



Palliative Care Models in Long-Term Care: A Scoping Review

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Abstract

Objective: The goal of this scoping review was to identify existing palliative models in long-term care (LTC) homes and differentiate between the key components of each in terms of training/capacity-building strategies; resident, family and staff support; and advance care planning (ACP) and goals-of-care discussions.

Methods: We conducted a scoping review based on established methods to summarize the international literature on palliative models and programs for LTC. We analyzed the data using tabular summaries and content analysis.

Results: We extracted data from 46 articles related to palliative programs, training/capacity building, family support, ACP and goals of care. Study results highlighted that three key components are needed in a palliative program in LTC: (1) training and capacity building; (2) support for residents, family and staff; and (3) ACP, goals-of-care discussion and informed consent.

Conclusion: This scoping review provided important information about key components to be included in a palliative program in LTC. Future work is needed to develop a model that suits the unique characteristics in the Canadian context.

Introduction

As the population ages, more people will die in long-term care (LTC) homes. In Canada, annual mortality rates of residents in LTC homes range from 27 to 52.3% (Canadian Institute for Health Information [CIHI] 2017). Similar trends have been noted in other countries, including the United States (US Department of Health 2003), the United Kingdom (Lievesley et al. 2011) and Australia (Australian Institute of Health and Welfare 2007). Despite these growth rates, research has shown that care at end of life is suboptimal in LTC, with pain and other symptoms being poorly managed especially for those with dementia (Teno et al. 2004); lack of attention given to advance care planning (ACP) and goals-of-care discussions (Castle 1997); issues of loss, grief and bereavement (Waldrop and Kusmaul 2012); widespread use of feeding tubes (Mitchell et al. 2003); and excessive reliance on hospitalizations to manage end-of-life care (Menec et al. 2009; Miller et al. 2001).

Despite the high mortality rates in LTC, most LTC homes do not have a formalized palliative program. In fact, a European study conducted in 29 countries assessed the current palliative care structures, methods and policies at the macro (national and regional policies/procedures), meso (non-government providers, palliative care providers, care home providers) and micro (directly engaged in providing palliative care to residents) levels (Froggatt et al. 2017). Researchers found that more than half of the countries included (55%; $n = 16$) had no evidence of any palliative care domains at the national/regional level. At the meso level, where palliative care activities include education and training, use of tools/frameworks, service models and research into palliative care practices, roughly half of the countries (49%; $n = 14$) showed no evidence of such activities. Finally, in terms of providing direct palliative care to residents at the micro level, 17% ($n = 5$)

countries did not practice palliative care at all, 42% ($n = 12$) practiced minimally and 17% ($n = 5$) showed sparse palliative care practice. It is notable to mention that in no country in this European study is there evidence of palliative care being provided in all LTC homes. Such enticing findings from this review have prompted the need to investigate palliative care provision in LTC in the Canadian context.

A recent report (Canadian Institute for Healthcare Information 2018) revealed that only one in 20 seniors (adults over the age of 65) who died in Canada received palliative care in LTC. Of those who did receive palliative care while in LTC, only 2% died in the hospital compared to 18% who did not receive palliative care, thus indicating a need for further palliative care implementation in Canadian LTC homes.

To date, there is no evidence of any reviews that explore existing palliative models specific to LTC. Having said that, there has been some work done to address ACP in LTC, a component of a palliative model. One review examined a series of qualitative studies that explored perceptions of residents and their family members about ACP discussions (Mignani et al. 2017). Interestingly, a key finding of this review was the scarcity of studies specifically involving ACP in LTC. Of the studies that were reviewed ($n = 9$), it was noted that despite their willingness to participate in ACP, many residents and families have little experience with ACP. They believed that ACP would require more time and attentiveness from healthcare professionals than typically given in a single interaction. Another systematic review that explored the efficacy of ACP programs in various populations found that when an ACP program included communication about end-of-life care in general, the incidence of end-of-life care discussions between residents, families and healthcare providers increased, which in turn improved outcomes such as quality of communication (Houben et al. 2014). These findings demonstrate a need for further exploration and implementation of ACP practices and programs that address end-of-life issues specific to LTC.

