

EMPIRICAL RESEARCH QUALITATIVE OPEN ACCESS

# Family Caregivers' Experiences of Long-Term Care Residents Living With Dementia During the COVID-19 Pandemic: An International Grounded Theory Study

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## ABSTRACT

**Aims:** Caution around the COVID-19 pandemic resulted in visitation restrictions to prevent the spread of the virus among vulnerable older persons living in long-term care (LTC), which posed a threat to individual well-being and family togetherness across the globe. The purpose of this study was to explore family caregiver's experience of having a person who is living with dementia residing in a long-term care facility during the COVID-19 pandemic.

**Design:** Qualitative descriptive study using constructivist grounded theory (GT) methodology.

**Methods:** The study was carried out in five countries: the United States, Switzerland, Hong Kong (China), United Kingdom and Japan. Data were collected between June 2021 and August 2022. In-depth understanding and initial theorising about experiences and social interactions between family members, residents and long-term care staff across cultural contexts, strategies from constructive GT were used. Data were collected through 15 semi-structured, in-depth interviews with 16 family members. Analysis included individual and team-based coding, memo-writing, constant comparison and category generation.

**Results:** Due to visit restrictions, families faced upsetting situations of exclusion. The caregiver participants experienced inequality, felt isolated and witnessed residents' despair and helplessness. Analysis revealed four subthemes to the basic social process of 'negotiating for access to maintain relational continuity': (1) Feeling excluded, isolated and upset; (2) facing depersonalising situations; (3) navigating challenging interactions; and (4) living with (post-) pandemic circumstances.

**Conclusion:** This study highlights the suffering experienced by family caregivers and their loved ones living with dementia in long-term care during COVID-19, demonstrating the key role that relationships play in family care. During similar public health crises, policies and infection prevention measures that depict family and close caregivers as visitors whose access needs to be regulated need to be altered into policies that enable a culture of partnership and inclusion acknowledging the importance of social interactions for health and well-being.

**Reporting Method:** The COREQ checklist was followed.

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## 1 | Introduction

There are an estimated 40 million caregivers worldwide who provide care for people living with dementia (Jeste, Mausbach, and Lee 2021). People living with dementia often need to move into long-term care facilities (LTCs) (e.g., residential care homes) when caregiving burden exceeds the threshold of family and close caregivers (Nunez 2021). Nonetheless, caregivers continue to be a unique source of social and emotional support for loved ones living with dementia, supporting their well-being (Hado and Friss Feinberg 2020). Family caregivers are central to quality of life for their loved ones living with dementia (Jeste, Mausbach, and Lee 2021). People living with dementia are deserving of person-centred care and this includes having loved ones involved in their day-to-day life. McCormack and McCance (2016) assert that being in relationship and within a social context are two important aspects for person-centred care, which could be jeopardised during the COVID-19 pandemic.

The connection, which the family or close caregivers provide, acts as an important context for person-centred dementia care (Fazio et al. 2018). The social restrictions in response to the COVID-19 pandemic (e.g., lockdowns of LTCs) did not prioritise the need of individuals living with dementia to connect and to be connected with caregivers and society (Ho et al. 2022), which exacerbated the social isolation and loneliness among those living in LTCs (Au Yeung et al. 2020; Ho et al. 2022). While a vast number of papers have investigated the consequences of social restrictions on people living with dementia in LTCs (e.g., Gordon et al. 2022), and several have explored the caregiver experience (e.g., Ickert, Stefaniuk, and Leask 2021; Mitchell et al. 2022), an international perspective that explores the global impact of caregiver experiences is lacking. Given that the COVID-19 pandemic is a global issue, we report the experience of family caregivers caring for their loved ones living with dementia from the United States, Switzerland, Hong Kong (China), United Kingdom and Japan during lockdowns of LTCs during the COVID-19 pandemic.

## 2 | Background

To provide context around the experience of family caregivers caring for loved ones living with dementia during the COVID-19 pandemic and resultant LTC facility lockdowns, it is important to begin with foundational information regarding dementia. The World Health Organization (WHO; 2023) defines dementia as an umbrella term referring to a collection of progressive, incurable diseases impacting cognitive function and behaviour. Dementia is currently the fifth leading cause of death globally and dementia care is responsible for significant fiscal and social load (World Health Organization (WHO) 2023). Although individuals younger than 65 years old may develop dementia, older age is the most significant risk factor for developing this progressive neurological disease; however, dementia is not a normal part of ageing (Alzheimer's Association 2024). In addition to

memory loss, poor judgement and confusion, people living with dementia experience decline in ability for self-care, including the ability to perform basic activities of daily living (ADL) as the disease progresses.

In fact, many individuals who live with dementia reside in LTCs due to the need for significant support of personal care (Nunez 2021). Caring for people living with dementia does not end when the individual is placed in the LTC. Tuijit (2021) suggested that caregiving for people living with dementia in LTCs is a triadic dynamic relationship, involving the loved one living with dementia, family caregiver and healthcare provider. The Convoy Model of Social Relations (Fuller, Ajrouch, and Antonucci 2020) takes the idea of the care triad further, describing the people who surround an individual as a part of a dynamic network—a convoy—that includes people who support and are supported by that individual. The health and well-being of an individual is affected by interpersonal relationships of that individual: These include family/informal caregivers and formal caregivers. These relationships are both positive and negative aspects in a caring relationship, for example, there are many challenges of caring for a person living with dementia (Nunez 2021). It is noteworthy that the Convoy Model describes maintaining quality interpersonal relationship with the individual living with dementia as crucially important for the well-being of family and other close caregivers.

