JAMDA 25 (2024) 105076

JAMDA

journal homepage: www.jamda.com

Original Study

Enablers and Barriers for End-of-Life Symptom Management Medications in Long-Term Care Homes: A Qualitative Study

Rhiannon L. Roberts MScPH[a,*], Christina Milani MSc[b], Colleen Webber PhD[a,b], Shirley H. Bush MBBS, MRCGP, PgDip Pall Med, FAChPM[a,b,c], Kaitlyn Boese MD[b], Jessica E. Simon MB ChB[d], James Downar MD, MSc[a,b,c], Amit Arya MD, CCFP (PC), FCFP[e,f], Peter Tanuseputro MD, MHSc[a,b,c], Sarina R. Isenberg MA, PhD[b,c,e,g]

[a] *Ottawa Hospital Research Institute, Ottawa, Ontario, Canada*
[b] *Bruyère Research Institute, Ottawa, Ontario, Canada*
[c] *Department of Medicine, Division of Palliative Care, University of Ottawa, Ottawa, Ontario, Canada*
[d] *Department of Oncology, Medicine and Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada*
[e] *Department of Family and Community Medicine, University of Toronto, Toronto, ON, Canada*
[f] *Kensington Research Institute, Toronto, Ontario, Canada*
[g] *School of Epidemiology and Public Health, Faculty of Medicine, Ottawa, Ontario, Canada*

ABSTRACT

Keywords:
Qualitative
end-of-life
end-of-life medications
enablers and barriers

Objectives: Long-term care (LTC) homes provide personal and medical care 24/7 to individuals unable to live at home due to illness or disability and are often the final place of care and death for their residents. Therefore, LTC homes are tasked with providing quality end-of-life care, often requiring injectable symptom management medications to relieve distressing symptoms (eg, pain). In this study, we aimed to understand the enablers and barriers to prescribing and administering end-of-life symptom management medications in LTC homes.

Design: Qualitative study.

Setting and Participants: From February 2021 to December 2022, we conducted virtual semi-structured interviews with health care providers (physicians and nurses) who worked in Ontario LTC homes and family caregivers of residents who died in LTC.

Methods: We analyzed interview transcripts using thematic analysis.

Results: We identified 4 themes related to factors that may impact the prescribing and administering of medications for end-of-life symptom management: (1) identifying the end-of-life period and symptoms, (2) communication among health care providers and between health care providers and family caregivers, (3) health care provider competency with end-of-life medications, and (4) resources for LTC staff to support medication prescribing and administrating.

Conclusions and Implications: In LTC, there are distinct challenges in the prescribing and administrating of end-of-life symptom management medications. Our findings can be used to inform interventions aimed at improving end-of-life care for LTC residents. However, these interventions require buy-in and investment from the provincial government and the LTC sector.

This study received funding from the College of Family Physicians of Canada COVID-19 Pandemic Response and Impact Grant Program. The opinions, results, and conclusions reported in this paper are those of the authors and are independent from the funding sources. This project has been funded in part by a contribution from Health Canada's Health Care Policy and Strategies Program. The views expressed herein do not necessarily represent the views of Health Canada. P.T. is supported by P.S.I. Graham Farquharson Knowledge Translation Fellowship. S.H.B. receives an Academic Protected Time Award from the Department of Medicine, University of Ottawa, Ottawa, Canada. The funders had no influence in study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit the article for publication.

Three of the authors of this paper had prior professional or personal relationships with four participants. To mitigate bias, these authors did not interview participants with whom they had relationships.

[*] Address correspondence to Rhiannon L. Roberts, Ottawa Hospital - Civic Campus, 1053 Carling Ave, Box 693M-07, Admin Services Building, Ottawa, Ontario K1Y 4E9, Canada.

E-mail address: rhroberts@ohri.ca (R.L. Roberts).

https://doi.org/10.1016/j.jamda.2024.105076
1525-8610/

Long-term care (LTC) homes provide personal and medical care 24/7 to individuals unable to live at home due to illness or disability. LTC homes are a common final place of care and death for their residents. In Ontario, Canada, 80% of LTC residents die in LTC rather than acute care.[1] Therefore, LTC homes should provide quality end-of-life care for residents in their last weeks and days of life. Optimal end-of-life care should integrate a palliative approach to care, which includes a holistic approach (eg, spiritual care, medications to treat physical symptoms, and mouth, eye, skincare, and family counseling) to address residents' physical, psychological, social, spiritual, and practical needs.[2] Although the ideal is for LTC homes to integrate comprehensive end-of-life care, it is still underutilized in practice.[3]

At the end of life, individuals can experience distressing symptoms, including pain, shortness of breath, and agitation due to delirium. These symptoms can be upsetting for residents and their families.[4-6] To manage these symptoms, end-of-life care guidelines recommend using symptom management medications.[1,7,8] Internationally, studies have reported <60% of LTC/nursing home residents received a prescription for an opioid (opioids being the most common class of medication prescribed at the end of life).[7,9] In addition, studies conducted in other settings, hospitals, palliative care units, and hospices have reported high prescribing rates for end-of-life medications in the final days of life: >80% of hospital decedents and >90% of individuals in palliative care units and hospices.[10,11] Yet, in Ontario, Canada, the use of these medications in LTC varies greatly. In a previous study, we examined prescribing end-of-life symptom management medications across the 626 LTC homes in Ontario, Canada, using routinely collected health administrative data, including prescription billing claims. We found that across homes, as few as 30% and as many as 80% of residents were prescribed at least 1 symptom management medication in their last 2 weeks of life.[1] As all Ontario LTC homes are regulated the same and have similar residents (due to the province's waitlist structure), we believe that the degree of home-level variation we observed in our findings likely indicates underuse of medications in some homes. In this current qualitative study, we aimed to understand the enablers and barriers to prescribing and administering end-of-life symptom management medications in LTC.

Methods

Study Design, Setting, and Participants

We conducted semi-structured interviews from February 2021 to December 2022 with health care providers (physicians and nurses) who work in Ontario LTC homes (since January 2020) and family caregivers of residents who had died in LTC before the interviews (March 1, 2018, to December 2022).

We recruited participants from 2 provinces in Canada, namely Ontario and Alberta. In both provinces, LTC homes are funded by the provincial government and mandated to provide residents with 24-hour nursing and personal care. Each LTC resident must also be assigned a health care provider (physician or nurse practitioner) responsible for their medical care. Depending on the LTC home and the type of provider, individual practitioners may work full-time or part-time at the LTC home (eg, 1 day a week). However, all practitioners must be available by phone or have arranged coverage when not in the LTC home.

Recruitment

We used a phased recruitment approach. First, we recruited participants from a single LTC home in Ontario to retrospectively understand how LTCs provided end-of-life medications for their residents before the COVID-19 pandemic (Phase 1). We then recruited participants from Ontario LTC homes with the highest and lowest prescribing rates of end-of-life symptom management medications, identified by the team's previous quantitative analysis (Phase 2).[1] However, this approach (recruiting from high- and low-prescribing homes) was unsuccessful and we expanded our recruitment to include all Ontario and Alberta LTC homes. We used various recruitment strategies, such as contacting LTC homes' director of care, LTC homes' patient and family council, team connections, and social media. A further description of our recruitment strategy and number of LTC homes and individuals contacted is in Supplementary Table 1.

Although all interviews were conducted virtually during the COVID-19 pandemic (March 2021 to November 2022), we asked health care provider participants to share their experiences of medication provision before the COVID-19 pandemic and reflect on how these behaviors changed during the COVID-19 pandemic.