Despite the lack of research specific to current palliative models and program implementation in LTC, there has been some headway into hospital and community settings. Two systematic reviews of this nature concluded that specialized palliative care is much more effective than conventional care (García-Pérez et al. 2009) and that communication between residents, families and healthcare providers; healthcare provider coordination; and rapid response to changes in resident needs and preferences are critical to embed in any palliative care practice (Lockett et al. 2014). A third systematic review explored existing reviews completed on the evidence of palliative care to inform the National Consensus Project Guidelines in California (Ahluwalia et al. 2018). They found that there is a substantial amount

of evidence (139 systematic reviews) to support that guidelines for quality palliative care exist, highlighting key components that are needed: (a) training and capacity-building strategies for healthcare providers, (b) family support and (c) ACP and goals-of-care discussions. However, none of these reviews was specific to LTC. These findings reinforce the need for more exploration in the LTC context.

Researchers in Australia have explored the current palliative care outcome measures that exist to assess the quality of palliative care in LTC and determine which is best suited for the LTC population (Parker and Hodgkinson 2011). Of the 10 measures available to assess palliative care outcomes in LTC, it was determined that the Family Perceptions of Care Scale is the most suitable outcome measure. This valuable information is helpful when considering how to measure palliative care practices upon the implementation of a palliative care model in Canada.

Finally, there has only been one related scoping review conducted to examine national palliative care documents in LTC across five Canadian provinces (Alberta, Ontario, Saskatchewan, Manitoba and Quebec; Hill et al. 2018). It was concluded that LTC-specific documents were absent, and all documents that do exist lack consistency on palliative topics. Given that there are no foundational documents in place, it can be confirmed that the likelihood of LTC homes having any sort of palliative care program is not promising. Thus, it is clear that there is a definite need to develop, implement and evaluate a palliative model in Canadian LTC homes to improve both quality of living and dying for residents and support for their family members. Again, despite this preliminary work to explore the LTC palliative documents across the country, there has not been any specific scoping or systematic reviews completed on palliative care models in LTC.

The goal of this scoping review was to identify existing palliative models in LTC homes and differentiate between the key components of each in terms of training/capacity-building strategies; resident, family and staff support; and ACP and goals-of-care discussions. A scoping review will be particularly useful, as it is evident that there has not been any research done to determine the current palliative models of care specific to LTC. The information retrieved from this review will be beneficial in providing evidence for the development of a palliative model to best suit the Canadian LTC context.

Methods

We conducted a scoping review based on established methods (Arskey and O'Malley 2005; Levac et al. 2010) to summarize the internationally published literature on palliative care models and programs for LTC. The five stages outlined in Arskey and O'Malley's framework were used: (1) identifying the research

question, (2) identifying relevant studies, (3) selecting the studies (4) charting the data and (5) collating, summarizing and reporting results. Our goal was to explore and map all relevant literature on the broad topic of palliative and end-of-life care in LTC settings and to identify recurring themes, using rigorous and transparent methods, to comprehensively search for all relevant literature and to analyze and interpret the data. As such, the criteria for exclusion and inclusion were based on relevance and not the quality of the studies.

Inclusion criteria were used to search for articles to allow for a broad overview of the literature. Studies were eligible if these pertained to palliative models in LTC settings (both provided by healthcare providers within the home and externally consulted). The search was not restricted by study type (consistent with a scoping review) or LTC home characteristics but was limited to articles written in English and published later than 2007 to ensure that the data were relatively recent and consistent with a palliative approach philosophy that emerged over the past decade. We did make an exception, however, for older publications if these were considered to be key in subsequent work (e.g., highly referenced by more than three included articles).

