

Evaluation of a Program Based on the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) Model

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Abstract

Background: Despite increased annual mortality in long-term care (LTC) homes, research has shown that palliative approaches to care are currently suboptimal in these settings. The purpose of this study was to evaluate resident, family, and staff outcomes associated with the Strengthening a Palliative Approach in LTC (SPA-LTC) program, developed to help encourage meaningful end-of-life discussions and planning. Methods: The study employs a mixed method design in four LTC homes across Southern Ontario. Data were collected from residents, families and staff of the LTC homes through chart reviews, surveys and interviews. Results: In total, 39 residents/families agreed to participate in the study. Positive intervention outcomes included a reduction in the proportion of emergency department use at end-of-life and hospital deaths for those participating in SPA-LTC, an improvement in interdisciplinary communication between staff, support for both families and staff involved, and increased family involvement in the care of residents. However, there were no significant pre-post differences in staff collaboration or comfort in providing end of life care. Conclusions: The benefits of SPA-LTC for families, residents and staff justify its continued use within LTC. Study results also suggest that certain enhancements of the program could further promote future integration of best practices within a palliative approach to care within the LTC context.

Background

As the population ages, more people will die in long-term care (LTC) homes. In Canada, annual mortality rates of residents in LTC range from 27-52.3%.¹ Similar trends have been noted in other countries including the United States,² the United Kingdom,³ and Australia.⁴ Despite these trends, palliative care continues to be suboptimal in LTC; with pain and other symptoms being poorly managed, especially for those with dementia;⁵ lack of attention to advance care planning (ACP)⁶ and issues of loss, grief and bereavement;⁷ widespread use of feeding tubes;⁸ and excessive reliance on hospitalizations.⁹

In response, a number of initiatives have been implemented to improve the quality of living and dying for LTC residents with a life-limiting illness and their families.¹⁰⁻¹³ Features that appear to support effective and sustained palliative care implementation and show some promise in improving care delivery include: (a) mechanisms that allow for the assessment and identification of gaps in current practices and philosophies, (b) mechanisms to help staff identify and activate a change in care planning based on key transition points, (c) formalized opportunities for communication between staff, residents and families, and (d) team-building strategies, champions or resource teams and collaborative learning opportunities.

Addressing these barriers and building the growing evidence aimed at improving identification, communication and capacity; our team developed a multi-component program, called Strengthening a Palliative Approach in LTC (SPA-LTC; Figure 1). It is consistent with the SPA-LTC model, that was developed based on a scoping review¹³ of the literature and stakeholder analysis.¹⁴ As such, the SPA-LTC program consists of the following core, evidence-informed components: (a) an interdisciplinary palliative champion team (to provide leadership and support implementation); (b) condition specific pamphlets (to provide information about condition-specific end of life trajectories to residents and families),^{15,16} (c) the Palliative Performance Scale (PPS) (to trigger end-of-life discussions);¹⁷ (d) Palliative Care Conferences (PCCs) (to provide a forum for family communication about end-of life preferences and needs)¹⁸; (e) Comfort Care Rounds (to support peer education, team building and case

discussions)¹⁹; and (f) post-bereavement follow up (to offer families grief support and links to community services).²⁰

To support implementation and sustainability in the real world, the program was refined in collaboration with study sites and leveraged existing palliative resources outside of the LTC home sector to provide guidance to LTC staff.¹⁴ For example, in the original iteration of our program we had conceptualized encouraging early communication on future end-of-life through care conferences offered to stable residents within six weeks of relocations and annually thereafter. However, our pre-implementation consultations with staff, residents and families revealed uncertainty regarding the feasibility of such discussions and hence we developed condition specific pamphlets instead.

The **goal of this study** was to evaluate the impact of the SPA-LTC program on residents, families and staff. Specifically, this study addressed the following research questions:

1. Does the SPA-LTC program improve:
 - a. hospital use at end-of-life for LTC residents
 - b. staff collaboration and comfort with caring for residents at end-of-life and their families?
2. What is the acceptability of the SPA-LTC program for family members, and staff?

Methods

This study used a mixed method (qualitative and quantitative) to address all of our research questions.^{20,21} Mixed methods research allows researchers to address complicated research questions and collect a richer and stronger array of evidence than can be accomplished by any single method alone.²¹ Our approach was grounded on participatory action research, which aims to pursue action (or change) and research (or understanding) within an emergent process.²² Participatory action research has been shown to promote the development, and implementation of quality end-of-life strategies in LTC by empowering staff, supporting the development of care practices in targeted areas seen by knowledge users as important and feasible, fostering collaborative learning and team work, and creating opportunities for sustainable change by enhancing existing capacities.^{10,22-26}

Data was collected at baseline, during the implementation of the intervention, and after the 18-month intervention period. Ethical approval was obtained from two universities (McMaster University: #14-863; McGill University: #281-1214).

Settings

We selected four separate LTC homes in southern Ontario which represented the mix of contexts found in LTC homes across Canada including for profit; not for profit; large (150 beds), medium (100-150 beds) and small (less than 100 beds); high turnover and low turnover; religious-based vs secular.²⁷ Table 1 shows a comparison of these sites. These conditions have also been found to impact the successful implementation and adoption of change efforts, with homes that are smaller, not-for-profit, and have low turnover rates identified as having better conditions to support change.²⁸⁰

Recruitment of Participants

Following a period of training, designated staff located in each participating LTC home administered the Palliative Performance Scale (PPS) to all residents. The PPS was used to screen participants for potential involvement because it provides a framework for measuring progressive decline in palliative residents.¹⁷ PPS scores can be divided into three stages: stable, 100-70%, transition, 60-40%, and end-of-life, 30% and less. There is evidence that the PPS produces valid, reliable measurement of progressive functional decline in a patient suffering from a terminal or incurable illness. Based on previous pilot work, guidelines have been developed for successful implementation of the PPS in LTC.¹⁷

Residents who were English-speaking and scored 40% or less on the PPS, and/or their family were invited by staff to learn more about the SPA-LTC program and consider participating in research. All potential participants were contacted by a member of the research team who reviewed the research their potential involvement. Written consent was obtained from the resident and/or family member.

