

BMJ Open 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

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ABSTRACT

Objective The COVID-19 pandemic has highlighted ongoing challenges to optimal supportive end-of-life care for adults living in long-term care (LTC) facilities. A supportive end-of-life care approach emphasises family involvement, optimal symptom control, multidisciplinary team collaboration and death and bereavement support services for residents and families. Community-based and palliative care specialist physicians who visit residents in LTC facilities play an important role in supportive end-of-life care. Yet, perspectives, experiences and perceptions of these physicians remain unknown. The objective of this study was to explore barriers and facilitators to optimal supportive end-of-life palliative care in LTC through the experiences and perceptions of community-based and palliative specialist physicians who visit LTC facilities.

Design Qualitative study using semi-structured interviews, basic qualitative description and directed content analysis using the COM-B (capability, opportunity, motivation - behaviour) theoretical framework.

Setting Residential long-term care.

Participants 23 physicians who visit LTC facilities from across Alberta, Canada, including both in urban and rural settings of whom 18 were community-based physicians and 5 were specialist palliative care physicians.

Results Motivation barriers include families' lack of frailty knowledge, unrealistic expectations and emotional reactions to grief and uncertainty. Capability barriers include lack of symptom assessment tools, as well as palliative care knowledge, training and mentorship. Physical and social design barriers include lack of dedicated spaces for death and bereavement, inadequate staff, and mental health and spiritual services of insufficient scope for the population.

Conclusion Findings reveal that validating families' concerns, having appropriate symptom assessment tools, providing mentorship in palliative care and adapting the physical and social environment to support dying and grieving with dignity facilitates supportive, end-of-life care within LTC.

Strengths and limitations of this study

- This study reports the supportive end-of-life care observations and experiences of 18 community-based and 5 specialist palliative care physicians who visit long-term care facilities.
- Individual qualitative interpretive descriptive responses reveal how knowledge, skill and environments shape the motivations and capabilities of individuals, as well as the opportunities for improvement.
- This study did not include a comparison between urban and rural settings.
- This study did not involve first-hand observations or recordings of supportive, end-of-life care within long-term care.
- Though not directly involved in this study, residents, allied care providers and families were involved indirectly through prior research conducted and published by members of the research team.

INTRODUCTION

The number of older people is increasing in Canada and around the world.^{1–5} Frailty is a life-limiting condition associated with increased mortality and comorbidity, high levels of physical, emotional and social disability, and an unpredictable illness trajectory.^{6–8} Though unpredictable in presentation and progression, frailty is a predictable cause of death.^{6,9,10} As the numbers of older adults with frailty increase, there will be an increased need for long-term care (LTC) facilities,^{11,12} staffed by individuals with end-of-life care knowledge and skill who are provided with needed infrastructure.¹⁰ In 2000, it was predicted that 39% per cent of Canadians

living in LTC would die in LTC by 2035.¹ In 2004, 20% of deaths were in LTC facilities in one Canadian province,¹³ and 27% by 2015 in another.¹⁴ In the USA, UK and the Netherlands about 25% of older people die in LTC facilities and about 20% internationally.¹⁵ Managers, regulators, clinicians and educators around the world face the challenge of implementing supportive end-of-life care principles, clinical practices and education within LTC facilities.^{10 16} The COVID-19 pandemic has acutely highlighted the need for high quality supportive end-of-life care in LTC, both from an individual resident/family and societal perspective.

Supportive end-of-life care is typically targeted towards people in decline and deemed terminal in the near future.¹⁷ In a collaborative model, supportive end-of-life care provides these individuals and their families access to supportive services throughout the disease trajectory to death.⁹ Support includes informational, physical, psychological and spiritual services.¹⁷ A palliative approach additionally emphasises optimal symptom control and the importance of family and friend involvement in the life of the dying person.¹⁷ A palliative approach for older adults with frailty in LTC facilities is an emerging, yet underdeveloped practice in LTC facilities^{18 19} in Canada,²⁰ the UK^{4 5 21} and around the world.^{22–25} Optimal supportive end-of-life care in LTC facilities should be individualised and collaborative. It should include community-based support services, a focus on optimal symptom control, and involve family and friends in the life of the dying person.