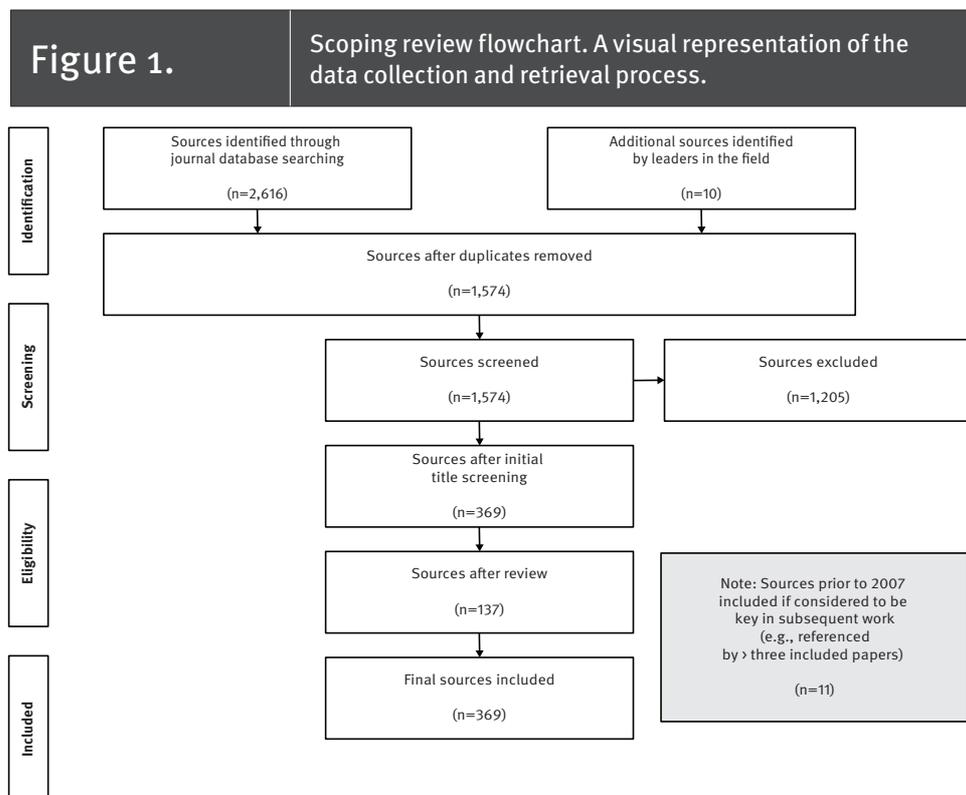
An extensive search was performed using EMBASE, Medline, CINAHL (Cumulative Index to Nursing and Allied Health Literature) and Health Star databases. We consulted with an information specialist at McMaster University to assist in developing a search strategy that would thoroughly cover all of our topic areas. We used broad search terms including “palliative care model,” “palliative model,” “palliative care program,” “end-of-life care model,” “end-of-life care program,” “long-term care,” “nursing home” and “care home” to capture a wide variety of programs. Results from each database search were compiled using Refworks. Duplicate results of identical studies were removed using the Refworks system, and the remaining articles were then scanned by three reviewers to ensure that the titles and abstracts fit the inclusion criteria. The full text of the articles remaining after the abstract screening was then reviewed by two individuals in detail. Next, two individuals extracted the eligible data to identify different types of models and their key components using the following headings: training/capacity-building strategies; resident, family and staff support; and ACP and goals-of-care discussions. This concluded the first three stages in the scoping review process.

To analyze the data extracted from the literature, two individuals synthesized the data using a combination of tabular summaries, qualitative content analysis (Vaismoradi et al. 2013) and team discussions. Descriptive tables were developed using emerging themes and subthemes identified by the reviewers to summarize all data extracted from the literature. Following this, the review team met weekly

to discuss the results of the aggregate data from each of the categories within our data extraction tool. We then completed a synthesis of the literature according to each of the identified themes/key deliverables as noted above. Table 1 (available at longwoods.com/content/25975) contains details about the summary of the literature related to palliative programs in LTC.

