



**Providing Palliative and End-of-Life Care in Long-Term Care
During the COVID-19 Pandemic: A Qualitative Study of
Clinicians' Experiences**

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Complete List of Authors:	Shamon, Sandy; McMaster University Faculty of Health Sciences, Family Medicine Gill, Ashlinder; McMaster University, Family Medicine Meadows, Lynn; University of Calgary, Family Medicine and Community Health Sciences Kruizinga, Julis; McMaster University, School of Nursing Kaasalainen, Sharon; McMaster University, Nursing Pereira, Jose; McMaster University Faculty of Health Sciences, Family Medicine, Palliative Care
Keywords:	Palliative medicine, Geriatric medicine, Public health, Health policy
More Detailed Keywords:	Palliative care, end-of-life, long-term care, COVID-19, Pandemic
Abstract:	<p>Background: A disproportionate number of COVID-19 related deaths in Canada occurred in Long-term care (LTC) homes, affecting residents, their families, and staff alike. This study explored the experiences of LTC clinicians with respect to providing palliative and end-of-life (EOL) care during the pandemic.</p> <p>Methods: Using a qualitative interpretive description design, LTC physicians and nurse practitioners (NPs) in Ontario, Canada, participated in semi-structured interviews. Interviews were undertaken virtually, recorded, and transcribed. Results were analysed iteratively using thematic analysis.</p> <p>Results: Twelve clinicians, which included seven physicians and five NPs, were interviewed. Five themes, each with three to four subthemes were described. The themes are: providing a palliative approach to care, increased work demands and workforce re-organization, communication and collaboration, impact of isolation and visitation restrictions, and impact on the providers' personal lives. Clinicians faced several concurrent challenges, including the uncertainty of the illness trajectory and prognosis, increased work demands, and staff and supply shortages. The increased workload, added roles, witnessing of many deaths, and resident and family distress caused by separation, resulted in feelings of moral distress and burnout. Prior integration of the palliative care approach in a home, palliative care training, flexibility, and</p>

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	<p>interprofessional collaboration mitigated the impact. Interpretation: The pandemic had a significant impact on clinicians caring for residents in LTC homes at the EOL. Strategies to improve palliative care and reduce the impact of future pandemics on LTC homes with respect to palliative care include training LTC staff in the principles of the palliative approach, strengthening clinical leadership and interdisciplinary collaborations to ensure quality palliative care guidelines, and access to expert palliative care consultants and system resources.</p>

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Reporting Guideline Checklist

**Consolidated criteria for reporting qualitative
research (COREQ)**

Adopted from :

Allison Tong, Peter Sainsbury, Jonathan Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *International Journal for Quality in Health Care*, Volume 19, Issue 6, December 2007, Pages 349–357, <https://doi.org/10.1093/intqhc/mzm042>

No	Criteria	Requirement met
Domain 1: Research team and reflexivity		
1	Interviewer/facilitator	√
2	Credentials	√
3	Occupation	√
4	Gender	√
5	Experience and training	√
6	Relationship established	√
7	Participant knowledge of the interviewer	√
8	Interviewer characteristics	√
Domain 2: study design		
9	Methodological orientation and Theory	√
10	Sampling	√
11	Method of approach	√
12	Sample size	√
13	Non-participation	NA
14	Setting of data collection	√
15	Presence of non-participants	NA
16	Description of sample	√
17	Interview guide	√
18	Repeat interviews	√
19	Audio/visual recording	√

**Providing Palliative and End-of-Life Care in Long-Term Care During the COVID-19 Pandemic: A
Qualitative Study of Clinicians' Experiences**

20	Field notes	√
21	Duration	√
22	Data saturation	√
23	Transcripts returned	√
Domain 3: analysis and findings		
24	Number of data coders	√
25	Description of the coding tree	√ (Represented by table 2)
26	Derivation of themes	√
27	Software	√
28	Participant checking	no
29	Quotations presented	
30	Data and findings consistent	√
31	Clarity of major themes	√
31	Clarity of minor themes	√

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3 **Providing Palliative and End-of-Life Care in Long-Term Care During the COVID-19**
4 **Pandemic: A Qualitative Study of Clinicians' Experiences**
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8 Sandy Shamon MD, CCFP (PC)¹
9 Ashlinder Gill MSc ¹
10 Lynn Meadows PhD ²
11 Julia Kruizinga RN, BNSc, MScN³ :
12 Sharon Kaasalainen RN, BScN, MSc, PhD ³ :
13 José Pereira MBChB, CFPC (PC), MSc, FCFP, PhD ^{1,4}
14
15

16 **Affiliations**

17 ¹ Division of Palliative Care, Department of Family Medicine, McMaster University

18 ² Cummings School of Community Medicine, University of Calgary.

