

Providing palliative and end-of-life care in long-term care during the COVID-19 pandemic: a qualitative study of clinicians' lived experiences

Sandy Shamon BHSc MD, Ashlinder Gill MSc, Lynn Meadows PhD, Julia Kruizinga MScN, Sharon Kaasalainen BScN PhD, José Pereira MBChB PhD

Abstract

Background: A disproportionate number of COVID-19-related deaths in Canada occurred in long-term care homes, affecting residents, families and staff alike. This study explored the experiences of long-term care clinicians with respect to providing palliative and end-of-life care during the COVID-19 pandemic.

Methods: We used a qualitative research approach. Long-term care physicians and nurse practitioners (NPs) in Ontario, Canada, participated in semistructured interviews between August and September of 2021. Interviews were undertaken virtually, and results were analyzed using thematic analysis.

Results: Twelve clinicians (7 physicians and 5 NPs) were interviewed. We identified 5 themes, each with several subthemes: providing a palliative approach to care, increased work demands and changing roles, communication and collaboration, impact of isolation and visitation restrictions, and impact on the providers' personal lives. Clinicians described facing several concurrent challenges, including the uncertainty of COVID-19 illness, staffing and supply shortages, witnessing many deaths, and distress caused by isolation. These resulted in burnout and feelings of moral distress. Previous training and integration of the palliative care approach in the long-term care home, access to resources, increased communication and interprofessional collaboration, and strong leadership mitigated the impact and led to improved palliative care and a sense of pride while facing these challenges.

Interpretation: The pandemic had a considerable impact on clinicians caring for residents in long-term care homes at the end of life. It is important to address these lived experiences and use the lessons learned to identify strategies to improve palliative care in long-term care homes and reduce the impact of future pandemics with respect to palliative care.

A large majority of people living in long-term care homes experience frailty and have multiple comorbidities, which compromise their quality of life and reduce their life expectancy.^{1,2} In Canada, before the COVID-19 pandemic, 8% to 17% of all deaths occurred annually in long-term care, and the average annual mortality rate in long-term care homes is estimated to be between 27% and 52.3%.³ The median life expectancy of residents in long-term care is 18 months after admission.^{1,4,5}

Despite these high morbidity and mortality rates, numerous studies have identified barriers and gaps related to the provision of palliative care in long-term care homes.⁶⁻⁹ There have been many calls over the years to improve palliative and end-of-life care in long-term care.^{3,7-11} The gaps were further exposed and accentuated during the COVID-19 pandemic when a disproportionate number of COVID-19-related morbidities and deaths in Canada and worldwide occurred in long-term care homes, particularly during the early waves. This had a major impact on residents, their families and the front-line staff.^{12,13} It is important to capture and understand

these experiences with the goal of addressing ongoing gaps and preparing for future pandemics.

The aim of this study was to explore and better understand the lived experiences of Ontario-based long-term care clinicians with respect to providing palliative and end-of-life care during the pandemic, with the goal of improving palliative care and identifying strategies to mitigate the impact of future pandemics on this area of care in long-term care homes. More specifically, the primary research question was, what are

Competing interests: Sandy Shamon is a volunteer board member and vice president with Ontario Long Term Care Clinicians, a not-for-profit organization with the vision "All Ontarians in long-term care will receive excellent care." No monetary compensation is provided for her role in the organization. No other competing interests were declared.

This article has been peer reviewed.

Correspondence to: Sandy Shamon, shamons@mcmaster.ca

CMAJ Open 2023 August 22. DOI:10.9778/cmajo.20220238

the lived experiences of Ontario long-term care clinicians with respect to providing palliative and end-of-life care during the COVID-19 pandemic?

Methods

We used a qualitative interpretive descriptive study design, based in the constructivist and naturalistic orientation to inquiry, to gain a broad in-depth understanding of the clinicians' lived experiences as they provided end-of-life care during the COVID-19 pandemic in long-term care homes.^{14,15}

All participants worked as either nurse practitioners (NPs) or medical doctors (MDs) in long-term care homes in Ontario, Canada, during at least 1 of the first 3 waves of the COVID-19 pandemic. Semistructured interviews with participants were conducted during the early phase of the fourth wave of the pandemic (from August to September 2021).

In 2021, there were approximately 627 long-term care homes in Ontario.¹⁶ The long-term care homes in Ontario generally care for frail older residents with multiple comorbidities, including dementia, hence requiring advanced personal and medical care. Their vulnerable health state and the congregate living setting led to rapid spread of SARS-CoV-2 and higher rates of complications and fatality during outbreaks. Clinicians often work as part of a multidisciplinary team in this highly regulated care setting. During the pandemic, stringent visitation restrictions and measures were imposed to prevent and limit the rapid spread of SARS-CoV-2 in this vulnerable population. Additionally, in the early stages and during outbreaks, residents were prohibited from social activities and dining together. By the time of the interviews, the restrictions had been somewhat relaxed, allowing for more regular visitations.¹⁷

To ensure anonymity, the location and size of the homes in which the participants worked are not shared in this article.

The Consolidated Criteria for Reporting Qualitative Research checklist was used to report the study.¹⁸

Sampling and recruitment

Purposive and snowball sampling were applied to recruit study participants. An email invitation was sent in July 2021 by the Ontario Long Term Care Clinicians organization to its approximately 300 members composed mainly of physicians and NPs who work in long-term care. The initial email invitation was shared with other nonmember long-term care clinicians, leading to further snowball recruitment of clinicians who worked in long-term care homes during the COVID-19 pandemic. Study information was shared, and participants provided informed consent to participate. Each study participant was given a gift card for the value of Can\$25 as an honorarium.

