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Palliative Care Implementation in Long-Term Care Facilities: European Association for Palliative Care White Paper

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A B S T R A C T

Objectives: The number of older people dying in long-term care facilities (LTCFs) is increasing globally, but care quality may be variable. A framework was developed drawing on empirical research findings from the Palliative Care for Older People (PACE) study and a scoping review of literature on the implementation of palliative care interventions in LTCFs. The PACE study mapped palliative care in LTCFs in Europe, evaluated quality of end-of-life care and quality of dying in a cross-sectional study of deceased residents of LTCFs in 6 countries, and undertook a cluster-randomized control trial that evaluated the impact of the PACE Steps to Success intervention in 7 countries. Working with the European Association for Palliative Care, a white paper was written that outlined recommendations for the implementation of interventions to improve palliative and end-of-life care for all older adults with serious illness, regardless of diagnosis, living in LTCFs. The goal of the article is to present these key domains and recommendations.
Design: Transparent expert consultation.
Setting: International experts in LTCFs.
Participants: Eighteen (of 20 invited) international experts from 15 countries participated in a 1-day face-to-face Transparent Expert Consultation (TEC) workshop in Bern, Switzerland, and 21 (of 28 invited) completed a follow-up online survey.
Methods: The TEC study used (1) a face-to-face workshop to discuss a scoping review and initial recommendations and (2) an online survey.
Results: Thirty recommendations about implementing palliative care for older people in LTCFs were refined during the TEC workshop and, of these, 20 were selected following the survey. These 20 recommendations cover domains at micro (within organizations), meso (across organizations), and macro (at national or regional) levels addressed in 3 phases: establishing conditions for action, embedding in everyday practice, and sustaining ongoing change.
Conclusions and implications: We developed a framework of 20 recommendations to guide implementation of improvements in palliative care in LTCFs.

The current changes in global demographics have led to an increased older population that creates a large public health challenge.[1] It is estimated that the older population, age 60 years and over will double from 11% to 22% between 2000 and 2050.[2] Dying and death are inevitably faced by an aging population, and the place of death is of concern to health commissioners and service providers. Where available, a proportion of older people will live and

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die in long-term care facilities (LTCFs).[3] In this article, we refer to LCTFs as: (1) A collective institutional setting where care is provided for older people who live there, 24 hours a day, 7 days a week, for an undefined period of time; (2) The care provided includes on-site provision of personal assistance with activities of daily living; and (3) Nursing and medical care may be provided on-site or by nursing and medical professionals working from an organization external to the setting.[4]

Palliative care aims to improve the quality of life of residents, their families, and their caregivers, and has been recommended for LTCFs.[5] The key features of general palliative care that are relevant in the LTCF context for older people (a considerable proportion of who have dementia) include autonomy of the individual, maintenance of dignity, the relationship between patient–healthcare professionals, quality of life, and communication.[6,7] There are many similarities between palliative care in LTCFs and general high quality person centered care in these settings. However, palliative care has a unique focus having the explicit and proactive attention to the end of life and what needs to be addressed to ensure that appropriate care is available and provided in this phase of life.[8] There is evidence from a large European study that the provision of general palliative care delivered in LTCFs is variable and needs improvement.[9,10]

The promotion and provision of palliative care in LTCFs has been subjected to scrutiny for many decades internationally.[11–13] During the last 30 years, a range of interventions have been developed and promoted to improve palliative care in LTCFs, but many have struggled with aspects of implementation and sustainability.[13] There is now a recognition that implementation of interventions in LTCFs requires a novel approach that also addresses change management and sustainability.[14]

There are many barriers to delivering palliative care in LTCFs, such as high staff turnover, low levels of staff education, financial pressures, and limited links with wider specialist palliative care services.[15] Although these are not unique to the implementation of palliative care initiatives, they reflect the context within which the change needs to be implemented. Therefore, ensuring the success of palliative care interventions requires an approach to implementation that can overcome inherent difficulties in promoting change in LTCFs.[16]

To date, there are no guidelines regarding strategies to be followed when implementing palliative care interventions, nor any practical recommendations for LTCFs and palliative care services working with them. This article seeks to combine and synthesize evidence identified from empirical research[10] and a scoping review,[15] working in partnership with the European Association for Palliative Care (EAPC), along with expert stakeholders, to develop a framework that outlines recommendations to support the successful implementation of palliative care interventions in LTCFs and formalize it in an EAPC white paper.