19 ³ School of Nursing, McMaster University

20 ⁴ Pallium Canada, Ottawa, Canada
21

22
23 1-Department of Family Medicine, Division of Palliative Care, McMaster University

24 100 Main Street West, 2nd Floor

25 Hamilton, Ontario

26 L8P 1H6

27 Canada

28 Phone: 905-525-9140

29 Fax: 905-521-5594
30

31
32 2-Cummings School of Community Medicine, University of Calgary

33 University of Calgary

34 2500 University Drive NW

35 Calgary Alberta T2N 1N4

36 CANADA
37

38
39 3-School of Nursing, McMaster University

40 McMaster University

41 1280 Main Street West

42 HSC 3H48C

43 Hamilton, ON L8S 4K1
44

45 **Keywords:** Palliative care, end-of-life care, long-term care, COVID-19, pandemic.
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47
48 **Abbreviations:** Long-term care (LTC), advance care planning (ACP), goals of care (GoC),
49 personal support workers (PSWs), registered practice nurses (RPNs), end-of-life (EOL)
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53 **Corresponding author:** Sandy Shamon¹, Division of Palliative Care, Department of Family
54 Medicine, McMaster University, Email: shamons@mcmaster.ca
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ABSTRACT

Background: A disproportionate number of COVID-19 related deaths in Canada occurred in Long-Term Care (LTC) homes. The pandemic affected residents, their families, and staff alike. This study explored the experiences of LTC clinicians with respect to providing palliative and end-of-life (EOL) care during the pandemic.

Methods: Using an interpretive description design, LTC physicians and nurse practitioners (NPs) in Ontario, Canada, participated in semi-structured interviews. Recruitment continued until data saturation was reached. Interviews were undertaken virtually, recorded, and transcribed. Results were analysed iteratively using thematic analysis.

Results: Twelve clinicians, which included seven physicians and five NPs, were interviewed. Five themes, each with three to four sub-themes were described. The themes are: providing a palliative approach to care, increased work demands and workforce re-organization, communication and collaboration, impact of isolation and visitation restrictions, and impact on the providers' personal lives. Clinicians faced several concurrent challenges, including the uncertainty of the illness trajectory and prognosis, increased work demands, and staff and supply shortages. They took on additional work hours and roles such as housekeeping and companionship of residents. The increased workload, added roles, witnessing of many deaths, and resident and family distress caused by separation, resulted in feelings of moral distress and burnout. Prior integration of the palliative care approach in a home, palliative care training, flexibility, and interprofessional collaboration mitigated the impact.

Interpretation: The pandemic had a significant impact on clinicians caring for residents in LTC homes at the EOL. Strategies to improve palliative care and reduce the impact of future pandemics on LTC residents and staff with respect to palliative and EOL care include training LTC staff in the principles of the palliative approach, strengthening clinical leadership and interdisciplinary collaborations to ensure quality palliative care guidelines and processes, and access to expert palliative care consultants and system resources.

BACKGROUND

A large majority of persons living in long-term care (LTC) homes have physical frailty and multiple co-morbidities, which compromise their quality-of-life and reduce their life expectancy.^{1,2} In Canada, before the COVID-19 pandemic, between 8% to 17% of all deaths occurred annually in LTC and the average annual mortality rate in LTC homes is estimated to be between 27% and 52.3%.³ The median life expectancy of residents in LTC 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 LTC homes.⁶⁻⁹ Therefore, there have been many calls over the years to improve palliative and EOL care in LTC.^{3,7-11} The gaps were exposed and accentuated during the COVID-19 pandemic. A disproportionate number of COVID-19 related morbidity and deaths in Canada and worldwide occurred in LTC homes, particularly during the early waves, with major impact on residents, their families, and the frontlines staff.^{12,13}

The aim of this study was to explore and better understand the lived experiences of Ontario-based LTC clinicians with respect to providing palliative and end-of-life (EOL) during the pandemic, with the ultimate goal of improving palliative care and identifying strategies to mitigate the impact of future pandemics on LTC homes.

