team acknowledges that their diverse professional and personal backgrounds shaped their perspectives in this study. The lead author brings expertise in aging and dementia care, informed in part by her personal caregiving experience for her grandmother, who lived in LTC until her death in 2016. Co-author SM also provided care to her mother in LTC prior to the COVID-19 pandemic. These experiences enhanced our sensitivity to the emotional, social, and structural dimensions of caregiving. However, consistent with Spradley's ethnographic methodology, we sought to adopt the role of observers rather than experts, aiming to understand the cultural meanings and lived experiences of care partners from their own perspectives, not filtered through our own assumptions or prior roles (Spradley, 1979). We do not compare different types of lived experience but rather distinguish between experiential knowledge and methodological practice to ensure reflexivity and interpretive clarity. While none of the team members had firsthand experience providing care to a loved one in LTC during the global pandemic, the team includes experts in health care research, long-term care practice, and caregiving, each contributing unique insights into the experiences of care partners during this unprecedented time. In line with best practices in reflexive ethnography, we have been mindful of our own positionalities throughout the research process to better center the voices of participants. These varied perspectives inform the study's approach to understanding the impact of the pandemic on both care partners and residents in Ontario LTC homes.

Data collection

Data were collected between June 28 and August 12, 2021, a period marked by fluctuating COVID-19 case rates and evolving public health guidelines, through 21 semi-structured ethnographic interviews conducted by the primary author (AM) who is a doctoral candidate. During our study period, the 'no visitor' policy was gradually replaced by more lenient protocols. Care partners were required to test negative for COVID-19 upon entering the home, masks were mandatory for everyone, and up to two visitors per resident were allowed, with outdoor visits being encouraged (Stall et al., 2020).

This study employed James Spradley's critical ethnography as both a theoretical framework and methodological approach (Spradley, 1979). Spradley's method focuses on uncovering the cultural knowledge of a group through systematic and structured techniques, emphasizing participants' perspectives and the meanings embedded in their experiences (Spradley, 1979). Spradley's approach aligns with the aim of our study, allowing us to prioritize the narratives of care partners during the COVID-19 pandemic. By doing so, we revealed how their perceptions of residents' experiences informed and shaped their own caregiving realities.

As a theoretical framework, Spradley's ethnography guided the exploration of caregiving experiences during the COVID-19 pandemic, emphasizing the ontological and epistemological dimensions of caregiving in LTC settings. As a methodological approach, it informed the structured design of ethnographic interviews, domain analysis, and subsequent thematic analysis.

Using James Spradley's ethnographic interview method, we facilitated participants in actively organizing information while guiding the discussion with descriptive, structured, and contrasting ethnographic questions (Spradley, 1979). We ensured respect of the following principles of ethnography: (a) humility and open exploration (by approaching interviews with a genuine curiosity about participants' lived experiences), (b) revising pre-conceived ideas (by remaining open to unexpected narratives that challenged our assumptions), (c) attentiveness to context (by situating participants' experiences within the unique structural and emotional conditions of the pandemic), and (d) the relationality of interviews (by fostering trust and reciprocity during interviews through shared emotions, recognizing the co-constructed nature of ethnographic knowledge generation) (Spradley, 1979). An interview guide was developed using an ethnographic conceptual framework to uncover the ontological (i.e., the nature of being) and epistemological (i.e., the scope of knowledge) underpinnings of caregiving during a global pandemic (Spradley, 1979). This guide was created by co-author (AB), who conducted a similar study in Quebec (Bourbonnais et al., 2024). The interviews were conducted with the mindset that there was much to learn from the care partners' self-narratives, and that their perspectives might uncover aspects not anticipated in the study's initial framing. The interviews were conducted in two parts: (a) structured sociodemographic questions (e.g., age, gender and marital status) about the care partner and resident, and (b) open-ended questions. Following Spradley's ethnographic method, the second part of the interview was organized around three types of ethnographic questions (Spradley, 1979): (a) descriptive questions (e.g., 'Can you please describe your experience as a care partner to a relative living in LTC during the pandemic?') to elicit broad accounts of caregiving; (b) structured questions (e.g., 'How did the pandemic affect your physical and mental health as a care partner?') to explore how participants organized their experiences; and (c) contrasting questions (e.g., 'What changes did you experience as a care partner during the pandemic, and were these changes consistent throughout each wave of the pandemic?') to uncover perceived changes or differences. These categories allowed us to facilitate deep, reflective dialogue while guiding the interview with structure and cultural sensitivity. Field notes were also taken during and immediately after interviews to describe interviewer observations of participant emotions. Throughout the interview, these emotions, reflections, and commonly used terms were carefully noted to better capture and illustrate their experiences.

The ethnographic disposition guided the interview process to be flexible, evolving as the interviews revealed new perspectives on the impact of COVID-19. This approach allowed care partners' concerns, whether directly related to the research topic or not, to shape the narrative and deepen the understanding of their lived experiences. The interviews were sensitive to the environment in which care partners experienced caregiving, paying attention to how external factors (like COVID-19 restrictions) influenced their responses.

