PALLIARE PROJECT

Interprofessional experiential learning (IPE) solutions: equipping the qualified dementia workforce to champion evidence informed improvement to advanced dementia care and family caring

EXECUTIVE SUMMARY

INTELLECTUAL OUTPUT 03: Experience of Advanced Dementia - Case Studies

LEAD PARTNER: Faculty of Health Sciences - University of Alicante, Spain


ACKNOWLEDGEMENTS: Anna Waugh, Jana Kašpárková, Anna Merta

The aim of the case studies was to exemplify the experiences and the range of typical settings for advanced dementia care in the seven
participating partner countries. The empirical data gathered on the experience of advanced dementia care in each country will inform the development of the European Best Practice Statement and the interprofessional modules on advanced dementia care. Case studies were chosen as the approach to capture the complex real life experiences of Advanced Dementia care. These were carried out between September 2014 and March 2015. The partner countries were Scotland, Slovenia, Portugal, Sweden, Finland, Czech Republic and Spain, with Spain as lead on this Intellectual Output. Each partner had to prepare at least three in-depth case study reports that highlighted the experience of care for the person with advanced dementia and their family carers. The case studies were to illustrate what is working well and not so well for people with dementia and family carers within a range of typical care settings in their own country.

Twenty-two case studies were developed through in-depth interviews with people with advanced dementia, family and caregivers. These case studies also included descriptions of the context of care; the context being the care setting and wider context of care within that partner country. Consequently, each of the case studies developed within this project has illuminated a unique set of experiences, tailored to a particular care environment that is considered typical within each partner-country. Those case studies have incorporated a series of in depth narrative accounts of care that explore the experiences of the person with advanced dementia and their relatives or primary carers. Importantly the case studies have illustrated what is working well or not so well for people with dementia and family carers in the seven participating countries.
The data analysis was done in four steps. First, each partner-team developed categories and subcategories of data based on the narrative accounts. Second, three of the Spanish Team analyzed all the narrative accounts, the categories and subcategories provided by each partner team. Third, each partner team extrapolated from the accounts what was ‘working well’ and ‘not so well’, that is to say, the positive and negative outcomes and experiences of care within each partner-country. Third, the Spanish team analyzed the cases again to observe the common themes that came up across all the case studies and their representativeness. Fourth, each partner-team was asked to provide a brief summary about what they considered that “works well” and “what works not so well” to validate the information previously provided and to also try overcome any loss of meaning through the data having been translated into English.

The scope and type of provision of dementia care and support is reflective of the policy context in partner countries. For example in southern Europe policies tend to support family integrated approaches whilst others tend to support individualised approaches to care and care giving. This was reflected in the findings which showed that, for example, Spain and Portugal have well developed multidisciplinary healthcare services but less well developed social care. Finland and Sweden have adopted a person centred approach with well developed social care and support services. We found little evidence dementia strategies and policies being evaluated.

What worked well tended to be the opposite of what worked less well, there were many strong similarities between partner countries in terms of what was working not so well. For example, a lack of coordination and communication between staff and caregivers, a lack of dementia
education for the professional workforce and caregivers, and a lack of funding specifically in relation to the number of professionals in dementia care, investment in dementia services, home adaptations and specific resources.

The main themes arising from the overall data analysis were: (1) When dementia is not detected and diagnosed early it limits the support strategies that can be put in place in order for people to live well for longer. (2) There is a lack of co-ordination between service providers and a lack of care planning in dementia care, which directly impacts on the quality and continuity of care for the person with dementia and their family care givers. (3) In many partner countries there is an expectation, under pinned by cultural values about gender, that female family care givers will adopt the caring role while in others, professionals are the only care givers. (4) The sleeping pattern of the person with dementia affects the quality of life for the individual and their family carers, it also influences the type of care provided. When the person with dementia sleeps well both they and their family care givers maintain better physical and mental health and experience less stress and distress. However when the person with dementia has disturbed sleep patterns they experience an increase in distressed behaviours. Over night sleep, rest and privacy was extremely important for carers yet professionals and those not directly caring for the person with dementia rarely recognised the importance of this in enabling the person with dementia and the family care giver to live well for longer and maximise their quality of life. (5) Caregivers appreciate learning from professionals about how best they can communicate with the person with dementia when verbal skills begin to diminish. (6) Comfort based care and the safety of the person with dementia were two
of the main concerns of family carers. (7) The person with dementia preferred to remain in an environment familiar to them, be connected to and sustain a social life and familiar routines. This seemed to allay some of the symptoms and enhance the quality of life. (8) There is a gap in evidence-based education on advanced dementia developed for both professional and non-professional caregivers. There is also a lack of qualified professionals who work in dementia care. This is despite education for the professional dementia workforce being a World Health Organization priority.

This highlights the importance of creating a range of social participatory and practice based learning resources to equip qualified practitioners from all health and social care disciplines to champion improvements to advanced dementia care in their workplace. The Dementia Palliare project will design education that makes use of modern technology, communication and networking to support learning in a virtual environment through membership of a facilitated virtual international community of practice. It will also design three interprofessional professional higher education modules on advanced dementia care; the content of which will reflect the main themes arising from the case studies.