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Examining how advance care directives are used for individuals with dementia living in residential accommodation: a literature review

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Examining use of Advance Care Directives by Registered Nurses For Individuals with Dementia living in residential accommodation: A literature review

Vivian Masukwedza; A/Prof Victoria Traynor & Prof Elizabeth Halcomb

Introduction

Individuals with dementia are generally capable of making care decisions in early stages of dementia. In advanced stages of dementia, the role of the individual with dementia in care decision making lessens, while the nominated family representative assumes more authority to direct any stated Advance Care Directives. Advance Care Directives (ACDs) allow individuals with dementia to express wishes regarding end of life care, long after losing capacity to do so. The phenomenon is complicated by inconsistencies in legislation for ACDs.

Selection Process of Studies Included in Review

A total of 89 studies were identified from the literature search. After removal of duplicates, 67 studies were screened for their relevance for this literature review. Publications (n=48) whose research focus was not dementia or ACDs were removed. Full text of the remaining 19 articles was accessed and four (n=4) studies on ACDs but not in dementia care were removed. A total of fifteen (n=15) studies were included in the review; comprising of twelve (n=12) Quantitative, two (n= 2) qualitative and one (n=1) mixed methods study.

Results

i). Legal Issues
• Inconsistencies in legislation related to ACDs. A set of ACDs in one jurisdiction may not be valid in another jurisdiction
• The legality status of ACDs in each state/territory does vary.

ii). Incidence use of ACDs
• Poor uptake of ACDs
• Poor implementation strategies of ACDs
• Poor adherence to ACDs.

iii). Outcomes of ACDs:
• Reduced hospital transfers and costs
• Psychological well-being of family carers as a result of reduced burden on decision making (Impact of Events Scale).
• Satisfaction with care amongst individuals with dementia and families measured by Satisfaction With Care At End Of Life in Dementia (SWC-EOLD).
• Quality of life for individuals with dementia using the Alzheimer’s Disease Related Quality of Life (ADRQL), there was weak association between quality of life and deterioration in clinical state.
• Those individuals with dementia with health proxies were more likely to have DNR or DNH orders.

Aims

The aims of the literature review were: to identify factors which promote and prevent the: i). introduction of ACDs to individuals with dementia living in residential accommodation; ii). completion of ACDs by individuals with dementia living in residential accommodation; and iii) adherence to the directions of ACDs completed by individuals with dementia living in residential accommodation.

Method

This investigation involved a careful selection of available literature relevant to addressing the study objectives. A systematic search of empirical studies was undertaken to locate international and local studies addressing the study objectives. Databases accessed were: CINHAL Plus Text, Medline, Web of Science and Scopus. Keywords words were used in the search and also the study employed a network approach where manual searching of the electronically retrieved sources was performed to identify any other relevant references through citations.

Conclusions

i). There was scarcity of quantitative research evaluating the use of ACDs.

ii). There is need for ACDs to be implemented in a systematic manner preceded by adequate education on the subject.

iii). ACDs enable individuals with dementia to participate in decision-making affecting their end-of-life care.

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