A Stakeholder Analysis of the Strengthening a Palliative Approach in Long-Term Care Model

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Abstract

Objective: The purpose of this study was to conduct a stakeholder analysis of the strengthening a palliative approach to long-term care (SPA-LTC) model and refine it based on feedback from long-term care (LTC) residents and their families, staff, researchers and decision makers.

Methods: We used a mixed-methods design to conduct a stakeholder analysis of the SPA-LTC model that consisted of two sequential components: qualitative focus groups with LTC staff followed by a quantitative survey with key stakeholders.

Results: Twenty-one LTC staff provided feedback about the SPA-LTC model after residents relocated to LTC, during advanced illness and at end of life and in the period of grief and bereavement. This feedback helped to guide revisions of the model. According to the survey results, the SPA-LTC model was well received by 35 stakeholders, but its feasibility was questioned.

Conclusion: The Canadian SPA-LTC model is evidence based and endorsed by LTC staff and stakeholders. Efforts are needed to determine the feasibility of implementing the model to ensure that residents' needs are made a priority while in LTC.

Introduction

In recent years, several programs or strategies have been developed within long-term care (LTC) contexts to improve the delivery of a palliative approach to care and build capacity to support sustainable change (Hockley and Froggatt 2006; Kaasalainen et al. 2019; Palliative Alliance 2017; Parker et al. 2010). As defined by Sawatzky et al. (2016, 2017), a palliative approach to care consists of an upstream orientation toward the needs of people living with life-limiting conditions and their families, adaptation of palliative care knowledge and expertise and operationalization of a palliative approach through integration into systems and models of care that do not specialize in palliative care. Importantly, a focus on advance care planning (ACP) helps to ensure early discussions about wishes and values that will contribute to goals of care and treatment decisions at end of life. ACP is a process aimed at ensuring that persons with serious chronic conditions reflect on, communicate and sometimes document values, wishes and preferences for future care (Rietjens et al. 2017; Sudore et al. 2017).

Features that are common across models to support effective and sustained implementation and show promise in improving care delivery include mechanisms to help staff identify and activate a change in care planning based on key transition points (Oxford County Palliative Care Committee 2012); formalized opportunities for communication between staff, residents and families (Ramsbottom and Kelley 2014); team-building strategies, champions or resource teams (Hockley and Froggatt 2006; Kaasalainen et al. 2012; Palliative Alliance 2017; Parker et al. 2010); and collaborative learning opportunities (Hockley and Froggatt 2006; Kaasalainen et al. 2012; Palliative Alliance 2017; Parker et al. 2010).

Some recently developed programs have begun to focus on building "in-house" capacity in LTC by leveraging external community supports for LTC homes (e.g., palliative consultants) to help implement a palliative approach to care (Badger et al. 2009; Hall et al. 2011; Parker et al. 2012; Strumpf et al. 2004). In this manner, programs draw on palliative expertise outside of the LTC sector to provide guidance to LTC staff (but not direct resident care) to build capacity within the LTC home. This provides a more sustainable approach, as the LTC staff are able to transfer and implement the knowledge learned from outside sources throughout the LTC home (Badger et al. 2009; Hall et al. 2011; Parker et al. 2012; Strumpf et al. 2004). As evidenced by research (Hall et al. 2011; Parker et al. 2012; Strumpf et al. 2004), programs that align with a palliative approach focusing on building capacity within LTC homes are recommended. Such programs have been successful in improving staff communication, increasing staff confidence, fostering choice for residents and increasing awareness of residents who were dying and their needs (Hall et al. 2011).

