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Improving Advanced Dementia Care

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Improving Advanced Dementia Care: An Interprofessional Palliare Learning Framework

Evidence from improvement science and culture change projects; leave us in no doubt that improvement is a complex and sometimes fallible undertaking. In long term care environments balance is required between efficacious treatment, rehabilitation and palliation. People with advanced dementia, many of whom require long-term care, have a myriad of dementia-related symptoms often presenting in tandem with comorbidities and frailty. A recent review of the literature highlighted that advanced dementia can range from months to years (Hanson et al., 2016). Van der Steen et al., (2014) calls for dementia appropriate palliative care. We acknowledge that when dementia is severe and terminal, end of life care is appropriate, however, for many individuals, there is an extended phase where dementia specific palliative approaches are required that enable the person to live the best life possible. This distinction between dying well and living well with advanced dementia is an important one, and one at the heart of a recently completed European Project Dementia Palliare <http://www.uws.ac.uk/palliareproject/>.

Dementia Palliare is a positive practice approach to evidence-informed interdisciplinary advanced dementia care, which creates a new narrative and importantly reveals the expert knowledge and expert practical know-how that is required to deliver good quality advanced dementia care within long-term care settings (Hanson et al., 2016). The Glasgow Declaration (Alzheimer Europe 2014), recognises the right of the individual to high-quality care throughout their illness, and it follows that this right is accompanied by an obligation for long term care providers to ensure that staff involved in the delivery of advanced dementia care are equipped to achieve best practice. To achieve this end research is required, as highlighted by the recent international survey reported by Morley et al., (2014), and education and leadership are also required as described within the Global Agenda for Nursing Home Practice (Tolson et al., 2011).

This Editorial provides an overview of the European Palliare Project, before focussing on the resultant interprofessional educational framework presented in the form of a Best Practice Statement (BPS) (Holmerova et al 2016). The BPS details what practitioners need to know to deliver good quality advanced dementia care focussed on living the best life possible (www.uws.ac.uk/palliareproject). For care providers and managers, the BPS reveals the complexity and expert knowledge that underpins good practice and leaves no doubt that investment is required in staff development alongside a skill and discipline mix which will ensure expert practice leadership from appropriately qualified professionals.

The Palliare Project was completed between 2014-2017 by a partnership of seven European countries (Czech Republic, Finland, Portugal, Scotland, Slovenia, Spain and Sweden). It was led by the team at the University of the West of Scotland and funded by the EU Erasmus+ Higher Education programme <https://www.erasmusplus.org.uk/>. The term Palliare, meaning

to cloak in support or to shield, this term was chosen to make a distinction between palliative care with its roots in non-dementia specific palliation and end of life care. Dementia Palliare requires a commitment to an interdisciplinary approach that is responsive to the range of support needs including those expressed by individuals and family. Building the evidence for Dementia Palliare involved 11 work streams and included the following research activities:-

- Literature Review
- Policy Analysis
- In-depth case studies
- Educational Gap Analysis
- Experiential learning pedagogical review

These research activities addressed the first study objective which was to understand and describe best practice for advanced dementia care during the extended palliative care phase, and to tease out the disciplinary knowledge and contribution to best practice.

The second study objective was to develop an innovative virtual interprofessional experiential learning solution to equip the qualified dementia workforce to transform practice and achieve good quality Dementia Palliare. Evidence gathered from the research activities informed the development of the educational framework which was developed and refined using consensus methods. Implementation involved the creation of an international online community of practice <http://dementia.uws.ac.uk/> and the development of interprofessional accredited undergraduate and postgraduate models related to advanced dementia practice (Palliare). A key feature of the educational approach is the combination of advanced dementia knowledge, and practical know-how with the skills and knowledge to lead and champion practice based change. This unique offering transcends the challenge of getting evidence into practice. The Palliare philosophy is framed around a value base that is focussed on the person with dementia but embraces the relationships within care and caring foregrounding family caring and partnership with practitioners.