Even prior to the COVID-19 pandemic, LTCs faced several challenges to providing high quality care inclusive of the caregiver. Some of these challenges include staff shortages, high resident to staff ratios and a lack of administrative support (Al-Jumaili and Doucette 2017). The pandemic highlighted these shortcomings and created more pronounced issues for people living with dementia and their caregivers (Mapira, Kelly, and Geffen 2019). While informal care provided by family and close caregivers usually continues for their loved ones living with dementia when they move to LTCs under normal circumstances (Hoek et al. 2021), LTCs' lockdowns during the pandemic created an unprecedented experience separating family caregivers from their loved one (Thirsk et al. 2022).

Family and close caregivers are a unique source of emotional and instrumental support for individuals living with dementia in LTCs (Hado and Friss Feinberg 2020), yet social restrictions imposed on LTCs present wholly new, and potentially stressful, situations for family and close caregivers and for their loved ones living with dementia alike (Kent, Ornstein, and Dionne-Odom 2020). Subsequently, family and close caregivers experienced negative impact on their own mental health because of their inability to fulfil their caregiving roles as usual (Faieta and Routier 2022). For example, a qualitative study in the Netherlands showed that family caregivers experienced various kinds of stresses in terms of alternative forms of communication strategies and concern for their loved one's safety (Smaling et al. 2022). Another qualitative study in Canada highlighted the unmet needs of family caregivers during the

## Summary

- What were the main study findings
  - The lockdown during the COVID-19 pandemic created an extraordinary experience separating family and close caregivers from their loved ones living with dementia residing in long-term care with little information about the experiences of family caregivers under this context.
  - Findings contribute perspectives on family and close caregivers negotiating for access to maintain relational continuity with experiences of being excluded, isolated and upset, facing depersonalising situations, navigating challenging interactions and living with (post-) pandemic circumstances.
  - Findings show that visitation bans, restrictions and non-transparent communication with long-term care staff and management led to families facing upsetting situations of exclusion, inequality, isolation and witnessing residents' despair and helplessness.
- What this paper contributes to the broader global community
  - Our findings, across five countries, encourage staff and management in long-term care settings to implement more family/close caregiver-friendly health measures and involve ways that support partnership and inclusion of a care triad in favour of the individual living with dementia in routine and extraordinary times such as during the COVID-19 pandemic.
  - A better understanding of family and close caregivers' contributions and residential aged care is important to build policies of partnership and inclusion, especially in extraordinary situations.
  - Policies of family and close caregiver exclusion will need to be altered into policies of partnership and inclusion, with public health measures being implemented in more family-friendly ways, especially during similar extraordinary situations.

COVID-19 pandemic in which family caregivers thought the under-resourced, continuing care system delayed pandemic planning, and persistent silos in health and community systems made caregiving more difficult (Parmar et al. 2021). As such, family and close caregivers of loved ones living with dementia were often called the invisible second patients, who were critical to the quality of life of the individual (Jeste, Mausbach, and Lee 2021), but who faced unforeseen barriers to maintaining the care relationship with their loved one. Therefore, to better understand family caregivers' experience of having a loved one with dementia living in an LTC during pandemic-related access restrictions across different care contexts and clusters, we undertook a qualitative investigation in five countries.

## 3 | Methods

### 3.1 | Aim

The aim of this study was to generate an in-depth understanding and initial theorising about the social interacting and engagement processes between family members, residents, LTCs staff

and management during the various phases of the pandemic in five different cultural contexts and continents. The following research questions guided the study:

- How do family caregivers experience the public health measures/policies, such as visitation restrictions, implemented in the LTCs during the pandemic?
- How do these public health measures/policies impact family caregivers' relationship with their loved one living with dementia, and the engagement and care received as a family (resident & family member)?
- What is family caregivers' experience of interacting with LTCs staff and management?

### 3.2 | Design

Strategies from constructive grounded theory (GT; Charmaz 2024) were used to explore interactions and engagement between family caregivers, their loved one with dementia and LTCs staff/management. GT is rooted in the sociological theory of symbolic interactionism, which posits that persons construct and assign meaning to events and actions as they interact with others. As a research methodology, GT studies social processes and the meanings assigned to these interactions (Charmaz 2024). The use of GT strategies is therefore particularly suited to answer the research questions and denotes a fitting methodological approach since little prior knowledge existed at the time of study conception in 2020. While GT is a refined and well-described qualitative methodology, it is not a fixed, controlled process of inquiry; rather, it can be flexible in its application and is marked by exploration, adaptation and refinement occurring through concurrent data collection and analysis (Charmaz 2024).

### 3.3 | Setting and Sample

The study was carried out in five countries or cities, namely the United States (Midwest), Switzerland (German-speaking part), Hong Kong (China), the United Kingdom (South England) and Japan (Western). These countries were included because they have a similar social care structure (e.g., elders living in a care facility rather than a family home), including LTC facilities that operate under governmental guidelines where people living with dementia often reside.