Interviews were conducted virtually via telephone (n = 5), Zoom (n = 14), Microsoft Teams (n = 1), and FaceTime (n = 1) based on the participant's preference, in adherence to public health measures. Upon obtention of participant consent, interviews were audio recorded (M = 46.2 minutes ±19.9) and transcribed using NVivo Transcription. The interviewer (AM) received training in ethnographic interviewing from experts at the Université de Montréal. This training included a review of Spradley's theoretical and methodological framework, mock interviews, and feedback sessions focused on the application of descriptive, structural, and contrasting questions (Spradley, 1979). To ensure fidelity to Spradley's method, the first interview was observed by three qualitative experts, who provided structured feedback and formally approved the interviewer's approach prior to resuming interviews. Additionally, a master's-trained nurse provided training on identifying verbal and non-verbal indicators of participant distress and responding appropriately. To further support participant well-being, participants were provided with a list of resources, including peer support, care partner toolkits, and suicide hotlines, both prior to and following their interview. Supplementary Material 1 presents the full interview guide and distress protocol.

Data analysis

All data were coded inductively in NVivo using a prefix based on one of four ethnographic groups (i.e., actions, experiences, context, or impact) as described by Spradley. These groups further reflected our engagement with the cultural domain under study and guided the construction of the analytical framework. Following Spradley's domain analysis approach (Spradley, 1979), the first and second author generated an initial codebook after coding five transcripts independently. Codes were then grouped into three hierarchical layers: (a) a cover term (i.e., the overarching concept or parent code), (b) included terms within the domain (i.e., descriptive subcodes or child codes capturing specific aspects of the cover term), and (c) a semantic relationship linking the included terms to the cover term (e.g., strict inclusion: 'toileting' is a kind of 'PSW role') (Onwuegbuzie et al., 2009).

The codebook was refined iteratively through team meetings involving three co-authors, where discrepancies were resolved by consensus to ensure consistency and alignment with Spradley's nine universal semantic relationships: (a) strict inclusion (i.e., X is a kind or example of Y), (b) spatial (i.e., X is a part of Y), (c) cause-effect (i.e., X is a result of Y), (d) rationale (i.e., X is a reason for doing Y), (e) location for action (i.e., X is a place for doing Y), (f) function (i.e., X is used for Y), (g) means-end (i.e., X is a way to do Y), (h) sequence (i.e., X is a step in Y), and (i) attribution (i.e., X is an attribute of Y) (Onwuegbuzie et al., 2009).

As patterns emerged, domains were organized into taxonomies based on the relationships listed to visualize how included terms clustered under cover terms and how domains related to one another. Cover terms were grouped if they shared a common characteristic (e.g., pertained to an experience wearing PPE). In accordance with Spradley's ethnographic framework, terms were interpreted in relation to their use within the broader cultural context (i.e., the COVID-19 pandemic) (Jones & Smith, 2017). A taxonomic analysis was then conducted to further organize domains, followed by componential analysis (Kenny et al., 2006) to identify similarities and differences across pandemic periods (e.g., Waves 1, 2, 3, and pre- or post-vaccination). Finally, a thematic analysis (Nowell et al., 2017) was used to synthesize recurring patterns and unique experiences, characterizing the caregiving context and cultural environment (Spradley, 1979). Themes were synthesized from taxonomically organized domains to highlight both common patterns and divergent experiences, deepening our understanding of the caregiving environment. This analysis also incorporated the interviewers' field notes taken during and immediately following each interview. These notes captured observations related to emotional intensity, sentiment (i.e., whether emotions expressed were positive or negative) and expressive cues such as crying, changes in voice tone, and emotive language. These non-verbal and paralinguistic cues allowed us to map the emotional landscape of care partner experiences during the pandemic. Additionally, biweekly team meetings between AM, AHS, and ATH were held to support cross-coding consistency and to discuss emerging domains and themes. Data saturation was reached when no new codes or themes emerged from the interviews (Saunders et al., 2018). Supplementary Material 2 presents our ethnographic codebook with examples of domains and included terms.

Rigor

Rigor was maintained throughout the study using established qualitative research practices (Johnson et al., 2020). A semi-structured interview guide was utilized and iteratively adjusted based on emerging insights, ensuring that questions remained relevant to participant lived experiences and the study's evolving context. Reflexivity was central to this process; the primary author kept a reflexive journal, documenting memos after each interview. These memos detailed observations about interview dynamics, including tone, rapport, and potential biases that could influence participants' storytelling (Olmos-Vega et al., 2023). This reflexive approach ensured ongoing awareness of the researcher's positionality and its impact on the research process (Olmos-Vega et al., 2023). Member reflection was employed to enhance credibility. Findings from earlier interviews were shared with subsequent participants, allowing them to engage with, validate, or critique emerging themes. This approach offered participants the opportunity to provide alternative perspectives and interpretations, enriching the data and ensuring the findings reflected diverse experiences (Olmos-Vega et al., 2023). Contextual sensitivity was also upheld in alignment with ethnographic principles, acknowledging and integrating cultural, social, and personal factors that shaped participants' narratives (Olmos-Vega et al., 2023).

Results

Participant sociodemographics

Most study participants were self-identified women (n = 13, 62%) with a mean age of 67.8 ± 11.6 years. The majority self-reported as White (n = 19, 90%) and retired (n = 13, 62%). A significant portion were landed immigrants (n = 5, 24%), and several identified as francophone (n = 4, 19%). Care was primarily provided to parents (n = 10, 48%), followed by spouses/partners (n = 8, 38%), friends (n = 2, 10%), and grandparents (n = 1, 5%). Among residents who they visited and cared for, most were female (n = 15, 71%) with a mean age of 85.6 ± 11.4 years. They had typically been in LTC for 4.3 ± 3.0 years, and the majority were alive at the time of the interviews (n = 17, 81%).