SPA-LTC Program

Prior to implementation of the SPA-LTC program, each site was invited to identify staff from interdisciplinary backgrounds to comprise a team of champion leaders who would receive training on best practices in a palliative approach to care, learn about the components of the SPA-LTC program and oversee implementation in study sites. Former work in the areas of culture change in LTC suggest this type of infrastructure holds promise in supporting implementation and sustainability.²³⁻²⁶ Once teams were established, each site was asked to conduct monthly comfort care rounds which comprised of case-based learning and exchange about topics of high importance to LTC staff.¹⁹ Palliative experts outside of the LTC sector facilitated these rounds and offered consultation services. Over time some sites used internal leaders to continue facilitating the rounds.

Participating residents and families were invited by staff to attend a Palliative Care Conference (PCC). The PCC component of the SPA-LTC program was adapted from the Palliative Approach Toolkit designed by Dr. Parker, an international co-investigator.¹² The Palliative Approach Toolkit has been implemented nationally in Australian LTC homes and supports a palliative approach in this context. Initially, we held a 'mock' PCC with staff to provide specific training and education about approaches and tips about what to expect and ways to deal with challenging situations. Together, staff reviewed the Guide to Conducting Palliative Care Conferences as a precursor to holding one and watched the training video, "On the Same Page". Documentation guides (Staff Planning Guide, Physician Fax Sheet, Good Palliative Care Plan, PCC Summary; all available upon request) from the Palliative Approach Toolkit were adapted for this study based on local contexts and to ensure they were consistent with the jurisdictional legal framework.

Condition specific pamphlets for five conditions of high prevalence in LTC were made available in participating LTC home via display boards or through staff distribution.^{15,16} Because these resources evolved from feedback received during the course of the project, no formalized protocol for administration was developed. Staff were instructed to consider distributing the pamphlets to those residents and families scheduled for a PCC. Likewise, bereavement pamphlets were developed and distributed to family members as directed by staff.²⁰

Data Collection and Analysis

Hospital Use at End of Life and Participating Resident Demographics

At baseline, administrative data (quantitative) was collected retrospectively for all residents who had died over the past year. The same data was collected at study end, 18-months later, for participating residents only. Data were collected for the following indicators: (a) number of resident deaths; (b) number of resident deaths that occurred at the hospital versus LTC home; and (c) number of residents who visited the emergency department visits in their last year of life. Relative risk reduction (RRR) and confidence intervals (CIs) were calculated for the proportion of resident deaths that occurred in hospital and emergency department use comparing the baseline (all residents) and post-implementation (participating residents only) data.

Chart reviews of participating residents also included demographic information, admission information (date and diagnosis), Charlson Comorbidity Index (a measure that aims to categorize comorbid medical conditions that can alter mortality risk)²⁹, PPS scores and palliative care conference notes. Chart data were analyzed using descriptive statistics (i.e., frequencies, percentages) for each home separately and were then summarized across all four sites at both time-points (i.e., before and after implementation).

Staff Collaboration and Comfort with End-of-Life Care

We administered pre-post surveys to staff to explore the impact of the SPA-LTC program on staff collaboration and comfort with caring for residents at end of life. The survey was composed of two questionnaires: the End-of-life Professional Caregiver (EPCS)³⁰ survey and the Intensity of Inter-Professional Collaboration (IIPC)³¹ and took about 10-15 minutes to completed. The EPCS is a 28-item scale with strong internal consistency ($\alpha=.96$). Each item scored on a 5-point Likert scale ranging from 1 (lowest level of skill) to 5 (greatest level of skill). It includes three subscales: a 12-item Patient-and Family-Centered Communication (PFCC); 8-item Cultural and Ethical Values (CEV); and 8-item Effective Care Delivery (ECD).³⁰ The PFCC subscale measures includes items focused on the comfort with discussing palliative issues (e.g., accepting a prognosis, goal setting, ACP, grief) with family and/or other health care professionals.³⁰ Items included in the CEV subscale are focused on providing culturally and ethically competent care, while ECD items relate to clinical competence (e.g., referring to hospice, familiarity with PC principles, linking with appropriate services when needed and navigating the system) and perceived availability of workplace support for palliative care.³⁰

The IIPC is an 18-item scale that measures two factors: care sharing activities and interprofessional co-ordination.³¹ Initial factor analysis and validation of this scale indicated that the main factors associated with interdisciplinary collaboration are most closely aligned to intragroup dynamics and values.³¹ Demographic and employment data such as age, gender, length of time working in LTC, occupational group, and involvement in care planning activities were also collected. Demographic data was analyzed using descriptive statistics. To compare differences between pre and post survey results, a multilevel model was used since not all participants were paired between pre- and post-implementation.

We worked with the LTC administrative staff to distribute the survey via inter-facility mail to all LTC staff. We also distributed surveys at staff educational events to improve the response rate. We tracked those staff who completed the survey and followed up with those who did not with a subsequent mail distribution. To encourage completion, we held a draw for a \$50 gift card at each participating LTC home, and draw entry was contingent on survey completion. All completed surveys were returned via mail.

