

Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review

Palliative Medicine
2016, Vol. 30(9) 807–824
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DOI: 10.1177/0269216316637239
pmj.sagepub.com


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Abstract

Background: Administration of non-beneficial life-sustaining treatments in terminal elderly patients still occurs due to lack of knowledge of patient's wishes or delayed physician–family communications on preference.

Aim: To determine whether advance care documentation encourages healthcare professional's timely engagement in end-of-life discussions.

Design: Systematic review of the English language articles published from January 2000 to April 2015.

Data sources: EMBASE, MEDLINE, EBM REVIEWS, PsycINFO, CINAHL and Cochrane Library and manual searches of reference lists.

Results: A total of 24 eligible articles from 10 countries including 23,914 subjects met the inclusion criteria, mostly using qualitative or mixed methods, with the exception of two cohort studies. The influence of advance care documentation on initiation of end-of-life discussions was predominantly based on perceptions, attitudes, beliefs and personal experience rather than on standard replicable measures of effectiveness in triggering the discussion. While health professionals reported positive perceptions of the use of advance care documentations (18/24 studies), actual evidence of their engagement in end-of-life discussions or confidence gained from accessing previously formulated wishes in advance care documentations was not generally available.

Conclusion: Perceived effectiveness of advance care documentation in encouraging end-of-life discussions appears to be high but is mostly derived from low-level evidence studies. This may indicate a willingness and openness of patients, surrogates and staff to perceive advance directives as an instrument to improve communication, rather than actual evidence of timeliness or effectiveness from suitably designed studies. The assumption that advance care documentations will lead to higher physicians' confidence or engagement in communicating with patients/families could not be objectively demonstrated in this review.

Keywords

Advance care planning, advance directives, end-of-life care, physician–patient relations, prognosis, communication barriers

What is already known about the topic?

- The belief that advance care documentation enhances the confidence of health professionals in engaging in end-of-life conversations is widespread.
- However, the effectiveness of advance care documentation on this communication has not systematically been evaluated.

What this paper adds

- The review confirms in-principle qualitative healthcare provider support for the concept.
- The review also indicates that there is insufficient high-level evidence to confirm that advance care documentation enhances timeliness or effectiveness of end-of-life communications.

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Implications for practice, theory or policy

- Having access to existing written preferences for end-of-life care at the time of hospital admission should provide an opportunity to encourage clinicians to start timely end-of-life conversations.
- More quantitative and rigorous studies are needed to support the perception that this documentation leads to involvement in end-of-life communication.

Introduction

Medical technology and curative procedures have rapidly advanced over the years leading to longer life expectancy for patients in various health states including irreversible advanced chronic illness.^{1,2} However, the question remains whether some of those life-sustaining treatments are appropriate for all patients, and whether the medical interventions delivered to patients accurately reflect patient and family wishes when dying is imminent. Some inappropriate decisions on prolonging life or administering non-beneficial treatment derive from the challenges faced by healthcare providers communicating bad news in a timely and effective way on diagnosis, treatment options or prognosis at the end of life (EOL).^{3,4}

In many cases, the admitting team does not recognise that the patient is at the EOL and dying patients generate unnecessary rapid response calls during hospitalisation.⁵ Moreover, they may not be aware of whether the patients wish to be told about their poor prognosis.⁶ This is in spite of their responsibility to allow the patient the right to know the truth⁷ and have their EOL care wishes honoured.⁸ While it is true that some terminal patients prefer not to be confronted by details of their prognosis,^{9,10} most patients and their families appreciate honesty¹¹ and want clear information in order to be involved in decision-making.¹² Satisfactory communication between medical staff, patients and caregivers about goals of care can be attained through training and practice.^{13,14} Honest physician–patient communication that is culturally sensitive¹⁵ should be an integral part of the management alongside assisting patients in formulating preferences that are in their best interest after explaining the benefits and harms of treatments.¹⁶ This, however, is not always achieved,¹⁷ and poor communication or inconsistent implementation of patient wishes continue to result in unsatisfactory patient outcomes.¹⁸

The barriers to satisfactory EOL communication are usually related to health systems factors, or healthcare provider and patient issues (Table 1). While these three domains may be intricately linked, it may be worth exploring their relative importance in individual cases. Examining whether advance care directives trigger clinician's involvement in EOL conversations may assist in identifying points for intervention.

The timing of EOL conversations between the patient, health professionals and caregiver is also very important

as early discussions can be used to guide EOL care preferences while the patient has the capacity to choose or refuse treatments.^{41,42} However, EOL conversations are known to occur far too late affecting the opportunity for patient preparation for and involvement in quality decision-making.⁴³

In this article, we refer to advance care documentation (ACD) as a generic term covering advance care directives, living wills or physician orders for life-sustaining treatment (POLST). These documents are said to facilitate decision-making at the EOL, reduce stress and anxiety for families³⁸ and prevent subsequent conflict. Several studies have shown the positive impacts of ACDs on patient satisfaction when engaging in ACD discussions with their physician.²⁶ There is also a strong association between ACDs and quality of dying⁴⁴ as well as a relationship between EOL care received and patient preferences.⁴⁵ Over a third of intensive care unit health professionals reported that a lack of ACD was a significant barrier to optimal EOL care in the intensive care unit.⁴⁶ While there is no unanimous agreement on the effectiveness of ACDs to reflect patient wishes at a time of crisis or to deliver satisfactory EOL care,^{39,47,48} previous studies including randomised controlled trials have shown that advance care planning (ACP) increases the likelihood of EOL discussion between health professionals, patient and caregivers.^{49,50} Despite this, the uptake of formal ACD reportedly remains below 26% across countries.^{40,50–53} Patients' wishes can also be made explicit by appointing a surrogate to make decisions if periods of incapacity arise at the EOL.^{45,54}

Communication with patients and surrogates after ACDs are formalised is a dynamic process as the disease progresses. It is not unusual for patients, families or caregivers to change their preference over time when facing unexpected complications, unacceptable symptoms, invasive procedures or escalating costs.^{55,56} It is not certain whether ACD guarantee that consumers will be satisfied especially if there is discordance between the patient and surrogates about perception and understanding of the EOL care wishes.³⁵ Furthermore, whether formally knowing a patient's wishes in the form of an ACD leads to engagement of health professionals in EOL discussions has not been widely researched. Therefore, we decided to investigate whether the presence of an ACD or equivalent

Table 1. Reasons for poor end-of-life communication.

