

# Measuring the Use of End-of-Life Symptom Relief Medications in Long-Term Care Homes—a Qualitative Study



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<https://doi.org/10.5770/cgj.27.712>

## ABSTRACT

### Background

At the end of life, individuals may experience physical symptoms such as pain, and guidelines recommend medications to manage these symptoms. Yet, little is known about the symptom management long-term care (LTC) residents receive at the end of life. Our research team developed a metric—whether residents receive one or more prescriptions for an end-of-life symptom management medication in their last two weeks—to explore end-of-life care for LTC residents. This qualitative study aimed to inform the refinement of the end-of-life prescribing metric, including the acceptability and applicability to assess the quality of a resident's symptom management at end-of-life.

### Methods

We conducted 14 semi-structured interviews with Ontario health-care providers (physicians and nurses) who work in LTC homes and family caregivers of residents who died in LTC. Interviews were conducted virtually between February 2021 and December 2022, and were analyzed using thematic analysis.

### Results

We identified three major themes relating to perceptions of the metric: 1) appropriateness, 2) health-care provider applicability, and 3) caregiver applicability. Participants noted that the metric may be appropriate to assess end-of-life care, but noted important nuances. Regarding applicability, health-care providers found value in the metric and that it could inform their practice. Conversely, caregivers found limited value in the metric.

### Conclusion

The proposed metric captures a very specific aspect of end-of-life care—whether end-of-life medications were prescribed or not. Participants deemed that the metric may reflect whether LTC homes have processes to manage a resident's end-of-life symptoms with medication. However, participants thought the metric could not provide a complete picture of end-of-life care and its quality.

**Key words:** qualitative; thematic analyses; end-of-life; long-term care; medications; metric

## INTRODUCTION

Palliative care is a holistic approach aiming to achieve the best quality of life and comfort for a person with a life-limiting illness and their family caregivers; this care can occur during, but is not limited to, the end of life.<sup>(1)</sup> Holistic palliative care is an iterative process requiring ongoing assessments and adjustments to an individual's care plan by health-care professionals to address the physical, psychological, social, spiritual, and practical needs of the person and their caregivers.<sup>(2)</sup> Quality end-of-life care involves a palliative approach to care. At the end of life, individuals may experience physical symptoms such as pain, shortness of breath, and agitated delirium, which can be distressing to both the individual and their caregivers. To address these symptoms, individuals and their caregivers often prioritize comfort care, including the use of medications to control these distressing symptoms.<sup>(3-5)</sup> Individuals who do not receive comfort care measures, including the use medications, may experience inadequate symptom control which could impact their care during the dying process.

Palliative care is an essential aspect of care that long-term care (LTC) homes are expected to provide. LTC homes provide personal and medical care to individuals unable to live in their own homes due to illness or disability. In Ontario, Canada—where an estimated 79,000 residents live in more than 600 LTC homes—the median survival after LTC admission is 18 months, and 80% of LTC residents have LTC as their place of death.<sup>(6-8)</sup> Therefore, LTC homes must be able to manage residents' end-of-life and death to minimize residents and their families from experiencing unnecessary distress and poor quality care at the end of life.

Canada uses quality indicators (e.g., restraint use in LTC, location of death) to monitor and improve the quality of care LTC homes provide. Quality indicators are not an absolute measure of quality, but reflect desired or undesired care.<sup>(9)</sup> In Canada, trends show the LTC sector generally improves its performance on reported quality indicators over time.<sup>(9-11)</sup> While Canada collects and reports on several LTC quality indicators, none provide insight into end-of-life care supports. To address this gap, our team developed a potential metric to explore symptom management for LTC residents' end of life.

The metric was developed using available administrative health data sets (i.e., via prescription claims data). The metric measures whether residents receive one or more prescriptions for an end-of-life symptom management medication in their last two weeks of life.<sup>(8)</sup> The list of symptom management medications was created by the research team and revised by palliative care specialists across Ontario. Palliative care specialists were palliative care physicians who work with LTC homes (within the home or as a consultant). The list comprises medications that are commonly recommended to alleviate residents' end-of-life symptoms, such as pain, anxiety, agitated delirium, shortness of breath, and nausea.<sup>(12-15)</sup> To date, we have used this metric in research studies to describe end-of-life symptom management prescribing in LTC homes in Ontario before and during the COVID-19 pandemic.<sup>(8)</sup> Our overall project aim is to use the metric to monitor the quality of end-of-life palliative care provided in LTC.

This qualitative study aimed to understand and inform the use of the end-of-life prescribing metric. Specifically, we aimed to determine the acceptability and applicability of the metric to assess the quality of residents' end-of-life care. We interviewed LTC physicians, nurses, and bereaved caregivers of LTC residents to understand their perceptions of this metric.

## METHODS

### Overview

This qualitative study is part of a larger multi-methods research project to evaluate end-of-life care in LTC. For the quantitative analyses, the team conducted retrospective cross-sectional studies. For each LTC home in Ontario, the team calculated the metric—the proportion of residents prescribed medication in the last two weeks of life. Homes were then grouped into quintiles based on the metric; in the top prescribing quintile, 83% of residents were, on average, prescribed

an end-of-life symptom management medication, while in the lowest prescribing quintile, only 38% of residents were prescribed an end-of-life symptom management medication.<sup>(8)</sup> The analysis was conducted twice, evaluating a period before COVID (January 17, 2017 to March 17, 2020) and during COVID (March 18, 2020 to March 17, 2021). The quantitative analyses are being replicated in Alberta.

### Study Design, Setting, and Participants

In this qualitative study, we conducted semi-structured interviews with health-care providers (physicians and nurses) who work in LTC homes and family caregivers of residents who died in LTC. Participants were from Ontario and Alberta. Recruitment and interviews occurred from February 2021 to December 2022.

Post-positivism informed our underlying epistemological assumptions, which combine positivism and interpretivism. Post-positivism focuses on the experiences of the majority and asserts there is no universal truth and that multi-dimensional evidence can be inferred by perceived data (e.g., interviews).<sup>(16)</sup>

### Recruitment

We used a phased recruitment approach. The intention of Phase 1 was to retrospectively understand LTC practice before COVID-19 (e.g., residents who died before COVID-19). The intention of Phase 2 was to understand LTC practice during COVID-19 and the large variations in prescribing practices seen in the quantitative study. In both Phase 1 and 2, we also intended to evaluate the acceptability and applicability of the metric to assess the quality of residents' end-of-life care.