Persons eligible to participate in this study were caregivers of individuals living with dementia living in LTCs for at least 6 months prior to the onset of the pandemic (cut-off date: March 2020). Family members and close caregivers were defined as close others who self-identify as having emotional ties or a primary care obligation towards the individual living with dementia, or who have been defined by the individual living with dementia as belonging to his or her family. They may or may not be related by biological or legal ties.

Participants needed to be at least 18 years old, able to cognitively understand and participate in the study and have sufficient language skills to be able to communicate in English (US, UK),

German (Switzerland), Cantonese (Hong Kong) or Japanese (Japan). Participants also needed to have had regular interaction with the care and/or management staff of the LTCs in which the people living with dementia resided during the pandemic, preferably starting with the lockdown and continuing in the next phases of the pandemic.

Purposive and snowball sampling strategies were used. Purposive sampling implies that participants are purposively selected based on their experience with the phenomenon under study (Palinkas et al. 2015). Snowball sampling is effective when participants may be difficult to locate (Naderifar, Goli, and Ghaljaie 2017) and was used to tap into informal networks of affected family and other close caregivers. Potential participants were recruited through a referral process from community agencies (e.g., social workers leading dementia support groups or nurses working in LTCs) and contacted via email. In each country, the researchers, who are all PhD prepared, contacted institutions via phone or email. The recruiter in each organisation then sought permission from family caregivers for the researcher to contact them and invite their participation in the study.

A priori determination of sample size is usually not feasible within qualitative research (Malterud, Siersma, and Guassora 2016). The number of participants required depends on the research question, the heterogeneity of participants, the richness and depth of collected data and the level of analysis and interpretation to be achieved (Boddy 2016). In GT, an initial sample is generated to develop preliminary insights and conceptual understandings, which then guides further targeted sampling to 'saturate' emerging concepts (Charmaz 2024). For the current study, the goal was for researchers in each country to recruit a sample of two to five participants with rich data.

### 3.4 | Data Collection

Data were collected between June 2021 and August 2022 through 15 semi-structured, in-depth individual or dyadic interviews with 16 family members, depending on their preference, at a location (i.e., home, LTCs) or mode (face-to-face, online meeting tool) of their choice. Interviews were conducted by six doctoral-prepared researchers with a background in nursing, psychology and occupational therapy. A semi-structured interview guide was jointly developed in English and then translated into German, Cantonese and Japanese, which provided questions to initiate, follow-up and probe, and end the interviews, but allowed for flexibility (Data S1). Narratives of concrete occurrences as well as reflections on their experience of interaction and care were sought. Narrative data reveal an experience as lived and acted in, providing examples of social interactions, whereas reflective data offer insights into participants' understandings, behaviours, thoughts and feelings (Kesselring, Chesla, and Leonard 2010).

Interviews started with family members' stories of interacting with their loved one living with dementia, LTCs' care and management staff and experience of institutional policies during the pandemic. Participants' experience was then explored in depth,

focusing on 'what happened' for them in the situation, including what this was like for them and how they acted in this new situation (Charmaz 2024). Participants completed a demographic form and provided information on the health and living situation of the individual living with dementia. Interviews were audio-recorded and transcribed verbatim by the researcher or a professional research transcriptionist. Transcripts were anonymised and checked for their accuracy by the research member who conducted the interviews.

### 3.5 | Data Analysis

Strategies from constructivist GT (Charmaz 2024) were used to analyse the data. GT begins with narrative data describing concrete realities, which are condensed using an iterative and comparative process to arrive at a conceptual understanding of the data (Clarke et al. 2023). Researchers moved back and forth between the data, emerging concepts and so on, which is key to GT analysis (Charmaz 2024).

Each country-specific research team, which consisted of at least two researchers, engaged in initial or open coding of their own data as soon as two to three interviews had been completed. Initial coding entails close reading of the text and labelling it line-by-line, usually using an English gerund. These initial codes were used to discern first analytical insights through regular, monthly research group interpretive meetings. Frequently appearing or interpretively highly relevant initial codes were taken together to form a focused code, which was used to sort and synthesise subsequent interviews. Once all available data have been coded in this way, focused codes that cut across interviews and countries were identified as recurrent themes and developed into preliminary categories; that is, conceptual understandings arising from or grounded in the data (Charmaz 2024). Focused codes and preliminary categories were compared across countries and verified with data and earlier versions through constant comparison, a process undertaken both within each country as well as the international research team. Preliminary categories were defined with memo-writing, their tentative properties were compared with the data and missing aspects were filled by using theoretical sampling in ongoing analysis in an additional two countries or cities (due to delays in data collection in the United Kingdom and Hong Kong, China). Memo-writing is a free-flowing, interpretive, crucial activity that occurs throughout the GT analysis process. Memo-writing occurred in relation to codes and categories, their interrelationship along with emerging insights. They were a key means to synthesise codes into categories, define the categories and explicate their properties.