METHODS

Design

A qualitative interpretive descriptive study design, based in the constructivist and naturalistic orientation to inquiry, was used to gain a broad in-depth understanding of the clinicians' lived experiences and narratives.^{14,15} Convenience and snowball sampling were applied to recruit LTC clinicians, specifically physicians and nurse practitioners working in LTC homes in Ontario, Canada. Invitations were sent by the Ontario Long Term Care Clinicians (OLTCC) organization to its approximately 300 members.

Data Collection Procedures

Participants were interviewed by three researchers (AG, JK, SS) using the Zoom™ virtual communication platform. Clinicians were asked short demographic questions followed by open-ended questions using an interview guide (**Appendix 1**). Interviews were audio recorded, and transcribed verbatim, then anonymized and entered into NVivo™ 2020 to aid data management and analysis. Interviewers debriefed with each other following interviews to ensure consistency in data collection. Recruitment continued until data saturation was reached based on consensus by the research team (AG, SS, SK, JP, LM). Field notes were used to document the researcher's observations and perceptions during each detailed interview. Data were collected

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3 from July to September 2021, 16 months after the pandemic was first declared in Canada and
4 just after the third wave.
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6 7 **Data Analysis**

8 Data collection and analysis were done using an iterative process allowing interviewers to
9 further explore emerging themes raised by participants in previous interviews.¹⁶ Team meetings
10 were held periodically to review and refine coding progress and receive input from the
11 interdisciplinary research members (SS, JP, SK, JK, AG, LM) to achieve trustworthiness and
12 investigator triangulation.¹⁷ All themes were identified through the coding process. Rigor was
13 ensured by using bracketing, reflexivity, audit trails and periodic consensus meetings. The
14 researchers further communicated to discuss and ensure sound expert interpretation of the
15 emerging knowledge patterns and their applicability to clinical practice and health policy.
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20 **Ethics Approval**

21 The study was reviewed and approved by the Hamilton Integrated Research Ethics Board
22 (HiREB) (#13507).
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24

25 **RESULTS**

26 *Characteristics of Sample*

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28 A total of 12 clinicians, 7 physicians and 5 NPs, were interviewed (**Table 1**). Most
29 participants were greater than 50 years of age and had more than 10 years of experience working
30 in the LTC setting. All participants reported additional training or clinical experience in
31 palliative care prior to the pandemic and felt comfortable with providing EOL care in the LTC
32 setting. Most had participated in Pallium Canada's Learning Essential Approaches to Palliative
33 Care 2-day course.¹⁸ Two had more advanced training and certification of added competency in
34 palliative care from the College of Family Physicians of Canada. Study participants delivered in-
35 person and virtual care during the pandemic.
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39 *Overview of Findings*

40 Results were organized into five broad themes each with three to four subthemes. The
41 main themes were: providing a palliative approach to care, increased work demands and
42 workforce re-organization, communication and collaboration, impact of isolation and visitation
43 restrictions, and impact on the clinicians' personal lives. Please see **Table 2** for corresponding
44 themes and illustrative quotes for each theme.
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46

47 *Providing a Palliative Approach to Care*

48 Three subthemes were identified in this theme; scaling up, preparedness, and the
49 uncertainty of the COVID-19 illness trajectory and prognosis. Participants reported that while
50 the core principles of the palliative care approach did not change, the focus and scale of some
51 aspects changed significantly. Advance Care Planning (ACP) and Goals of Care (GoC)
52 discussions became more urgent and intense. During outbreaks, a higher demand was placed on
53 providers to prepare residents and families for possible rapid change in conditions given the
54 illnesses' high mortality in this population at the time. The imposed visitation restrictions
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3 required that these conversations be conducted virtually via telephone or videoconferencing, a
4 new added challenge for the clinicians and the LTC home. Early GoC discussions became
5 standard processes within some homes.
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7 The existence of a palliative approach strategy in the home pre-pandemic, including
8 routine ACP and GoC discussions, and EOL order sets and processes, facilitated pandemic
9 preparedness. Staff who had previous training in the palliative care approach were more
10 comfortable providing this care, including difficult EOL discussions, recognizing decline in
11 residents' health and monitoring and managing EOL symptoms.
12

13 Providers struggled with the uncertainty related to the presentation of COVID-19 related
14 symptoms and unpredictable disease trajectory and prognosis. These added to the stress of
15 difficult EOL discussions and care planning.
16