In Phase 1, we recruited participants from a single LTC home (February to March 2021). In Phase 2, we started by recruiting participants from homes with the highest and lowest prescribing rates as identified through our quantitative analyses (June to August 2021). However, due to low response rates, we expanded our recruitment to all Ontario LTC homes and to Alberta LTC homes where the research team had professional connections (August 2021 to November 2022). A further description of our recruitment strategy is in Appendix A.

### Data Collection

The core research team responsible for recruitment, data collection, and analysis consisted of an experienced qualitative researcher and the principal investigator of the study (S.R.I.), two research coordinators (C.M., R.L.R.), and a research associate (C.W.), who met weekly (core research team). A larger co-investigator team supported this core team (A.A., K.B., S.B., J.D., D.L., J.S.). The entire team met monthly to discuss study design, recruitment, analysis, and interpretation.

S.R.I., C.M. and R.L.R. conducted interviews using Zoom.<sup>(17)</sup> Interviewer details are included in Appendix B. S.R.I. provided training to the other interviewers on how to effectively conduct an interview. The interviewer obtained verbal consent from participants and administered a demographics survey.

The core researcher team collaborated to create the first iteration of the interview guides. Pilot interviews were

conducted with D.L. (caregiving experience) and K.B. (health-care provider experience), representing our two population subgroups. The development of the interview guides was iterative; we modified the guiding questions after each pilot and the first six interviews (which spanned Phases 1 and 2). Guiding questions were similar for our health-care providers, physicians and nurses, with some addressing potentially different roles and perspectives. Guiding questions for family caregivers were unique to the caregiving perspective. Interview guides were not provided to participants. The final interview guides are in Appendix C. Interviews were audio-recorded, transcribed verbatim, and de-identified. Interviewers made field notes following the interviews. Transcripts were not provided to interviewees for correction.

### Data Analysis

We analyzed transcripts using a coding reliability approach and thematic analysis.<sup>(18,19)</sup> All analysis stages were completed collectively by the core research team. S.R.I. trained C.M., C.W., and R.L.R. in effective coding and ensuring consistency across coders. First, the core team conducted close readings of transcripts to understand the interviews thoroughly. Second, the core team identified and arranged preliminary codes into a coding frame. The codebook evolved as new interviews were transcribed and read. Once no new codes were developed, the core team determined that thematic saturation had been reached.<sup>(20)</sup> They inserted the finalized codebook (Appendix D) into qualitative analysis software (MAXQDA),<sup>(21)</sup> along with the interview transcripts. The core team established reliability and accuracy of thematic coding through group and consensus coding. The core team group-coded three randomly chosen transcripts. The core team then separately coded a randomly selected transcript and merged the coded transcripts into one working document using MAXQDA. The core team then consensus-coded this merged transcript, discussed their coding rationale, and adjusted the coding frame to accommodate newly emerging patterns. The remaining ten 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 we developed from the data. The core team then refined, defined, and named our themes, and found exemplary quotations. Interviewees were not consulted on the feedback.

### 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 1, 2021, #20210207-01H).

## RESULTS

### Participant Characteristics

We interviewed 15 participants, 14 from Ontario and one from Alberta. We excluded the single Alberta transcript from our

analysis as the interview suggested differences in practice across provinces. We determined we could not fully capture those differences with only one interview. Of the Ontario transcripts, there were six physicians, five nurses, and three family caregivers from seven of Ontario's 626 LTC homes. Of the Ontarian participants, half (n=7, 50%) were female, and a third (n=5, 36%) were aged 60 to 69. Half (n=7, 50%) were from private not-for-profit LTC homes, and the majority (n=10, 71%) were from non-religious LTC homes. Of the health-care providers (n=11), the majority (n=9, 81%) had previous palliative care training (e.g., residency program or professional development courses) and were in a managerial or leadership role within their home (n=7, 64%). Participant demographics are in Table 1. The average interview length was 40 minutes (24 to 51 minutes).

### Themes

We identified three major themes relating to perceptions of the metric: 1) appropriateness, 2) healthcare provider applicability, and 3) caregiver applicability. Exemplary quotes for all themes are in Table 2.

#### *Appropriateness of the Metric*

Both types of participants, health-care providers and caregivers, commented that the metric might be appropriate to assess end-of-life care. Appropriateness is the perceived fit of the innovation to address a particular issue or problem.<sup>(22)</sup> Participants generally agreed that the metric was promising as a measure of end-of-life care in LTC, but noted nuances.

For many, they emphasized that the metric is necessary but not sufficient to assess end-of-life care. Participants flagged that some aspects of end-of-life care do not require medications (e.g., spiritual care and mouth, eye, and skin care). Participants felt that these types of care are as important at the end of life as medications and are not captured by the metric. Additionally, they noted that the metric only captures prescribed and not administered medications because the data were obtained from administrative health databases (i.e., via prescription claims data). Participants flagged instances when a medication was prescribed but not administered, even when the need was present (e.g., the resident died before the pharmacy filled the prescription). Additionally, they flagged instances where the resident had a medication prescribed, but it was not administered because it was no longer needed (e.g., a prescriber ordered an entire end-of-life order set in preparation for symptoms that did not materialize). The metric cannot differentiate between these two scenarios.

Participants also noted that the metric does not reflect whether the prescribed medication aligns with the resident's preferences and addresses the resident's symptom(s). Some caregivers shared that they preferred not to use medications until all other avenues had been exhausted. Caregivers also expressed their desire to balance their family member's comfort achieved via getting medications with the compromised levels of alertness that can result from certain medications. In each of these cases, knowing that a resident received a

prescription for a medication does not provide information on whether that medication aligned with the resident's or caregiver's preferences nor whether it sufficiently addressed the resident's symptoms.