Themes

We identified four overarching themes that encapsulate both the experiences of care partners and their perceptions of the well-being of residents in LTC homes during the COVID-19 pandemic. These themes illustrate how the pandemic affected the physical, psychological, and sociocultural well-being of residents, as reported by their care partners: (a) masks and miscommunication, (b) loneliness and loss, (c) from interaction to isolation, and (d) loss of the advocacy role. Care partners then recommended three supportive actions to address future infectious disease outbreaks: (a) use of transparent masks, (b) increased presence of allied health professionals in LTC, and (c) programs to enrich residents' daily lives. Figure 2 illustrates a care partner's journey in LTC during the first

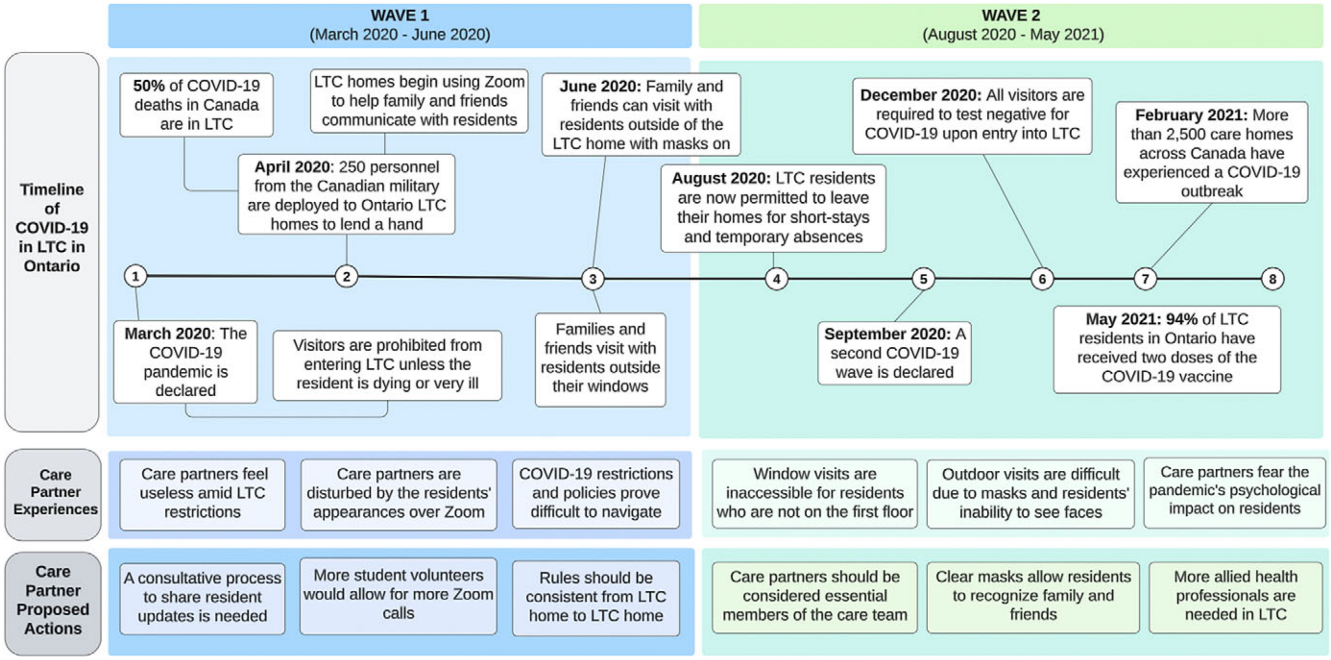

Figure 2. A care partner's journey in LTC in Ontario during the COVID-19 pandemic.

and second waves of the COVID-19 pandemic in Ontario, highlighting each theme and the corresponding supportive actions, suggested by care partners.

Before presenting the themes, we briefly introduce two recurrent emotional and behavioural responses observed by care partners: grief and behavioural disturbances. Grief, in this context, refers to the profound emotional distress experienced by residents in response to loss, most notably the deaths of spouses or fellow residents during the pandemic. Care partners described manifestations of grief such as visible sorrow, crying, or expressions of longing, often exacerbated by the lack of formal bereavement supports. Behavioural disturbances, meanwhile, encompass observable changes in mood and conduct, including increased agitation, disrupted sleep, and loss of appetite, which care partners interpreted as manifestations of emotional suffering, isolation, and despair. These observations offer critical insight into the emotional and psychological toll of the pandemic on residents and lay the foundation for the themes that follow.

Theme 1: Masks and miscommunication.

From the perspective of care partners, PPE, particularly masks, posed significant challenges for residents in LTC. Participant FS04 noted, ‘I think that the residents had great trouble. I still think they do. It’s the masks. They cannot hear anything’. Care partners expressed concerns that masks hindered residents’ ability to communicate effectively with staff, limiting conversations to simple yes or no responses. One care partner described how they believed visual and auditory impairments further complicated these challenges during virtual or outdoor visits:

> At the present time I am only able to have Skype calls with my mother. Due to my mom’s macular degeneration and hearing loss, and her distress and discomfort with the surgical mask, the outdoor visits in the noisy sunny garden are torture for her. We have to sit far apart; she cannot see or hear me well especially since my face is masked (Participant FC08).