Perspective	Detailed reason
Health professional	<ul style="list-style-type: none"> • No desire to take away hope from the patient^{19,20} • Health professional discomfort discussing subject due to prognostic uncertainty²¹ • Physician's challenge balancing patient and family expectations²² • Patient not sick enough to warrant the discussion^{23,24} • Clinicians unaware of the patient's resuscitation preferences¹⁸ • Physicians' own beliefs that patients infer they are dying so no need to be explicit¹¹ • Physicians lack of understanding and beliefs about appropriateness of limiting care²⁵ • Physicians' language barriers and concerns about patients being troubled by the conversation²⁶ • Difficulties or variation in interpretation of advance care directives in clinical care^{27,28}
Patient/family	<ul style="list-style-type: none"> • Patient perception that health providers have responsibility to initiate discussion^{29,30} • Deferring the responsibility to others^{31,32} • Health provider perception that it is only relevant for sick and older patients³³ • Poor understanding of advance care directive paperwork³⁴ • Discrepancies in surrogates' interpretation of patient wishes³⁵ • Patients change their mind on preferred care as diseases progress³⁶ • Cultural propensity to avoid open discussions of death³⁷
Health system	<ul style="list-style-type: none"> • Time constraints in a stressful work environment^{19,25,28} • Availability of trained staff³⁸ • Advance care directives already executed are inaccessible/not documented^{25,39} • Low prevalence of written advance care directives⁴⁰ at decision-making time

document would enhance clinicians' involvement in initiating EOL discussions and whether that engagement was perceived or measured as *effective*.

Methods

We conducted a review of English language articles published from January 2000 to April 2015 using six databases: EMBASE, MEDLINE, EBM REVIEWS, PsycINFO, CINAHL and Cochrane Library. We further searched the grey literature for empirical studies and manual reference searches from eligible studies.

Search strategy

We searched six databases combining the most relevant terms in the abstract or title: 'Advance care directive' OR 'Care Plan\$' OR 'Living will' OR 'Patient wish' OR 'Health directive' OR 'Power of Attorney' OR 'Informed consent' OR 'Care options' AND Communicat\$ OR Skill\$ OR Conversation OR Discus\$ OR Confiden\$ OR Initiat\$ OR Prognos\$ OR 'Bad news' OR 'Break news' OR 'Physician-patient relations' OR Nurse OR 'Social worker' OR 'Health professional' OR 'Health practitioner' AND 'End-of-life OR Terminal OR 'Death and Dying' OR Resuscitat\$ OR 'Palliative care' OR 'Intensive care' OR Emergency. The term 'health professional' could include but was not limited to allied health staff, medical and nursing students, doctors and nurses and any other health professional who was involved in the provision of EOL care in the clinical setting. Figure 1 presents the process.

Inclusion and exclusion criteria

The target populations (P) were patients admitted to any hospital department for whom EOL communications were desirable, for example, elderly and critically ill. Interventions (I) targeted were any form of healthcare provider discussion on EOL care – whether individual or as a family conference – with patients or families following sighting of documentation expressing patient's preferences. Comparators (C) were *usual care* or no intervention. The outcomes (O) of interest searched for were either quantitative or qualitative indicators of *effectiveness* including but not limited to clinician's experience in EOL discussions guided by ACD; self-reported satisfaction after access to ACD; increased confidence in discussions on treatment decisions; improved attitudes or motivation towards the value of ACDs; changed beliefs, knowledge or perceptions of benefit from having the ACD; or measured improvement in the decision-making process as a result of the existence of ACD. Studies were included if they reported associated outcomes on discussion/communication even if this aspect was not their main focus. All study (S) types from randomised controlled trials, cohort, cross-sectional surveys, quasi-experimental, before-after interventions to qualitative assessments were deemed eligible for inclusion. Case studies and expert opinion pieces were excluded.

Data collection and quality assessment

Two authors independently screened eligible papers to be included in this review during May 2015. Quality assessment was conducted using a custom-made standard

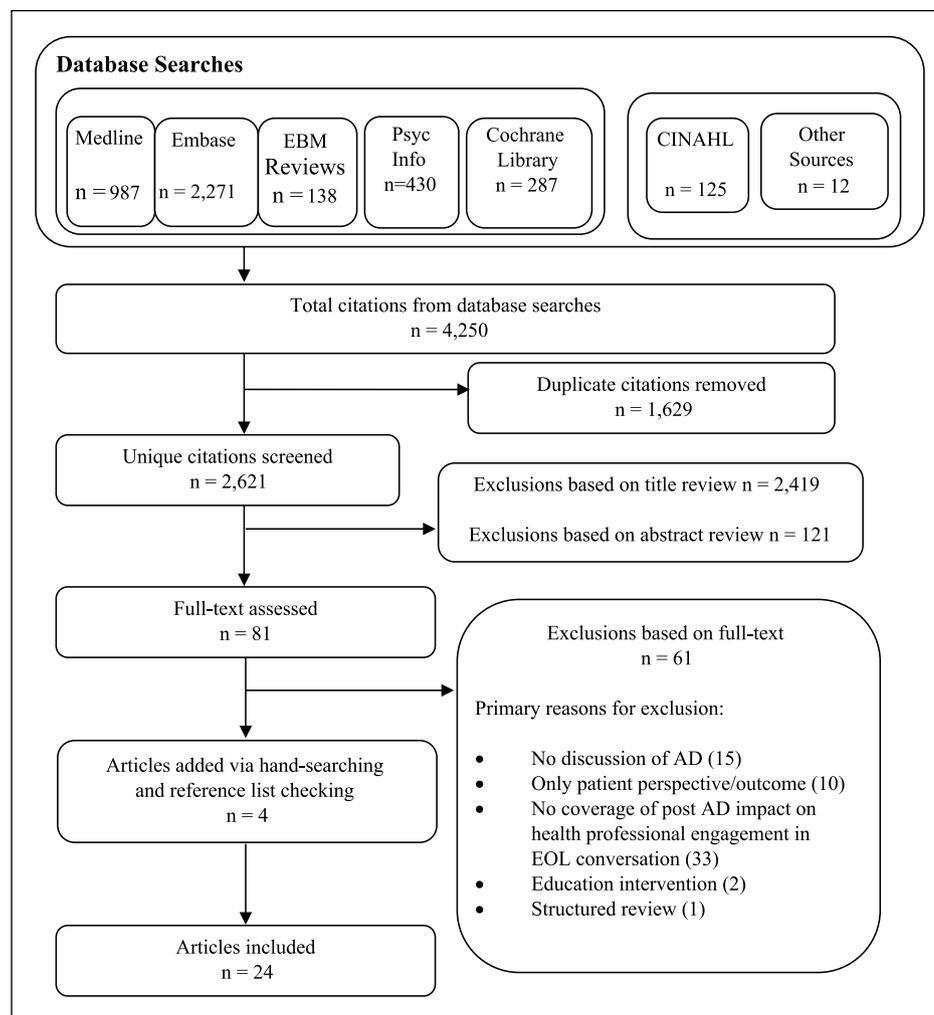


Figure 1. PRISMA diagram with data extraction process and eligibility assessment.

instrument to cover the wide range of study types relevant to this review, including a maximum score of 12 by adding one unweighted point for each of the items (Appendix 1). Data were then extracted from eligible papers that included the level of evidence, clarity of the definition of effectiveness and outcome measurement; appropriateness of study design, subject selection, sample size, response rate, completeness of outcome measurements and analysis constituted the core bias assessment. Where there was disagreement on study eligibility, a third reviewer was used to reconcile any differences. No ethics approval or consent was required as the study was a review of the literature and no patient/family/healthcare professional contact was necessary or attempted.