Methods

Research Design

A 2-stage Transparent Expert Consultation (TEC),[17] comprising an expert workshop and an online survey, was undertaken to prepare and refine recommendations derived from evidence concerning implementation of palliative care in LTCFs identified during the PACE research[10] and scoping review[15] (Figure 1). TEC methods have been developed and used within palliative care research to generate consensus about methodological and practice

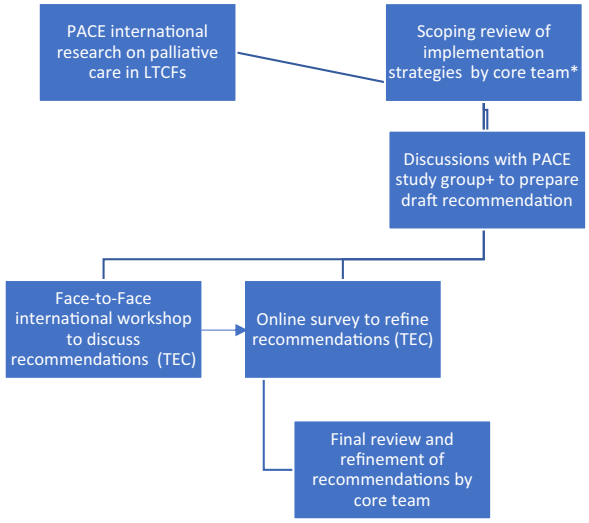

Fig. 1. Flowchart showing the development of the recommendations on implementing palliative care interventions in LTCFs. *Core team (KF, DCM, SP, LVdB). +PACE study group members listed in Acknowledgments.

issues.[17] The white paper was led by a core team (KF, LVdB, DCM, and SP) and a wider consultation with the PACE study group from 8 countries [Belgium, Finland, Ireland, Italy, Netherlands, Poland, Switzerland, and the United Kingdom (UK)] (listed in the Acknowledgements).

Sources of Evidence Informing the First Set of Recommendations

Evidence to support the recommendations was derived from several sources both within and beyond the Palliative Care in Older People (PACE) study. A cluster randomized control trial of the PACE Steps to Success program designed to support the delivery of palliative care in LTCFs was undertaken in 7 European countries (Belgium, Finland, Italy, Netherlands, Poland, Switzerland, and UK).[10] It comprised a 1-year multicomponent train-the-trainer program for LTCFs that aims to stepwise (involving 6 steps) implement a palliative care approach into the day-to-day routines in LTCFs. In summary, although the trial showed some positive effects related to differences in staff knowledge, there was no significant improvement in resident's end of life symptoms in the last week of life as rated by LTCF nurses.[10] The process evaluation showed that it was feasible to implement the PACE program but also highlighted the difficulties of implementing a complex intervention across 7 countries in the LTCF context. There was evidence of considerable variability in implementation both within and across countries.[18] More details of all the PACE studies[3,9,10,18–21] and key findings are presented in Table 1.

In addition, we conducted a scoping review to identify strategies used in the development and implementation of interventions on palliative care in LTCFs including barriers and facilitators that influence implementation. The review identified 8902 abstracts, from which 61 studies were included. A matrix of implementation was developed with 4 implementation strategies (facilitation, education/training, internal engagement, and external engagement) and 3 implementation stages (conditions to introduce the intervention, embedding the intervention within day-to-day practice, and sustaining ongoing change).[15] The themes identified in the scoping review were used to structure and develop 30 recommendations. This process was undertaken by the core team and the PACE study group.