Results

Initially, we retrieved 2,616 studies. Once the duplicates were removed, we were left with 1,574 studies. Following the title review based on the inclusion and exclusion criteria, we were left with 369 studies, and we were then left with 137 following the abstract review. Apart from our formal database search, we contacted members of our research team and external partners who are all leaders in the field to capture some of the gaps in the published literature or grey literature. Using this method, we were able to access 10 additional sources. Based on abstract reviews, we used the full-text reviews to narrow down the results to the 46 most relevant articles that addressed the four key areas (i.e., palliative models and programs; training/capacity-building strategies; resident, family and staff support; ACP and goals-of-care discussions; Figure 1).



Of the 46 relevant articles, 27 reported on palliative models or programs in LTC. The majority were from the United States ($n = 14$), five from the United Kingdom, four from Canada, two from Australia and one each from Belgium and France. An additional 19 articles addressed one or more of the key components of the model (i.e., training/capacity building; resident, family and staff support; ACP) but did not include or describe a specific palliative program or model. Of these articles, seven were from Canada, five from the United States, four from the United Kingdom, two from Australia and one from Belgium. The majority of the studies used mixed methods ($n = 28$), 12 used quantitative methods only and the remaining six were qualitative studies.

Description of different types of palliative models/programs in LTC

Based on the scoping review, there are four main types of palliative programs that have been developed and reported in the literature for use in LTC homes. Within each program, various training/capacity-building strategies are identified along with family support, ACP and goals-of-care discussions. Each is discussed separately below.

Model 1: External specialist end-of-life care model

In this model, residents once deemed “in the final days of life” are referred to an external specialist palliative care team by an on-site physician, and they receive direct clinical care from the specialist team. This specialist team often includes physicians, nurses and social workers who all have special training and skills in palliative care. Carlson et al. (2011) stated that all residents would have access to specialist palliative care, but it is primarily offered to those at end of life. This model is limiting in terms of general access to quality palliative care for all residents, and it is contingent on access to specialist palliative care teams in the local region. This model also precludes a palliative approach to care prior to the resident being deemed “at end of life” and limits continuity of care, which could involve a lack of staff expertise during acute, unpredictable illness episodes, resulting in unnecessary hospitalizations (Carlson et al. 2011). However, despite these limitations, this model has been shown to lower hospitalization rates and improve family members’ ratings of the care that residents received at end of life (Casarett et al. 2005).

Model 2: In-house end-of-life care

This model is similar to Model 1, in that it focuses mostly on supporting residents once they reach the end stage of a disease or are considered to be near the end of life, but it involves providing hospice-like care within the LTC home, not relying on external specialist care. This model is most common for residents who have dementia, whereby care can be tailored to disease-specific needs (Kovach et al. 1996; Simard and Volicer 2009). As such, staff who work within these hospice

units can be specially trained to provide individualized care, while being cognizant of common issues and approaches necessary to promote quality of life within a specific chronic condition. Basson et al. (2002) found that using a palliative care mobile unit to provide care to residents at end of life helped support families and medical teams to manage end-of-life symptoms and psychological suffering and avoid unnecessary hospitalizations. However, some of these strategies may not be the most efficient approach for smaller LTC homes. Also, Parker et al. (2012) stated that this type of model may not support continuity of care and the maintenance of relationships among residents, family and staff.

Model 3: In-house capacity building within a palliative approach

The third model involves building capacity within the LTC home to promote quality palliative care with the added benefit of providing access to all residents in the LTC home, not just those identified as needing palliative care in the last few months of their life. Within this model, capacity-building activities are paramount, such as (a) developing leadership or champion teams in palliative care (Hanson et al. 2005; Ouslander et al. 2014; Phillips et al. 2006), (b) providing education to all staff about a palliative approach to care (Gatchell et al. 2012; Hanson et al. 2005; Kortess-Miller et al. 2007; Parker et al. 2012) and (c) conducting ongoing “check-ins” to monitor progress and involve audit and feedback or plan, do, study and act quality improvement cycles (Hanson et al. 2005). Unlike the specialist palliative model (Models 1 and 2), this model allows for LTC staff to assess and respond to emerging issues in a timely manner, given that their daily contact with residents attunes them to knowing the residents’ and family members’ values, personal goals and care preferences (Ersek and Wilson 2004). Evaluation findings of this type of model showed improved staff retention rates and family satisfaction, higher documented cardiopulmonary resuscitation and ACP completion rates and fewer hospitalizations (Hanson et al. 2005).