17 ***Increased Demands and Workforce Reorganization***

18 Staffing challenges, role changes, and shortages in supplies and resources were reported.
19 Regular duties and staffing levels in LTC homes were significantly disrupted. Staff who
20 contracted the virus, were exposed to infected persons, or experienced symptoms, even with
21 unconfirmed COVID-19 illness, had to self-isolate for up to two weeks. Lack of access to
22 widespread testing in the first waves of the pandemic meant that some staff may have been
23 unnecessarily quarantined. These amplified pre-existing staffing challenges and impacted the
24 quality of EOL care. There were inadequate numbers of trained staff to initiate care conferences
25 with families, monitor and assess residents, and accompany residents when families were unable
26 to visit in-person.
27

28 Participants experienced increased workload resulting from sicker residents and reduced
29 staffing levels. This led to added work hours and additional roles. Nurses were asked to provide
30 housekeeping, care managers to provide bedside care, and personal support workers (PSWs) or
31 registered practice nurses (RPNs) to bag deceased bodies when funeral home staff were not
32 permitted within the home. Staff, particularly PSWs, took on the role of companion for residents
33 in the absence of their families, adding to their workloads.
34

35 Some participants who were also medical directors took on more advocacy work to
36 ensure their homes had access to PPE and supplies, which were often lacking in the initial
37 pandemic phases. Supply shortages, particularly during the early waves of the pandemic, with
38 personal protective equipment (PPE), some injectable palliative care medications, oxygen tanks
39 and test kits, added to the providers' distress and work burden.
40

41 Rapid deaths and visitation restrictions resulted in complicated grief responses in
42 residents and families, requiring more emotional support from already over-stretched front-line
43 nursing staff who may not have had core palliative care skills. Staff also found themselves
44 providing more peer emotional support to colleagues.
45

46 In undertaking these role changes and responsibilities, participants also expressed pride in
47 what they and their colleagues had done and accomplished under such trying circumstances.
48

49 ***Communication and Collaboration***

50 Increased communication with colleagues and residents' families was described. This
51 was often conducted virtually by telephone or video conferencing. Clinicians tried their best to
52 provide updates to families and facilitate virtual video visits between residents and families as
53 frequently as possible despite staffing shortages amidst severe visiting restrictions. Some
54 participants described providing families their personal telephone numbers or emails to facilitate
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3 connection, re-assurance and psychosocial support as families experienced fear and guilt
4 themselves.

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6 Virtual communication required additional resources, processes, and communication and
7 technology skills. Virtual meetings often required the presence of staff at the bedside, which was
8 challenging given the staffing shortages. Occasionally, external palliative care teams and
9 outreach nurses helped to facilitate communicating with families when staff were overwhelmed.
10 A collaborative team effort emerged with increased sharing of responsibilities and co-learning
11 within LTC homes to optimize care.

12
13 Communication and collaboration with professionals and entities external to the LTC
14 home increased, both virtually and in-person. Some participants collaborated closer with
15 hospitals and regional geriatrics and palliative care specialists. Some also connected with LTC
16 communities of practice such as the Ontario Long-Term Care Clinicians, to apply emerging best
17 practices amidst rapidly changing clinical guidelines and evolving public health orders and
18 recommendations. Ministry mandates for assistance from the acute care sector were largely
19 helpful. Information exchange with public health authorities around changing directives,
20 particularly during outbreaks was helpful when offered consistently and effectively.

21
22 While clinicians largely described supportive and constructive working relationship with
23 external hospital, geriatrics, and palliative care teams, some reported suboptimal experiences.
24 These occurred when those external teams sometimes did not understand LTC or did not have
25 any experience in it, leading to unhelpful advice and poor takeover experiences in some cases
26 when external teams took charge of care in the facility, they neglected the input of the LTC staff
27 who knew the home and their residents better. External clinical consultants who were more
28 familiar with the LTC setting greatly facilitated care and collaboration.

30 31 ***Impact of Isolation and Visitation Restrictions***

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33 Restrictions on family visitations and social activities, and physical distancing, prevented
34 usual care processes. The use of PPE accentuated the sense of isolation, loneliness and reduced
35 human touch. Clinicians reported witnessing residents experiencing hastened deterioration,
36 cognitive decline, depression and feelings of hopelessness, and lonely deaths as a result of these
37 restrictions.