Previous work from members within our research team and others has identified barriers to optimal supportive end-of-life care in LTC facilities from the perspectives of front-line staff, nurses, residents and families.^{21 24 26 27} Physician perspectives remain largely unexplored. This study aimed to identify barriers and facilitators to optimal supportive end-of-life palliative care for adults with frailty from the perspective of community-based and palliative specialist physicians who visit LTC facilities.

METHODOLOGY

Design

We used semi-structured interviews, basic qualitative description²⁸ and deductive content analysis²⁹ to determine barriers and facilitators to providing supportive end-of-life care from the perspective of physicians working in LTC. Basic qualitative description has as its goal a comprehensive summary of events in terms of participants experiences and perceptions.²⁸ Michie's COM-B (capability, opportunity, motivation - behaviour) theoretical framework was used to determine the higher level categories, and inductive analysis was conducted to identify particular themes.³⁰ The Michie framework is a behaviour system comprised of three categories: Motivations, Capabilities and Opportunities. Motivations include the thoughts, feeling, beliefs and attitudes that energise and direct behaviour. Capacities include the tools,

knowledge and skills required to perform a behaviour. Opportunities include aspects of the physical and social environments that constrain or support possibilities for the desired behaviour.³⁰

Analysis

The specific coding scheme was based on the motivation, capacity and opportunity factors that participants perceived as barriers to optimal supportive end-of-life care. NVivo³¹ software was used by PH to organise and store the emergent findings. PH, JH-L and SB reached consensus on the initial findings. To ensure ecological validity, emergent codes and exemplars were checked, adapted and themes developed iteratively through feedback provided by all members of the research team.²⁹ Ecological validity is the assurance that all members of a social community share the same meanings.²⁹ Given the belief that participants' projected meanings inevitably change with context, transcripts were not shared with participants for comment.²⁹ Preliminary findings were, however, checked with participants by circulating a preliminary analysis and inviting feedback. Team members (11) included physicians, experts and researchers working in LTC (PH, MA, PQ and NV), geriatrics (JH-L, SES and SB), gerontology (LV, TS and SK) and palliative care (AS). Queries in interpretation were checked throughout, against the data and coding scheme, to ensure consistency. Analysis ceased when no new information emerged from the interviews (data saturation). The Consolidated criteria for Reporting Qualitative research (COREQ) was used as the reporting framework.³²

Sample

We purposively sampled all physicians working in LTC in urban, rural or both urban and rural settings across Alberta, and in all five provincial health zones (North, Edmonton, Central, Calgary and South). Potential participants were made aware of the study and invited to participate through an email distributed by health-care leaders within each health zone. We included all consenting and eligible respondents. The consent form, approved by the University of Calgary's Conjoint Health Research Ethics Board (CHREB), was sent to participants prior to the interview. Participants were advised that they could withdraw from the study at any time. No one did. In Canada the overwhelming majority of physicians who see patients in nursing homes/LTC centres participate in other clinical activities (eg, community clinics and/or hospitals). Only 0.7% of family physicians in Alberta and Canada identified their primary site of practice as exclusively LTC³³ (National Physician Survey 2014). There is no specialist training for the practice of LTC medicine in Canada, and care is delivered in a collaborative team setting with periodic physician visits. Every LTC facility has a Medical Director, available to the site for direct patient care, overseeing ongoing medical care, development of clinical policy and quality improvement activities.³⁴

The interview guide (online supplementary appendix A) included both broad questions and probing questions. Interview questions aimed to identify interviewees' perceptions of supportive end-of-life care in LTC, including perceived challenges related to frailty diagnosis, assessment, care management and of relationships between physicians, staff and family members. Though the guide was not pilot tested, questions were rephrased for clarity and understanding during the interview interactions.