Data Collection

Four authors made up the core team and were responsible for recruitment, data collection, and analysis: a qualitative researcher and the principal investigator of the study (S.R.I.), 2 research coordinators (C.M., R.L.R.), and a research associate (C.W.), who met weekly. A larger co-investigator team (A.A., K.B., S.B., J.D., D.L., J.S.) supported this core team and met monthly to discuss each project phase.

The core team created the interview guides. We used the first iteration of the guide for 2 pilot interviews [with team members D.L. (caregiving experience) and K.B. (health care provider experience)]. We modified the guide following these 2 pilot interviews, preliminary results from our quantitative analyses, and the first 6 interviews (conducted in Phases 1 and 2). The health care provider interview guide had differing guiding questions for physicians and nurses to address potentially different roles (eg, prescribing vs administering) and perspectives. The interview guide for caregivers (ie, family or friends of the resident in LTC) included questions to understand their caregiving experience for a resident at the end of life. The final interview guides are in the Supplementary Material. Core team members, S.R.I. (trainer) and R.L.R. and C.M. (trainees) conducted interviews using Zoom.[12] Interviewer characteristics are included in Supplementary Table 2. Interviewers obtained verbal consent and administered a demographics survey before starting the interview. Interviews were audio-recorded, transcribed verbatim, and de-identified. The interviewer took field notes. The core team met after each completed interview to debrief, ensure consistency in administering interview questions, and compare transcripts and observations.

Data Analysis

We analyzed transcripts using a coding reliability approach to thematic analysis.[13,14] The core team thoroughly read the interview transcripts and identified and arranged preliminary codes into a codebook. Transcripts were not returned to participants. The codebook was modified as new interviews were transcribed and read. Once no new codes were developed, the core team determined that thematic saturation had been reached.[15] The core team inserted the finalized codebook and interview transcripts into qualitative analysis software (MAXQDA).[16] The core team established the reliability and accuracy of thematic coding through group and consensus coding. First, the core team group-coded 3 randomly chosen transcripts. Second, the core team separately and independently coded a randomly selected transcript and then merged the 4 coded versions into one working document using MAXQDA. For each code segment in the transcript, the core team discussed their coding rationale and came to a consensus. Through group and consensus coding, the codebook was further modified to accommodate newly emerging patterns. The remaining 10 transcripts were double coded by the core team, who ensured agreement between coders through discussion and comparison. The core team then reviewed the coded segments and explored preliminary patterns before identifying core themes that they developed from the data. They finally refined, defined, and named the themes, and found exemplary quotations. Findings were not shared with participants.

Ethics Approval

We received approval from the Bruyère Research Ethics Board (REB) (December 7, 2020, #M16–20–060) and the Ottawa Health Science Network REB (April 19, 2021, #20210207–01H).

Results

Participant Characteristics

We interviewed 15 participants, 14 from Ontario and 1 from Alberta. We excluded the Alberta transcript from our analysis as we cannot fully capture the differences between Ontario and Alberta with only 1 interview from Alberta. The Ontario participants included 6 physicians, 1 nurse practitioner, 4 registered nurses or registered practical nurses, and 3 family caregivers from 7 of Ontario's 626 LTC homes. Of the Ontarian participants, half (n = 7, 50%) were women, and a third (n = 5, 36%) were aged 60 to 69. Half (n = 7, 50%) were from private not-for-profit LTC homes, and most (n = 10, 71%) were from LTC homes without religious affiliation. Of the health care providers (n = 11), most (n = 9, 81%) had previous palliative care training (eg, physician residency program or professional development courses) and were in a managerial or leadership role within their home (n = 7, 64%). Although we did open recruitment to all Ontario LTC homes, most of our participants were from high-prescribing homes (n = 11, 79%). Participant demographics are in Table 1. No participants dropped out of the study. The average interview length was 40 minutes (range 24 to 51 minutes).

Themes

We identified 4 major themes related to factors that may impact the provision (prescription and administration) of medications for end-of-life symptom management: (1) identifying the end-of-life period and symptoms, (2) communication among health care providers and between health care providers and family caregivers, (3) health care provider competency with end-of-life medications, and (4) resources for LTC staff. Exemplary quotes for each major theme are in Table 2. We also evaluated the impact of the COVID-19 pandemic on the provision of medications for end-of-life symptom management.

Identifying the end-of-life period and symptoms

Health care providers noted that it is difficult to identify when a resident has entered the end-of-life period and is experiencing associated symptoms. The health care providers discussed how newer or temporary staff may not have experience within the LTC sector or with end-of-life care and may find it difficult to recognize and manage end-of-life symptoms. In addition, newer and temporary staff likely do not have experience with a specific LTC home and, therefore, are not familiar with the residents (ie, knowing a resident's baseline and, subsequently, what represents a change from baseline), which can also affect the provision of end-of-life medications. Participants also reflected on how it is particularly difficult to identify the end-of-period or symptoms in residents with end-stage dementia who are nonverbal.

Table 1
Caregiver and Health Care Provider Participants' Sociodemographic Characteristics and Health Care Provider Professional Characteristics

Characteristic	n	%
Gender		
Woman	7	50
Man	7	50
Age		
30–39	3	21
40–49	2	14
50–59	1	7
60–69	5	36
70–79	3	21
Type		
Family caregiver	3	21
Health care provider (physician)	6	43
Health care provider (nurse practitioner)	1	7
Health care provider (registered nurse or registered practical nurse)	4	29
Affiliated LTC home		
Funding model		
Municipal	3	21
Private for-profit	2	14
Private not-for-profit	7	50
Do not know	2	14
Religious affiliation		
No	10	71
Yes	4	29
Prescribing rates, based on quintile		
Top prescribing quintile	11	79
Bottom prescribing quintile	1	7
Unknown	1	14
Specific to health care providers (n = 11)		
Years in health care		
0–9	2	18
10–19	2	18
20–29	3	27
30–39	2	18
40–49	2	18
Years in current role		
0–4	3	27
5–9	2	18
10–14	0	0
15–19	0	0
20–24	2	18
25–29	4	36
Formal training in palliative care provision (eg, residency program, professional development courses)		
No	2	18
Yes	9	82
Leadership or management role within the LTC home		
No	4	36
Yes	7	64
Specific to family caregivers (n = 3)		
Previously lived with your family member		
No	2	67
Yes	1	33

Communication among health care providers and between health care providers and family caregivers

Participants flagged 2 important communication avenues for end-of-life medication provision: communication among health care providers and between health care providers and family caregivers.

