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Exploring the Information Needs of Families of Patients with Advanced Dementia on Discharge from Acute Care

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Abstract Background: Dementia is a term used to describe a category of disorders characterized by a gradual decline in both cognitive and functional capability (McCabe et al 2016). In Ireland today, it is estimated that 55,000 people are living with the condition (HSE, 2018). It is predicted that this number will double over the next 20 years, with a projected 113,000 people expected to be living with dementia by 2036. Over the past 10 years published literature has highlighted the importance of information provision to careers as a means of optimizing care in dementia. However, little is known regarding the specific information needs of informal caregivers of patients with advanced dementia on discharge from acute care.

Aim: The aim of this study was to explore the information needs of informal caregivers of people with advanced dementia on discharge from the acute setting.

Methods: A qualitative descriptive design was employed. A convenience sample of 6 informal careers of people with advanced dementia was recruited. Participants were interviewed face-to-face using a semi structured interview topic guide. Thematic analysis was used framed by the work of Braun & Clarke (2006).

Results: Participants expressed a strong desire for more information. Three themes were seen following data analysis. 1) Understanding, experience and source of knowing in dementia 2) Information need and 3) Preferred type and source of information. A particular need for information on disease pathophysiology and managing changes in personality and cognition was highlighted with no preference as to who provides the information, once the individual is knowledgeable in the area. Whilst written information was acknowledged as being useful, face-to-face conversations were consistently highlighted as being the optimal form of communication. Conclusion: Currently, informal careers of people with dementia do not receive adequate information regarding the illness. Healthcare professionals need to provide information to careers across all stages of the disease.

Biography

Dr. Nicola Cornally is currently a Senior Lecturer at the Catherine McAuley School of Nursing and Midwifery, University College Cork. Nicola has been PI/Co-PI on 5 nationally funded projects in the area of dementia palliative care, healthcare design for dignified end-of-life care and contemporary end of life issues including advance care planning; funded by the Heath Research Board (HRB), Irish Hospice Foundation (IHF) and GSK. She is currently the national lead on a EU JPND funded project implementing comfort care guidance for family of people with Advanced Dementia. She is the programme lead for the MSc Nursing Studies and is co-director of Health Services Research for the School. She was recently appointed to the Strategic Scientific Committee for the AIIHPC Palliative Care Research Network. She currently supervises 6 PhD/MSc Res students and a postdoctoral researcher, primarily with a focus on palliative and end-of -life care

5

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