Canadian Journal on Aging / La Revue canadienne du vieillissement

www.cambridge.org/cjg

From Compliance to Care: Qualitative Findings from a Survey of Essential Caregivers in Ontario Long-Term Care Homes

James Conklin[1,2], Maryam Mohammadi Dehcheshmeh[2], Douglas Archibald[2,3], Jacobi Elliott[4,5,6], Amy Hsu[2,3], Anita Kothari[7], Paul Stolee[4] and Heidi Sveistrup[2,8]

[1]Department of Applied Human Sciences, Concordia University, Montreal, QC, Canada, [2]Bruyère Research Institute, Ottawa, ON, Canada, [3]Department of Family Medicine, University of Ottawa, Ottawa, ON, Canada, [4]School of Public Health Sciences, University of Waterloo, Waterloo, ON, Canada, [5]Western University, London, ON, Canada, [6]Lawson Health Research Institute, London, ON, Canada, [7]School of Health Studies, Western University, London, ON, Canada and [8]School of Rehabilitation Sciences, University of Ottawa, Ottawa, ON, Canada

Article

Cite this article: Conklin, J., Dehcheshmeh, M.M., Archibald, D., Elliott, J., Hsu, A., Kothari, A., Stolee, P., & Sveistrup, H. (2024). From Compliance to Care: Qualitative Findings from a Survey of Essential Caregivers in Ontario Long-Term Care Homes. *Canadian Journal on Aging / La Revue canadienne du vieillissement* **43**(4), 538–547.
https://doi.org/10.1017/S071498082400014X

Received: 13 October 2023
Accepted: 17 February 2024

Mots-clés:
vieillissement; proche aidant essentiel; proche aidant familial; soins de longue durée; COVID-19; pandémie

Keywords:
aging; essential caregiver; family caregiver; long-term care; COVID-19; pandemic

Corresponding author:
La correspondance et les demandes de tirésàpart doivent être adressées à : / Correspondence and requests for offprints should be sent to: James Conklin, Department of Applied Human Sciences, Concordia University, Montreal, QC (james.conklin@concordia.ca).

Résumé

Contexte La pandémie de la COVID-19 a mis en évidence l'importance des soins prodigués par les membres de la famille et les amis proches aux personnes âgées vivant dans un foyer de soins de longue durée (SLD). Notre équipe en science de la mise en œuvre a aidé trois foyers de SLD de l'Ontario à mettre sur pied une intervention permettant aux membres de la famille d'entrer dans les foyers pendant les périodes de fermeture pour cause de pandémie.
Objectif Nous avons utilisé diverses méthodes pour soutenir la mise en œuvre, et cet article présente les résultats d'une enquête menée à l'échelle de l'Ontario pour nous aider à comprendre la nature des soins prodigués par les proches aidants.
Méthodes utilisées Nous avons mené une enquête auprès des proches aidants de l'Ontario.Une des questions ouvertes de l'enquête a permis d'obtenir un ensemble substantiel de données qualitatives que nous avons analysées à l'aide d'une procédure de codage et de thématisation, ce qui a permis d'en dégager 13 thèmes.
Résultats Les 13 thèmes révèlent des lacunes dans le secteur des SLD en Ontario, des efforts déployés pour y faire face et des efforts pour influencer le changement et l'amélioration.
Discussion Nos résultats indiquent que les proches aidants jugent nécessaire d'assumer des rôles vitaux afin de combler deux lacunes du système actuel : ils fournissent des soins psychosociaux et affectifs (et parfois même des soins de base) aux résidents, et ils jouent un rôle de surveillance et de défense des droits pour compenser les failles du régime actuel défini par sa conformité à la réglementation.

Abstract

Background The COVID-19 pandemic highlighted the importance of the care provided by family members and close friends to older people living in long-term care (LTC) homes. Our implementation science team helped three Ontario LTC homes to implement an intervention to allow family members to enter the homes during pandemic lockdowns.
Objective We used a variety of methods to support the implementation, and this paper reports results from an Ontario-wide survey intended to help us understand the nature of the care provided by family caregivers.
Methods We administered a survey of essential caregivers in Ontario, and a single open-ended question yielded a substantial qualitative data set that we analysed with a coding and theming procedure that yielded 13 themes.
Findings The 13 themes reveal deficiencies in Ontario's LTC sector, attempts to cope with the deficiencies, and efforts to influence change and improvement.
Discussion Our findings indicate that essential caregivers find it necessary to take on vital roles in order to shore up two significant gaps in the current system: they provide psychosocial and emotional (and sometimes even basic) care to residents, and they play a monitoring and advocacy role to compensate for the failings of the current regulatory compliance regime.

Background and objectives

The COVID-19 pandemic had a devastating impact on many long-term care (LTC) homes around the world, exacerbating and highlighting problems in the way that national health

systems provide care to older persons (Estabrooks et al., 2020; Heckman et al., 2021). Early in the pandemic, Canada had a higher proportion of COVID-19 deaths in LTC homes than all other OECD countries, with older residents in LTC and retirement homes representing nearly 80 per cent of all COVID-19 deaths in Canada (Stall et al., 2021b). The highest proportion of LTC COVID-19 deaths (81%) among OECD countries (where the average was 38%) occurred in Canada (Canadian Institutes for Health Information, 2020).

In the final report published by Ontario's LTC COVID-19 Commission, the commissioners acknowledged:

> When COVID-19 struck Ontario, it devastated the long-term care sector. At the time of writing, 11 staff and almost 4,000 residents had lost their lives. Deaths among long-term care residents represent more than half of all of Ontario's COVID-19 deaths, even though long-term care residents make up only 0.5 per cent of the population. Many more residents and staff were infected, with a reported 14,984 resident and 6,740 staff cases by March 14, 2021. (Marrocco et al., 2021, p. 11)

Policy makers and health leaders had no roadmap to follow when the pandemic struck, and this paucity of knowledge included uncertainty about the likely effects of preventing family members from entering LTC homes when the homes were experiencing a COVID-19 outbreak. A rapid review carried out in 2021 of English-language literature on the presence of essential caregivers (who usually, but not always, are family members) in LTC homes during periods of infectious disease outbreaks found only two research studies (along with 13 policy documents) on the subject (Palubiski et al., 2022). As additional health services researchers share their findings from studies conducted in the first 2 years of the pandemic, we are gaining an understanding of the measures taken and the results achieved. For the purposes of this paper, we are especially interested in the policies that affected the ability of essential caregivers to enter LTC homes and provide support to residents during periods of lockdown. In the spring of 2020, Ontario (and other Canadian provinces) issued directives whereby all LTC homes were required to lock down their facilities from visitors.

