

Review article

Advance care planning: A systematic review of randomised controlled trials conducted with older adults



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ABSTRACT

Advance care planning (ACP), involving discussions between patients, families and healthcare professionals on future healthcare decisions, in advance of anticipated impairment in decision-making capacity, improves satisfaction and end-of-life care while respecting patient autonomy. It usually results in the creation of a written advanced care directive (ACD). This systematic review examines the impact of ACP on several outcomes (including symptom management, quality of care and healthcare utilisation) in older adults (>65 years) across all healthcare settings. Nine randomised controlled trials (RCTs) were identified by searches of the CINAHL, PubMed and Cochrane databases. A total of 3646 older adults were included (range 72–88 years). Seven studies were conducted with community dwellers and the other two RCTs were conducted in nursing homes. Most studies did not implement a standardised ACD, or measure the impact on quality of end-of-life care or on the death and dying experience. All studies had some risk of bias, with most scoring poorly on the Oxford Quality Scale. While ACP interventions are well received by older adults and generally have positive effects on outcomes, this review highlights the need for well-designed RCTs that examine the economic impact of ACP and its effect on quality of care in nursing homes and other sectors.

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1. Introduction

With the ageing of society worldwide but particularly in the European Union [1], there are increasing numbers of older adults experiencing cognitive impairment [2,3], frailty [4] and comorbidity [5]. These are associated with an increased incidence of adverse healthcare outcomes including hospitalisation [4], poorer quality of life [6] and increased healthcare expenditure [7]. There is concern that some potentially inappropriate admissions of the frailest patients, often from nursing homes, might be avoidable with better communication, documentation and planning [8–10], particularly towards the end-of-life (EOL). Complicating this, a large percentage of those at the EOL (40% of those dying) require decision making about treatment in their final days of life, although most (approx. 70%) lack decision-making capacity [11].

Advance care planning (ACP) is a process of communication between individuals, families and healthcare professionals (HCPs), to understand, discuss and plan future healthcare decisions in the event that an individual loses capacity [12]. ACP may result in the completion of a written advance care directive (ACD) reflecting the individual's preferences for future healthcare. ACP and ACDs improves the quality of EOL care and patient and relative satisfaction, while respecting patient autonomy [12,13]. ACP is also associated with improved quality of care at the end of life, less in-hospital death and increased use of hospice [14]. It can be facilitated by trained HCPs or can occur as part of routine patient care and can be delivered in a wide variety of settings. Review of EOL care preferences for older people [National Health Service] shows that in the event of a terminal illness, most would rather not receive futile life-sustaining treatments, artificial nutrition and/or parenteral hydration [15–17]. Yet, even among severely or terminally ill patients, few have an ACD documented in their medical record stating their express healthcare preferences [18]. Only one-quarter (26.3%) of all Americans have completed an ACD with the most frequently reported reason for not having one being lack of awareness [19]. In terms of ACP uptake and its impact on clinical outcomes, studies implementing EOL care interventions with older adults, such as psychosocial interventions [20,21] or palliative care leadership teams [22,23], show mixed effects on outcomes such as caregiver burden, distress, decisions to forego certain medical treatments, pain assessment, and hospice referral. A number of recently published systematic reviews have evaluated the effects of ACP in specific settings such as palliative care [24] and nursing homes [25,26]. Others have studied observational or quantitative methodologies, such as surveys and chart reviews to report descriptive data [27]. Others have included adults of all ages, extending beyond the effects of ACP and ACD implementation by investigating the effects of EOL communication, life-sustaining treatment preferences, EOL decision making and living wills [28]. While ACP can be implemented with all age-groups, it is most applicable to older adults as global death rates are concentrated at older ages [29]. Furthermore, there are differences in patterns of death and dying between younger and older cohorts, depending on location of death and treatment preferences [30–32]. This systematic review focuses

exclusively on randomised-controlled trials (RCTs) conducted with older adults, paying particular attention to the outcome measures used such as symptom management, quality of care at the EOL and healthcare utilisation. To our knowledge, this is the first systematic review of RCT implementing ACP interventions, conducted solely with older adults, across settings.

2. Methods

2.1. Search strategy and selection criteria

A systematic review of the literature was conducted using CINAHL and PubMed/MEDLINE. The search was conducted before January 2015. Details of the electronic search strategy, including the search terms used, are contained in Table 1. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed in this systematic review [33].

Papers were identified, for inclusion based on the following criteria:

- (i) Randomized controlled trial,
- (ii) Using an ACP intervention (i.e. a process of communication between individuals, their family, and healthcare professionals, to understand, reflect on, discuss and plan for future healthcare decisions that may or may not result in the completion of a written ACD),
- (iii) Sample of older adults (≥ 65 years old),
- (iv) Reported in English.
- (v) Conducted in any setting e.g. home, hospice, nursing home, community or hospital.

