

2014 Commissioned Research on Dementia care

Chief Investigator: Professor Gerard Leavey, Ulster University

Title of research project: Communication and services for caregivers of people with dementia (CASCADE)

Abstract: Dementia is a major public health concern, costly in personal, social and economic terms. Caregiving for people with dementia can be stressful and many carers of dementia experience deterioration in their mental health and wellbeing. Better knowledge of dementia and good communication with professional services may help family caregivers to cope better and may be protective of their mental health and wellbeing. However, in NI, and elsewhere, we know very little about the communication needs of families, the extent to which these needs are met and by whom. Nor do we know about the impact on family carers when knowledge and communication with professionals is poor. We propose to undertake a study using quantitative and qualitative methods to examine the importance of communication in dementia caregiving. This study, led by an experienced and interdisciplinary research team in collaboration with caregivers and health professionals, will build knowledge and theory on communication, coping, social support and the mental health of dementia caregivers. In addition, we will examine the acceptability and practical utility of a 'dementia passport' in everyday use and from a range of perspectives. The key purposes of the passport are: to facilitate family to service and inter-professional communication through the complexities of multi-disciplinary care; to allow patients and families the opportunity to consider the challenges which dementia may bring and to allow them to express choices about how these challenges might be managed. Our proposed study provides a unique opportunity to explore barriers to implementation and use of this communication tool as patient and carer needs evolve. The integrated evidence from the different strands of the study will be useful to family carers and support services across a range health problems and will be invaluable in building further work in this area.