Coding and memo-writing were country and language-specific activities involving at least two researchers in each country or city. Monthly interpretive research team meetings were held, sharing coding lists, memos and interview excerpts to facilitate analysis. Raw data were in their original language (i.e., English, German, Cantonese and Japanese), but codes and memos were written in English to facilitate collective analysis (Chen and Boore 2010). As such, analysis moved back and forth until a consensus and model structure was achieved that answered the research questions and reflected the data.

### 3.6 | Rigour

The rigour of this study was ensured in the following way (Stahl and King 2020). In each country or city, when possible, two experienced qualitative researchers independently identified codes and categories. They met regularly to reach a consensus on the categorisation and coding. The categories developed codes and categories were then brought to the international group where the synthesised categories and codes were shared for the purpose of peer validation. This step assured the confirmability of the findings. An audit trail was developed for the dependability of this study in each country or city. The audit trail records the vigorous course of data analysis in GT method with thick and detailed descriptions of the process and experience being studied, as well as the process of reflections, contributing to the transferability (Charmaz 2024).

### 3.7 | Ethical Considerations

Ethical approval was obtained at the principal research institute (Minnesota State University, Mankato; #1727904-2) of the first author at the time the study was begun. The study was then submitted to the responsible ethics committee in each country or city by the local principal investigator, as required by national laws and regulations specific to the country. Data collection commenced after approval had been obtained. Careful attention was given to explaining the voluntary nature of this study and all aspects of the study during the consent process. The researchers expressed the importance of maintaining anonymity and this was achieved by use of study participant numbers, and country designation, for instance 'US 1'. Data were analysed using transcripts that had been cleaned of all personally or potentially identifying information by the researcher conducting the interview before sharing transcripts with the research team.

## 4 | Results

### 4.1 | Participant Characteristics

Sixteen family members of individuals living with dementia living in LTCs participated (43.8% spouses, 50% children or 6.3% others). Participants were predominantly women (81.3%) (see Table 1). Interviews lasted on average 77 min and took place over the phone or online via video call platforms (67%, mainly by long distance due to the pandemic social distancing recommendations) or face to face (33%). One interview involved two family members; all others were individual interviews.

### 4.2 | Core Theme

The data showed a nuanced picture of the complexity of family or close caregivers' experiences when having a loved one living with dementia residing in an LTC during the COVID-19 pandemic. The analysis uncovered rich understanding about the social interacting and engagement processes between family members, LTCs staff and management and residents

**TABLE 1** | Caregiver and persons with ADRD characteristics.

| Carers                                                 | <i>n</i> |             |
|--------------------------------------------------------|----------|-------------|
| Age [in years] M ± SD                                  | 16       | 64.9 ± 12.1 |
| Gender [female] <i>n</i> (%)                           | 16       | 13 (81.3)   |
| Relation to the person with ADRD <i>n</i> (%)          | 16       |             |
| Spouse                                                 |          | 7 (43.8)    |
| Children                                               |          | 8 (50.0)    |
| Others                                                 |          | 1 (6.3)     |
| Educational level <i>n</i> (%)                         | 15       |             |
| University degree                                      |          | 10 (66.7)   |
| Others                                                 |          | 5 (33.3)    |
| Employment level <i>n</i> (%)                          | 15       |             |
| Full time                                              |          | 3 (20.0)    |
| Part time                                              |          | 4 (26.7)    |
| Retired                                                |          | 8 (53.3)    |
| Health outcomes M ± SD                                 |          |             |
| Self-perceived health [score range: 1–10]              | 15       | 7.8 ± 1.8   |
| Well-being [score range: 1–10]                         | 14       | 7.6 ± 1.3   |
| Stress level [score range: 1–10]                       | 14       | 6.3 ± 2.8   |
| Number of visits per week before pandemic [max] M ± SD | 14       | 4.1 ± 2.1   |
| Distance to facility [minutes] M ± SD                  | 15       | 32.0 ± 37.1 |
| <b>Person with ADRD</b>                                |          |             |
| Age [in years] M ± SD                                  | 15       | 82.9 ± 9.5  |
| Gender [female] <i>n</i> (%)                           | 15       | 10 (66.7)   |
| Type of dementia <i>n</i> (%)                          | 9        |             |
| Alzheimer disease                                      |          | 5 (56.0)    |
| Vascular dementia                                      |          | 3 (33.0)    |
| Frontotemporal lobe degeneration                       |          | 1 (11.0)    |
| Time since ADRD diagnosis [years] M ± SD               | 15       | 8.0 ± 4.9   |
| Barthel Index (score range: 0–20) M ± SD <sup>a</sup>  | 15       | 7.1 ± 6.7   |
| Lives in single room <i>n</i> (%)                      | 15       | 10 (66.7)   |
| <b>LTC facilities</b>                                  |          |             |
| Type of facility <i>n</i> (%)                          | 15       |             |
| Public facility                                        |          | 13 (86.7)   |
| Private facility                                       |          | 2 (13.3)    |
| Size of facility <i>n</i> (%)                          | 15       |             |
| 50 residents                                           |          | 6 (40.0)    |
| 51–100 residents                                       |          | 8 (53.3)    |
| 101–200 residents                                      |          | 1 (6.7)     |

<sup>a</sup>Barthel-Index Wade and Collin (1988).

during various phases of the pandemic in different countries or cities.