38
39 Participants also reported witnessing increased expression of anxiety and guilt amongst
40 families because of their inability to be at their loved one's bedside. To help mitigate resident
41 loneliness, staff members often became "like family", and tried their best to spend additional
42 time at the resident's bedside to provide greater comfort and connectedness at time of death.

43
44 Usual rituals that facilitated healthy grief at the time of death, such as conducting honor
45 guards for deceased residents and remembrance events, were mostly halted, further impairing
46 healthy mourning, and complicating the grieving process for residents, families, and staff alike.

47 48 ***Impact on Clinicians' Personal Lives***

49
50 Participants reported significant feelings of emotional trauma and guilt resulting in
51 burnout and moral distress. These emotions were both experienced by clinicians and witnessed in
52 colleagues. Staffing and supply shortages, changing public health directives, unprecedented
53 clinical needs, physical isolation and distancing, and visitation restrictions all prevented
54 clinicians from applying what they felt was optimal care, and added to their distress. Participants
55 described feelings of helplessness at times, including when witnessing and supporting residents
56 who were "heartbroken" or had "lost their will to live" due to isolation. Clinicians who had to
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3 send COVID-19 positive residents to local hospitals during outbreaks were internally conflicted
4 and felt that they were abandoning their residents and imposing additional burden on the already
5 under-resourced and overstretched hospitals and healthcare system.

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7 During times of outbreaks, some clinicians provided care around-the-clock, including
8 evenings and weekends. This accentuated fatigue and impacted their personal and family lives
9 leading to emotional and physical burnout.

10 Some described lack of attention by the healthcare system and media on the impact of the
11 pandemic on LTC workers. They felt that their own emotional trauma and needs were and
12 continue to be ignored. Many LTC staff have been left traumatized and their trauma and burnout
13 remains unaddressed in many cases.
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16 17 **INTERPRETATION**

18
19 In this study, physicians and nurse practitioners working in LTC homes in Ontario,
20 Canada described a spectrum of experiences and effects, both challenging and rewarding, related
21 to providing palliative and end-of-life care during the COVID-19 pandemic. Foremost amongst
22 these were physical and psychological exhaustion and distress caused by, among others,
23 attending to high levels of suffering and unprecedented numbers of deaths amongst residents over a
24 relatively short period of time, witnessing residents dying alone due to visitation restrictions,
25 undertaking difficult EOL discussions at a large scale and under trying circumstances, and
26 providing support to anxious and grieving families at a distance.
27

28
29 Multiple factors contributed to these experiences including excessive workload, changing
30 roles and added responsibilities, staff shortages, increased communication demands, using new
31 technologies and virtual approaches. Additional factors included uncertainty about the virus and
32 concerns about contracting the virus and infecting their own families, shortages of supplies such
33 as PPE and palliative care medications in the early waves, limitations on direct contact with
34 residents and their families, altered routines, and periodically changing public health mandates.
35

36 These findings are consistent with those reported in previous studies across several
37 countries, in LTC and other care settings.¹⁹⁻²⁴ An additional finding in our study related to the
38 role of external resources mobilized to assist the LTC homes; while the assistance of military and
39 hospital personnel and consultants were appreciated, lack of experience with and understanding
40 of the LTC setting was an impediment.

41 The experiential narratives in this study show that LTC staff demonstrated innovation and
42 creativity in their response to the pandemic. This has been reported in other studies.^{20, 25} Most
43 participants described introducing improvements related to EOL discussions in their homes.
44 They reported strengthened interpersonal relationships amongst staff, increased multidisciplinary
45 collaboration within and outside of the homes, and expressed increased pride and meaning in
46 their work. They made personal sacrifices driven by altruism while dealing with their own
47 distress. The ability of LTC staff to adapt to the extraordinary demands and finding meaning and
48 fulfillment in their work has been ascribed psychological capital which is characterized by hope,
49 optimism, resilience, and self-efficacy.^{26,27}
50

51 Importantly, our study highlights strategies to improve palliative care and help mitigate
52 the impact of similar pandemics in LTC homes in the future. These include training all LTC staff
53 with core skills to provide palliative and EOL care, multidisciplinary clinical collaborations and
54 leadership that promote the integration of quality palliative care clinical guidelines and practices
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3 such as routine ACP, GoC discussions and symptom assessment in everyday practice, as well as
4 ensuring established access to specialized palliative care and geriatrics consultants and nurses
5 with LTC experience to provide additional support when needed. These strategies have
6 previously been emphasized by experts and researchers in the field, including pre-
7 pandemic.^{7,10,25,28-31}
8

