

# The Cost of Isolation: A Protocol for Exploring the Experiences of Family Caregivers

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## ABSTRACT

**Background:** Recent research has found that family (e.g., informal, unpaid) caregivers to those in long-term care can experience significant risk of social isolation, a harmful social outcome linked to poor health and wellbeing. For many, the COVID-19 global pandemic has been a time marked by challenges that have exacerbated existing risk of social isolation and has likely impacted mental health and wellbeing among caregivers. As such, this paper outlines a protocol to investigate the extent to which the COVID-19 pandemic has impacted the psychological health and well-being of family caregivers of people living in residential long-term care.

**Methods/Design:** A descriptive phenomenological design and photovoice methodology will be used alongside focus groups to capture the perspectives and voices of 15-20 family caregivers. Data will be analyzed thematically, and themes will be developed collaboratively alongside participants. A secondary analysis will be guided by a cumulative inequality lens to consider how the COVID-19 pandemic has differentially affected caregivers.

**Discussion:** The results will fill a significant gap in the existing literature on caregiver isolation during this pandemic and inform the development and/or refinement of caregiver supports.

**Keywords:** social isolation, long-term care, caregiving, family caregivers, Covid-19, psychological wellbeing, mental health

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# 1. Background

## 1.1 Prevalence of social isolation

Whilst social isolation can occur across the life span, up to 50% of individuals over 60 years of age are at higher risk for social isolation (Holt-Lunstad et al., 2015; Shor, Roelfs & Yogev, 2013). Moreover, this risk accumulates over time, contributing to greater overall risk of social isolation in later life (Caspi et al., 2006; Landeiro et al., 2017). This is a concerning reality, as social isolation has been associated with a 29% increased risk of heart disease and a 32% increased risk of stroke, among other harmful outcomes (National Academies of Sciences, Engineering, and Medicine, 2020). Furthermore, individuals experiencing social isolation and/or risk of isolation are likely to have suffered additional risk during the COVID-19 global pandemic (Plagg et al., 2020).

Research indicates that older people – especially those with dementia and/or with limited socioeconomic means – tend to experience social inequalities (United Nations General Assembly, 2015) and are more likely to be seriously affected by the pandemic. For individuals without the tools to connect with those outside of the home, social distancing could have a severe longer term impact, in exacerbating behavioral and psychological symptoms of dementia, leading to further isolation (Banerjee et al., 2020) and surges in mental health concerns in this already at-risk population. This can also apply to individuals living within long-term care (LTC) settings, as well as family members (Grenade & Boldy, 2008). Aspects of the LTC environment including regimen and regulations significantly impact whether a person becomes socially isolated and can either facilitate or hinder efforts to enhance social connections among residents (Boamah et al., 2021). Currently, LTC residents account for approximately 17.0% of COVID-19 cases in Canada and 82% of all related deaths (Holroyd-Leduc & Laupacis, 2020) due in part to aspects of the LTC home (e.g., communal living) which may promote the rapid spread of infectious disease (Applegate & Ouslander, 2020; Louie et al., 2007). As a result of both lockdown measures and fear of contagion, many older adults who depend on frequent visits from family and friends are becoming increasingly isolated (Vahia et al., 2020).

## 1.2 Rise in caregiver isolation

Family caregivers (e.g., informal, unpaid) play a crucial role in the social relationships and support networks of older adults. In the province of Ontario, Canada, an estimated 3.3 million people (29% of the provincial population) are informal caregivers, and most (84%) care for a family member (The Change Foundation, 2015). These carers spend an average of 11 hours a week providing care (Turcotte, 2013) including emotional support and companionship, which accounts for 90% of their role (The Change Foundation, 2018). Evidence suggests that family caregivers have higher levels of stress and lower levels of subjective well-being than non-caregivers (Ferrant et al., 2014; Pinqart & Sörensen, 2003). In particular, family caregivers of people with dementia encounter greater risk of developing physical health problems (Vitaliano et al., 2003), especially those who are psychologically distressed or are facing behavioral difficulties of the cared-for person (Pinqart & Sörensen, 2007). During this period of quarantine and/or social distancing, family caregivers are also experiencing increased stress and isolation, and may be at risk of developing mental health issues (Vahia et al., 2020). Evidence suggests that roughly 40-70% of family caregivers experience clinical symptoms of depression and feelings of isolation associated with the caregiving experience (Banerjee et al., 2020).