Scholars have known for some time that relatives and friends provide important care and support for older people living in LTC homes, and that these caregivers play relatively undefined and even unrecognized roles in the homes (Barken & Lowndes, 2018). Past studies have found that caregiver relationships with LTC staff can be adversarial and can work to the detriment of the well-being of residents (Hoek et al., 2021), and that these caregivers' '…skilled caring expertise tends to be invisible' (Barken & Lowndes, 2018, p. 61). Some have argued that it is vital to find ways to create a collegial partnership among paid and unpaid caregivers in LTC settings (Gallant et al., 2022).

Preventing caregivers from entering LTC homes during the pandemic left residents isolated and deprived of access to their families, who previously had provided daily care to their loved ones (Bardon, 2021). Decades of believing that families are the major transmitters of infections in LTC homes based on little evidence led to the imposition of these visiting restrictions in Canadian and international LTC homes, despite the recognition of the importance of their resident–family communication during the pandemic (Hado & Friss Feinberg, 2020). Recent data from LTC homes and hospitals in several countries show that visitors had little or no impact on the spread of COVID-19 among residents, and that residents were more likely to receive the virus from temporary staff or the staff who are in contact with multiple residents and may practice poor hand hygiene and PPE application (Low et al., 2021; Nguyen et al., 2021). Moreover, visiting restrictions are not included among the recommendations by some studies to reduce the risk of spreading COVID-19 in LTC facilities (Stall et al., 2021a).

We now know that LTC residents, their families, and staff were impacted by visitor restrictions in various ways. In the case of residents, studies show that social isolation significantly impacts personal health and quality of life (QoL), and that visiting restrictions led to a decline in physical health, and increases in isolation, loneliness, and mood disorders (Bethell et al., 2021; Ferdous, 2021). Furthermore, responsive behaviours increased in residents with dementia, resulting in an increase in prescribing of antidepressants and antipsychotic medications (Ferdous, 2021; Hugelius et al., 2021; Low et al., 2021; Smaling et al., 2022).

According to Dupuis-Blanchard et al. (2021), five key drivers impacted the experiences of Canadian families during the pandemic: lack of workforce, communication deficits with staff to receive news about their residents, concerns about the quality and quantity of care, staying on top of changing directives, and the autonomy of residents. After being prohibited from visiting residents, families started developing negative emotions, including guilt, fear, stress, and worry about their residents (Hugelius et al., 2021; Low et al., 2021). In particular, families of residents living with dementia were worried about the quality of care provided to their residents (Hindmarch et al., 2021; Smaling et al., 2022).

Staff, on the other hand, faced additional workload and burnout caused by the absence of families providing daily care and emotional support to residents (Hugelius et al., 2021; Low et al., 2021; Smaling et al., 2022). Staff turned into residents' substitute family and reported exhaustion from excessive work and emotional fatigue (Palacios-Ceña et al., 2021).

Our project is based on a partnership we formed with three Ontario LTC homes that were implementing a designated care partner intervention to allow some family members to enter LTC homes during pandemic lockdowns. We used a variety of methods to support the implementation process, measure impacts, and mobilize the knowledge gleaned through our partnership. This paper reports some of the results from one such method, which was an Ontario-wide survey of family caregivers who supported a resident of an Ontario LTC home. The survey was intended to produce an understanding of the nature of the care provided by Ontario's family caregivers. The results of the quantitative survey are presented in a separate paper. Here, we are concerned with the extensive responses we received to the one open-ended qualitative question that was included in the survey.

Research design and methods

Ethics approval for our study was obtained from the Research Ethics Board of the Bruyère Research Institute (reference number M16-21-002). All research participants who contributed data to this study gave written informed consent by responding to the following question that was presented to them at the start of the survey: 'I agree to participate in this study on family caregiving in long-term care. I understand that my participation is voluntary and that my name will not be associated with my responses'.

We developed an online survey whose purpose was to shed light on the roles, tasks, and experiences of essential caregivers as they supported residents in Ontario LTC homes. The development of our survey was based on a literature review on essential caregivers'

https://doi.org/10.1017/S071498082400014X Published online by Cambridge University Press

roles and experiences in residential care settings. We adapted items from the Family Involvement Questionnaire – LTC to record the frequency and time spent by essential caregivers in visiting and providing care to the resident (Fast et al., 2019). The survey was supplemented with additional items related to social activities, meals, and financial matters (Fast et al., 2019), as well as questions concerning direct and indirect care tasks (Keating et al., 2001). The survey also included items derived from research that was pertinent for the Ontario context (Cohen et al., 2014; Fast et al., 2019; Keating et al., 2001; Reid et al., 2007; Tsai et al., 2012). The qualitative portion of the survey, which we report on in this manuscript, asked the following question: *We are interested in hearing more about your experience. You are welcome to use the space below to share your interpretations, feedback, and reflections on the level of involvement and importance of family members (or other care partners) in providing hands-on care for residents in long-term care homes.*

Because the questions were derived from previously developed instruments capturing family involvement in nursing homes, we were able to rely on the significant testing of questions that had already been conducted by previous research teams. For example, the 'Family Involvement Questionnaire – LTC' instrument developed by Fast et al. (2019) involved 410 family members in the process of validating the questions that ultimately were included in the instrument. In addition to this, we pilot-tested our survey with an unpaid adult–child caregiver and used the think-aloud method (Ericsson & Simon, 1984) to identify questions that were unclear or irrelevant for LTC in Ontario. Two members of the research team reviewed the caregiver's comments and revisions were agreed on and implemented. The resulting final survey was then created and administered using Microsoft Forms.

We recruited participants through Family Councils Ontario, a not-for-profit organization supporting essential caregivers and family councils in LTC homes across Ontario. We also advertised the study through the Ontario Caregiver Organization, an organization supporting over 3.3 million caregivers in the province, as well as the Ontario Health Coalition, whose mandate is to protect and improve the public health care system. Finally, we directly approached 22 LTC homes that one member of our team had collaborated with on previous research projects; of these, 6 agreed to distribute the survey to family members and designated care partners of residents in their facility. Data were collected between April 8 and June 11, 2021.

The research protocol was approved by the Bruyère Research Institute Research Ethics Board (Protocol #M16-21-002).

The survey was completed by 192 Ontario caregivers, of whom 71 per cent (n = 159) were children of an LTC resident and 15 per cent (n = 32) were the spouse of a resident. Table 1 provides a summary of the demographic characteristics of survey respondents.

The 119 respondents who answered the open-ended question provided a large volume of qualitative data about the experiences of caregivers during the first wave of the COVID-19 pandemic, when visitation rights were suspended in Ontario LTC homes, and during the second wave when visitation rights were restored. When placed in a Word document, the raw data that we received in answer to this question consisted of 23 single-spaced pages (or 13,381 words) of commentary. Some comments were brief, consisting of a few sentences, while others ran to lengthy paragraphs. For example, among the 25 lengthiest submissions were those that contained the following number of words: 604, 471, 464, 462, 432, 379, 373, 315, 295, 285, 256, 255, 254, 252, 224, 223, 211, 204, 193, 176, 165, 163, 162, 160, and 159 (and many others ran between 100 and 160 words). To gain an appreciation of the length of these open-ended commentaries, note that the paragraph you are reading contains 160 words. This suggests that many people who filled out this survey had a great deal to contribute in their own voice.