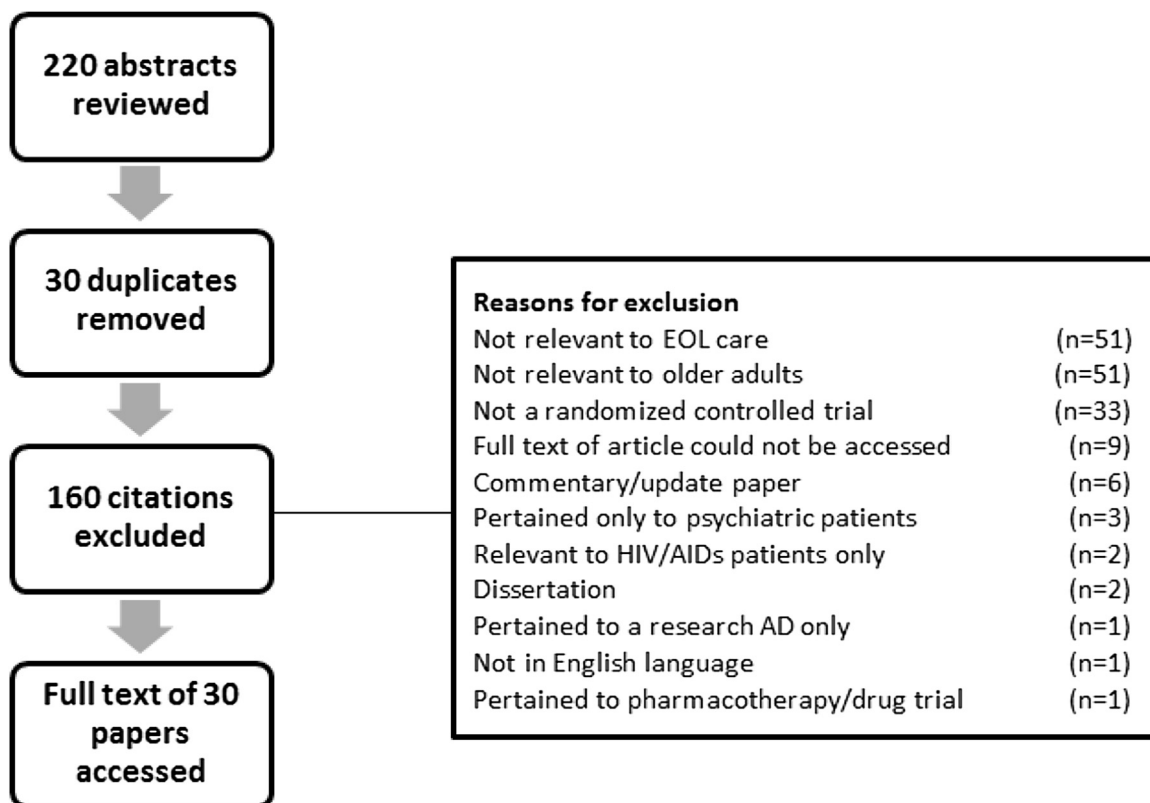
The selection process used is outlined in Fig. 1. The titles and abstracts of the selected articles were screened for the inclusion criteria and the full articles were retrieved. Overall, 220 abstracts were reviewed. Thirty duplicates were removed from this sample and 160 citations were excluded for various reasons (see Fig. 1). This left a sample of 30 papers where the full text was obtained. Four of these papers described a study protocol only (did not report results) and were excluded. Seventeen papers were excluded for the following reasons: did not pertain to an EOL intervention ($n = 1$), only described the theoretical basis of the intervention ($n = 1$), was not an RCT ($n = 1$), was not specific to older adults ($n = 6$), was not an ACP intervention e.g. rather the implementation of a palliative care leadership team or referral to a palliative care team ($n = 8$). Nine papers were included in the final analysis.

A secondary search of the Cochrane database was then conducted to ensure that other important RCTs had not been missed. Five systematic reviews were sourced that were relevant to ACP. Two of these were specific to EOL care in older adults. Of these two relevant reviews, one was a protocol only and the other was a completed review that evaluated palliative care interventions. Since the interventions were not specific to ACP, they were not included in the review.

Table 1
Search strategy.

Search Details	CINAHL Citations	PubMed Citations	Total Citations
Search #1: "Advance directive" OR "Advance care directive" OR "Healthcare directive" OR "Health care directive" OR "Advance care planning"	1842	4083	5925
Search #2: "Randomised Controlled Trial" OR "Randomized Controlled Trial"	28,965	464,742	493,707
Search #3: "Long term care" OR "long-term care" OR "residential care" OR "nursing home"	41,979	45,784	87,763
Search #4: "End of life" OR End-of-life OR Palliative	33,785	71,163	104,948
#1 AND #2	28	93 ^a	121
#1 AND #2 AND #3	4	5	9
#2 AND #3 AND #4	6	16	22
#1 AND #2 AND #4	16	52	68
Number of articles reviewed from combined searches	54	166	220

^a = Limited by age (>65yrs).