Moreover, care partners felt that the introduction of full PPE gear (including masks, face shields, gloves, goggles, and gowns) prevented residents from recognizing their family members during visits: ‘Last summer we got to go outside but you had to be masked and six feet away. He did not even recognize me’ (Participant MS01).

To illustrate the impact of mask-wearing on residents living with dementia as perceived by care partners, one care partner shared a poignant account: ‘A friend of mine’s sister lives in this home. She has dementia and cannot wear a mask. As soon as we try to put the mask on her, she starts to panic. And so, for months, she could not take her sister outside because her sister could not wear the mask. And yet, she could have accompanied her sister to the elevator, assured that no one else was there, gotten off and gone straight to the garden’ (Participant FS01).

These narratives reflect care partners’ interpretations of how PPE requirements in LTC ultimately disrupted relational continuity with residents. While essential for infection control, such measures were seen by care partners as barriers to effective communication and connection, thus hindering their ability to interact meaningfully with residents, and in some cases, even to be recognized by them.

Theme 2: Loneliness and loss

Care partners highlighted that many residents experienced profound unresolved grief following the loss of their friends, partners/spouses, and neighbours who contracted COVID-19 during outbreaks in LTC. ‘Since the death of his wife who also lived in the same home and, since he did not really have any care for his bereavement, I think he suffered a lot’ (Participant FS01). Compounding this grief, according to care partners, was the residents’ lack of awareness about visitor restrictions and their limited understanding of COVID-19 as a deadly virus. Care partners shared that many residents mistakenly assumed that their friends and relatives had died from COVID-19, as they did not visit due to the restrictions. Care partners noted that these misunderstandings fostered feelings of abandonment and significantly heightened the emotional distress and grief experienced by residents.

> ‘My mother was mentally depressed. Very sad. Very, very sad. Even though she had dementia, she knew something was wrong. She knew we were not there. She had a little bit of anger, I think, and she wasn’t angry before [the pandemic]’ (Participant FC03).

Three care partners expressed concerns that their friends and relatives seemed to be ‘letting themselves die’ (Participant FGC01) due to the absence of visits, describing increased sleep duration and refusal to eat as signs of this despair: ‘The depression really took over. The loneliness and the isolation…he did not have a will to eat anymore. You know, we saw very quickly that he was really weak and declining and that he really lost everything to look forward to, every reason he had for keeping himself alive’ (Participant FGC01). The care partners noted that this despair was not only due to the lack of social interactions but also compounded by the severe isolation imposed by the pandemic restrictions. Residents were confined to their rooms with no communal activities or dining and were often left not understanding why they were being kept alone all day. One care partner referred to this condition of resident despair as ‘Covid loneliness’ (Participant MC03), attributing it to the death of his mother:

> She did not have COVID, but I think she died of COVID loneliness. Even when I went in, she could not talk. She used to talk but now, I could barely understand her. But at least she knew we were there. The dog used to jump up on the bed…but then we just stopped going (Participant MC03).

These narratives underscore the profound toll that social isolation and loss took on residents’ emotional and psychological well-being within LTC settings during the pandemic, according to their care partners, revealing the deep-seated impact of unresolved grief.

Theme 3: From interaction to isolation

During the COVID-19 pandemic, care partners observed that all residents in LTC were confined to their rooms to mitigate viral transmission. Simultaneously, all resident activities and communal dining were suspended, which care partners reported exacerbated the loss of mobility and cognition among many residents. They noted a heightened incidence of health concerns, such as bed sores, ingrown toenails, and exacerbated incontinence, underscoring the impact of prolonged confinement and reduced activity on residents’ physical well-being. Care partners observed their friends and relatives experiencing difficulties in clear communication and lucidity due to prolonged social isolation:

> *He is a very social person. And then, for the first few months of the pandemic, he had to stay in his room all day. He was not allowed to communicate with even the resident who has the room opposite him. There was no social activity for them. And so, if someone did not have*

> *dementia at the start of the pandemic, one can well imagine the inevitable decline for someone who is deprived of a social life for so long (Participant FS01).*

In addition to social isolation, care partners emphasized that visitor restrictions during the pandemic deprived residents of essential physical touch, which they considered crucial for their well-being, and also caused significant emotional turmoil for the care partners themselves:

> *I think that the worst was the lack of human contact for everybody. You could not even hold hands. Even when we got to do outside visits, you could not. One poor man waved at me because he recognized me but did not recognize his own son. He started wheeling towards his family and the staff had to come and grab him and pull him back and put the brakes on his wheelchair. That was really hard. We all need that physical contact. My wife would reach out to us. She wanted to grab our hands or something, right? And we could not because of the glass (Participant MS01).*

As shared by care partners, many residents experienced heightened agitation, frustration, and feelings of abandonment due to visitation restrictions, which, in turn, took a profound emotional toll on care partners. Many described intense guilt over placing their relative in LTC and a deep sense of helplessness as they witnessed their loved ones suffer in isolation. One care partner shared the emotional turmoil she experienced during this period:

> *She did not really want to go into long-term care. And then, when she ended up there, because of the pandemic, she could not have any visitors [crying]. She did not understand that there was a pandemic, so as far as she was concerned, she'd been put there so they could take care of her instead of us. So, I got a few calls from the doctor saying 'what do we do? Do we let her die?' Naturally, selfishly, I wanted to keep her [crying]. It was just a really difficult time* (Participant FC05).