TABLE 1.  
Caregiver and healthcare provider participants' sociodemographic characteristics and healthcare provider professional characteristics

		<i>n</i>	%
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%
	Healthcare provider (Physician)	6	43%
	Healthcare provider (Registered Nurse or Nurse Practitioner)	5	36%
<i>Affiliated long-term care home</i>			
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%
<i>Specific to healthcare providers (n=11)</i>			
Years in Healthcare	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 (e.g., residency program, professional development courses, etc.)	No	2	18%
	Yes	9	82%
Leadership or management role within the LTC home	No	4	36%
	Yes	7	64%
<i>Specific to family caregivers (n=3)</i>			
Previously lived with your family member	No	2	67%
	Yes	1	33%

### **Health-care Provider Applicability**

Applicability relates to the relevance and usefulness of applying the metric to assess end-of-life care.<sup>(23)</sup> Health-care providers thought they would use the metric at both the home and individual provider levels. At the LTC home level, health-care providers described using the metric at quarterly staff meetings to assess performance and gauge areas for improvement, similar to other LTC quality indicators. At the individual provider level, some health-care providers stated that they would compare their prescribing rates to the average and “high-performers” to learn how to improve their practice. In contrast, other health-care providers stated they would not use the metric as they perceived that they would be penalized if their prescribing rate for end-of-life medications was higher than the average. Importantly, health-care providers and caregivers thought the metric's goal should be to improve the services provided to LTC residents (e.g., use of the metric as an educational tool), rather than a tool to be used for punitive purposes.

Health-care providers stated that to use the metric, they would need a defined prescribing range or threshold that indicates “good” practice. However, none of the participants could ascertain or estimate the right range or threshold to indicate quality end-of-life care. Interviewees said that, while they use medications to manage residents' symptoms, they felt that a situation wherein 100% of LTC residents were prescribed an end-of-life symptom management medication before death would not be ideal. They shared instances where medication is not—and should not—be prescribed as some residents die suddenly, some do not experience symptoms which require medications, and in other circumstances, the medications do not align with the patient or caregivers' preferences.

### **Caregiver Applicability**

Family caregivers expressed that the metric does not reflect the residents' or caregivers' experience. For each caregiver, although their family member received an end-of-life symptom management medication, there were moments of great distress when medications were not started in a timely fashion or not given frequently enough, especially in the case of pro re nata (PRN) or “as needed” medications. As is, caregivers saw little value in using the metric as a tool to support decision-making in selecting an LTC home for their family member. Many other considerations (e.g., geography, friends' experiences, staff with palliative care training) were more important in their decision-making than this metric.

Caregivers and health-care providers advocated for other metrics that included caregivers' perspectives on residents' end-of-life experiences. Participants suggested ways to collect these experiences (e.g., exit surveys), the types of questions that should be included (e.g., Do you feel your family member was comfortable at the end-of-life), and other metrics (e.g., evaluating the process of shared decision-making between caregivers and the medical team). However, some participants acknowledged the challenges in scaling these strategies, including the logistic challenges in obtaining caregiver experiences across multiple institutions across the province.



**DISCUSSION**

**Main Findings**

In this study, we interviewed LTC health-care providers and caregivers of deceased LTC residents to determine the acceptability and applicability of an end-of-life prescribing metric. This study identified three themes for considering this metric’s potential use and ability to assess end-of-life care within LTC. First, the metric can identify some aspects of end-of-life care but is not an absolute measure. Second, the metric can be used by health-care providers or LTC homes to compare their practice to others, but it is necessary to define and establish an acceptable range or threshold. Finally, the metric does not

sufficiently reflect the caregiver’s experience, and caregivers offered suggestions for more meaningful metrics.

**Interpretation**

End-of-life care is complex and involves various types of care (e.g., spiritual, relational, mouth, eye, and skin care, medications) to address residents’ physical, psychological, social, spiritual, and practical needs. End-of-life care cannot be captured through a single global measure, but individual measures may reflect aspects of end-of-life care.

The proposed metric is only specific to whether a prescriber prescribes a subcutaneous end-of-life symptom management medication for a resident in the two weeks

TABLE 2 (part 1 of 2).  
Exemplary codes

<i>Theme</i>	<i>Sub-theme</i>	<i>Quote<sup>a</sup></i>
Appropriateness of the metric	Positive perception	2CG1: I think medications are a very critical indicator about the quality of the end-of-life experience for the patient. Interviewer 1: And why do you think that? Can you elaborate a little bit? Participant 2CG1: Because based on my experiences, the right medications can make that experience less stressful. And the quality of life is monumentally better. And with the wrong medications or not access to what you need, the end-of-life experience for my dad would have been horrific. So, the access to the right medications is critical. And it was critical to my dad’s last week of his life.
	Necessary but not sufficient	2HCP2: So, you look at medications, but mouth care, eye care, skin care, all those things are not specifically mentioned. You know, calling the volunteers, pastoral care, all those things are not specifically mentioned, which are equally important, right? It’s not all meds. [laughs]
	Medication does not mean appropriate care	Interviewer: Okay, you mentioned that it [indicator] could be helpful, but there would have to be a long list of questions after it. Do you mind describing what some of those questions would be? 1CG1: Well, I think you’d have to have questions to ask, why was the medication given? ... as I’ve said already, because medication per se is not necessarily the answer; it’s the appropriateness and adequacy of the medication interventions in dealing with the symptoms that the resident presents with is what’s critical.
Health-care provider applicability	Using the indicator within the home	2HCP4: I think it’s worthwhile providing the information to the home. Someone like the director of care, or the administrator, so it can be brought up at the medical staff meetings every three months. And just like we do this with a number of things. Like our opiate prescribing rates, benzo prescribing rates, various other stuff. And seeing this would be another quality indicator to add there, I think. And become a point of discussion.
	Using the indicator to inform health-care provider’s practice	If you knew about your home’s performance on the indicator, how might that influence your personal practice? 2HCP8: It would. As a physician, I would have a chance to be able to see how I compared to – if given access to it, they often will give an average or the high performer. It’ll give me a sense as to where I am with respect to “high performers.” It also gives me a chance to reflect on what my personal goal with that number is. Is it too high? Is it too low? And develop these ideas for how I would impact my practice or what areas I might want to learn more about. And then, from a medical director point of view, it would be most helpful to have access to – to be able to, again, as I mentioned before, we discovered when they were outliers within our home. And it’s allowed an opportunity to reduce variability and support excellence in prescribing.
	Difficult to identify the “correct” threshold for prescribing	How do you think this quality indicator should be reported or provided in feedback? Do you think there should be a certain level of reporting, so provincially, regionally, just at the facility level, or even just at the individual prescriber level? 2HCP11: I think that that’s really hard without an understanding of what the standard is. So, like, you can put a number out there, but what is the optimal and what are people reaching toward, right? Is it 100? Is it 90? Is it all the medications? Is it just one of the medications? So, I think it’s really hard to without further understanding of the context of it.

