

Best Evidence Summaries of Topics in Mental Healthcare

BEST in MH *clinical question-answering service*

Question

In adults with dementia, what aspects of advanced care planning are effective in improving patient outcomes?

Clarification of question using *PICO* structure

Patients: Adults with dementia

Intervention: Aspects of advanced care planning

Comparator: Any other aspects of care planning

Outcome: Patient outcomes

Plain language summary

More high quality research is needed to explore the effects of different advanced care planning interventions, and to determine which aspects of these interventions are effective, in adults with dementia.

Clinical and research implications

There is currently insufficient evidence to adequately assess the effects of Advanced Care Planning (ACP) interventions for people with dementia. All of the available evidence relates to education and training programs delivered in nursing homes and involving either staff alone, or staff, residents and family members. The characteristics of the nursing home residents in these studies are poorly described, with only one study specifically mentioning people with dementia. The very limited evidence available suggests that ACP interventions may have some effect in increasing ACP-related outcomes (e.g. number of 'Do Not Resuscitate' orders and documentation of residents' preferences in relation to specific treatments), however, these effects are inconsistent and often not statistically significant. There is also some limited evidence to suggest that ACP interventions may be associated with reduced hospitalisation rates. All of the available evidence describes the effects of ACP interventions in comparison to usual care.

High quality studies, preferably using participant level randomisation, are needed to adequately explore the effects of different ACP interventions in people with dementia. It is important to specify the clinical characteristics of patients included in such studies, as the level of cognitive impairment is likely to be an important modulator of the effectiveness of ACP interventions.

What does the evidence say?

Number of included studies/reviews (number of participants)

We identified two systematic review, which were considered to have partial relevance to this evidence summary.^{1,2} Both systematic reviews aimed to assess the effectiveness of Advanced Care Planning (ACP) interventions. The intervention assessed were education and training interventions about ACP and all included studies had usual care as the comparator condition; no studies were identified which compared the effectiveness of different types of care planning. The two reviews included seven unique studies (three studies were common to both reviews). All studies were conducted in residential nursing homes. Reporting of participant (nursing home resident) characteristics was poor and only one study specifically mentioned the inclusion of people with dementia. The main outcome measures reported were ACP-related outcomes, including discussion and documentation of ACP (all studies), health-care resource use (4 studies), and satisfaction with healthcare provision (2 studies).

Main findings

Six of the seven unique studies, included in two systematic reviews,^{1,2} reported information to suggest that ACP interventions were associated with increases in at least one ACP-related outcomes (discussion and/or documentation of ACP), however, this effect only reached statistical significance in three studies and, in some instances, was not consistent across different ACP-related outcomes (e.g. increased discussion did not consistently translate into increased documentation). It should also be noted that the only study which specifically included patients with dementia was included in only one of the reviews¹ and did not report sufficient information to assess the effects of the intervention on ACP-related outcomes. All four of the studies that assessed health-care resource utilisation, including the only study reporting inclusion of patients with dementia, found that ACP interventions were associated with reduced hospitalisation rates. Only two studies reported information about satisfaction with healthcare provision and these reported inconsistent results;

one found no difference between the ACP intervention and control and the other found that the ACP intervention was associated with significant increases in satisfaction with care.

Authors conclusions

Robinson 2012 – The authors stated that there is limited evidence for the effectiveness of advance care planning in people with cognitive impairment/dementia in terms of advance care planning documentation and health-care use. They also noted that, in terms of capacity to discuss advance care planning, nursing home settings may be too late for people with dementia.

Wickson 2014 – The authors concluded that the programs assessed indicated a variety of positive impacts in the planning and provision of end-of-life care for residents and their family members, most notably, increased Advance Care Planning discussion and documentation.

Reliability of conclusions/Strength of evidence

The limited evidence included in this summary is derived from a total of seven studies, included in two systematic reviews, both of which had significant methodological limitations. No studies were identified which compared the effectiveness of different types of care planning; all of the studies included in both reviews used usual care as the control condition. Details of study participants were very sparsely reported and, where allocation to intervention or control group occurred, this was at the institutional (nursing home) level. Overall, the available evidence was insufficient to draw any firm conclusions about the effects of ACP in people with dementia.

What do guidelines say?

Nice guidelines do not comment on advanced care plans for people with dementia

Date question received: 25/04/2016

Date searches conducted: 10/04/2016

Date answer completed: 23/05/2016

References

Systematic reviews

1. Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., Howel, D., Exley, C. (2012) A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing*, 41(2), p263-269
2. Wickson-Griffiths, A., Kaasalainen, S., Ploeg, J., McAiney, C. (2014) A Review of Advance Care Planning Programs in Long-Term Care Homes: Are They Dementia Friendly? *Nursing Research and Practice*