Care partners believed that the lack of social interaction and physical contact not only led to emotional distress but also seemed to accelerate the physical and cognitive decline of residents. According to these beliefs, this sense of isolation highlighted the crucial role that human interaction and touch play in the overall well-being of LTC residents. Moreover, the enforced isolation highlighted the need for better pandemic preparedness in LTC, ensuring that the social, psychological and emotional needs of residents are considered alongside infection control measures in future health crises.

Theme 4: The loss of the advocacy role

Resident loneliness emerged as a major concern for care partners amidst COVID-19 restrictions in LTC. Despite being permitted to videoconference with residents once per week, care partners voiced concerns that their friends and relatives often felt confused during these calls and did not benefit from the virtual contact. Care partners shared that many residents struggled to interact effectively with the screen, hindering their ability to benefit from virtual social interactions.

> *Different social workers would facilitate the Zoom call each week and some social workers were really good in terms of having conversations with my grandpa and my family that was on Zoom. But then other social workers kind of just set up the technology and sat there and, you know, it was difficult for my grandfather to hear and understand and make sense of the conversations that were happening (Participant FGC01).*

Another significant worry expressed by care partners was their loss of advocacy on behalf of residents. Care partners feared that without their physical presence in the LTC home, residents' needs might go unmet or inadequately communicated to staff.

> *I rely on nurses to update me by phone if she has any problems or injuries. That's all. There is nothing I can do for her because of the restrictive rules on visits. But no one is doing for her what I used to. I have often been appalled by seeing how unkempt she looks, how drugged and zombie-like, and her long and dirty fingernails, during Skype calls. There is nothing I can do about it (Participant FC08).*

This sense of powerlessness and frustration was echoed by many care partners. Participant FS01 succinctly captured these concerns, stating, 'For me, it is a very obvious discrimination against vulnerable people who were not able to advocate for themselves. And, I find that there is no other health sector where we would have allowed such discrimination against the elderly and the vulnerable' (Participant MC01). The emotional toll of the COVID-19 pandemic was significant, as residents felt abandoned, according to care partners, who were unable to provide the necessary advocacy and support. 'The older we get, the more we realize how important it is not to abandon these people' (Participant FC05). This ageist neglect underscored a broader societal failure to value and protect LTC residents, many of whom are older adults, exacerbating their sense of isolation and vulnerability during an already challenging time.

Supportive actions for future pandemics

At the end of each interview, care partners were explicitly invited to share their own recommendations for supportive actions they expected to see on behalf of the LTC homes, local governments, public health units, and/or the public in the event of future pandemics. The supportive actions described in this section reflect both direct participant suggestions and thematic interpretations derived by the authors from participants' narratives. These actions are organized in relation to the key issues that participants identified as impacting the well-being of residents and care partners during the COVID-19 pandemic. Importantly, many care partners offered recommendations aimed at improving the well-being of residents, often prioritizing residents' needs over their own.

Supportive Action 1: Use of transparent masks

Care partners valued the introduction of masks or face shields that were clear and transparent because they enabled residents to see the speakers' mouths, facilitating better communication between residents and staff, as well as between residents and care partners. Unlike traditional masks, transparent masks and face shields did not obscure care partners' faces to the extent that residents could not recognize them, thereby reducing confusion. Transparent masks allowed residents to rely on lip reading and the analysis of facial expressions – critical communication tools that are lost behind opaque masks. This improved visual and emotional connection, making interactions more meaningful and less disorienting for residents. Consequently, many care partners recommended that care homes maintain transparent masks readily available for visitors in the future, particularly during influenza outbreaks. This practice was recommended to enhance the quality of resident-care partner interactions, reduce anxiety, and improve overall well-being for both parties.

Supportive Action 2: More allied health professionals in LTC

Care partners recognized the dedication and resilience of LTC staff, who, despite the immense challenges and risks associated with COVID-19, continued to provide essential care and made notable efforts to facilitate videoconferencing between residents and their families during visitation restrictions. However, they also advocated for increased staffing of allied health professionals in LTC settings. This enhancement was described as crucial to mitigating the health decline experienced by residents due to prolonged room and bed restrictions during the pandemic. By bolstering the presence of allied health professionals, care partners believed that the quality of care would be significantly improved, addressing both the physical and emotional toll on residents. They foresaw significant physical health consequences as a result of the pandemic and emphasized the necessity of additional allied health professionals to deliver essential physiotherapy, occupational therapy and rehabilitation services. They also voiced concerns about the psychological and emotional impacts of the pandemic on residents, highlighting the importance of professional support to comprehensively address these issues. Expanding the presence of allied health professionals, such as psychosocial and mental health specialists, could enhance residents' physical recovery and emotional well-being, promoting a comprehensive care approach in LTC that supports the needs of both residents and care partners.

