

Palliative Care in Long-term Care Settings for Older People: findings from an EAPC Taskforce

The work of the European Association for Palliative Care (EAPC) Taskforce on Palliative Care in Long-term Care Settings for Older People is now completed. How can such care be improved? **Elisabeth Reitingер, Katherine Froggatt, Kevin Brazil, Katharina Heimerl, Jo Hockley, Roland Kunz, Hazel Morbey, Deborah Parker and Bettina S Husebo** briefly describe the Taskforce's methods and key findings

A changing demography across European and other developed countries is leading to an older and, in many cases, more dependent population. Consequently, the demand for long-term care is changing. This has, in turn, led to the consideration of new models of service delivery, funding and quality management in the long-term care sector.¹

A significant proportion of older people (defined as those aged 65 and over) die in long-term care settings – approximately 20% in the UK² and 15% in Austria.³ Older people living in long-term care facilities (LTCFs) in Western societies often have non-cancer comorbidities, and there is a high prevalence of dementia in this population.^{4,5}

Palliative care is acknowledged as an appropriate approach to support these people as they are nearing death and is being promoted in LTCFs in a number of ways.⁶ However, there are challenges in the implementation of new approaches, partly due to the complexity of care provision.

For many years, the European Association for Palliative Care (EAPC) has encouraged a focus on palliative care for older people in LTCFs.⁷ In 2011, to further develop activity at a European level, the EAPC Taskforce on Palliative Care in Long-term Care Settings for Older People was formally recognised.⁸ Its aim was to identify and map the different ways of developing palliative care in long-term care settings across Europe. This paper summarises the work of the Taskforce, its methods and some of its key findings.

A Europe-wide mapping exercise

Thirteen European countries were involved in the work of the Taskforce: Austria, Belgium, France, Germany, Ireland, Italy, the Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and the UK. The initial task was to establish a European network of experts. These 'country informants' had to have relevant practice, research and/or educational experience, as well as links to specialists in their respective countries.

Once country informants had been identified, a two-phase mapping exercise was conducted in collaboration with them.

- Phase 1 involved the collection of contextual information about palliative care and long-term care provision for older people in each country. The information obtained concerned: the older population; the nature and types of long-term care settings; the wider funding and regulatory contexts; and key drivers for change.
- In Phase 2, country informants were asked to identify, in their respective countries, initiatives in the fields of clinical practice development, education and research that had been designed to improve palliative care in long-term care settings. Data about each initiative, their focus and impact were collected, summarised, collated and made available as a compendium, which can be found on the website of the International Observatory on End of Life Care.*

The initial task was to establish a European network of experts

As the data used in this mapping exercise were already in the public domain, ethical approval was not required.

Key findings

Country contexts

The 13 countries involved in this mapping exercise ranged in population size from 4.5 million (Ireland) to over 80 million (Germany). As a proportion of the population, the percentage of individuals aged 65 and over varied from 11.4% in Ireland to 21% in Italy. In most countries, more than 15% of the population were aged 65 years and over.⁹⁻¹¹ The proportion of long-term care beds available for older people varied from 16 beds per 1,000 inhabitants in Italy to over 84 beds per 1,000 inhabitants in Sweden.^{9,12} The information about the country contexts (summarised in Table 1) gives an idea of the complexity of the health- and social care sectors within which palliative care is being provided in LTCFs.

Identified initiatives

Over 60 initiatives promoting palliative care provision in LTCFs have been identified, to date, in Austria, Belgium, France, Germany, Ireland, the Netherlands, Norway, Spain, Sweden, Switzerland and the UK. To classify these initiatives, the Taskforce members agreed on a typology adapted from work in relation to organisational change.^{13,14} The typology considers the level of change at which initiatives are focused: individual level (staff, family, resident); group or team level; organisational level; regional or network level; and national level. Examples of the types of initiatives are given in Table 2.