Acceptability of the SPA-LTC Program

Family Members

At study end all family members of enrolled residents were invited to participate in telephone interviews to capture their perceptions and experiences of the SPA program, with particular focus on attending a PCC. Questions focused on how supported family felt and whether their concerns were met during the PCC, and their comfort level with end of life discussions. Interviews focused on: (a) how helpful was the PCC, (b) how supported did you feel by staff during the PCC, (c) how well were your concerns addressed at the PCC, and (d) how comfortable did you feel making arrangements or decisions after the PCC.

Staff

LTC staff at each study site were invited to participate in a post implementation focus group to explore (a) their experiences with implementing the SPA-LTC program; (b) related barriers and facilitators; and (c) suggestions for refining the program to make it more user-friendly in the practice setting. Three focus groups took place at each participating LTC site for a total of 12 focus groups. Each site conducted a focus group with regulated staff, unregulated staff, and the site palliative champion team. Qualitative data were transcribed and coded using thematic content analysis.³²

Results

Characteristics of Participating Residents

The total number of residents living within the four participating LTC homes was 551, and staff completed PPS scores for 99% (n=543) (Figure 2). Of these residents, 20% had a PPS score between 30-40% (n=110) and 1% (n=5) had a PPS score less than 30%. Of the 115 eligible participants 39 residents/families agreed to participate in the study representing a response rate of 34%. Of the 39 participating residents, 23 (59%) were female, and 34 (87%) had a diagnosis of dementia. The average Charlson Comorbidity Index score was 7.13 (Table 2).

Hospital Use at End-of-Life

Baseline chart audits revealed that 25.6% (141/551) of all LTC residents living within the four participating homes died in the year prior to study implementation, with the majority of the 141 resident deaths (71.6%) occurring at the LTC home (Table 3). Of the 141 residents who died, 92(65.3%) of them visited emergency departments during the last year of life.

At study end, the same data were collected for participating residents only. Of them, 87.2% (34/39) had a PCC during our 18-month data collection period (Figure 2), with 80.7% (21/26) having a PCC before they died (Table 3). Findings indicate that there were statistically significant reductions in rates of hospital deaths (RRR: 72%, CIs: 0.05, 0.93) and emergency department visits (RRR: 54%, CIs: 0.0.15, 0.73) during the last year of life for residents who participated in the SPA-LTC program.

Staff Collaboration and Comfort with End-of-Life Care

Of the 697 surveys distributed at baseline, 317 were completed and returned to study investigators, for a total response rate of 45%. The response rate by occupational group was 45% for personal support workers/care aides (126/317), 50% for support staff (109/219), and 55% for registered staff (82/148). Staff members were primarily female (86.9%) with the majority (82%) aged 35 and older (Table 4 shows a summary of staff demographics). Most participants earned a college diploma or higher (79.7%) and were employed on a full-time basis (64%). The participants had a mean of 10.6 (SD = 8.5) years of experience working in LTC and a mean of 8.5 years (SD=7.6) working with their current employer. Fifty-six percent of participants reported that they had attended care conferences, with 74% of registered staff and 31% of support staff endorsing this item. Seventy-two percent of participants reported that they had contributed to the development of care plans for residents, with 91% of registered staff and 39% of support staff endorsing this item.

At study end, of 702 staff surveys distributed, 176 were completed and returned to study investigators, for a total response rate of 25%. Like baseline survey participants, respondents were primarily female (81.3%) with the majority (75%) aged 35 and older. Most had earned a college diploma or higher (85.2%) and were employed on a full-time basis (61.4%). Participants worked a mean of 10.2 years (SD = 12.2) in LTC and 8.0 years (SD = 8.0) with their current employer. Forty-six percent of participants reported that they attended care conferences and 65.9% of participants reported that they contributed to the development of resident care plans.

Mean total and sub-scores of the End-of-Life Professional Caregiver Survey (EPCS) and Intensity of Inter-Professional Collaboration (IIPC) Survey were compared between pre- (n = 317) and post-implementation groups (n = 176; Table 5). No significant differences were found between pre- and post-implementation groups for both EPCS and IIPC total and sub-scores. The model showed no significant differences after adjusting for occupational group (Personal Support Workers vs. Nurses & Allied Health vs. Support Staff).

Acceptability of the SPA-LTC Program

Family Members

Eight of the 34 family members whose relatives had PCCs agreed to be interviewed on their experiences. Since the PCCs were the most visible component of the SPA-LTC program for residents and families, interviews focused predominantly on experiences with PCCs and overall experiences with end of life care. Family members reported that they felt well supported at the PCC and that it was helpful for them. However, one family member reported missing the physician presence at the PCC. The majority of family members reported that they discussed end-of-life issues at the meeting and that their concerns and the kind of care and services wished for at end-of-life were addressed at the meeting.

One family member stated, “*The quality of my experience was great. I feel like everybody knows what's going to happen when it starts to happen, and there's comfort in that, and what will be a terrible and difficult time will be less terrible and difficult because we all know what she wants*” (Site 4). When probed to respond about how their family member’s care had changed after the meeting, one participant stated, “*my mom used to take all kinds of vitamins and so on, they removed all of that, because she was regurgitating, so that helped*” (Site 1)

Participants made a few recommendations about how the SPA-LTC program could be improved, mostly recommending earlier discussions with families about end-of-life issues to facilitate preparation, prioritizing pain and comfort for residents, optimizing the social worker role in promoting a positive end-of-life experience in LTC, and providing grief and bereavement support to families should they need it.

For example, one family member stated, “*Do whatever they can to make him comfortable, that's what my priority would be. Also letting me know what's going on...basically just giving me the information I needed for him, like being kept up-to-date*”.