Analysis

After eligibility assessment was finalised, most studies were found to be qualitative. We conducted a combination of textual narrative analysis and thematic synthesis⁵⁷ as we were interested in assessment of commonalities across

published studies, heterogeneity of reported outcomes and critical appraisal of the publications. Outcomes were summarised by two reviewers independently producing tables describing summaries of common findings and comparing results as the work progressed. Discrepancies were resolved in consultation with a third reviewer (search strategy results and quality assessment form available from the authors).

Results

A total of 24 studies involving 23,914 patients, bereaved family members, doctors, nurses, community care staff, government policy-makers and judges from 10 countries (United Kingdom=8, United States=6, Other Europe=5, Australia=2, Japan=2 and Israel=1) met the criteria for inclusion.

The majority of studies included used qualitative methodology such as participant observation, focus groups and in-depth interviews (10). A second set of studies (eight) used mixed-methodology such as open-ended questions

and surveys together. The remaining studies (six) were quantitative and included retrospective cross-sectional reviews, cross-sectional surveys, prospective studies, descriptive correlation studies and scoring of standard instruments (Appendix 2).

With the exception of one large cohort study which audited records for evidence of EOL communication, most studies targeted the views of doctors (14/24), followed by the nurses' opinions (8/24) and less often patients or family perspective (3/24). A quarter (6/24) of the studies covered more than one perspective, with 4 of 24 including subjects derived from community health groups, consumers, bereaved family members, ambulance staff, judges, government policy-makers and other unspecified participants. Sample sizes ranged from 12 to 17,097 participants, with half of the studies including less than 100 participants.

Among the research questions in the 24 included studies, only five targeted the issue of EOL discussion or communication in relation to ACDs (Appendix 3).^{51,52,58-60} Other studies reported associated issues as part of their outcomes, with the focus of their studies being the patients or healthcare providers' satisfaction, experiences, attitudes, beliefs and practices, the formulation of the ACD or training-related issues.

We investigated the definitions of effectiveness which were used and found that they were mostly perception-based, with some emphasising future possibilities rather than actual experience. The studies largely (18/24) found staff had positive attitudes towards the use of ACP documents as instruments to improve communications with patients and families, and encouraged or facilitated future care planning (Table 2). Six studies reported negative results, including bereaved family members' concerns with the absence of physician communication during the dying process when there was no ACD;⁷¹ low opportunity for physicians to use the living will by not receiving a copy, even when they were available;⁶⁶ difficulty in managing difference between patient and surrogate's views during physician communications;³⁷ difficulty for healthcare workers introducing the subject of whether there was an existing ACD or encouraging the formulation of one;⁷⁴ uncertainty in the timeliness of ACP and role of clinicians especially in the case of documenting dementia⁶⁷ and the inability to execute existing advance directives due to poor knowledge and concerns of caregivers.⁵⁸

The definitions and outcomes were predominantly based on opinions, attitudes, beliefs and personal experience rather than on some standard replicable measure of effectiveness in triggering the discussion (Table 3). However, the one large cohort study in six hospitals compiled information on actual evidence of an end-of-life discussion being held in the first 24 h of admission in patients with a written plan of care on admission.⁵¹ Their findings are compelling in that a statistically significant association indicated that the ACD prompted the discussion. Common

qualitative findings included ACDs as icebreaker or a tool to initiate conversation;^{28,72,76} ACD providing an opportunity for health professionals to talk about the EOL^{52,61,63,66} and that the ACD improved communication between health professionals, medical staff and patients.^{73,75}

Discussion

To our knowledge, this systematic review is the first to provide an overview of the effect that formally knowing the patient's wishes through written advance care plan⁷⁷ or equivalent (ACD, living will or POLST) has on health professionals' engagement in initiating and conducting effective EOL communications. We identified 24 articles that reported directly or indirectly on ACDs influencing health professionals' engagement in conversations, although the timeliness was often not specified. However, excepting the two cohort studies,^{51,53} the methods used by published studies were mostly qualitative and the level of evidence on which this review relies is low (III and IV).⁷⁸ It appears that evidence to date cannot confidently provide an answer to the question of effectiveness of ACD on triggering the conversation. Therefore, no causality can be attributed, and only summaries of common findings or hypotheses can be generated on the usefulness of ACDs on EOL communications.

The uptake of ACDs was reported as very low in several studies. Reports ranged from 10% in US hospitals,⁵¹ 14% in the Australian community,⁴⁰ 16% in the general older population in The Netherlands⁵² and up to 25% among palliative care patients in Switzerland.⁵³ This might have led to the absence of data about their effectiveness. Even though these figures are low in terms of uptake, this is not necessarily an indicator of effectiveness. It may also reflect lack of awareness, perceived non-importance of expressing wishes, perception that ACDs are not binding or enforceable⁷⁹ or poor knowledge on how to implement patient preferences. Different settings may also influence the uptake of ACDs because conversations may be easier to initiate in palliative units or nursing homes where death is expected and there is time for discussions, compared to critical and general hospital wards where decisions are prompted by a crisis or a more curative focus may prevail.

The assumption that ACDs will lead to higher confidence or engagement of physicians in communicating with patients and families could not be demonstrated in this review. The literature reviewed compared the expressed wishes in ACDs, living wills, POLST or some other formal document with actual treatments received, surrogates concordance on understanding of wishes and patient/family satisfaction with decision-making.¹⁶ However, there was a scarcity of articles on the impact of ACDs in stimulating EOL discussions by treating clinicians after the advance plan has been formulated (by them or someone else), despite recognition that preferences are not stable over time. The absence of documentation of indicators of

Table 2. Qualitative and quantitative indicators of effectiveness domains reported.