Participating physicians emphasized the instrumental role of LTC nursing staff in identifying residents' end-of-life symptoms and helping physicians prioritize residents needing medications for symptom management. Physicians noted that they could not assess all their residents on each of their visits to an LTC home due to their high resident caseload and limited days working in LTC, therefore they rely on nurses to prioritize residents. In some cases, the physicians noted nurses would share in the medication decision-making, including dose and frequency, as nurses were more familiar with the residents. However, this 2-way

Table 2
Exemplary Quotes Note, Participant Codes Correspond to the Phase of Recruitment (Phase 1 or 2), the Type of Participant, and the Participant Number Based on Sequential Participation

Theme	Subtheme	Quote
Identifying end-of-life period and symptoms	LTC experience	2HCP4: And often the nurses and the staff at our long-term care facility, they're really great. So, we have a really low turnover rate. Our staff know our long-term care residents really well. It's the same PSWs who provide care every day for years. And they're good at basically identifying residents and notifying me. I am in twice a week, Tuesdays and Thursdays. So, I don't get to see everybody every time that I'm in. So, usually they let me know if they're worried about somebody.
Identifying end-of-life period and symptoms	End-of-life period	2HCP4: But a lot of people who have severe maybe end-stage dementia who are nonverbal, who are kind of basically chronically on the edge. Like they could pass away tomorrow or they could live for another year. So, in those cases it can be difficult. But obviously, acute illness, or an acute deterioration are signs that someone's at the end of life.
Identifying end-of-life period and symptoms	End-of-life symptoms	Interviewer: Are there any factors that help a resident receive their medications or barriers that might prevent them from getting that medication? 2HCP3: Yeah, that's a really good question because, you know, about 60% have dementia. So, they can't ask. So, we have to go by visual cues. So, the nurses, if they're grimacing or act upset or agitated, will go ahead and give the shot. That's a huge barrier really.
Communication	Between HCPs	Interviewer: So, how else do you involve nurses in end-of-life medication decision-making? Are they involved in those choices? 2HCP3: Yeah. The nurses are really key because they recognize when the patient is dying. They'll tell us. And then, I always talk to the nurse about it because they have the most information. And they sort of share in the amount of drug to give and how often to give it because they're right there around the clock. You know, we just come in for a few minutes a day. 2HCP10: But at other homes, you've got some nurses who are afraid to call the doctor on call because not all the doctors may be feeling the same. You've got a variety of physicians and knowledge and willingness to be bothered, right? And [00:48:37 unintelligible] "Oh, don't call the doctor. Don't bother him. You'll get your ear chewed off." But that's, again, it's the communication between the staff and the comfort level.
Communication	Between HCP and CG	Interviewer: Are there other things that really facilitate that interaction or that help a resident's symptoms become relieved? 2HCP10: Yeah, so, if you've got a family member who's there at their side, that's helpful. Because they're going to be more acutely aware of the distress. And they might pick up on that a little bit better than some of us that come in, pop in for a moment, administer medication on the order of the doctor. So, quite often, the family will advocate and say, "You know what? I don't think she's comfortable enough." 2CG1: Not only do I not even know the doctor, but the doctor's not there. There's another doctor covering. And we said, "This is not working. I can't go through this." And the doctor who was covering said, "Well, I don't know your dad well enough to prescribe for you what kind of things you might need." And I'm going, "Well, then why are you on call if you can't do this to help us? This is really the most horrific day of my life. I'm wrestling with my dad. And you know what? It's awful for me, but I don't want my dad's last day on this planet to be like this....This is not the way I want my dad to spend the last day together with me on this planet, this agitated." And she was saying, "No, I don't feel that I can do that." And it wasn't until we basically said that we were going to go above this person and report this person that they're not providing the care to my father, that we basically said, "You know, there are medications that can help my dad. There are medications that can alleviate this." And we basically had to threaten to say, "We're going to go above you, because there's no way. This is not the way it should be." And because of that, I think ... Because what happened then is the actual doctor got back in touch with us. ... But I know there are specific medications that helped my dad, and it made a big difference. And that made the last few days.
HCP Competency	Comfort	2HCP1: And I've noticed, when I'm not around to give that PRN medication, they will often not give it, citing that they're comfortable and they're quiet. And then after about 6 hours, well, they can't get their pain under control. You didn't give the PRN. You didn't keep them comfortable. So, that's when we have to go to the physician and say, "Increase the regular dose," because they're not giving the PRN when needed. 1HCP1: We just had a nurse the other day, we had a resident who had just severe dyspnea and end-of-life heart failure. And I came out, it was 4:00, and I was like our resident needs something for breakthrough. His respirations quite rapid. He's like, "Well, he doesn't have pain." I'm like, I know, but he's [spis-nic] and he needs the medication. She's like, "Okay, well, he gets a straight order at 5:00." I'm like, okay, but it's 4:00, so we need to give something now. She's like, "Well, I don't want to kill him." I'm like, good, I don't want you to kill him either, but I'd like you to support his symptom management at end of life. And she just kind of laughed, she's like, "Am I being ridiculous?" I was like, maybe. I didn't say that but I was like, I can support you after but let's get the Dilaudid sub-q now and then we'll have a discussion after. Because like we are wasting his time and he's struggling and he can't breathe. So let's get the meds into him, I'll support you, and then we'll have a discussion afterwards. 2HCP10: And if I've ordered it every hour, I say, "Don't be afraid to give it every hour." And I'll tell them, "Look if they're distressed," I say, "Give them that and call me back in 20 minutes, 30 minutes, so we can assess what that was." Because what I do find is that often, the nurses aren't, themselves, used to dealing with end of life, and they tend to under dose. They're afraid to give it. They're afraid that they're going to hurt them, they're going to kill them, they're going to euthanize them with the hydromorphone at reasonable doses.
HCP competency	Education	Interviewer: Okay. And so, when you talk about when someone started practicing and recent changes in palliative care practice, are you saying that the prescribers, physicians, NPs who have been in the practice longer might not be as up to date on current practices? 2HCP11: Or, other way around, new grads might not—I think that people just get into their own practice that they've been practicing for 40 years, which isn't crazy in some of the long-term care homes. Then it's different because it wasn't the same—or what I understand of it, at least, wasn't the same necessary palliative care culture. And the same drugs weren't being used. The same care wasn't being given. The population in long-term care has changed. Interviewer: Okay, so more kind of contemporary, newer teachings in palliative care, the people who have been

(*continued on next page*)

Table 2 (*continued*)

Theme	Subtheme	Quote
		around for a while, stuck in their ways, so to speak, might not be as caught up on? Respondent: Yeah. … So, I think it's a cohort effect as well as also where you're practicing.
Resources for LTC staff	End-of-life order sets	2HCP8: I think the order set helped a lot. We did an audit—we did see some variability just about 7 years ago. Six or 7 years ago. We saw differences in how often people were receiving end-of-life medication. And we've had different feedback from families about the quality of the end-of-life care. We did surveys of family members afterwards. We get their—we've been doing that for a very long time. And I triggered that concern that maybe not everyone was getting the same access to palliative care medication. So, that was the big driver of getting an end-of-life order set. And since then, the variability dropped. We're not getting the same complaints. I can't speak on their behalf, but I can say all the physicians that are in the home have used the end-of-life order set have prescribed medications.
Resources for LTC staff	Coaching	Do you feel supported in delivering end-of-life care within your home? 1HCP2: Yes. Yeah, we have actually a nurse that comes to the unit, and even though you have end-of-life order sets, she would reassess that order and she would see the patient, and she would help us educate the staff. Like when, okay, this one should be now. Or maybe we could increase this one. Or maybe we can switch this one to something else.
Resources for LTC staff	Mentoring	2HCP10: So, I find it's necessary to tell them [nurses], "Look, if you think they're still uncomfortable, if their heart rate is—if they're still over 100, or their heart rate hasn't settled down a little bit, if their respiratory rate is still in the 30s and hasn't come down for the high 20s, and they still got that look on their brow, and they still seem distressed and not comfortable, don't be afraid to give them the PRN dose of the hydromorphone." And if I've ordered it every hour, I say, "Don't be afraid to give it every hour." And I'll tell them, "Look if they're distressed," I say, "Give them that and call me back in 20 minutes, 30 minutes, so we can assess what that was."