The integrative literature review found surprisingly little research to inform this stage of practice and a preoccupation with the end of life and dying (Hanson et al., 2016). Debate surrounding staging dementia and inconsistent terminology and in some papers a failure to distinguish the type of dementia undermined the quality of the available evidence. However, that evidence which was available clearly pointed to a need for a positive approach to practice that embraces physical, psychological, social, spiritual and existential need. Highlighting aspects amenable to change such as coping strategies, physical activity, social environment, pain management, nutrition and quality of interactions to optimise quality of life, reduce distress and loneliness. Needless to say, this requires a new narrative and way of conceptualising this stage of care and the complexity of Palliare and caring partnerships with both the recipients of care and family.

Twenty-two case studies conducted across the seven partner countries generated a long list of things that were not working well and in all countries and a shorter list was generated of

what was working well for individuals and family. For brevity we will not report all here, let it suffice to say that communication with family is often poor and services fragmented. Lack of family carer education undermines their confidence and abilities to sustain care at home, with sleep disturbance and incontinence being common factors in admission to long term care. Perceptions about the quality of long-term environments varied, at worse these, were described as warehousing environments at best they were described as sanctuaries and safe havens.

Only one country out of the seven partners had a national workforce development framework, the Scottish Promoting Excellence Framework, which sets out the level of skill and knowledge for health and social care professionals working with people with dementia extending from the level of informed awareness to expert practice (Scottish Government, 2011).

Best Practice Statements are intended to guide practice and promote a consistent and cohesive approach to care. They are drawn from the best available evidence at the time they are produced, recognising that the levels and types of evidence vary. The evidence used to inform the BPS included the findings from the evidence gathering activities described above and the White Paper defining optimal palliative care in older people with dementia (van der Steen et al., 2014). The BPS embraced the principles of the Glasgow Declaration (Alzheimer Europe, 2014) and the Dementia Engagement and Empowerment Project (DEEP) Guidelines on language about dementia (2014). The process of development was consultative (Figure 1). The first and second draft was developed within the Palliare project team. During all stages of development, the team embraced the principles of full participation of people with dementia and their families through cycles of drafting and feedback with user groups.

To ensure that essential learning was gained from the range of experience across the seven European countries, consultation and feedback was facilitated through the Alzheimer and/or dementia organisations in each of the seven European countries. The participants attending the first Palliare project consensus conference in Prague June 2015 were invited to comment on the second draft. Between August and October 2015 the seven partners working with local and national Alzheimer organisations invited people living with dementia, family caregivers, professional staff and educators to come together and comment on the third draft of the BPS. Notes from discussion groups were taken and collated, written feedback from individuals and groups were collated by project partners. These were synthesised and woven into the fourth draft. This penultimate draft was presented to the Board of Alzheimer Europe and circulated through the Dementia Palliare website and via social media.

Insert Figure 1 about here

The statement is divided into six sections covering:

Section 1: Protecting rights, promoting dignity and inclusion

Section 2: Future planning for advanced dementia

Section 3: Managing symptoms and keeping well

Section 4: Living the best life possible

Section 5: Support for family and friends

Section 6: Advancing Dementia Palliare practice

The sections are designed to provide a logical and clear information flow. Each section contains a table corresponding to the 'what, why and how' of best practice. 'What' summarises the content and the role of the professional. 'Why' expands on the reason for the statement. 'How' demonstrates how the statement can be achieved, highlighting the underpinning philosophy of the statement and explicit skill requirements to achieve best practice. Key challenges highlight areas that may require specific action or development.

The International Association of Gerontology and Geriatrics (IAGG) programme of development identified the cornerstones of the development agenda as education, research, leadership and status raising (Tolson et al., 2011). Flowing on from this, several international surveys have established that dementia should be prioritised within this global development agenda (Morley et al., 2014, Rolland et al 2014). At a time when economics are challenging and resources are limited it is essential that we use our resources, including educational resources efficiently (Ibrahim & Davis 2013, WHO 2012). We contend that the collaborative and interdisciplinary foundations of Dementia Palliare exemplify the underpinning of prudent approaches. Indeed we have argued elsewhere (Tolson et al., 2016) that Prudent Palliare approaches, that include international alliances for learning, have much to offer and could accelerate improvement in advanced dementia care and raise not only the quality of the care experience but also through education raise the status of this complex area of practice.

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