Author, publication, year	Indicator domains				Indicator descriptors
	Knowledge	Attitude	Beliefs	Experiences	
Qualitative and quantitative					
Willmot et al. (2013) ⁶¹		✓	✓	✓	<ul style="list-style-type: none"> • Doctors generally thought that ACDs could be helpful. • ACDs were considered useful for doctors as they can provide the opportunity to have conversations with patients' families and friends about withdrawing or withholding treatment. • Percentage of physicians expressed comfort in discussing ACP. • Percentage of physicians reported discussing advance directives with appropriate patients. • There were statistically significant positive correlations between physician comfort in ACP discussions and (1) their likelihood of initiating the discussion. • Percentage of nurses agreed that the presence of a living will encourage discussion between the patient and healthcare providers about the patient's preferences. • Living wills not already in effect made discussions with patients and families easier. • Percentage of those felt that decisions had been easier to make. • Attitudes of ADs were perceived as a communication aid and facilitating decision-making. • Percentage of participants stated that advance directives are rather an instrument to further the conversation between a patient, relatives and a doctor than to give directives for action in the concrete decision-making situation. • Percentage of physicians who had/did not have more opportunity to communicate with patient/family after receiving living will. • Percentage of physicians who received a living will did not change their course of therapy as a consequence of receiving living will.
Snyder et al. (2012) ⁶²	✓	✓	✓	✓	
Scherer et al. (2006) ⁶³	✓	✓	✓	✓	
Schiff et al. (2006) ⁶⁴		✓	✓	✓	
Van Oorschot and Simon (2006) ⁶⁵	✓	✓			
Masuda et al. (2003) ⁶⁶	✓	✓	✓	✓	
Qualitative only					
Poppe et al. (2013) ⁶⁰	✓	✓	✓		<ul style="list-style-type: none"> • ACP should be discussed sooner rather than later. Some staff said that patients were worried that by discussing ACP, patients would no longer be allowed to make decisions, and thus detailed information on ACP should be given before discussion takes place. • ACP documentation had given staff a structure and staff found that conversations were now initiated earlier. • Staff felt that wider wishes of the resident were now known and documented. • Mostly concerned about the inability to execute ADs (%). • Percentage with experience and percentage comfortable with the use of ADs. • Knowledge deficit and concerns of health caregivers may hinder communication about patients' preferences towards end of life. • The majority expressed uncertainty over the general value of ACP, whether current service provision could meet patient wishes, their individual roles and responsibilities and which aspects of ACP were legally binding; the array of different ACP forms and documentation available added to the confusion. • In dementia care, the timing of when to initiate ACP discussions was an added challenge. • Staff felt ACP provided choices for residents and encouraged better planning decisions. • Mental Capacity Act and ACP did formalise conversations and gave support to decisions made about care. • ACP seen as enabler of communication and provides opportunities to build relationships with families and prevent future conflict.
Stone et al. (2013) ⁵⁹	✓	✓	✓	✓	
Meron et al. (2012) ⁵⁸	✓	✓	✓	✓	
Robinson et al. (2013) ⁶⁷	✓	✓	✓	✓	
Stewart et al. (2011) ⁶⁸		✓	✓		
Wilson et al. (2010) ⁶⁹	✓		✓	✓	
Seymour et al. (2010) ³⁷	✓	✓	✓	✓	

Table 2. (Continued)

Author, publication, year	Indicator domains				Indicator descriptors
	Knowledge	Attitude	Beliefs	Experiences	
Jeong et al. (2010) ⁷⁰				✓	<ul style="list-style-type: none"> • RN who experienced discomfort and sadness in undertaking ACP ultimately become more positive in their experience post transition. Positive words used to describe the experience of RNs included acceptance, confidence, satisfaction, relief, comfort, happiness, reassurance.
Teno et al. (2007) ⁷¹				✓	<ul style="list-style-type: none"> • Perceived quality of end-of-life care in those with and without an AD. • Bereaved family members who reported that the decedent did not have an AD were more likely to report concerns with physician communication (AOR).
Bern-Klug et al. (2004) ⁷²		✓			<ul style="list-style-type: none"> • Advance directives set the stage for conversations about EOL care. 'It gives you some basis to talk with the family'. 'They set the stage for a conversation'. 'It lets me know they have at least started thinking about it'.
Barbour et al. (2003) ⁷³		✓			<ul style="list-style-type: none"> • Advance care directives as an agent of communication. • 'Main advantage of an advance directive is as a tool for communication between the medical staff, the rest of the multi-disciplinary team, the patient and the patient's loved ones'. • 'It's difficult to broach the subject with a patient whereas someone coming to you with clearly having thought about it, having views on these topics, it's a point from which you can start discussion'.
Quantitative only					
Nakazawa et al. (2014) ⁷⁴		✓			<ul style="list-style-type: none"> • Percentage with ACP had more difficulty assessing patient decision-making capacity and asking about EOL care and had low confidence in treatment decisions guided by AD.
Onwuteaka-Philipsen et al. (2012) ⁵²		✓			<ul style="list-style-type: none"> • Having an ACD may increase the odds of discussing preferences with the physician about preference on EOL decisions.
Auerbach et al. (2008) ⁵¹		✓			<ul style="list-style-type: none"> • Documentation of a surrogate decision-maker were only moderately associated with a code status of end-of-life discussion (odds ratio). • Independent effects attributable to the site the patient was enrolled or whether the patient had any pre-existing documentation (odds ratio).
Jezewski et al. (2005) ⁷⁵		✓		✓	<ul style="list-style-type: none"> • Percentage of nurses agreed that the presence of a living will encourage discussion between a patient and healthcare providers about the patient's preferences.
Hildén et al. (2004) ²⁸		✓		✓	<ul style="list-style-type: none"> • Advantages of a living will: <ul style="list-style-type: none"> • Acts as an icebreaker in discussing EOL treatments • Makes decision-making easier
Hildén et al. (2004) ⁷⁶		✓		✓	<ul style="list-style-type: none"> • Advantages of a living will: <ul style="list-style-type: none"> • Acts as an icebreaker in discussing EOL treatments. • Makes decision-making easier.
Pautex et al. (2008) ⁵³				✓	<ul style="list-style-type: none"> • Motivations for patients who completed advance directives <ul style="list-style-type: none"> • To enhance communication with caregivers • To enhance communication with surrogates • There was no significant difference in satisfaction with explanations from the physician or nurse between patients with or without advance directives either at the stage of formulation or up to 3 weeks later.

ACD: advance care documentation; AD: advance directive; ACP: advance care planning; AOR: adjusted odds ratio; EOL: end of life.
^a'Other' includes Perceptions^{61, 71} Experiences^{58,59,63,64,66,67,70,71,73,75,76} and Satisfaction⁵³.

Table 3. Estimates of effectiveness, usefulness or impact of ACDs on staff communications.