CG, family caregiver; HCP, health care provider; NP, nurse practitioner; PSW, personal support worker.

communication and decision-making depends on how familiar nurses are with the residents and the relationship between physicians and nurses. One physician noted that nurses do not always reach out to physicians about resident symptoms, particularly to physicians on call, as the nurses are "afraid" of bothering the physician.

Considering communication between caregivers and LTC staff, all caregiver participants shared their experiences of alerting LTC staff that the resident was distressed and needed symptom management medications immediately. In all instances, they perceived that LTC staff was hesitant to prescribe or administer symptom management medications: nurses did not want to give pro re nata (PRN) (ie, as-needed) medications until the next "scheduled" dose or the on-call physician felt they were not familiar enough with the resident to prescribe the medications. In addition, one participating caregiver only met the physician caring for their resident after their resident died. In all instances, the resident received medications only after caregiver advocacy (sometimes for hours); in all cases, the medications relieved the residents' distressing issues. Health care providers emphasized the vital role of caregivers in end-of-life symptom management, noting that caregivers are more familiar with the resident's needs and sometimes will notify the health care providers of those needs.

Health care provider competency with medications

Health care providers' comfort with providing end-of-life symptom management medications also affects a resident's likelihood of receiving them. Most health care providers stated they were comfortable providing (ie, prescribing or administering) these medications. Only 1 physician noted that they are not always comfortable prescribing these medications due to uncertainty with medication choice for the resident (ie, the right medication for the symptom or dose). Although most provider participants stated they were comfortable providing (prescribing and administering) medication, they believed their colleagues were not always comfortable. Many mentioned that nurses could be "scared" to administer prescribed end-of-life symptom management medications (eg, opioids), fearing the medication would harm the resident (eg, "hasten death"). Health care providers reflected on how their nursing colleagues do not always administer PRN medications in a way that could be deemed timely due to their nursing colleague's fear of these medications. Participants also discussed instances when their colleagues relied on scheduled medications rather than administering PRN doses when the resident displayed increased symptoms.

Participants did not agree on how education affects a health care provider's comfort in prescribing and administering medications. Some participants thought older physicians might be less likely to prescribe these due to a lack of familiarity with current palliative care practices.

Resources for LTC staff

Participants reported LTC homes' resources: end-of-life order sets, education sessions, coaching/mentoring, and specialist palliative care consulting services can improve the provision of end-of-life medications. Health care providers discussed how standardized end-of-life order sets—a list of common symptoms and applicable medications—have improved the use of these medications within the homes. Participants reflected on how end-of-life order sets can improve health care providers' knowledge and comfort with these medications. The presence of an order set and its comprehensiveness could also contribute to the variability of prescribing across LTC homes. In one case, a participant noted that the variability in prescribing end-of-life symptom medications decreased after the home implemented a standardized end-of-life order set. LTC homes have also used training sessions about end-of-life symptoms and medications (eg, the safety of appropriately dosed opioids at the end of life) to improve health care provider competency. In addition, LTC homes have used coaching and mentoring to improve the use of end-of-life medications. Coaching or mentoring can be ongoing (eg, pairing nurses who are uncomfortable with these medications with a health care provider with extensive palliative care training, in which they review medication orders and resident symptoms) or at the moment (eg, a physician providing clear instructions to nurses on signs that indicate a resident is in distress and when to administer medications). Finally, LTC homes have consulted specialist palliative care physicians or nurse practitioners to inform their care approach for a resident, especially when a resident has complex health issues (eg, multimorbidities).

Impact of the COVID-19 pandemic

Health care provider participants who practiced in LTC before and during the COVID-19 pandemic felt that the provision of end-of-life symptom management medications within their LTC homes had not been noticeably affected by the pandemic. Unfortunately, as we only had 1 caregiver whose family member died in LTC during COVID, we can not capture differences before and during the COVID-19 pandemic for the caregiving experience.

Discussion

In this study, we interviewed LTC health care providers and family caregivers of deceased LTC residents to understand how LTC homes prescribe and administer end-of-life symptom management medications. We identified 4 themes that influence whether medications are prescribed and administered: identification of the end-of-life period and symptoms, communication between health care providers and between health care providers and family caregivers, health care provider competency, and having resources available for LTC staff. When asked whether end-of-life symptom management medication practices changed during COVID, health care participants indicated no noticeable changes.

Interpretation

We identified many barriers for LTC residents to receive end-of-life symptom management medications. The first barrier to end-of-life medication prescribing and administering was identifying when a resident is at the end of life and displaying the associated symptoms. Compared with those with an acute event or advanced cancer, residents who are frail or have dementia typically have a slow and gradual decline.[17-19] Therefore, decline trajectories for residents with non-cancer illnesses are unpredictable, making it challenging to know if they are at the end of life.[18] Identifying end-of-life symptoms can be particularly difficult in individuals with dementia, as behavioral responses in residents with dementia can be very similar to expressions of pain.[20] As a large proportion of LTC residents have dementia (more than 70%), difficulty distinguishing between dementia and pain could lead to challenges in providing end-of-life medications.[21] In addition, identifying distressing end-of-life symptoms is challenging when staff do not know the resident's baseline. When staff know the resident well, they can detect subtle changes, including signs and symptoms of pain or delirium.[18,22] However, staff shortages are common in LTC, and staff attrition has worsened since the COVID-19 pandemic.[23-25] Therefore, homes often rely on new or temporary staff who have not had the time to build relationships with residents and know their baselines. Caregivers can, and do, monitor for signs and symptoms of a resident's end of life and request medications to manage distressing end-of-life symptoms.[26] Therefore, caregivers play a large role in end-of-life symptom management; however, health care providers need to make a more concerted effort to incorporate caregivers' perspectives into their medication decision-making. In our study, all caregivers' concerns about their resident's distressing symptoms were met with initial hesitancy to action.

Another barrier in medication management was a lack of health care provider comfort with end-of-life medications, specifically opioids. In a similar study examining enablers and barriers to optimal end-of-life care in LTC in Alberta, participating physicians stated that community-based physicians were reluctant to prescribe opioids.[20] They also stated that residents did not always receive prescribed opioid medications, leading them to assume that nursing staff lacked confidence and comfort with opioid administration.[20] A fear of opioids is not new; it has been reported for several decades and is common among providers within and beyond the LTC sector.[27] Studies of health care providers within the community report similar discomfort with prescribing and administering these medications due to fear of misuse and a lack of confidence in the right medication and dose.[28,29] The 2 previous barriers (identifying end-of-life period and managing symptoms) rely on communication between health care providers and family caregivers. Yet, there are several communication challenges reflected in the literature. Inadequate end-of-life communication may be due to a variety of issues, including limited physician presence and participation in LTC homes, staff discomfort in discussing and managing the dying process, and a lack of systems (ie, processes and documentation) in place to support end-of-life conversations.[22,30,31] Physicians' limited time spent in LTC hinders their ability to build relationships with residents, their caregivers, and staff, and participate in discussions about the resident's care (eg, care conferences). With physicians' limited time in LTC, it is difficult for clinical staff to build trust with each other, which may lead to issues with end-of-life medication provision, including physicians not trusting a nurse's clinical judgement on the resident's need for pain medication.[31-33] Physicians' lack of trust in nurses' clinical judgement is previously reported in other LTC medication management (appropriate prescribing of antibiotics for urinary tract infections).[32] Additionally, caregivers want frequent communication with health care providers about a resident's declining condition and at the end of life, but in reality, communication is limited, and caregivers may not even know who the physician who is caring for the resident (as reflected in our study).[30,34]