The identified initiatives can also be classified according to who the change is focusing on in the first place – staff members, family members or residents. For example, educational initiatives can be designed either for care workers, for interdisciplinary team members or for family members – the final outcome being better care for residents. Some of the initiatives seek to address issues encountered in clinical practice. Others took a broader perspective, looking at change in the wider cultural context within which care is provided; for example, change through organisational development. For details about all initiatives, see the compendium* and the Taskforce's report.**

Table 1. Country context information

Topics	Findings
Types of LTCFs	Care in LTCFs is generally provided at two levels: for people with high dependency and those with low dependency. In some countries (eg, France, Germany), care is also provided in a third tier linked to hospitals
Status of long-term care providers	A mixed economy of providers (public, not-for-profit and private) exists in most countries. Public sector funding of providers of long-term care dominates in countries with a 'strong social model', ¹² such as Norway and Sweden. Not-for-profit providers are significant in Germany, Italy, Austria and France; they are often affiliated to faith-based groups (predominantly Christian). Private providers are dominant in Ireland, Spain and the UK, but are also present in other countries
Funding	Funding reflects the wider structures for health- and social care provision and thus comes from mixed sources: <ul style="list-style-type: none"> • Public funding through health- and social care • Personal funding from individuals (private insurance or own capital/income; family contributions) In a number of countries, public funding is allocated through means testing. Funding can be different for healthcare and for social care
Regulation	The long-term care sector is regulated in all countries. This occurs either at a national or at a regional level. Specific regulations for palliative care in nursing homes exist in a few countries (eg, France, Germany)

LTCFs = long-term care facilities

Table 2. Types of initiatives designed to promote palliative care provision in long-term care settings at different levels

Level of change	Types of initiatives
Individual level (resident, family, staff)	<ul style="list-style-type: none"> • Assessment tools • Communication and information interventions • Education • Leadership development • Clinical assessment tools
Group/team level	<ul style="list-style-type: none"> • Interprofessional education • Interprofessional rounds
Organisational level	<ul style="list-style-type: none"> • Shared working between palliative care, hospice teams and LTCFs • Specialist palliative care units in LTCFs • Organisational development
Regional/network level	<ul style="list-style-type: none"> • Regulation • (Inter)professional networks
National level	<ul style="list-style-type: none"> • Legal frameworks • National strategies • Funding policies • Standards and guidelines for palliative care in long-term care

LTCFs = long-term care facilities

Complexity of implementing change

A number of factors influence how palliative care in long-term care settings can be improved in Europe. These factors include:

- Whether or not long-term care facilities are acknowledged as being home for the older people who live there
- Whether differentiated service provision is available to meet varying levels of need
- What the roles of the different types of providers are

- Whether the importance of quality management and assurance processes for supporting development is recognised
- Who is responsible at what level for improving care within both palliative care and long-term care.

The development of palliative care within LTCFs is a complex process that needs to occur at multiple levels. Many of the initiatives we identified illustrate this. For example, in order to improve care for individual patients, a pain assessment initiative will require collaboration between the LTCF and the local specialist palliative care organisation while at the same time fitting in the broader framework of national guidelines. Similarly, national policy initiatives require implementation at regional, organisational and local levels if they are to have an impact upon the delivery of care to individual patients.

The role of long-term care organisations as mediators for change and new developments requires further consideration. The organisational context for change is important in long-term care settings, as organisational culture influences how individuals and teams work. Furthermore, for organisational change to happen, bottom-up initiatives involving residents, families and staff need top-down support.

Our review of current initiatives also shows that there are sustainability issues.¹⁵ Many initiatives have their origins in short-term project work or research grants, have not yet been appraised and their further development is uncertain.

The future

Our Taskforce sought to identify and map the different ways of improving palliative care in long-term care settings across Europe. Its work provides a useful base for further work in clinical practice and research. Although now completed, this work is part of a wider process of international collaboration, and it is anticipated that expertise and experience will continue to develop and be exchanged.

* The Taskforce's compendium of initiatives can be found at: www.lancs.ac.uk/shm/research/ioelc/projects/eapc-taskforce-ltc

** The Taskforce's report is available at: www.eapcnet.eu/Themes/Specificgroups/Olderpeople/Longtermcaresettings.aspx

Acknowledgements

The authors would like to thank the European Association for Palliative Care (EAPC) for its practical support. They would also like to thank the country informants and advisory group members who contributed to this EAPC Taskforce's work: Sigrid Beyer, Georg Bollig, Manuel Luis Vila Capelas, Clodagh Cooley, Marie-France Couilliot, Vito Curiale, Luc Deliens, Claudia

Gamondi, Marjolein Gysels, Sue Hall, Geryl Hynes, Hubert Jocham, Lennarth Johansson, Mary-Lou Kelley, Frank Kittelberger, Julie Ling, Mary McCarron, Mirella Minkman, Massimo Monti, Maria Nabal, Jane Österlind, Roeline Pasman, Sophie Pautex, Tinne Smets, Jenny van der Steen, Marie-Claire Vannes and Marian Villez.