Data collection procedures

Interviews were conducted by 1 of 3 researchers (A.G., J.K. and S.S., all female researchers with experience in qualitative research methods) using the Zoom virtual communication platform. Data were collected in August and September 2021,

16 months after the pandemic was first declared in Ontario, Canada. Clinicians were asked short demographic questions followed by open-ended questions, using an interview guide (Appendix 1, available at www.cmajopen.ca/content/11/4/E745/suppl/DC1). The interview guide was developed by the research team. Team members all have experience in qualitative research, and 2 have clinical experience in palliative care and long-term care (S.S. and J.P.).

Interviewers met after their first completed interview to debrief, ensure consistency in administering the interview questions, and compare transcripts and field notes taken to record observations or nonverbal cues during the interviews. In addition to exploring the clinicians' experiences, the guide also included a question on potential strategies that could help improve palliative care in long-term care homes. Interviews were audio recorded and transcribed verbatim, then anonymized and entered into Nvivo 2020 to aid data management and analysis. Interviewers continued to debrief with each other and the research team periodically following interviews to ensure consistency in data collection. Recruitment continued until data saturation was reached as determined by consensus of the research team (A.G., S.S., S.K., J.P. and L.M.).

Data analysis

Data analysis was done using an iterative thematic analysis in which researchers reviewed the transcripts to identify major themes.¹⁹ The primary investigator (S.S.) led the initial analysis with support from A.G., and together they completed the analysis and refined the identified themes based on feedback from the other researchers (S.K., J.P., L.M. and J.K.). Team meetings were held periodically to achieve consensus. The research team exercised reflexivity by consciously discussing whether any of their own pre-existing assumptions and experiences were influencing the analysis and how to mitigate this as they analyzed the data. Additionally, the involvement of more than 2 researchers in data analysis allowed for investigator triangulation to further ensure trustworthiness of the data analysis and validity of the study.²⁰

Ethics approval

The study was reviewed and approved by the Hamilton Integrated Research Ethics Board (no. 13507).

Results

A total of 12 clinicians (7 physicians and 5 NPs) belonging to various communities of practice were interviewed (Table 1). Interviews lasted from 45 to 90 minutes. Most participants were older than 50 years and had more than 10 years of experience working in the long-term care setting. They came from various geographical regions and long-term care homes. All participants reported additional training or clinical experience in palliative care before the pandemic and felt comfortable with providing end-of-life care in their long-term care practice. Most had participated in Pallium Canada's Learning Essential Approaches to Palliative Care 2-day course.²¹ Two had more advanced training and certification

Table 1: Demographic characteristics of participants

Characteristic	No. of participants <i>n</i> = 12
Age, yr	
< 40	2
40–49	3
50–59	4
≥ 60	3
Experience in long-term care, yr	
< 10	3
10–19	7
≥ 20	2
Provided virtual care	
Yes	10
No	2
Role	
Attending physician	7*
Medical director	7*
Nurse practitioner	5
Additional training in palliative care	
Yes	12†
No	0
Certificate of added competence in palliative care or care of the elderly‡	2
Note: LTC = long-term care. *All attending physicians were also medical directors of a long-term care home. †The majority were with short palliative care training, such as Pallium Canada's Learning Essential Approaches to Palliative Care courses (about 15 hours of training). ‡Certification by The College of Family Physicians of Canada either through a 1-year residency in palliative care or through a practice route recognition process.	

of added competency in palliative care from The College of Family Physicians of Canada. Study participants delivered in-person and virtual care during the pandemic.

Overview of findings

Several themes and subthemes were identified. The main themes were as follows: providing a palliative approach to care, increased work demands and changing roles, communication and collaboration, impact of isolation and visitation restrictions, and impact on the clinicians' personal lives. Table 2 shows the corresponding themes and illustrative quotations to support each theme.

Providing a palliative approach to care

Three subthemes were identified in this theme: scaling up, preparedness, and the uncertainty of the COVID-19 illness trajectory and prognosis. Participants reported that while the core principles of the palliative care approach did not change, the focus and scale of some aspects were altered considerably,

describing the change as “a mass casualty event, except it was a mass palliative care event” (MD6). Discussions about advance care planning and goals of care became more urgent and intense. During outbreaks, a higher demand was placed on providers to prepare residents and families for a possible rapid change in condition given the infection's high mortality in this population at the time. Early goals-of-care discussions became standard processes within some homes.

The existence of a palliative approach strategy in the home prepandemic, including education, routine discussions about advance care planning and goals of care, and end-of-life order sets and processes, facilitated pandemic preparedness. Staff who had previous training in the palliative approach were more comfortable providing this care, including having difficult end-of-life discussions, recognizing decline in residents' health, and monitoring and managing end-of-life symptoms.

Providers struggled with the uncertainty related to the presentation of COVID-19 symptoms and unpredictable disease trajectory and prognosis early in the pandemic. One participant described a case where the resident “got really sick overnight and died suddenly” (NP2). These added to the stress of difficult end-of-life discussions and care planning.

Increased demands and changing roles

Staffing challenges, role changes, and shortages in supplies and resources were reported. Regular duties and staffing levels in long-term care homes were substantially disrupted. Staff who contracted the virus, were exposed to infected people or experienced symptoms, even with unconfirmed SARS-CoV-2 infection, had to self-isolate for up to 2 weeks. These amplified pre-existing staffing challenges and affected the quality of end-of-life care, such as when “there wasn't enough staff to watch symptoms and to give a PRN [pro re nata, medication taken as needed]” (NP2). There were inadequate numbers of trained staff to initiate care conferences with families, monitor and assess residents, and accompany residents when families were unable to visit in person.