Another family member stated:

I really appreciated that I could make preparations prior to her passing, rather than waiting so that I'm not under a rush when I have to do it....you don't have much time to make these decisions, and if it's your first time, its not an easy thing...so it's preparing... (Site 4)

Finally, a family member emphasized the importance of supporting families who may be struggling, especially during the bereavement phase:

If the family members need grief counselling...because at times I wondered where would you go for that sort of thing if it becomes necessary...I mean the death is expected when someone's old but you don't know it's gonna affect you right? (Site 3)

Staff

Overall, 20 champion team members, 27 nurses/registered staff and 40 personal support workers (PSWs)/support staff participated in the focus groups (see Table 6 for characteristics of staff who attended a focus group). The four main themes emerged from the analysis including benefits, facilitators, challenges and recommendations/suggestions.

Benefits

Staff identified several benefits of the intervention: improved interdisciplinary communication; opportunities to reflect and share experiences; increased family involvement in care; improved practices and skills. Staff commented that they appreciated being more supported through comfort care rounds; comfort care rounds provided an opportunity to reflect on experiences and to explore other perspectives. For example, a staff member stated, “... I think a lot of the times when deaths happen we don't really get a chance to kind talk about it. It just kind of happens and I mean you talk about it with your team but then you just move on, move on. But you don't really get a chance to reflect and think about it. So, I thought it was really nice to have the comfort care rounds to have an opportunity to share experiences” (Site 4, champion team).

Staff thought that the intervention increased family involvement in resident care. One staff member stated, "those families who are not speaking for how many years and they come together at the same time...but they come because of the resident and that's important" (Site 4, CT). Staff also described palliative care conferences as an effective way to communicate with the family and identify their concerns.

In addition to family involvement, the intervention also improved practice. There were more initiatives from staff to start palliative care and end-of-life care conversations early, with some staff members interested in starting them with residents and families at the time of admission. There were also observed changes in practice across all disciplines. For example, "Dietary has been more involved with foods that provide comfort...the PSWs are more comfortable I think coming forward and expressing what they'd like to see and how their residents are being handled...so there's a lot more multi-disciplinary input" (Site 3, PSW). Staff thought that specialized skills and knowledge related to implementing a palliative approach to care are beneficial. Staff provided positive feedback about the staff training and mentioned that they often looked for opportunities to update their skills.

Facilitators

Staff thought that all components of the SPA-LTC program helped to facilitate the delivery of care in different ways. Many staff agreed that the comfort care rounds provided opportunity for critical reflection surrounding death. One nurse stated, "yeah so the comfort care rounds have kind of pushed me to think more about the residents' death... to critically think about death and analyze it so that the next one can be better" (Site 3, Nurse). Furthermore, overall, the pamphlets were seen as very informative. However, there was some criticism of the pamphlet design, as one nurse said, "the only thing I would say is it's very busy...just a lot of information" (Site 3, Nurse). Champion team meetings were seen as excellent facilitators of inter-disciplinary communication. They especially facilitated the delivery of patient-centered care in the end-of-life. For example, one staff member stated, "when you're at end of life, it's the whole person you have to be considerate of and so you need input from every area" (Site 4, champion team). Palliative care conferences were also seen as beneficial as they allowed residents who were cognitively capable to describe "what they really want to happen in the end" (Site 4, Nurse). This helped staff be more prepared regarding the type of care they should provide at end-of-life and facilitated the delivery of patient-centered and family-centered care. Similarly, the Palliative Performance Scale helped staff to tailor their activities and tasks based on their functional status to best suit the needs of the resident.

Challenges

Staff also expressed challenges they experienced throughout the implementation. Initially, implementing multiple intervention components was difficult, as one staff member described, "It was difficult to get it going and we're trying really hard to maintain it [and] to incorporate it into our daily life here" (Site 3, CT). With regards to the comfort care rounds, one health care aide stated, "the comfort rounds are at an awful time. Like right after supper, or right after lunch that's toileting time and transporting time" (Site 3, PSW). Furthermore, staff described power inequality and lack of communication. They felt there was a lack of communication between PSWs and the rest of the healthcare team. One PSW explained, "we don't go in the conference, they don't ask us" (Site 4, PSW), further explaining that it was the nurses who usually attend the conferences. Therefore, PSWs felt that it was challenging to be involved in the intervention and to integrate a palliative approach within their practice due to the lack of communication and involvement in intervention components.

Furthermore, staff noted that their values of care continue to differ and conflict with those of families. Some said, "families hold expectations that their loved one may recover" (Site 3, Nurse). Some families were also perceived as being "uncomfortable talking about death" (Site 3, Nurse), which served as a barrier when trying to implement intervention components. It is evident that LTC homes continue to have inadequate resources for palliative care, as the staff to resident ratio was mentioned throughout the interviews as a barrier to time management and quality of care.

Recommendations

Staff offered several recommendations to improve the intervention as well as their ability to implement a palliative approach in LTC. In particular, staff thought that "the whole philosophy of LTC, in Ontario anyway, needs to be revamped" (Site 1, champion team). Recommendations for improvement included educating family members about LTC so that they are prepared, conducting comprehensive assessments of the resident to identify goals of care early on, and encouraging better continuity of care through clear communication as residents transfer between facilities.

Staff thought that it was important to have discussions about end-of-life and goals of care prior to moving into LTC. Recognizing that this does not happen and in order to provide education effectively, staff made suggestions on the most appropriate time to disseminate pamphlets, with one nurse suggesting, "I think it would be best if it was given at the first family care conference...and it should be communicated to families that if, if you need another one...that you could have more" (Site 3, Nurse). Another nurse suggested, "It would be ideal I think to have them on an as needed basis" (Site 3, Nurse). Staff thought that this would be beneficial for both residents and the staff at the LTC home. As one staff member stated that it is "...better when you know that somebody is at end of life ... then from beginning we won't go and treat him like a resident who is on level 3 or 4 [high function], we will actually provide that comfort care from the beginning..." (Site 2, champion team).