Model 4: In-house capacity building with external support from palliative specialists

This model is a hybrid of Models 1 and 3, whereby the focus is on developing capacity within the LTC home, but it also draws on palliative expertise outside of the LTC sector to provide guidance to LTC staff but not direct resident care (Badger et al. 2009; Hall et al. 2011; Parker et al. 2012; Strumpf et al. 2004). Within this model, the goal is to build capacity within the LTC home using a more sustainable approach. This type of model is consistent with a palliative approach to care; examples include the Gold Standards Framework (National Gold Standards Framework Centre 2018) and the Palliative Approach Toolkit (Parker et al. 2012). An evaluation of this type of model showed promising results, including increased engagement of family caregivers at end of life, use of palliative care conferences, use of a care pathway and documentation of pain and dyspnea

assessments (Hall et al. 2011; Parker et al. 2012; Strumpf et al. 2004). Other studies have shown higher rates of physician visits in the last week of life (Strumpf et al. 2004) and decreased rates of inappropriate hospital use (Hockley 2013). Based on this analysis, Model 4 is most appropriate to help guide the development of a palliative model of care in Canada because it aligns with current trends and palliative care philosophy whereby the focus is on symptom management, ACP and providing family support that begins at the time of relocating to an LTC home (or earlier).

Key components of palliative models in LTC

Training and capacity-building strategies for LTC staff

All the models include a focus on training and capacity-building strategies; however, in Models 3 and 4, there is a focus on strategies for a palliative approach to care not just for end of life. The literature related to these strategies in LTC described both internal strategies (e.g., educating staff, developing a champion team) and external strategies (e.g., leveraging supports and consultants outside of LTC home; Models 1 and 4 only). The majority of literature reviewed acknowledged the current gaps in the knowledge of LTC staff, including (a) effective symptom management, especially pain management; (b) the dying process and how to know when someone is dying; (c) implementing a palliative approach for residents with chronic diseases; and (d) ACP. Hence, providing education and skills training related to palliative care to LTC staff is paramount (Caplan et al. 2006; Ersek and Wilson 2004; Froggatt et al. 2009; Gatchell et al. 2012; Giuffrida 2015; Hickman et al. 2014; Kortess-Miller et al. 2007; Lee et al. 2013; Morris et al. 2013; Phillips et al. 2009; Roberts and Gaspard 2013).

Internal training and capacity-building activities have been recommended to “skill-up” LTC staff to provide quality care. Educational sessions related to a specific component of a palliative program are recommended for quick uptake of information that can be readily applied to practice, such as managing palliative symptoms. Managing palliative symptoms such as pain, dyspnea, fatigue, anxiety, delirium, nausea/vomiting, irregular bowel functioning, oral care and depression is consistently reported as important (Hall et al. 2011; Hickman et al. 2014; Lee et al. 2013; Ouslander et al. 2014; Parker et al. 2012; Parker and Wilson 2015; RNAO 2011; Vandenberg et al. 2006). Pain is the most common symptom at end of life but is often not recognized and, hence, not treated effectively (Hall et al. 2002; Strumpf et al. 2004). Best practice guidelines/care pathways have been developed to help guide clinical practice (Parker and Wilson 2015; RNAO 2011).

Other education sessions focused on using the Palliative Performance Scale (PPS) as a strategy to assess functional decline in residents who potentially could be nearing end of life. In a pilot evaluation, LTC staff reported that PPS training

sessions helped identify residents who were nearing end of life (Kaasalainen et al. 2014). Moreover, Gill et al. (2011) found that training about using the PPS in LTC helped staff deliver care promptly and be responsive to residents' immediate needs, so staff were able to prioritize appropriately.

