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Effectiveness of interventions to increase participation in advance care planning for people with a diagnosis of dementia: A systematic review

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ABSTRACT

Background: Advance care planning involves considering, discussing and documenting future wishes in case a person is unable to make or communicate decisions. Given people with dementia are at high risk of future decisional incapacity, it is critical that advance care planning occurs early in the illness trajectory.

Aim: To determine (i) the number of intervention studies published between 1997 and July 2017 that aimed to increase advance care planning for persons with dementia; (ii) the methodological quality of studies; and (iii) the effectiveness of interventions in increasing advance care planning for persons with dementia.

Design: Systematic review.

Data sources: Medline, Cochrane, EMBASE, PsycINFO and CINAHL were searched for articles published from 1997 to July 2017. Studies were included if they utilised a methodologically robust study design and reported on an intervention designed to increase participation in advance care planning for persons with dementia that was targeted at the person with dementia and/or a carer/family member. Methodological quality was assessed independently by two authors.

Results: Four studies met criteria for inclusion. Methodological quality was variable. Two studies did not report analyses comparing advance care planning outcomes for intervention and control participants. A third study found no effect for a nurse-facilitator intervention. The fourth study found that a structured conversation about end-of-life care with a family member increased the likelihood of advance care orders being listed in residents' records.

Conclusions: There is little evidence about effective strategies to improve participation in advance care planning for persons with dementia. Methodologically rigorous intervention trials are needed to test interventions that encourage timely participation..

What is already known about the topic?

- Advance care planning is important for people with dementia given the progressive nature of the disease and its impact on cognitive capacity.
- No systematic reviews have synthesised the evidence about strategies that increase participation in advance care planning for persons with dementia.

What this paper adds

- Very few methodologically rigorous studies have examined the effectiveness of interventions in increasing participation in advance care planning for persons with dementia.
- Studies that have been conducted have various methodological weaknesses.
- A discussion of the methodological challenges of conducting research with individuals with declining cognitive capacity is included.

Implications for practice, theory, or policy

- It is not possible to recommend effective ways of increasing participation in advance care planning for persons with dementia given the limitations of the current evidence base.
- Well-designed randomised controlled trials are needed that examine ways of engaging persons with dementia to participate in advance care planning before capacity declines.
- Future studies should include examination of the cost-effectiveness of interventions, and the impact of advance care planning on end-of-life care outcomes.

BACKGROUND

Dementia is a life limiting illness characterised by progressive cognitive decline that interferes with social and/or occupational functioning, and typically causes changes in behaviour and personality.¹ In 2010 it was estimated that almost 36 million people globally had a diagnosis of dementia, with the prevalence expected to double every twenty years, in part due to the increasing proportion of older adults in the population.²

Advance care planning is the process of considering, discussing and documenting future wishes so these can be acted upon if a person has reduced capacity to be able to make decisions or speak for themselves³. Advance care planning is usually carried out through discussion by a person with their healthcare providers and families, with the intent of developing an advance care directive, a legally binding document that expresses preferences for future medical treatment. Communicating values and preferences by engaging in advance care planning has been shown to have a number of benefits including reducing the likelihood of estate distribution disputes, financial exploitation, and unwanted medical care⁴⁻⁶, as well as increasing awareness and knowledge without diminishing hope or increasing hopelessness or anxiety⁷. Having an advance care plan has also been shown to reduce stress, anxiety, and depression in surviving relatives and those who need to make decisions on behalf of a person⁸.

Advance care planning is critical for people with dementia for a number of reasons. Firstly, there is increasing recognition that people with dementia receive sub-optimal care at the end of life. People with dementia have been shown to receive less appropriate pain relief⁹ and fewer medical services, compared to persons without dementia.^{10, 11} Use of invasive and non-palliative medical care at the end of life is also high, with persons with dementia more likely to receive feeding tubes and be prescribed antibiotics than persons diagnosed with cancer.¹² Secondly, persons with dementia commonly experience apraxia, decreased mobility, dysphagia, a complete loss of the ability to perform usual activities of daily living, and an inability to communicate as the disease advances.¹³ As compared to other conditions, it is more certain that the capacity of people with dementia to communicate and make decisions will decline.¹⁴ When a person with dementia has lost the capacity to communicate their wishes and engage in decision making, family members/carers are often called on to make decisions about a wide range of financial, lifestyle and health issues on their loved one's behalf. The likelihood of the person with dementia receiving unwanted care may be increased where discussions of wishes has not occurred. For example, a study by Denning et al., found that family carers and persons diagnosed with dementia had only low to moderate agreement about preferences for end of life treatment.¹⁵ Thirdly, people with dementia often experience multiple transitions across care settings (e.g. between nursing home and hospital).¹⁶ Without having an advance care plan in place, the risk of unwanted care may be higher, as caregivers may not always be able to provide guidance about the patient's wishes, and health care providers may be unfamiliar with personal and medical history.

For example in one study, patients with severe dementia who had an advance directive in the form of a living will received significantly less aggressive care at the end of life, compared to similar patients without such a directive.¹⁷

Research suggests that people with dementia are able to communicate their values and preferences and meaningfully participate in making decisions about care,¹⁸ even when dementia is more advanced.¹⁹ Early engagement in advance care planning may enhance the delivery of respectful person-centred care to persons with dementia at the end of life by increasing the likelihood that advance care planning accurately reflects values and wishes. Early engagement in advance care planning may also facilitate communication of preferences and wishes with caregivers, increasing the likelihood that such preferences are met in the future. However, the limited current evidence available suggests that uptake of advance care planning among people with dementia is low. For instance, a US study examined participation in advance care planning amongst people with a diagnosis of mild cognitive impairment or early dementia who did not have an advance care directive in place when they initially presented for cognitive evaluation at a University Alzheimer's disease research centre. Five years later, only 39% of people had initiated advance care planning.²⁰ Another study showed that a written advance directive was present for only 17.5% of Flemish residents of nursing homes with dementia who had died.²¹ An Australian study examined uptake of advance care planning by clients with mild cognitive impairment or recently diagnosed dementia and their families attending a specialist memory clinic. Of 48 carers (52.2%) and 34 clients (35.1%) who participated, only 4% of carers and 8.8% of clients completed advance care planning documentation.²² The rise in the number of people being diagnosed with dementia,² the significant personal and societal costs associated with suboptimal care at the end of life, and the potential benefits of advance care planning highlight the need for high level evidence regarding strategies that are able to increase participation in advance care planning in this population.