Table 1. Sociodemographic characteristics of survey respondents

	Adult children (n = 159)	Spouse/partner (n = 32)
Age		
26–49	9	0
50–59	54	0
60–69	79	6
70–79	17	16
≥80	0	10
Gender		
Man	23	14
Woman	136	18
Ethnicity		
White	140	30
Other	14	2
Education completed		
Below bachelor's degree	65	17
Above bachelor's degree	91	15
2019 household income		
<$99,999	62	14
>$100,000	67	11
Employment status		
Employed	73	6
Unemployed	82	26
Frequency of visits to LTC home		
Few times a year/monthly	11	0
Weekly/daily	148	32

Note: Not all respondents answered all demographic questions.

We applied qualitative coding and theming procedures to determine what the data might reveal about the experiences of our survey participants. We used a process that is consistent with recommendations from qualitative methodologists, and in which several of our team members are proficient (Conklin et al., 2011; Hsieh & Shannon, 2005; Saldaña, 2013). We applied an exploratory holistic coding method that allowed us to sort the data into meaningful clusters before undertaking a full thematic analysis (Hsieh & Shannon, 2005; Saldaña, 2013), and then used a theming procedure that allowed us to identify and describe the broad patterns of ideation, behaviour, and social structuring that were revealed through participant experiences (Conklin, 2021). Figure 1 provides a visual summary of our analytical process.

The first step described below relied on a pen-and-paper technique, and subsequent steps made use of MS Word's structured table functionality. This type of approach is often used when it aligns with the experience and expertise of the lead analyst (Mattimoe et al., 2021), and it can also help analysts to become

https://doi.org/10.1017/S071498082400014X Published online by Cambridge University Press

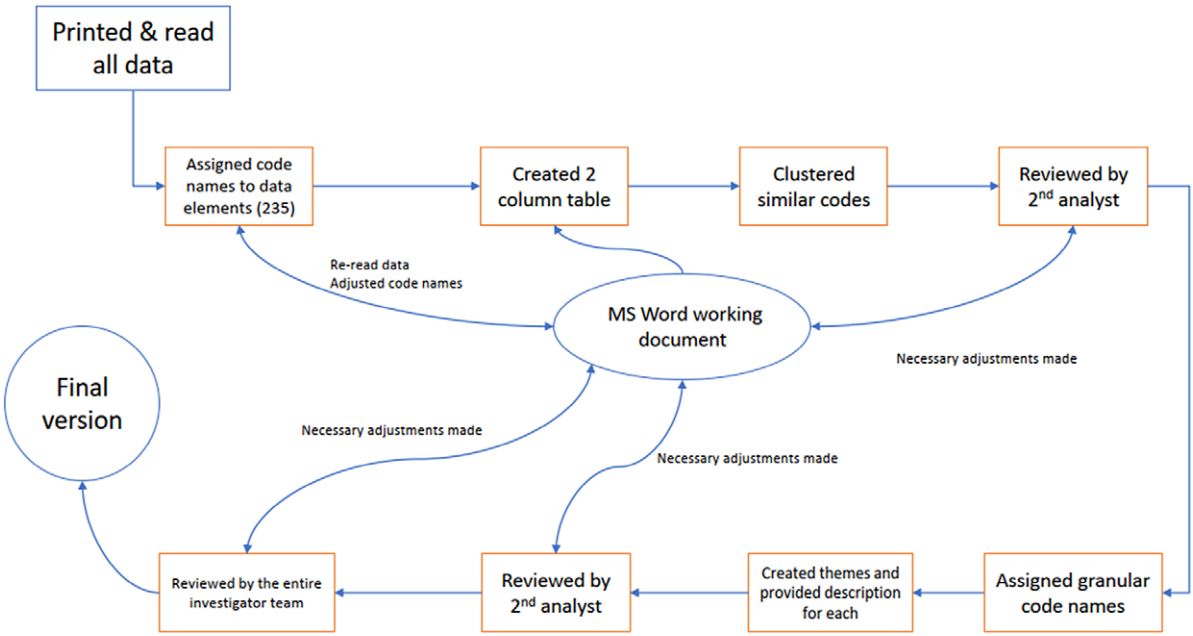

Figure 1. Our analytical process.

more immersed in the data, to arrive at more informed choices concerning codes and themes (Mattimoe et al., 2021; Saldaña, 2013), and to enhance rigor by slowing the analytical process and allowing for a more thoughtful interaction with the data (Maher et al., 2018).

To start with, one analyst created an MS Word *Analysis Working Document* (termed *working document* hereafter) where all the raw data were imported. The analyst then coded the data. This was done by printing the data file, reading through the file, circling portions of data, and writing down potential code names in the margins. On three occasions during the coding process, the analyst returned to the start of the printed document, reread the data, and considered the wording of the code names, making small adjustments to some code names. When completed, code names had been assigned to 235 data elements.

The analyst then returned to the working document and created a new section with a two-column table. The left column was reserved for code names and the right column for individual segments of coded data (with each code name and data element occupying a separate row). The analyst then sorted the table into clusters of similar codes. To do this, the analyst printed out a list of all code names. The analyst then created a new section of the working document, and copied and pasted the code table into this section. The analyst then created a new left-most column for the table. The analyst then read through the coded table, assigning numbers to the new column to identify codes that had similar or complementary meanings.

Before proceeding further, a second analyst undertook a detailed review of the work done to this point, considering whether any codes were improperly assigned, or whether other discrepancies or errors were evident. This second analyst identified eight concerns, mostly having to do with other ways in which a piece of data might be coded. The second analyst also identified some additional codes that could be added to the initial coding table. The two analysts met to discuss the concerns, and reached an agreement on how each concern should be handled. In addition, as part of this step, the two analysts considered whether numeric clusters associated with fewer than 10 codes should be integrated or combined with the codes associated with another number. As a result of these steps, 246 data elements were now sorted into 13 categories of meaning.

The first analyst then copied the coded and sorted table into a new section of the working document, and reorganized the tables so that all code names and data elements associated with the same number were contiguous with each other. The first analyst then performed a more granular sort on each of the numeric code clusters. For example, the analyst reviewed all codes associated with the number 1, and added a letter (A through D) to further sort the codes into more granular sets of meaning. In the case of these '1' codes, 1A was associated with codes that involved simple assertions about families being on the care team; 1B was associated with codes asserting the importance of the care provided by family members; 1C was associated with codes linking family care with resident well-being or health; and 1D was associated with codes asserting the importance of family presence for monitoring care and well-being. The first analyst then created a working title for each cluster, a count of the number of coded data segments in the cluster, and a brief description of each granular subcode.

