

GUEST EDITORIAL

Provision of Palliative Care to People With Advanced Dementia: Challenges and Developments. The Palliare Project

Wilson Correia de Abreu, PhD, Full Professor
Porto School of Nursing, Portugal

Dementia is a significant and increasing public health problem that impacts individuals, their family and friends, caregivers and society. Almost 35.6 million people were affected by dementia worldwide in 2010. It is estimated that this number will nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (1).

Although dementia mainly affects older people, it cannot be seen as part of aging. The syndrome has physical, psychological, social, and economic impact on caregivers, families, and global society. Substantial increases in health and social care costs are required to deal with this major public health problem and workforce challenge. Dementia is one of the major causes of disability and dependency among older people worldwide. It is clear why this has become a globally alarming issue. The question is not solely associated with health care expenditure. Dementia is a social condition intimately related to demographic issues, social welfare, problems concerning family caregivers, their work capacity and, more importantly, with dignity and human rights. Dementia syndromes, particularly in the advanced stages, can strongly impact expenditure in health care delivery and social welfare.

Clinically, dementia is a syndrome of diverse etiology, leading to progressive cognitive decline, functional impairment and dependence on self-care. There is deterioration in memory, thinking, behavior and the ability to perform everyday activities. As a condition associated normally with older people, it is often accompanied by comorbidities and not rarely associated with pain and different organ dysfunctions. In the advanced and severe stages, the syndrome also affects family caregivers, since caring for a person with dementia requires increasing and complex levels of support. The social and family contexts often undermine the understanding of the disease and the need to deliver palliative care.

Research shows that much can be done to fight the incidence and prevalence of the syndrome – prevention, therapeutic regimen and, in later stages, palliative care. The modifiable risk factors of dementia are scarce. Prevention includes the control

of risk factors for vascular disease, such as diabetes, hypertension, obesity, cholesterol, and depression, as well as lifestyle factors such as smoking, physical inactivity, and poor diet. The therapeutic regimen has to follow better guidelines related to the type and causes of the syndrome. Memory stimulation is important to delay the progression of the syndrome. In the advance stage of dementia, palliative care can be a real solution to the functional and cognitive decline. However, palliative care needs of patients with dementia are often poorly addressed; symptoms such as pain are underdiagnosed while these patients are over-subjected to burdensome interventions (2).

Concerning palliative care, all across Europe and generally in developed countries, palliative care delivery has been extended and increasingly acknowledged by National Health Care Systems. Palliative care means delivery of care to patients suffering from severe and/or advanced and progressive illnesses aiming to promote the quality of life and well-being.

Seven countries decided to develop a project, which was evaluated and further funded by the EU program Erasmus+, under the coordination of the University of West of Scotland (3). The partners were Scotland (University of the West of Scotland, Debbie Tolson and Rhoda MacRae), Czech Republic (Charles University, Iva Holmerova and Radka Veprkova), Finland (Turku University of Applied Sciences, Anne Merta and Pirkko Routsalo), Portugal (Escola Superior de Enfermagem do Porto, Wilson Abreu), Slovenia (Faculty of Health Care Jesenice, Simona Hvalic Touzery and Katja Pesjak), Spain (University of Alicante, Manuel Lillo-Crespo and Maria Jose Cabanero), and Sweden (Linnaeus University, Elizabeth Hanson and Amanda Hellstrom). The project partners had the support and worked closely with national dementia organizations in the countries and with Alzheimer Europe.

The partners were selected to include dementia experts from different disciplines with international repute and academics with track record in the development of innovative experiential learning methods. All the partners had proven research, scholarship and educational project management abilities and all project teams included professors and senior team members with international standing.

Correspondence to W. Correia de Abreu, Porto School of Nursing / CINTESIS, Rua Dr. António Bernardino de Almeida, 4200-072 Porto, Portugal. E-mail: wjabreu@esenf.pt

The project strengthened interprofessional collaboration across all health and social care disciplines involved in dementia care across the partner countries. It was an opportunity to facilitate the review and augment matters such as current workforce preparation and, importantly, encourage new thinking on future dementia workers.

The partner countries were all at different stages in terms of advancing dementia care with the mid-extended palliative care phase most neglected in terms of educational opportunities. All partners and partner countries bring with them unique strengths and different perspectives which will assist in reframing the European dementia narrative with anticipated enhancement of the status of dementia care career choices and open up career pathways through mobility and virtual mobility.

The project aims to develop a transformational interprofessional experiential learning solution (based on a CoP model) as the first step toward the establishment of a sustainable collaborative virtual European Dementia Academy. The experiential learning model was chosen to provide exposure to best European practices through virtual mobility and equip the professional dementia workforce to champion evidence-informed improvements in advanced dementia care and family caring. The project consisted of a preparatory stage providing the building blocks for the second implementation stage and it will finish in 2016.

In the first phase, our purpose was to promote an interprofessional understanding of best practice for advanced dementia care and family caring during the extended palliative care stage of the illness, and an understanding of the contribution of different disciplines to the achievement of best practice. In the second phase, we developed an innovative virtual interprofessional experiential learning solution to equip qualified dementia workforce to improve advanced dementia care and deliver best practice.