Supportive Action 3: Programs to enrich residents' daily lives

Care partners advocated for initiatives to enrich the daily lives of residents and support them in navigating grief post-COVID-19. They emphasized the importance of ongoing efforts to enhance the lives of LTC residents, regardless of pandemic conditions. Suggestions included increasing the involvement of student volunteers, organizing personalized social activities, and actively engaging families in resident activities to foster enriching visits and combat resident loneliness.

Establishing regular feedback mechanisms from care partners to continually assess the effectiveness of implemented initiatives and ensure they remain responsive to evolving resident needs and preferences was also deemed beneficial. This feedback loop could inform adjustments and improvements to existing programs, fostering a dynamic and supportive environment within LTC.

Discussion

Our results highlight the essential role of care partners in the well-being of LTC residents, emphasizing their significant involvement in the lives of their friends and relatives. Compared to Chu et al.'s sample, which primarily included employed daughters of LTC residents aged 55–64, our study cohort was older, more often retired, and included a more diverse range of caregiving relationships, including spouses and friends (Chu et al., 2023). These differences likely shaped the caregiving experience and perspectives reported, emphasizing the importance of contextual variation in understanding caregiver narratives. Participants identified four overarching themes reflecting the impact of the COVID-19 pandemic on residents' experiences, as observed by their care partners: (a) masks and miscommunication, which reflects how the use of PPE hindered verbal and non-verbal communication; (b) loneliness and loss, capturing the profound emotional toll of restricted visitation and social isolation; (c) from interaction to isolation, illustrating the shift from meaningful engagement to a lack of connection with care partners and peers; and (d) the loss of the advocacy role, underscoring the exclusion of care partners from the LTC setting and its detrimental effects on resident care. These findings build on longstanding concerns in gerontology and health services research about chronic social isolation and the erosion of relational continuity in LTC, and show how COVID-19 restrictions intensified these issues through both physical separation and policy neglect (Cooke et al., 2022). Our findings echo key themes identified by Chu et al. (2023), including care partner distress, resident decline, and the loss of caregiving roles during COVID-19. However, our analysis extends this work by foregrounding the communication barriers posed by PPE, deepening the discussion of unresolved grief and failure to thrive, and explicitly framing the exclusion of care partners as a form of structural ageism and systemic discrimination. These insights contribute to a more clinically and politically attuned understanding of care partner and resident experiences during pandemic-related lockdowns in LTC. Our themes further mirror the trauma patterns described by Chu et al. (2022), including prolonged separation, inability to provide care, harmful interactions, and enduring powerlessness, while adding new dimensions related to communication, helplessness, and social isolation.

This said, positive aspects also emerged in our data, such as the adoption of transparent masks to improve communication and recognition of LTC staff's commitment to resident care. These findings highlight how care partners adapted to support residents despite significant barriers and offer lessons for building resilience and mitigating harm during future crises. Importantly, our findings support calls for a shift towards relationship-centered care models in LTC, which emphasize the collaborative roles of care partners, staff, and residents in enhancing well-being (Dupuis-Blanchard et al., 2021). This perspective extends family-centered care by recognizing the interdependence between residents and care partners as central, not peripheral, to care quality (Cooke et al., 2022). Integrating care partner voices into decision making can help address the power imbalances and systemic inequities exacerbated during the pandemic.

These emotional narratives also offer insight into the psychological and clinical dimensions of resident decline during the pandemic. Care partner testimonies described resident despair, emotional withdrawal, and relational loss. These observations, grounded in lived experience, can be understood through psychological and gerontological frameworks. For example, the poignant remark from participant MC03 that their relative 'died of COVID loneliness' can be interpreted not only as a symbolic articulation of loss but also as indicative of *failure to thrive*, a clinical syndrome in older adults characterized by weight loss, functional decline, and increased vulnerability, often in the absence of acute illness (Robertson & Montagnini, 2004). Similarly, care partner accounts of apathy, tearfulness, or disengagement align with the presentation of *depressive symptoms in dementia*, which are both underdiagnosed and undertreated in LTC (Dorfman et al., 2020). The recurring theme of social severance, including the loss of peer and familial bonds, reflects elements of *relational deprivation*, a form of psychosocial stress particularly detrimental to individuals with cognitive impairment, whose relationships often anchor identity and orientation (Fauth et al., 2012).

The structural conditions underlying these psychological harms were particularly evident in the strict visitor restrictions which disrupted relationship-centered care and highlighted ethical dilemmas about balancing infection control with resident mental health and well-being (Stall et al., 2020). These restrictions also revealed power asymmetries within LTC systems, where residents and their care partners had limited agency or input in shaping policies that profoundly affected them (Kortes-Miller et al., 2023). The consequences were profound: care partners recounted residents expressing suicidal thoughts, reflecting emotional distress, isolation, trauma, and abandonment, experiences echoed in the literature (Chu et al., 2022). The trauma of being a spectator to the residents' decline was also deeply distressing for care partners, as demonstrated in Chu et al.'s study.

Further, decisions made at higher levels of governance often excluded resident and care partner consultation, reinforcing their marginalization (Kortes-Miller et al., 2023). While many measures were implemented based on the best available evidence at the time, urgency led to decisions prioritizing institutional efficiency and risk aversion over residents' autonomy and rights (Estabrooks et al., 2020). These decisions reflect not only institutional practices but also structural ageism, a form of discrimination embedded in policies, norms, and governance structures that systematically devalue older adults and exclude them from meaningful participation in decisions affecting their lives (Farrell et al., 2022). Acknowledging the interplay between public health imperatives and embedded ageism is essential for developing inclusive, ethically grounded approaches to decision making in LTC during crises (Kortes-Miller et al., 2023).