In the next step, the analyst used the following procedure to synthesize the data into theme names and descriptions. First, the analyst copied the two cluster tables from the previous step into a new section of the working document. The analyst then merged all the data cells (in the right-most column) for each subcluster of codes (in other words, the cells for the 1A codes, the cells for the 1B codes, etc.). Then, the analyst read through the code names and data for the cluster. At this point, the analyst began to write a description that synthesized the meaning of the 1A codes, drawing on wording from the code names and the data, and incorporating quotations to ensure that the description remained close to the data. This procedure was continued with each subcluster of codes (1B, 1C, etc.). When all subclusters were complete, the analyst wrote a brief paragraph as the overall theme description, in some cases simply drawing on the topic sentences for each subcluster

https://doi.org/10.1017/S071498082400014X Published online by Cambridge University Press

Table 2. A comparison of the four dominant themes

#*	Theme name
72	Serious problems and deficiencies are caused by this LTC home's culture, management, staff, policies, and practices
32	Families are (or should be) a full part of the care team in long–term care homes
27	Some long–term care homes and their staff and volunteers were described in extremely positive terms
26	LTC staff behaviour is characterized by neglect and incompetence, and family members are treated with resentment or indifference

*Number of times the codes associated with this theme appear in the data.

description. Finally, after reviewing the results of this work, the analyst gave a name to the theme. This was then repeated for the 13 other code clusters.

In the next analytical step, the analyst performed some comparisons on the themes. This was done by creating tables showing the number of instances of the coded data for each theme, the theme name, and the theme description. The tables were sorted to compare the data in terms of the number of occurrences of data elements associated with different themes. This step allowed us to determine whether the experiences of these participants were largely homogenous, or whether there were diverse and even inconsistent experiences evident in the data. As evident in Table 2, which shows an output from this analytical step, the data clearly suggest a diversity of experience.

The final analytical step involved creating a general commentary on the themes. This was done by reviewing the work produced in the previous steps and noting the interesting features about the patterns evident through the theming. At the conclusion of this step, the entire working document was shared again with the second analyst, who reviewed the work and provided comments and suggestions. The resulting final working document was then shared with the full investigator team for review and discussion. The findings that resulted from this analysis form the basis for the next section of this paper.

We provide the full working document as Supplementary File 1, so readers can examine the complete details of our analytical process.

Results

Table 3 shows the theme names and descriptions that emerged from the analysis, along with representative quotations.

Discussion and implications

An overall tendency made evident through our analysis is that participants often described general or specific experiences, and then explained the meaning or significance that they attributed to

Table 3. Theme names and descriptions

Theme name	Description and representative quotations from the data	Number of data elements
Serious problems and deficiencies are caused by this LTC home's culture, management, staff, policies, and practices	The culture, policies, practices, management and staff of LTC homes, in other words the LTC home as *a* whole, gives rise to numerous negative or even horrific experiences for both residents and family members. We were told of a general malaise and/or numerous problematic situations arising in homes, of endemic poor care and neglect, and of needless suffering. In some cases, it seemed that LTC homes had prioritized items such as staff contentment, diminishing or suppressing complaints, financial success, or procedural convenience, over and above resident care and well–being. Not surprisingly, we heard numerous specific stories of bad experiences related to specific residents and homes. Representative quotations: • 'It is extremely distressing to feel like *a* "visitor" to my mother's home and to lose all control of decision making and personal care of our mother'. • 'The Administrators and Unit Managers were not empathetic and in some cases they created a "toxic environment" for their employees, residents and caregivers'. • '…LTC processes, systems were broken or non–existent …internal and external communications with staff and families'.	72
Families are (or should be) a full part of the care team in long-term care homes	Many participants asserted that family members are (or should be) full members of the care team in long-term care homes, so they may be able to provide the care needed by residents. Some suggested that without the presence of family, the level of care is likely to decline to unacceptably low levels. Representative quotations: • 'Families are an essential component in a resident's level of care – we are part of the team and we have *a* role to play'. • 'I think it is extremely important to have family members involved in the care of their loved one as the care provided by the LTC staff is very inconsistent'. • 'Family members want to be a part of the "care team" and to be fully involved in every level of care'.	32
Some long-term care homes and their staff and volunteers were described in extremely positive terms	Some participants said that their residents lived in good long-term care homes with staff that are (for the most part) wonderful and caring. We were told of positive and respectful workplaces, with amazing staff and volunteers. Representative quotations: • 'I know my dad is liked and looked after and he is safe'. • 'The staff are awesome, they genuinely show that they care and are willing to share info with me about my parent'. • 'The LTC home where my brother resides is an amazing place'.	27
LTC staff behaviour is characterized by neglect and incompetence, and family	In describing their negative experiences with long-term care, many participants singled out the poor behaviour of LTC frontline staff and spoke of unacceptable levels of incompetence and neglect. Participants said that staff often seemed to resent them, that communication was frequently poor,	26

(Continued)

https://doi.org/10.1017/S071498082400014X Published online by Cambridge University Press