Staff are not always comfortable discussing and managing the dying process. Staff do not always feel comfortable discussing death as they are uncertain about the resident" decline and do not want to give up hope that the resident will "bounce back."[22] Therefore, dying may only be identified when the resident is in their final hours of life, when it may be too late to prescribe or administer end-of-life medications.[22,30] A lack of systems and training to support end-of-life conversations also contributes to communication issues. Structured, multidisciplinary end-of-life care conferences and documentation can facilitate this communication.[31,35] Finally, the COVID-19 pandemic worsened existing communication issues between caregivers and health care providers as LTC homes restricted visitors in attempts to control the spread of COVID-19.[36]

Consistent with existing literature, this study identified potential enablers for end-of-life medication provision as important for building LTC health care providers' competency with end-of-life care. This potential education via mentorship, coaching, and resources for physicians and nurses, included access to specialist palliative care consulting services.[35] Combining learning opportunities (eg, education with on-site peer coaching) is significantly more effective for knowledge transfer than education sessions alone (even when the education sessions include practice).[37] The formal implementation of a champion model in LTC homes may facilitate on-site mentoring and coaching, although mentoring and coaching may also occur through less formal models.[38] It is beneficial for LTC nurses and physicians to receive learning opportunities about end-of-life medications and LTC.[35] Nurses are vital in recognizing distressing symptoms, communicating residents' needs to prescribers and families, and administering required medications. The administration of medications is not solely a technical task but requires considerable decision-making skills about the need for and timing of these medications, especially with PRN medications.[29] Therefore, nurses need strong foundational knowledge and practice with end-of-life medications. It is, however, challenging to build this foundational knowledge in LTC, in part due to staffing shortages, staff turnover, and limited financial support to back-fill positions of those receiving training or paid education time; therefore it is difficult for staff to attend education sessions, especially for temporary staff who do not work exclusively in LTC.

For the additional enabler of staff resources, participants reflected on how standardized end-of-life order sets helped their practice and how variability in order sets could lead to differences in prescribing practices across LTC homes. In the hospital setting, previous studies have shown that standardized care plans can improve several processes of end-of-life care, including the appropriate alignment of symptoms and medications.[39-41] However, health care providers have suggested that end-of-life order sets should not be a checklist but a tool that compliments the prescriber's critical thinking and the residents' care preferences.[41,42] Importantly, end-of-life order sets are only a tool, and their success depends on addressing the other barriers related to end-of-life medication provision, including health care provider knowledge, comfort, and experience.[29,37]

Limitations

First, we only included study participants from a single province in Canada: Ontario. Therefore, the applicability of or results to other jurisdictions is limited, as LTC is provincially regulated. Second, we attempted to interview individuals from LTC homes with high- and low-prescribing rates of end-of-life medications to compare prescribing practices. However, because of low recruitment rates, we had to expand interviews to all LTC homes, regardless of prescribing practices. Although we did expand recruitment to all homes, irrespective of prescribing rates, most participants were from high-prescribing homes. Therefore, we suspect that we were not able to capture all enablers and barriers of prescribing, especially those in homes with low rates of prescribing. Third, our sample size ($n = 14$) is smaller than the roughly 20 participants in most health services qualitative studies. We recruited during the COVID-19 pandemic, which may have contributed to our recruitment challenges. Many LTC homes were overburdened and short-staffed, and few homes and health care providers were willing to participate in our study. Although we expanded our collection time frame and sampling strategy to maximize the number of potential participants, we still had limited participation. Our fourth limitation is selection bias in that the few individuals who did participate may have been less affected by the pandemic and thus had more availability for and interest in participating. Also, most of our participants (9 of the 11 health care providers) had formal palliative care training, and a few were also palliative care leads within their LTC homes. These participants likely had different views on end-of-life medication prescribing than most staff. Finally, only 2 health care participants were nurses; therefore, our findings predominantly represent the views of physicians and not nurses. Therefore, we cannot fully capture all barriers and enablers faced by staff (eg, registered nurses) and may be missing key elements that affect the provision of end-of-life medications. However, our findings do align with those found in previous studies suggesting these are common issues across LTC homes.

Conclusions and Implications

There are distinct challenges in the process of prescribing and administering symptom management medications at the end of life for residents in LTC. Our findings can be used as a launching pad for intervention development. For example, training could be developed to counteract provider discomfort around prescribing and administering symptom management medications, supplemented by resources to educate and support family caregivers about these medications and the dying period. Ongoing education could be provided by palliative care specialists around identifying the end-of-life period and managing distressing symptoms. However, these proposed changes require ongoing buy-in and investment from the health care funders, LTC sector, and LTC home management so staff can attend education or training sessions.

Disclosures

The authors declare no conflicts of interest.

Acknowledgments

We thank Denyse Lynch who provided invaluable insight into her caregiving experience and was instrumental in the project's development and early analyses.

References

1. Tanuseputro P, Roberts R, Milani C, et al. Palliative End-of-Life Medication Prescribing Rates in Long-Term Care: A Retrospective Cohort Study. *J Am Med Dir Assoc*. 2024;25:532–538.e8.
2. Health Standards Organization. Long-term care services. 2023. Accessed March 24, 2023. https://store.healthstandards.org/products/long-term-care-services-can-hso21001-2023-e
3. Xiong B, Freeman S, Banner D, Spirgiene L. Hospice use and one-year survivorship of residents in long-term care facilities in Canada: a cohort study. *BMC Palliat Care*. 2019;18:1–18.
4. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004;291:88–93.
5. Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ (Can Med Assoc J)*. 2006;174:627–633.
6. Registered Nurses' Association of Ontario. End-of-life care during the last days and hours. 2011. Accessed November 8, 2023. https://rnao.ca/bpg/guidelines/endoflife-care-during-last-days-and-hours
7. Jansen K, Haugen DF, Pont L, Ruths S. Safety and effectiveness of palliative drug treatment in the last days of life-A systematic literature review. *J Pain Symptom Manage*. 2018;55:508–521.e3.
8. Fraser Health Authority. Hospice palliative care symptom guidelines [internet]. Fraser Health Authority. 2023. Accessed March 20, 2023. https://www.fraserhealth.ca/employees/clinical-resources/hospice-palliative-care#.ZB3dG3bMK5d
9. Bailey FA, Williams BR, Goode PS, et al. Opioid pain medication orders and administration in the last days of life. *J Pain Symptom Manage*. 2012;44:681–691.
10. Koivu L, Pölönen T, Stormi T, Salminen E. End-of-life pain medication among cancer patients in hospice settings. *Anticancer Res*. 2014;34:6581–6584.
11. NHS Benchmarking Network. *National Audit of Care at the End of Life: Second Round of the Audit (2019/20) Report England and Wales*. NHS Benchmarking Network; 2020.
12. Zoom meetings & Chat. Zoom video communications Inc. 2022. Accessed January 15, 2022. https://zoom.us/meetings
13. Boyatzis R. *Transforming qualitative information: Thematic analysis and code development*. Sage Publications, Inc; 1998.
14. Guest G, MacQueen K, Namey E. Applied thematic analysis [eBook]. SAGE publications, Inc.. 2012. Accessed March 24, 2023. https://methods.sagepub.com/book/applied-thematic-analysis
15. Creswell J, Poth C. *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications; 2016.
16. *MAXQDA*. VERBI Software; 2022.
17. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. *JAMA*. 2003;289:2387–2392.
18. McCleary L, Thompson GN, Venturato L, et al. Meaningful connections in dementia end of life care in long term care homes. *BMC Psychiatr*. 2018;18:307.
19. Atchison K, Wu P, Toohey A, et al. Barriers and facilitators to care of frail older adults in the long-term care setting. presented at: Canadian Geriatrics Journal 42nd Annual Scientific Meeting. 2023. Accessed January 3, 2024. https://www.proquest.com/docview/2823695302?pq-origsite=gscholar&fromopenview=trueProQuest
20. 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.
21. Tanuseputro P, Hsu A, Kuluski K, et al. Level of need, divertibility, and outcomes of newly admitted nursing home residents. *J Am Med Dir Assoc*. 2017;18:616–623.
22. Cable-Williams B, Wilson D. Awareness of impending death for residents of long-term care facilities. *Int J Older People Nurs*. 2014;9:169–179.
23. Dass AR, Deber R, Laporte A. Forecasting staffing needs for Ontario's long-term care sector. *Healthc Policy*. 2022;17:91–106.
24. Pasieka C. "It is truly the wild west': Ontario non-profit LTC homes demand caps on temp agency fees. CBC. 2023. Accessed October 23, 2023. https://www.cbc.ca/news/canada/toronto/calls-grow-to-clamp-down-on-wild-west-of-temp-agencies-in-long-term-care-1.6747093
25. Registered Nurses' Association of Ontario. Long-term care systematic failings: two decades of staffing and funding recommendations. 2020. Accessed January 3, 2024. https://rnao.ca/sites/default/files/2021-05/RNAO_LTC_System_Failings_June_2020.pdf
26. Auclair I, Bourbonnais A. The Involvement of caregivers in the end-of-life care of an older adult living in a long-term care home: a qualitative case study with nurses and relatives. *Can J Nurs Res*. 2024:8445621241247862.
27. Stimmel B. Under-prescription/over-prescription: narcotic as metaphor. *Bull N Y Acad Med*. 1985;61:742–752.