Results

Systematic reviews

Author (year)	Search date	Inclusion criteria	Number of included studies	Summary of results	Risk of bias
Robinson et al 2012	January 2010	<p>Participants: People with acquired cognitive impairment of any age including people with dementia, and people who are chronically cognitively impaired but do not fulfil the accepted criteria for dementia. Studies conducted in any care environment were included.</p> <p>Intervention: Advance Care Planning (ACP) interventions: Advance directive(s); living will; advance care planning; power of attorney; intervention; completion; advance statement; advance refusal of treatment; preferred place of care; values history.</p> <p>Comparator: Usual care</p> <p>Outcome: Not specified in the inclusion criteria</p> <p>Study design: Randomised controlled trials (RCTs), non-RCTs, controlled before-and-after studies (CBAs) and interrupted time series analyses (ITS) with at least three data points before and after the intervention.</p>	4 studies	<p>This systematic review aimed to assess the effectiveness of advance care planning interventions in people with cognitive impairment and dementia.</p> <p>The review included four studies, all conducted in nursing homes, 2 from the USA, 1 from Canada, and 1 from Australia. The reporting of participant characteristics was limited, however, the authors noted that none of the included studies was specifically targeted at people with dementia; two studies included people with mild to severe cognitive impairment, one study included people with mild to moderate dementia and no relevant details were reported about the population of the fourth study. The mean age of study participants ranged from 78 to 81 years and the proportion judged to have decision making capacity varied, up to a maximum of 36%.</p>	<p>The objective of the review was clearly stated and appropriate inclusion criteria were defined (reported in an online appendix).</p> <p>Eighteen bibliographic databases were searched (including grey literature sources) and searches were supplemented by hand searching of reference lists and contact with experts. However,</p>

				<p>Two studies (Caplan et al. and Molloy et al.) evaluated a specific advance directive programme, 'Let Me Decide,' in which trained nurses provided education to nursing home residents and their families, and to nursing home staff. One study (Morrison et al.) trained social workers in advance care planning, using small group workshops and role play sessions. The final study (Hanson et al.) trained palliative care teams to deliver educational sessions to nursing home staff. Usual care was the comparator for all studies, either using a before and after design, or randomising nursing homes to the intervention or control.</p> <p>Only one study (Molloy et al.) assessed residents' and families' satisfaction with health-care; this study found no difference between the intervention and control nursing homes.</p> <p>All studies assessed ACP outcomes. Three studies found that the intervention was associated with increases in the numbers of written ACP-related outputs: Hanson et al. Reported a small increase in the number of</p>	<p>only very limited search terms were reported and only English language studies were included.</p> <p>Two reviewers were involved at all stages of the review process, minimising the potential for error and bias.</p> <p>The methodological quality of included studies was assessed and results were reported, in full, in an on-line appendix.</p> <p>The use of a narrative synthesis was appropriate.</p>
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				<p>'Do Not Resuscitate (DNR)' orders, but no change in the numbers of living wills or power of attorney documents; Molloy et al. found a small, but not statistically significant increase in the rate of completion of Advance Directives (ADs); Morrison et al. found significant increases in documentation of patients' preferences in relation to resuscitation, artificial nutrition, intravenous antibiotics and hospitalisation. The only study which specifically included patients with dementia (Caplan et al.) did not report sufficient information to assess the effects of the intervention on ACP up-take.</p> <p>Three studies also reported data on healthcare utilisation. Two studies (Molloy et al. and Caplan et al.) found that the intervention was associated with reduced hospitalisation rates, and one study (Hanson et al.) found that the intervention was associated with a significant increase in hospice use.</p>	
Wickson-Griffiths et al (2014)	May 2013	<p>Participants: Studies in long-term care home settings were included; no further inclusion criteria were specified with respect to study participants.</p> <p>Intervention: Advance Care Planning (ACP) and</p>	6 studies	<p>This review appears to have aimed to assess the effectiveness of advance care planning programs in long-term care home settings.</p> <p>The review included six studies, of which</p>	No research objective was explicitly stated, however, inclusion criteria were