The increased demands led to added work hours and additional roles. Nurses were asked to provide housekeeping, care managers to provide bedside care, and personal support workers (PSWs) or registered practice nurses (RPNs) to bag bodies when funeral home staff were not permitted within the home. Staff, particularly PSWs, took on the role of companion for residents in the absence of their families and “would sit beside them as they were dying. One PSW sang to one of the residents” (NP2).

Some participants who were also medical directors took on increased advocacy work to ensure their homes had access to personal protective equipment (PPE) and supplies. Supply shortages, particularly during the early waves of the pandemic, with PPE, some injectable palliative care medications, oxygen tanks and test kits, added to the providers' distress and work burden.

In undertaking these role changes and increased responsibilities, participants also expressed pride in what they and their colleagues had done and accomplished under such trying circumstances.

Table 2 (part 1 of 4): Themes, subthemes and illustrative quotations

Theme 1: Providing a palliative approach to care	
Scaling up	<p>“So, prepandemic, we had a good flow, we had lovely processes. During our outbreak, all of those just went by the wayside.” (NP1)</p> <p>“So, we did, yeah, we started having conversations about goals of care. And we were already doing that, but, like, during the pandemic we even started reaching out even more with the families.” (MD2)</p> <p>“So, it was pretty much the same approach to palliative care before and during, but, like, during the pandemic you had to do it on a mass scale all at the same time . . . Like, nobody foresaw anything like this. Like, nobody foresaw the need to provide — this was like a mass casualty event, except it was a mass palliative care event. Like, that isn’t part of anybody’s training.” (MD6)</p>
Preparedness	<p>“And I would add that it’s not just myself but our whole organization. We had actually just had a LEAP course that I had trained 2017/18ish, where all of our front-line staff were brought in there.” (MD1)</p> <p>“We have a nurse practitioner that works between both of our homes and she’s extremely strong in palliative care.” (MD1)</p> <p>“So, there was work done before COVID, knowing that a palliative approach to care was key to preventing ED transfers. I had started the work before COVID, talking about that every resident coming into long-term care, we should advocate for a palliative approach to care focusing their goals of care on their quality — what it means for their quality of life and what that looks like in terms of medical treatment.” (NP2)</p> <p>“And I think that what kind of came out of the pandemic was this requirement that if we’re going to change culture, we can’t change it when somebody is dying; we need to change it from the minute they walk in the door. So, more conversations about what people’s goals of care are.” (MD5)</p> <p>“There needs to be opportunities to have some kind of education for those agency staff or those organizations that are going to come in and support the homes, both in infection control, but also palliative and end-of-life care, having conversations, difficult conversations, because that’s not something that’s always provided in a basic program.” (NP5)</p> <p>“And I think all that person-centred driven things is what sort of helped us establish our palliative care, end of life. We have you know, the committee, the order set. Like, there was just a culture of, you know, this is a person’s last home, you know, we are privileged to provide them this care, we are privileged to provide the care to their family.” (MD7)</p>
Uncertainty of illness trajectory and prognosis	<p>“And she burst out in tears, and she said, ‘She died.’ I had seen her the day before and she was having tea and she was just diagnosed with COVID, and she got really sick overnight and died suddenly.” (NP2)</p> <p>“But one of the most poignant end-of-life things that happened — I have to point out, and I hope in your study this comes out, we had no way of predicting who would die and who wouldn’t.” (NP3)</p>
Theme 2: Increased demands and changing roles	
Staffing challenges	<p>“The issue was more so that we had had a staffing crisis, which means that the staff that were trained weren’t necessarily the ones that we had, including the army.” (MD1)</p> <p>“So, hopefully all those things could be done earlier in future. But, of course, we didn’t have things like the rapid test to start with either.” (MD3)</p> <p>“There wasn’t enough staff to watch symptoms and to give a PRN. So you had to, you know, check them yourself and kind of aggressively schedule and up orders and check and check and check.” (NP4)</p> <p>“Nobody helped these homes with their staffing and people died really quickly. So, to me, it was a manpower issue.” (MD5)</p>
Role changes and added responsibilities	<p>“Staff were bagging bodies. They had never bagged a body in their whole career. It was upsetting; it was so hard for them . . . And even that support, I remember one of the residents was dying, and one of the PSWs was at the resident’s side. There was no family because they just, they’re elderly, their spouses are elderly, their kids are elderly. They put themselves at risk . . . But the PSWs would sit beside them as they were dying. One PSW sang to one of the residents. It was heartbreaking to see them.” (NP2)</p> <p>“I think the most memorable is the care that was given by the PSWs and RPNs. The dedication they had to those residents, the love that they showed them when their families weren’t around.” (NP2)</p> <p>“So, the only person who really sat with her, gave her care was the director of care, who did a lot of feeding and just trying to get her to take sips of, you know, fluids.” (MD3)</p> <p>“The other thing I did for that home was a lot of advocacy work . . . So, I did a lot of work calling public health, calling our MPP, and I went on media, which is way beyond my comfort zone.” (MD3)</p> <p>“Yeah, there were many cases where we really supported them very well, where the nurse, like, you know, were, like, you know you did right by that person.” (NP4)</p> <p>“Although I wasn’t feeling very energetic about my clinical work, I was feeling incredibly energetic about my advocacy work.” (MD5)</p> <p>“And, so, I really saw PSWs coming up really in a tremendous way to be there in a different way for families. They were there holding hands after their shift because family couldn’t be there. Or they were the ones bringing the phone or the iPad into the room, so that families could have conversations with them. We didn’t do that before the pandemic.” (MD5)</p>