Table 1
Details of Research Questions, Methods, and Key Findings of PACE Studies That Informed the Recommendations

Research Aims	Methods	Key Findings	Indicative Publications
What is the need and nature of palliative care provision in LTCFs in Europe?	Mapping survey of 29 countries	Implementation supported by drivers at macro, meso and micro levels Variable development of approaches to palliative care implementation in LTCFs across Europe	Froggatt K, et al.[3]
What were the palliative care needs of deceased residents in LTCFs in 6 countries?	Cross-sectional mortality follow-back study of deceased LTCF residents in 6 countries	Population still has care needs, physical, psychological, information, involvement Variation within and between countries re quality of care (life/dying), staff knowledge	Ten Koppel M, et al.[20]
Does the PACE Steps to Success development and educational intervention for staff in LTCFs improve general palliative care?	Cluster randomized control trial (CRCT) 7 countries (Belgium, Finland, Italy, Netherlands, Poland, Switzerland, UK).	Trial outcomes demonstrate that the intervention improved staff knowledge and attitudes toward palliative care but did not change the quality of end of life care in the last week of life.	Van den Block L, et al.[10]
Process Evaluation of the PACE CRCT	RE-AIM framework	Implementation quality was variable and challenging, some difference in staff attendance between countries and facilities; several recommendations for better implementation made based on process evaluation.	Oosterveld-Vlug MG, et al.[18]

Process of Preparing the White Paper Recommendations

The PACE project and a scoping review was used by the core team to prepare an initial 30 recommendations. These were then discussed with an international EAPC taskforce consisting of 13 recognized experts in palliative care, geriatric medicine, and management of LTCFs from different disciplinary backgrounds, taking account of geographic and cultural diversity, was established (see Acknowledgements). Our intention was to recruit people working at strategic and senior operational level rather than at a clinical level. Experts were selected by their academic research activities (including publications and track records) and via international networks. These experts were given the responsibility of preparing the white paper on behalf of the EAPC Board of Directors. KF and LvdB co-chaired the taskforce based on their expertise in this interdisciplinary field. These experts participated in the TEC face-to-face expert workshop (in Bern, Switzerland, in May 2018) and, otherwise, virtual contact was used. The core team led the collation and synthesis of the evidence that forms these recommendations.

Transparent Expert Consultation Procedures

Expert workshop

The draft recommendations were discussed at a 1-day face-to-face expert workshop held in Bern, Switzerland, on May 23, 2018. The purpose of the expert workshop was to discuss the initial recommendations on strategies for implementation of interventions to improve palliative care for older people residing in LTCFs. Following an introduction to the scoping review and PACE results, the full-day workshop took the form of 3 separate facilitated discussions, recorded by notes. The outcomes of the expert workshop were agreement on which recommendations were to be included and/or potentially deleted, feedback on recommendations that needed further revision, and identification of omissions of key issues.

Online survey

Following the expert workshop, recommendations were reformulated as an online survey, hosted by Qualtrics. The code banks for the 9 subthemes identified from the scoping review[15] were integrated with the refined recommendations of the workshop to create 30 recommendations for the online survey. The survey was e-mailed to the same 13 experts from the workshop and 15 others (n = 28) based in 16 countries across Europe, North America, and Australia. All were selected as either international expert in palliative care, long-term care, and/or aging, and included workshop attendees and other experts identified subsequently. Respondents were asked to rate each recommendation on a scale of 1 to 5, with 1 being very important and 5 being unimportant. Then, they were asked to identify the top 5 most important recommendations and finally to rank their 5 most important recommendations. Respondents could provide general free-text comments about each recommendation and its wording. The ratings were combined to give 3 categories: not important, slightly important and neutral; or important and very important. The wording of the recommendations was revised based on the comments received in the online survey.

Synthesis of Recommendations

The recommendations were further reviewed and refined based on the contribution of each of the following components: evidence from the PACE project, the scoping review, TEC workshop, and the online survey (Figure 1). During this final process, recommendations ranked below 20 were eliminated, and we refined the wording, where necessary, to improve clarity. The recommendations were categorized as micro, meso, or macro, and mapped against the 3 developmental stages of intervention implementation, which are explained in detail later.