Table 3. *Continued*

Theme name	Description and representative quotations from the data	Number of data elements
members are treated with resentment or indifference	and that staff workload may have contributed to this unfortunate situation. Representative quotations: • 'My experience was that my involvement was sometimes viewed as unwelcome, and it was often *a* struggle to engage fruitfully with staff'. • 'What support we needed from the PSWs was frequently provided with *a* "you're bothering me" negative attitude, despite the fact that we were kind, appreciative and asked for very little support'. • 'Staff would cover things up, make excuses'.	
Long–term care's deficiencies cause suffering among family and necessitate extra efforts and expenditures	The shortcomings and problems in the long-term care sector have produced worry and suffering, and have led some families to pay for additional care in order to ensure the health and safety of their residents. Representative quotations: • 'I, along with many families have suffered tremendously physically, emotionally, and financially'. • 'The hurt is still profound'. • 'To conclude … I must say, it is incredibly stressful and exhausting, to feel as though I must watch literally everything related to the care of my LO [loved one], due to *a* lack of trust in the way the whole system is designed'.	16
The LTC home and staff try hard, but there are problems, including a lack of interaction	Some participants acknowledged how difficult the frontline staff job is, and acknowledged the efforts made by many of these staff, but nonetheless indicated that the quality of care and life for residents is unacceptably poor. Some specifically mentioned the lack of social interaction and loneliness that characterizes life in a long-term care home. Others emphasized that the problem primarily stems from the way frontline staff work is organized and managed. Representative quotations: • 'No social contact or occasional checks by PSW's. They had no time for that'. • 'I found the staff and facility provided reasonable care within the system as it is structured'. • 'The staff did the best they could with the staff they had….not enough staff to provide proper care…2 PSW's to put 22 ppl to bed….not good!'	15
The deficiencies and shortcomings of long-term care are systemic and can be found throughout the entire sector	Several participants suggested that years of government neglect has produced a failed LTC sector in Ontario. Some of those who offered sector–wide comments called for an end to for–profit long-term care. Some participants noted that the neglect, abuse, and other shortcomings of LTC homes results in families stepping in to provide additional support for their resident, and this increasing role of families tends to shore up the systemic deficiencies of long-term care. Representative quotations: • 'I, along with many families have … seen how the various governments over decades did not act on the many commission reports, submitted long before Covid–19. Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained'. • 'I certainly developed mistrust in the long-term care system and its values…' • 'The system is deeply flawed and under–funded'.	13
The rules imposed in long-term care homes during the pandemic have contributed to sharp declines in health and well–being	Several participants reported that during the pandemic the health and well–being of their resident declined, and sometimes declined rapidly and badly. Other participants described how difficult it was to follow the overly restrictive rules imposed by the LTC home during the pandemic. Some participants have found the pandemic rules to be unfair and possibly even inhumane, reducing a long-term care resident to the status of *a* prisoner. Representative quotations: • 'My father … went from being able to walk, converse, feed himself, pee, wash his hands, try to dress himself to losing 40 lbs, being confined to a wheelchair, unable to feed himself a diet that now consists of puréed food, unable to communicate, screaming most of the time'. • 'I have noticed my mother decline rapidly, due to the continued isolation, loneliness, lack of mental stimulation, lack of socialization lack of access to her religious services, lack of foot care and hair care (basic grooming is denied), and denial of visits of her spouse'. • '…she is a prisoner within her LTC home. As my mother said to me "I know what it is like to be captured. There are a lot of rules and because I am captured I have to listen"'.	13
There is insufficient staffing in long-term care homes	Insufficient staffing in long-term care homes make it difficult or even impossible for the homes to provide an adequate level of care for residents. This situation also puts additional pressure on existing staff, and as well as creating problems for residents and family members. Representative quotations: • 'There is not enough staff to provide proper care and I worry my mother is being neglected'. • 'There just wasn't enough staff to talk to residents or communicate with residents or feed residents'. • 'The facility was understaffed and the staff over worked. The staff did not really have the time to spend quality time with the residents'.	12
The situation in long-term care homes could be improved through staff training and improved communications	Some participants considered ways of improving the deficiencies evident in long-term care, and offered comments and suggestions related to the need to provide more training for staff, and to create more extensive two–way exchanges of information between homes and families. Representative quotations: • 'The staff who deal with my mother's care need much more training about dementia'. • 'I think more training is needed for staff – I would urge trainers to clearly communicate and reinforce regularly the need to respect residents and be professional and attentive at all times'. • 'LTC homes should trust family members as they are important stakeholders and should establish open channels of communication where all parties can cooperate and express concerns'.	8

(Continued)

https://doi.org/10.1017/S071498082400014X Published online by Cambridge University Press

Table 3. *Continued*

Theme name	Description and representative quotations from the data	Number of data elements
Despite the current difficulties, family members must cooperate with managers and staff in long-term care homes	A few participants said that family members should be civil and cooperate when in long-term care homes, and suggested that some responsibility for the difficulties experienced in the sector may stem from family members. Representative quotations: • 'I had family members who were creating negative and destructive relationships with all the staff, causing major conflict with all of their visits in LTC …' • 'Families are important; however, families should not have the right to be abusive to staff …' • 'Families should learn to work cooperatively with the LTC homes and be ready to be supportive of staff as they are trying their best'.	6
Family Councils are (or could be) a useful resource to support families and residents	Family Councils are *a* useful resource that can support all residents in *a* facility, including those whose families do not live nearby, and should be run in a manner that makes it possible for all family members to participate and have a voice. Representative quotations: • 'It is vital for Family Councils to be *mandated* at all LTC homes. These provide a critical link and safety mechanism for resident care, especially where some residents don't have family nearby, or family is absent from care'. • 'The Family Council has also been a strong support for caregivers, providing information and an opportunity to talk to family members of other residents and share information and experiences'. • 'The family council meetings are a place to discuss items of common interest'.	3
The long-term care sector needs national standards and a better deal for frontline workers	Some called for improvement focused on the entire long-term care sector, and called for government action to create national standards for care. There was also a desire for greater accountability, and for improvements in the pay scales for frontline workers. Representative quotations: • 'There needs to be enforceable national standards in LTC'. • 'I don't think we should have to be concerned about the care our loved ones are getting in LTC. There ought to be *a* standard across the board and every resident ought to get the same good care whether a family member is with them or not'. • 'I feel we need both the Federal and Provincial Governments to make long-term care reform a priority …'	3

those experiences. It was interesting to see that the quality of their experiences (negative or positive) was sometimes attributed to specific individuals who worked in the LTC home, and at other times to broader organizational or even systemic factors that shaped the behaviour of individual actors. For example, the themes 'Serious problems and deficiencies are caused by this LTC home's culture, management, staff, policies, and practices' (associated with 72 data elements) and 'LTC staff behaviour is characterized by neglect and incompetence, and family members are treated with resentment or indifference' (26 data elements) tend to attribute negative experiences to specific actors or structures within individual LTC homes. However, the themes 'The LTC home and staff try hard, but there are problems, including a lack of interaction' (15 data elements) and 'The deficiencies and shortcomings of long-term care are systemic and can be found throughout the entire sector' (13 data elements) offer a situationist interpretation (Ross & Nisbett, 2011), suggesting that the attitudes and behaviour of decision makers and frontline workers in the LTC home are heavily influenced by external pressures that often emanate from the provincial Ministry of Health and LTC.

Overall, the themes indicate that participants have observed three distinct tendencies within the LTC sector of Ontario's health system. One tendency concerns deficiencies within the sector; the second concerns attempts to cope with the deficiencies and produce positive outcomes within the sector; and the third concerns a tendency towards change and improvement. The suggestions for improving the deficiencies of LTC include integrating families more fully with the LTC staff team, increasing the number of frontline staff, providing more staff training, improving the two-way communication between homes and families, making better use of Family Councils to support families and residents, providing better compensation for frontline staff, and creating national standards for LTC.

Viewing the data as revealing conflicting impulses within the system suggests that a force-field analysis may be useful (Shrivastava et al., 2017). This analysis offers a way of considering the array of forces that might promote or impede change within a human system. Reconsidering our themes in this manner produces Figure 2.

Finally, the thematic analysis draws our attention to the importance of essential caregivers. The essential role of caregivers in providing care to residents is clear throughout the data. The second strongest theme is the assertion that essential caregivers should be an integral part of the care team. Even many negative comments include statements confirming the vital caregiving role played by family and close friends.

The people who contributed qualitative data to our survey were responding to an invitation to tell us about their experiences as essential caregivers, and about the level of involvement and importance of essential caregivers who provide hands-on care to residents in LTC homes. As the themes discussed above indicate, their answers delineate a pattern with three major strands of meaning. First, the care provided by essential caregivers is perceived to be essential. Second, the care offered by the management and staff of many LTC homes is seen as deficient. Third, the deficiencies arise at least in part from the design and operation of the existing system of LTC, suggesting that policy makers must take action to improve the care provided in Ontario LTC homes.