Table 2 (part 2 of 4): Themes, subthemes and illustrative quotations

Supply and resource shortages	<p>“We didn’t have any of the surgical masks. We had to make a trade with one of the local hospitals where we gave them a bunch of our N95 masks, and they sent us a bunch of regular surgical, medical masks. You know, that was the kind of stuff that was going on just to have enough face coverings for people.” (MD4)</p> <p>“There wasn’t enough media attention that this was a problem for decades and even in the best of homes the outbreaks still would have occurred. Like, they prepped the hospital like nothing and didn’t give anything to the homes. Like, the hospital staff had masks, but we didn’t, right.” (NP4)</p> <p>“And then she called me because she couldn’t find an oxygen tank because so many people were so sick all at once.” (MD6)</p> <p>“And so, one of my first calls, when it was becoming abundantly clear that things were changing very quickly, was to my pharmacy to say, “How much [hydromorphone do] we have in stock?” (MD7)</p>
Theme 3: Communication and collaboration	
Engaging families	<p>“Our team just really pulled together and bonded with our residents much more closely. We became like the proxy family members, and so it did develop some very close relationships with our residents and their care providers.” (NP1)</p> <p>“So, we did, yeah, we started having conversations about goals of care. And we were already doing that but, like, during the pandemic we even started reaching out even more with the families.” (MD2)</p> <p>“I think that has been, yeah, that part has become very rewarding now to be able to speak to the families regularly. And just seeing how rewarding that is, how appreciative they are, like that’s probably the most rewarding thing in long-term care.” (MD2)</p>
Communication and collaboration during outbreaks	<p>“I used my own Zoom account and was able to get 23 family members or different homes set up on one Zoom call with their matriarch of the family. And it was nice, because they were from all over the country, all over the continent.” (MD1)</p> <p>“And I’d say, ‘Well, we could send her to hospital but she’s 90 years old, they’re not going to intubate.’ Well, what are they going to do? You know, they’re going to do the same thing that we’re doing, basically. I had that conversation quite a bit.” (MD4)</p> <p>“So, 2 NPs and 2 palliative physicians went in to assess the situation. We saw over 50 residents in a day, just to assess their status for end-of-life symptom management needs.” (NP4)</p> <p>“You know, our attendings were great, our attendings did all the notifications for the positives, spoke to all the families.” (MD7)</p>
Communication within long-term care homes	<p>“I mean, I think the big one was, like, not having continuity with the staff. And that’s something we are still struggling with. Like, with palliative care, for me to be able to have those conversations, a big part of what I tell families is that like the home, the main reason it’s a more comfortable place is that there is a lot of familiarity between the residents and the staff, the residents know the environment, they know the staff, the staff know the residents.” (MD2)</p> <p>“And we did have regular meetings, even as the medical director for the 2 homes, like, we were having regular meetings ... We were always, like, we were always working together with the director of care, with the executive director to kind of plan if things were to get bad.” (MD2)</p>
Communication externally	<p>“But each region had an incident command centre, you know, all this stuff. All people that were not in long-term care, so that was very problematic for everyone. They didn’t speak long-term care language.” (NP3)</p> <p>“I feel there was so much inconsistent messaging ... They did not meet people where they were at, at all. And I think they needed to ask them, what did you need, not tell them what they needed ... It didn’t matter in COVID. I got told, ‘You don’t have to go.’ I thought, I have to go. I cannot sit and watch any of this. I have to be able to help somebody in some regard.” (NP3)</p> <p>“I worked closely with the specialists and the physicians that were also going into support, and so it was a collaborative model.” (NP5)</p> <p>“Even some of the palliative care docs, they don’t have long-term care experience, so they didn’t understand.” (MD5)</p>

Communication and collaboration

Increased communication with colleagues and residents’ families was described. This was often conducted virtually by telephone or video conferencing. Clinicians tried their best to provide updates to families, increased having goals-of-care conversations, and facilitated virtual visits between residents and families as frequently as possible, particularly if they were actively dying, despite staffing shortages and amid severe visiting restrictions. Some participants described providing families their personal telephone numbers or emails to facilitate

connection, reassurance and psychosocial support as families expressed “feel[ing] so guilty about not going in” (NP2).

Increased communication demands often required the presence of staff at the bedside, which was challenging given the staffing shortages and lack of continuity necessary in palliative care. Participants expressed the importance of increased communication and collaboration within the home’s leadership. One participant highlighted “even as the medical director for the 2 homes ... we were always working together with the director of care, with the executive director to kind of plan