Other recommendations were to further facilitate the integration of a palliative approach. These recommendations included: addressing religion and culture, bereavement support interventions, and personal care items, such as open back clothing and hygiene baskets. One PSW suggested a new bereavement ritual, using placemats, stating that "when someone passes we [can] put [the mat] on their place where they used to sit and then people can sign and just say a few words or anything they want to say. It's kind of like closure" (Site 4, PSW).

Discussion

These study findings support the SPA-LTC program. Across four LTC sites, this program reduced hospital use at end-of-life, with significant reductions in emergency department use and hospital deaths. Qualitative findings indicated that family members experienced PCCs positively.

Other research also supports the effectiveness of multidisciplinary team meetings (such as PCCs) that include family members and residents (if able), to reduce hospital use for LTC residents.³³⁻³⁵ For example, Phillips et al. (2013) found that PCCs improve medication management and support a palliative approach to care for people with advanced dementia in LTC.³⁶ However, they stated that PCCs are feasible if the identified barriers are addressed and the facilitators optimized, namely related to the capacity of physicians to contribute to the interdisciplinary care planning. Certainly, the demands placed on staff to organize and hold PCCs is important to

consider, as suggested by our qualitative study results. Perhaps optimizing already scheduled annual care conferences in LTC could help offset the demands of holding an additional PCC. To do this, the annual care conferences would need to be adapted to include more emphasis on ACP and goals of care discussions, which generally is not the case. Clearly, a shift in culture is needed to fully integrate a palliative approach to care.

Research suggests that the absence of ACP contributes to higher rates of hospital transfers of LTC residents.³⁷ As such, the need for ACP to be regularly occurring in LTC is increasingly recognized.^{38,39} LTC residents and their families have reported that more preparation and information helps them make critical decisions later on when end-of-life is near³⁹, which is consistent with our study findings. This is even more important for those residents who have cognitive impairment, who have limited time that they can engage in ACP discussions with their family or LTC staff. There is a need for ACP documentation so staff at palliative care conferences can reflect on previous discussions so that goals of care at end-of-life can be developed with residents/families/substitute decision makers.

We believe the positive findings from this study can be partially attributed to using participatory action research methods, which aims to pursue action (or change) and research (or understanding) within an emergent process.²² The emphasis of PAR on collaboration, action, and reflection was particularly advantageous in this study as it allowed for strategies to be developed in response to the identified gaps in care to meet needs of each LTC home in a timely manner. For example, untapped resources and expertise that currently existed outside of the LTC home were leveraged, such as local community palliative consultants, to help build capacity within each participating LTC home to implement the SPA-LTC program. Similarly, Heals (2008) examined the use of hospice link nurses providing a 24-hour telephone advice line, formal education, and opportunities for LTC staff to discuss difficult issues and concerns with the hospice nurses.⁴⁰ They found improvements noted in documentation and care planning. Other research has found similar results with leveraging palliative consultants, including: (a) a growth in referrals, positive culture changes within LTC, and more use of tools used in family meetings⁴¹, (b) decreased emergency calls from LTC and use of hospital⁴²; and, (c) improved resident pain and functional status.⁴³

Using a PAR approach also supports sustainability of a program or intervention as it strives to build capacity within an organization to promote change that can be maintained over time.²² Given the challenges that were reported in our study findings (e.g., inadequate resource, lack of support), which seem to be a normal part of practice change and the fact that they were recognized by participants, this could be viewed as positive in the context that these challenges have been offset by various intervention strategies (e.g. development of a champion team, access to external supports, education and training).

Another strategy that is emerging as a potential benefit to LTC homes to help avoid ED transfers at end-of-life is the community paramedic outreach program. This involves paramedics receiving additional training in: (1) geriatric assessments and management, (2) end of life care, (3) primary wound closure techniques, and (4) point of care testing.⁴⁴ Medical oversight is provided by a physician along with guidelines, available to LTC homes between 9am and 9pm, seven days a week. Paramedics are dispatched by the communication center when requested by LTC staff and must communicate with either the overseeing physician or the LTC physician at each visit to make decisions about plans for care.⁴⁴

It was disappointing that we did not find a significant improvement in staff knowledge and comfort with implementing a palliative approach to care. Although education and training have been identified as a critical

need for LTC staff, findings of quantitative studies of education programs are inconsistent. Our study findings could reflect that the fact that not all staff who completed the survey attended the training sessions. Our focus was to 'train the trainers' but clearly there is a need to ensure all staff benefit from organization's training. Future work should ensure that all staff attend training, including personal support workers/care aides and support staff, since they reported less comfort and higher needs related to engaging and supporting residents and families within a palliative approach. Our survey findings may reflect the lack of widespread education and skilling up, only champion teams attended education sessions. Other explanations for the lack of significant improvements in staff knowledge and comfort in palliative care could be lack of power due to our small pre-post sample size and inability to conduct a nested analysis within each site. Most likely, these study findings are due to the very small numbers of residents and families who participated in a palliative care conference so staff which limited staff exposure to 'practice' and gain confidence in their abilities to implement a palliative approach.

Strengths and Limitations

There were strengths and limitations to this survey. First, this study used a pre-post study design with no control group so our only control measure was our baseline scores, which could have accounted for some bias in our sample. Also, we were not able to compare the characteristics of our baseline sample of residents with the participating (post) resident sample so we could not assess if the two samples were comparable for our analysis. Also, the lack of significant improvement in staff collaboration and comfort with end of life care could be due to our small sample. Finally, our small response rate of family members who agreed to be interviewed so interpretation of the acceptability of the SPA-LTC should be taken with caution.