Ethics and Consent

This article reports on the dissemination activities linked to the PACE study where National Health Service ethical approval was obtained on September 10, 2015 from National Research Ethics Service Committee North East—Newcastle and North Tyneside, UK (Ref: 15/NE/0261). All participants were informed that the activities formed part of the PACE project. Participants in the TEC workshop were formally asked to provide written informed consent to have their

views recorded via written notes and were made aware that these notes would be used to develop an EAPC white paper, which would be published. Survey respondents were emailed individually with information about the purpose of the survey and were informed that results would be published. Completion of the online survey was taken as implied consent. The survey was completed anonymously, and no data was collected in the survey that could be used to identify respondents.

Results

Eighteen (of 20 invited) people attended the TEC workshop. Their demographic characteristics are 5 men and 13 women, from European countries (14), Australia (1), Canada (1), New Zealand (1), and USA (1). The majority held clinical (10), research (14), and/or policy development roles (2) (Table 2). Their backgrounds were in palliative care and gerontology. For the online survey, 21 (of 28 invited) accessed the survey (response rate: 82%); no demographic data were collected.

Thirty recommendations were delineated as strategies for the development and implementation of palliative care in LTCFs. The numbered list reflects the order of priority for supporting implementation from the online survey (Table 3).

The recommendations covered 3 domains of activity: micro level, which relates to care within the LTCF, meso level, which relates to care across sectors and organizations, and macro level, which relates to regional and country factors such as policies and standards. Cross-cutting these activity domains are 3 process stages, which reflect the implementation process from initial "establishing conditions to introduce the intervention," to "embedding the intervention within day-to-day practice," and finally "sustaining ongoing change." We present the refined list of 20 recommendations (where the lowest-ranked 10 recommendations were deleted) within 3 levels across stages (Figure 2).

Domains and Stages in the Framework of Strategies for Implementation

We provide details of the domains of activity followed by the stages in the process of implementation.

The macro-level priorities identified here as competencies, regulatory frameworks, funding mechanisms, and legislation are required across the implementation process. They provide the wider context for the successful implementation of palliative care interventions. Depending upon the level of wider integration of palliative care in the country, not all 4 elements may be required.[4]

At the **start** of the process of implementation, several issues need to be addressed within (micro) and across organizations (meso) to ensure successful implementation.

To **start the implementation process**, it is recommended that appropriate resources are available to support an intervention's implementation, in the form of information, equipment, sufficient staffing, and time to make changes. Within-organization activity (micro) is ensured by an environment that has strong management support alongside appropriate preparation and information for individuals (both staff and residents and their families) who will be affected by the change.

Embedding the intervention in the LTCF is supported by ongoing education and training (which should be linked into national palliative care programs) and needs to be located in daily practice, with reflective elements. Integration of the intervention is supported when there is a fit with organizational values. Ensuring there is flexibility to adapt the intervention will lead to ensuring that the intervention becomes embedded into the routine care practices.

To sustain new changes, sustainability should be addressed at the start of the implementation process. This is manifested as the elements of the new intervention become a part of routine care. Underpinning this is sustaining a culture of reflective learning at an organizational level to ensure continuing quality improvement. An example of reflective learning would be reflective debriefing groups held regularly to review care provision following the death of a resident.[22]

The within-organization priorities are reflected by the LTCF's engagement across organizations with other health and social care providers, including specialist palliative care services. A shared acknowledgement of a need for palliative care, and what this might look like, is balanced by the practical need for appropriate facilitation, either external to a LTCF or internally with external support. Teamwork within and across organizations is promoted through management support from external sources either within the LTCF organization or the wider health and social care economy.

It is worthy of note that certain aspects, such as the availability of written document resources, were not endorsed by the experts. The expense and time in preparation of written resources may not be a good investment; instead, preparation of resources accessible by multiple media (electronic and internet resources) may be more beneficial. The lower ranking of written documentation might also