Table 2 (part 3 of 4): Themes, subthemes and illustrative quotations

Theme 4: Impact of isolation and visitation restrictions	
Family distress	<p>“His family was not able to come in because of their own health issues and fears around contracting COVID. So, like, I was talking about the FaceTiming with that family, myself and the RN were in the room FaceTiming with his family when he took his last breaths.” (NP1)</p> <p>“Residents were dying without their families, and if their families did come in, they had mask, gloves, they had gowns on. There wasn’t that physical, that ability to physically touch their family member dying. And even that support, I remember one of the residents was dying, and one of the PSWs was at the resident’s side. There was no family because they just, they’re elderly, their spouses are elderly, their kids are elderly. They put themselves at risk. And I know that I would say to families, they’d feel so guilty about not going in, but the bottom line, I would say, if your spouse or parent could talk to you, would they want you to take that risk to come see them? And all their answers were, “No.” But the PSWs would sit beside them as they were dying. One PSW sang to one of the residents. It was heartbreaking to see them.” (NP2)</p> <p>“So, I think there’s going to be a lot of kind of complicated grieving after this, because there wasn’t the ability to have closure and visiting at the bedside, holding vigil So, prepandemic we had a good flow, we had lovely processes. During our outbreak, all of those just went by the wayside, even something like we have a quilt, and we do an honour guard, and we kind of say our goodbyes at the door when the funeral home comes. We weren’t able to do any of that stuff because of cohorting and infection control.” (NP2)</p>
Resident distress	<p>“He missed his family so much and they were so involved that I think he died from a broken heart. He just stopped eating and drinking. He faded away.” (NP1)</p> <p>“Yeah, because we had lots of residents becoming sick, not because of COVID, but just because of, like, them not eating and drinking and I think isolation was a big part of it, feeling depressed.” (MD2)</p> <p>“Residents were dying without their families, and if their families did come in, they had mask, gloves, they had gowns on. There wasn’t that physical, that ability to physically touch their family member dying.” (NP2)</p> <p>“Like, I think their quality of life and there was no visits from their family, there was of course no programming going on, they were in their room for much of the pandemic, and I think they just decided they would stop eating and drinking and call it a day. And they mostly did die alone rather than with staff at the home.” (MD3)</p> <p>“But, you know, I would say the impact of the visitor restriction was far greater than the impact of COVID on our home.” (MD7)</p>
Impact on staff	<p>“We became like the proxy family members, and so it did develop some very close relationships with our residents and their care providers.” (NP1)</p> <p>“There wasn’t that physical, that ability to physically touch their family member dying. And even that support, I remember one of the residents was dying, and one of the PSWs was at the resident’s side.” (NP2)</p>
Theme 5: Impact on clinicians’ personal lives	
Burnout	<p>“Basically had one doctor who ended up trying to cover for up to 200 patients because, you know, the other doctor wouldn’t come in and the other doctor got COVID. So he was like stretched to the point of breaking.” (MD3)</p> <p>“I really felt that it was my responsibility to do that; and I never turned my phone off for the first 9 months until it was quite evident that I just couldn’t be on 24/7 anymore.” (MD5)</p>
Impact on personal life	<p>“Well, you know what, I spent a lot of nights lying awake worrying over this nursing home that I lost And worrying about getting sick and, you know, worried about what’s happening to my practice and my life.” (MD4)</p> <p>“So, again, I think most of what the pandemic has done has changed me personally. I don’t think it’s affected my clinical work with patients It’s kind of the background when I’m home. And I’m a very resilient person and I’m a very energetic person, but even people who know me know that it’s impacted me somewhat.” (MD5)</p>

if things were to get bad” (MD2). Occasionally, external palliative care teams and outreach nurses helped to facilitate communicating with families when staff were overwhelmed. A collaborative team effort within long-term care homes with increased sharing of responsibilities emerged to optimize care.

Communication and collaboration with professionals and entities external to the long-term care home also increased, both virtually and in person. Some participants collaborated closer with hospitals and regional geriatrics and palliative care

specialists. Some also connected with long-term care communities of practice such as the Ontario Long Term Care Clinicians, to apply emerging best practices amid rapidly changing clinical guidelines and public health directives.

While clinicians largely described supportive and constructive working relationships with public health, external hospitals and consultants, some reported suboptimal experiences. These occurred when messaging was inconsistent and external teams sometimes did not understand the regulated long-term

Table 2 (part 4 of 4): Themes, subthemes and illustrative quotations

Moral distress and emotional trauma	<p>“The posttraumatic stress that some of the staff are still experiencing, it was a bit shocking to hear and still it would bring tears to some of the staff, after a year. You know, it just brought forward that not everybody is comfortable asking for help and trying to help them sort of recognize that they need some help is hard.” (NP2)</p> <p>“I really struggled with the thought of transferring them to hospital. I had worked with all the families that were sick, that the best thing for them was to be in their home, not to go to hospital, and to have that shift, and the decision was made from the administrative point So, I had some residents that were close to dying that I struggled with transferring them to the hospital because I felt they may even die on the transfer. So, I really did struggle with that decision; however, I didn’t have any say in it. I was the external person.” (NP2)</p> <p>“And I have loaded people in ambulances who are actively dying because the family did not know they were dying.” (NP3)</p> <p>“And, you know, I mean, I was very frustrated by the fact that because my particular home was in a low incident location, it was given very low priority, despite the fact that a quarter of its residents were COVID-positive So I was very frustrated that at that time vaccines weren’t given. I mean I thought that was very poor prioritization of somebody sitting in an office not looking at the real situation.” (MD3)</p> <p>“And this is the messaging that didn’t get there. We hear about everyone that’s unhappy about not having essential visitors, and people in, but they really didn’t give the staff — nobody has talked about how hard it would be for them to lose 22 people on their unit when they took care of them for 3 and 4 years.” (NP3)</p> <p>“So, guess what. One would assume that we would learn from the first wave, wouldn’t we? One would assume that. I’m trying not to be too glib, but really, I’m so exhausted, right.” (NP3)</p> <p>“But so much of it was wrong and not well thought out and problematic. And so I had people crying, sitting in the corner crying that they could not deliver what they needed to deliver. It was overwhelming.” (NP3)</p> <p>“Yeah. And the trauma of what we saw and what we did was — you shouldn’t have to support as many deaths in a year as we did.” (NP4)</p> <p>“So, yeah, I’m sure many of us have PTSD. So, yeah, I think at some point you just have to recognize that maybe I need to get well myself.” (NP4)</p> <p>“So, like, ideally, I would have liked more family visits than were allowed. And I was expecting the homes to be able to accommodate that, but it didn’t happen as I was thinking.” (NP4)</p> <p>“And, you know, in end-of-life care, my philosophy has always been people should be surrounded by those that they love at that time. And that became more difficult as the pandemic went on.” (MD5)</p> <p>“Extremely challenging, guilt-provoking, you know, I remember crying — I don’t normally cry easily. Sad, like all the time, like constantly sad. Yeah, it was awful. It was just awful And all of the people who died, which was, like, about 40% of the residents, like, they all died within 2 and a half weeks.” (MD6)</p>
-------------------------------------	---