Implications for Practice

Based on our study findings, we developed some implications for practice, research and policy:

1. Provide increased communication through multiple strategies to improve staff knowledge of program and decrease uncertainty. Strategies may include:
 - Regular verbal communication at daily huddles regarding the program's weekly scheduled topic
 - Printed resource material i.e. pamphlet, available to both staff and families regarding program goals, structure and activities, including participant guidelines and 'selective sharing'; and online learning opportunities for staff to cater to different learning styles
2. Provide opportunities for inter-professionalism with participation of front-line staff in program. Strategies may include:
 - Inviting front-line staff to provide educational presentations to the group
 - Inviting a designated staff representative and case manager in addition to the nurse manager to attend occasional meetings to receive and provide feedback on group member's concerns
3. Consider availability and use of technology to provide long-distance access to the program. Strategies may include:

- Use of teleconference or video conference to facilitate long-distance participation in meetings to be more inclusive of family members
- Dissemination of meeting educational handouts electronically through a web platform for open access to all
- Audio recording of meetings to be shared with non-attending CG
- Voluntary linking of CGs through email if desired

Conclusions

Despite the study limitation, this study does provide support for the SPA-LTC program in improving hospital use at end of life and improving family satisfaction with care. Study results also suggest that certain enhancements of the program could further promote future integration of best practices within a palliative approach to care within the LTC context. Future work is needed to evaluate the SPA-LTC program using a randomized control trial with larger sample sizes to provide stronger support for its use and spread in other LTC homes.

Abbreviations

LTC: long term care

SPA-LTC: Strengthening a Palliative Approach in Long Term Care

PPS: Palliative Performance Scale

PCC: Palliative Care Conferences

EPCS: End-of-life Professional Caregiver

IIPC: Inter-Professional Collaboration

PFCC: Patient-and Family-Centered Communication

CEV: Cultural and Ethical Values

ECD: Effective Care Delivery

SD: standard deviation

RRR: relative risk reduction

CI: confidence intervals

ACP: advance care planning

Declarations

Ethics approval and consent to participate: This study was approved by the Hamilton Integrated Research Ethics Board (#14-863), the McGill University Ethics Review Board (#243-1214). Written consent was obtained from all

participants.

Consent for publication: Not applicable.

Availability of data and materials: All data generated or analysed during this study are included in this published article. The datasets generated and/or analysed during the current study are not publicly available due to constraints of our ethical review approvals related to privacy laws.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: All authors have read the manuscript and have approved its submission. SK and TS: ultimate authority over any activities of study design; collection, management, analysis, and interpretation of data; writing of the manuscript for publication. SK, TS: conducted data analysis. GT, LM, PH, LV, AWG, SS, VDH, ME, VDH, JP, DP, JY provided critical feedback on interpretation of study results and writing of the manuscript.

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Tables

Table 1: Comparison of Sites

Site	Profit/Not-for-profit	# of beds	Administrator Turnover rate	Diversity
1	For-profit	206	Moderate	Culturally diverse, various faiths
2	For-profit	169	High	Culturally diverse
3	For-profit	64	Moderate	Many residents without family/once homeless
4	Not-for-profit	112	Low	Operates within the context of Jewish culture and values

Table 2: Characteristics of Participating Residents (N=39)

Characteristic	n (%)	Mean (SD)[1]
Sex		
Male	16 (41)	
Female	23 (59)	
Age at the time of enrolment (years)		84.6 (10.9)
Length of Stay in LTC (years)		5.6 (3.3)
Charlson Comorbidity Index		7.1 (2.00)
Palliative Performance Scale		
· <30%	3 (7.7)	
· 30-40%	36 (92.3)	

[1] Standard Deviation

Table 3: Site of Death and Emergency Department (ED) Visits in the Last Year of Life at Baseline (All Residents) and Post Implementation (Participating Residents Only)

OUTCOME	Pre n=141 n (%)	Post n=26 n (%)	RRR ^a	Confidence Intervals
Had PCC before Death	N/A	21(80.7)	—	—
Hospital Deaths	40 (28.4)	2 (7.7)	72%	0.05, 0.93
ED Visits	92 (65.3)	8 (30.8)	54%	0.15, 0.73

Notes: ^aRRR = Relative Risk Reduction

Table 4: Staff Survey Demographic and Employment Characteristics by Occupational Group[1]

Demographics Characteristic	Pre-Implementation (n = 318)	Post-Implementation (n = 176)
Sex, n (%)		
Male	41 (12.9)	24 (13.6)
Female	274 (86.2)	143 (81.3)
Age, n (%)		
Under 25	5 (1.6)	8 (4.5)
25 to 34	50 (15.7)	27 (15.3)
35 to 44	82 (25.8)	43 (24.4)
45 to 54	100 (31.4)	52 (29.5)
55 to 64	63 (19.8)	38 (21.6)
65+	11 (3.5)	4 (2.3)
Highest Level of Education Completed, n (%)		
High School or Equivalent	64 (20.1)	25 (14.2)
College	143 (45.0)	83 (47.2)
Undergraduate Degree	42 (13.2)	25 (14.2)
Graduate Degree	54 (17.0)	30 (17.0)
Other	9 (2.8)	6 (3.4)
Occupational Group, n (%)		
PSW	127 (39.9)	61 (34.7)
Nurses & Allied Health	81 (25.5)	53 (30.1)
Support Staff	110 (34.6)	62 (35.2)
Employment Status, n (%)		
Full-Time	200 (62.9)	108 (61.4)
Part-Time	112 (35.2)	63 (35.8)
Casual	2 (0.6)	2 (1.1)
Years Working in LTC, mean (SD)	10.7 (8.5)	10.2 (12.2)
Years with Current Employer, mean (SD)	8.6 (7.6)	8.0 (8.0)
Attended rounds, n (%)	178 (56.0)	84 (47.7)
Reviewed residents' charts, n (%)	210 (66.0)	113 (64.2)
Wrote residents' charts, n (%)	160 (50.3)	94 (53.4)
Attended care conferences, n (%)	158 (49.7)	81 (46.0)
Contributed to care plans, n (%)	208 (65.4)	116 (65.9)