At the core of family and close caregivers' experience of visitation bans or restrictions was their *negotiation for access to maintain a relational continuity* with their loved one living with dementia (see Figure 1). After some time of initial acceptance and lack of a sense of agency due to the unexpectedness of visitation bans, they did everything possible to gain access, maintain the relationships and interact regularly with the individual living with dementia in order continue to provide care and emotional support. They looked for and created varying ways to access LTCs, both formal and informal, for example, through official communication with LTC management, or via relationship they had with LTC staff. It was crucial to them to receive information about the mental and physical health of their loved one living with dementia, the epidemiological situation in the LTCs, and the activities and measures LTCs take to care for residents. They lived with constant fear of missing something essential or for not being able to be present when needed. Then, family caregivers integrated their own experiences during the chaos of the pandemic, some tried to change their minds while making sense of it as painful and difficult experiences, others found positive meaning in the experience. Each expressed their attitude of trying to continue caring for and engaging in a meaningful relationship with their loved one with dementia, to somehow coexist with the post-pandemic.

This core—or basic social process of *negotiating for access to maintain relational continuity* had four themes (1) Feeling excluded, isolated and upset; (2) Facing depersonalising situations; (3) Navigating challenging interactions; and (4) Living with (post-) pandemic circumstances (see Figure 1).

#### 4.2.1 | Theme 1: Feeling Excluded, Isolated, and Upset

This theme captures family experiences of unexpected exclusion from visiting, communicating and staying in touch with their loved ones due to the visit restrictions and implemented protective measures. Caregivers understood the necessity of protecting individuals living with dementia from possible exposure to the virus, but this exclusion from the care-triad and the separation

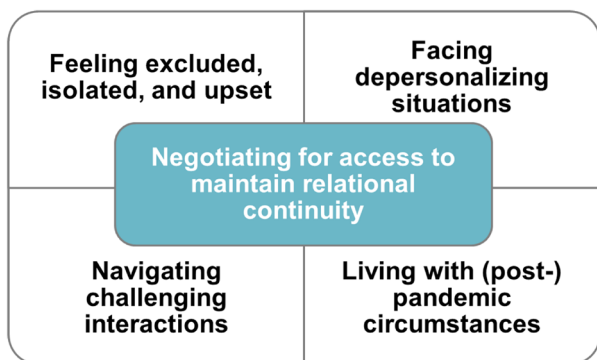


FIGURE 1 | Overview of findings.

that abruptly and forcibly deprived them of connection to residents was difficult for participants.

I feel like separated...because of obviously the COVID rules we weren't actually allowed to even go in there.  
(United Kingdom, 2)

Other caregivers, particularly as the pandemic wore on, were worried about their loved one's isolation in what should be considered their home. Recognising that their loved ones were likely to remain in this living situation until their death combined with the separation was difficult to bear.

A lot of the people in these facilities, this is their last stop. And it is their home and I just feel like <the care facility is> cutting them off from everything the way they did it.  
(United States, 2)

Because of the sudden exclusion and drastic measures of isolation, family caregivers were deeply concerned about no longer being able to see their loved one living with dementia. This concern was expressed in worst-case scenarios, for instance, that their loved one might die alone or that there would be no opportunity to say goodbye if the worst-case scenario happened:

That has been a moment for me where I felt like... maybe it's the last time. And when you don't see each other anymore ... and, I cried...  
(Switzerland, 4)

Due to the persistent stress and their responsibility as providers, some of the family members often felt alone within their wider family, as other support structures broke away. In some cases, they were the only ones within their family that was skilled or willing to find ways to maintain their role as a caregiver during the lockdown. They also struggled with their own emotions and a sense of powerlessness within their families:

...I was completely alone...I mean, now the whole responsibility has actually come over to me... Because I have been, more or less, the window to the mother ... Because no one was allowed in anymore. And that was already a burden.  
(Switzerland, 1)

Furthermore, family members felt worried, helpless and upset, that they were robbed of the possibility to react to the needs, worries and fears of their loved one due to visitation bans or limited information from LTC management and staff. Caregivers missed the sense of closeness, and warmth; feeling distressed by being excluded from the care-triad and not being able to conduct their routines as family caregivers:

During the 14 days that my mom had quarantine, I had many emotional images forming in my mind, including <that> she was completely isolated and helpless; being alone in the room; There were also

images in my mind that she might hurt herself or be hurt, In my mind, she might fall and be trapped and bruised, and everything might be wrong ...

(Hong Kong, 2)

The caregivers described feelings of stress and concern about the well-being of their loved one with dementia; an inability to see and be aware of how their loved one was doing physically and emotionally. This in combination with inconsistent, or a lack of, information added to the sense of concern and worry for their loved one.

#### 4.2.2 | Theme 2: Facing Depersonalising Situations

This theme captures the emotional moments and situations in which family caregivers have noticed a dramatic decline in the mental, physical and cognitive health of their loved one resulting from isolation during the pandemic lockdown of care facilities or have felt their identity as caregivers shaken by the injury to their dignity.