While a number of previous systematic reviews have synthesised the literature on advance care planning across a range of populations²³, there has been limited synthesis of the evidence regarding the impact of interventions for people with dementia. For instance, Houben and colleagues conducted a systematic review of the efficacy of advance care planning interventions in different adult patient populations, with only one of 55 studies identified focusing on persons with dementia.⁶ Another review conducted in 2010 examined the effectiveness of advance care planning interventions for people with cognitive impairment and dementia²⁴. Although four interventions were identified, none of these specifically focused on persons with dementia, but rather nursing home residents with different levels of cognitive impairment. Reviews that have focused on advance care planning and dementia have only examined the barriers and enablers to advance care planning²⁵. A recent 2018 review examined the effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers.²⁶ Most of the 18 interventions

identified in the review found advance care planning to be associated with some improved end-of-life outcomes. However no recent reviews have examined the peer-reviewed published literature to determine which intervention strategies are most effective in increasing participation in advance care planning for people with dementia. Furthermore, there has been limited consideration of the quality of evidence synthesised, with no reviews specific to advance care planning and dementia examining the type of studies conducted, their methodological quality and their impact. Assessing the methodological quality of studies is critical to ensuring the validity of outcomes, and thus contribute to guiding future research and practice,

Therefore, the aim of this was review was to determine the:

1. Number of intervention studies that aimed to increase participation in advance care planning for persons with dementia published over the past 20 years (1997-2017);
2. Methodological quality of interventions assessed against Effective Practice and Organisation of Care (EPOC) criteria;
3. The effectiveness of interventions in increasing advance care planning for persons with dementia..

METHODS

Literature search

The electronic databases Medline, Cochrane, Embase, PsycINFO and CINAHL were searched in July 2017 using a combination of Medical Subject Headings (MeSH) and keywords (see Appendix 1 for the full search strategy). The reference lists of included studies and the reference lists of relevant review papers were also manually searched to identify any additional studies. This was further supplemented by a Google Scholar search using the words 'intervention; advance care planning; dementia; Alzheimer's' with the first 100 results examined for relevance.

Inclusion and exclusion criteria

Studies were included if they were published in English from 1997 onwards and reported on an intervention designed to improve the prevalence of advance care planning for persons with dementia. The advance care planning outcome could be a primary or secondary outcome of the implemented intervention, and could be targeted at the person with dementia and/or a carer/family member. Outcomes could include discussion or completion of any type of medical planning instrument (e.g. advance directive; living will; advance statement; advance refusal of treatment; do not resuscitate order; do not intubate order, do not hospitalise order); or a document outlining preferred place of care, goals of care or values. Advance care planning was conceptualised broadly given differences between jurisdictions in how advance care planning is defined and enacted, and how advance care planning concepts, policy and laws have evolved over time²⁷. Studies were included only if they used one of the Effective Practice and Organisation of Care²⁸ (EPOC) accepted study designs (i.e. randomised controlled trial, non-randomised controlled trial,

controlled before and after study or interrupted time series trial). Case studies, commentaries, conference abstracts, protocol papers, editorials and reviews were excluded.

Data coding and extraction

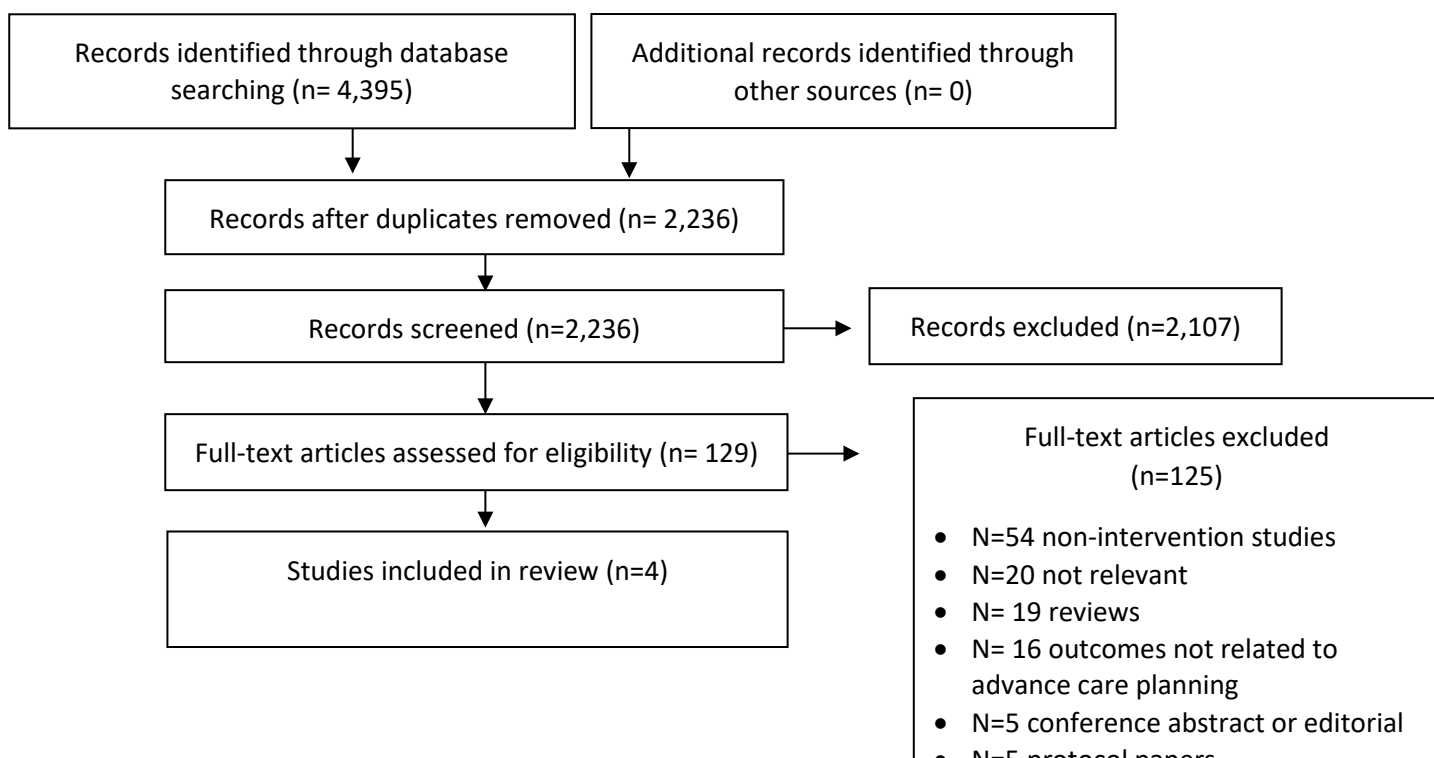
All retrieved abstracts were initially assessed by one author (JB) against the inclusion and exclusion criteria and rejected if the study did not meet eligibility criteria based on assessment of the title and abstract. Remaining full text articles were then independently reviewed by two authors (JB and HT) and studies which met all criteria were retained for review. Any discrepancies were resolved through discussion. The methodological quality of all intervention studies was then assessed against EPOC risk of bias criteria by two authors (MF and EM), with any discrepancies resolved through discussion with a third author (JB). For each included study, the following information was extracted to determine the effectiveness of the intervention in increasing the prevalence of advance care planning: sample characteristics (number of participants, age, gender, diagnosis), inclusion and exclusion criteria, details of the intervention and control conditions, outcome measures, follow-up time points, outcomes (see Table 1).