TABLE 2 (part 2 of 2).  
Exemplary codes

Theme	Sub-theme	Quote <sup>a</sup>
Caregiver applicability	Indicator does not reflect the entirety of the caregivers' experience	2CG1: And I think you'd want to link that [indicator] with how well did it meet the needs. Because if you look at my dad's chart, it's going to look like, oh, look at this person. He got everything he was supposed to. But you don't realize the trajectory that took us to get that and what hell. Yeah, so I think if you just look at what people got, you might not know the whole story. But I think it's important to know what they got.
	Informing how to choose a LTC home	Interviewer: That's fair. As a caregiver, would you have used this indicator to determine which home your father would go into, if you saw a home had a high prescribing rate for end-of-life symptom management medications versus a home that had a lower rate of prescribing? 1CG1: No, because a blunt measure like that wouldn't tell me anything about whether or not the prescribing was appropriate. I had a whole series of indicators that I was looking at when I chose the home that Dad would go into. And so, for instance, the fact that they had an end-of-life or a palliative care physician would be a big indicator. The funding model was absolutely critical to me in choosing the home; the kind of supports that they provided. But no, not necessarily that indicator.
	Need for Patient-centric metrics	1CG1: And so the first thing I would think you might do is have, you know, sort of satisfaction surveys, exit surveys from residents, you know, like a period of time - or not residents, but family members. But I realize the problem with that is that if the family member is going to transfer a lot of their own feelings about the end of life onto whatever satisfaction surveys they're going to give you. And that's not going to be a valid indicator either. So I think you're caught between a rock and a hard place, and I don't know how to advise you, because I would be very, you know, reluctant to use an indicator about how much medication was given at end of life without knowing why it was given or, you know, what you were trying to accomplish with that. But I don't know how you'd get any other kind of - I mean, I think that - I don't know how you'd do it other than through qualitative-type interviews and things like that. And yet that's impossible to do on a large scale - and to be able to have it done over multiple institutions and on a sector-wide basis.

<sup>a</sup>Note, participant codes correspond to the Phase of recruitment (Phase 1 or 2), the type of participant (CG – family caregiver or HCP – health-care provider), and the participant number based on sequential participation.

before their death. Using the Donabedian Framework<sup>(24)</sup> to categorize health-care indicators, resident health outcomes (e.g., pressure ulcers), processes within an LTC home (e.g., use of restraints), or the structure of LTC (e.g., staffing ratios; training), the proposed metric aligns with process indicators. Process indicators measure the program's activities and outputs (direct products/deliverables of the activities), and together they indicate whether the program is implemented as planned.<sup>(24,25)</sup> Before a prescriber prescribes an end-of-life medication, LTC staff must correctly identify that residents are approaching the end of life and identify end-of-life symptoms, be comfortable in managing (prescribing and administering) end-of-life symptoms, and communicate effectively with families (e.g., how to manage symptoms in a way that aligns with the goals of care). These issues of identification, management, and communication at the end-of-life have been highlighted in previous studies exploring optimal end-of-life care in LTC.<sup>(26-30)</sup> The proposed metric may be a proxy for this process (identification, management, and communication of end-of-life) and indicate whether LTC homes and prescribers have processes to manage a resident's end of life. We hypothesize that differences across these steps (e.g., identification, comfort, and communication) may contribute to differences in prescribing rates.

### Comparison to Existing Indicators

Nationally, Canada uses 14 LTC quality indicators.<sup>(31,32)</sup> Like these LTC quality indicators, our metric also uses administrative data, which reduces the operational burden on LTC staff to collect data. However, with the proposed metric and other indicators, it is difficult to capture resident-centred care only using only administrative data. Resident-centred care is respectful of, and responsive to, individual resident preferences, needs, and values, and ensures that resident values guide all clinical decisions.<sup>(21)</sup> Unfortunately, resident and caregiver values are collected through multiple avenues (e.g., a one-off clinical note or home-specific goals of care form either attached to a physical chart or integrated with the electronic medical record), if collected at all, making this information difficult to access on a systematic scale.<sup>(33)</sup> Like other quality indicators, LTC homes or prescribers could also use the metric to understand how their practice compares to others. However, before they can use the metric, we recommend defining a range or threshold of appropriate prescribing. Without such a range or threshold, the metric may be inconsistently interpreted. As reflected through the interviews, some health-care providers perceived high prescribing rates as the goal, albeit recognizing that the ideal prescribing rate is not 100%. Other providers thought they would be penalized if their prescribing rates were

higher than average. We hypothesize that those who thought they would be penalized for high prescribing interpreted the metric similarly to commonly used metrics, such as measures of potentially inappropriate prescribing of antipsychotics in LTC, where a lower prescribing rate is the goal. Additionally, we recommend that decision-makers determine how they might want the indicator to be used, which can help guide determining a range or threshold.

Compared to existing indicators, this metric is specific to end-of-life (measured medication use during the last two weeks of life). Dying residents can experience symptoms that are distressing to them and their families. Therefore, comfort care (including medications to address these symptoms) is important to quality end-of-life care. In the preliminary quantitative study evaluating the metric, there was a two-fold difference in prescribing rates across Ontario's LTC homes, indicating a large range in prescribing practice across Ontario.

### Future Directions

There is an appetite to strengthen the delivery and evidence of palliative care in Canada. In 2017, the Government of Canada passed the *Framework on Palliative Care in Canada Act* (Bill C-277).<sup>(34)</sup> In its accompanying report, one of the five strategic objectives is to support health system quality improvement through enhanced data collection and research. Additionally, reports reflecting on the impact of the COVID-19 pandemic on LTC homes emphasize the need for end-of-life palliative care.<sup>(35)</sup> The proposed metric could be one way to measure and potentially improve end-of-life palliative care in LTC.

However, we would need to refine the metric further before it could be used across provinces. First, to further understand the appropriateness of the metric, we propose partnering with LTC homes to review medication charts to understand how often prescribed medications are administered. In such a partnership, we could also review advance care plans or goals of care forms to understand if the prescribed medications align with resident and caregiver preferences. Second, we must define a range or threshold to mark a “good” care standard. We would need to partner with LTC homes and staff to help define this standard.