9 Several study limitations are noted. The study did not include PSWs, RPNs, registered
10 nurses or other LTC staff. It did not explore the experiences of residents and families. The
11 participants all had some prior palliative care training, and this may have affected their
12 experiences. The interviews occurred during the third pandemic wave, almost sixteen months
13 after the beginning of the pandemic, which may have introduced recall bias and inaccuracies.
14 Since participation in the study was voluntary, a selection bias may also have occurred.
15

16 17 **Conclusion** 18

19 Providing palliative and EOL care to residents in Ontario LTC homes during the COVID-
20 19 pandemic, especially in the early waves, had a major impact on clinicians and staff in those
21 homes and affected their work and personal lives in many ways, both negatively and positively.
22 While dying and death are not uncommon in this care setting given the frailty and co-morbidities
23 of most residents, dealing with unprecedented levels of morbidity and mortality during the
24 pandemic amidst shortages in staffing and resources took a significant toll on clinicians.
25 Notwithstanding this impact, clinicians were able to demonstrate innovation, introduce
26 improvements and find meaning and pride in their work.
27

28
29 Calls to improve the integration of palliative care into everyday practice in LTC homes
30 can no longer go unheeded. The pandemic has exposed longstanding gaps in this area in the LTC
31 sector. These gaps contributed to the toll exacted by the pandemic on residents, families and staff
32 alike. Fortunately, as highlighted in this study, there are well elaborated strategies to incorporate
33 palliative and EOL care as an integral aspect of providing quality person-centered care in LTC
34 homes and it is possible to model after examples across the country where this has been done
35 successfully.
36
37

38 39 **Acknowledgements** 40

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42 contribution to this project by conducting background research and their role as research
43 assistants with the Division of Palliative Care, Department of Family Medicine, McMaster
44 University.
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46

47 **Competing interests**

48 None relevant to the design, conducting, or reporting of study outcomes.
49

50 51 **Data Sharing Statement**

52 Given the personal and private nature of the interviews, which may easily identify participants,
53 data will not be available for sharing.
54

55 **Funding** 56 57 58 59 60

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3 This study was funded and supported by the Division of Palliative Care, Department of Family
4 Medicine at McMaster University.
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Confidential

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2 **Qualitative Study of Clinicians' Experiences**
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5 **October 30, 2022**
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7 Dear editors at CMAJ Open,
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11 Our study research team is enthusiastic about submitting the manuscript titled,
12 Providing Palliative and End-of-Life Care in Long-Term Care During the Covid-19 Pandemic: A
13 Qualitative Study of Clinicians' Experiences, for publication in CMAJ Open.
14
15

16 When the COVID-19 pandemic was declared in March of 2020, early members of the
17 research team were involved at various capacities, in academic, advocacy and educational
18 efforts aimed specifically at improving quality of palliative care and end-of-life experiences in
19 LTC homes prior to the pandemic. Given the toll of the COVID-19 pandemic on LTC homes and
20 the need for more evidence to better understand the barriers and gaps in quality of care
21 towards the end-of-life in this care setting, the research team set out to utilize their
22 interdisciplinary collaboration and examine this from the perspective of clinical providers who
23 worked in LTC homes and provided end-of-life care during the pandemic. The researchers
24 sought to obtain a comprehensive understanding of the barriers and challenges faced by
25 clinicians (medical doctors and nurse practitioners) as they narrated their experiences. As far as
26 we know, this is the first study of its kind in this field where clinicians shared personal and real-
27 life rich data around their experiences working in LTC homes during COVID-19. There are
28 generally not many studies that interviewed clinicians directly during the COVID-19 pandemic
29 with the goal of understanding their experiences, which were often overlooked during the
30 pandemic in favour of focused media attention on crisis reporting. And yet, given the challenges
31 faced by our healthcare system today, it is most critical that we engage clinicians in health
32 system reform and understand their experiences. The qualitative interpretative descriptive
33 study design indented to capture an understanding of the clinicians' experiences as
34 comprehensively and broadly as possible. The clinicians in this study shared important details
35 that will inform improving palliative care in the LTC setting. The content and narratives shared
36 by participants and reported in this study are necessary to provide a holistic understanding of
37 the gaps in care and barriers to transformations in care, including palliative care. We chose
38 CMAJ Open since the study took place in a Canadian care setting and given your journal's
39 reputable history in publishing content that aims to bridge knowledge translation and lead to
40 meaningful impact on practice and health policy.
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48 We look forward to hearing from you and ultimately share our study findings with the
49 readers of CMAJ Open.
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51 Sincerely,
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54 Sandy Shamon MD PC CCFP
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16 **Affiliations**

17 ¹ Division of Palliative Care, Department of Family Medicine, McMaster University

18 ² Cummings School of Community Medicine, University of Calgary.