Table 2
Characteristics of Transparent Expert Consultation Workshop Participants

Participant Numbers	Country	Area of Expertise	Clinical Expertise in LTCFs
1.	Belgium	International organization – policy advocate	
2.	Australia	Gerontology and palliative care – nursing	
3.	Belgium	Elderly care physician	Yes
4.	Belgium	Gerontology and palliative care -research	
5.	Canada	Gerontology and palliative care – nursing	Yes
6.	Finland	Gerontology and palliative care - research	
7.	Ireland	Gerontology and palliative care - practice and policy development in	
8.	Netherlands	Gerontology and palliative care - research	
9.	Netherlands	Gerontology and palliative care - research	
10.	New Zealand	Gerontology and palliative care – nursing	Yes
11.	Poland	Elderly care physician	Yes
12.	Portugal	Elderly care physician	Yes
13.	Switzerland	Nurse specialist in long-term care provision	Yes
14.	Switzerland	Palliative care Physician and expertise in long- term care provision	Yes
15.	United Kingdom	Expertise in primary care nursing	
16.	United Kingdom	Palliative care nursing and long- term care provision – nursing	Yes
17.	United Kingdom	Gerontology research	
18.	United States of America	Gerontology and palliative care – physician	Yes

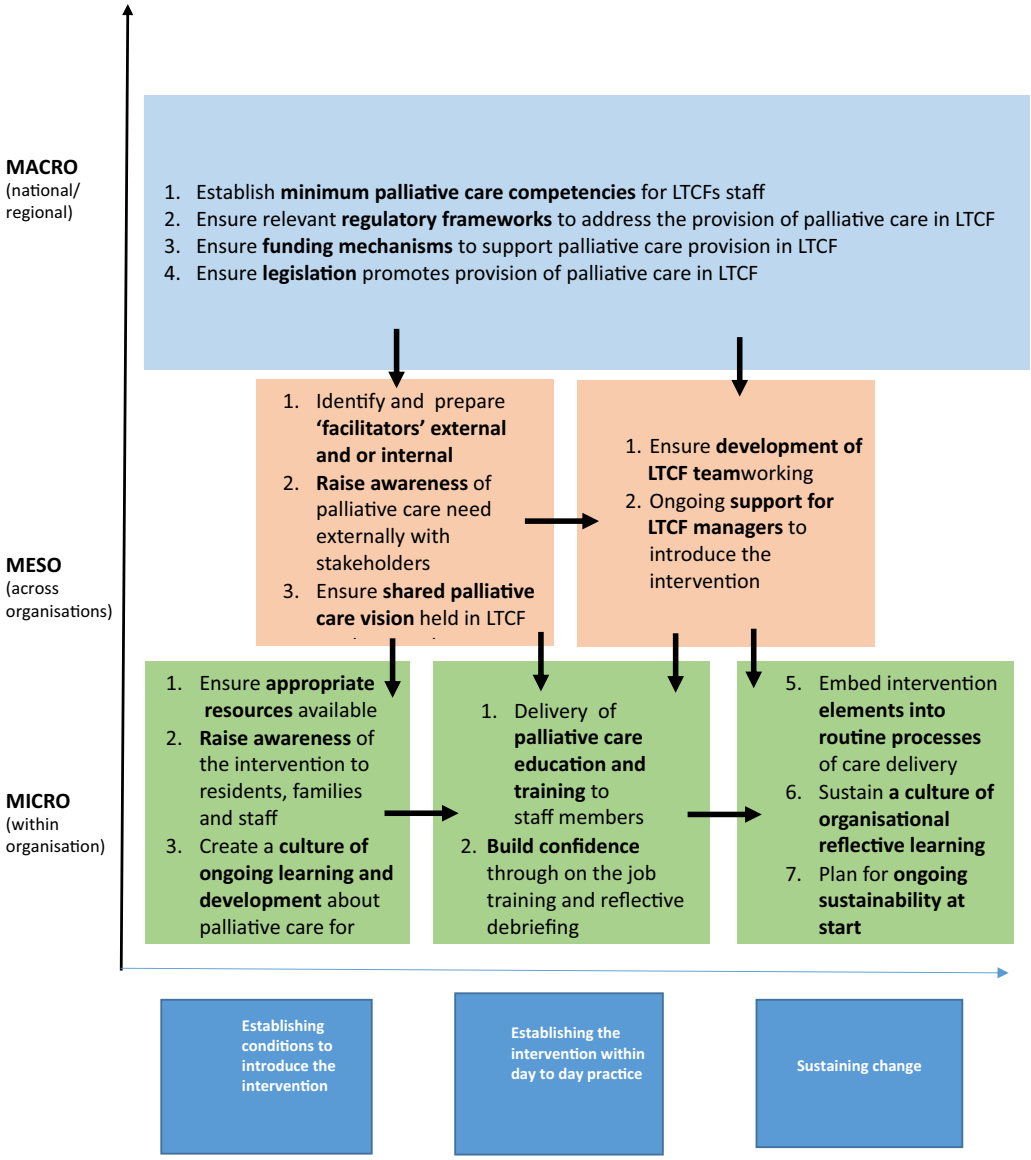

Fig. 2. Framework of recommendations showing domains and stages.

be indicative of experts highlighting that documents do not implement themselves and that it is more important how documents are used by facilitators in practice to achieve integration than the mere existence of written resources. Although engagement with services and practitioners outside the LTCF was identified as an important priority, working together with other LTCFs was ranked lower. This may reflect the wider health economy and impact of a competitive market with regard to funding of LTCF provision in some countries.[3]

Discussion

This is the first study we are aware of that has formulated recommendations on strategies for implementation of palliative care interventions in LTCFs based on international research with experts. The recommendations aim to guide how palliative care can be introduced, embedded, and sustained in LTCFs.

Our TEC study offers a framework of recommendations at each level in which strategies can be implemented and has outlined the processes involved, although we acknowledge that change is unlikely to be linear. Building upon a scoping review,[15] which focused predominantly upon micro and meso domains, the TEC processes have expanded the focus to highlight strategies at the macro level, including national level policies, LTCF standards, and ultimately the healthcare systems and geopolitical contexts in which they operate. The World Health Organization[23] has called for governments to integrate palliative care into national healthcare systems for people across the life span. In terms of relative importance, macro-level recommendations were identified as creating this culture in which meso and micro changes can be enacted. Recommendations such as establishing minimum general palliative care competencies for LTCF staff and ensuring relevant regulatory frameworks address the provision of palliative care in LTCFs require the support of macro-level factors, which may be outside the scope of specific interventions being delivered.[3]

