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Dementia and Advance Care Planning: Whose Decision?

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Dementia and Advance Care Planning: Whose Decision?

Kerry Jones, Birchley, G., Clare, L., Huxtable, R, Wlater, T., & Dixon, J.

Background

Globally there are approximately 36 million people living with dementia. This is expected to rise to 66 million by 2030. EoLC strategies have focused on the trajectory of malignant disease. Yet people with later stage dementia have complex and psychological needs. The consequence of this along with legal complexities is that Pwd receive undignified treatment [tests, ANH] and unrecognised pain.

The Study

This study mapped the primary evidence base in what is a heterogeneous and complex field. Reviewing this evidence is invaluable to informing future research and recommendations. Several research questions guided our search on 25 eligible papers:

1. Who is involved in the decision making process?
2. How are decisions made?
3. In what way do systemic factors impact?

Results

Legal issues

- Complex and internationally varied [Belgian Right's Act, MCA, 2005, US Patient Self Determination Act, 1991]
- Assumption of directives to reduce burden
- AD – legally binding recording decisions about treatment and care if incapacitated
- Advance statements- verbal and written not legally binding
- Willingness to document ACP/AD

Family involvement and health professionals in ACP

- Complex proxy decision making resuscitation, hospitalisation, artificial nutrition and hydration, antibiotics, analgesics, diagnostic tests.
- Incongruence between assumed wishes of person to family member

Including the person with dementia in ACP

- Treatment options not fully realised [DNAR but ANH]
- Difficult to imagine and hypothesise future selves
- Variance in content of documents to record wishes

Systemic barriers to EoLC

- Pathways of care and the impact of hospitalisation, staff skills
- Lack of Out Of Hours care, integrated care, training – whose responsibility

Recommendations

- Decision making not one off event but necessitates adjustment along with a dementia pathway that is unpredictable.
- Training needs to focused on QOL of care and viewed annually
- Surrounded by people important to the dying
- Does not mean high tech environs
- Vigilant well supported staff – communicating and coordinating care [Admiral nurse]

Full article: [Jones, K., Birchley, G., Huxtable, R., Clare, L., Walter, T., & Dixon, J. \(2016\). End of life care: A scoping review of experiences of Advance Care Planning for people with dementia. *Dementia: the international journal of social research and practice*. DOI: 10.1177/1471301216676121](#)