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Article

Insight into the Experiences of Caregivers of Older Adults in Long-Term Care Homes: A Photovoice Study

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ABSTRACT: *Background*: Carers (or care partners) of adults in LTC contribute substantially to the health and well-being of their loved ones by providing physical care, emotional support, and companionship. Despite their critical role, little is known about how caregivers have been impacted by the pandemic. The purpose of this study was to explore the lived experiences of caregivers of people living in long-term care (LTC) homes during the initial phases of the COVID-19 pandemic and potential supports and resources needed to improve caregivers' quality of life. *Design*: An interpretive descriptive approach that incorporated photovoice method was used. *Methods*: Using purposive sampling strategy, six family carers in Ontario, Canada were recruited between September and December 2021. Over a four-week period, caregivers took pictures depicting their experience of the pandemic that were shared in a virtual focus group. Visual and text data were analyzed using thematic analysis with an inductive approach. *Findings*: Caregivers expressed feelings of frustration, confusion, and joy. Emerging themes included: (*i*) feeling like a "criminal" amidst visitor restrictions and rules; (*ii*) experiencing uncertainty and disappointment in the quality of care of long-term care homes; (*iii*) going through burnout; and (*iv*) focusing on small joys and cherished memories. *Conclusions*: The combination of visual and textual methods provided unique insight into the mental distress, isolation, and intense emotional burdens experienced by caregivers during the pandemic. *Impact*: Our findings underscore the need for LTC organizations to work in unison with caregivers to optimize the care of residents and support mental health of caregivers.

Keywords: caregivers; mental health; older adults; long-term care; photovoice; art-based research; focus group; meaningful engagement; quality of life

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1. Introduction

Informal (or unpaid) caregivers, typically family members or friends of older adults, represent a significant demographic in Canada and are an essential part of the healthcare team. Pre-pandemic, one in four Canadians aged 15 years or older, approximately 7.8 million people, reported providing care to a family member with a long-term health condition, disability, or aging-related needs (Statistics Canada, 2018). In 2017, the estimated cost of caregiving in Canada was $33 billion CAD (Tal & Mendes, 2017). The demand for informal caregivers (also known as care partners or carers) nationwide is expected to double over the next 30 years (Battams, 2017). A 2020 report revealed that the number of informal caregivers increased by 9.5 million from 2015 to 2020 in the United States

(The National Alliance for Caregiving and Public Policy Institute, 2020). Caregivers perform a variety of tasks with different levels of intensity, most (90%) of which consist of emotional support and companionship (Statistics Canada, 2018; The Ontario Caregiver Association, 2021). On average, caregivers spend up to ten hours per week on caregiving responsibilities (Statistics Canada, 2018), which can impact domains of life outside of the care they provide. The vast majority of caregivers (>75%) are simultaneously employed and make adjustments to their paid work arrangements (e.g., miss work, reduce hours, retire early) as a result of their caregiving responsibilities (Keefe, 2011; Sinha, 2013). In Canada, most caregivers are women (53%) and between 45-64 years of age (Andren & Elmståhl, 2008) – characterized as wives, daughters, daughters-in-law, and other close women friends and female next of kin.

Studies (Andren & Elmståhl, 2008; Keefe, 2011) have shown that caregivers often neglect their personal health and discontinue health-promoting behaviors such as physical activity and thus are more likely to experience depressive symptoms and feelings of isolation related to the caregiving experience compared to formal or non-caregivers (Family Caregiver Alliance, 2016). Moreover, caregivers report high levels of anxiety and other mental health issues deriving from stress, persistent hardships, psychological pressure, and serious emotional problems (Andren & Elmståhl, 2008; Czeisler et al., 2020).

At the height of the COVID-19 pandemic, caregivers of people in LTC in particular experienced increased stress and faced unique challenges related to strict policies and restrictions from visitation, placing them at greater risk of developing mental health issues and increased isolation (Fingerman & Pillemer, 2021). Despite their critical role in supporting direct care provision, caregivers of people living in LTC homes were not recognized as "essential" and had to witness residents confined to their rooms with minimal to no social interactions. The radical shift in their daily activities due to the social/physical distancing and stay-at-home orders and reports of high death toll in LTC caused a great deal of anxiety and social isolation among LTC residents and caregivers, especially for caregivers who live alone (Fingerman & Pillemer, 2021).