### **1.3 Theoretical approach**

Our study will be guided by cumulative inequality (CI) theory (Ferraro & Shippee, 2009; Ferraro et al., 2009), a life-course informed perspective used to investigate how disadvantage accumulates over time leading to health and social inequities across groups and individuals. CI theory asserts that social systems create inequality which then increases exposure to further risk, and that this accumulation process in turn shapes life course trajectories and can contribute to premature mortality. CI theory will guide and inform the study to shed light on the ways in which the pandemic has differentially affected caregivers to those in LTC homes.

### **1.4 Study aim and objectives**

The goal of the proposed study is to investigate the acute and longer term impact(s) of social isolation on the psychological health and well-being of family caregivers of older people in LTC homes in Ontario. We aim to deepen our understanding of the experiences of family caregivers, their perceived challenges, and the unique supports required to improve their quality of life. Our research is structured around two objectives: (1) to gain a deeper understanding of how social isolation linked to physical and social distancing has impacted the psychological health and wellbeing of family caregivers of people living with dementia; and (2) to identify the perceived challenges of social isolation experienced by family caregivers, and the supports and resources needed to improve their quality of life.

## **2. Methods/Design**

### **2.1 Study design**

In this study, we will employ a qualitative descriptive phenomenological (DP) design, a form of naturalistic inquiry that seeks to understand a phenomenon in its natural state. Although DP does not require the depth of interpretive penetration or “moving far from or into the data”, it is designed to provide a representative accounting of both events and the meanings attributed to these events while staying close to the participants’ everyday language (Maxwell, 1992; Sandelowski, 2000).

### **2.2 Ethics in data collection**

This study has been reviewed and approved by the Hamilton Integrated Research Ethics Board (HiREB) (# 13276). Our study is designed with due consideration of the conventional ethical standards within the context of community realities and expectations. All participants will be given a description of the study and their role and expectations as a participant including the ethics of photography and the importance of consent will be discussed with the group to explain the need to obtain consent from potential photograph subjects and asking for their permission prior to the photographs and the fact that some people may not want their photograph taken. An instructional guide will be provided to the participants with a brief written explanation of the project, how the photos would be utilized and space to obtain signatures from individuals who the photographers desired to photograph. Also, guarantees of confidentiality, the right to refuse to participate or to withdraw from participation and the freedom to refuse to discuss particular questions will be ensured. Using high-quality community-based research approach, the research team will make concerted efforts to address important issues related to participant compensation, informed consent, confidentiality, strategies to address sensitive or stigmatizing topics including, but not limited to in-depth training offered to focus group leads prior to data collection.

## 2.3 Participants

The sampling strategy will consist of a purposive sample of fifteen to twenty family caregivers, a sufficient sample size for the type of design (Sandelowski, 2000). Study eligibility criteria include: family caregivers of older adults in LTC settings over the age of 18; able to communicate and understand basic English; no visual or fine motor limitations that would preclude using a Tablet-camera; and ability to provide written, informed consent.

## 2.4 Recruitment

The project team has partnered with several organizations including partners in LTC settings, the Alzheimer's Society of Ontario, and Family Councils Ontario. With the support of these partners, a diverse group of family caregivers from all demographics will be recruited through the distribution of digital brochures to local organizations and agencies, family and senior centers across North and Southwestern Ontario in rural and urban communities, and through social media platform (e.g., Twitter, Facebook). All recruitment materials will be written in lay English.

## 2.5 Photovoice and focus groups

Photovoice (PV) and focus groups, will be used to address the study objectives.

