

Palliative dementia care: lessons from a European perspective

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Introduction

It is ambitious to say that this viewpoint is able to provide a European perspective. Defining 'Europe' can mean anything between 28 countries within the European Union (notwithstanding the impending the impending UK 'Brexit') and up to 50 countries if you include all dependent territories with different health systems, policies and priorities. To some extent, the future direction of palliative care for dementia patients in Europe has taken a positive turn and there has been strong innovation in cross-national working in this area, some linked to the work of the European Association for Palliative Care. Palliative dementia care is part of a growing clinical, organizational and societal discourse where strengthening evidence and enhanced practice wisdom bring the challenges and the opportunities of this complex care delivery to the fore. However, we cannot and should not be complacent. Ferri and Jacob (1) report that by 2030, up to 75 million people will be living with a dementia diagnosis predominantly in low and middle income countries. Despite recent report of a decrease in prevalence in some European countries (2), there remain substantive concerns for policy and practice in terms of how dementia is misrepresented as a normal part of ageing, issues of stigma and how dementia is seen from a cultural perspective, variation in clinical and social assessment and the attention given to its place in responsive and transformative healthcare policy (1). Dementia still remains a significant cause of morbidity, mortality and concomitant burden to health care service provision across Europe. Caring for people with dementia also reflects how we see moral and ethical issues such as respect, dignity, suffering and hope in our society.

The need for consistent and structured integration of dementia palliative in Europe is recognised (3). The

'IMPACT' study across 5 EU countries sought to develop a model of palliative care in dementia accounting for cultural difference and commonality. This was set against a backdrop of earlier studies which clearly demonstrated the challenges in providing palliative care in and of itself, in terms of description, service provision, access, professional roles and responsibilities and specific deficits in community care provision (4-6). For palliative dementia care, the landscape remains under-developed. Pathways of palliative dementia care are lacking, the evidence base, though growing, remains weak and the interface between palliative and older person care, particularly from the social and political context needs greater definition (7). The model of care proposed within IMPACT (4) offers a framework which establishes shared and meaningful core principles namely, comprehensive assessment, shared decision-making, a structured iterative approach to care planning and a framework which supports care givers, both lay and professional across the trajectory of illness. This is one model. No doubt, others will emerge. Given that good quality pan-European work is now evident, it does question whether efforts to develop better palliative dementia care would be served best by a focus on consolidating current outputs to embed best practice, rather than expanding the range of scope of studies which are essentially asking the same questions?

Defining palliative dementia care

A most significant contribution to our understanding of palliative dementia care has been offered by Jenny van der Steen and colleagues (8). Based on a five round Delphi process, 64 experts across 23 countries evaluated 11 domains and 57 recommendations to achieve consensus

around a clear definition of palliative dementia care, incorporating many aspects of the IMPACT study (4) but also including issues of prognostication and the recognition of dying. Notably, only moderate consensus was achieved in relation to aspects of futile treatment (such as nutrition and hydration) and applicability of palliative care. The paper proposes a transitional model, reflecting cognitive function against goals of care, moving from robust cognitive capacity through life prolonging and functional maintenance to a time of maximizing comfort as deterioration occurs. A particular strength of this work is that it also highlights the gaps and contexts in which palliative dementia care occurs. The evidence in this field is, at best, modest and that what is known has largely focused on institutional rather than community settings. It also acknowledges the need to blend care with local custom, culture and practice, an important issue when dealing with an amorphous entity such as the EU.

The community context of palliative dementia care is being addressed (9) highlighting barriers and facilitators that need to be considered for optimal care delivery—timing of advance care planning, family communication, resource allocation and opportunity for multidisciplinary working. These are not only problems for patients and families living with dementia but the future projections in terms of impact on health systems makes a compelling argument for a reorientation of health service delivery to meet impending need.

In reality, despite the very positive developments in the field, we remain unclear about when people with dementia actually need palliative care? The context of community as home increasingly means long-term care settings for many older people. A recent study (10) considered this question across 6 long-term care settings using a qualitative case vignette approach and team discussion. The results highlighted the complexity in making this decision and the difference, rather than similarity across countries in terms of time trajectories and changing goals of care. The study indicated that palliative dementia care could be applied either early in the disease trajectory (as a chronic life-limiting illness), when advanced or when it was evident that treatments or interventions were burdensome and futile. This highlights the subjectivity in clinical decision-making. Our planning for future care needs to pay attention to this.

Conclusions

The EU Joint Programme for Neurodegenerative Disease

Research (JPND, www.neurodegenerationresearch.eu) have recently called for research in innovative health and social care, including palliative care. Their list of potential research areas includes care pathways, outcome measures, cost-effectiveness and supportive technologies, all of which speak to a palliative care agenda. However, the field of palliative dementia care is new and for the immediate future, we need stronger evidence on what the integration of palliative dementia care means and what quality indicators exist or can be adapted or applied from other areas such as cancer care. Within this, key questions can be answered, including when does palliative dementia care begin, how can carers be supported, and what advance care planning add to or detracts from care delivery. We need to know how to care better. This offers our best way forward.

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Footnote

Conflicts of Interest: The author has no conflicts of interest to declare.

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