RESULTS

Search Results

An overview of the search results and the study coding process is outlined in Figure 1 using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)²⁹ four-phase flow diagram. A total of 4,395 citations were initially retrieved from database searches. Following removal of duplicate citations, 2,236 citations were screened for eligibility with 129 of these citations included in the full text review. A total of eight interventions studies were identified, of which four met the EPOC study design criteria and were included in the review.

Figure 1. PRISMA Flowchart.



Characteristics of included studies

The characteristics of the four included studies are provided in Table 1. As studies reported multiple outcomes, of which the advance care planning outcome was a primary outcome only for one study³⁰, the advance care planning outcome of interest is presented in italics in Table 1. Advance care planning outcomes included Presence of Medical Order for Life-Sustaining Treatments³¹, completion of a do not resuscitate order, writing of an advance care plan³⁰ and the End-of-Life Treatment Decisions Scale for cardiopulmonary resuscitation (CPR), mechanical ventilation and tube feeding.³²

Two studies were randomised controlled trials,^{30, 31} one was a cluster randomised controlled trial³³ and one a before-and-after controlled study.³² None of the included studies included an economic analysis of the cost effectiveness of the implemented intervention. All studies were published in the last seven years. Two studies were conducted in the United States of America (USA)^{31, 32} and two in the United Kingdom (UK).^{30, 33} The intervention strategies used in all four studies were targeted at increasing documentation or decision making about advance care planning by carers of people with dementia, rather than the person with dementia. In two studies, the person with dementia to which the caregiver was providing support was residing in a nursing home,^{31, 33} in one the person with dementia was admitted to hospital³⁰ and in one the person with dementia was attending an adult day centre.³² Three interventions used varied structured one-on-one family meetings or consultations with caregivers to deliver education and provide an opportunity to complete an advance care plan.^{30, 31, 33} One intervention involved face-to-face group sessions with caregivers that aimed to enhance knowledge, self-efficacy and behavioural skills to make end-of-life treatment plans.³²

EPOC risk of bias

The methodological quality of the included studies according to EPOC criteria are provided in Table 2. One study was rated low risk of bias on seven of the eight criteria.³³ The remainder received ratings of high or unclear risk of bias across three or more criteria.³⁰⁻³² Baseline characteristics were judged high or unclear risk for three studies, while two studies were judged high risk for protection against contamination. Several other risks of bias were identified.

Effectiveness of interventions

Of the four studies identified, two did not report statistical analyses comparing the advance care planning outcome of interest for intervention and control participants^{30, 32}. Sampson et al³⁰ examined the effectiveness of face-to-face consultations with the caregiver, informed by a clinical assessment, in increasing the preparation of an advance care plan. Participants were caregivers of people with advanced dementia who had been hospitalised (n=33). A clinical assessment was first conducted to assess dementia severity, delirium, communication, pressure sore risk and severity, food and fluid intake, swallowing, feeding and pain. From this clinical assessment, a list of active problems was generated for discussion with the caregiver. Up to four face-to-face consultations occurring at least 5 days apart were then conducted with the caregiver to provide information about dementia and palliative care and to discuss the problems identified. As part of the consultations, carers were provided with an opportunity to develop an advance care plan using an adapted version of the UK National Health Service Preferred Priorities of Care tool. Despite the care planning discussions being well received, only seven (32%) caregivers developed an advance care plan. Rates of development of an advance care plan were not reported for the control group. Bonner et al³² examined the feasibility of implementing the Advanced Care Treatment (ACT)-Plan intervention with African American caregivers of persons with dementia (n=82). Four weekly educational sessions were delivered to caregivers by African American advanced practice nurse facilitators. Sessions included case studies, self-reflection, storytelling and guided discussions to enhance knowledge, self-efficacy and behavioural skills to make end-of-life treatment plans. Education delivered as part of the sessions covered information about dementia and disease progression, discussions of benefits of CPR, mechanical ventilation, and tube feeding, and the use of advance care planning. The intervention was found to be feasible and appropriate for African American caregivers. Self-efficacy and knowledge about dementia, CPR, mechanical ventilation and tube feeding increased for intervention participants but not for controls. A greater proportion of caregivers in the intervention group than in the control group changed their decision regarding the use of CPR, mechanical ventilation and tube feeding post-intervention, however no statistical analysis was reported.

Reinhardt et al³¹ assessed the effectiveness of information and support provided to family members about the benefits and disadvantages of treatment decisions on satisfaction with care and family member's wellbeing (n=110). Secondary outcomes included the presence of a Medical Order for Life-Sustaining Treatments (MOLST) in the person with dementias' medical chart and the presence of seven interventions: do not resuscitate (DNR), do not intubate (DNI), do not hospitalise (DNH), orders for no feeding tube, antibiotics and intravenous fluids, and desire for comfort care. A physician and palliative care social worker conducted one face-to face structured conversation about end-of-life care with a family member, which included the provision of information about resuscitation, hospitalisation, artificial nutrition and hydration

and pain and symptom management. Any care-related decisions made during the meeting, such as decisions to update advance care plans, were communicated to the primary care team. The palliative care social worker provided a follow-up phone call with family members every two months to follow-up on issues discussed in the meetings. Those in the intervention condition were more likely to have had a MOLST added to their relative's chart over the course of the study, and to have decided on medical options (DNR, DNI, DNH, No feeding tube) to be listed in the person with dementia's advance directive.