28. Khalil H, Garett M, Byrne A, et al. Mapping end-of-life and anticipatory medications in palliative care patients using a longitudinal general practice database. *Palliat Support Care*. 2022;20:94–100.
29. Wilson E, Morbey H, Brown J, Payne S, Seale C, Seymour J. Administering anticipatory medications in end-of-life care: a qualitative study of nursing practice in the community and in nursing homes. *Palliat Med*. 2015;29:60–70.
30. Hennings J, Froggatt K, Keady J. Approaching the end of life and dying with dementia in care homes: the accounts of family carers. *Rev Clin Gerontol*. 2010; 20:114–127.
31. Durepos P, Kaasalainen S, Sussman T, et al. Family care conferences in long-term care: exploring content and processes in end-of-life communication. *Palliat Support Care*. 2018;16:590–601.
32. Valmadrid LC, Schwei RJ, Maginot E, Pulia MS. The impact of health care provider relationships and communication dynamics on urinary tract infection management and antibiotic utilization for long-term care facility residents treated in the emergency department: a qualitative study. *Am J Infect Control*. 2021;49:198–205.
33. Brazil K, McAiney C, Caron-O'Brien M, Kelley ML, O'Krafka P, Sturdy-Smith C. Quality end-of-life care in long-term care facilities: service providers' perspective. *J Palliat Care*. 2004;20:85–92.
34. Motamedi M, Brandenburg C, Bakhit M, et al. Concerns and potential improvements in end-of-life care from the perspectives of older patients and informal caregivers: a scoping review. *BMC Geriatr*. 2021;21:729.
35. Kaasalainen S, Sussman T, McCleary L, et al. Palliative care models in long-term care: a scoping review. *Nurs Leadersh (Tor Ont)*. 2019;32:8–26.
36. Chu CH, Stamatopoulos V, Yee AV. "We've all lost so much": the long-term care home experiences of essential family caregivers during COVID-19. *Can J Aging*. 2023;42:284–296.
37. Schwellnus H, Carnahan H. Peer-coaching with health care professionals: what is the current status of the literature and what are the key components necessary in peer-coaching? A scoping review. *Med Teach*. 2014;36:38–46.
38. Tappen RM, Wolf DG, Rahemi Z, et al. Barriers and facilitators to implementing a change initiative in long-term care using the INTERACT® quality improvement program. *Health Care Manag*. 2017;36:219–230.
39. Bailey FA, Williams BR, Woodby LL, et al. Intervention to improve care at life's end in inpatient settings: the BEACON trial. *J Gen Intern Med*. 2014;29:836–843.
40. Bailey FA, Burgio KL, Woodby LL, et al. Improving processes of hospital care during the last hours of life. *Arch Intern Med*. 2005;165:1722–1727.
41. Lau C, Stilos K, Nowell A, Lau F, Moore J, Wynnychuk L. The comfort measures order set at a tertiary care academic hospital: is there a comparable difference in end-of-life care between patients dying in acute care when CMOS is utilized? *Am J Hosp Palliat Care*. 2018;35:652–663.
42. Harasym PM, Afzaal M, Brisbin S, et al. Multi-disciplinary supportive end of life care in long-term care: an integrative approach to improving end of life. *BMC Geriatr*. 2021;21:326.

Supplementary Material

Supplementary Table 1
Recruitment of Participants

Time Frame	Description	Contacted	Response	Completed Interviews
Phase 1				
Feb–Mar 2021	We worked with the director of care at our Phase 1 site. The director of care shared our recruitment poster with health care providers that worked in the LTC home and caregivers of residents that died before COVID-19.	1 LTC	1 LTC agreed to participate	2 HCP 2 CG
Phase 2				
Strategy: Comparing homes in the top and bottom quintile of end-of-life prescribing, as determined by our quantitative research and established on page 2 of the manuscript.				
Jun 2021	Contacted the directors of care in 4 homes (two from the top quintile and 2 from the bottom quintile).	4 LTC	1 LTC declined 3 LTC no response	0
Jul 2021	Contacted the directors of care in 16 additional homes (8 from the top quintile and 8 from the bottom quintile).	16 LTC	3 LTC declined 13 LTC no response	0
Aug 2021	Contacted the directors of care in 20 additional homes (8 from the top quintile and 8 from the bottom quintile).	20 LTC	1 LTC declined 19 LTC no response	0
Aug 2021	Contacted the directors of care or generic emails for the remaining LTC homes and family councils in the top and bottom quintiles. We also expanded recruitment to all second top and bottom quintiles. Finally, we contact Ontario patient and family advisory networks.	142 LTC 3 networks	2 LTC declined 140 LTC no response 3 networks responded	0
Aug 2021–Dec 2022	Leveraged the research teams' connections with LTC homes and HCPs working in LTC.	3 LTC >20 HCP.	2 LTC homes agreed to participate HCP agreed to be interviewed 1 CG agreed to be interviewed	11 HCP 1CG
May 2022 – Dec 2022	Expanded recruitment to Alberta and leveraged team connections.	2 HCP 1 network	1 HCP did not respond 1 network did not respond	1 HCP
June 2022	Posted to social media (Twitter and Linkedin).	n/a	No eligible participants	0
Ended recruitment				

CG, family caregiver; HCP, health care provider includes physicians and nurses.

Supplementary Material. Interview Guide

Health Care Provider Interview Guide

Section: Context of care.

1. How do you recognize that a resident is at the end of life?

Section: Home and team-based questions.

Today we are going to be talking about your experiences in delivering end-of-life care in LTC, and specifically the prescribing of symptom management medications at the end of life. We recognize that this past year has been very difficult on all health care providers, and that LTC has been particularly hard hit. We want to get a better understanding of how end-of-life (EOL) care is provided in your home, and how it changed during the pandemic.