[1] Total number may not equal 100% due to missing responses

Table 5: Pre- and Post-Implementation Mean EPSCS and IIPC Total Scores and Subscales

Scores	Pre-Intervention		Post-Intervention		$\beta^{[*]}$	<i>p</i> -value
	Mean	SD	Mean	SD		
EPCS[†]	2.45	0.947	2.43	1.028	-0.09	0.229
PFCC[‡]	2.61	1.000	2.58	1.130	-0.05	0.568
CEV[§]	2.49	1.050	2.46	1.080	-0.11	0.165
ECD[**]	2.19	0.999	2.17	1.060	0.01	0.875
IIPC[††]	3.95	0.716	4.01	0.677	0.05	0.416
IP[##] Caring	3.94	0.764	4.01	0.721	0.06	0.387
IP Coordination	3.97	0.754	3.99	0.741	0.01	0.868

[*] Beta

[†] End-of-Life Professional Caregiver Survey

[‡] Patient and Family Centered Communication

[§] Cultural and Ethical Values

[**] Effective Care Delivery

[††] Intensity of Inter-Professional Collaboration

[##] Inter-Professional

Table 6: Staff Focus Group Demographics

CHARACTERISTIC	Champion Team		Nurses/Registered Staff		PSWs/Support Staff		Total	
	(N=20)		Staff (N=27)		Staff (N=40)		(N=87)	
	n	%	n	%	n	%	n	%
Role	N=20		N=27		N=38		N=85	
Male	3	15.0	5	18.5	2	5.3	10	11.8
Female	17	85.0	22	81.5	36	94.7	75	88.2
Professional Group	N=17		N=27		N=36		N=80	
Registered Nurse	5	29.4	17	63.0	1	2.8	23	28.8
Registered Nurse Practitioner	0	0.0	1	3.7	0	0.0	1	1.3
Registered Social Worker	2	11.8	1	3.7	0	0.0	3	3.8
Physiotherapist	1	5.9	0	0.0	0	0.0	1	1.3
Technician	0	0.0	0	0.0	0	0.0	0	0.0
Administrative Staff	0	0.0	0	0.0	0	0.0	0	0.0
Housekeeper or Cleaner	0	0.0	0	0.0	4	11.1	4	5.0
Personal Support Worker (PSW)	0	0.0	0	0.0	27	75.0	27	33.8
Total	9	52.9	8	29.6	4	11.1	21	26.3
Age Range	N=20		N=27		N=38		N=85	
Under 25	0	0.0	0	0.0	2	5.3	2	2.4
26 to 34	6	30.0	4	14.8	7	18.4	17	20.0
35 to 44	7	35.0	8	29.6	10	26.3	25	29.4
45 to 54	3	15.0	13	48.1	11	28.9	27	31.8
55 to 64	3	15.0	12	44.4	7	18.4	22	25.9
Total	1	5.0	0	0.0	1	2.6	2	2.4
Employment Status	N=20		N=27		N=39		N=86	
Full-Time	20	100.0	18	66.7	28	71.8	66	76.7
Part-Time	0	0.0	9	33.3	11	28.2	20	23.3
Employment Conditions	N=20		N=26		N=38		N=84	
Hired by LTC	18	90.0	24	92.3	36	94.7	78	92.9
Contracted by LTC	2	10.0	2	7.7	2	5.3	6	7.1