The absence of social interactions led to suffering for the individuals living with dementia, which was difficult for family caregivers to witness, demonstrating the vulnerability of their loved ones through emotional release and somatic complaints, thus, progression of dementia:

...my husband's dementia got worse in the last six months. Well when he speaks, I'm doing a lot of guessing and agreeing with him...he is at the late stage of dementia...

(United Kingdom, 1)

For the family caregiver, one of the most frustrating situations was observing inconsistencies in COVID-related practices and limitations in the staff's ability to safely care for their loved ones. This experience seemed to heighten the caregiver's perception of depersonalisation. One caregiver shared the following.

I think if you're going to do Protocol one time you do it the next time, or if you're going to do this, you do it, you'd be consistent and that's where I think they weren't consistent about some things.

(United States, 2)

Furthermore, families reported negative experiences caused by insufficient quality of care from LTC staff and non-transparent or lack of communication by LTC management about their loved one living with dementia health. Caregivers expressed concerns about the LTC's measures prioritising protection of older persons from infections while seemingly not taking into account the impact on their loved one's well-being through implemented policies and related decisions that might also risk the loved ones' life:

...I was shocked to see that his mouth was full of food left over, with dental plaque and tartar on the teeth

and blood on the gums. I want to kill myself. I had cared for my husband for ten years; he never had a bad tooth. I am very upset...

(Hong Kong, 2)

These circumstances led to feelings of mistrust in situations where the care and communication provided was inconsistent and lacked clarity.

The honest answer is that I don't trust them/you anymore... too much has happened.

(Switzerland, 1)

Family caregivers not only experienced neglect of care in LTCs but saw an absolute dis-engagement of families or caregivers in their role as essential care partners providing care to their loved one living with dementia. This led to feelings of devaluation and marginalisation as well as being wounded in dignity as a human being from LTC staff and management.

And I felt degraded, hurt and simply also powerless by this unnecessary harshness as well as no longer <being> perceived as a relative, but only as a foreign body, as a visitor.

(Switzerland, 1)

Instead of being recognised as important partners in providing safety and well-being for the individual living with dementia, family caregivers were posited to be a threat:

I made the mistake of...My mom's hearing aid was coming out of her ear, and I just got up and put it in her ear, because it was falling out... well they <LTC staff> happened to see me do it and away she went to quarantine for two weeks...and that was awful...awful for me.

(United States, 1)

#### 4.2.3 | Theme 3: Navigating Challenging Interactions

This theme captures the family caregivers' struggle to tease out their connection to their loved one while facing numerous obstacles in providing care within the constraints of the COVID-19 policy. And the attitudes and behaviours of the staff of LTC in the process affected the family's trust or distrust towards the LTCs.

There was a lack of information necessary for the caregiver to engage with their loved one in adapted ways based on COVID-19 policies, so they negotiated in whatever ways they could. For instance, one caregiver stated,

It was a long time before they (staff) said I could go in his (husband's) bedroom and nobody told me that he's changed his room... when I found out the minute that he's been moved to the ground floor, I was upset.

I did write and say I wasn't very happy about his room being changed and they apologized.

(United Kingdom, 2)

Navigating barriers to interactions with the loved one living with dementia required persistence by these caregivers. One caregiver shared their vigilance in pursuing a connection with their loved one:

We (my father, sisters and myself) did whatever we could do. So as soon as there was a green light to have a FaceTime call, we booked in with that, as soon as there was a green light for visits behind the screen we booked in for that.

(United Kingdom, 1)

Because people with dementia have cognitive decline and have difficulty communicating verbally, communication through the five senses, such as eye contact and physical touch, is extremely important for them to feel connected and secure with others. Physical isolation and online communication were insufficient to meet this aspect of person-centred care for the individuals living with dementia.

There was a remote visit, but when we actually met remotely...he was just sleeping all the time. If there was someone there, <they were> saying to him, 'Look over there you are connected with your wife'.

(Japan, 1)

Caregivers felt compelled to advocate for their loved one's rights to have family present in their care and found ways to continue their influence on the care experience their loved ones received. One caregiver shared how important it was for her that her mother was wearing a nice outfit.

I wanted her to wear this because it'll look good together...and I sat with people who don't have any color coordination, but they <staff> sounded kind of put out but I'm sorry that you have to do all this, but I can't come in and help so...

(United States, 1)

Although caregivers were faced with this dichotomy of lived experiences, desiring to care for their loved one living with dementia in LTCs but facing barriers to providing care during the pandemic, they also had empathy for the difficult work the facility staff carried out; especially for those staff members providing direct care. For instance, one caregiver stated:

The staff must be tired too, and there will be many limitations. Because not all staff are seasoned staff.

(Japan, 4)

In situations where LTC staff recognised the importance of family presence, and as a part of the trinity of care, the caregivers trusted the staff and felt safe entrusting their loved one's care to them.

I was quite reassured when I saw my mom getting familiar with the chief nurse and some nurses... Then I knew she liked these nurses and I was truly reassured.

(Hong Kong, 1)

On the other hand, when they were excluded from the triad of care and unable to maintain a connection with the resident, they experienced impersonal situations, such as poor communication with LTCs staff and deterioration of the loved one's health, which increased their mistrust of the LTC.