Note: ED = emergency department, LEAP = Learning Essential Approaches to Palliative Care, MD = medical doctor, MPP = Member of Provincial Parliament, NP = nurse practitioner, PRN = pro re nata (medication taken as needed), PSW = personal support worker, PTSD = posttraumatic stress disorder, RPN = registered practice nurse.

care environment or have any experience in it, leading to unhelpful advice and poor takeover experiences in some cases. External clinical consultants who were more collaborative and familiar with the long-term care setting greatly facilitated care, including end-of-life care.

Impact of isolation and visitation restrictions

Restrictions on family visitations and social activities, and physical distancing, prevented usual palliative care processes. Clinicians witnessed residents experiencing hastened deterioration, cognitive decline, depression, feelings of hopelessness and lonely deaths as a result of these restrictions. The use of PPE accentuated the sense of isolation, loneliness and reduced human touch. Participants often sounded emotional as they reported witnessing a resident “fade away” and feeling “heartbroken” because of the social isolation more so than the COVID-19 illness.

Participants also reported witnessing increased expression of anxiety and guilt among families because of their inability to be at their loved one’s bedside. To help mitigate resident loneliness, staff members often became like family, and tried their best to spend additional time at the resident’s bedside to

provide greater comfort and connectedness during the last hours of life.

Usual rituals that facilitated healthy grief at the time of death, such as conducting honour guards for deceased residents and remembrance events, were mostly halted, further impairing healthy mourning for residents, families and staff alike. One participant expressed concern for “complicated grieving after this, because there wasn’t the ability to have closure and visiting at the bedside” (NP2).

Participants expressed concern about the continuation of strict visitation policies, stating the importance of having the presence of loved ones at the time of death as a core element in the philosophy of palliative care.

Impact on clinicians’ personal lives

Participants reported powerful feelings of emotional trauma and guilt, resulting in burnout and psychological distress. These emotions were both experienced by clinicians and witnessed in colleagues. During times of outbreaks, some clinicians provided care around the clock, including evenings and weekends. One clinician stated, “I never turned my phone off for the first 9 months” (MD5). This accentuated fatigue and

affected their personal and family lives, leading to feeling “stretched to the point of breaking” (MD3).

Participants described feelings of helplessness and distress at times, describing the shock of “support[ing] as many deaths in a year as [they] did” (NP4). In one case “about 40% of residents ... all died within 2 and a half weeks” (MD6). Clinicians who had to send SARS-CoV-2-positive residents to local hospitals during outbreaks, following an order to decant residents in overstretched homes, were internally conflicted and felt that they were abandoning their residents who “were close to dying ... and may even die on the transfer to the hospital” (NP2), but “the decision was made from the administrative point” (NP2) and the clinicians felt they had little control over some of these decisions.

Some described frustration with the health care system and media for not addressing the impact of the pandemic on long-term care workers. They felt that their own emotional trauma and needs were and continue to be ignored, stating as an example the grief associated with losing many residents they knew for years over a short period.

Interpretation

In this study, physicians and NPs working in long-term care homes in Ontario, Canada, described a spectrum of experiences and effects, both challenging and rewarding, related to providing palliative and end-of-life care during the COVID-19 pandemic. Foremost among these were physical and emotional exhaustion resulting from increased work demands, attending to high levels of suffering caused by isolation and unprecedented numbers of deaths, altered care delivery routines, and shortages of equipment and human resources. These, along with uncertainty, fear, and frequently changing public health directives and messaging led to burnout and moral distress.

Some of the study findings are similar to those reported in previous publications across several countries.^{22–28} The heightened distress of health care professionals caused by the COVID-19 pandemic, for example, has been reported by others.^{29,30} However, to our knowledge, the previously published studies did not describe detailed accounts and experiences of long-term care clinicians working and providing end-of-life care in long-term care homes. This is important as experts call for the inclusion of care provider experiences in health care reform.³¹ The assistance of military and hospital personnel and consultants was appreciated. However, lack of experience with and understanding of the highly regulated long-term care setting and the absence of effective leadership on the ground was an impediment to quality care. Perception by participants that some residents declined and “faded away” because of isolation rather than COVID-19 is a finding that has not previously been reported to our knowledge.

In this study, long-term care staff demonstrated innovation and creativity in their response to the pandemic. This, to some degree, has been described in other care settings.^{23,32} Study participants and colleagues made personal sacrifices to help their residents and long-term care homes while dealing with their own distress. The ability of long-term care staff to

adapt to the extraordinary demands, introduce improvements, and find meaning and fulfillment in their work has been identified as psychological capital, which is characterized by hope, optimism, resilience and self-efficacy.^{33,34}

Importantly, our study highlights strategies to improve palliative care and help mitigate the impact of similar pandemics in long-term care homes in the future. These include training all long-term care staff with core skills in palliative care, fostering a culture that embraces the philosophy of palliative care, effective communication and multidisciplinary collaborations, and leadership that promotes the integration of quality palliative care and related clinical tools and guidelines. Practices and processes that promote an effective palliative approach should include early discussions about advance care planning and goals of care, routine symptom assessment, grief and bereavement resources, and ensuring access to specialized palliative care teams with long-term care experience to provide additional consultation, education and quality improvement support when needed. In our study, long-term care homes that had previously established these palliative approach processes managed better than those that did not. These strategies have previously been emphasized by experts and researchers in the field.^{3,7,10,28,32,35–37}

Limitations

We recognize several limitations of the study. The study did not include PSWs, RPNs, registered nurses or other long-term care staff. It did not explore the experiences of residents and families. The ages of study participants were skewed toward more mature clinicians. This, however, may arguably be representative of the clinicians who currently tend to work in and practise long-term care medicine. The participants all had some prior palliative care training, and this may have affected their experiences. Since participation in the study was voluntary, alternative perspectives of those with different experiences may not have been fully captured.