Although the literature reports the effects on COVID-19 on formal caregivers, few have focused on the impact of the pandemic on caregivers' mental health and their relationships with residents. The disproportionate impact of COVID-19 on mortality and morbidity among older adults in LTC, and unprecedented social isolation of residents and caregivers, render it critical to understand the lived experiences of caregivers of residents in LTC during the pandemic. Such knowledge is invaluable and can inform strategies for improving the health and well-being of caregivers, and in turn, that of the residents for whom they provide care. The present study therefore aims to investigate the experiences of caregivers of people living in LTC homes during the initial phases of quarantine using photovoice and to identify the supports and resources needed to improve caregivers' quality of life.

2. Methods

2.1. Study Design

This study employed an interpretive, qualitative design and incorporated steps of the photovoice method (e.g., photo-documentation and elicitation) as outlined by Wang and Burris (1997). This design was chosen as it facilitates the understanding of a phenomenon in its natural state by enabling participants to develop their own voice and stories around their experiences (Thorne, 2016). In this study, we collected and combined photographic images with narrative text data generated from focus group discussions with caregivers.

2.2. Photovoice

Photovoice is an arts-based research method in which people use cameras to document their own stories, experiences and realities (Wang & Burris, 1997). As a participatory action research method, photovoice enables individuals or communities to record and share their lived experiences in order to promote empowerment, create awareness and spur societal change (Golden, 2020; Wang & Burris, 1997). Based on the premise that participants are experts on their health and the social issues they face, photovoice involves participates in the creation of knowledge (Wang & Burris, 1997). Photovoice has three main goals: 1) it enables individuals to record and reflect on the strengths and concerns in their community; 2) it promotes critical dialogue about important issues through the use of photographs; and 3) it can be used to engage policymakers (Wang & Burris, 1997). These aims extend beyond the individual approach to emphasize and recognize community expertise and policy change and encourage critical examinations of power.

Photovoice method was selected for this study because it offers participants a way to convey the 'feel' of specific events, which is often lost with research methods relying solely on oral or written data. Photovoice is often used to study issues related to health inequities and health promotion such as mental health (Catalani & Minkler, 2010), physical activity (Mahmood et al., 2012), and age-friendly environments (Novek & Menec, 2014). It offers an effective and novel way to engage diverse groups including vulnerable, marginalized and/or stigmatized populations which is often excluded from research and other aspects of social life (Golden, 2020; Wang & Burris, 1997). Although photovoice is gaining in popularity and has been used broadly with a variety of populations including children, youth, and adults to address an array of public health concerns and social justice issues (e.g., research related to sensitive topics) due to its broad health equity goals (Catalani & Minkler, 2010; Golden, 2020), few studies have applied this method to understand the experiences of older adults and/or caregivers. Although photovoice's application to caregiver population is still in its infancy, it nonetheless offers a creative and effective way to involve this group, who is frequently left out of research and policy decisions. This study furthers the use of photovoice with caregivers by merging narratives/stories with photographs to better understand the experiences of caregivers of older adults during the pandemic.

2.3. Sampling and Recruitment

Using purposive and snowballing sampling techniques, participants were recruited through community partners and social media between September and December 2021. We sent a recruitment email with digital brochures to administrators of local family and LTC groups, agencies, and senior centres in rural and urban communities across Ontario for distribution. As well, study posters were shared on social media platforms. (e.g., Twitter). All recruitment documents were written in plain English (see Study Protocol for additional information – Boamah et al., 2021). The selection criteria for inclusion were: informal caregiver 18 years or older who took care of an older adult living in Ontario LTC home (for any length of time), spoke and understood English and could provide informed consent. Participants with motor or visual impairments were excluded if they were unable to use a camera or take photos. Due to social distancing measures in 2021, some of the research activities (meetings and focus group) were conducted online which required participants to have Internet connection. Potential participants were asked to contact the principal investigator via email if they were interested in participating in the study or had questions about participations. Initially, nine potential expressed interest to participate however, a total of six caregivers consented, while the remaining three could not participate due to personal obligations. All recruitment materials were written in English and plain language.