A variety of strategies for providing additional training in LTC have been robustly described in the literature. Gatchell et al. (2011) found that LTC staff who attended monthly in-services about core palliative care topics over six months reported significant improvements in application of palliative concepts in patient care; greater improvement was also reported for staff who attended more sessions. Moreover, staff confidence increased after attending three interprofessional workshops about how to implement a palliative approach to dementia care (Roberts and Gaspard 2013) and after participating in a rural palliative care education program (Kortes-Miller et al. 2007). Interestingly, Brazil et al. (2012) found that nurses who scored very low on a palliative care knowledge quiz reported high confidence levels in providing palliative care, indicating that sometimes staff are not aware of their knowledge gaps yet still feel confident of providing quality palliative care.

The importance of developing palliative champion teams is widely acknowledged as a way to build capacity within LTC homes and to facilitate sustainability of a program (Carlson et al. 2011; Hockley and Froggatt 2006; Kaasalainen et al. 2016; Kelley and McKee 2013; Morris et al. 2013; Phillips et al. 2006). In Australia, Phillips et al. (2006) developed a toolkit to help LTC homes develop a multidisciplinary team approach to care planning. They recommend that the team comprise a wide range of care providers, including the LTC physician, to ensure that care planning is holistic in nature to meet resident and family needs. Teams meet regularly to review the status of all residents to ensure that all residents and their families have access to a palliative approach. Kelley and McKee (2013) suggested that each LTC home needs to structure its champion team according to the wishes of the LTC home and focus on clinical care, education, advocacy, building relationships internally and building relationships with community partners that they deem important to assist with implementing a palliative program at their LTC home.

External capacity-building strategies have also been reported in the literature related to both Models 1 and 4. Given the growing complexity of care for LTC residents and the current lack of capacity of LTC homes to manage their needs, there is interest in exploring resources outside of the LTC home to help LTC staff increase skills that are relevant to managing challenging resident situations, ultimately minimizing ER (Emergency Room) transfers. Types of external supports reported in the literature are nurse practitioners or physicians (Casarett et al.

2005; Hanson et al. 2005; Kaasalainen et al. 2016), nurses with specialty palliative training (Caplan et al. 2006; Hickman et al. 2016; Hockley and Froggatt 2006; Wickson-Griffiths et al. 2015), hospital physicians or nurses (Lee et al. 2013), hospice staff (Heals 2008; Lee et al. 2013), paramedics (Jensen et al. 2014) or a combination of outreach staff (Morris et al. 2013).

Hockley (2013) recommended using a “high-facilitation” approach to counteract the “low” context of care. Specifically, she recommended that community outreach palliative care nurses conduct regular visits to the LTC home. For example, reflective debriefing, described within the Gold Standards Framework (National Gold Standards Framework Centre 2018), involved outreach nurses visiting LTC homes and guiding staff through a series of questions including the following:

- (a) What occurred leading up to the death of the person or the specific event?
- (c) How did people feel about how things went, what went well and what did not go well?
- (c) What else could you have done and what would the outcome have been?
- (d) What can be learned and what would I do differently next time?

Another strategy used for reflective debriefing, termed comfort care rounds (CCRs), leveraged external experts, such as palliative nurse consultants or nurse practitioners, to support LTC home staff. CCRs provided an LTC home-wide forum for case-based discussions about deceased residents or those who are dying (Wickson-Griffiths et al. 2015). These occurred bimonthly and mainly focused on providing palliative care education, reflecting on resident cases and providing peer support for staff and volunteers. Pilot evaluation of CCRs showed that these (a) provided new learning about palliative care, (b) improved communication and relationships between staff members, (c) increased confidence in providing palliative and end-of-life care, (d) empowered personal support workers (PSWs) in providing and discussing palliative care, (e) provided opportunities for debriefing and reflection and (f) increased awareness and use of palliative care human resources (Wickson-Griffiths et al. 2015).