**(I) Photovoice:** PV methodology will be employed to capture the visual voices and imagery that exemplify the lived experiences of family caregivers. PV is a process in which individuals use cameras to photograph their realities, thus focusing on issues of greatest concern to them. Communicating these issues to policy makers, health care providers, and advocates facilitates and mobilizes change (Wang et al., 2004). Photovoice, (visual) arts-based research, is a form of qualitative inquiry that emphasizes constructivism, critical interpretation, and contextualism (Sullivan, 2005). Through constructivism, participants have the opportunity to construct their own understanding and knowledge of their realities through photographs that represent their lived experiences, which addresses objective #1. The PV method emphasizes that participants are co-researchers who direct the identification of themes, not the primary investigators (Wang, & Burris, 1997). PV is an effective tool to use in our study as it aids in the collection and dissemination of knowledge in a way that enables family caregivers to be involved in identifying and assessing the strengths and concerns they face during and after the COVID-19 pandemic, create dialog, and share knowledge of their experiences and priorities (Hergenrath et al., 2009). Prior to starting the study, family caregivers will engage in a facilitated orientation/meeting with the research team about the aims of the project, role clarification, pragmatics about the ethics around photography, and shared ideas of elements to photograph. Since participants are to reflect on their own experiences, there is no additional consent required from the LTC home. Family caregivers will be provided with training/guidance on how to take photos to tell a story using a Tablet-device with camera. During a 2-4-week timeframe, participants will be asked to take as many photographs as they wish to complete this assignment, while also deciding on their top five selections for viewing at future virtual focus group sessions. The goal of selecting these top five is to have the participants choose those photographs that most accurately reflect the reality of what the participants want to convey at follow up focus group sessions.

**(II) Focus group:** After the maximum 4-week period of taking photographs, two one-hour **virtual** focus group discussions will be held with family caregivers via Zoom Web/Video Conferencing. Participants will connect and attend the virtual sessions on the Tablet device. Using the James Lind Alliance (JLA) approach to the Priority Setting Partnership (PSP) process

(James Lind Alliance, 2013), caregivers will share, discuss and contextualize the photographs taken and mutually identify themes under the broad categories of challenges or supports, during the first focus group; this addresses objective #2. In the second focus group session, caregivers will discuss their pre-selected five most meaningful images, individually examine their photographs and direct where they will be placed under the various themes. Participants will have an opportunity to speak to their selected photographs in response to the team facilitator's questions. In particular, the "SHOWeD" guide (Shaffer, 1983) will be used to stimulate discussion around the following questions: "*What is happening in this photo? Can you describe the experience? How has your life changed in terms of your relationships since the pandemic? and What can we do to improve it?*" The discussion will be further contextualized with CI theory-informed questions related to access to resources such as '*What does this picture tell us about caregivers' decision-making regarding visitations and social activities in LTC? What can be done on an individual and institutional level to reduce isolation and improve physical and mental wellbeing?*' The SHOWeD technique helps to identify the dynamics underlying and surrounding social issues – the social, economic, and political contexts that support ideologies and control the resources and strategies necessary to bring about change (Shaffer, 1983). Notes taken from the first focus group will be used to assist the facilitation of the subsequent session. Both focus group sessions will be audio recorded, and the researchers will engage in memoing (e.g., recording of reflective notes about concepts and their relationships).

## **2.6 Data analysis**

Photographs taken by participants will be collected as the primary data set, in addition to notes from the focus group discussions. Digital images will be downloaded from participants' cameras to portable hard drives (for secure data storage purposes) and viewed on a password protected computer for the purposes of the focus group discussion. All data will be de-identified. Participant photographs will be systematically assigned numbers. During the focus group discussion, the assigned numbers will be referenced in order for the statements to be linked to the photographs under discussion. This documentation process will enable the researchers to examine photographs as well as the accompanying statements from the transcripts during data analysis.

All digital audio-recordings will be transcribed verbatim and thematically analyzed using NVIVO software. Using the Morse and Richards' (2002) three process framework: 1) topic coding; 2) creating categories; and 3) abstracting or conceptualizing, we will perform the thematic analysis of the transcripts. Initially, we will perform open coding of the data, which will involve careful line-by-line reading of each transcript for possible meaning. We will use units of meaning — consisting of words, phrases, sentences or paragraphs to describe the meaning and produce an understanding of the focus of inquiry. Themes will be developed in partnership with the participants and validated by the participants, through interactive discussion in an open forum. To maintain confidentiality, no personal identification will be collected/shared, and only group data will be presented in public forum.