2.4. Data Collection

Data collection and analysis involved the 3-stage process of photovoice: 1) *selecting* – participants take and choose the photographs to be discussed; 2) *contextualizing and storytelling* – occurs during focus group discussions; and 3) *codifying the themes* – identifies issues and different meanings that may generate from an image (Wang & Burris, 1997). Prior to initiating data collecting, a preliminary meeting was held virtually with potential participants which served as an information session for the study and to build rapport with participants due to the sensitive nature of the topic (mental health challenges). The meeting provided opportunity to address any methodological challenges concerning aspects of photovoice (e.g., instructed how to operate a camera, the number of photographs to be taken, or the type of camera to use; operating Zoom) and any ethical issues (e.g., asking for verbal or written consent when taking photographs of people; the 'power' of photography and its unforeseen repercussions). Participates who expressed interest after attending the meeting provided oral and written informed consent to the use of their photographs for dissemination, have focus group discussions audio-recorded, and pseudonymized use of the data. Participants were informed that their involvement in the study is voluntary and that they could withdraw at any time.

Stage I of Photovoice (selecting): Over a course of 4-weeks, participants were asked to take any photographs they wanted and/or felt reflected their experiences during the pandemic and the places, objects, and moments that were important to them. There were no restrictions on the number of photographs participants could take; however, they had to select five images that they felt comfortable sharing and discussing during a focus group session. Participants who did not have a photo-capturing device (e.g., phone, tablet, or digital camera) with which to take photographs were provided with a tablet. A photovoice log template was given to participants to record information about each of their photos including the date and time the photos were captured and brief descriptions of their photos. At the two- to three-week mark and again at four weeks, reminders were sent to participants by email as a way of checking in and for them to submit their photos, if they had not yet done so. Participants were also reminded to provide their availability for an online focus group session.

Stage II of Photovoice (contextualizing and storytelling): At the end of the 4 weeks, participants were invited to an online focus group to reflect and share their stories through photographs and communicate their experiences. The focus group was held virtually using Zoom videoconferencing software, which lasted about 60 minutes. Participants who did not have access to technology to engage in the focus group were offered digital support to facilitate their participation. The discussions began with each participant describing their experience of taking photographs followed by description of their photographs one by one and seeking feedback and comments from other participants. To facilitate the discussion, a focus group guide was developed based on a review of the literature on specific concepts such as social isolation/inclusion, COVID-19 impact in LTC, experiences of caregivers in LTC, and needs of residents in LTC. Notes made by the research team during the focus group was also included as data to capture physical and emotional responses observed. In-depth account of the photovoice process including data collection challenges is available elsewhere (Boamah et al., 2022). Participants received $30 gift card by mail for their participation.

2.5. Ethical Considerations

This study received ethics approval from the Hamilton Integrated Research Ethics Board (REB) (#13276). All methods were carried out in accordance with the REB's guidelines and regulations including informed consent to participate in the study.

2.6. Data Analysis

In line with qualitative interpretive description (Thorne, 2016), inductive analysis was conducted of the photographs and text in parallel, with iterative cross-referencing of emerging themes (Wang & Burris, 1997). We drew on reflective thematic analysis to analyze the data by systematically identifying, organizing and capturing patterns of meaning across narratives (Thorne, 2016). We explored similarities and differences between images/photographs shared by the participants and the complementary narratives provided by participants. Photos shared did not contain identifiable content. Each participant was given a pseudonym which served as an identifier (ID) during the focus group, transcribing the recorded data and presenting the findings. Focus group data were transcribed verbatim and uploaded to NVivo data management software (version 12.0) (QSR International Pty Ltd., 2018).