The highly ranked recommendations reflect all domains of activity, although more focused on meso-level and micro-level processes. Creating a culture of ongoing development for staff requires a commitment to educational opportunities and resource allocation, in terms of staff time and payment. In addition, creating a culture in which staff feel comfortable reflecting on current practice and addressing areas for improvement requires explicit support from

Table 3
Recommendations Ranked by Priority for Implementation (Shaded Recommendations Not Included in Framework)

1	Embed changes into the day to day, routine practices, and processes of care delivery running of the LTCF
2	Support implementation through delivering training on palliative care
3	Establish minimum palliative care competencies for LTCFs staff delivered through continuing professional development
4	Identify, prepare and provide ongoing support to facilitators: either external and/or internal to the LTCF
4	Raise awareness of palliative care with all interested parties: residents, relatives, LTCF staff, primary care, secondary care, and specialist services
6	Ensure a clear vision for palliative care provision is shared by all staff and management
6	Adopt a flexible approach to integration to ensure a fit with the LTCF culture
6	Ensure relevant regulatory frameworks address the provision of palliative care in LTCFs
9	Prepare the LTCF for change by raising awareness of the intervention
9	Ensure appropriate resources required such as staff time, funding for equipment, are available from the onset
11	Build confidence through on the job training and reflective debriefing
12	Create a culture of ongoing learning and development for staff
13	Support LTCF managers in introducing and sustaining ongoing palliative care provision
13	Ensure active, overt management support for implementation of the intervention is required
13	Assess and support team working within the LTCF to support the implementation of a palliative care intervention
13	Ensure care funding mechanisms enable palliative care provision in LTCF
13	Ensure legislation supports provision of palliative care in LTCFs eg, with regard to medication
18	Plan for ongoing sustainability from the offset, ie, training new staff, funding facilitation etc.
18	Adopt a flexible and tailored to implementation, based on education level, availability and responsibilities of staff
18	Sustain a culture of organizational reflective learning cycles
21	Advocate palliative care within LTCFs at a national and international level
21	Ensure palliative care provision in LTCFs is present in national palliative care and ageing strategies (reflecting national legal, financial, regulatory frameworks)
21	Provide written material, such as resource folders, for reference
21	Ensure that intervention, and related implementation resources, have clear aims, outcomes and guidance on individual responsibilities
25	Ensure development of links with wider specialist palliative care services
25	Build on existing links between LTCF and wider health and social care services to support palliative care provision
27	Use examples and case studies that are specific to the LTCF within training
28	Enable access to further information and support about palliative care
28	Integrate implementation of palliative care with ongoing audit cycles to review progress
28	Establish relationships with other LTCFs enhance the capacity to deliver new programs of care