Additional work is required to support the implementation of the refined metric. First, additional metrics should be developed and packaged together to create a more comprehensive assessment of end-of-life care. Most importantly, resources to support LTC staff, residents, and caregivers are required for LTC homes to have the opportunity, capability, and motivation to provide quality end-of-life care, including (but not exhaustive) how to identify an individual approaching end-of-life, and managing symptoms with medications appropriately.

Finally, future development of indicators needs to include the resident and caregiver perspective. Although there has been a consensus to involve individuals and their caregivers in indicator development, in practice, very few do.<sup>(36)</sup> One systematic review that assessed quality indicator development, regardless of sector, found limited indicators (n=11) included

individuals or their caregivers.<sup>(36)</sup> Residents and caregivers (e.g., the resident is comfortable during the dying process) must select topics for future indicators. Specifically for end-of-life, residents and caregivers have reported that they most value quality communication with health-care providers (i.e., frequent, accessible, timely, clear, comprehensive, consistent, compassionate, and realistic) and shared decision-making about care decisions.<sup>(29,30)</sup> Individuals and caregivers are also guiding researchers in understanding the utility of indicators. This study evaluated the utility of this metric from a caregiver perspective—a novel approach in the existing literature.

### Limitations

Our study's findings may have limited transferability to other jurisdictions due to Ontario's organization, structure, and culture within LTC homes. Further, data collection occurred during the COVID-19 pandemic, when there was extensive strain on the LTC sector in Ontario and other areas. Our team had difficulty with data collection and had to expand our collection timeframe and sampling strategy to maximize the number of potential participants. It is possible that the few who agreed to participate were less affected by the pandemic (i.e., were from LTC homes with few to no outbreaks), and thus had more availability for, and interest in, participating. We cannot ascertain how the pandemic and its associated challenges may have influenced participants' responses. Finally, of the health-care provider participants, the majority had previous palliative care training and a leadership position within their LTC home. These health-care provider participants may have different views on end-of-life prescribing and the potential use of the metric than other staff within the home.

### CONCLUSIONS

In this study, we interviewed LTC health-care providers and caregivers of deceased LTC residents to determine the acceptability and applicability of the refinement of the end-of-life prescribing metric. The proposed metric captures a small aspect of end-of-life palliative care—whether end-of-life medications are prescribed. Participants deemed that the metric reflects whether LTC homes have processes to manage a resident's end-of-life symptoms with medication. However, participants thought the metric could not provide a complete picture of end-of-life care and its quality.

### ACKNOWLEDGEMENTS

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

### CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal's* policy on conflicts of interest disclosure and declare there are none. Three of the authors of this paper had prior professional or personal relationships with four participants.

To mitigate bias, interviewers did not interview participants with whom they had relationships. Additionally, nine authors helped develop the indicator. The indicator was used in the quantitative phase of the overarching research program.

## FUNDING

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. PT is supported by PSI Graham Farquharson Knowledge Translation Fellowship. SHB 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.

## REFERENCES

- World Health Organization. Palliative care [internet]. Geneva: World Health Organization; 2020. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.
- Health Standards Organization. Long-term care services. Ottawa: Health Standards Organization; 2023. Contract No.: ICS Code: 11.020.10.
- Ernecoff NC, Zimmerman S, Mitchell SL, Song MK, Lin FC, Wessell KL, *et al*. Concordance between goals of care and treatment decisions for persons with dementia. *J Palliat Med*. 2018 Oct 1;21(10):1442–47.
- Teno JM, Claridge BR, Casey V, Welch LC, Wetle T, Shield R, *et al*. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004 Jan 7;291(1):88–93.
- Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, *et al*. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ*. 2006 Feb 28;174(5):627–33.
- Canadian Institute for Health Information. Long-Term Care Beds in Canada—Data Table. Ottawa: CIHI; 2021.
- Tanuseputro P, Chalifoux M, Bennett C, Gruneir A, Bronskill SE, Walker P, *et al*. Hospitalization and mortality rates in long-term care facilities: does for-profit status matter? *J Am Med Dir Assoc*. 2015 Oct 1;16(10):874–83.
- Tanuseputro P, Roberts RL, Milani C, Webber C, Clarke A, Isenberg S, *et al*. Palliative end-of-life medication prescribing rates in long-term care: a retrospective cohort study. *JAMDA Forecoming* 2024.
- Wilkinson A, Haroun V, Wong T, Cooper N, Chignell M. Overall quality performance of long-term care homes in Ontario. *Healthc Q*. 2019 Jul 1;22(2):55–62.
- Poldrugovac M, Amuah JE, Wei-Randall H, Sidhom P, Morris K, Allin S, *et al*. public reporting of performance indicators in long-term care in Canada: Does it make a difference? *Can J Aging*. 2022 Dec;41(4):565–76.
- Ivers NM, Taljaard M, Giannakeas V, Reis C, Williams E, Bronskill S. Public reporting of antipsychotic prescribing in nursing homes: population-based interrupted time series analyses. *BMJ Qual Saf*. 2019 Feb 1;28(2):121–31.
- 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 Feb 1; 55(2):508–21.
- Registered Nurses' Association of Ontario. End-of-life care during the last days and hours. Toronto, ON: RNAO; 2011.
- Fraser Health Authority. Hospice palliative care symptom guidelines [internet] British Columbia: Fraser Health Authority; n.d. Available from: <https://www.fraserhealth.ca/employees/clinical-resources/hospice-palliative-care#.ZB3dG3bMK5d>
- Lindqvist O, Lundquist G, Dickman A, Bükki J, Lunder U, Hagelin CL, *et al*. Four essential drugs needed for quality care of the dying: a Delphi-study based international expert consensus opinion. *J Palliat Med*. 2013 Jan 1;16(1):38–43.
- Panhwar A, Ansari S, Shah A. Post-positivism: an effective paradigm for social and educational research. *Int Res J Arts Human*. 2017;45(45):253–59.
- Zoom Video Communications Inc. Zoom meetings & chat. California, USA: Zoom Video Communications Inc; 2022. <https://www.zoom.com/en/products/virtual-meetings/>
- Boyatzis R. Transforming qualitative information: thematic analysis and code development. Thousand Oaks, CA: Sage Publications; 1998.
- Guest G, MacQueen K, Namey E. Applied Thematic Analysis [eBook]. Thousand Oaks, CA: SAGE Publications, Inc.; 2012. Available from: <https://methods.sagepub.com/book/applied-thematic-analysis>
- Creswell J, Poth C. Qualitative inquiry and research design: choosing among five approaches. Thousand Oaks, CA: Sage Publications; 2016.
- VERBI Software. MAXQDA. Berlin, Germany: VERBI Software; 2022.
- Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, *et al*. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. *Admin Policy Ment Health*. 2011 Mar;38(2):65–76.
- Dictionary.com. Definition: Applicability [internet]. Available from: <https://www.dictionary.com/browse/applicability>
- Donabedian A. An introduction to quality assurance in health care. Oxford, UK: Oxford University Press; 2002.
- Canadian Medical Association. CMA, in collaboration with Scotiabank and MD Financial Management, launch new Wellness Support Line to help Canadian physicians and medical learners [press release]. June 15, 2020. CMA website, 2020. Available from: <https://www.cma.ca/about-us/what-we-do/press-room/cma-collaboration-scotiabank-and-md-financial-management-launch-new-wellness-support-line-help#:~:text=June%2015%2C%202020-,CMA%2C%20in%20collaboration%20with%20Scotiabank%20and%20MD%20Financial%20Management%2C%20launch,a%20new%20Wellness%20Support%20Line>
- Cable-Williams B, Wilson D. Awareness of impending death for residents of long-term care facilities. *Int J Older People Nurs*. 2014 Jun;9(2):169–79.
- Harasym P, Brisbin S, Afzaal M, Sinnarajah A, Venturato L, Quail P, *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 Aug 1;10(8):e037466.