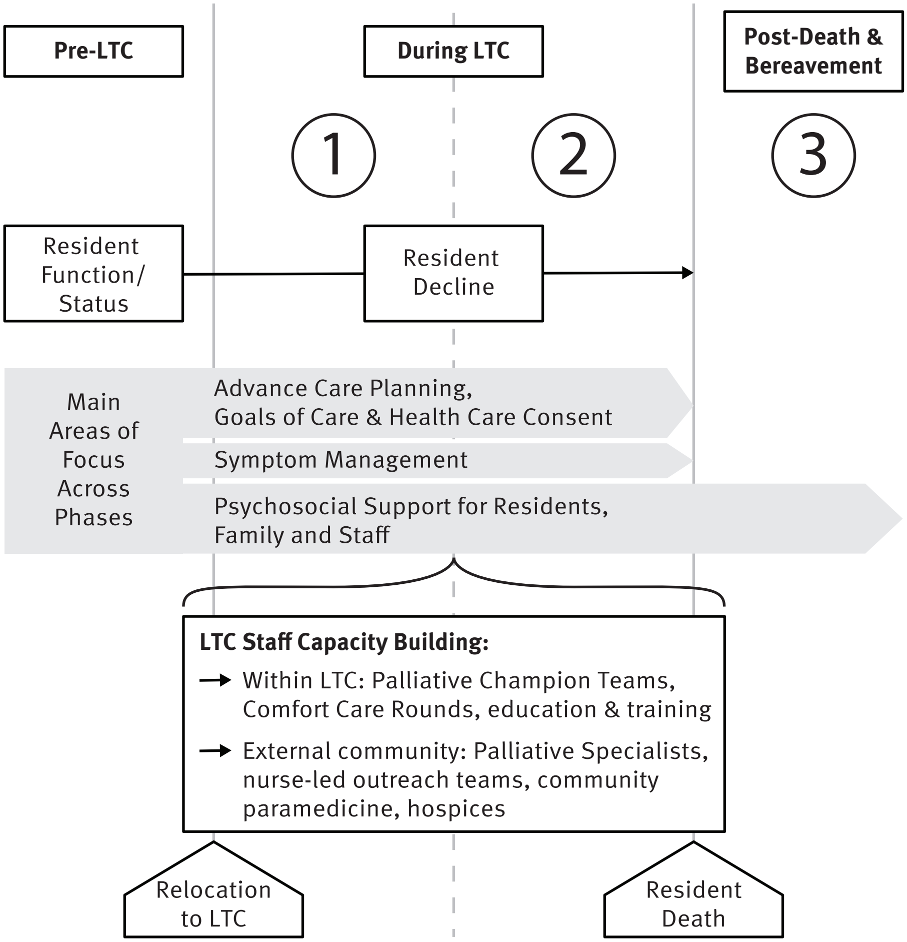
Moreover, programs that focus on increasing an LTC home's ability to implement a palliative approach by recruiting resources from outside the LTC sector are promising, as evidenced by increased engagement of informal caregivers at end of life, greater use of palliative care planning conferences, increased use of a care pathway and increased documentation of pain and dyspnea assessments (Hall et al. 2011; Parker et al. 2012; Strumpf et al. 2004). Studies have also shown indicators of improved medical care, including higher rates of physician visits in the last week of life (Strumpf et al. 2004) and decreased rates of inappropriate hospital use (Hockley 2013) when leveraging external resources to support LTC homes. These findings indicate that the use of palliative programs that involve recruiting resources from outside the home is beneficial to both the LTC organization and residents alike.

Based on the scoping review findings (Kaasalainen et al. 2019), it is clear that a model encompassing a palliative approach to care ensures that quality care is provided across the life trajectory of a resident living in an LTC home, including close attention paid to each resident's needs. Models that focus on end-of-life care only preclude early engagement of ACP discussions that could help prepare all parties involved (residents, family, staff) for end-of-life decisions and reduce the stress and guilt associated with these decisions. Ideally, these discussions would be initiated before entering LTC.

Also, a palliative model that accommodates varying needs across different stages or phases is important to ensure "the right care at the right time." Previous work based on a scoping review emphasized the benefits of leveraging both internal (e.g., palliative champion teams) and external (e.g., community palliative consultants) resources to promote a sustainable approach to implementing a palliative approach to care in LTC (Kaasalainen et al. 2019). Hence, we developed the Strengthening a Palliative Approach in LTC (SPA-LTC) model that includes three phases: (a) after moving in to LTC, (b) progressing into advanced illness/end-of-life and (c) during grief and bereavement (Figure 1). There are three areas of focus (ACP, goals of care and healthcare consent; symptom management; and psychosocial support for residents, family and staff) across each of the three phases.

The goal of this study was to understand LTC staff and stakeholders' perceptions about the SPA-LTC model to refine it for use within LTC homes. Specific aims included (a) to explore LTC staff perceptions about the SPA-LTC model; (b) to refine the model based on staff feedback; and (c) to complete a stakeholder assessment of the suitability, desirability, feasibility and potential for use of the palliative model of care within LTC homes.