PH, an experienced interviewer, conducted the interviews over the telephone in a private office. The interviews were conducted between 12 October 2018 and 28 November 2018. The duration of interviews was 18 to 80 min. A relationship with participants was developed during the interviews, not before. There were no repeat interviews. Interviews were digitally audio-recorded, anonymised, transcribed by professional transcribers and stored on a password and finger-print protected laptop computer during data collection. Transcriptionists signed a confidentiality agreement. Fieldnotes were made during and after the interviews. On realising that the audio-recorder had failed in one case, PH made and used extensive fieldnotes recorded during and immediately following the interview. On completion of the study, all audio files, fieldnotes and transcripts were transferred to a password protected, secure drive behind a firewall. The digital recorder was erased. Recruitment and data collection ceased with data saturation.

Patient and public involvement

Though not directly involved in this research study, LTC residents and families were involved in prior research conducted by members of the research team. Families of LTC residents also participated in further research that built on the findings of this study.

RESULTS

In total 23 physicians were interviewed, including 18 community-based and 5 specialist palliative care physicians who visit LTC facilities and represent all five geographical health zones in Alberta (South, Calgary, Central, Edmonton and North). The majority (52%) practiced in a medium/large population centre (12/23) (see table 1). The group included 12 women, 13 participants aged above 50 years and 12 with less than 20 years of practice.

The analysis identified areas for improvement in each of the categories of Motivations, Capabilities and Opportunities. Motivation barriers related to families include frailty knowledge gaps, care expectations and grief emotions. Facilitators include the communication strategies that participants develop to mediate family-physicians communication, trust relations and the development of advance care plans. Capability barriers include the lack of standardised symptom assessment and management tools. Symptom assessment and management facilitators in the face of symptom assessment concerns include friendly,

Table 1 Demographic characteristics of study participants (n=23)

Characteristics	N
Female	12
Age (years)	
30–40	5
40–50	5
50–60	9
>60	4
Duration of clinical practice (years)	
<10	6
10–20	5
>20	12
Population size of location of where clinical practice is located*	
Large and medium	12
Small and rural	9
Both	2
Member of a primary care network †	17

*Urban area: a population of at least 1000 and a density of 400 or more people per square kilometre. Large population: a population of 100 000 or over. Medium population: a population of between 30 000 and 99 999. Small population: a population of between 1000 and 29 999; Rural: all parts outside an urban area.

†Primary care network: family physicians and other healthcare providers who work together within a team-based setting to provide integrated primary healthcare.

open relationships with LTC nursing and care aide staff. Opportunity barriers in the physical environment include the lack of dedicated spaces and inadequate LTC staff for residents nearing end-of-life. Opportunity barriers in the social environment include limited awareness within the healthcare system of the unique spiritual and mental health needs of LTC residents. Facilitators include the willingness of LTC staff and administrators to adapt the physical environment within the current design of LTC facilities to enable dying and grieving with dignity.

Motivational barriers and facilitators

Barriers and facilitators to family involvement

The belief that families lack some frailty knowledge, have unrealistic expectations and express understandable, yet difficult grief emotional reactions motivated some participants to perceive families as barriers to optimal care. Participants based their assessment on the belief families have difficulty accepting that frailty means permanent change over time, 'they are not accepting of the condition their loved one is in. It's hard for them to accept that change has happened' (P18). Participants believed that families regard acute treatments as curative rather than rehabilitative, 'they expect the physio and the nursing and the medications to correct all these things, help with feeding and often times individuals, you do see them improve. And so, the family thinks they're going to

continue to get better' (P03). Participants found it challenging to interrupt the belief held by some families that physicians withhold treatments or other care practices, 'families, often believe that there are undisclosed treatments or care modalities that we are not talking about' (P20). Participants could feel frustrated by families' lack of knowledge and unrealistic expectations, 'I can't give you more brain cells, I can't give you better joints. If someone comes up with a way to fix Alzheimer's, we'll be in joyful heaven' (P11). Participants could feel challenged by the belief held by some family members that involvement in care gives families the right to challenge physician-patient boundaries and to impose their rights as decision-makers, 'that agent wants to be involved in everything, and I am not saying it is a bad thing to be involved, but sometimes, it has no boundaries. That has become a challenge' (P18).