Author, publication, year	Basis for measure of effectiveness used	Outcome concept and estimate
Nakazawa et al. (2014) ⁷⁴	Practices and attitudes regarding ACP.	Physician practices regarding ACP: discrepancies found between ordering DNR after asking patient (75.8% recognised importance, only 33% practiced it). 62.6% recognised ACD's importance, 30.3% practiced it. Physicians who had negative practices re. ACP had more difficulty assessing patient decision-making capacity and asking about EOL care and had low confidence in treatment. Decisions guided by AD.
Poppe et al. (2013) ⁶⁰	Interviews on ACP discussions, motivation for ACP and timing of the discussion.	All carers agreed that ACP was a positive experience that made them think about the future and prompted further discussions with the patient and other family members. Patients' carers and staff agreed that discussions should be held earlier.
Willmott et al. (2013) ⁶¹	A range of perspectives.	ACDs were considered useful for doctors in that they can provide the opportunity for doctors to have conversations with patients' families and friends about withdrawing or withholding treatment. Doctors generally thought that AHDs could be helpful, they also expressed reservations about their use and were concerned that such documents could potentially present a barrier to the provision of good patient care.
Stone et al. (2013) ⁵⁹	Experience of staff, residents and families having ACP discussions. ACP document used as the Gold Standard Framework.	The ACP documentation had given staff a structure and staff found that conversations were now initiated earlier. Staff felt that wider wishes of the resident were now known and documented.
Robinson et al. (2013) ⁶⁷	Personal views and focus groups of palliative care and dementia patients/relatives and volunteers, social services and legal professionals.	Perception that ACP is a good idea in theory but implementation is flawed with challenges including ability to meet patient wishes, anxiety, legal implications and uncertainty about responsibilities.
Meron et al. (2012) ⁵⁸	Attitudes towards ADs and examine experience, beliefs and practices.	48% had experience in discussing ADs. 88% thought ACDs are positive and 71% felt comfortable using them. Respondents were mostly concerned with executing ACDs (67%).
Snyder et al. (2012) ⁶²	Survey of knowledge, attitudes and experience of primary care physicians.	ACP discussions and referrals to palliative care often occur near the EOL. Physicians' personal and professional experience with ACP may be contributing to some barriers to these discussions.
Onwuteaka-Philipsen et al. (2012) ³²	The change in and discussion about preferences and the influence of having an advance directive.	A combination of preferring non-treatment and having an ACD increased the odds of discussing preferences with the physician most, for discussing preferences on resuscitation for instance to 10.7.
Stewart et al. (2011) ⁶⁸	Interviews on personal views with care managers, community nurses and patient families.	Staff and family perceived that ACP provided choice. Facilitators for ACP were early initiation of discussions, family involvement to establish preferences, residents and staff being well-known to each other and staff training.
Wilson et al. (2010) ⁶⁹	Opinions and knowledge of staff about their use of documentation for the recording of issues relating to the Mental Capacity Act and examined practices in association with additional ACP documents held by service users.	Staff stated that the introduction of documentation had not changed their working practices as they were already discussing it; however, the Mental Capacity Act and ACP did formalise conversations and gave support to decisions made about care. Some staff had gaps in their knowledge in relation to ACP documents and this influenced their confidence to discuss these issues with users and family.
Seymour et al. (2010) ³⁷	Focus groups with community nurses.	Nurses saw their roles in ACP as engaging with patients to elicit care preferences, facilitate family communication and enable a shift of care focus towards palliative care. They also perceived challenges to ACP.
Jeong et al. (2010) ⁷⁰	Participant observation, field note recording, semi-structured interviews and document analysis.	Factors that enhanced ACP include 'back-up from family members and other nursing staff'. The inhibiting factors are 'lack of time', 'a culture of do everything and don't go there' and 'lack of family involvement'.
Auerbach et al. (2008) ⁵¹	Presence of chart documentation that the admitting team had discussed care plans with the patient within the first 24h of hospitalisation.	Documentation of a surrogate decision-maker was only moderately associated with a code status discussion (adjusted odds ratios all less than 2.0). Patients' site of enrolment (odds ratios 1.74–5.14) and informal notations describing prehospital care wishes (e.g. orders for 'do not resuscitate'/'do not intubate'; odds ratios 3.22–11.32 compared with no pre-existing documentation).

Table 3. (Continued)

Author, publication, year	Basis for measure of effectiveness used	Outcome concept and estimate
Pautex et al. (2008) ⁵³	Patient questionnaire on satisfaction with involvement in the decision process.	There was a trend for higher satisfaction and lower depression and anxiety scores among patients who completed ACDs. Authors recommended patients should be encouraged to complete ACDs to improve communication and ease many fears.
Teno et al. (2007) ⁷¹	Written ADs and family members' perceptions of the quality of EOL care.	Bereaved family members who reported that the decedent did not have an AD were more likely to report concerns with physician communication (AOR 1.4). Family members of decedents without an ACD were 1.2 times more likely to report one or more concerns with amount of information about what to expect while dying.
Schiff et al. (2006) ⁶⁴	Geriatricians' experience and views on living will.	Living wills not already in effect made discussions with patients and families easier. It was easier to approach the subject of EOL care with the patient (96%) and relatives (76%). Some (32%) had found that it increased the time they spent discussing these issues with the patient; only a tiny proportion felt that this was an inappropriate use of time with the patient (3.4%) and/or the relatives (5.0%). Attitudes on ACDs were perceived as a communication aid and facilitating decision-making.
Van Oorschot and Simon (2006) ⁶⁵	Physician's and judges' perspectives on the dying process.	82.2% of nurses agreed that the presence of a living will encourage discussion between a patient and healthcare providers about the patient's preferences.
Scherer et al. (2006) ⁶³	Professional experience with EOL decision-making.	There was 86% agreement that the presence of a living will encourage discussion between a patient and healthcare provider about the patient's preferences.
Jezewski et al. (2005) ⁷⁵	Knowledge and attitudes of AD.	Advantages of living will: 'acts as an icebreaker in discussing EOL treatment n = 275' and 'makes decision-making easier n = 261'. The most notable problems associated with living will: 'Insufficient discussion of the content of the will due to lack of time n = 195'.
Hildén et al. (2004) ²⁸	Common experiences and attitudes in decision-making at the EOL, views on the role of patients and family members in these decisions – effectiveness as icebreaker.	Advantages of living will: 'acts as an icebreaker in discussing EOL treatment n = 226' and 'makes decision-making easier n = 233'. The most notable problems associated with living will: 'Insufficient discussion of the content of the will due to lack of time n = 214'.
Hildén et al. (2004) ⁷⁶	Nurses' experiences with EOL decision-making and their views of their roles, patient and families. Measuring the advantages and problems of living will – effectiveness icebreaker.	Half the physician respondents reported that advance directives were more useful as a mechanism for initiating discussions about care than as a vehicle for actually directing care: 'It gives you some basis to talk with the family'. 'They set the stage for a conversation'. 'It lets me know they have at least started thinking about it'.
Bern-Klug et al. (2004) ⁷²	Physicians perspectives on ACD – ACD used as a mechanism for initiating discussions.	34% of physicians had more opportunity to communicate with patient/family after receiving living will. 69% of physicians who received a living will not change their course of therapy as a consequence of receiving living will.
Masuda et al. (2003) ⁶⁶	Attitudes and experiences of physicians with patients who had living wills.	Qualitative results from focus groups re communication: 'main advantage of an advance directive is as a tool for communication between the medical staff, the rest of the multi-disciplinary team, the patient and the patient's loved ones'. 'It's difficult to broach the subject with a patient whereas someone coming to you with clearly having thought about it, having views on these topics, it's a point from which you can start discussion'.
Barbour et al. (2003) ⁷³	Attitudes to AD, AD as an agent of communication.	