Figure 1. Strengthening a palliative approach in long-term care (SPA-LTC) model.



Methods

Design

We used a mixed-methods design to conduct a stakeholder analysis of the SPA-LTC model that consisted of two sequential components: qualitative staff focus groups followed by a stakeholder survey that included both qualitative and quantitative questions. Both components were focused on assessing staff perceptions about the SPA-LTC model.

Focus groups

Four focus groups were held with a total of 21 staff members from four LTC homes in southern Ontario who were key "palliative champions" to assess their perceptions about the SPA-LTC model. Each focus group included between four and eight participants with several disciplines represented (e.g., nurses, personal support workers/care aides, social workers, physiotherapists, housekeepers, dietary aides and recreation therapists). Participants were given a copy of the SPA-LTC model, with key activities listed (Table 1), and were interviewed for their feedback about each of the three phases of the model. The interview focused on participants' experiences, needs, strengths and concerns providing (or receiving) palliative care in their LTC home. All deliberations were audio-recorded, transcribed and thematically analyzed. Based on feedback from LTC staff, the research team met to determine how to best revise and refine the components and key activities of the SPA-LTC model (Figure 1 and Table 1). The revised version of the model (Figure 1) was then used in the subsequent survey.

Survey

Next, we asked key stakeholders (i.e., practitioners, researchers, decision makers) from five provinces in Canada to complete an online survey to assess both the importance and feasibility of each of the key activities in the model (Figure 1). We worked through our existing networks in these provinces to recruit stakeholders based on the following criteria: (a) were knowledgeable about palliative care and LTC homes, (b) represented each group (e.g., practitioners, researchers, decision makers) from each province and (c) presented diverse disciplines viewed as important to implement the SPA-LTC model in LTC (e.g., physicians, nurses, lawyers, social workers, personal support workers/care aides, LTC home managers). We used a similar approach to that of a previous stakeholder assessment study (Hadjistavropoulos et al. 2011). That is, each key activity of the SPA-LTC model was rated using a five-point Likert scale regarding perceived importance and feasibility for use in LTC homes. This approach was shown to be useful to elicit ratings of high and low endorsement of activities for both importance and feasibility from individuals working in different roles and regions of the Canadian

Table 1. Key activities of each phase of the palliative model in LTC focus on residents and families

Phase	Activities
1. After relocating to LTC	• Support resident and family during adjustment to living in LTC; address "losses" of resident and family • Complete full assessment upon admission, including medication review and level of frailty; ongoing as deemed necessary • Complete CPR (Cardiopulmonary Resuscitation) documentation at six-week conference; ensure substitute decision maker is identified • Introduce concept of a palliative approach to residents and family and prepare them for expected changes in health conditions • Begin proactive discussion with resident and family about advance care planning with preferred tools
Significant resident decline/advanced chronic illness triggered by one or more of the following: • PPS (Palliative Performance Scale) score <40% • J5c checked on RAI MDS (Resident Assessment Instrument Minimum Data Set) • >2 general indicators on SPICT (Supportive and Palliative Care Indicators Tool) • "No" to the question: "Would you be surprised if the resident died within six months?"	
2. Advanced illness/ end of life	• Support the resident and family through life review, emerging issues and final separation • Review medications in consultation with the physician, pharmacist and nurse; continue only those deemed necessary or for comfort measures • Ensure end-of-life medications are prescribed and dispensed for residents at the beginning of this phase, not the end (see medication form) • Revisit advance care planning discussions, discuss goals of care and obtain consent for treatment plan; hold palliative care conference (see forms) • Continue to monitor symptoms, especially pain, anxiety and constipation; implement RNAO (Registered Nurses Association of Ontario) end-of-life guidelines • Help prepare residents and family for changes, especially physical, in last hours of life
3. Grief and bereavement	• Provide after-death care and guidance for family about funeral arrangements • Conduct a post-bereavement phone call six weeks after resident death to "check-in" with family members and offer support as needed • Communicate and provide support to other residents • Offer bereaved family members the opportunity to attend a peer support group

LTC = long-term care.

healthcare system related to the field of interest (Hadjistavropoulos et al. 2011). In doing so, it was possible to distinguish items that were rated highly for importance but lowly for feasibility so that strategies to implement these activities could be developed accordingly.