My biggest concern was that if their <LTC> staff weren't fully understanding... how compliant <with safe guards> were they when I wasn't there.

(United States, 2)

Family caregivers were persistent in trying to maintain a connection with the resident and were looking for ways to be involved. In the process, trust was strengthened when LTC staff continued to communicate with the family caregivers about the loved one's health and the content of his or her care as a member of the care triad, and mistrust was created when communication between LTC staff and family caregivers was weak or lacking.

#### 4.2.4 | Theme 4: Living With (Post-) Pandemic Circumstances

This theme captures family caregivers' concerns about the future. Their experiences of care or absence thereof, as well as exclusion instead of partnership, continued to shape their interactions with and perceptions of LTCs during less restrictive times, while family caregivers began to look into the future with life after the pandemic. Families witnessed the negative consequences of isolation on residents' mental and physical health (i.e., somatic complaints and cognitive decline). At the same time, they had experienced inadequate care and staff behaviour, leading to more fundamental questions around the adequacy of LTCs as an institution. Pre-existing doubts around quality of care that had been ignored or put aside before the pandemic could no longer be ignored. The crisis and its (incompetent) management uncovered more foundational problems within LTCs, such as lack of sufficiently qualified staff, negative attitudes towards families' roles and expertise and poor leadership and management.

There's been some things that occurred during the pandemic that I don't think should have occurred, but it did so you know it's done, it's over we just got to move forward. I can't do anything about it... but life goes on.

(United States, 1)

The caregivers demonstrated a tenacity in their role. Through the experience of caring for their loved one living with dementia during the pandemic, the caregivers reflected on the impact this experience had on their lives and on their perspectives about the pandemic.



Covid-19 profoundly changed how I see people, including my wife and others. I feel that I can find happiness living with my wife who has dementia. Even during the Covid-19 pandemic, I am alive, thanks to God.

(Japan, 2)

Family caregivers integrated their own experiences in the chaos of the pandemic. Some tried to shift to a more positive frame of mind while making sense of the experience as painful and difficult, while others found positive meaning in the experience, but each expressed their attitude of trying to manage to live with the situation of the pandemic (post-pandemic).

## 5 | Discussion

This is the first study to explore from an international perspective, caregiver's experiences of having a loved one living with dementia in an LTC facility during the COVID-19 pandemic. Findings from this study suggest that close family caregivers of individuals living with dementia living in a care facility during the COVID-19 pandemic faced significant and distressing separation from their loved ones. Caregivers felt isolated and were upset witnessing their loved one living with dementia experiencing declining health, inadequate physical and emotional care, despair, helplessness and loneliness. They faced challenging barriers to maintaining the relational connection with their loved ones and persevered despite persistent and evolving visit restriction practices. These findings are consistent with findings in the study by Midtbust et al. (2021) that demonstrated a sense of ongoing responsibility for loved ones living in LTC facilities, where there was concern about quality of care the loved one received.

LTC lockdowns created unprecedented experiences separating family caregivers from their loved ones living with dementia (Thirsk et al. 2022). Furthermore, the COVID-19 pandemic has caused great difficulty and burden in the work of LTC staff (Hering et al. 2022). In this context, the observation of how COVID-19-related policies were or were not consistently followed coupled with the lack of communication between care facility administration and the family caregivers created distrust for the family caregivers. This caused them to question the quality of care their loved one was receiving. These inconsistencies were incredibly frustrating for the family caregivers. Family caregivers also questioned the impact of visit restrictions on the health and well-being of their loved ones. Similar to a study by Anderson and Jao (2022) who reported the impact of isolation during the LTC lockdown for dementia patients, many family caregivers reported a decline in their loved one's overall health and a marked worsening of their loved one's dementia symptoms.

Despite the challenges family caregivers faced, they persevered in their striving to remain connected to their loved one. They overcame multiple barriers including physical distancing to find ways to remain an integral part of their loved one's life and care. Family members continued to find ways to provide physical care and to advocate for their loved one living with dementia in LTC. This is consistent with other studies that have demonstrated the role of family caregivers for their loved ones providing direct and indirect care (Ross, Carswell, and Dalziel 2001; Hado and Friss Feinberg 2020).

It is widely understood that the COVID-related lockdowns tremendously affected family caregivers, and that there were many shortcomings in care delivery and lack of inclusion of the care triad in care provision (Mitchell et al. 2022; Ickert, Stefaniuk, and Leask 2021). Family caregivers in this study were upset when witnessing their loved one experiencing declining health, and perceived inadequate physical and emotional care for their loved one. However, when staff recognised the importance of the connection between the individuals living with dementia and their families and provided care on behalf of the families while confirming the families' wishes, the families were able to maintain trust in the staff and a psychological connection with their loved one. Their identity as family caregivers in the relationships they had was maintained and supported. This enabled them to move forward strongly even in the difficult situation of physical separation during the pandemic. Therefore, in the event of a similar pandemic in the future, it will be necessary to implement infection control measures while maintaining the triad of care; helping families and the individual living with dementia maintain their connection: physical, psychological and social, which is consistent with the triad of care model.