The theme of *masks and miscommunication* highlights verbal and non-verbal communication barriers due to PPE use, consistent with calls for improved communication aids in LTC (Stall et al., 2020). The lack of tailored solutions for residents with sensory impairments or dementia echoes findings that these groups were often excluded from pandemic policymaking (Estabrooks et al., 2020). Similarly, the theme of *loneliness and loss* deepens existing literature on the psychological impact of isolation (Hindmarch et al., 2021) by sharing care partners' detailed accounts of abandonment and grief.

Physical distancing and visitor restrictions, coupled with reliance on Zoom and FaceTime and an insufficient supply of iPads, failed to meet the needs of residents with dementia or sensory impairments, especially those with limited digital literacy (Chu et al., 2022). While technologies were often positioned as substitutes for in-person visits, Chu et al. (2022) demonstrate the futility of poorly implemented virtual visits in LTC. Their findings highlight how systemic underinvestment in infrastructure, staffing, and digital literacy undermined the potential benefits of virtual connection (Chu et al., 2022). Care partners reported emotional distress, technical challenges, and a lack of support for residents with cognitive or sensory impairments, ultimately leaving many feeling helpless and excluded from care. Some families even discontinued virtual visits altogether due to the emotional harm they caused, a decision that brought significant guilt and grief (Chu et al., 2022). This underscores the ethical consequences of promoting technological solutions that are neither accessible nor appropriately supported within the LTC context. These gaps underscore the importance of applying a health equity lens to policymaking, considering the social determinants and functional realities of LTC residents.

The theme from interaction to isolation builds on relational continuity theory (Dyer et al., 2022), reinforcing the importance of consistent social connections for resident well-being. Care partners described how restricted visitation and staffing shortages reduced engagement, exposing tensions between infection control and resident autonomy. This highlights the need for a human rights lens, where autonomy is affirmed as fundamental to resident well-being (Bethell et al., 2021).

Finally, the loss of the advocacy role reflects systemic ageism and structural inequities, contributing to ongoing critiques of the designation of care partners as 'non-essential' (Baumann et al., 2024). Our findings echo previous calls to integrate care partners into policymaking as essential interest holders (Kortes-Miller et al., 2023). Regular consultation with LTC workers, residents, and care partners could have informed more responsive decisions. Establishing an advisory committee of these stakeholders could guide policy, especially in crises. There is also a notable gap in the literature on residents without visitors. For many, their primary social networks were peers and staff, who often acted as surrogate family (Bethell et al., 2021). The abrupt disruption of these relationships, compounded by staffing shortages that further diminished the presence of familiar care partners, warrants deeper investigation.

Excluding care partners unless a resident was critically ill or palliative disregarded their essential role in supporting daily living and well-being. For example, pandemic restrictions disrupted mealtime routines where shared dining fostered community and support. Even after restrictions eased, care partners were barred from dining spaces, ignoring the importance of shared meals (Keller et al., 2024). This 'non-essential' label not only undervalued care partners' contributions to daily care, emotional support, and advocacy but also perpetuated ageism by failing to recognize their role in maintaining dignity and quality of life (Hindmarch et al., 2021). The decision to restrict care partners in this manner reveals a structural bias that undervalues the significant, ongoing involvement of individuals who are integral to the well-being of residents, further compounding the neglect and marginalization experienced by residents in LTC (Baumann et al., 2024). Many care partners expressed deep frustration with the lack of consistent communication from LTC homes, particularly regarding visitation policies, resident health updates, and COVID-19 outbreaks. They often felt disempowered and excluded from key decisions, needing to advocate persistently to obtain even basic information. In many instances, their essential role was acknowledged only after sustained efforts or media attention, highlighting a systemic failure to meaningfully recognize and involve them (Chu et al., 2023).

Consequently, many care partners and researchers advocate for adopting a relationship-centered approach within LTC frameworks, departing from the current person-centered practice (Dupuis-Blanchard et al., 2021). This approach emphasizes applying social, cultural, and political perspectives to enhance the health and well-being of residents, promoting collaborative relationships among practitioners, staff, and care partners (Dupuis-Blanchard et al., 2021). Our findings support the theory of relational continuity in gerontology, emphasizing the crucial role of maintaining social connections for residents (Dyer et al., 2022). Pandemic-related visitor restrictions disrupted these connections, resulting in significant emotional and psychological impacts on both residents and care partners. This underscores the need for LTC policies that balance infection control with the preservation of residents' autonomy, liberty, and social interaction, moving towards a human rights-based and relationship-centered framework (Vernon-Wilson et al., 2023). Such an approach must address the power imbalances and structural inequities exposed during the pandemic, ensuring that residents and care partners are meaningfully included in both caregiving and policy decisions. It is important to acknowledge that this study captures residents' experiences through the perspectives of care partners, which may not fully align with residents' own views. Future research should directly engage residents to gain a more comprehensive understanding of their lived experiences.