Written comments were also sought using open-ended questions to elicit additional information about key activities that should be considered within this setting. We used Dillman's modified tailored design method approach (Dillman et al. 2009; Hoddinott and Bass 1996), whereby an initial e-mail to request participation in the survey was followed by two-week and one-month reminders to non-responders to encourage a respectable response rate.

Results

Focus groups

Among the 21 focus-group participants, the majority were female (85.7%) and between the ages of 25 and 44 years (61.9%; Table 2). Many were nurses (23.8%) and most had received some palliative training (95.2%). All participants worked full time, and most were employed by the LTC home (90.5%) compared to being contracted by the LTC home (9.5%).

Table 2. Stakeholder analysis: characteristics of focus-group participants

	N	Percentage of total respondents (%)
Gender		
Male	3	14.3
Female	18	85.7
Professional group		
Registered nurse	5	23.8
Registered nurse practitioner	0	0
Registered social worker	2	9.5
Physiotherapist	1	4.8
Dietician	1	4.8
Administrative staff	2	9.5
Housekeeper or cleaner	0	0
Other	9	42.8
Age range		
Under 25	0	0
25–34	6	28.6
35–44	7	33.3
45–54	4	19.0
55–64	3	14.3
›65	1	4.8
Employment status		
Part-time	0	0
Full-time	21	100.0
Employment conditions		
Employed in long term care	19	90.5
Contracted in long term care	2	9.5

Phase 1: after relocating to LTC

Most participants agreed that if end-of-life discussions were held in Phase 1, conversations around this issue would be easier in Phase 2. There was a consensus that CPR (Cardiopulmonary Resuscitation) documentation needs to be done within a few days of admission because changes in health status can happen quickly and perhaps should be included in the pre-admission package or Phase 1 of the model. In addition, participants concurred that a care plan for each resident should be developed early on in this phase.

At all of the sites, a resident–family conference is held six weeks after admission. Most participants agreed that the timing of the six-week conference was appropriate, as the staff have had sufficient time to understand the resident and their needs. It was suggested that "…if we have a list of the expectations at that meeting, like an agenda, these are the things that we are going to be discussing…give it to them before the meeting then they know that we will be discussing this" (Site 2). Participants from all sites emphasized that having the physician attend the six-week conference was very important.

Participants emphasized the need to address symptom management across all levels of the model, including Phase 2, but that "…specific symptom management we don't usually do until Phase 3" (Site 4).

Phase 2: advanced illness/end of life

Most participants agreed that reassessing medication in this phase was important. However, some stated that continued monitoring of symptoms might be difficult, especially if staff members are new or the site is short-staffed.

There was consensus that a score of 30% on the Palliative Performance Scale (PPS) was not a reliable indicator of nearing end of life in this phase, as "30% does not answer the question – not in LTC" (Site 1), but there was no consensus with regards to deciding on a better tool/indicator to identify approaching end of life. It was suggested that using a frailty score/measure to account for the complexity of the resident's condition would be helpful.

It was noted that there is a role for recreation therapy at this stage especially, if the role involves providing the palliative mobile cart. Participants also emphasized the importance of providing support and guidance for families – that this activity may happen in Phase 2 in addition to Phase 3. Also, many endorsed the need to address any wishes that the resident may have expressed that are not yet in the care plan, which could be included within the "revisit ACP discussions" key activity of the SPA-LTC model.

One participant added, "I like the balance of the recommendations because at first it would say support the family and resident but it's more emotionally social aspect and spiritual...then you move on to the review of medication…I like the balance approach and holistic approach" (Site 2).

Phase 3: grief and bereavement

Supporting family was seen as an important activity in this phase. However, most participants were concerned about performing a six-week post-bereavement phone call to check-in with family members due to a lack of resources, previous mixed reactions to this activity from family members and managing difficult family politics.

Instead, most agreed that some contact with the family after death was important, although it could take different forms such as e-mailing or a phone call shortly after the death. Most agreed that providing information about funeral arrangements was important in this phase, but this may be challenging for staff, as this information may not be readily available.

In addition, many participants also reported the need for ongoing staff support in this phase. Although some participants felt that offering the opportunity to attend a peer support group was a good idea, in practice it would be challenging due to staff overload and lack of specific training. Attending funerals may be another key activity in Phase 4, as some sites do this already.