senior managers.[18] These are largely dependent on the LTCF leaders to facilitate an organizational culture supporting change. The results indicate that meso-level activities are central to creating a culture in which interventions can be implemented and sustained.

Confirming previous findings,[24,25] identifying and supporting external and internal facilitators was rated as an important aspect of meso-level implementation. This indicates that wider cultural change is needed in the LTCF before facilitation can enable staff to improve palliative care. The use of internal "champions" has been identified as facilitating implementation of change in LTCFs, although the nature of their preparation is less well-understood.[26] Further research is needed to understand the interplay between the context for change and facilitation during the implementation process.[27,28] Facilitation alone is not enough. Attention is also required prior to starting, if palliative care practices are to be successfully introduced.[29] This includes consideration of the capacity and stability of management and staffing, the fit between current care values and the practices being introduced.

A key issue identified related to recommendations that support the sustainability of the intervention within the LTCF. If changes are not embedded in day-to-day practice, the improvements in practice from the intervention may be lost once key actors, either the manager, staff champions, or the implementation team, depart.[30] Staff turnover (both managers and staff) further impede the incorporation of the intervention into routine practice.[31] There needs to be more investigation examining sustainability of palliative care interventions in LTCFs.

Of interest is whether or not the implementation of palliative care interventions creates different challenges to the implementation of other interventions in LTCFs. The complexity of palliative care interventions can lead to more challenges, as there are multiple components to be changed, including values.[32] The presence of dying and death as an integral element of palliative care may raise other barriers not seen with other types of health-based interventions. Death anxiety is known to affect healthcare staff's ability to engage with patients and family who are facing dying and bereavement,[33] and this may also shape their willingness to engage with new practices that increase their involvement with difficult conversations and people who are actively dying.

The impact of addressing individual recommendations is difficult to establish, as many are intertwined; for example, ensuring a clear vision for palliative care needs to be shared by all staff and management and precedes raising awareness of general palliative care with all interested parties including residents, relatives, LTCF staff, and external and specialist services. Thus, we suggest that the framework provides a mechanism to be used flexibly, recognizing that LTCFs will vary in how they operate, and the diversity of specialist palliative care services and their integration within the LTCF sector in many countries.[3] This reflects the different cultural contexts with respect to development of health economies and social norms regarding dying and to the diversity of social or nursing home models identified in previous research.[34]

Strengths and Limitations

Our study has several strengths, including robust methods to generate and refine the recommendations[17] with new evidence on outcomes and processes, working with international multidisciplinary experts. The final synthesis of recommendations is presented within domains of activity and stages, indicating how and when recommendations may best be used in practice. A limitation is that we relied on international experts,[35] while LTCF staff, residents, or families were not consulted. The recommendations are not meant to be exhaustive but merely a starting point for action and further research.

Conclusions and Implications

Improving palliative care in LTCFs is complex and requires commitment to general palliative care on all levels, throughout the stages of development and implementation. We suggest translation, dissemination, and implementation of these recommendations in practice and policy making. We consider that further refinement of

the recommendations is required to ensure their efficacy and adaptation to LTCF settings, especially by those people working within specific LTCFs. This framework of recommendations represents an important first step in assisting those who seek to implement interventions to improve palliative care in LTCFs and other environments including home care services and inpatient hospitals.

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