	<p>end of life or palliative care programmes with a main aim of promoting ACP. An adequate description of the ACP program assessed had to be available.</p> <p>Comparator: Not specified in the inclusion criteria</p> <p>Outcome: Not specified in the inclusion criteria</p> <p>Study design: Comparative studies, with a control group; un-controlled studies and before and after designs were excluded.</p>		<p>three (Morrison et al., Hanson et al. and Molloy et al.) were also included in the Robinson 2012 review, described above. Of the three studies not described above, 2 were conducted in the USA and 1 in Hong Kong. These studies are described below.</p> <p>The reporting of participant characteristics was very limited; all three studies mentioned cognitive impairment, but not specifically mentioned dementia.</p> <p>Each of the three additional studies evaluated a different intervention: Chan and Pang evaluated the 'Let Me decide' program, using interviews with residents to explore values and care preferences; Casarett et al. used a Promoting Residents' Involvement in Decisions at End-of-Life (PRIDE) assessment to identify residents preferences and communicated these to physicians; Strumpf et al. assessed the Promoting Excellence in End-of-Life program, which involved developing palliative care teams in two long-term care homes and providing educational training and support to staff. All studies used usual care as the control condition.</p>	<p>defined. The inclusion criteria stated that 'before-after designs' were excluded, however, the review included two such studies.</p> <p>Four bibliographic databases were searched, but no search terms were reported. Searches were supplemented by examination of relevant websites.</p> <p>One reviewer assessed studies for inclusion, and no details were reported about the numbers of reviewers involved in data extraction.</p> <p>The authors</p>
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			<p>All three studies found that the intervention was associated with an increase in ACP-related activities and discussion, however, this increase only reached statistical significance in Strumpf et al., and none of the three studies reported an increase in ACP-related documentation.</p> <p>Chan and Pang also found that the intervention was associated with a statistically significant increase in knowledge of residents' ACP amongst family members and care home staff, as well as improved stability in treatment preferences and quality of life amongst residents.</p> <p>Casarett et al. found that the intervention was associated with increased adherence to the wishes of the resident or their substitute decision maker, increased satisfaction with care and reduced hospitalisation. It should be noted that numerical data were not provided for any of the results reported.</p>	<p>reported that the methodological quality of included studies was assessed, but no details of the components of this assessment were provided and the results were not reported.</p> <p>The use of a narrative synthesis was appropriate.</p>
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Risk of bias

Systematic reviews

Author (year)	RISK OF BIAS				
	Inclusion criteria	Searches	Review process	Quality assessment	Synthesis
Robinson et al (2012)	😊	😔	😊	😊	😊
Wickson-Griffiths et al (2014)	😔	?	😔	😔	😊

😊 Low risk

😔 High risk

? Unclear risk

Search details

Source	Search Strategy	Number of hits	Relevant evidence identified
<i>Guidelines</i>			
NICE	Dementia	31	
MEDLINE	(advance AND care adj3 (plan OR plans OR planning)).ti,ab (advance AND next AND (directive* OR decision*)).ti,ab (living adj2 will*).ti,ab (living adj2 will*).ti,ab ((patient OR patients) adj5 (advocat* OR advocacy)).ti,ab (power AND of AND attorney).ti,ab ("end of life" OR EOL) adj5 (care OR discuss* OR decision* OR plan OR plans OR planning OR preference*).ti,ab (terminal AND care).ti,ab (treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab (treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 dement*.ti,ab exp DEMENTIA/ 41 OR 42 40 AND 43 (advance AND care adj3 (plan OR plans OR planning)).ti,ab (advance AND next AND (directive* OR decision*)).ti,ab (living adj2 will*).ti,ab ((patient OR patients) adj5 (advocat* OR advocacy)).ti,ab (power AND of AND attorney).ti,ab ("end of life" OR EOL) adj5 (care OR discuss* OR decision* OR plan OR plans OR planning OR preference*).ti,ab (terminal AND care).ti,ab (terminal AND care).ti,ab	1001	

	(treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab (treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 dement*.ti,ab exp DEMENTIA/ 54 OR 55 53 AND 56		
EMBASE	(advance AND care adj3 (plan OR plans OR planning)).ti,ab (advance AND care adj3 (plan OR plans OR planning)).ti,ab (advance AND next AND (directive* OR decision*)).ti,ab (living adj2 will*).ti,ab ((patient OR patients) adj5 (advocat* OR advocacy)).ti,ab ((patient OR patients) adj5 (advocat* OR advocacy)).ti,ab (power AND of AND attorney).ti,ab (("end of life" OR EOL) adj5 (care OR discuss* OR decision* OR plan OR plans OR planning OR preference*).ti,ab (terminal AND care).ti,ab (treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab (treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab (treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab (treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab 15 OR 16 OR 17 OR 19 OR 20 OR 21 OR 22 OR 24 15 OR 16 OR 17 OR 19 OR 20 OR 21 OR 22 OR 24 dement*.ti,ab dement*.ti,ab exp DEMENTIA/ exp DEMENTIA/ exp DEMENTIA/	1650	

	26 OR 28 25 AND 29 25 AND 29 31 [Limit to: (Publication Types Journal or Report or Review)]		
PsycINFO/CINAHL	(advance AND care adj3 (plan OR plans OR planning)).ti,ab (advance AND care adj3 (plan OR plans OR planning)).ti,ab (advance AND next AND (directive* OR decision*)).ti,ab (living adj2 will*).ti,ab ((patient OR patients) adj5 (advocat* OR advocacy)).ti,ab (power AND of AND attorney).ti,ab (("end of life" OR EOL) adj5 (care OR discuss* OR decision* OR plan OR plans OR planning OR preference*)).ti,ab (terminal AND care).ti,ab (terminal AND care).ti,ab (treatment adj5 (refus* OR withhold* OR withdraw*)).ti,ab 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 dement*.ti,ab exp DEMENTIA/ 10 OR 11 9 AND 12 13[Limit to: (Record type Journal Article or Peer-reviewed Journal)]	558	

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