Other external capacity-building strategies that have optimized external supports have been successful in cultivating knowledge and skill and include experiential learning activities, whereby PSWs or care aides “shadowed” hospice workers to build their capacity to provide palliative care (Kaasalainen et al. 2012). As a result, PSWs stated that they felt more comfortable talking about death and dying with other staff, residents and family members. The PSWs thought that other LTC staff would benefit from this type of palliative education as well.

In most cases, a contract negotiation must take place between the LTC home and the external consultant organization to formalize the partnership. Some contracts require the LTC homes to “buy out” time for the consultant (Carlson et al. 2011; Hanson et al. 2005), whereas other consultants offer their services within their current role descriptions so there are no costs to the home. An example of a no-cost model exists in Ontario, Canada, where palliative pain and symptom management consultants and outreach nurse practitioners (Kaasalainen et al. 2016) provide outreach services. In the United Kingdom (Heals 2008), LTC homes must pay a nominal amount to not only offset costs but also promote more commitment to the partnership (personal communication, Kinley et al. 2014). The Gold Standards Framework (2018) involves hospice link nurses who provide a 24-hour telephone advice line, formal education and opportunities for LTC staff to discuss difficult issues and concerns with the hospice nurses. Outcomes from this framework are positive, with improvements noted in documentation and care planning (Heals 2008). Other studies about using consultants have found improvements in care within the LTC home as well, including (a) a growth in referrals, positive culture changes within LTC and more documentation about family meetings (Morris et al. 2013); (b) decreased emergency calls from LTC homes and hospitalizations (Caplan et al. 2006); and (c) improved resident pain and functional status (Kaasalainen et al. 2016).

It is important to note, however, that two of these studies used study nurses to provide support to the homes, meaning that once the study ended, the support ended as well, limiting the sustainability of the intervention (Caplan et al. 2006; Hickman et al. 2016). A more sustainable approach is recommended, whereby LTC homes work with currently employed practitioners in the system to maximize benefit.

Resident, family and staff support

The scoping review findings highlight the need to provide support to residents, family and staff, specifically related to the psychosocial aspect of care. An example of support for staff includes reflective debriefing (Lee et al. 2013; Phillips et al. 2006; Wickson-Griffiths et al. 2015), which is described above. Providing family support has been identified as a critical need in the literature, especially during the bereavement phase (Hickman et al. 2016; Hudson et al. 2012; Lee et al. 2013; Livingston et al. 2013; Ouslander et al. 2014; Phillips et al. 2006; Temkin-Greener et al. 2009; Vandenberg et al. 2006). Hudson et al. (2012) proposed four phases with corresponding recommendations to provide support to family: (a) setting up family caregiver support, which first involves the family and the resident (if able) discussing ACP; (b) assessing the need and establishing a plan of care to convene a family care conference (FCC); (c) helping family prepare for death; and (d) supporting family through bereavement.

ACP, goals-of-care discussions and informed consent

The opportunity for FCCs provides occasion for discussion and care planning in advance of a crisis resident situation, where family may be faced with making difficult decisions. FCCs can be a useful way to assist residents and family members to clarify goals of care, consider site of care options and share information to develop authentic partnerships with staff (Sussman and Dupuis 2012, 2014). Generally, LTC staff only manage to involve residents and their family members to some extent, and evaluations show that active practice and implementation of ACP needs much improvement, most notably with respect to the staff's comfort level and knowledge (Ampe et al. 2016; Carlson 2007; Hall et al. 2011; Hockley et al. 2013). Hickman et al. (2016) found that for about half of the residents in their study, the most common reason for no ACP conversation was that the registered nurse "had not gotten to the resident yet." Despite the noted challenges, many of these studies have shown promising results in terms of residents dying in their preferred location, decreased ER transfers and increased family satisfaction. The Australian Palliative Approach Toolkit (Parker et al. 2012) is the most well-developed model in terms of supporting homes to implement FCCs, with open access to tools and videos to help educate and guide staff.