Conclusion

Providing palliative and end-of-life care to residents in Ontario long-term care homes during the COVID-19 pandemic, especially during the early waves, had a major impact on clinicians and staff in those homes and affected their work and personal lives in many ways, both negatively and positively. Notwithstanding this impact, clinicians were able to demonstrate collaboration and innovation, introduce improvements, and find meaning and pride in their work. Strategies to address their burnout and collective trauma and grief are needed. It is important to identify and implement strategies to improve palliative care in long-term care homes and reduce the impact of future pandemics with respect to palliative care.

References

1. Tanuseputro P, Chalifoux M, Bennett C, et al. Hospitalization and mortality rates in long-term care facilities: Does for-profit status matter? *J Am Med Dir Assoc* 2015;16:874-83.
2. Hill AD, Stukel TA, Fu L, et al. Trends in site of death and health care utilization at the end-of-life: a population-based cohort study. *CMAJ Open* 2019;7:E306-15.

3. Kaasalainen S, Sussman T, McCleary L, et al. Palliative care models in long-term care: a scoping review. *Nurs Leadersb (Tor Ont)* 2019;32:8-26.
 4. Brink P, Kelley ML. Death in long-term care: a brief report examining factors associated with death within 31 days of assessment. *Palliat Care* 2015;9:1-5.
 5. Tanuseputro P, Hsu A, Kulusi K, et al. Level of need, divertibility, and outcomes of newly admitted nursing home residents. *J Am Med Dir Assoc* 2017;18:616-23.
 6. *Ontario's Long-Term Care COVID-19 Commission: final report*. Toronto: Queen's Printer for Ontario; 2021. Available: <https://files.ontario.ca/mltc-ltcc-final-report-en-2021-04-30.pdf> (accessed 2022 Sept. 24).
 7. Kaasalainen S. Current issues with implementing a palliative approach in long-term care: Where do we go from here? *Palliat Med* 2020;34:555-7.
 8. Wiersma E, Marcella J, McNulty J, et al. 'That just breaks my heart': moral concerns of direct care workers providing palliative care in LTC homes. *Can J Aging* 2019;38:268-80.
 9. Brazil K, Bédard M, Krueger P, et al. Barriers to providing palliative care in long-term care facilities. *Can Fam Physician* 2006;52:472-3.
 10. Moore CD, Payne S, Van den Block L, et al.; PACE. Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: a scoping review. *Palliat Med* 2020;34:558-70.
 11. Harasym P, Brisbin S, Afzaal M, et al. Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: a qualitative descriptive study of community-based and specialist palliative care physicians' experiences, perceptions and perspectives. *BMJ Open* 2020;10:e037466.
 12. COVID-19's impact on long-term care. Ottawa: Canadian Institute for Health Information; 2021. Available: <https://www.cihi.ca/en/covid-19-resources/impact-of-covid-19-on-canadas-health-care-systems/long-term-care> (accessed 2022 Sept. 24).
 13. Thompson D-C, Barbu M-G, Beiu C, et al. The impact of COVID-19 pandemic on long-term care facilities worldwide: an overview on international issues. *BioMed Res Int* 2020;2020:8870249. doi: 10.1155/2020/8870249.
 14. Thorne S, Kirkham SR, O'Flynn-Magee K. The analytic challenge in interpretive description. *Int J Qual Methods* 2004;3:1-11.
 15. Hunt MR. Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qual Health Res* 2009;19:1284-92.
 16. Long-term care homes in Canada: How many and who owns them? Ottawa: Canadian Institute for Health Information; 2021. Available: <https://www.cihi.ca/en/long-term-care-homes-in-canada-how-many-and-who-owns-them> (accessed 2023 Mar. 25).
 17. COVID-19 long-term care resources. Ottawa: Public Health Ontario. Available: <https://www.publichealthontario.ca/en/diseases-and-conditions/infectious-diseases/respiratory-diseases/novel-coronavirus/long-term-care-resources> (accessed 2023 Mar. 26).
 18. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349-57.
 19. Burnard P. A method of analyzing interview transcripts in qualitative research. *Nurse Educ Today* 1991;11:461-6.
 20. Archibald MM. Investigator triangulation: a collaborative strategy with potential for mixed methods research. *J Mixed Methods Res* 2016;10:228-50.
 21. Pereira J, Giddings G, Sauls R, et al. Navigating design options for large-scale interprofessional continuing palliative care education: Pallium Canada's experience. *Palliat Med Rep* 2021;2:226-36.
 22. *Pandemic experience in the long-term care sector: How does Canada compare with other countries?* Ottawa: Canadian Institute for Health Information; 2020. Available: <https://www.cihi.ca/sites/default/files/document/covid-19-rapid-response-long-term-care-snapshot-en.pdf> (accessed 2022 Sept. 24).
 23. Palacios-Ceña D, Fernández-Peña R, Ortega-López A, et al. 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. *Int J Environ Res Public Health* 2021;18:10099.
 24. Van der Roest HG, Prins M, van der Velden C, et al. The impact of COVID-19 measures on well-being of older long-term care facility residents in the Netherlands. *J Am Med Dir Assoc* 2020;21:1569-70.
 25. Impact of restrictive public health measures on long-term care residents, family, and staff [issue note]. CanCOVID; 2021. Available: <https://cancovid.ca/wp-content/uploads/2021/12/CanCOVID-Issue-Note-LTC-restrictive-measures-EN.pdf> (accessed 2022 Sept. 24).