We appreciate that there are many components of EOL care. However, we are specifically looking at medications given at the EOL for symptom management. We are going to ask you questions about these medications.

2. What factors influence the decision to begin medications for symptom management for residents who are recognized as being at the EOL?

- Prompt: Resident factors (eg, resident or family member preferences)
- Prompt: Provider factors (eg, familiarity with meds)
- Prompt: Home factors (eg, time/shift pressures)

3. What are residents' and/or caregivers' roles in the use of EOL medication?

- How are families involved in discussions concerning EOL medications? If so, how? If not, why not?

[For Physicians]

4. Can you tell me about your experience prescribing medications for EOL symptom management?

5. How much expertise or training in palliative care do you have?

6. Do you have access to palliative care specialists (physicians or nurses), consultations or other resources?

- If so, how do they support you with EOL symptom management prescribing?

7. What symptoms do you typically prescribe EOL medications for?

- Pain
- Shortness of breath
- Delirium
- Nausea
- Terminal secretion
- Anxiety
- Agitation

8. Do you ever use palliative care or EOL order sets (or symptom management kits)?

- How do you use these order sets?

9. For what proportion of residents do you prescribe the following types of medications in the last 2 weeks of life? Potential answer options: less than 25%, 25%–50%, 50%–75%, more than 75%?

- Opioids
- Other analgesics
- Benzodiazepines
- Antipsychotics
- Sedatives

10. Are residents typically administered their prescribed medications?

- If yes, what helps a resident receive their EOL care medications?
- If no, what barriers prevent residents from receiving their EOL care medications? Are these barriers related to challenges with administering or with resident's acceptance of the medication?

11. The following questions pertain to symptom management medications prescribed during the last 2 weeks of life, at which point most residents have often lost their ability to swallow. How comfortable are you prescribing EOL symptom management medications?

- Types of medications (eg, opioids)
- Routes of delivery (ie, oral, subcutaneous, injectable)

12. Reflecting on the past few questions concerning your comfort with types of medications and routes of delivery, how do you think your colleagues' (other physicians or nurses) comfort levels compare?

13. How has the provision of symptom management medications at the EOL changed in your home(s) during the COVID-19 pandemic?

- Prompt: Were there medication shortages?
- Prompt: Were there resource issues (equipment or staffing) that affected the delivery of EOL symptom management medications? Where their communication or coordination issues?
- Prompt: What strategies did your team take in response to these changes?
- Prompt: Were there differences between the early phases of the pandemic (March 2020—September 2020), and the latter phases (October 2020—now)?

14. What proportion of COVID-positive residents were prescribed EOL medications to manage symptoms? Which medications and which symptoms? What was the route of delivery? How did that compare with the non-COVID patients who died during COVID?

15. During the pandemic, was there a difference in the frequency that COVID-negative residents received EOL symptom management medications, compared with pre-pandemic times?

[For registered nurses and registered practical nurses]

1. Can you tell a bit about your experience with medication administration for EOL symptom management?
2. Do you have expertise or training in palliative care? What?
3. Do you have access to palliative care specialists (physicians or nurses), consultations, or other resources?
   - If so, do they support you with EOL symptom management administration?
4. What symptoms do residents typically receive EOL medications for?
   - Pain
   - Shortness of breath
   - Delirium
   - Nausea
   - Terminal secretion
   - Anxiety
   - Agitation
5. Are palliative care or EOL order sets (or symptom management kits) used in the home?
   - How do you use these order sets?
6. For what proportion of residents do you prescribe the following types of medications in the last 2 weeks of life? Potential answer options: less than 25%, 25%—50%, 50%—75%, more than 75%?
   - Opioids
   - Other analgesics
   - Benzodiazepines

  - Antipsychotics
  - Sedatives

7. Are residents typically administered their prescribed medications?
   - If yes, what helps a resident receive their EOL care medications?
   - If no, what barriers prevent residents from receiving their EOL care medications? Are these barriers related to challenges with administering or with resident's acceptance of the medication?
8. The following questions pertain to symptom management medications prescribed during the last 2 weeks of life, at which point most residents have often lost their ability to swallow. How comfortable are you administering EOL symptom management medications?
   - Types of medications (eg, opioids)
   - Routes of delivery (ie, oral, subcutaneous, injectable, infusion pump)
9. Reflecting on the past few questions concerning your comfort with types of medications, do you think your colleagues share your views or differ?
10. How has the provision of symptom management medications at the EOL changed in your home during the COVID-19 pandemic?
    - Prompt: Were there medication shortages?
    - Prompt: Were there resource issues (equipment or staffing) that affected the delivery of EOL symptom management medications? Where their communication or coordination issues?
    - Prompt: What strategies did your team take in response to these changes?
11. How did your home's practices regarding EOL prescribing change during the early phases of the pandemic from March 2020 to September 2020?
    - How has this changed from October 2020 to now?
12. What proportion of COVID-positive residents were prescribed EOL medications to manage symptoms? If so, which medications and which symptoms? What was the route of delivery? How did that compare with the non-COVID patients who died during COVID?
13. During the pandemic, was there a difference in the frequency that COVID-negative residents received EOL symptom management medications, compared with pre-pandemic times?

Section: Indicator questions.

It is often said that you can't improve what you can't measure. Quality indicators are things we can measure and help us assess how well a health care service is working.

- [For example, Ontario uses a quality indicator that measures the percentage of LTC home residents without psychosis that are on antipsychotic medications. LTC homes with a high percentage of nonpsychotic residents on antipsychotic medications compared with their peers, indicates that the home may have room to improve.]
- [For example, Ontario uses a quality indicator that measures how long a patient waits to see a specialist after being referred. The longer the patient waits to see the specialist indicates poorer access to care.]
- [For example, Ontario uses a quality indicator that measures the percentage of people who had their surgery within a provincial target time. The fewer individuals who had their surgery in the targeted time indicates less timely care provided.]
- [For example, Alberta uses a quality indicator that measures the percentage of residents who had falls in the past 30 days within an LTC home. Homes with a high percentage of falls indicates there are opportunities for improvement within the home.]
- [For example, Alberta uses a quality indicator that measures the percentage of residents who were physically restrained daily. Homes with a high percentage may be engaging in inappropriate practices.]

We are proposing a new quality indicator to assess the delivery of EOL care provided at LTC homes. The new quality indicator could help identify homes that need additional support for EOL care.

This new quality indicator will measure the percentage of residents in their last 2 weeks of life who are prescribed at least 1 symptom management medication—focusing on subcutaneous medications that are given when residents lose their ability to swallow near the EOL. We think this indicator is a proxy to palliative care delivery, as these medications are prescribed only when a prescriber has thought about the EOL needs of residents. Unlike any other potential indicators of the quality of palliative care in LTC, the data required to measure this indicator are readily available and can be immediately used to identify homes and physicians with high and low rates of prescribing.