28. Carlini J, Bahudin D, Michaleff ZA, Plunkett E, Shé É, Clark J, *et al.* Discordance and concordance on perception of quality care at end of life between older patients, caregivers and clinicians: a scoping review. *Eur Geriatr Med.* 2022 Feb;13(1):87–99.
29. Motamedi M, Brandenburg C, Bakhit M, Michaleff ZA, Albarqouni L, Clark J, *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 Dec; 21(1):729.
30. Lee E, Sussman T, Kaasalainen S, Durepos P, McCleary L, Wickson-Griffiths A, *et al.* The relationship between caregivers' perceptions of end-of-life care in long-term care and a good resident death. *Palliat Support Care.* 2020 Dec;18(6):683–90.
31. Canadian Institute of Health Information. Your Health System [internet] Ottawa, ON: CIHI; 2023 [Available from: [https://yourhealthsystem.cihi.ca/hsp/indepth?lang=en&\\_ga=2.259284042.1390645241.1584620109-180361114.1584620109#/](https://yourhealthsystem.cihi.ca/hsp/indepth?lang=en&_ga=2.259284042.1390645241.1584620109-180361114.1584620109#/)]
32. Health Quality Ontario. Long-term care home performance in Ontario [internet] Toronto, ON: Health Quality Ontario; 2023 [Available from: <https://www.hqontario.ca/System-Performance/Long-Term-Care-Home-Performance>]
33. Seow H, Snyder CF, Mularski RA, Shugarman LR, Kutner JS, Lorenz KA, *et al.* A framework for assessing quality indicators for cancer care at the end of life. *J Pain Symptom Manage.* 2009 Dec 1;38(6):903–12.
34. Health Canada. *Framework on Palliative Care in Canada Act, 2019.* S.C.2017,c.28. <https://laws-lois.justice.gc.ca/PDF/F-31.5.pdf>
35. Rochon PA, Li JM, Johnstone J, Brown KA, Armstrong P, Tanuseputro P, *et al.* The COVID-19 pandemic's impact on long-term care homes: five lessons learned [internet]. Ottawa: Ontario COVID-19 Science Advisory Table; 2022.
36. Kötter T, Schaefer FA, Scherer M, Blozik E. Involving patients in quality indicator development—a systematic review. *Patient Prefer Adher.* 2013;7:259–68.

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**APPENDIX A. Recruitment of participants**

<i>Time Frame</i>	<i>Description</i>	<i>Contacted</i>	<i>Response</i>	<i>Completed Interviews</i>
<i>Phase 1</i>				
Feb – Mar 2021	We worked with the Director of Care at our Phase 1 site. The Director of Care shared our recruitment poster with healthcare 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
<i>Phase 2</i>				
<i>Strategy: Comparing homes in the top and bottom quintile of end-of-life prescribing, as determined by our quantitative research.</i>				
Jun 2021	Contacted the Directors of Care in four homes (two from the top quintile and two from the bottom quintile)	4 LTC	1 LTC declined 3 LTC no response	0
Jul 2021	Contacted the Directors of Care in sixteen additional homes (eight from the top quintile and eight from the bottom quintile)	16 LTC	3 LTC declined 13 LTC no response	0
Aug 2021	Contacted the Directors of Care in twenty additional homes (eight from the top quintile and eight 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 healthcare providers 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
June 2022	Posted to social media (Twitter and LinkedIn).	n/a	No eligible participants	0
<i>Ended recruitment</i>				

HCP = health-care provider includes physicians and nurses; CG = family caregiver; LTC = long-term care home.

**APPENDIX B. Research team**

The following three individuals conducted the interviews<sup>a</sup>. Their characteristics reflect those at the time of the interviews.

<i>Name</i>	<i>Credentials</i>	<i>Position</i>	<i>Gender</i>	<i>Previous experience</i>
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.	Female	Dr. Isenberg has a PhD in Social and Behavioural Sciences from the Johns Hopkins Bloomberg School of Public Health, a Masters 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.
Rhiannon L. Roberts <sup>b</sup>	MScPH	Research Coordinator at the Ottawa Hospital Research Institute	Female	Rhiannon had no previous experience with qualitative work. She was trained by Dr. Isenberg.
Christina Milani <sup>c</sup>	MSc	Research Coordinator at the Bruyère Research Institute	Female	Christina had no previous experience with qualitative work. She was trained by Dr. Isenberg.

<sup>a</sup>In the interview, interviewer shared minimal details about the study—all are reflected in the interview guide in Appendix C. In two interviews, core team member CW observed the interview but did not participate.