Stage III of Photovoice (codifying the themes): First, two members of the research team (MY & HG) immersed themselves in the data by reading the transcripts and noting initial observations and reactions to the content. Using a consensus-building process, each author provided a unique perspective to the interpretation of the data and came to an agreement on how to synthesize the visual and narrative themes represented in the data. Afterwards, they performed the initial coding to identify and organize data relevant to the study questions using process and descriptive coding methods (Saldaña, 2016). In order to extract the underlying meaning, we first combined codes based on conceptual similarities. Many related and overlapping codes were grouped together into a single, meaningful unit to describe each theme. Third, after all the transcripts were coded, we organized, collated and summarized the data in order to find patterns that relate to the study aim across the sample by (i) collapsing similar themes; (ii) separating those that were distinct; and (iii) removing those that were repetitive or irrelevant. Fourth, we (SB & RW) cross-checked to the narrative to ensure that the themes matched the data. For the final two steps, the themes were reviewed, discussed and refined by the research team until consensus was reached, with the aim to enhance the credibility of the analysis.

2.7. Rigour

Reflexivity and reflection of how power displays in the research process are important thus, various approaches were used to address Lincoln and Guba's (1985) trustworthiness criteria (e.g., credibility, transferability, dependability, and confirmability) to ensure that the research team upheld rigour in qualitative research (e.g., auditing the transcripts against the recordings). Investigator triangulation was used to ensure rigour, trustworthiness and credibility of findings by seeking feedback from all members of the research team who had expertise in LTC, caregiving, social inclusion/isolation, older adults, and dementia care research. Investigator triangulation also helped to support the validation of data (Lincoln & Guba, 1985). To confirm that the codes corresponded with the experiences of family carers, anonymized findings were distributed to them. Well-described and fulsome descriptions of the setting and sample of the study were provided so that findings could be relevant to other contexts.

3. Findings

Of the nine potential participants that initially expressed interest, six caregivers confirmed their participation. Five self-identified as female and lived in Ontario, Canada. All participants in this study have been caregivers to their parents in LTC for an average of 3 years. Additional details about the study participants are listed in Table 1.

Table 1. Sample demographics for study participants .

Demographic	**Participants (%)**
Location	Ontario = 5 (83.3%) Alberta = 1 (16.7%)
Sex	Female = 5 (83.3%) Male = 1 (16.7%)
Relation to person in long-term care	Child (100%)
Length of time caring for person in long-term care (time spent on home care not included)	Mean: 2.63; Standard deviation: 1.63 P-01 = 1.75 years P-02 = 3 years P-03 = 1.5 years P-04 = 5.5 years P-05 = 1 year P-06 = 3 years

3.1. Overview of Themes

Based on participants' responses, we identified four major themes from the analyses which summarized caregivers' experiences including the emotional/mental burden of caregiving and difficult experiences relating to COVID-19 (see Table 2). To exemplify these themes and sub-themes, participant quotes are presented alongside study IDs and photographs. Caregivers in this study referred to family members as loved ones and therefore we opted to maintain use of this term throughout this paper.

Table 2. Themes.

Themes
1. Feeling like "*a criminal*" amidst visitor restrictions and rules
2. Experiencing uncertainty and disappointment in the quality of care of long-term care homes: "*you don't really see what is going on*"
3. Going through "*a burnout*"
4. Focusing "*on small joys*" and cherished memories

Theme 1: Feeling like a "criminal" amidst visitor restrictions and rules. Caregivers reported that they were met with many roadblocks when attempting to interact with their loved ones, other residents, and staff. One caregiver took a photo of a screening sign to show the first thing caregivers saw when they visited the LTC home. At the entrance, visitors were greeted by this sign, had to stop and read it, and follow rules surrounding infection prevention and control, social distancing, symptom monitoring and vaccination. Caregivers went through rigorous screening processes, and some felt that cameras were being used to ensure that they complied with rules. Caregivers expressed that the visitor rules did not 'make sense' for visitors; for instance, they had to stay six feet apart while transporting residents in a wheelchair or having to complete a rapid test despite being fully vaccinated. Participants in the focus group compared their experiences as a caregiver in LTC homes to that of being in a "*prison*" environment. As one caregiver explained:

"Through this whole thing, it's been really hard because I kinda feel like I am a criminal, wanting to touch my mom, give her a hug and just the rules have been all over the place. And who enforces those rules? Some people are more compassionate and will allow more things. Other people won't…" (P-06)

Due to the arduous screening process, caregivers expressed that the important feeling of a home environment was lacking and replaced with one of stress and discomfort instead. In some LTC homes, staff used video surveillance to survey caregivers and reminded them of restrictions/rules that they had failed to obey. Although necessary for health and safety, these experiences caused feelings of uneasiness that contributed to the experience of feeling of being a "criminal". One caregiver was medically exempt from receiving the COVID-19 vaccine and felt that they experienced additional barriers to visiting such as requiring more frequent COVID-19 tests. This caregiver was also not permitted to bring their mother home or outside of the LTC home and faced more physical distancing requirements compared to caregivers who were vaccinated.

Caregivers perceived that they felt 'stuck', constrained and motionless because they did not know how/if conditions would improve with the pandemic and how to ensure that residents received quality care. One participant shared a photo of two rocks touching side-by-side to describe her feelings with regards to being 'stuck between a rock and a hard place'. Another caregiver described the pandemic as being stopped at a traffic stoplight and waiting for clear directions. One photo was taken by a caregiver in a car on a rainy day to portray the lack of clarity related to COVID rules in LTC, and explained in the following quote:

> *"I felt the lack of clarity and was driving my son across Canada, but that's a whole other story. But I just felt with the COVID rules, there was no clarity, there was no…You never knew what was going on. I felt like I was just going forward but there were no real clear directions."* (P-06)

Theme 2: Experiencing uncertainty and disappointment in the quality of care of long-term care homes. Caregivers experienced uncertainty in whether the social and care needs of their loved ones were being met without their presence in LTC homes. At times they experienced disappointment with the level of care provided to their family members. One photo taken by a caregiver revealed disappointment regarding their mother being confined to a small dark room in order to comply with isolation protocols. It was difficult to assess the condition of their loved ones and play an active role in care without this information when they connected virtually:

> *"They actually implemented video calls on a weekly basis very quickly and it was great. But again, that was limited. I can see her [mom], and she looks okay, but that's not the only [thing]. With dementia, these people refuse to go to bed, shower, things like that. You know, you don't really see what is going on just seeing her on the video. It's better than nothing of course, that helps. But they need care."* (P-01)

Caregivers were strong advocates for their family members and put in place strategies to ensure they were receiving quality care such as frequent communication with managers and ensuring that they had small joys such as snacks and meals from home. Unfortunately, some caregivers also had negative experiences where their questions or meeting requests went unanswered during care transitions in LTC. This demonstrated how quality of care could vary drastically by home in an inequitable way:

> *"The first [home] that my mother was in, even though she was only there for three months or so, whenever I would call, the social worker was wonderful. She'd call me 2 or 3 times a day to tell me how she is transitioning. But this place that she's in now, I just got this feeling that I was asking too much or pushing too hard… So, if I can't ask the social worker about this because there's no standardization across the board, who am I supposed to turn to?"* (P-05)

The rules and resources including recreational activities available in LTC also varied by homes. Certain LTC homes were allowing more access to loved ones than others, and this created a lot of inconsistencies in expectations. Some caregivers perceived that their family councils were helpful in answering their questions while others felt that their councils were not functional. Differences were noted across for profit and non-profit homes, as well based on the location of the home (e.g., urban, rural location). There was a perceived need for consistency across all LTC homes with regards to caregiver support:

> *"So, I think I have a very good relationship with the nurse manager. Whenever I send him an email, he replies on the same day basis. That's great. But not every single place would do that so it just, I think that piece should be more consistent across Ontario. Some homes are for profit, some are non-profit… I'm not saying for profits are bad, but there should be a consistency for how they run homes including family support, caregiver support."* (P-01)