Eleven intellectual outputs (IO) were defined, as stated in the project:

- IO1 – Literature review: experience of advanced dementia. The literature review aimed to create a shared understanding of dementia care and family care associated with extended palliative care. It was found that the extended palliative phase was synonymous with end-of-life care and there were few robust concepts that embraced living the best life possible during this advanced phase. This finding illuminated the need for a new practice approach for advanced dementia care.
- IO2 – Dementia policy review. A review of dementia-related health and social care policy and strategy documents, action plans, and workforce development frameworks found that all 7 coun-

tries had some type of a national action plan for generic palliative care. The place of palliative care for people with advanced dementia ranged from family home and hospital to care homes.

- IO3 – Experience of dementia-case studies. A total of 22 case studies from 7 countries allowed the inclusion and experiences of people with advanced dementia. This identified a number of recurring themes considered to be important for care experiences to be positive: early diagnosis, good coordination between service providers, future planning, support and education for caregivers and families, thus, enabling the person to live the best life possible.
- IO4 – Best practice statement. This important document is designed for the professional European workforce (personnel). This best practice statement offers a new positive practice approach for supporting people with advanced dementia (6). It has the following sections: (a) protecting rights, promoting dignity and inclusion; (b) future planning for advanced dementia; (c) managing symptoms and keeping well; (d) living the best life possible; support for family and friends; and (e) advancing dementia Palliare practice.
- IO5 – Educational gap analysis. An educational gap analysis was undertaken to identify the existing education in dementia available to the professional workforce. We found that there was a lack of formal education on dementia. Dementia education is particularly limited in undergraduate programs.
- IO6/IO7 – Virtual community of practice. We developed a virtual community of practice (CoP) based on the best available evidence on experiential learning. The community of practice gives practitioners access to resources and an opportunity to participate in discussion forums in multiple languages. It is a space for those interested in advanced dementia to share and learn from one another.
- IO8 – Interprofessional education. Four accredited education modules on advanced dementia care for health and social care professionals across Europe were developed: (a) positive practice development in advanced dementia care; (b) rights, risks and ethics in advanced dementia care; (c) contemporary advanced dementia care; and (d) achieving change in advanced dementia care. The modules will be delivered online and will be accessible to professionals across the globe. This will enhance the impact of modern universities to provide professional lifelong learning and their commitment to offer evidence-based education that maximizes the quality of student experience.
- IO9/IO10 – Trained experiential learning facilitators. We trained an interdisciplinary interna-

tional team of educators to be experiential learning facilitators. They will continue to moderate the community of practice and act as the inaugural faculty for the proposed virtual Dementia Academy.

- IO11 – Sustainability plan. The sustainability plan seeks to address 2 opportunities. The first is to support the continuation of the new educational program. The second is to prepare a viable business model to use the virtual learning environment and community of practice to be the foundation of the virtual European Dementia Academy.

We are positive that Palliare represents an added value to equip the professional dementia workforce to champion evidence-informed improvements in advanced dementia care and family caring.

Evidence shows that contrary to what occurs with patients suffering from other health conditions, pain is often underrated (4, 5). Patients are more exposed to complications, recurrent hospitalization and questionable invasive therapies (6–9). In these situations, palliative care contributes to reducing hospitalization and health care expenditure, and provides comfort and well-being for patients and families (10). Contradictory to the proven benefits of palliative care for people with advanced dementia, there are still no substantial efforts to include these specific policies in the national health care systems as well as in defining palliative care referral criteria. Moreover, it is extremely important that people with advanced dementia can be supported by professionals with specific training in palliative care for people with dementia (2). Palliative care allows reducing hospitalization periods, rehospitalisation and unnecessary medication, or aggressive interventions.

References

1. Pot AM, Petrea I. Bupa/ADI report: 'Improving dementia care worldwide: Ideas and advice on developing and implementing a National Dementia Plan'. London: Bupa/ADI; 2013.
2. Van der Steen J, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al; European Association for Palliative Care (EAPC). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014;28(3):197-209.
3. Palliare Project. Interprofessional experiential learning (IPE) solutions: equipping the qualified dementia workforce to champion evidence informed improvement to advanced dementia care and family caring. European Erasmus + Project (Reference 2014-1-UK01-KA203-001819).
4. Barry HE, Parsons C, Passmore AP, Hughes CM. Pain in care home residents with dementia: an exploration of frequency, prescribing and relatives' perspectives. *Int J Geriatr Psychiatry* 2015;30(1):55-63.
5. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, et al. The clinical course of advanced dementia. *N Engl J Med* 2009;361(16):1529-38.
6. Dasgupta M, Dumbrell AC. Preoperative risk assessment for delirium after noncardiac surgery: a systematic review. *J Am Geriatr Soc* 2006;54(10):1578-89.
7. Witlox J, Eurelings LS, de Jonghe JF, Kalisvaart KJ, Eikelenboom P, van Gool WA. Delirium in elderly patients and the risk of postdischarge mortality, institutionalization, and dementia: a meta-analysis. *JAMA* 2010;304(4):443-51.
8. Fick D, Steis MR, Waller JL, Inouye SK. Delirium superimposed on dementia is associated with prolonged length of stay and poor outcomes in hospitalized older adults. *J Hosp Med* 2013;8(9):500-5.
9. Robinson TN, Raeburn CD, Tran ZV, Angles EM, Brenner LA, Moss M. Postoperative delirium in the elderly: risk factors and outcomes. *Ann Surg* 2009;249(1):173-8.
10. El-Jawahri A, Greer JA, Temel JS. Does palliative care improve outcomes for patients within curable illness? A review of the evidence. *J Support Oncol* 2011;9(3):87-94.