19 ³ School of Nursing, McMaster University

20 ⁴ Pallium Canada, Ottawa, Canada
21

22
23 1-Department of Family Medicine, Division of Palliative Care, McMaster University

24 100 Main Street West, 2nd Floor

25 Hamilton, Ontario

26 L8P 1H6

27 Canada

28 Phone: 905-525-9140

29 Fax: 905-521-5594
30

31
32 2-Cummings School of Community Medicine, University of Calgary

33 University of Calgary

34 2500 University Drive NW

35 Calgary Alberta T2N 1N4

36 CANADA
37

38
39 3-School of Nursing, McMaster University

40 McMaster University

41 1280 Main Street West

42 HSC 3H48C

43 Hamilton, ON L8S 4K1
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48 **Abbreviations:** Long-term care (LTC), advance care planning (ACP), goals of care (GoC),
49 personal support workers (PSWs), registered practice nurses (RPNs), end-of-life (EOL)
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53 **Corresponding author:** Sandy Shamon¹, Division of Palliative Care, Department of Family
54 Medicine, McMaster University, Email: shamons@mcmaster.ca
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Table 1: Participants Demographics

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Age	< 40 years	2
	40-49 years	3
	50-59 years	4
	≥ 60 years	3
Years of Experience in LTC	<10 years	3
	10 – 19 years	7
	≥ 20 years	2
Utilized Virtual Care	Yes	10
	No	2
Roles	Attending Physician	7*
	Medical Director	7*
	Nurse practitioners	5
Additional Training in Palliative Care	Yes	12**
	No	0
Certificate of Added Competence in Palliative Care or Care of the Elderly***		2

*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 (approximately 15 hrs training)

*** Certification by the College of Family Physicians of Canada either through a one-year residency in palliative care or through a practice route recognition process.

Table 2: Themes, Subthemes, and Illustrative Quotes

Theme 1: Providing a Palliative Approach to Care	
Scaling up	<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” [P3]</p> <p>“So pre-pandemic we had a good flow, we had lovely processes. During our outbreak, all of those just went by the wayside” [P4]</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” [P11]</p> <p>“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” [P11]</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 frontline staff were brought in there” [P1]</p> <p>“We have a nurse practitioner that works between both of our homes and she's extremely strong in palliative care” [P1]</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” [P7]</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” [P8]</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” [P12]</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” [P14]</p>

<p>Uncertainty of illness trajectory and prognosis.</p>	<p><i>“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” [P7]</i></p> <p><i>“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” [P9]</i></p>
<p>Theme 2: Increased Demands and Workforce Reorganization</p>	
<p>Staffing challenges</p>	<p><i>“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” [P1]</i></p> <p><i>“Nobody helped these homes with their staffing and people died really quickly. So to me it was a manpower issue” [P8]</i></p> <p><i>“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.” [P13]</i></p>
<p>Role changes, added responsibilities and going the extra mile.</p>	<p><i>“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” [P5]</i></p> <p><i>“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” [P5]</i></p> <p><i>“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” [P7]</i></p> <p><i>“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” [P7]</i></p> <p><i>“Although I wasn’t feeling very energetic about my clinical work, I was feeling incredibly energetic about my advocacy work” [P8]</i></p> <p><i>“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” [P8]</i></p>

	<p><i>"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. So that's my nature" [P9]</i></p> <p><i>"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" [P13]</i></p>
<p>Supply and resource shortages</p>	<p><i>"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" [P5]</i></p> <p><i>"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" [P6]</i></p> <p><i>"And then she called me because she couldn't find an oxygen tank because so many people were so sick all at once" [P11]</i></p> <p><i>"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] we have in stock?" [P12]</i></p> <p><i>"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" [P13]</i></p>
<p>Theme 3: Communication and Collaboration</p>	
<p>Engaging families</p>	<p><i>"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" [P3]</i></p> <p><i>"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 things in long-term care" [P3]</i></p> <p><i>"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" [P4]</i></p>
<p>Communication internally within LTC home</p>	<p><i>"And we did have regular meetings, even as the medical director for the two 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" [P3]</i></p> <p><i>"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</i></p>