Figures

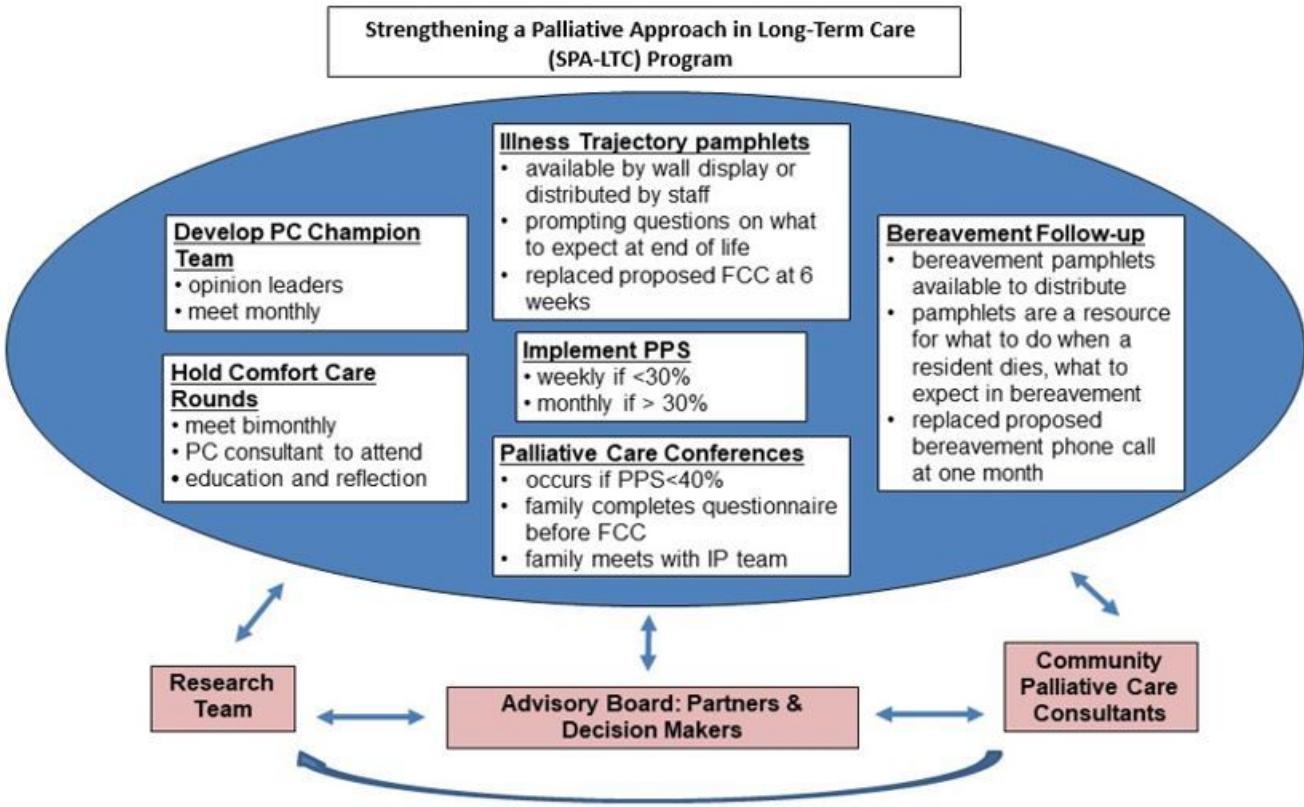


Figure 1

PC = Palliative Care PPS = Palliative Performance Scale

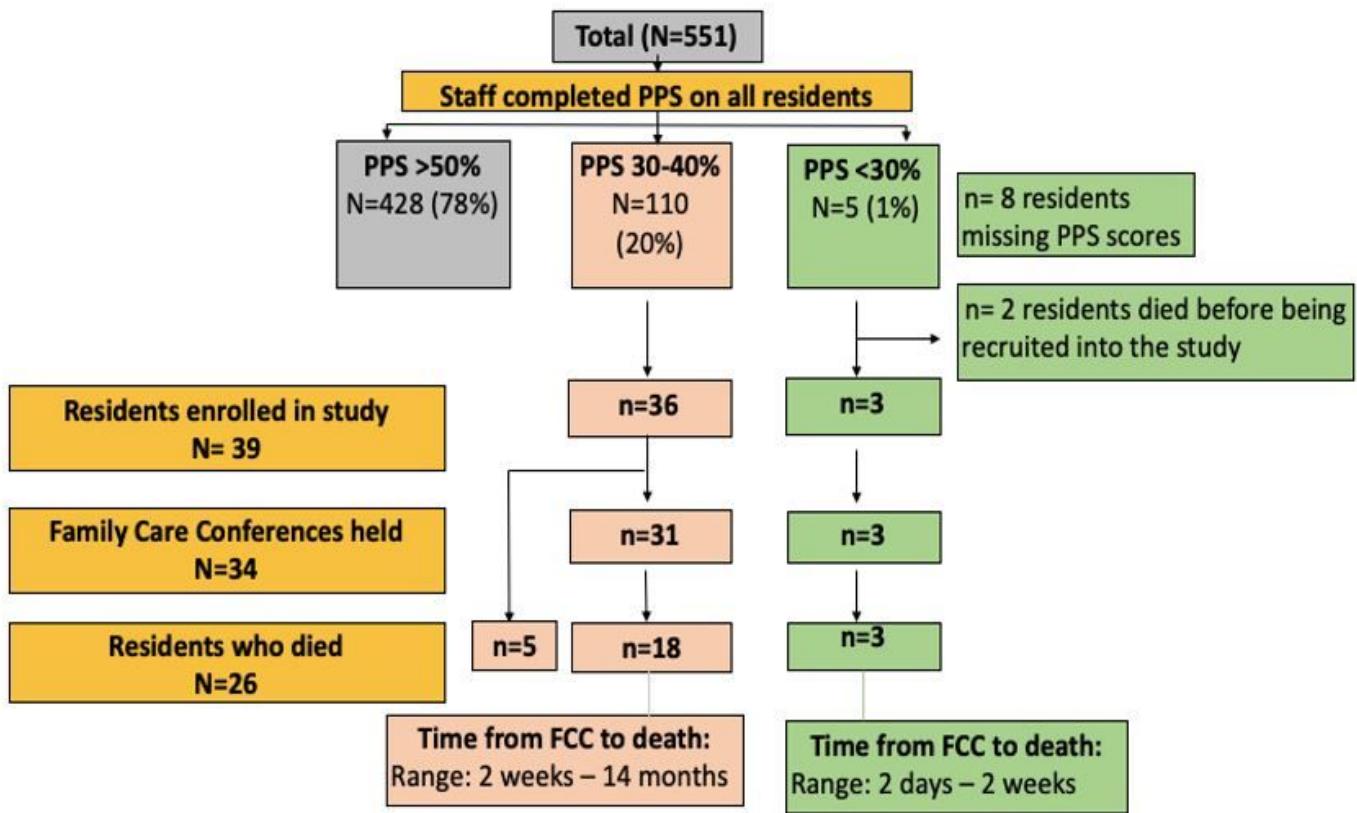


Figure 2