Survey

Of the 52 individuals who were sent a survey invitation, 35 completed the survey for a response rate of 67.3% (Table 3). Of the responders, 34.3% (n = 12) were practitioners, 40% were researchers (n = 14) and 25.7% (n = 9) were decision makers. The majority of participants were female (85.7%), and the largest age group was those between 55 and 64 years (32.4%). The most prevalent discipline represented was nursing (40%) and almost half were from Ontario.

Table 3. Stakeholder analysis: characteristics of survey participants

	N	Percentage of total respondents (%)
Gender		
Male	5	14.3
Female	30	85.7
Professional group		
Practitioner (RN, RPN, v aide)	12	34.3
Researcher	14	40.0
Decision maker (administrator, policy advisor)	9	25.7
Age range		
Under 25	0	0
25–34	6	17.6
35–44	6	17.6
45–54	10	29.4
55–64	11	32.4
›65	1	2.9
Discipline		
Administration	6	17.1
Nursing	14	40.0
Medicine	3	8.6
Law	0	0
Physiotherapy	1	2.9
Other (e.g., social work, recreation therapy)	11	31.4
Years worked in LTC		
Mean SD	18.8 11.7	
Province of employment		
Manitoba	5	14.3
Ontario	17	48.6
Saskatchewan	3	8.6
Alberta	5	14.3
Quebec	4	11.4

LTC = long term care; RN = registered nurse; RPN = registered nurse practitioner; SD = standard deviation

Although all activities in the model received a relatively high level of endorsement for importance, introducing the concept of a palliative approach to residents and families and beginning proactive discussions with residents and family about ACP were seen as slightly less feasible to implement in an LTC environment (results highlighted in Table 4, available at longwoods.com/content/25974).

Discussion

This study contributed to the refinement and evaluation of an evidence-based, Canadian palliative model, called SPA-LTC, drawing from our knowledge about palliative programs and their components that have been implemented in LTC internationally. Study findings demonstrate that the SPA-LTC model was well received by a group of stakeholders, but they questioned the feasibility of implementing ACP in LTC. It was widely acknowledged that earlier discussions about wishes, values and ACP are currently lacking and are not integrated into the trajectory of care and that the focus has primarily been on providing care at end of life. Perhaps these activities would be better suited to occur before relocation to LTC. A model that focuses on the need to engage residents and families in earlier discussions about values and wishes is needed to help prepare residents/family for goals-of-care decisions later on.

A number of palliative programs have been developed within LTC contexts to promote a palliative approach to care and build capacity to support sustainable change (Kaasalainen et al. 2018), most notably the Gold Standards Framework in the UK (Badger et al. 2009; Hall et al. 2011; Hockley and Froggatt 2006; Kinley et al. 2014; National Gold Standards Framework Centre 2018) and the palliative approach toolkit in Australia (Parker and Wilson 2015). Core programmatic features that appear to support effective and sustained implementation and show promise in improving care delivery include mechanisms that allow for the assessment and identification of gaps in current practices and philosophies (Palliative Alliance 2017); mechanisms to help staff identify and activate a change in care planning based on key transition points (Gill et al. 2011); formalized opportunities for communication between staff, residents and families (Ramsbottom and Kelley 2014); and team-building strategies, champions or resource teams and collaborative learning opportunities (Hockley and Froggatt 2006; Kaasalainen et al. 2012; Parker et al. 2010; Wickson-Griffiths et al. 2015). These features have been incorporated into the components of the SPA-LTC model (Figure 1).

Within the SPA-LTC model, palliative champion teams are positioned to create change in LTC homes. They can receive specialty training and mentorship from an external palliative consultant (nurse or physician) to help guide internal activities, while also providing leadership to other staff at their LTC home. In this model, a "train-the-trainer" philosophy can guide the implementation approach; however, it is dependent on strong buy-in and support from staff and administration in the home.

Conclusion

The importance of implementing a palliative approach in LTC has been well recognized. The Canadian SPA-LTC model represents such a model and is endorsed by a variety of LTC stakeholders, including staff, decision makers and researchers. However, challenges exist related to introducing a palliative approach to residents and families and implementing ACP early on in the LTC trajectory. Efforts are needed to implement ACP using a feasible approach, to ensure that residents' and their families' needs are met throughout their time in LTC.

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