On the other hand, participants recognised the importance of giving families time and space to grieve during the dying process, 'we've got to recognise that even when they're alive (residents with frailty), people are grieving' (P10). Participants also understood that difficult emotions can represent unmet concerns and family members' need for validation, 'it's because they feel invalidated or they're scared or whatever' (P04). Some participants saw emotions as opportunities to hear and validate family concerns as they emerge. For example, one participant called a worried family member early and often in the care trajectory. These telephone conversations continued until the family member developed enough confidence in the physician's care and competence to end the conversations, 'I started calling, like almost every week to the point where they say, "You don't have to call me anymore"'. (P04). The belief that families can resist the transition to comfort care from usual care motivated other participants to initiate goals of care conversations and advance care plans early in the disease trajectory, 'have those end-of-life conversations hopefully beforehand so the family is prepared' (P06).

Capability barriers and facilitators

Barriers and facilitators to symptom control

Capability barriers relate to symptom assessment and management concerns and to nursing involvement in narcotic medication usage. Facilitators included developing friendly, equitable and collaborative relationships with front-line carers and families.

The paradox of treatment for older adults with frailty is that interpreting and treating dementia responsive behaviour as an indication of pain can negatively impact both the brain and the body, causing new issues. On the other hand, the impact of withholding pain treatment medication to protect the brain from harm can increase suffering due to inadequately controlled pain.

I think the biggest symptom in long-term care is probably the behaviours, but see then that feeds into pain, because often you see behaviour with individuals with

cognitive impairment, who are unable to express themselves well when they are in pain, or when they are anxious (P03).

Participants felt that routine symptoms assessments would help prevent crisis situations, 'assessing the symptoms, on a routine basis, would be so helpful to prevent people from getting to crisis', and believed that having a standardised cognitive assessment tool in particular would be helpful, 'having standardised tools for cognitive assessment would be helpful' (P15). Acknowledging the complex nature of symptom assessment in older adults with frailty, 'differentiating pain from agitated delirium, it can get quite complicated', physicians felt that front-line carers would benefit from additional training, 'I don't think that all the staff in LTC facilities have had enough training for these assessments' (P15). Participants also acknowledged, however, that no tool or specialised training can resolve the larger problem of overextended staff.

You are dealing with staff that are extremely busy providing bedside care. So, asking them to go back and look at those resources and bring out the tools that you have to use for pain assessment for a patient who is not communicative, it's just not going to happen (P15).

Participants found it difficult to trust new or casual staff to provide optimal end-of-life care, 'if it's a new staff, if it's someone I'm talking to I can tell they're like, they don't—I don't think they know what they're doing' (P04). Trust concerns motivated some participants to involve the family in end-of-life care, 'I'm calling and calling and calling and calling and calling their family because I don't trust the staff' (P04). To resolve the problem of trust relationships, participants worked to develop friendly and equitable relationships with front-line care providers.

When we know each other, they just call me. They don't do this whole, oh what if she yells at me. That's never going to happen. There's no hesitation. It's, 'I'd better call her'. So, there's none of that stuff that makes—which would be very, very disruptive. If they were worried about calling (P04).

Community-based participant-physicians observed that residents did not always receive narcotic medication as ordered, 'often times they're not used' (P05). This led them to believe that nursing staff lacked confidence and comfort with narcotic administration in this population. These physicians speculated that front-line staff might perceive narcotics as drugs used to hasten death, 'staff lack of experience, training or lack of comfort in using those medications, maybe a stigma with using opioids and maybe hastening death' (P05). Palliative care specialist physician-participants perceived community-based physicians as reluctant to prescribe narcotics, 'I certainly see in my peers that they have stopped prescribing anything other than Tylenol for pain control and Tylenol doesn't

always cut it especially for anxiety and shortness of breath that can be very common at end-of-life' (P09). Both community-based and specialist physicians believed that giving LTC nursing staff and physician providers mentorship in palliative practices would improve narcotic use and staff-physician relationships.