Our findings are consistent with those of Kemp (2021), who found that families' contribution to care has been invisible and taken for granted. Essential caregivers such as family members have been viewed as 'visitors' and during the pandemic were prohibited from

https://doi.org/10.1017/S071498082400014X Published online by Cambridge University Press

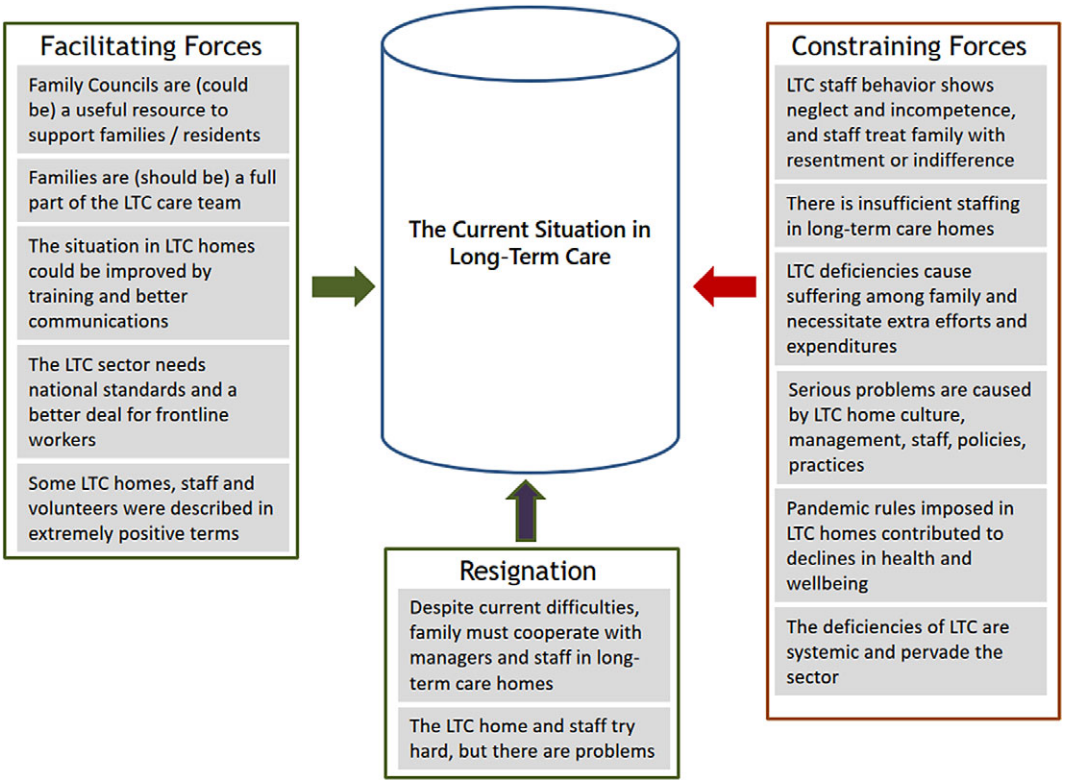

Figure 2. The thematic data presented through force-field analysis.

visiting their residents based on a biomedical model prioritizing infection control. However, the pandemic has shed light on the importance of the care provided by essential caregivers. It highlighted selfhood, human connections, and partnerships between formal and informal care partners and care receivers. Kemp wrote that 'Families do more than visit' (2021, p. 147), and this is surely correct.

Our findings are also consistent with recent studies establishing the importance of this full role played by essential care partners in LTC homes. As others have found, our study shows that visitation restrictions had severe negative impacts on both residents and their families, including strong emotionality and trauma (Cornally et al., 2022; Thirsk et al., 2022). Our work also offers additional support for studies showing the negative impact of a lack of social interaction, declines in the health of residents, and the importance of the advocacy and monitoring role played by family (Cornally et al., 2022). Like Cornally et al. (2022), our findings point to the importance of care provided by both essential caregivers and LTC frontline staff and indicate that the people playing these roles would benefit from forging a mutually supportive partnership to improve the care and support received by residents.

We suggest that our most important finding is that essential caregivers have taken on two vital roles in order to shore up significant gaps in the current system. First, they provide care to LTC residents. They do this by providing psychosocial and emotional support for residents, and they sometimes also take responsibility for aspects of basic care. Our data suggest that providing psychosocial and emotional support is a role that is happily assumed by essential caregivers, and is often merely an extension of relationships that have long existed between essential caregivers and residents. However, our data also suggest that many essential caregivers have found it necessary to assume responsibility for providing some of the basic care that is the responsibility of frontline staff.

Second, essential caregivers also play a monitoring and advocacy role that many of our participants describe as vital to the health and well-being of residents. They notice changes or anomalies in the resident's condition and share their observations with LTC staff. Moreover, they also notice problems or omissions in the care provided to a resident, and if the problem is not addressed they escalate their advocacy by complaining to supervisors and managers and demanding the situation be rectified.

This latter point is important because Ontario's Ministry of Health and LTC has attempted to assure the quality of care in LTC homes primarily through the creation and strengthening of a compliance regime. For example, on October 26, 2021, 18 months after the COVID-19 pandemic hit Ontario, the ministry announced that it would continue to 'fix' LTC by investing $20 million before the end of the year to hire 193 inspections staff (which would double the number of Ontario LTC compliance inspectors) and by improving the inspections program. The Ministry news release that contained this announcement claimed that this measure would '…ensure every resident experiences the safest and best QoL, and … [would] hold homes to account for the care they provide' (Ontario Government News Release, 2021).

However, some studies suggest that Ontario's reliance on compliance may produce adverse unintended consequences. For example, Hande et al. (2021) have pointed out that '[m]ore than two decades of research emphasize LTRC staff's difficulties in abiding by rigid regulations while also trying to respond to resident needs and preferences in order to approximate a balance of safe care and QoL …' (p. 540), and that '…current Canadian funding levels do not adequately support staff to exercise the

https://doi.org/10.1017/S071498082400014X Published online by Cambridge University Press

flexibility recognized in these promising policies. Thus, staff may remain stuck between a rock and a hard place when deciding which policies to follow and which activities to abandon because of time, funding, and staffing constraints' (p. 549). Others have pointed out that the use of compliance regulations does not seem to enhance the adoption of best practices in the care of older adults (Crick et al., 2020).

Our findings thus draw attention to the fact that the current situation has produced two informal or unpaid roles that are carried out by family and friends: the role of caregiver and the role of advocate. To some extent, the caregiver role is to be expected, given that an essential caregiver is an appropriate person to provide some of the relational care and support that residents need. However, the current LTC system is exploiting this role by requiring that many essential caregivers take on a basic care role that is properly the responsibility of the LTC home. Moreover, family and friends are also acting as informal compliance inspectors, noticing gaps and shortcomings in the care that is provided and in the health and well-being of residents, and reporting these deficiencies to staff and managers.