<sup>b</sup>RRL 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.

<sup>c</sup>CM contacted all individuals who expressed an interest participating in the study through email. She provided all interested individual with a consent form and arranged interview times.

## APPENDIX C. Interview guide

### Healthcare 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 healthcare providers, and that LTC has been particularly hard hit. We want to get a better understanding of how EOL care is provided in your home, and how it changed during the pandemic

We appreciate that there are many components of end-of-life care. However, we are specifically looking at medications given at the end-of-life 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 end of life?
  - Prompt: Resident factors (e.g., resident or family member preferences)
  - Prompt: Provider factors (e.g., familiarity with meds)
  - Prompt: Home factors (e.g., 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 end-of-life medications for?
  - Pain
  - Shortness of breath
  - Delirium
  - Nausea
  - Terminal secretion
  - Anxiety
  - Agitation
8. Do you ever use palliative care or end-of-life order sets (or symptom management kit (SMK))?
  - How do you use these order sets?

9. For what proportion of residents do you prescribe the following types of medications in the last two 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 end-of-life care medications?
  - If no, what barriers prevent residents from receiving their end-of-life 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 two 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 (e.g., opioids)
  - Routes of delivery (i.e., 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 end-of-life 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 end-of-life 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 end-of-life 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 end of life symptom management medications, compared to pre-pandemic times?



**[For RNs and RPNs]**

9. Can you tell a bit about your experience with medication administration for EOL symptom management?
10. Do you have expertise or training in palliative care? What?
11. 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?
12. What symptoms do residents typically receive end-of-life medications for?
  - Pain
  - Shortness of breath
  - Delirium
  - Nausea
  - Terminal secretion
  - Anxiety
  - Agitation
13. Are palliative care or end-of-life order sets (or symptom management kits (SMK)) used the home? How do you use these order sets?
14. For what proportion of residents do you prescribe the following types of medications in the last two weeks of life? Potential answer options: less than 25%, 25%-50%, 50%-75%, more than 75%?
  - Opioids
  - Other analgesics
  - Benzodiazepines
  - Antipsychotics
  - Sedatives
15. Are residents typically administered their prescribed medications?
  - If yes, what helps a resident receive their end-of-life care medications?
  - If no, what barriers prevent residents from receiving their end-of-life care medications? Are these barriers related to challenges with administering or with resident's acceptance of the medication?
16. The following questions pertain to symptom management medications prescribed during the last two 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 (e.g., opioids)
  - Routes of delivery (i.e., oral, subcutaneous, injectable, infusion pump)
17. Reflecting on the past few questions concerning your comfort with types of medications, do you think your colleagues share your views or differ?
18. How has the provision of symptom-management medications at the end-of-life 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 end-of-life symptom management medications? Where their communication or coordination issues?
  - Prompt: What strategies did your team take in response to these changes?
19. How did your home's practices regarding end-of-life prescribing change during the early phases of the pandemic from March 2020-September 2020?
  - How has this change from October 2020-now?
20. What proportion of COVID-positive residents were prescribed end-of-life 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?
21. During the pandemic, was there a difference in the frequency that COVID-negative residents received end of life symptom management medications, compared to 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 long-term care home residents without psychosis that are on antipsychotic medications. Long-term care homes with a high percentage of nonpsychotic residents on antipsychotic medications compared to 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 that had their surgery within a provincial target time. The fewer individuals that had their surgery in the targeted time, less timely care provided.]
- [For example, Alberta uses a quality indicator that measures the percentage of residents that had falls in the last 30 days within a long-term care 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 that 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 end-of-life care provided at long-term care homes. The new quality indicator could help identify homes that need additional support for end-of-life care.

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

22. Do you have experience using quality indicators within your home? Please explain/provide an example?
23. To what extent do you agree or disagree that measuring the percentage of residents in their last two weeks of life that are prescribed symptom management medications can be used to assess the quality of end-of-life care within a home?
24. What are the potential benefits in knowing at a home-level the percentage of residents in their last two weeks of life that are prescribed symptom management medications?
25. What are the potential limitations or concerns in knowing at a home-level the percentage of residents in their last two weeks of life that are prescribed symptom management medications?
  - a. How much have you encountered end-of-life medications being prescribed but not administered?
  - b. Have you ever encountered a situation where these medications were prescribed but other end-of-life care services were not received? What did this look like?
  - c. Can residents generally receive good quality end-of-life care services but not be prescribed end-of-life medications? What did this look like?
26. How do you think this quality indicator should be reported or provided in feedback? Which level should it be reported at provincial, regional (i.e., sub-LHIN), facility, or physician level?
27. If you knew about your home's performance on the indicator, how might that influence your practice?
28. Our initial data shows large variations in prescribing rates for end-of-life symptom management medications across homes. What do you think might explain this large range in practice?
29. What other indicators of quality end of life 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

30. 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 end-of-life care means to you? (i.e. participants own definition of end-of-life care)

Below are some definitions of end-of-life care:

- Ontario Palliative Care Network defines end-of-life 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 end-of-life care but also can be delivered earlier in the disease trajectory

### Section: Receiving end-of-life care

4. What end-of-life care services did your [relationship: family member or friend] receive in the last two 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 end-of-life care services received in their last two 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 end-of-life did your [relationship: family member or friend] have? (Obj 2)

**Section: Medications**

There are many aspects to good end of life care. However, we are specifically looking at medications given at the end-of-life 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 two 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 EOL?
10. What factors made it easier or would have made it easier for your [insert relationship with the resident] to receive end-of-life medications? (e.g., 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 end-of-life medications? (e.g., administration of medications, patient refusal to receive medications)
12. Was end-of-life 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] end of life 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 that had their surgery within a provincial target time. The fewer individuals that had their surgery in the targeted time, less timely the care provided.]
- [For example, Alberta uses a quality indicator that measures the percentage of residents that had falls in the last 39 days within a long-term care 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 that 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 long-term care homes that may need support delivering palliative care and end-of-life care. One measure we are exploring is the percentage of residents that are prescribed medicines to help manage symptoms during their last two 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, this data is 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 (e.g., morphine/hydromorphone) is a good indicator to capture how well a LTC home is providing end of life 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 end-of-life prescribing was available, would you factor this indicator into your decision about which LTC home to choose?
19. What other end-of-life 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?