 26. Cooke HA, Wu SA, Bourbonnais A, et al. Disruptions in relational continuity: the impact of pandemic public health measures on families in long-term care. *J Fam Nurs* 2023;29:6-17.
 27. Dujardin J, Schuurmans J, Westerdun D, et al. The COVID-19 pandemic: a tipping point for advance care planning? Experiences of general practitioners. *Palliat Med* 2021;35:1238-48.
 28. Kruizinga J, Lucchese S, Vellani S, et al. Perspectives across Canada about implementing a palliative approach in long-term care during COVID-19. *BMC Palliat Care* 2023;22:32.
 29. Shaukat N, Ali DM, Razzak J. Physical and mental health impacts of COVID-19 on healthcare workers: a scoping review. *Int J Emerg Med* 2020;13:40.
 30. Experiences of health care workers during the COVID-19 pandemic, September to November 2021. Ottawa: Statistics Canada; modified 2022 June 23. Available: <https://www150.statcan.gc.ca/n1/daily-quotidien/220603/dq220603a-eng.htm> (accessed 2023 Mar. 26).
 31. Mate K. On the Quintuple Aim: Why expand beyond the Triple Aim? [blog]. Boston: Institute for Healthcare Improvement; 2022 Feb. 4. Available: <https://www.ihl.org/communities/blogs/on-the-quintuple-aim-why-expand-beyond-the-triple-aim> (accessed 2023 Mar. 26).
 32. Shamon S. Person- and family-centered approach offers healing in long-term care during the COVID-19 crisis. *J Palliat Med* 2021;24:630-1.
 33. Rodriguez-Jimenez M, Guerrero-Barona E, García-Gomez A. Mental health and psychological capital among Spanish health care workers during COVID-19 pandemic. *Med Clin (Barc)* 2021;156:357-8.
 34. Youssef C, Luthans F. Positive organizational behavior in the workplace: the impact of hope, optimism, and resilience. *J Manage* 2007;33:774-800.
 35. Cloutier D, Stajduhar KI, Roberts D, et al. 'Bare-bones' to 'silver linings': lessons on integrating a palliative approach to care in long-term care in Western Canada. *BMC Health Serv Res* 2021;21:610.
 36. Collins RL, Williams EM, Moser AL, et al. The role of the medical director in Ontario long-term care homes: impact of COVID-19. *J Am Med Dir Assoc* 2022;23:1603-7.
 37. Browne D, Roy S, Phillips M, et al. Supporting patient and clinician mental health during COVID-19. *Can Fam Physician* 2020;66:e190-2.
- Affiliations:** Division of Palliative Care (Shamon, Gill, Pereira), Department of Family Medicine, Faculty of Health Sciences, McMaster University, Hamilton, Ont.; Department of Community Health Sciences, Cumming School of Medicine (Meadows), University of Calgary, Calgary, Alta.; School of Nursing (Kruizinga, Kaasalainen), Faculty of Health Sciences, McMaster University, Hamilton, Ont.; Pallium Canada (Pereira), Ottawa, Ont.
- Contributors:** Sandy Shamon contributed to early inception and formulation of the study purpose, participated in study design alongside methodology experts, conducted interviews and data collection as well as the final data analysis, interpretation and writing of the final manuscript and revision. Ashlinder Gill assisted in coordinating and organizing the study to completion, from ethics approval, recruitment, conducting interviews and data collection, to data analysis and writing of the final manuscript, in particular the results section. Lynn Meadows participated in study design, ensuring sound qualitative methodology was followed during data collection and throughout the data analysis, and contributed to writing and approving the final manuscript and revision. Julia Kruizinga actively participated in all stages of the study since inception and design, conducted interviews and gathered data, and contributed to editing and approval of data analysis and the final manuscript. Sharon Kaasalainen contributed to early study design, data analysis and interpretation and review of the final manuscript. She worked closely with coauthor Julia Kruizinga as her thesis supervisor. She was actively involved in writing the revision manuscript. José Pereira supported the study from early inception, and contributed to study design and data analysis. He particularly contributed to reviewing, editing and approving the final and revised manuscript. All authors gave final approval of the final version to be published and agreed to be accountable for all aspects of the work.
- Funding:** This study was funded and supported by the Division of Palliative Care, Department of Family Medicine at McMaster University.
- Content licence:** This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY-NC-ND 4.0) licence, which permits use, distribution and reproduction in any medium, provided that the original publication is properly cited, the use is noncommercial (i.e., research or educational use), and no modifications or adaptations are made. See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>
- Data sharing:** Given the personal and private nature of the interviews, which may easily identify participants, data will not be available for sharing.
- Acknowledgements:** The authors thank Ashwak Rhayel and Yvonne Mbinda for their contribution to this project by conducting background research and their role as research assistants with the Division of Palliative Care, Department of Family Medicine, McMaster University.
- Supplemental information:** For reviewer comments and the original submission of this manuscript, please see www.cmajopen.ca/content/11/4/E745/suppl/DC1.