A secondary analysis of the resulting themes will be carried out using a CI lens (Ferraro & Shippee, 2009; Ferraro et al., 2009) to investigate the possible role of cumulative inequality in the experiences of the caregivers. This process will serve to better contextualize the experiences and risks articulated by the caregiver participants within the broader literature on exclusion, (dis)advantage, and the life course (Dannefer, 2003).

## **3. Discussion and Implications**

Given that the intersection of this pandemic, social isolation, and mental health is a new phenomenon, the anticipated findings of this research will have several significant

implications. First, the findings will benefit people living in LTC homes and their family caregivers, and the general public by deepening our understanding of barriers and facilitators to social connection among caregivers and providers. Second, findings will benefit the broader population (including older people, caregivers, and service providers) by uncovering new information about social isolation and the accumulation of risk factors for social isolation. Third, findings will benefit both caregivers and LTC residents alike through the development of policy actions, strategies, and programs (e.g., outreach, caregiver support) to address the priority concerns expressed by caregivers in this study.

As we enter a fourth wave of the COVID-19 pandemic and its ending remains unknown, the knowledge gained will be mobilized quickly to help address the acute and longer term physical, social and psychological health needs of family caregivers and strengthen adaptive mental health care service capacity and flexibility in the community and in LTC for people experiencing ongoing isolation through service delivery training and capacity building. We anticipate the findings will provide strong rationale for enhanced supports going forward to promote the well-being of caregivers both during the remainder of, and beyond, the COVID-19 pandemic.

This study offers various strengths including the use of Photovoice (PV) methodology to capture and further understand the experiences of isolation through the eyes of family members in real time. The use of Photovoice with caregivers provides an exciting tool with which researchers can work together with participants and can provide numerous opportunities for social and cultural change around social isolation. While PV has been employed by researchers in different disciplines to explore and address a variety of culturally diverse groups and community issues, few studies have used PV method to explore social isolation among family caregivers (Brownie et al., 2011) and the existing studies that incorporated PV with this group have been mostly descriptive, lacking in-depth exploration and analysis (Ronzi et al., 2016). The use of both PV and focus group interviews will provide a much deeper understanding of the reality of family caregivers' daily lives, the importance of human interaction, social norms and other underlying factors that shape family caregivers' mental health and wellbeing. This study will therefore extend and build upon the existing literature, and while also illuminating the possible role(s) of cumulative inequality and adversity.

With these strengths, there are also potential limitations. In particular, there might be stigmatization attached to social isolation and the caregiver role and those with loved ones with dementia. Furthermore, the findings may be connected to class, race, and social situation. Therefore, this study might not capture a broad range of caregiver challenges and experiences of family caregivers across the country. However, the findings may be transferrable to similar social and cultural contexts. Additionally, qualitative studies with small sample sizes provide rich, in-depth data that cannot be captured in large, survey-based studies. As such, the results of the present study will be both meaningful and valuable to the field regardless of whether the sample of participants is directly representative of the broader population (Polit & Beck, 2010).

#### **4. Knowledge and Dissemination Strategy**

Our study findings will be disseminated widely via community reports, fact sheets, visual/digital stories, conference presentations, research manuscripts, and social media. With the consent of participants, we will showcase their images and thematic interpretations, and involve broader members of the health care community to see, hear, and learn from the images and critical reflections of carers around social connectedness and isolation during and post pandemic. COVID-19 being the first global pandemic of its kind in recent decades, the images and stories will also be shared with members of the community including local health agencies, non-for-profit organizations, hospitals and University health science and public libraries, in

order to increase awareness and create social change. The display of the images is important because it is a powerful and unique way to convey a message that is both compelling and accessible to both academic and lay audiences. Digital storytelling offers participants an opportunity to clarify personal, community, ethnic and cultural identity and meaning and supports and engages the community in research processes (Moffitt & Vollman, 2004). Additionally, the findings will be published in open access health and social science journals and delivered as poster and oral presentations at community events and relevant academic conferences at local, national and international forums, and through workshops.

## Declarations

**Competing interests:** None declared.

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