	<i>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" [P3]</i>
Communication externally	<p><i>"Even some of the palliative care docs, they don't have long-term care experience, so they didn't understand" [P8]</i></p> <p><i>"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" [P9]</i></p> <p><i>"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" [P9]</i></p>
Communication and collaboration during outbreaks	<p><i>"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" [P1]</i></p> <p><i>"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"[P6]</i></p> <p><i>"You know, our attendings were great, our attendings did all the notifications for the positives, spoke to all the families" [P12]</i></p> <p><i>"So, two NPs and two 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" [P13]</i></p>
Theme 4: Impact of Isolation and Visitation Restrictions	
Family distress	<p><i>"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" [P4]</i></p> <p><i>"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 able 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</i></p>

	<i>beside them as they were dying. One PSW sang to one of the residents. It was heartbreaking to see them” [P7]</i>
Resident distress	<p><i>“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”[P3]</i></p> <p><i>“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” [P4]</i></p> <p><i>“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” [P5]</i></p> <p><i>“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” [P7]</i></p> <p><i>“But, you know, I would say the impact of the visitor restriction was far greater than the impact of COVID on our home” [P12]</i></p>
Impact on staff	<p><i>“We became like the proxy family members, and so it did develop some very close relationships with our residents and their care providers” [P4]</i></p> <p><i>“There wasn’t that physical, that able 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” [P7]</i></p>
Category 5: Impact on Clinicians’ Personal Lives	
Burnout	<p><i>“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” [P5]</i></p> <p><i>“I really felt that it was my responsibility to do that; and I never turned my phone off for the first nine months until it was quite evident that I just couldn’t be on 24/7 anymore” [P8]</i></p>
Impact on personal life.	<p><i>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 [P6]</i></p> <p><i>“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” [P8]</i></p>

**Moral distress
and emotional
trauma**

“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” [P5]

“The post-traumatic 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” [P7]

“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” (P7)

“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”[P8]

“And I have loaded people in ambulances who are actively dying because the family did not know they were dying” [P9]

“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 three and four years” [P9]

“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” [P9]

“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” [P9]

“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 two and a half weeks” [P11]

“Yeah. And the trauma of what we saw and what we did was — you

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<p><i>shouldn't have to support as many deaths in a year as we did" [P13]</i></p> <p><i>"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" [P13]</i></p> <p><i>"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"[P13]</i></p>
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Appendix A: Interview Questions and Guide

Study Questionnaire

1. Age
2. How long have you worked in LTC
3. What is your role in the LTC home(s) you work in (choose all that apply)
4. Did your end-of-life care in LTC include virtual care during the COVID-19 Pandemic?
5. Do you have extra training in addition to residency? Please describe (ex. CAC in palliative care or Care of Elderly)
6. Are you a member of any of the following LTC and Palliative care organizations/ communities of practice? (select all that apply).
 - a. Ontario Long-Term Care Clinicians
 - b. OMA Section on Palliative Medicine
 - c. OMA Section on LTC/ Care of the Elderly
 - d. Other, please specify

Interview Guide

Palliative approach and end-of-life care experience

1. How would you describe your experience practicing as a clinician in providing palliative and end-of-life care in your LTC home(s) during the COVID-19 pandemic?
2. Please tell me about an impactful or memorable end-of-life experience in your LTC home during COVID-19.
3. How has your understanding and practice of a palliative approach to care been impacted by the COVID-19 pandemic?

Impact on clinicians and families

4. How has the COVID-19 pandemic impacted you either professionally or personally?
5. What is your understanding of residents and families' perceptions of the end-of-life care received by their loved ones during the COVID-19 pandemic?

Clinician's preparedness in providing a palliative approach to care

6. How prepared did you feel to provide quality palliative approach and end-of-life care in your LTC home during COVID-19, in the spring of 2020? How about during the second wave, and now?
7. What types of supports or resources did you find most valuable in helping you provide a palliative approach to care during this time?

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Recommendations for the future

- 8. What suggestions do you have to your LTC home and the system moving forward about providing a quality palliative approach to care and end-of-life care?

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