In recent years, with the development of information and communication technology, many LTCs introduced video visits during the COVID-19 pandemic (Ickert et al. 2020). This was true for the current study. Nevertheless, video visits with people with advanced dementia present communication challenges (e.g., the loved one sleeping, or not being able to focus on the visit). Since people with advanced dementia may have difficulty communicating verbally, they often communicate through nonverbal behaviour (Hubbard et al. 2002). Nonverbal communication is extremely important for connecting with others and gaining a sense of security. These communication challenges may cause a greater sense of psychological separation. Our findings show that family caregivers maintained a connection with loved ones not only through verbal interactions but also through nonverbal communication such as eye contact and physical touch, and in this way, they tried to recognise each other's presence. Our findings also suggest that video visits with people living with dementia require at least some LTC staff's intervention, such as hands on support and explanation connecting families and their loved ones.

This study included data from five geographically different countries. Interestingly, there were no significant differences in our findings across these countries or cities. Although there are likely to be nuanced cultural differences, these did not seem to demonstrate as key differences in our data, which suggests that we were able to identify a universally lived experience. Caregivers in all five countries or cities demonstrated a level of advocacy on behalf of their loved ones living with dementia. The lack of significant cultural differences in the data may be due to the fact that this investigation explored core, essential issues between caregivers and individuals living with dementia not bound by nation (Ross, Carswell, and Dalziel 2001).

### 5.1 | Limitations

Delays in obtaining ethical consent in some countries, changes in research staff availability and continued restrictions due

to the pandemic clearly limited the feasibility of recruitment and resulted in a relatively small sample size for a qualitative-descriptive study drawing on GT strategies. In other words, the categories and themes may not have been fully saturated, and we were unable to develop a theory. The use of analysis strategies from constructivist GT enabled a rigorous and transparent analysis process. All participants were members of the same blood or legal family, which may have introduced the experience of a narrowly defined 'family' caregiver in the results. We chose to recruit only family caregivers over the age of 18 who were legally able to provide informed consent for study participation; however, the authors acknowledge that individuals under age 18 may also provide care to family members living with dementia. Due to the apparent stress of participants' experience shared during interviews, the research team decided not to re-contact participants to confirm findings. This may have impacted findings, though the consistency of the data across five countries was viewed as a form of confirmation. However, this study is the first international cross-cultural examination focused on understanding the social processes within family caregivers' experience of having a loved one living with dementia living in LTCs during the COVID-19 pandemic.

## 6 | Implications

Family and other close caregivers have a significant role in the care of individuals living with dementia residing in LTC facilities. These care partners must be viewed not as an occasional visitor, and therefore an optional component to the resident's care and life, but as an integral and inter-related, significant partner and contributor in the care of the individual living with dementia.

Policy language needs to be updated to reflect the important role family and other close caregivers have as a part of the care triad. Family-friendly language should be included in these policies that is inclusive of family and close caregivers.

Effective and timely communication is of key importance during times of crisis such as the COVID-19 pandemic. Some facilities improved their communication practices during the pandemic and this supported caregiver's trust in the care provided to their loved ones. However, for most participants, communication declined during the pandemic, and this had significant negative impacts on the caregiver's mental health and well-being, how they viewed the care facility and their level of concern for their loved one living with dementia. Enhancing avenues of communication during times outside of such crises between care facility staff and administrators would help to streamline communication when another healthcare crisis arises.

This study focused on family caregivers, who are critical to the quality of life of individuals living with dementia and revealed the experiences of family caregivers who have a loved one with dementia in LTCs in the context of limited access. Findings from this study are relevant beyond the context of the COVID-19 pandemic, pointing to the need to view people living with dementia and their caregivers as dignified and respected, integral to the health and well-being of one another's lives, and as partner in care.

## 7 | Conclusions

This study highlights the suffering experienced by family and close caregivers and people living with dementia in LTC during the COVID-19 pandemic. Our findings demonstrate the key role that relationships play in family care. Families are essential to the health and well-being of their loved ones living with dementia in LTC. Future studies could include care staff as well as a larger sample of family caregivers. Policies that depict family and close caregivers as visitors whose access needs to be regulated ought to be changed into policies that enable a culture of partnership and inclusion to promote resident and family well-being. Infection prevention measures will need to be implemented in more caregiver-friendly ways, especially during a similar public health crisis, to acknowledge the importance of social interactions for influencing health and well-being. The optimum time to enact these changes is now.

### Author Contributions

**Kristen Abbott-Anderson:** conceptualisation, methodology, validation, investigation, writing – original draft. **Rahel Naef:** conceptualisation, methodology, validation, investigation, formal analysis, writing – original draft. **Qëndresa Thaqi:** conceptualisation, methodology, validation, investigation, formal analysis, writing – original draft. **Yoko Higami:** conceptualisation, methodology, investigation, writing – original draft. **Saika Yamauchi:** conceptualisation, methodology, investigation, writing – original draft. **Ken Hok Man Ho:** conceptualisation, methodology, investigation, writing – original draft. **Pat Chung:** conceptualisation, methodology, investigation, writing – original draft.

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### Conflicts of Interest

The authors declare no conflicts of interest.

### Data Availability Statement

Data available on request from the authors.

### Peer Review

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.16718>.

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### Supporting Information

Additional supporting information can be found online in the Supporting Information section.