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A QUALITATIVE ANALYSIS OF BARRIERS TO FUTURE CARE DISCUSSIONS WITH FAMILY MEMBERS OF CARE HOME RESIDENTS WITH ADVANCED DEMENTIA

Kirsten J Moore,¹ Margaret Elliott,¹ Nuriye Kupeli,¹ Sarah Davis,¹ Jane Harrington,¹ Victoria Vickerstaff,¹ Anna Gola,¹ Bridget Candy,¹ Michael B King,² Gerard Leavey,³ Rumana Z Omar,⁴ Steve Morris,⁵ Irwin Nazareth,⁶ Elizabeth L Sampson,¹ Louise Jones¹. ¹University College London, Marie Curie Palliative Care Research Department, Division of Psychiatry, London, United Kingdom; ²University College London, Division of Psychiatry, London, United Kingdom; ³University of Ulster, Bamford Centre for Mental Health & Wellbeing, Derry/Londonderry, United Kingdom; ⁴University College London, Department of Statistical Science, London, United Kingdom; ⁵University College London, Department of Epidemiology and Public Health, London, United Kingdom; ⁶University College London, Research Department of Primary Care and Population Health, London, United Kingdom

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Introduction Discussion about care preferences and end of life wishes between family and staff on entry to a care home is an important predictor of family satisfaction with end of life care for residents with advanced dementia.

Aim(s) and method(s) This paper aims to examine issues relating to end of life discussions with family members of residents with advanced dementia. Data were collected during piloting of the Compassion intervention that engaged an Interdisciplinary Care Leader (ICL) in two care homes and aimed to improve end of life care for residents with advanced dementia. Data included the ICL's reflective diary, time record and interviews with family carers, care home staff, GPs and other health professionals. The ICL assessed 30 residents with advanced dementia and had 37 conversations of at least 15 minutes with family members. Qualitative data were thematically analysed by two researchers.

Results Family members described not having discussed end of life care with healthcare professionals, despite interest in learning more. Nurses described lack of time and confidence as barriers to these discussions. While healthcare professionals described conflicts with family about goals of care, these barriers were not experienced by the ICL.

Conclusion(s) This study identified a gap in provision of information and support for family members in decision making around end of life care. Findings suggest benefits of having a co-ordinator with dementia and end of life knowledge and communication skills, and who has adequate time to communicate with family to plan end of life care for the growing number of people who have dementia.