One might argue that the current system seems broken both in terms of the delivery of its core service to older Ontarians, and also in terms of the compliance safeguards that have been established to assure the quality of the core service. In both cases, essential caregivers must plug the gaps of this broken, malfunctioning system. The fact that the system's current performance is predicated on two informal and unpaid roles is a clear indication that something is wrong, that there is a gap in the system that is being filled in an emergent and often haphazard manner that is bound to produce unfair results and frequent failures. We suggest that the solution is not to invest further in a compliance regime that has for decades failed to deliver the expected results. Instead, investments must be made in the LTC homes themselves, especially to increase the staffing levels and training of PSWs and other frontline workers.

Our findings provide support for the claims that the problems in LTC are systemic. The data were provided by people who act as essential caregivers to residents in Ontario LTC homes. Our coding and thematic analysis shows that essential caregivers have similar experiences of LTC, experiences that highlight deficiencies, neglect, suffering, and chronic understaffing. Moving forward, we agree with Mackenzie (2022) who recommends that health care leadership guide staff, policymakers, and LTC home operators through a cultural shift embracing family members as care partners whose importance is no less than frontline staff. To start this cultural shift, the health care sector should promote and strengthen the principle that residents are moved to LTC homes not to be cured but to live in physical comfort while engaging in the activities they enjoy.

Limitations

This paper reports findings from a survey that was made available to caregivers throughout Ontario, and people who were aware of the survey made their own decision about whether or not to complete the survey. It is not possible for us to determine if many or most of those who self-selected to complete the survey did so because they shared certain characteristics or opinions. This makes it impossible for us to determine the extent to which our survey respondents are representative of the larger population of caregivers.

Supplementary material. The supplementary material for this article can be found at http://doi.org/10.1017/S071498082400014X.

Acknowledgements. The authors wish to acknowledge the efforts of the 119 Ontarians who contributed the qualitative data on which this article is based. The authors would also like to acknowledge the invaluable support that they received from Healthcare Excellence Canada, the Canadian Institute of Health Research, the Centre for Aging and Brain Health Innovation, the Ontario Centres for Learning, Research, and Innovation in Long-Term Care at Bruyère, and the Ontario Caregiver Organization.

References

Bardon, E. (2021). An ethical approach to considering family presence during COVID-19. *Healthcare Management Forum*, **34**(3), 193–195.

Barken, R., & Lowndes, R. (2018). Supporting family involvement in long-term residential care: Promising practices for relational care. *Qualitative Health Research*, **28**(1), 60–72.

Bethell, J., Aelick, K., Babineau, J., Bretzlaff, M., Edwards, C., Gibson, J.-L., Hewitt Colborne, D., Iaboni, A., Lender, D., Schon, D., & McGilton, K. S. (2021). Social connection in long-term care homes: A scoping review of published research on the mental health impacts and potential strategies during COVID-19. *Journal of the American Medical Directors Association*, **22**(2), 228–237.e25. https://doi.org/10.1016/j.jamda.2020.11.025

Canadian Institute for Health Information. (2020). *Pandemic Experience in the Long-Term Care Sector: How Does Canada Compare with Other Countries?* CIHI.

Cohen, L. W., Zimmerman, S., Reed, D., Sloane, P. D., Beeber, A. S., Washington, T., Cagle, J. G., & Gwyther, L. P. (2014). Dementia in relation to family caregiver involvement and burden in long-term care. *Journal of Applied Gerontology*, **33**(5), 522–540. https://doi.org/10.1177/0733464813505701

Conklin, J. (2021). *Balancing Acts: A Human Systems Approach to Organizational Change*. University of Toronto Press.

Conklin, J., Kothari, A., Stolee, P., Chambers, L., Forbes, D., & Le Clair, K. (2011). Knowledge-to-action processes in SHRTN collaborative communities of practice: A study protocol. *Implementation Science*, **6**(1), 1–11.

Cornally, N., Kilty, C., Buckley, C., O'Caoimh, R., O'Donovan, M. R., Monahan, M. P., O'Connor, C.D., Fitzgerald, S., & Hartigan, I. (2022). The experience of COVID-19 visitor restrictions among families of people living in long-term residential care facilities during the first wave of the pandemic in Ireland. *International Journal of Environmental Research and Public Health*, **19**(11), 6559.

Crick, M., Devey-Burry, R., Hu, J., Angus, D. E., & Backman, C. (2020). The role of regulation in the care of older people with depression living in long-term care: A systematic scoping review. *BMC Geriatrics*, **20**(1), 1–10.

Dupuis-Blanchard, S., Maillet, D., Thériault, D., LeBlanc, F., & Bigonnesse, C. (2021). 'Be their advocate': Families' experience with a relative in LTC during the COVID-19 pandemic. *Canadian Journal on Aging* **40**(4), 628–638. https://doi.org/10.1017/S0714980821000398

Ericsson, K. A., & Simon, H. A. (1984). *Protocol Analysis: Verbal Reports as Data*. MIT Press.

Estabrooks, C. A., Straus, S., Flood, C. M., Keefe, J., Armstrong, P., Donner, G., Boscart, V., Ducharme, F., Silvius, J., & Wolfson, M. (2020). *Restoring Trust: COVID-19 and the Future of Long-Term Care*. Royal Society of Canada.

Fast, C. T., Houlihan, D., & Buchanan, J. A. (2019). Developing the family involvement questionnaire-long-term care: A measure of familial involvement in the lives of residents at long-term care facilities. *The Gerontologist*, **59** (2), e52–e65. https://doi.org/10.1093/geront/gnx197

Ferdous, F. (2021). Social distancing vs social interaction for older adults at long-term care facilities in the midst of the COVID-19 pandemic: A rapid review and synthesis of action plans. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, **58**, 004695802110442. https://doi.org/10.1177/00469580211044287

Gallant, N. L., Hardy, M. S., Beogo, I., Conklin, J., Connelly, D., Kaasalainen, S., Keefe, J., Robitaille, A., Yous, M., Fanaki, C., & Cameron, C. (2022).

Improving family presence in long-term care during the COVID-19 pandemic. *Healthcare Quarterly*, **25**(SP), 34–40.

Hado, E., & Friss Feinberg, L. (2020). Amid the COVID-19 pandemic, meaningful communication between family caregivers and residents of long-term care facilities is imperative. *Journal of Aging & Social Policy*, **32**(4–5), 410–415. https://doi.org/10.1080/08959420.2020.1765684

Hande, M. J., Keefe, J., & Taylor, D. (2021). Long-term residential care policy guidance for staff to support resident quality of life. *The Gerontologist*, **61**(4), 540–551.

Heckman, G. A., Kay, K., Morrison, A., Grabowski, D. C., Hirdes, J. P., Mor, V., Shaw, G., Benjamin, S., Boscart, V. M., Costa, A. P., Declercq, A., Geffen, L., Sang Lum, T. Y., Moser, A., Onder, G., & van Hout, H. (2021). Proceedings from an international virtual townhall: Reflecting on the COVID-19 pandemic: Themes from long-term care. *Journal of the American Medical Directors Association*, **22**(6), 1128–1132.