ACP: advance care planning; AD: advance directive; DNR: do-not-resuscitate; ACD: advance care documentation; EOL: end of life; AOR: adjusted odds ratio.

effectiveness of ACP in triggering further EOL discussions suggests either patient or professional avoidance or systemic inertia. This may be related to factors such as the combination of busy hospitals and treating team's beliefs and assumptions that the conversation is not required after an ACD has been formulated. The barriers identified in Table 1 do not appear to have been addressed by the presence of ACDs in the reviewed studies.

We found that while health professionals reported positive perceptions of the use of ACDs (18/24 studies), actual evidence of their engagement in EOL discussions or confidence gained from accessing previously expressed wishes from an advanced care directive was not generally measured from the studies included. Our review found only one well-designed study providing high-level evidence that informal notations describing wishes prompted EOL discussions.⁵¹ A smaller cohort study⁵³ found no statistically significant difference between patient or surrogate satisfaction on receiving information about the terminal nature of the illness after or at the time of formulation of an ACD.

EOL conversations can be challenging and rewarding for doctors and patients. They require time, sensitivity, knowledge and honesty. Some perceive this involvement as one of the best things doctors can do for the dying patient.⁸⁰ But the timing of broaching the subject of ACP does not have to be at the vulnerable moment of irreversible crisis. It is more productive to discuss ACDs before the terminal stages, during routine examinations before drastic decisions are required.⁸¹ Others view the ACP documentation as a process undertaken by patients and families to prepare for the future, with clinicians acting on their wishes and offering medical information as necessary.⁸² Healthcare providers' opinions not favouring ACP documentation included being useful only when there is no other source of information; in the absence of a conversation when the relevant staff member is not available, to ACP documentation not considered as important as the EOL discussion⁸³ while others considered knowledge of ACP of no importance in EOL discussions unless the staff member involved in initial discussion was present.

Trust between patient and physicians is an important component in the ACP process.⁸² Generally, the studies in this review make no mention of the level of trust or duration of provider-patient care prior to the EOL discussion. Hence, they did not assess whether this was a significant factor enhancing the likelihood of engaging in EOL discussions.

Strengths and limitations

We integrated the literature after an extensive and rigorous search for all study types (Appendix 4) by two independent reviewers and involved a third to resolve discrepancies in inclusion criteria. Eligible studies included multiple countries and many thousands of participants among patients and healthcare providers. Hence, some of the qualitative findings may apply across various settings.

Despite the above, a weakness of this review is that we can only provide an answer to our research question from sound evidence in only one study as the majority of eligible articles included studies of low-level evidence (predominantly level IV), small sample sizes, mostly qualitative approaches, as well as heterogeneity of subject selection and outcome measurements. With one exception, the quantitative studies were also low-level evidence being derived from surveys of subjective perceptions. These studies had heterogeneous outcome descriptions, which precluded the combination of findings in a meta-analysis to estimate measured effectiveness.⁸⁴

Only 7 of the 24 studies included in this review^{28,51,64,66,71,75,76} had large enough sample sizes (from 301 to 17,097) to reassure readers of the potential generalisability of findings, but these were still subjective outcomes such as opinions, experiences and perceptions. Non-English publications were excluded to language restrictions and this may have generated biases on the influence that culture may have on the initiation of EOL discussions following the formulation of ACDs. The quality assessment yielded overall low scores (19/24 scored 6 or less) including two conference abstracts^{52,58} which had insufficient data for quality assessment. Low scores were driven mainly by the inappropriate selection of study design for an effectiveness assessment, small sample sizes, lack of details on participant's selection, single-centre studies and absence of quantitative analyses. This bias assessment indicates limited external validity and generalisability of the results presented here, even for the large cohort, conducted in six hospitals from a single country.

In sum, the lack of scientific evaluation in the studies included in this review means that the evidence for effectiveness of written ACD in triggering EOL discussions is not sufficient. More high-level evidence studies need to replicate the findings of the large US cohort study and studies addressing the importance of indigenous or ethnically and culturally diverse influences on both uptake of ACDs and initiation of EOL communications. While the limitations of conducting trials in palliative care are acknowledged, the relevance of this research to clinical practice justifies efforts to back-up health policy with stronger evidence.⁸⁵

Implications for research and practice

There is in-principle support for the perceived effectiveness of ACD in triggering EOL discussions. Further rigorous studies and public and clinical debate are warranted in the area of measured effectiveness of ACD to improve health professional engagement and timeliness of EOL communications once they are formalised. If ACD is to inform future care, they need to become dynamic instruments where changing priorities and preferences are addressed as well as changing treatment options according to severity, proven effectiveness and patient risk. We recommend that effectiveness evaluations go beyond perception, experience and

satisfaction and move into further large quantitative studies such as randomised control trials or cohort interventions on the measurable effect of ACP documentation on subsequent EOL communications.

Conclusion

For many years, it has been reported that commencing an early EOL conversation can potentially prevent futile treatments and patient suffering.⁸⁶ However, the question that has not yet been answered despite our extensive review is whether having prior written preferences for EOL care encourages this timely conversation.

Perceived effectiveness of ACD in encouraging EOL discussions appears to be high but is mostly derived from qualitative studies or cross-sectional opinion surveys. This may indicate a willingness and openness of patients, surrogates and staff to perceive advance directives as an instrument to improve communication, rather than actual evidence of timeliness or effectiveness from suitable study designs. There is only concrete evidence of effectiveness from a single large study, but replication studies in other settings are needed to establish generalisability of results. Cohort or randomised controlled studies are more appropriate to shed light on the impact of pre-formulated patient wishes on healthcare provider willingness and engagement in initiation of EOL discussions.