One is to schedule medications in as a trial period. And saying, then we are going to look at this in 2 weeks' time or in 1 weeks' time or in a months' time and say are you better, worse or the same and intentionally letting family and patient and nursing staff know you are doing that (P23).

Shift away from being the primary permission and provider into being more of a coach and an enabler we are now able to be more in a coaching, directing, supporting role (P17).

Opportunity barriers and facilitators

Barriers and facilitators to community-based services

Participants assume that frail, older residents will die in their LTC facilities, 'eventually they're going to go (die), all of them in that long-term facility' (P07). They believed, therefore, that LTC facilities should be designed to enable death, dying and grieving with dignity for these patients and their families, 'usually they're two-bed wards and sometimes when the family are grieving it's tough to do it when there's somebody else in the room' (P02). Facilitators in the face of limitations in design include adapting the physical environment when and as needed by creating ad hoc end-of-life care beds and by filling the area with life, 'having a little more greenery or even some occasional animals or things like that more frequently' (P21).

While physicians acknowledge end-of-life care as more intense than usual care, they also regard high quality end-of-life care as non-negotiable, 'the intensity of care, you know, if it is, like I'm describing, requires you do the best job'. Physicians observed that while addressing the end-of-life care needs and expectations can help improve the experience for residents and families, doing so could impact overextended LTC staff within an overextended healthcare system.

So much is demanded of them and there is a risk of burnout for them, then compassion for the residents goes down and it's kind of gets to be a vicious cycle (P21).

Participants found community-based mental healthcare services for LTC residents focussed more on dementia, 'we do have geriatric mental health, and what they do is dementia' (P04), and less on end-of-life, 'I would so much appreciate help from psychologists, from a chaplain, from social workers, but not all the time those resources are available' (P15). Though perceived as important for residents, 'I could have a Hindi patient and I could have a Muslim patient or a Christian patient, and to find out if they have the need for spiritual care would be just a

wonderful thing' (P13) participants felt that spiritual carers should also have medical knowledge, 'they try to fit in—but they don't have clinical experience, and they don't have medical—like you know what I mean?' (P04). Worried about political correctness, however, physicians hesitated to provide spiritual care themselves, 'there's a hesitation among us to talk about spiritual issues because we are so scared that we're going to be politically incorrect where we use the words' (P13).

DISCUSSION

Our theoretical and analytical approach produced knowledge of how study participants transform perceived barriers into facilitators in their care practices. The barriers identified fall into three main categories: family involvement, symptom management, and environment.

Strengths and weaknesses in relation to other studies and importance differences in results

A key aspect of optimal supportive end-of-life care in LTC facilities is the involvement of family and friends in end-of-life decisions and care for the dying person.^{7 35} A key finding of this study is *just how* the physician-participants interviewed involve families in end-of-life decisions and care. Using interviews with LTC care providers and thematic analysis, other research studies found families reluctant to participate in conversations about death, dying and that grief emotions can defer end-of-life care and decisions conversations.²⁴ Other interview and focus group studies suggest that residents, families and staff lack or defer opportunities for *talking about* their end-of-life decisions and care among themselves^{21 24} and with physicians.^{24 36 37} Using interviews and descriptive interpretive content analysis, this study identified how participants responded to families' fears in the face of declines in a resident's health status. Study participants responded to what they perceived as family anxiety and fear by engaging these families in conversations. Participants additionally perceived and used families' experiences of uncertainty, anxiety and fear as opportunities to initiate advance care planning conversations. One of the key components to providing palliative care within LTC includes advanced care planning and goals of care discussions.³⁸

Symptom management

Another significant finding is how participants, who visit LTC facilities, perceive and respond to the problem of differentiating, assessing and managing pain and responsive behaviours of residents. Studies using surveys have identified pain and responsive behaviours in LTC as having the greatest impact on care providers and residents.^{39 40} These studies also find that favourable (to providers) work environments also have lower rates of pain in residents and inappropriate use of antipsychotic medications,³⁹ and that pain and responsive behaviours and inappropriate antipsychotic medication use can be reduced through work environment modifications.⁴⁰



Participants in this study additionally suggest that developing, having and using a standardised responsive behaviour (cognitive) assessment tool on a routine basis would help LTC care providers distinguish responsive behaviours from pain, and in so doing, reduce inappropriate medication practices. Participants also noted that the lack of a standardised cognitive assessment tool made routine responsive behaviour assessments difficult, if not impossible, for already overextended staff. Similarly, in this study, community-based and palliative care specialist physicians identified differences in what LTC staff and physicians (community-based and palliative specialists) perceive as appropriate narcotic medication use in frail, older adults at end-of-life.