Theme 3: Going through burnout. Caregivers visited their family members frequently during the pandemic, and sometimes daily after work. They experienced burnout due to numerous responsibilities in addition to caring for a loved one in LTC. One caregiver shared a photo of a serene beach view as she would come to this location to sit on a bench, meditate, and cry to release her emotions related to stress and burnout. Caring for older persons with dementia can be inherently difficult even without additional challenges from COVID-19, as one participant noted:

> *"Every time I leave [the home], I just think "Lord, it's so hard" and so I go and sit there [at the beach] and sometimes I have a box of peanuts and I cry because it's been difficult or because she's going through a struggle, or she asks me about my dad who's been gone seventeen years. "When am I going home" and "why can't you bring me to your house" and all those little things."* (P-05)

The additional stresses from social isolation may also compound onto the burnout from the caregiving experience. The following quote helps to illustrate this point:

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> *"Every single day, I'll be there… It hasn't been easy at all, because she is unilingual, she is head strong, oh my God. She is paranoid. I am there every day, particularly after work. I will be honest with you guys, I did burnout. It was like, done. The burnout came and that was wild to see."* (P-03)

Theme 4: Focusing on small joys and cherished memories. Despite all the negative impacts that COVID-19 brought on the ability of caregivers to visit and care for their family members, they reported finding peace by bringing small joys to the lives of their family members, for example through braiding the resident's hair, volunteering in the LTC home, holding hands, taking outdoor strolls together, and having conversations about the past. As well, photos with grandchildren and great grandchildren visiting were shared. The ability for family to provide companionship was described as particularly meaningful. Many caregivers shared photos of joyous moments, citing how these moments provided the positive uplift that they needed. One caregiver captured the moment beautifully in the following quote:

> *"All the recreational and social programs pretty well got cut, which was brutal for our loved ones in LTC. The stimulation alone and the socialization is key. We kinda had to create our own fun, create our own things to do and keep her stimulated and at the same time she loved it. It was something to do, braid her hair and it keeps her hair out of her eyes."* (P-02)

4.1. Discussion

Using a photovoice method, this study illuminated the experiences of caregivers to better understand the impact of the pandemic on both caregivers and the family members for whom they provide care. The current study builds on limited studies investigating the utility of photovoice with caregivers of people living in LTC homes during the initial phases of the COVID-19 pandemic. Our findings illustrate the usefulness of qualitative description and photovoice for capturing the unique challenges that caregivers faced and strategies they adopted to navigate through the COVID-19 crisis. A significant contribution of this study is the powerful imagery and depth of insight into the unique experiences of caregivers during a pandemic. Deeper insight beyond what could have been captured by words or photos alone was elicited from the combination of photographic and focus group data as similarly reported in other studies using photovoice (Wang & Burris, 1997). Moreover, the flexibility of the photovoice process fostered collaboration and networking opportunities for caregivers with varying experiences to support each other. In this study, the photovoice process extended beyond utility as a research method to promote introspection and connection among caregivers. In this sense, caregivers were empowered to narrate their own stories and recognize their strengths and capabilities throughout a challenging period in their lives.

In this study, caregivers shared that they felt like they were under video surveillance and treated as "criminals" amongst the rules and restrictions enforced in LTC homes. They perceived that LTC homes had a prison-like environment with little consideration for the emotional and psychological needs of residents and caregivers. Similar sentiment was expressed in a study by Nash and colleagues (2021) where caregivers reported that window visits made them feel that they were in prison. Other studies (Sutter-Leve et al., 2021; Ickert et al., 2021) have explored the role of caregivers in supporting loved ones during the COVID-19 pandemic and found that the caregiving role and identity was devalued. In many instances, caregivers were not permitted to provide care or perform their usual duties in LTC homes and were not consulted by Public Health units to discuss how caregivers could remain involved in the care of their family members (Ickert et al., 2021). Instead of being included as part of the care team, integral to the well-being of their family member, caregivers felt that they were treated as an "inconvenience" when their calls for updates were left unanswered (Sutter-Leve et al., 2021) and were excluded from decision and policymaking. Consistent with other studies (Ickert et al., 2021; Kusmaul et al., 2022; Sutter-Leve et al., 2021; Paananen et al., 2021), caregivers expressed increased feelings of isolation and exclusion from their family member and LTC homes. Further, caregivers reported lack of support in coping with stress and had limited access to health and social

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services which further contributed to the growing isolation, building further upon the growing literature of health and social effects experienced by caregivers during the COVID-19 pandemic.

