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Supporting Excellence in End of Life Care - SEED' - how can family doctors support end of life care for people with dementia and their families?

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Background: The number of people with age-related diseases like dementia is predicted to double by 2040. People with advanced dementia experience similar symptoms to those dying with cancer yet professional carers find prognostication difficult and struggle to meet palliative care needs, with physical symptoms undetected and untreated. While elements of good practice in this area have been identified in theory, the factors which enable such good practice to be implemented in real world practice need to be better understood.

Aim: To determine a range of key stakeholder views on the key factors influencing the commissioning and provision of good quality care towards and at the end of life care for people with dementia.

Design: Semi-structured telephone and face-to-face interviews with topic guide, verbatim transcription and thematic analysis.

Setting/Participants: UK based study; sample comprised a range of key stakeholders in dementia care and/or palliative care (n=30 care commissioners; n=).

Results: Commissioners identified 4 key factors influencing good practice in end of life care for people with dementia were identified from the expert interviews: leadership and management of care, integrating clinical expertise, continuity of care, and use of existing guidelines. Care providers (n=65) identified 3 key challenges to delivering high quality end of life care in dementia: having timely, early planning discussions; identifying the dying phase and ensuring a good death with prevention of distress.

Conclusions: Appropriate and timely use of clinical expertise could prevent hospitalisation and ensure continuity of care; in the UK, a lack of integration between health and social care undermines the provision of continuity of care. Further work is needed to understand if, and how, existing guidelines and tools developed for generic end of life care can contribute to good quality end of life care for those with dementia.