**APPENDIX D. Codebook**

<i>Category</i>	<i>Parent Code</i>	<i>Child Code</i>	<i>Description</i>
Medications	Alignment of medications with goals of care at end of life	Medication administration aligns with a caregivers' or residents' goals or values	Discussion around prescribing/delivery of EOL medications aligning with the caregiver's or residents' goals or values
Medications	Appropriateness of medication	Deprescribing medication	Discussion around deprescribing of medications
Medications	Appropriateness of medication	Medication addressing the residents' symptoms	Discussion around a medication resolving or alleviating or not alleviating the resident's symptoms, including adequate dosage. Including description of which symptoms are being addressed by medication.
Medications	Appropriateness of medication	Previous medications informing new prescribing	Description of what medications patient was previously on and how they were considered in prescribing decision-making
Medications	Availability of medication		Discussion of a LTC home having emergency medication kits or afterhour access (e.g., overnight or weekends) or on-site pharmacy
Medications	Caregiver advocacy around medications		Discussions around how the caregiver advocated for their loved one to receive EOL medications.
Medications	Caregiver and health care worker communication and decision-making about medications	Discussions about medications	Conversations about meds administered/prescribed e.g., do you want medications for your family member, what medications
Medications	Comfort with medication prescribing/administration	Caregiver perspective of health care provider comfort	Discussions around the interviewee's (caregiver) perspective of health care providers' (HCP) comfort in prescribing/administering medications (across medication classes and routes of administration).
Medications	Comfort with medication prescribing/administration	Others (Health Care Provider Colleagues)	Discussion around the interviewee's perception of health care providers' (HCP) comfort in prescribing/administering medications (across medication classes and routes of administration). Code also includes discussion around characteristics of a HCP that affect their comfort levels of prescribing/administering medications. Codes can include HCP perception of other HCP or caregiver perception of HCP.
Medications	Comfort with medication prescribing/administration	Self (Health Care Provider)	Comfort level and prescriber characteristics that impact their comfort prescribing EOL medications
COVID	COVID	Caregiver visitation restrictions	Discussions around how COVID protocols impacted family visitations (e.g., lack of family visits led to less monitoring and advocacy of the resident).
COVID	COVID	Staffing shortages	Discussions around staffing issues during COVID (e.g., staffing shortages, use of agency nurses, nurses with limited LTC experience)
COVID	COVID	Practice changes	Discussions around how health provider or facility practices changed occurred during COVID-19.
COVID	COVID	Medication shortages	Discussions around medication shortages or supply issues during the COVID-19 pandemic.



**APPENDIX D. Codebook (continued)**

<i>Category</i>	<i>Parent Code</i>	<i>Child Code</i>	<i>Description</i>
Communication	Dynamic - Physician-nurse	Nurse's perspective	Discussion around a nurse's interaction/ communication with physicians concerning medications – e.g., approaching physicians to modify medication dosages, flagging the initiation of medications, etc.
Communication	Dynamic - Physician-nurse	Physician's perspective	Discussion around a physician's interaction/ communication with nurses concerning medications – e.g., frequency they're approached to modify or initiate medications, perspective of nurse's comfort administering medications,
Medications	End-of-life medications	Antipsychotics	
Medications	End-of-life medications	Anxiety medications	
Medications	End-of-life medications	Benzodiazepines	
Medications	End-of-life medications	Nausea	
Medications	End-of-life medications	Non-opioid analgesics	
Medications	End-of-life medications	Opioids	
Medications	End-of-life medications	Respiratory secretions medications	
Medications	End-of-life medications	Sedatives	
Medications	End-of-life order sets		Discussion of a LTC home having end-of-life order sets (even if the LTC home does not use the order set)
Indicator	Indicator	Caregiver use (Applicability)	Discussion around using the indicator to decide which LTC home a caregiver would send a loved one
Indicator	Indicator	Criticism or skepticism (Acceptability)	Discussion around criticism or skepticism of the indicator – its use, purpose, what the indicator cannot capture, etc.
Indicator	Indicator	Difference in prescribing rates across LTC homes	Discussions around differences in home prescribing rates, including speculation of why these differences exist
Indicator	Indicator	Health care provider use (Applicability)	Discussion around using the indicator to inform their practice of prescription or administration of EOL medications
Indicator	Indicator	Inaccurate interpretation/ Interpretation of indicator to identify individuals	Whether the individual perceives the indicator is an indicator at the individual-level e.g., an indicator that can be used to identify individuals at the end of life
Indicator	Indicator	Praise or positive perception (Acceptability)	Discussion around the acceptance of the indicator – its use, purpose, what the indicator can capture, etc.
Indicator	Indicator	Suggestions	Suggestions regarding other potential indicators to use to capture receipt of EOL/PC care, how to use the indicator
Indicator	Indicator	Reporting	Discussions around reporting of the indicator (e.g., level of reporting, how it should be reported, nuances to reporting)

**APPENDIX D. Codebook (continued)**

<i>Category</i>	<i>Parent Code</i>	<i>Child Code</i>	<i>Description</i>
PC	Palliative care involvement with meds	Resources	Discussion around receipt of care related to EOL medications from a physician or nurse who specializes in palliative care. OR resources (e.g., community support) enables prescribing or administering EOL medications--resources can be internal or external to the home.
PC	Palliative care involvement with meds	Training	Discussion around how palliative care training
CoC	Relational continuity of care	Clinicians	Discussions around the physicians that care for a resident (e.g., whether they know the resident, practice in the home regularly)
Medications	Characteristics impacting administering meds	HCP	Discussion around a HCP's behaviour that may impact administering medications
Medications	Characteristics impacting administering meds	Resident	Discussion around a resident's behaviour that may impact administering medications – agitation, combative behaviour, restlessness, doing better
Medications	Timeliness of medication administration	PRN	Discussions around PRNs (e.g., staff recognizing the need for a medication or not)
Medications	Timeliness of medication administration	Timeliness of initiation	Discussion around starting EOL medications for a resident often in relation to whether the symptoms were addressed on time OR description of symptoms that lead to initiation of prescriptions
Medications	Timeliness of medication administration	Timeliness of scheduled dosages	Discussions around the timing of prescribing or administering medications after initiation