1. Do you have experience using quality indicators within your home? Please explain/provide an example?
2. To what extent do you agree or disagree that measuring the percentage of residents in their last 2 weeks of life who are prescribed symptom management medications can be used to assess the quality of EOL care within a home?
3. What are the potential benefits in knowing at a home-level the percentage of residents in their last 2 weeks of life who are prescribed symptom management medications?
4. What are the potential limitations or concerns in knowing at a home-level the percentage of residents in their last 2 weeks of life who are prescribed symptom management medications?
   a. How much have you encountered EOL medications being prescribed but not administered?
   b. Have you ever encountered a situation in which these medications were prescribed but other EOL care services were not received? What did this look like?
   c. Can residents generally receive good quality EOL care services but not be prescribed EOL medications? What did this look like?
5. How do you think this quality indicator should be reported or provided in feedback? Which level should it be reported at provincial, regional (ie, sub-local health integration network), facility, or physician level?
6. If you knew about your home's performance on the indicator, how might that influence your practice?
7. Our initial data show large variations in prescribing rates for EOL symptom management medications across homes. What do you think might explain this large range in practice?
8. What other indicators of quality EOL care would you like to see explored at the system level?
   - Suggestions regarding existing health admin data
   - Suggestions regarding non-health admin data

Section: Wrap up.

9. Is there anything else that I haven't asked you that you would like to share?

Family Caregiver Interview Guide

For this interview, we are going to refrain from using the name of your [insert relationship] to make it easier to de-identify the interview. We will instead be describing the person as [insert relationship].

Section: Context of care.

1. Can you tell us a bit about your [insert relationship with the resident]?
2. What brought them to LTC?
    - How long were they in LTC?
    - May I ask when they died?
    - Was the death related to COVID-19?
3. Can you tell us what EOL care means to you? (ie, participant's own definition of EOL care)

Below are some definitions of EOL care.

- Ontario Palliative Care Network defines EOL care as care for people in decline who are expected to die in the foreseeable (near) future. It constitutes "active care" aimed at helping residents and families to prepare for death, ensure comfort, and to make care decisions that are consistent with the resident's prognosis and goals of care.
- Palliative care can include EOL care but also can be delivered earlier in the disease trajectory.

Section: Receiving EOL care.

4. What EOL care services did your [*relationship: family member or friend*] receive in the last 2 weeks of life?
    - Was this care given before the COVID-19 pandemic (before March 2020)?
    - Was this care given during the COVID-19 pandemic (March 2020—present)?
    - Did your [insert relationship with the resident] have a consultation/receive care from a palliative care physician?
5. What was your level of satisfaction in the EOL care services received in their last 2 weeks of life?
    - What was good about the care received?
    - What could have been better?
    - Were there any services that you thought they should receive that they didn't receive?
6. What symptoms at the EOL did your [*relationship: family member or friend*] have? (Obj 2)

Section: Medications.

There are many aspects to good EOL care. However, we are specifically looking at medications given at the EOL for symptom management. We are going to ask you questions about these medications.

7. Did your [*relationship: family member or friend*] receive medications for any of their symptoms in the last 2 weeks of life?
    - Which medications or types of medications did they receive—injectables, subcutaneous, etc?
    - Did the medication help manage your [*relationship: family member or friend*] symptoms?
8. Were you and/or your [*relationship: family member or friend*] more comfortable with certain types of medication administration over others? Did you feel that a certain type was more acceptable?
9. What discussions did you have with the nurse or doctor concerning the prescribing of medications at the EOL of your loved one? Who initiated the discussions?
    - How helpful, informative were these discussions in enabling you to feel re-assured that your loved one's quality of life was still important?
    - What would better prepare you to discuss the prescribing of medications for your loved one at the EOL?
10. What factors made it easier or would have made it easier for your [insert relationship with the resident] to receive EOL medications? (eg, communication between patient and provider)
11. What factors made it harder or would have made it harder for your [insert relationship with the resident] to receive EOL medications? (eg, administration of medications, patient refusal to receive medications)
12. Were EOL medications received when your loved one needed them? Was it at the appropriate time? Do you think it should have been earlier or later?
13. What role did medications play in the overall quality of your [insert relationship] EOL care?
14. How much do you think COVID-19 impacted the medications (type or amount) your [family member or friend] received?

Section: Indicator questions.

It is often said that you can't improve what you can't measure. Quality indicators are things we can measure and help us assess how well a health care service is working.

- [For example, Ontario uses a quality indicator that measures how long a patient waits to see a specialist after being referred or to have hip surgery. Longer waiting times tells us the health care system is not working so well.]
- [For example, Ontario uses a quality indicator that measures the percentage of people who had their surgery within a provincial target time. The fewer individuals who had their surgery in the targeted time indicates that less timely care was provided.]
- [For example, Alberta uses a quality indicator that measures the percentage of residents who had falls in the last 39 days within an LTC home. Homes with a high percentage of falls indicates there are opportunities for improvement within the home.]
- [For example, Alberta uses a quality indicator that measures the percentage of residents who were physically restrained daily. Homes with a high percentage may be engaging in inappropriate practices.]

We are interested in using a new quality indicator to identify LTC homes that may need support delivering palliative care and EOL care. One measure we are exploring is the percentage of residents who are prescribed medicines to help manage symptoms during their last 2 weeks of life. For example, we can measure if a pain killer like morphine was prescribed in the final weeks of life. [Unlike any other indicators of palliative care, these data are readily available for all LTC residents and can be immediately used to identify homes and prescribers with high and low rates.]

15. To what extent do you agree or disagree that using palliative care medications (eg, morphine/hydromorphone) is a good indicator to capture how well an LTC home is providing EOL care? How come?
16. What would be the benefits of this sort of indicator?
17. What problems can you imagine using this sort of indicator?
18. If you had a choice about which LTC home you or your family member went to and this indicator about EOL prescribing was available, would you factor this indicator into your decision about which LTC home to choose?
19. What other EOL quality indicators would you like to see?

Section: Wrap up.

20. In view of our project's aim to improve quality of medication care, what else that I haven't asked about you would like to share in helping achieve that aim for future residents?

Supplementary Table 2
Interview Team

Name	Credentials	Position	Gender	Previous Experience
Dr Sarina R. Isenberg	PhD, MA	• Chair in Mixed Methods Palliative Care Research at Bruyère Research Institute • Assistant Professor in the Department of Medicine and School of Epidemiology and Public Health at the University of Ottawa, • Assistant Professor in the Department of Family and Community Medicine at the University of Toronto • Adjunct Professor at the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health • Affiliate Investigator in the Clinical Epidemiology Program at the Ottawa Hospital Research Institute • Adjunct Scientist at ICES University of Ottawa.	Woman	• Dr Isenberg has a PhD in Social and Behavioral Sciences from the Johns Hopkins Bloomberg School of Public Health, a Master of Arts in English Literature from Queen's University, and a Bachelors of Arts in English Literature from McGill University. • Dr Isenberg's mixed methods research focuses on examining access to palliative care for marginalized and non-cancer populations, and testing ways to improve access and quality of care. She has led several qualitative health services research studies.
Rhiannon L. Roberts	MScPH	Research Coordinator at the Ottawa Hospital Research Institute	Woman	Rhiannon had no previous experience with qualitative work. She was trained by Dr Isenberg.
Christina Milani	MSc	Research Coordinator at the Bruyère Research Institute	Woman	Christina had no previous experience with qualitative work. She was trained by Dr Isenberg.

The following 3 individuals conducted the interviews. Their characteristics reflect those at the time of the interviews.
R.L.R. had a personal relationship with one of the participants. She asked the participant to participate in the study. She did not participate in their interview.
C.M. contacted all individuals who expressed an interest in participating in the study through e-mail. She provided all interested individuals with a consent form and arranged interview times.
In the interview, the interviewer shared minimal details about the study—all are reflected in the interview guide in the Supplementary Material. In 2 interviews, core team member C.W. observed the interview but did not participate.