Hindmarch, W., McGhan, G., Flemons, K., & McCaughey, D. (2021). COVID-19 and long-term care: The essential role of family caregivers. *Canadian Geriatrics Journal*, **24**(3), 195–199. https://doi.org/10.5770/cgj.24.508

Hoek, L. J., van Haastregt, J. C., de Vries, E., Backhaus, R., Hamers, J. P., & Verbeek, H. (2021). Partnerships in nursing homes: How do family caregivers of residents with dementia perceive collaboration with staff? *Dementia*, **20**(5), 1631–1648.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, **15**(9), 1277–1288.

Hugelius, K., Harada, N., & Marutani, M. (2021). Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review. *International Journal of Nursing Studies*, **121**, 104000. https://doi.org/10.1016/j.ijnurstu.2021.104000

Keating, N., Fast, J., Dosman, D., & Eales, J. (2001). Services provided by informal and formal caregivers to seniors in residential continuing care. *Canadian Journal on Aging/La Revue Canadienne Du Vieillissement*, **20**(1), 23–46. https://doi.org/10.1017/S0714980800012125

Kemp, C. L. (2021). #MoreThanAVisitor: Families as 'essential' care partners during COVID-19. *The Gerontologist*, **61**(2), 145–151.

Low, L.-F., Hinsliff-Smith, K., Sinha, S. K., Stall, N. M., Verbeek, H., Siette, J., Dow, B., Backhaus, R., Devi, R., Spilsbury, K., Brown, J., Griffiths, A., Bergman, C., & Comas-Herrera, A. (2021, May). Safe visiting is essential for nursing home residents during the COVID-19 pandemic: An international perspective. *Journal of the American Medical Directors Association*, **22**(5), 977–978. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7908840/pdf/main.pdf

Mackenzie, I. (2022). Visit restrictions highlight crucial role of family members in long-term care: The British Columbia experience. *Healthcare Management Forum*, **35**(1), 21–24.

Maher, C., Hadfield, M., Hutchings, M., & De Eyto, A. (2018). Ensuring rigor in qualitative data analysis: A design research approach to coding combining NVivo with traditional material methods. *International Journal of Qualitative Methods*, **17**(1), 1–13.

Marrocco, F. N., Coke, A., & Kitts, J. (2021). *Ontario's Long-Term Care COVID-19 Commission: Final Report*. https://files.ontario.ca/mltc-ltcc-final-report-en-2021-04-30.pdf

Mattimoe, R., Hayden, M., Murphy, B., & Ballantine, J. (2021). Approaches to analysis of qualitative research data: A reflection on the manual and technological approaches. *Accounting, Finance & Governance Review*, **27**(1), 1–16.

Nguyen, L. K. N., Howick, S., McLafferty, D., Anderson, G. H., Pravinkumar, S. J., Van Der Meer, R., & Megiddo, I. (2021). Impact of visitation and cohorting policies to shield residents from COVID-19 spread in care homes: An agent-based model. *American Journal of Infection Control*, **49**(9), 1105–1112. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8264278/pdf/main.pdf

Ontario Government News Release. (2021, October 26). *Ontario launching new and improved inspections program for long-term care*. https://news.ontario.ca/en/release/1001041/ontario-launching-new-and-improved-inspections-program-for-long-term-care

Palacios-Ceña, D., Fernández-Peña, R., Ortega-López, A., Fernández-Feito, A., Bautista-Villaécija, O., Rodrigo-Pedrosa, O., Arnau-Sánchez, J., & Lizcano-Álvarez, Á. (2021). Long-term care facilities and nursing homes during the first wave of the COVID-19 pandemic: A scoping review of the perspectives of professionals, families and residents. *International Journal of Environmental Research and Public Health*, **18**(19), 10099. https://doi.org/10.3390/ijerph181910099

Palubiski, L. M., Tulsieram, K. L., Archibald, D., Conklin, J., Elliott, J., Hsu, A., Stolee, P., Sveistrup, H. & Kothari, A. (2022). Guidance to (re) integrate caregivers as essential care partners into the LTC setting: A rapid review. *Journal of the American Medical Directors Association*, **23**, 778–809.

Reid, R. C., Chappell, N. L., & Gish, J. A. (2007). Measuring family perceived involvement in individualized long-term care. *Dementia*, **6**(1), 89–104. https://doi.org/10.1177/1471301207075640

Ross, L., & Nisbett, R. (2011). *The Person and the Situation*. Pinter & Martin.

Saldaña, J. (2013). *The Coding Manual for Qualitative Researchers* (2nd ed.). Sage.

Shrivastava, S. R., Shrivastava, P. S., & Ramasamy, J. (2017). Force field analysis: An effective tool in qualitative research. *Journal of Current Research in Scientific Medicine*, **3**(2), 139.

Smaling, H. J. A., Tilburgs, B., Achterberg, W. P., & Visser, M. (2022). The impact of social distancing due to the COVID-19 pandemic on people with dementia, family carers and healthcare professionals: A qualitative study. *International Journal of Environmental Research and Public Health*, **19**(1), 519. https://doi.org/10.3390/ijerph19010519

Stall, N. M., Brown, K. A., Maltsev, A., Jones, A., Costa, A. P., Allen, V., Brown, A. D., Evans, G. A., Fisman, D. N., Johnstone, J., Juni, P., Malikov, K., McGeer, A., Rochon, P. A., Sander, B., Schwartz, B., Sinha, S. K., Smith, K., Tuite, A. R., & Hillmer, M. P. (2021a). *COVID-19 and Ontario's Long-Term Care Homes*. Ontario COVID-19 Science Advisory Table. https://doi.org/10.47326/ocsat.2021.02.07.1.0

Stall, N. M., Brown, K. A., Maltsev, A., Jones, A., Costa, A. P., Allen, V., Brown, A. D., Evans, G. A., Fisman, D. N., Johnstone, J., Juni, P., Malikov, K., McGeer, A., Rochon, P. A., Sander, B., Schwartz, B., Sinha, S. K., Smith, K., Tuite, A. R., & Hillmer, M. P. (2021b). COVID-19 and Ontario's long-term care homes. *Journal of Elder Policy*, **1**(3), 65–110. https://doi.org/10.18278/jep.1.3.3

Thirsk, L. M., Stahlke, S., Perry, B., & Gordon, B. (2022). #Morethanavisitor: Experiences of COVID-19 visitor restrictions in Canadian long-term care facilities. *Family Relations*, **71**(4), 1408–1427. https://doi.org/10.1111/fare.12712

Tsai, H.-H., Tsai, Y.-F., & Huang, T.-S. (2012). Development and validation of the Family Meaning of Nursing-Home Visits Scale. *Journal of Clinical Nursing*, **21**(15–16), 2108–2117. https://doi.org/10.1111/j.1365-2702.2012.04150.x