A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia

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CRD summary
The authors concluded that there was limited evidence for the effectiveness of advance care planning in people with cognitive impairment or dementia and that nursing home settings may be too late for people with dementia to discuss advance care planning. The authors' conclusions appear to be a fair reflection of the limited evidence available and are likely to be reliable.

Authors' objectives
To determine the effectiveness of advance care planning interventions in people with cognitive impairment and dementia.

Searching
Twelve databases (including MEDLINE and The Cochrane Library) were searched to January 2010 for studies in English. Search terms were reported in an appendix. Reference lists of retrieved articles were handsearched. Experts were consulted and conference proceedings, abstracts and theses were searched to locate grey literature.

Study selection
Eligible studies were randomised controlled trials (RCT), non-RCTs, controlled before-and-after studies and interrupted time series analyses with three or more data points pre- and post-intervention. Study populations had to contain participants of any age with acquired cognitive impairment who were residing in any care environment. Eligible interventions included any aspect of advance care planning; all control arms had to receive usual care.

Mean participant age ranged from 78 to 87 years (where reported). Half of the studies included participants with cognitive impairment that ranged from mild to severe; one study excluded people with severe dementia. All included studies were conducted in nursing homes. Half of the studies solely focused on implementation of advance care planning; the other half investigated advance care planning as part of a wider hospital implementation in palliative care or the home. Studies were conducted in North America or Australia.

Two reviewers independently selected studies for inclusion; discrepancies were resolved by discussion or via a third reviewer.

Assessment of study quality
Risk of bias was assessed for sequence generation, allocation concealment, baseline characteristics, completeness of outcome data, baseline outcomes, blinding, contamination, full outcome reporting and other sources of bias. Responses were scored as yes (low risk), no (high risk) or unclear (unknown/uncertain risk).

Two reviewers independently performed the risk of bias assessment; the authors did not state how any discrepancies were resolved.

Data extraction
The authors did not state how many reviewers extracted the data.

Methods of synthesis
Extracted data were categorised as relating to advance care planning outcomes, patient health or health care utilisation and presented as a narrative synthesis.

Results of the review
Four studies (3,074 participants) were included in the review: one RCT (1,133 participants), one non-RCT (139 participants) and two controlled before-and-after studies (1,802 participants). Low risks of bias were mainly assessed.
for allocation concealment (three studies), healthcare outcomes reported at baseline (three studies) and protection against contamination (three studies). High or unknown risks of bias were assessed for sequence generation, reporting of baseline characteristics and completeness of data/blinding.

At most 36% of intervention participants and 41% of control participants were judged as having the capacity to make decisions (three studies). Increased documentation of patient preferences for care was observed in the intervention groups compared with controls (three studies); two studies reported that this difference was significant.

Compared with control groups, intervention groups showed significant reductions in hospitalisation rates (two studies) and a significantly increased rate of hospice service utilisation (one study). Only one study investigated participant health as an outcome; it reported a significant increase in uptake of pain assessment for an intervention group over the control group. No significant difference in pain medication use was found between them.

Authors' conclusions
There was limited evidence of variable quality for the effectiveness of advance care planning in people with cognitive impairment or dementia in relation to advance care planning documentation and healthcare use. At the point of entry to a nursing home, the capacity of people with dementia might be too diminished for them to discuss advance care planning.

CRD commentary
The review questions were clear and inclusion criteria were replicable. An extensive range of relevant databases were searched and attempts were made to locate grey literature. The restriction of the search to studies in English increased the possibility that language bias was present. Efforts were made to minimise reviewer error and bias during study selection and quality assessment but this was unclear for the stage of data extraction. It appeared that appropriate quality assessment criteria were used; results were variable. Study characteristics were presented and the narrative method of synthesis was appropriate for the data reported. The authors acknowledged that some of the studies were unclear about inclusion and exclusion of participants according to levels of cognitive impairment and that confounding factors may have been present in two of the included studies.

The authors' conclusions appear to be a fair reflection of the limited evidence available and are likely to be reliable.

Implications of the review for practice and research
Practice: The authors stated that earlier timing of advance care planning in dementia is important, with additional review upon entry to a nursing home.

Research: The authors stated that further high quality research would provide stronger support for advance care planning to become part of routine dementia care. The acceptance of advance care planning by people with dementia and their families and the point at which this might occur would be equally important to research.

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