Declaration of interest

The authors declare that there is no conflict of interest.

References

1. Nies H, Leichsenring K, van der Veen R et al. *Quality Management and Quality Assurance in Long-Term Care. European Overview Paper*. Utrecht, Vienna: Interlinks, 2010.
2. Office for National Statistics. Mortality Statistics General Series DH1 No. 38. Review of the Registrar General on Deaths in England and Wales, 2005. London: Office for National Statistics, 2007. www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--general--england-and-wales--series-dh1--discontinued-/no--38--2005/index.html (last accessed 08/07/2013)
3. Statistik Austria. Todesursachenstatistik 1984–2008. Tabelle zu Sterbeorte. Vienna, November 2009 [Official Austrian statistics on cause and place of death].
4. Hall S, Petkova H, Tsouros AD, Costantini M, Higginson IJ (eds). *Palliative Care for Older People: Better Practices*. Copenhagen: WHO, 2011.
5. Kojer M, Schmidl M (eds). *Demenz und Palliative Geriatrie in der Praxis. Heilsame Behandlung Unheilbar Dementer Menschen* [Dementia and palliative geriatric care in clinical practice. Caring for incurable patients with dementia]. Vienna: Springer, 2011.
6. Froggatt K, Brazil K, Hockley J, Reitinger, E. Improving care for older people living and dying in long term care settings: a whole system approach. In: Gott M, Ingleton C (eds). *Living with Ageing and Dying: End of Life Care for Older People*. Oxford: Oxford University Press, 2011: 215–225.
7. Froggatt K, Heimerl K. Palliative care in long-term settings: a new web resource. *European Journal of Palliative Care* 2008; **15**: 244–247.
8. Froggatt K, Reitinger E. Palliative Care in Long-Term Care Settings for Older People: introducing an EAPC Task Force. *European Journal of Palliative Care* 2011; **18**: 26–28.
9. Organisation for Economic Co-operation and Development. *Help Wanted? Providing and Paying for Long-term Care*. Paris: OECD, 2011.
10. Statistik Austria. Statistik des Bevölkerungsstandes. Vienna, May 2012 [Official Austrian population statistics].
11. Central Statistics Office Ireland. *This is Ireland. Highlights from Census 2011*. Statistical Tables and Appendices. Dublin: CSO, 2011.
12. Riedel M, Kraus M. The Organisation of Formal Long-term Care for the Elderly. Results from the 21 European Country Studies in the ANCIEN Project. www.ceps.eu/book/organisation-formal-long-term-care-elderly-results-21-european-country-studies-ancien-project (last accessed 10/06/2013)
13. Ferlie EB, Shortell SM. Improving the quality of health care in the United Kingdom and the United States: a framework for change. *Milbank Q* 2001; **79**: 281–315.
14. Heimerl K. *Orte zum Leben – Orte zum Sterben. Palliative Care in Organisationen Umsetzen* [Places to live – places to die. Implement palliative care within organisations]. Freiburg: Lambertus, 2008.
15. Hockley J, Watson J, Oxenham D, Murray SA. The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. *Palliat Med* 2010; **24**: 828–838.

Elisabeth Reitinger, Associate Professor, IFF – Palliative Care and Organisational Ethics, University of Klagenfurt in Vienna, Austria; Katherine Froggatt, Senior Lecturer, International Observatory of End of Life Care, Lancaster University, UK; Kevin Brazil, Professor, Palliative Care, Queens University Belfast, Ireland; Katharina Heimerl, Associate Professor, IFF – Palliative Care and Organisational Ethics, University of Klagenfurt in Vienna, Austria; Jo Hockley, Nurse Consultant (Care Homes), St Christopher's Hospice, London, UK; Roland Kunz, Head of Department, Palliative Geriatrics, Hospital Affoltern, Affoltern am Albis, Switzerland; Hazel Morbey, Research Associate, Faculty of Health and Medicine, Lancaster University, UK; Deborah Parker, Associate Professor and Director, Blue Care Research and Practice Development Centre, University of Queensland, Brisbane, Australia; Bettina S Husebo, Associate Professor, Department of Public Health and Primary Health Care, University of Bergen, Norway