

Evidence from the development and testing of Compassion, a theory based complex intervention for a model of integrated care for people with advanced dementia towards the end of life.

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Background

Care for people with advanced dementia (AdvD) at the end of life (EOL) is an acknowledged priority in the EAPC White Paper 2015. In the UK, most people with AdvD reside in care homes, but few studies have explored the clinical context of their care and what might improve EOL experiences. Care is dependent on the skills and support of multi-professional care teams. We provide evidence for an integrated approach to care for people with AdvD and those close to them.

Method

Using a realist approach we developed Compassion, a theory-based model for care at the EOL in AdvD. We hypothesised that EOL care could be improved by increased understanding of symptoms and unmet health and social care needs, prompt recognition and appropriate management by professionals working with healthcare assistants and family carers, underpinned by awareness of the natural progression of dementia. We collected data from: a cohort study of clinical context, qualitative data to understand context-mechanisms and outcomes (CMO) affecting care, a UK-wide RAND/UCLA consensus on intervention components and implementation of Compassion in two care homes. Compassion comprised two core components: (i) an integrated approach to care; (ii) formal training and support for carers. Considering our data as a whole, we used realist logic to test our hypothesis.

Results

Care is determined by over-arching concepts: (i) chronicity of the clinical trajectory (ii) uncertainty regarding prognosis (iii) low levels of staff confidence and morale (iv) lack of trust between professional teams. We present qualitative and quantitative data to support our realist logic of analysis and CMO configurations to explain existing outcomes.

Conclusion

An integrated approach to EOL care in AdvD is acceptable in practice. Implementation requires in-depth understanding of factors affecting behaviours of people with AdvD and those caring for them. Further work is needed to explore effects of integrated care on outcomes.