Brazil et al³³ examined the effectiveness of an intervention to improve family carer uncertainty in decision making about care (n=197). A secondary outcome was completion rates for do not resuscitate orders. Caregivers were mailed a booklet entitled 'Comfort care at the end of life for persons with dementia - A guide for caregivers'. A trained nurse facilitator held two meetings with the caregiver. In the first meeting, contents of the book were reviewed and the facilitator assisted the caregiver to reflect on the person with dementia's goals, values, beliefs and end of life care options. In the second meeting, caregivers reviewed a draft advance care plan prepared by the facilitator based on previous discussions, made necessary changes, and signed the plan. The advance care plan was then placed into the medical record. No significant effects were found for completion of do not resuscitate orders between the intervention and control group.

DISCUSSION

Main Findings

Only four identified studies met EPOC criteria for methodologically rigorous study design and were included in the review. All the included studies exhibited some level of risk of bias, and two of the four studies were small pilot studies. All studies included face-to-face consultations with healthcare providers with the aim of providing education and/or increasing knowledge of advance care planning. There was some indication of the potential effectiveness of one intervention involving face-to-face structured conversation about end-of-life care for increasing participation in advance care planning³¹. Overall, studies examined a limited range of advance care planning outcomes. Of note, all four studies recruited carers of people with dementia, rather than the person with dementia. Additionally three of the four studies³¹⁻³³ recruited carers of people with advanced dementia and so in the majority of studies the advance care planning intervention was being carried out when the capacity of the person with dementia was likely to be significantly reduced. Guidelines both in Australia³⁴ and internationally^{35, 36} recommend that people with dementia engage in advance care planning early in their illness, before capacity reduces. In doing so, there is less need to rely solely on proxy views later in the illness, especially since views about desired future medical care between a person with an illness and their family members or carers are often discordant³⁷⁻³⁹. There is limited information about when people diagnosed with dementia would prefer advance care planning conversations to occur⁴⁰.

Evaluating the acceptability of advance care planning at different time points from diagnosis could guide clinical decision making about the most appropriate timing of discussions for people with dementia.

The fact that no studies recruited people with dementia may be at least partly due to the difficulties with undertaking research with this population. The first and most significant barrier is difficulties with reliably identifying whether people with dementia have capacity to provide informed consent. Obtaining informed consent for trial participants can be complicated even for those without impaired cognitive capacity. For people with cognitive impairment, tools are being developed to assess capacity to consent, such as the University of California, San Diego Brief Assessment of Capacity to Consent.⁴¹ Using such tools may help to facilitate development of intervention studies targeted at the person with dementia. Dementia research can be impeded by other factors including: difficulty in recruiting participants (e.g. locating eligible clients), access (e.g. lack of transportation to research site), participant fears and concerns (worry that it will be too complicated), gatekeepers (e.g. physicians not seeing enrolling their clients in research as a priority, or believing that participation is too burdensome or upsetting), uncertain prognosis/disease trajectory, and the political hierarchy and culture particularly if working across a number of institutions.^{42, 43}

Aside from the multitude of methodological barriers, there are many additional barriers to undertaking research in this area. Firstly, dementia is not commonly perceived as a terminal illness⁴⁴. This may mean that participation in advance care planning, particularly at the time of diagnosis, is not deemed of high importance or relevance. Secondly, there is concern that discussing advance care planning may cause unnecessary stress and anxiety among persons newly diagnosed with dementia⁴⁵. However there is strong evidence from systematic reviews that patients and families who participated in advance care planning do not report elevated levels of stress, anxiety or depression compared to patients or families who did not participate in advance care planning⁴⁶. Studies conducted with persons with dementia and their families have also found that well-implemented advance care planning interventions have positive effects, helping participants to think about the future, make wishes known, and consequently be less worried about the future⁴⁷.

Limitations of the study

The findings of this systematic review should be interpreted in light of several limitations. Firstly, the search strategy may not have captured all relevant studies given that the wide variety of outcomes that studies examining advance care planning may incorporate. However, the search strategy identified several studies that used specific advance care planning outcomes such as do not resuscitate orders, and that a comprehensive manual search strategy was implemented, providing confidence that relevant studies meeting the eligibility criteria were not missed. Secondly, only studies published in English were included, which may mean that relevant studies published in other languages were not included.

What this study adds

Dementia is a disease characterised by progressive cognitive decline. It is therefore critical that advance care planning is a routine part of dementia care, and occurs while the person has sufficient capacity. Despite the importance of advance care planning for people with dementia, this review found that very few studies have examined the effectiveness of interventions in this area.

Well-designed intervention trials are needed to identify interventions that increase rates of participation in advance care planning for people with dementia, as well as establish their cost-effectiveness and sustainability. Given all interventions were face-to-face and thus were resource-intensive, it is important that future studies incorporate some examination of the relative cost-benefit of the intervention. Future studies should also consider exploring the acceptability, feasibility and effectiveness of less resource intensive interventions that empower people with dementia and their families to engage in advance care planning. For example, web-based advance care planning programs developed for individuals with other diseases have been shown to increase documentation of end of life preferences by 25-30%⁴⁸. Such interventions may also have benefits for persons with dementia and their carers.

Conclusions

There is little evidence regarding effective strategies to improve participation in advance care planning for persons with dementia. Methodologically rigorous intervention trials that test interventions to encourage participation in advance care planning early in the illness trajectory are urgently needed.

Declarations

Authorship

JB, RSF and AW conceived of the review aims and search strategy. JB and HT screened all articles against inclusion criteria. MF and EM rated the studies for methodological quality. All authors contributed to drafting the review or revising it critically for important intellectual content. All authors have approved the version to be published and have participated sufficiently in the work to take public responsibility for appropriate portions for the content.

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Declaration of conflicts of interest

The author(s) declare that there is no conflict of interest.