Authors' contributions

E.L. contributed to design, systematic online searches, compilation of data, data analysis and interpretation, and preparation of article; M.C.-M. contributed to conception and design, manual searching of reference lists, quality assessment, data analysis and interpretation, and preparation of draft and final article. K.Y.O. conducted concurrent systematic online searches and manual reference searching, quality assessment and contributed to preparation of article. S.A.T. and K.H. contributed to manual searching and provided input in the preparation of article.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This review was funded by a grant from the National Health and Medical Research Council of Australia (grant # 1054146).

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Appendix 1. Brief – systematic review – ACD to improve EOL communication (Reviewer) _____ Article # _____

Author (surname of first 3 authors & year of publication)

Title (Brief article title)

Quantitative or qualitative

Quantitative qualitative Mixed methods

QUALITY ASSESSMENT

- | | |
|--|---|
| 1. Study_Type | <input type="checkbox"/> Systematic review <input type="checkbox"/> RCT <input type="checkbox"/> Cohort <input type="checkbox"/> Cross-sectional survey
<input type="checkbox"/> Case-control <input type="checkbox"/> Retrospective record review <input type="checkbox"/> Before-After
<input type="checkbox"/> other _____ |
| 2. Clear description of project objectives | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Clear description of intervention | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable /no intervention |
| 4. Type of comparison_group | <input type="checkbox"/> No comparison group <input type="checkbox"/> same group before intervention
<input type="checkbox"/> equivalent group in same setting <input type="checkbox"/> equivalent group in another setting <input type="checkbox"/> Other _____ |
| 5. Sample size | Total _____ (≥ 100 subjects = 1 point; < 100 subjects = 0 points) |
| 6. Clear patient selection criteria | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not specified |
| 7. Random selection of subjects | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not specified |
| 8. Clear definition of outcome measures | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Mixed |
| 9. All intended/measured outcomes reported (or selected only) | <input type="checkbox"/> Yes, all <input type="checkbox"/> No, selected <input type="checkbox"/> Not specified |
| 10. Response rate | _____% <input type="checkbox"/> Not specified
<input type="checkbox"/> < 50 % <input type="checkbox"/> 51–80% <input type="checkbox"/> > 80 % |
| 11. Incomplete data (% lost to follow-up at the time of outcome assessment) | _____% (≤ 20 % loss to f-up = 1 point; > 20 % 0 points)
<input type="checkbox"/> more on one group than the other <input type="checkbox"/> Unknown |
| 12. Quantitative analysis included various potential confounders or effect modifiers | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable |

Total quality score out of 12 _____.

Appendix 2. Characteristics of included studies and quality assessment (24 studies).

Author, publication year	Country	Sample size	Target group				Qualitative study methods	Quantitative study methods	Quality score out of 12
			Doctors	Nurses	Patient/family	Other ^a			
Qualitative and quantitative									
Willmott et al. (2013) ⁶¹	Australia	Stage 2 n = 18 interviews n = 19 for focus groups Stage 3 n = 37					Exploratory study. Mixed methods (1) engaging with a critical reference group (2) semi-structured interviews and focus groups	(3) Online survey	4
Snyder et al. (2013) ⁶²	United States	123	✓				Open-ended questions in survey	Investigator-generated survey	5
Scherer et al. (2006) ⁶³	United States	210	✓				Open-ended question on the survey	Descriptive correlation study using 115-item survey	6
Schiff et al. (2006) ⁶⁴	United Kingdom	812	✓				Qualitative postal questionnaire	Quantitative postal questionnaire	6
Van Oorschot et al. (2006) ⁶⁵	Germany	(n = 1196) n = 727 doctors n = 469 judges 448	✓			✓	Written survey	Agree/disagree questionnaire	7
Hildén et al. (2004) ²⁸	Finland	408	✓				Semi-structured questionnaire with opportunity for free text comments	Postal questionnaire with quantifiable pre-coded answers	5
Hildén et al. (2004) ⁷⁶	Finland	408		✓			Semi-structured questionnaire with opportunity for free text comments	Postal questionnaire with quantifiable pre-coded answers	5
Masuda et al. (2003) ⁶⁶	Japan	301	✓				Qualitative study using open-ended questions	Self-administered survey	5
Qualitative only									
Poppe et al. (2013) ⁶⁰	United Kingdom	12 Patients 8 carers 6 staff members 28	✓				In-depth interviews		3
Stone et al. (2013) ⁵⁹	United Kingdom	95	✓				Qualitative descriptive interviews -semi-structured interview -individual interviews		5
Robinson et al. (2013) ⁶⁷	United Kingdom	34 Staff 14 patients 26	✓			✓	Qualitative study using focus groups and individual interviews Individual semi-structured interviews		4
Stewart et al. (2011) ⁶⁸	United Kingdom	26	✓			✓	Semi-structured interviews using focus groups, face-to-face and telephone interview		6
Wilson et al. (2010) ⁶⁹	England	26	✓			✓	Semi-structured interviews using focus groups, face-to-face and telephone interview		4

(Continued)

Appendix 2. (Continued)

Author, publication year	Country	Sample size	Target group				Qualitative study methods	Quantitative study methods	Quality score out of 12
			Doctors	Nurses	Patient/family	Other ^a			
Seymour et al. (2010) ³⁷	United Kingdom	23		✓			Focus groups and workshops	3	
Jeong et al. (2010) ⁷⁰	Australia	13		✓			Case study involving participant observation, field notes recording, semi-structured interviews and data analysis	4	
Teno et al. (2007) ⁷¹	United States	1,553			✓		Telephone interviews	8	
Bern-Klug et al. (2004) ⁷²	United States	12	✓				Tape-recorded interviews	2	
Barbour et al. (2003) ⁷³	Scotland	Interview (n = 12) Focus groups (n = 34)	✓	✓		✓	Focus groups and interviews	2	
Quantitative only									
Nakazawa et al. (2013) ⁷⁴	Japan	99	✓				Single cross-sectional survey	6	
Onwuteaka-Philipsen et al. (2012) ⁵²	The Netherlands	LASA (n = 168) ADC (n = 184)				✓	Retrospective cross-sectional quantitative study	5	
Meron et al. (2012) ⁵⁸	Israel	77	✓				Cross-sectional survey	3	
Auerbach et al. (2008) ⁵¹	United States	17,097			✓		Administration data and chart abstraction nested in an observational cohort study	9	
Jezewski et al. (2005) ⁷⁵	United States	794		✓			Descriptive correlation study using a questionnaire survey	7	
Hildén et al. (2004) ²⁸	Finland	448	✓				Postal questionnaire	8	
Pautex et al. (2008) ⁵³	Switzerland	53			✓		Cohort study. Written questionnaire plus symptom assessment including anxiety and depression	8	

^aOther = community health groups, consumers, bereaved family members, ambulance staff, judges, government policy-makers, unspecified.