The engagement and involvement of LTC physicians is paramount to implement ACP and goals-of-care discussions effectively, including holding FCCs, which is a key component of a palliative approach (Hieu et al. 2010). Phillips et al. (2009) stated that integrating a palliative approach in LTC homes requires physicians to have greater awareness of this paradigm as well as additional opportunities to be effectively engaged in care planning. However, many have noted challenges with engaging physicians (Hall et al. 2011). Barriers to engaging them include role ambiguity, sporadic caseloads and limited palliative training (Phillips et al. 2009).

Discussion

This scoping review provides a synthesis of current knowledge about core components of palliative programs for the LTC sector. Most notably, the scoping review findings point to the need for a program to be grounded within a palliative approach. This approach focuses on improving quality of life for LTC residents, including symptom control, dignity and comfort and acknowledging the needs of families. It can be initiated well before the terminal stages of illness through early identification, assessment and treatment of pain, physical, psychological, social and spiritual needs (Kristjanson et al. 2003). The findings are consistent with the jointly endorsed Quality End-of-Life Care Coalition of Canada and the Canadian Hospice Palliative Care Association national framework for a palliative approach to care of persons with chronic, progressive, life-limiting illness that promotes a seamless transition from chronic disease management to appropriate end-of-life planning and care.

Moreover, this review is timely given the current palliative context within Canada. With Canada's dismal ranking of 18th in the world for provision of palliative care, it is time for Canada to take definitive steps toward improving end of life experiences. Bill C-277, which received royal assent in late 2017, lays the foundation for significant improvements, supporting the development of a much-needed palliative framework in Canada (Government of Canada 2018). Given the aging population and the projected numbers of people living and dying in LTC (CIHI 2017), LTC homes must be guided by a palliative approach to care that includes an emphasis on the following: (a) training and building capacity within LTC; (b) providing support to residents, families and staff across the living–dying trajectory; and (c) engaging residents and families in ACP, goals-of-care discussions and healthcare consent. This scoping review highlights the current state of knowledge related to palliative programs and their key components in LTC homes, which may help inform future directions within Canada from a policy, practice and research perspective.

Study findings highlight that education alone is not enough to change practice, and thus, a multifaceted, capacity-building approach is needed to support practice change, including the following:

- the addition of an external mentor to facilitate training (Heals 2008; Hickman et al. 2016; Lee et al. 2013; Roberts and Gaspard 2013);
- external expert nurse or hospice consultation (Bliss and While 2007; Caplan et al. 2006; Morris et al. 2013);
- development of an internal champion or champion team (Hickman et al. 2016; Morris et al. 2013); and
- regular debriefing and case conferencing (Lee et al. 2013; Phillips et al. 2006; Wickson-Griffiths et al. 2015).

Strengths and limitations

This scoping review has some strengths and limitations. Although we identified many relevant keywords to guide our search, we may have missed articles that used different keywords. Also, we decided to focus our review on some key content areas that were embedded in many of the palliative models that we found in our preliminary searches for this study. This may have limited the breadth of content areas that we explored (i.e., symptom management), but at the same time, it allowed us to focus our efforts on topics that have not been explored previously. Given the abundance of literature and best practice guidelines published on symptom management, we felt it was more prudent to search topics that were relatively unexplored previously. Finally, in keeping with the tenets of scoping reviews, we did not exclude articles based on methodological quality, nor did we

critically appraise studies based on the quality of methods used, which not only allowed us to explore the literature more broadly but also could have led to some poorer-quality studies being included in our analysis.

Conclusion

Overall, this review has helped to consolidate the key components of existing palliative models of care in the LTC sector. The success of these models and their components should be considered during the development or adaptation of future palliative models. Finally, researchers, clinicians and decision makers must focus on evidence-based palliative models that accommodate the local context to ensure that the needs of residents, families and staff within Canadian LTC homes are met.

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