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REFERENCES

1. Chertkow H, Feldman HH, Jacova C, et al. Definitions of dementia and predementia states in Alzheimer's disease and vascular cognitive impairment: consensus from the Canadian conference on diagnosis of dementia. *Alzheimers Res Ther* 2013; 5 (Suppl 1).
2. Prince M, Bryce R, Albanese E, et al. The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers Dement* 2013; 9: 63-75.
3. Singer PA, Robertson G and Roy DJ. Bioethics for clinicians: 6. Advance care planning. *CMAJ* 1996; 155: 1689-1692.
4. Gardiner PA, Byrne GJ, Mitchell LK, et al. Financial capacity in older adults: a growing concern for clinicians. *Med J Aust* 2015; 202: 82-85. 2015/01/30.
5. Tilse C, Wilson J, White B, et al. *Having the Last Word? Will making and contestation in Australia*. 2015. University of Queensland.
6. Houben CH, Spruit MA, Groenen MT, et al. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2014; 15: 477-489. 2014/03/07. DOI: 10.1016/j.jamda.2014.01.008.
7. Green MJ, Schubart JR, Whitehead MM, et al. Advance Care Planning Does Not Adversely Affect Hope or Anxiety Among Patients With Advanced Cancer. *J Pain Symptom Manage* 2015; 49: 1088-1096. 2014/12/30. DOI: 10.1016/j.jpainsymman.2014.11.293.
8. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345. 2010/03/25.
9. Evers MM, Purohit D, Perl D, et al. Palliative and aggressive end-of-life care for patients with dementia. *Psychiatr Serv* 2002; 53: 609-613. Research Support, U.S. Gov't, P.H.S. DOI: <https://dx.doi.org/10.1176/appi.ps.53.5.609>.
10. Burton L, German P, Gruber-Baldini A, et al. Medical care for nursing home residents: differences by dementia status. Epidemiology of Dementia in Nursing Homes Research Group. *J Am Geriatr Soc* 2001; 49: 142-147.
11. McCarthy M, Addington-Hall J and Altmann D. The experience of dying with dementia: a retrospective study. *Int J Geriatr Psychiatry* 1997; 12: 404-409. DOI: 10.1002/(sici)1099-1166(199703)12:3<404::aid-gps529>3.0.co;2-2.
12. Ahronheim J, Morrison R, Baskin S, et al. Treatment of the dying in the acute care hospital. Advanced dementia and metastatic cancer. *Arch Intern Med* 1996 156: 2094-2100.
13. Helmes E, Merskey H, Fox H, et al. Patterns of deterioration in senile dementia of the Alzheimer type. *Arch Neurol* 1995; 52: 306-310.
14. Cognitive Decline Partnership Centre. *Future planning and Advance Care Planning* 2016.
15. Denning KH, King M, Jones L, et al. Advance care planning in dementia: Do family carers know the treatment preferences of people with early dementia? *PLoS One* 2016; 11: e0159056.
16. Callahan CM, Arling G, Tu W, et al. Transitions in care for older adults with and without dementia. *J Am Geriatr Soc* 2012; 60: 813-820. DOI: 10.1111/j.1532-5415.2012.03905.x.
17. Nicholas LH, Bynum JPW, Weir DR, et al. Advance Directives And Nursing Home Stays Associated With Less Aggressive End-Of-Life Care For Severe Dementia Patients. *Health Affairs* 2014; 33: 667-674.
18. Karel MJ, Moye J, Bank A, et al. Three methods of assessing values for advance care planning: comparing persons with and without dementia. *J Aging Health* 2007; 19: 123-151.
19. Mozley CG, Huxley P, Sutcliffe C, et al. 'Not knowing where I am doesn't mean I don't know what I like': cognitive impairment and quality of life responses in elderly people. *Int J Geriatr Psychiatry* 1999; 14: 776-783.
20. Garand L, Dew MA, Lingler JH, et al. Incidence and predictors of advance care planning among persons with cognitive impairment. *Am J Geriatr Psychiatry* 2011; 19: 712-720.
21. Vandervoort A, Houttekier D, Vander Stichele R, et al. Quality of Dying in Nursing Home Residents Dying with Dementia: Does Advanced Care Planning Matter? A Nationwide Postmortem Study. *PLoS One* 2014; 9: e91130.
22. Lewis M, Rand E, Mullaly E, et al. Uptake of a newly implemented advance care planning program in a dementia diagnostic service. *Age and Ageing* 2015; 44: 1045-1049.

23. Brinkman-Stoppelenburg A, Rietjens JA and van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliative Med* 2014; 28: 1000-1025.
24. Robinson L, Dickinson C, Rousseau N, et al. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age Ageing* 2012; 41: 263-269. 2011/12/14. DOI: 10.1093/ageing/afr148.
25. Jethwa KD and Onalaja O. Advance care planning and palliative medicine in advanced dementia: a literature review. *BJPsych Bull* 2015; 39: 74-78. 2015/07/21. DOI: 10.1192/pb.bp.114.046896.
26. Dixon J, Karagiannidou M and Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: A systematic review and critical discussion. *J Pain Symptom Manage* 2018; 55: 132-150.
27. Sabatino CP. The evolution of health care advance planning law and policy. *Milbank Q* 2010 88: 211–239.
28. Effective Practice and Organisation of Care (EPOC). EPOC Resources for review authors. , <http://epoc.cochrane.org/epoc-specific-resources-for-review-authors> (2015).
29. Moher D, Liberati A, Tetzlaff J, et al. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 2009; 6: e1000097.
30. Sampson EL, Jones L, Thune-Boyle ICV, et al. Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention. *Palliative Med* 2011; 25: 197-209.
31. Reinhardt JP, Chichin E, Posner L, et al. Vital conversations with family in the nursing homes: Preparation for end-stage dementia care. *J Soc Work End Life Palliat Care* 2014; 10: 112-126.
32. Bonner G, Wang E, Wilkie DJ, et al. Advance care treatment plan (ACT-Plan) for African American family caregivers: A pilot study. *Dementia* 2014; 13: 79-95.
33. Brazil K, Carter G, Cardwell C, et al. Effectiveness of advance care planning with family caregivers in dementia nursing homes: A paried cluster randomized controlled trial. *Palliative Med* 2017: 1-10.
34. Guideline Adaptation Committee. *Clinical Practice Guidelines and Principles of Care for People with Dementia*. 2016. Sydney: Guideline Adaptation Committee.
35. National Institute for Health and Care Excellence. Dementia: supporting people with dementia and their carers in health and social care (CG42), <https://www.nice.org.uk/guidance/cg42> (2006).
36. Alzheimer's Association. Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes: Phase 3 End-of-Life Care, https://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp (2007).
37. Meeker MA and Jezewski MA. Family decision making at end of life. *Palliat Support Care* 2005; 3: 131-142.
38. Ayalon L, Bachner YG, Dwolatzky T, et al. Preferences for end-of-life treatment: concordance between older adults with dementia or mild cognitive impairment and their spouses. *Int Psychogeriatr* 2012; 24: 1798-1804. 2012/05/22. DOI: 10.1017/S1041610212000877.
39. Shalowitz DI, Garrett-Mayer E and Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med* 2006; 166: 493–497
40. van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, et al. Factors associated with initiation of advance care planning in dementia: a systematic review. *J Alzheimers Dis* 2014; 40: 743-757.
41. Jeste D, Palmer BW, Appelbaum PS, et al. A new brief instrument for assessing decisional capacity for clinical research. *Arch Gen Psychiatry* 2007; 64: 966-974.
42. LeBlanc TW, Lodato JE, Currow DC, et al. Overcoming recruitment challenges in palliative care clinical trials. *J Oncol Pract* 2013; 9: 277-281.
43. Ridda I, MacIntyre CR, Lindley RI, et al. Difficulties in recruiting older people in clinical trials: An examination of barriers and solutions. *Vaccine* 2010; 28: 901-906.
44. Sachs GA, Shega JW and Cox-Hayley D. Barriers to Excellent End-of-life Care for Patients with Dementia. *J Gen Intern Med* 2004; 19: 1057-1063. DOI: 10.1111/j.1525-1497.2004.30329.x.
45. Dickinson C, Bamford C, Exley C, et al. Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *Int Psychogeriatr* 2013; 25: 2011-2021.