With increased workload and demands placed on LTC staff during the pandemic, caregivers expressed concern that personalized care was not being provided for their family members and felt that they should be permitted to fill this critical gap for residents in this and other studies (Hindmarch et al., 2021). For caregivers that were able to visit their loved ones in LTC, witnessing deterioration they attributed to social isolation was similarly distressing for caregivers (Paananen et al., 2021). Persons living with dementia in LTC in particular were perceived as experiencing cognitive, mental, and physical decline related to restrictions and lack of socialization (Hindmarch et al., 2021; Paananen et al., 2021). Access restrictions to LTC homes brought on by COVID-19 have been found to have negative impacts for caregivers including increased social isolation and strain and decreased quality of life (Hindmarch et al., 2021). Findings from the present study support this literature and highlight the need for increased consideration for psychosocial well-being among both caregivers and care recipients in LTC homes.

A significant cause of distress reported by caregivers in the current study was the lack of communication about their family member and conditions in the LTC home. The everchanging rules enforced in homes created significant barriers for caregivers to support their loved ones. Communication from leadership in LTC homes and access to their family members was even more critical during COVID-19 than previous, yet caregivers reported receiving little to no updates about the status of residents (Sutter-Leve et al., 2021). Being uninformed and unable to witness the care provided to family members raises concerns about the quantity and quality of care delivered and leads to increased stress and poor mental health among caregivers (Sutter-Leve et al., 2021).

Numerous inconsistent policy discussion regarding rules and regulations across LTC homes were noted in this and other studies (Chu et al., 2021; Ickert et al., 2021). In the present study, caregivers perceived inconsistencies in visitor restrictions, policies, and adherence across LTC homes in Ontario which prompted feelings of uncertainty, distress, and powerlessness. In some LTC homes, recreational and therapeutic activities were maintained, however in other homes, activities stopped during the early state of the COVID-19 pandemic potentially placing residents at earlier risk for deterioration (Genoe & Johnstone, 2021). Some LTC staff have also been reported as being lenient with rules and more compassionate towards caregivers than others. Particularly for persons with dementia in LTC, public health rules and COVID-19 are perceived as having many weaknesses (Ickert et al., 2021). For example, isolating residents living with dementia were left alone in their rooms with no activities can exacerbate responsive behaviours (Hindmarch et al., 2021; Ickert et al., 2021; Nash et al., 2021). Physical distancing requirements negatively impact relationships and interactions between caregivers' and persons with dementia specifically because individuals with dementia may not understand the reasoning behind social distancing. Caregiver refusals/avoidance of physical contact (e.g., hug, touch, affection) can also lead to emotional outbursts and responsive behaviours (Ickert et al., 2021; Nash et al., 2021). This could lead to negative self-perceptions among residents with dementia. There is therefore a need for flexibility in how rules and regulations are designed and imposed to accommodate the needs of residents and maintain their quality of life.

Despite the challenges brought on by the pandemic resulting in LTC home restrictions, caregivers in this study recognized that the quality of life of their family members was a priority and made efforts to lift their spirits with the limited amount of time they had for visits. COVID-19 led to opportunities for caregivers to tap into their creativity to create joyful moments for their family members in LTC during a difficult time. Ickert and colleagues (2021) found that isolation protocols led to reduced mobility, weight loss, and depression among residents in LTC homes because of a lack of socialization and stimulation (Ickert et al., 2021). In response to these challenges, the authors found that caregivers adapted their approach to optimize and make the best use of their limited/restricted visiting time by reflecting ahead on pleasant and meaningful topics for discussion and spending time outdoors (Ickert et al., 2021). Caregivers recognized that maintaining and fostering meaningful connections was more important than ever before partly because opportunities to connect were lacking during the pandemic (Kusmaul et al., 2022). Our study provided unique contributions with regards to the extent of creativity that caregivers incorporated during their visit and their ability to tailor to the needs and life stories of their family members.