Participants in our study also described communication breakdowns with LTC staff during the pandemic, often due to confusion surrounding rapidly changing visitor directives. These issues highlighted the lack of preparedness, insufficient funding, staffing shortages, and the erosion of trust between families and care teams, problems long present in Ontario's LTC system (Conklin et al., 2024). Still, the pandemic created opportunities to listen to care partners and act on their recommendations to improve LTC. For example, participants advocated for transparent masks to facilitate speech comprehension, lip-reading, and non-verbal communication, particularly for residents with hearing impairments or cognitive challenges. Transparent masks also challenge the ageist assumption that older adults must adapt to communication barriers, rather than receive appropriate accommodations (Kilaru & Gee, 2020). These efforts reflect a broader critique of top-down LTC governance and a demand for policy decisions that recognize older adults' communication preferences and sensory needs (Kilaru & Gee, 2020).

Participants also called for more allied health professionals in LTC homes, pointing to a persistent underinvestment in emotional, psychological, and social supports for residents. These priorities reflect a devaluation of relational care and an ongoing marginalization of residents' and care partners' voices.

This study contributes to ongoing efforts to center the lived realities of care partners in LTC and to amplify their recommendations for improving care during future infectious disease outbreaks, health emergencies, or pandemics. As one participant reflected: 'We as a society can be measured in how we care for those less able than ourselves. This is a good measure of society and we're failing. We're failing on many fronts' (Participant MC01).

Future pandemic preparedness in LTC should focus on recognizing and supporting the pivotal role of care partners (Kortes-Miller et al., 2023), revisiting visitor policies to prioritize relational and emotional needs (Carbone et al., 2023), addressing systemic issues within LTC systems and adopting more resilient and flexible care models that promote holistic resident care.

Strengths and limitations

This study's findings are specific to French and English-speaking care partners in urban LTC homes in Ontario, which limits generalizability to care partners in rural LTC homes or those from diverse linguistic, cultural, and socioeconomic backgrounds. The voices of care partners from racialized communities or those supporting residents with diverse cultural or linguistic needs were unfortunately underrepresented. This limits the study's ability to capture the nuanced experiences of these groups, who may face unique challenges and barriers in the LTC system. Addressing this gap in future research is critical for developing equitable, culturally responsive policies and practices in LTC. However, the adoption of Spradley's ethnographic approach provided a direct description of the caregiving culture during a global pandemic, enhancing study validity. While ethnography typically involves multiple methods of data collection, such as participant observation and document analysis, this study focused solely on interviews. The reliance on one method may limit the depth and breadth of the findings, as it did not incorporate these other forms of data that could have enriched our understanding of the caregiving experience, such as observing interactions within LTC homes or reviewing institutional policies. Participants who chose to engage in follow-up interviews may have had particularly salient or emotionally charged experiences that motivated their participation, which could influence the types of narratives shared. Despite this limitation, we conducted interviews with 21 participants, exceeding the recommended seven to 12 for ethnographic studies (Hennink et al., 2017). This larger sample size ensured a comprehensive exploration of diverse perspectives and contributed to achieving robust data saturation. This approach yielded unique insights into the impact of COVID-19 on care partners and residents, shedding light on the impact of directives and policies that were incongruent with supporting mental health and well-being and not tailored to the unique lived realities of those living in LTC during the pandemic in Ontario. By amplifying the voices of care partners, the study underscores the imperative to not only enhance models of care for LTC residents during health crises but also to improve the processes by which policy decisions are made. This includes considering ethical dimensions, such as the emotional and psychological harms caused by directives and infection control measures, while ensuring that efforts to prevent unnecessary death and suffering from infectious diseases remain a priority.

Implications

The findings of this analysis have implications that extend beyond the LTC and gerontology sectors, offering valuable insights for policymakers, public health professionals, and researchers across various disciplines. For example, in hospital settings, rehabilitation centers, and home care services, public health practitioners can apply these findings to design pandemic preparedness strategies that prioritize relational care and social connections alongside infection control. Additionally, these insights can inform community-based initiatives aimed at supporting older adults and other populations at risk of social isolation during public health crises. Similarly, the emphasis on relationship-centred care could inform education and training programs in healthcare and social work, underscoring the importance of collaborative relationships between practitioners, care partners, and patients. For fields such as sociology and anthropology, this study highlights critical intersections of systemic ageism, power dynamics, and structural inequalities, providing a lens to explore similar issues in other institutional and community-based care settings. Finally, insights into the adaptation of digital technologies during the pandemic can inform innovations in human–computer interaction and technology development, particularly in creating more inclusive and accessible solutions for populations with diverse cognitive and sensory needs.

Conclusion

Our study highlights the profound impact of the COVID-19 pandemic on LTC residents, as perceived by their care partners. These insights reveal an urgent need for enhanced support strategies in infectious disease outbreaks and future pandemics. Care partners advocate for transparent masks to facilitate communication, increased staffing of allied health professionals, and initiatives that enrich resident quality of life through meaningful activities and family engagement. By implementing these strategies, we can create a more inclusive and supportive LTC environment that prioritizes resident well-being and prioritizes care partner inclusion. This approach aims to rectify systemic deficiencies exacerbated during pandemics and promote more resilient care practices. Future research should delve into the ethical dimensions of LTC visitation policies, particularly their impact on resident rights, caregiving dynamics, and quality of life. Special attention should also be given to marginalized populations, such as 2SLGBTQIA+ individuals, Indigenous communities, and Black residents, whose experiences are often underrepresented in the literature.

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