46. Brinkman-Stoppelenburg A, Rietjens JA and van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliative Med* 2014; 28: 1000-1025.
47. Poppe M, Burleigh S and Banerjee S. Qualitative Evaluation of Advanced Care Planning in Early Dementia (ACP-ED). *PLoS One* 2013; 8: e60412.
48. Sudore RL, Boscardin J, Feuz MA, et al. Effect of the prepare website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans: A randomized clinical trial. *JAMA Internal Medicine* 2017. DOI: 10.1001/jamainternmed.2017.1607.

Table 1. Characteristics of included studies.

Reference	Sample	Eligibility	Intervention	Outcomes	Findings
Country	Setting; Sample (N; Age; Gender); Diagnosis of PWD	Inclusion criteria	Intervention strategies; Control	Primary outcomes; secondary outcomes; follow-up time points	
Sampson 2011³⁰	<u>Setting:</u> Two acute medical wards in one teaching hospital.	<u>Inclusion criteria (PWD):</u>	<u>Intervention strategies:</u>	<u>Primary outcome:</u>	<i>Seven intervention carers made an ACP. No statistical tests undertaken because of small sample size and attrition.</i>
UK	<u>Sample:</u> N= 33 patient-carer dyads; I= 22, C= 11.	▪ Advanced primary degenerative dementia (at least FAST stage 6D, plus incontinence and requiring assistance with all activities of daily living).	▪ 30-minute palliative care needs assessment. Results of assessment discussed with clinical team and management plan developed.	▪ Whether carer formulated advanced care plan	
Randomised controlled trial (RCT)	Carers: Mean age 59 years; 47% female. Patient: Mean age 87 years, 81% female.	▪ Unplanned admission for a treatable medical illness.	Findings from assessment used to inform discussions with carer.	<u>Secondary outcomes:</u>	
	<u>Diagnosis:</u> advanced primary degenerative dementia.	▪ Had an informal carer who was able to give informed consent.	▪ Up to four structured consultations with carers. First consultation included knowledge about the patients' dementia and prognosis, physical needs, social support, records of preferences for care and previous documentation of AD or ACP. Subsequent consultations included education about dementia, role of palliative care, and ACP. Carers were given the opportunity to complete an ACP for the person with dementia.	Carer related	
			<u>Control:</u> Received an information pack on palliative care and ACP.	▪ Kessler Distress Scale; ▪ Euroqol-5D; ▪ Decision Conflict Scale; ▪ Decision Satisfaction Inventory; ▪ State anger Scale; ▪ Life Satisfaction Scale; ▪ Satisfaction with End-of-Life Care in Advanced Dementia Scale; ▪ Carer rated pain and distress of PWD (1-5 scale).	
				<u>Follow-up:</u> 6 weeks and 6 months post-baseline. Carers of patients who died followed-up 3 months after death.	
Bonner 2014³²	<u>Setting:</u> Five adult day care centres (N=2 I; N=3 C).	<u>Inclusion criteria:</u>	<u>Intervention strategies:</u>	<u>Primary outcome:</u> Protocol adherence (attrition, attendance and instrument completion).	<u>Primary outcome:</u>
USA		<u>Caregivers:</u>	▪ Four weekly group sessions conducted with caregivers by		▪ 14 dropped out after 1 st session. ▪ 68 attended all sessions (35 I, 33 C)

- As studies reported multiple outcomes, the ACP outcome of interest is presented in italics. PWD: Person with dementia. AD: Advance directive. ACP: Advance care plan. I: Intervention group. C: Control group. RCT: Randomised controlled trial. C-RCT: Cluster randomised controlled trial. CPR: Cardio-pulmonary Resuscitation. KDS: Knowledge of Dementia Scale. CKS: Comfort with Knowledge Scale. CTDM: Confidence in Treatment Decisions Made. EOLTDS: End-of-Life Treatment Decisions Scale. MOLST: Medical Order for Life-Sustaining Treatments. DNR: Do not resuscitate. DNI: Do not intubate. DNH: Do not hospitalise. DCS: Decisional conflict scale. FPCS: Family perceptions of care scale.