Physical and cultural environment

This study, like others,^{41–45} revealed factors within the physical and social environments of LTC facilities that affect the dying, death and bereavement experiences of residents and families. Physical factors reported in the literature include noisy environments, crowded rooms and inadequate staffing.⁴⁵ Physical barriers to optimal dying, death and grieving reported by the physicians interviewed for this study similarly report the lack of dedicated rooms, greenery, animal visits and inadequate staffing. Factors such as leadership, data feedback processes, staff interaction patterns and resources are reported in the literature as modifiable indicators of high or low quality organisational contexts in LTC.³⁹ What the present study adds is knowledge of how the physicians modify their care practices in the face of organisational barriers to optimal care. For example, the physicians interviewed talked about mobilising and involving families in care of the dying when the physicians felt unable to mobilise, involve or trust LTC staff to provide high quality care. This study also supports prior research reporting the high prevalence of unmet mental health and spiritual health needs of LTC residents with frailty approaching end-of-life.^{7 46 47} This study provides further support for improved staff to resident ratios at imminent end-of-life.^{39 45}

The meaning of the study and possible explanations and implications for clinicians, policymakers, administrators, researchers and medical educators

Our findings help explain perceived barriers to family involvement in care, optimal symptom assessment, and control and involvement of end-of-life care culture and practices within LTC. Other studies perceive communication problems with care providers as barriers to family involvement in decisions and end-of-life care.^{21 24} By explicating just how physicians respond to communication problems with families, this study revealed communication problems as opportunities to enable family involvement and conversations about advance care planning. What we do not know is how residents and families use communication problems with providers to accomplish their goals, how care providers respond or the effects on end-of-life care costs and outcomes.

Policymakers and administrators should consider re-design of the physical and social environment within LTC facilities to better support the care needs of residents. Clinical researchers should develop and evaluate pain and symptom assessment tools for use in LTC for people with frailty, including among those with cognitive impairment. Health administrators and clinical leaders should also support LTC staff and physician involvement in palliative care education, mentorship and skills training programmes.

Weaknesses of the study and unanswered questions for future research

Some possible limitations could be considered scope for future research. We did not specifically explicate differences in the experiences of physicians working in rural versus urban LTC facilities. Physicians in urban settings may have easier access to community-based services and the social environment of LTC facilities in rural settings may facilitate friendly relationships between staff, families and physicians. This analysis was limited to accounts of experience and specifically the experiences of physicians. Accounts are not the same as lived experience. Future research should include recording of naturally occurring conversations and ethnographic observations of social interaction between physicians, families, residents and staff.

CONCLUSION

To better optimise supportive end-of-life care in LTC facilities, educators, researchers and policymakers should focus on the specific communication strategies that strengthen relationships, the development and use of a needed assessment tools, palliative care training and mentorship, and physical and cultural re-design.

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Contributors All authors participated in one or more aspects of the study design and execution. JH-L and LV designed the study. PH conducted the interviews and performed the initial data analysis. PH, JH-L and SB reached consensus on the initial findings. Emergent codes and exemplars, identified by PH and JH-L, were checked, adapted and themes developed iteratively through feedback provided by PQ, SB, AS, LV, SK, SES, TS and NV. MA provided assistance with the literature review. All authors (PH, JH-L, MA, AS, LV, PQ, SK, SES, TS, NV and JH-L) were involved in writing and reviewing the manuscript for publication and agree to be held accountable for all aspects of the work in ensuring any questions related to the accuracy or integrity of the work are appropriately investigated and resolved.

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