Appendix 3. Research questions/aims of included studies and their relationship to advance care documentation (24 studies).

Nakazawa et al. (2014) ⁷⁴	<ul style="list-style-type: none"> • Palliative care physicians' practices and attitudes regarding ACP and the characteristics of physicians who have positive or negative practices concerning ACP.
Willmott et al. (2013) ⁶¹	<ul style="list-style-type: none"> • To gather data on the content and usability of the AD form, particularly from the perspective of the individuals who are being encouraged to record their wishes about treatment to guide decision-making at a later time. • To explore the perspectives of health professionals who rely on this document when making treatment decisions.
Poppe et al. (2013) ⁶⁰	<ul style="list-style-type: none"> • To explore the acceptability of discussing ACP with people with memory problems and mild dementia shortly after diagnosis.
Meron et al. (2012) ⁵⁸	<ul style="list-style-type: none"> • To examine experiences, beliefs and practices (including communication) of healthcare staff, associated with the use of ADs in Israel, in relation to patients with palliative care needs.
Onwuteaka-Philipsen et al. (2012) ⁵²	<ul style="list-style-type: none"> • To study the preferences of older people in the last 3 months of life on forgoing treatments, the change in and discussion about these preferences and the influence of having an AD on this.
Stone et al. (2013) ⁵⁹	<ul style="list-style-type: none"> • To explore the experience of staff, residents and families having ACP discussions in an nursing care home context.
Robinson et al. (2013) ⁶⁷	<ul style="list-style-type: none"> • To examine critically the views and experiences of a wide range of professionals, clinical and non-clinical, on ACP in two clinical areas, dementia and palliative care, where professionals may be more likely to introduce it due to a future loss of mental capacity and the presence of a terminal illness.
Snyder et al. (2013) ⁶²	<ul style="list-style-type: none"> • To evaluate how palliative care physicians' personal and professional experience with palliative care might affect comfort with and utilisation of ACP, palliative care and hospice.
Stewart et al. (2011) ⁶⁸	<ul style="list-style-type: none"> • To explore the views of care home staff and families regarding ACP in homes providing nursing care or personal care only.
Wilson et al. (2010) ⁶⁹	<ul style="list-style-type: none"> • Accessed the views of staff working with the MCA, particularly in relation to ACP for care at the end of life.
Seymour et al. (2010) ³⁷	<ul style="list-style-type: none"> • To examine how community nurses working in palliative care understand ACP and their roles within ACP. • To identify factors that may facilitate or constrain community nurses' implementation of ACP during patient care. • To identify community nurses' educational needs to assist them in implementation of ACP practice.
Jeong et al. (2010) ⁷⁰	<ul style="list-style-type: none"> • To report the findings of a case study that explored the phenomenon of advanced care planning and advance care directives in residential care settings in Australia.
Pautex et al. (2008) ⁵³	<ul style="list-style-type: none"> • To better characterise patients with advanced oncological disease who decided to complete ADs. • Measure the effect of ADs' completion on the satisfaction level with end-of-life care from both patients and their relatives. • To determine what were the patient's motivations for deciding to formulate ADs and what were the main cited items in the completed ADs. • To evaluate the practical utility of ADs when patients had become incompetent.
Auerbach et al. (2008) ⁵¹	<ul style="list-style-type: none"> • To understand which patient clinical, sociodemographic and preference-related factors, as well as factors related to their site of care were associated with documentation that a code status discussion took place at the time of hospital admission.
Teno et al. (2007) ⁷¹	<ul style="list-style-type: none"> • The association between written ADs and the quality of end-of-life care.
Schiff et al. (2006) ⁶⁴	<ul style="list-style-type: none"> • To determine geriatricians' experience of and views on living wills.
Van Oorschot and Simon (2006) ⁶⁵	<ul style="list-style-type: none"> • To analyse and compare the surveys on German doctors and judges on end-of-life decision-making regarding their attitudes on the advance directive and on the dying process.
Scherer et al. (2006) ⁶³	<ul style="list-style-type: none"> • To describe critical care nurses' knowledge, attitudes, confidence and experiences regarding advance directives and end-of-life decision-making.
Jezewski et al. (2005) ⁷⁵	<ul style="list-style-type: none"> • To determine oncology nurses' knowledge of, attitudes toward, and experiences with advance directives
Bern-Klug et al. (2004) ⁷²	<ul style="list-style-type: none"> • To identify and develop categories of information about physicians end-of-life perspectives and to identify areas for further research.

(Continued)

Appendix 3. (Continued)

Hildén et al. (2004) ²⁸	<ul style="list-style-type: none"> To investigate Finnish physicians' experiences of decisions concerning living wills and DNR orders and their views on the role of patients and family members in these decisions.
Hildén et al. (2004) ⁷⁶	<ul style="list-style-type: none"> To investigate Finnish nurses' experiences with end-of-life decisions and their views of the role of patients, family members and themselves in these decisions. Compared the nurses' views with the results of their previous study on physicians' thinking on these issues.
Masuda et al. (2003) ⁶⁶	<ul style="list-style-type: none"> To investigate Japanese physicians' experiences with patients who had a living will at the time of death and their attitudes towards living wills.
Barbour et al. (2003) ⁷³	<ul style="list-style-type: none"> To discover the views of health professionals in the Greater Glasgow area on advance directive and its merits in improving care.

ACP: advance care planning; AD: advance directive; MCA: Mental Capacity Act; DNR: do-not-resuscitate.

Appendix 4. Appendix database search strategy for OvidSP: Medline.

Search	Results
1. (Advance care directive OR Care Plan\$ OR Living will OR Patient wish OR Health directive OR Power of Attorney OR Informed consent OR Care options).ti,ab	32,140
2. Limit 1 to (English language and yr="2000 – 2015")	20,185
3. (Communicat\$ OR Skill\$ OR Conversation OR Discus\$ OR Confiden\$ OR Initiat\$ OR Prognos\$ OR Bad news OR Break news OR Physician-patient relations OR Nurse OR Social worker OR Health professional OR Health practitioner). ti,ab.	2,179,737
4. Limit 3 to (English language and yr="2000 – 2015")	1,255,190
5. (((End-of-life OR Terminal OR Death) and Dying) OR Resuscitat\$ OR Palliative care OR Intensive care OR Emergency OR Hospice care OR Nursing home). ti,ab.	303,968
6. Limit 5 to (English language and yr="2000 – 2015")	171,536
7. 2 AND 4 AND 6	987