Reference Country Design	Sample Setting; Sample (N; Age; Gender); Diagnosis of PWD	Eligibility Inclusion criteria	Intervention Intervention strategies; Control	Outcomes Primary outcomes; secondary outcomes; follow-up time points	Findings
Controlled before and after study	<u>Sample:</u> African American caregivers of persons with dementia: N=82. Mean age: 59.8 (I), 58.3 (C). Female: 77% (I), 82% (C). Care receivers: N= 68. Mean age: 81.4 (I), 78.7 (C). Female: 80% (I), 88% (C). <u>Diagnosis:</u> Dementia.	- Relative of care receiver; - Designated decision maker; - Have knowledge about the care receivers recent and past medical history. <i>Care receivers:</i> - African American; - Have physician generated diagnosis of dementia; - No written ACP.	African American advanced practice nurse facilitators. - Intervention included case studies, self-reflection, storytelling and guided discussions to enhance knowledge, self-efficacy and behavioural skills to make end-of-life treatment plans in advance. - Education covered information about dementia and disease progression, discussions of benefits of CPR, mechanical ventilation, and tube feeding, and use of ACP. <u>Attention control:</u> received four interactive discussions about various health promotion topics.	<u>Secondary outcomes:</u> Caregiver outcomes - Knowledge of Dementia Scale (KDS); - Comfort with Knowledge Scale (CKS); - Confidence in Treatment Decisions Made (CTDM); - End-of-Life Treatment Decisions Scale (EOLTDS) for CPR, mechanical ventilation and tube feeding.	- All 68 completed pre and post instruments with an average 96% of items completed. <u>Secondary outcomes:</u> - No effect found for KDS, CKS, CTDM when multivariate analysis used. - Univariate analysis found effect in CTDM for I but not for C. <i>Greater proportion of large (34% vs 3%) and medium (22% vs 9%) intervention effect for CPR (chances of recovery) for I compared to C (p<0.001). No effect for mechanical ventilation or tube feeding.</i> <i>Changes in decisions regarding use of CPR, mechanical ventilation and tube feeding. Trend greater changes for I group but no statistical analysis reported.</i>
Reinhardt 2014³¹	<u>Setting:</u> One large nursing facility.	<u>Inclusion criteria:</u>	<u>Intervention strategies:</u>	<u>Primary outcomes:</u>	<u>Primary outcomes:</u>
USA	<u>Sample:</u> N=110 primary contact persons for residents with dementia. Could be family, friend or healthcare agent.	Family members listed as primary family/friend contact of nursing home resident with advanced dementia (cognitive	- Physician and palliative care social worker conducted face-to face structured conversation about end-of-life care with family member (average 47 min). - Information about the benefits and risks of resuscitation, hospitalisation, artificial nutrition	- Symptom Management at the End-of-Life in Dementia Scale; - Satisfaction with care; - Satisfaction with care at End-of Life in Dementia Scale; - PHQ-9; - Satisfaction with Life Scale.	- No effect on Symptom management scale mean score, PHQ-9 or satisfaction with life scale. - Satisfaction with care: I: T1-7.7; T2-7.9; T3-8.2; C: T1-7.6; T2-7.8; T-7.3 (p<0.05). - Satisfaction with care scale: I: T1-27.3; T2-30.2; T3-30.6; C: T1-27.7; T2-30.6; T3-28.0 (p<0.05).

- As studies reported multiple outcomes, the ACP outcome of interest is presented in italics. PWD: Person with dementia. AD: Advance directive. ACP: Advance care plan. I: Intervention group. C: Control group. RCT: Randomised controlled trial. C-RCT: Cluster randomised controlled trial. CPR: Cardio-pulmonary Resuscitation. KDS: Knowledge of Dementia Scale. CKS: Comfort with Knowledge Scale. CTDM: Confidence in Treatment Decisions Made. EOLTDS: End-of-Life Treatment Decisions Scale. MOLST: Medical Order for Life-Sustaining Treatments. DNR: Do not resuscitate. DNI: Do not intubate. DNH: Do not hospitalise. DCS: Decisional conflict scale. FPCS: Family perceptions of care scale.

Reference Country Design	Sample Setting; Sample (N; Age; Gender); Diagnosis of PWD	Eligibility Inclusion criteria	Intervention Intervention strategies; Control	Outcomes Primary outcomes; secondary outcomes; follow-up time points	Findings
	<i>Family members.</i> Mean age=59.6 years, 78.7% female (I). Mean age 58.9 years, 80% female (C). <i>Residents:</i> Mean age= 86 years, 85% female (I). Mean age= 85 years, 76% female (C). <u>Diagnosis:</u> Advanced dementia.	performance scale score = 4,5,6). - English or Spanish speaking. - Not currently receiving hospice care.	and hydration and pain and symptom management provided to family member. If care-related decisions were made during the meeting (e.g. additions to ACPs), this was communicated to the primary care team. The palliative care social worker provided a follow-up phone call with family members every 2 months to follow-up on issues discussed in the meetings. C: Usual care, with the addition of telephone contact at baseline and 2 month intervals to control for any effect of greater contact with intervention families.	<u>Secondary outcomes:</u> - Presence of Medical Order for Life-Sustaining Treatments (MOLST) form in medical record; - Seven orders in the MOLST: Do not resuscitate (DNR), Do not intubate (DNI), Do not hospitalise (DNH), no feeding tube, no IVs, no antibiotics and comfort care. <u>Follow-up:</u> 3 and 6 months after baseline.	<u>Secondary outcomes:</u> <i>Presence of MOLST. No effect over time for control. Effect found within I: T1-78.7; T2- 100.0% (p<0.01).</i> <i>Seven orders in MOLST. No effect found for control. Effect found within I for 4 of the 7 orders: DNR T1-72.3; T2- 93.6%, (p<0.01); DNI T1-57.4; T2- 83.0%, (p<0.001); DNH T1-10.6; T2- 30.0%, (p<0.001); No feeding tube T1- 36.2; T2- 57.4%, (p<0.01).</i>
Brazil 2017³³	<u>Setting:</u> 24 nursing homes with dementia nursing category (12 I, 12 C). <u>Sample:</u> N= 197 family members of residents with dementia. C: N=117 (39%). Mean age 59.9	<u>Inclusion:</u> Family members most responsible for residents with a diagnosis of dementia judged as not having the decisional capacity	<u>Intervention strategies:</u> - Caregivers mailed a booklet 'Comfort care at the end of life for persons with dementia- A guide for caregivers'. - A trained nurse facilitator held two meetings with caregiver. In first meeting, contents of the book were reviewed and facilitator	<u>Primary outcome:</u> - Decisional conflict scale (DCS). <u>Secondary outcomes:</u> - Family perceptions of care scale (FPCS); - General health questionnaire; - Completion rates for DNR; - Hospital admissions.	<u>Primary outcome:</u> - Significant difference in mean DCS score: C: 30.7 vs I: 18.3 (p<0.001). Effect found for 4/5 of DCS subscales (informed, support, uncertainty, and effective decision). <u>Secondary outcomes:</u> - Significant difference in mean FPCS score: C: 133.6 vs I: 144.6 (p=0.01).