5.1. Strengths and Limitations

The strengths of the present study include the use of multiple forms of data (i.e., photographs and narrative text). To our knowledge, this study is the first photovoice study with caregivers/care partners of people living in LTC homes and in a virtual focus group session. The visual component enabled participants to actively engage with the photographs, and the focus group discussions provide the group a chance to think critically about their events despite the sensitive nature of the topic. Photovoice offered participants a way to express themselves in a way that is often missed with research methods relying solely on oral or written data. One potential limitation of this study is the gender imbalance in the sample (females=5; male=1), which can be attributed to the small sample size. The study was conducted in only two regions of Canada – Ontario and Alberta. All participants consisted of caregivers for a parent and no information regarding the health condition of older adults in LTC was collected. Further, the lack of diversity in this study can be attributed to several influencing factors, including the small sample size. In this instance, funding restraints also limited the extent to which widespread recruitment was feasible. To address this challenge in future studies, we recommend a multi-faceted recruitment strategy across multiple regions to ensure diverse voices are captured.

5.2. Implications

The findings of this study have several implications for LTC administrators and policymakers including the need to recognize the importance of informal caregivers (or care partners) and designate their role as 'essential' and integral components of the care team. Administrators should involve caregivers part of a family council of the LTC home, virtually or in person, to advocate for residents and should be offered opportunities to join online support groups to facilitate sharing of information and encouragement to fulfil the role of a caregiver (Hado & Friss Feinberg, 2020). Further, caregivers must be included in the policy and decision-making process and care plans of their loved ones. Caregivers should be provided with clear and consistent messaging related to changes in LTC policies including visitor rules and regulations. Clear communication channels with LTC homes (e.g., administrators, unit managers) are critical to ensure that caregivers are being regularly informed about the care of their family members in a timely manner (Hado & Friss Feinberg, 2020). In special circumstances where quarantine is warranted, there should be some flexibility in rules and policies, when possible, to accommodate caregivers in supporting the needs of residents to maintain their quality of life. Preliminary evidence in support of these recommendations has been identified in a recent study (Hathaway et al., 2023) and indicate that administrators in LTC settings feel positively about policies that designate family caregivers as 'essential'. We are encouraged by this initial evidence and recommend further evaluation of these promising policies.

An additional implication stemming from this study related to photovoice as a method of data collection and participant engagement. As seen in the present study, we found photovoice to be a promising tool for engaging caregivers. In terms of eliciting rich data regarding lived experiences, this method was highly effective and encouraged participants to reflect on what they saw, felt, and experienced. We recommend future studies of caregivers – both in-person and virtual – employ this method. The creative nature of photovoice serves to bridge the gap between participants and researchers. This study demonstrated that the method could be applied successfully and meaningfully in virtual settings with caregivers, which is an encouraging finding in and of itself.

6. Conclusion

COVID-19 continues to have harmful effects on both caregivers (or care partners) and residents of LTC. Our study provides a unique perspective on some of the initial and ongoing challenges that caregivers and older adults face during the pandemic and offers opportunities and solutions for change in LTC. Given the state of current affairs and how resource constrained the LTC sector is, the economic and emotional support that caregivers offer to residents should be valued and appreciated. Our findings reveal the need to recognize the important role that caregivers play in the care of their family members. Meaningful visits and interactions between caregivers and residents are necessary to support the wellbeing and quality of life of both groups. The findings underscore the urgent need to provide innovative, pragmatic, and multi-sectoral approaches including accessible mental health support for caregivers. LTC homes and public health units should revisit policies to ensure that caregivers have access to their loved ones.

Declarations

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Institutional Review Board Statement: Ethics approval was obtained from the Hamilton Integrated Research Ethics Board (HiREB) in 2021 and renewed on March 1, 2022 (approval number: 13276).

Informed Consent Statement: Informed consent was obtained from all participants involved in the study, including audio recordings and pseudonymized use of the data.

Data Availability Statement: The data presented in this study are available upon reasonable request from the corresponding author.

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