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Reference Country Design	Sample Setting; Sample (N; Age; Gender); Diagnosis of PWD	Eligibility Inclusion criteria	Intervention Intervention strategies; Control	Outcomes Primary outcomes; secondary outcomes; follow-up time points	Findings
RCT (C- RCT)	years; 61.5% female. I: N=80 (25%). Mean age 61.6 years; 81.0% female. Age and gender of residents not reported. <u>Diagnosis</u> : Dementia.	to complete and ACP.	assisted caregiver to reflect on PWD's goals, values, beliefs and end of life options. ▪ In second meeting, caregivers reviewed a draft ACP prepared by the facilitator based on previous discussions, made necessary changes and signed the ACP. ACP placed in medical record and sent to GP. C: received usual care.	<u>Follow-up</u> : Questionnaire mailed 6 weeks after baseline data collection completed.	Effects also found on two of the FPCS subscales (family support, communication). ▪ <i>No significant difference for any other secondary outcomes, including completion rates for DNR.</i>

- As studies reported multiple outcomes, the ACP outcome of interest is presented in italics. PWD: Person with dementia. AD: Advance directive. ACP: Advance care plan. I: Intervention group. C: Control group. RCT: Randomised controlled trial. C-RCT: Cluster randomised controlled trial. CPR: Cardio-pulmonary Resuscitation. KDS: Knowledge of Dementia Scale. CKS: Comfort with Knowledge Scale. CTDM: Confidence in Treatment Decisions Made. EOLTDS: End-of-Life Treatment Decisions Scale. MOLST: Medical Order for Life-Sustaining Treatments. DNR: Do not resuscitate. DNI: Do not intubate. DNH: Do not hospitalise. DCS: Decisional conflict scale. FPCS: Family perceptions of care scale.

Table 2. Assessment of methodological quality of included intervention studies according to EPOC risk of bias criteria.

Reference	Allocation sequence	Allocation concealment	Baseline outcome measurements	Baseline characteristics	Incomplete outcome data	Knowledge of allocated interventions	Protection against contamination	Selective outcome reporting	Other risk of bias
Sampson 2010 ³⁰	U	L	U	U	H	L	H	L	Very small pilot study, amendment made to published protocol. High attrition over data collection time periods.
Bonner 2014 ³²	H	H	L	H	L	H	L	L	Small pilot study.
Reinhardt 2014 ³¹	U	U	L	L	L	L	H	L	Analysis for secondary outcomes used chi square within groups rather than multivariate analysis with time interaction
Brazil 2017 ³³	L	L	L	H	L	L	L	L	None.

L= Low risk of bias: Plausible bias unlikely to seriously alter the results. H=High risk of bias: Plausible bias that seriously weakens confidence in the results. U=Unclear risk of bias: Plausible bias that raises some doubt about the results.

Appendix 1

Database: Ovid MEDLINE Jan 1997- 16th August 2017

1	exp Dementia/
2	(dement* or alzhem*).tw.
3	1 or 2
4	exp Advance Care Planning/
5	(advance* adj2 (plan* or directive* or decision making)).tw.
6	("health care directive*" or healthcare directive*).tw.
7	Terminal care/
8	"end of life".tw.
9	"living will*".tw.
10	4 or 5 or 6 or 7 or 8 or 9
11	3 and 10
12	limit 11 to (english language and yr="1997 - current")
13	limit 12 to (case reports or comment or editorial or letter or news)
14	12 not 13

Database: Embase Jan 1997- 16th August 2017

1	exp dementia/
2	(dement* or alzhem*).tw.
3	1 or 2
4	advance care planning/
5	living will/
6	terminal care/
7	(advance* adj2 (plan* or directive* or decision making)).tw.
8	("health care directive*" or healthcare directive*).tw.
9	"end of life".tw.
10	"living will*".tw.
11	4 or 5 or 6 or 7 or 8 or 9 or 10
12	3 and 11
13	limit 12 to (english language and yr="1997 -Current")
14	limit 13 to (books or "book review" or chapter or conference abstract or conference paper or "conference review" or editorial or letter or note)
15	13 not 14

Database: PsycINFO Jan 1997- 16th August 2017

1	exp dementia/
2	alzheimer's disease/
3	(dement* or alzhem*).tw.
4	1 or 2 or 3
5	(advance* adj2 (plan* or directive* or decision making)).tw.
6	advance directives/
7	treatment planning/
8	("end of life" or "health care directive*" or "healthcare directive*").tw.
9	"living will*".tw.
10	5 or 6 or 7 or 8 or 9
11	4 and 10
12	limit 11 to (english language and yr="1997 -Current")

13	limit 12 to (chapter or "column/opinion" or "comment/reply" or editorial or letter)
14	12 not 13
15	limit 14 to "O200 book"
16	14 not 15

Database: CINAHL Jan 1997- 16th August 2017

1	(MH "Dementia+")
2	TI (dement* or alzhem*) OR AB (dement* or alzhem*)
3	1 or 2
4	(MH "Advance care planning")
5	TI (advance* n2 (plan* or directive* or "decision making")) OR AB (advance* n2 (plan* or directive* or "decision making"))
6	TI ("health care directive*" or "healthcare directive*") OR AB ("health care directive*" or "healthcare directive*")
7	(MH "Terminal Care")
8	TI ("end of life" or end-of-life) OR AB ("end of life" or end-of-life)
9	(MH "Living wills")
10	TI "living will*" OR AB "living will*"
11	4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10
12	3 AND 11
13	3 AND 11 Limiters- Published Date: 19970101-20171231
14	3 AND 11 Narrow be language- English

Cochrane Jan 1997- 16th August 2017

1	MeSH descriptor: [Dementia] explode all trees
2	dement* or alzhem*:ti,ab,kw (Word variations have been searched)
3	#1 or #2
4	MeSH descriptor: [Advance Care Planning] explode all trees
5	advance near/2 (plan* or directive* or "decision making")
6	"health care directive" or "healthcare directive":ti,ab,kw (Word variations have been searched)
7	MeSH descriptor: [Terminal Care] this term only
8	"end of life":ti,ab,kw (Word variations have been searched)
9	"living will*":ti,ab,kw (Word variations have been searched)
10	#4 or #5 or #6 or #7 or #8 or #9
11	#3 and #10 Publication Year from 1997