**Fig. 1.** PRISMA flow diagram of the search strategy.

2.2. Data extraction and quality assessment

Data extracted from articles included information on authors, country, date of publication, study design, sample size, sample characteristics, mean age at baseline of intervention, types of interventions, duration of intervention, and follow-up information. Two independent reviewers extracted data. Special attention was paid to the types of outcomes used and the effects of the ACP interventions on these outcomes. Similar to a recently published review of ACP interventions [34], each study was rated using the risk of bias criteria recommended by the Cochrane Effective Practice and Organisation of Care (EPOC) Review Group [35]. Additionally, the frequently used Oxford five-point scoring system [36] was used to

assess the quality and validity of the RCTs included in the review. The Oxford scale [36] uses the following three criteria:

- Is the trial randomised (1 point awarded and additional point if method is given and appropriate)?
- Is the trial double-blind (1 point awarded and additional point if method given and appropriate)?
- Were withdrawals and dropouts described and assigned to different treatments (1 point)?

According to this scale, trials that score three or more are considered relatively free of bias.

Table 2
Sample Characteristics.

Study ^a	Participants n		Age Mean years (range or SD)		Gender% Female	
	Intervention	Control	Intervention	Control	Intervention	Control
Brown et al. (1999)[37]	619	628	81.0 (NR)	81.2 (NR)	66.2	62.7
Detering et al. (2010) [38]	154	155	85 (82–88) ^b	84 (81–87) ^b	NR	NR
Ditto et al. (2001) [39]	163 (healthcare directive)	82	Total only reported: 73.0 (0.3)			
Grimaldo et al. (2001)[40]	100	100	73.3 (5.5)	72.3 (5.8)	43	38
Molloy et al. (2000) [41]	527	606	82.0	84.1	68.31	78.2
Morrison et al. (2005) [42]	43	96	87 (75–100)	86 (65–102)	84	NR ²
Sampson et al. (2010) [43]	22	10	88 (71–96)	85 (76–95)	NR	NR
Schwartz et al. (2002) [44]	31	30	79.88 (7.47)	80.83 (4.82)	90	77
Yamada et al. (1999)[45]	62	55	Total only reported: 74.1 (70–91)		NR	NR

^a = Studies are presented in alphabetical order.^b = median and interquartile range; NR = not reported.

3. Results

A final sample of nine studies [37–45] met the inclusion criteria and were included in the review. The sample was heterogeneous, in terms of setting, types of interventions, methods and outcomes measured.

3.1. Study characteristics

Six studies were conducted in the USA [37,39,40,42,44,54]; one in Australia [38]; one in Canada [41]; and one in the UK [43]. The nine studies included 3646 individuals, aged 65 or older (Table 2) and two studies included the bulk of these participants. The first study [37], recruited a population-based sample in the Kaiser Permanente Colorado Region, USA. The second study [41] included residents in six nursing homes, in Ontario, Canada. The setting for each study varied and included individuals from nursing homes (n=2), acute medical wards in large teaching hospitals (n=2), primary care practices (n=2), the medical office of a health maintenance organisation (n=1), a preoperative clinic (n=1), and a university-affiliated Veterans Affairs Medical Centre (n=1). Samples recruited for studies were mixed and all study samples consisted of older adults (≥ 65 years old). Three studies included family members [39,41,43]. The mean age of study participants at baseline ranged from 72.3 to 88.0 years.

3.2. Characteristics of the interventions

The types of ACP interventions varied considerably (Table 3). The majority were informational in nature i.e. provided verbal, written, or video information about ACP and how to complete an ACD, sometimes combined with a discussion about EOL care preferences. The aim of the interventions was generally to improve the accuracy of proxy decision-making, rather than to impact on the actual EOL care delivered. Two studies implemented education for healthcare staff [38,41]. Only one study implemented a standardised ACD [41]. Across the nine studies included there was considerable variation in who implemented the ACP intervention. Most of the studies involved the use of questionnaires and or other materials such as videotapes rather than formal face-to-face discussions, although trained interviewers usually facilitated their delivery. Only five studies involved direct discussions initiated by trained healthcare professionals. These included (nursing home) social workers [42], nurses (or allied healthcare professional) [38,41,44] and in one study, anaesthesiologists [40]. In only two studies did these receive formal training or education [38,41].

3.3. Reported outcome of the interventions

Three studies did not specify a primary outcome measure [40,42,45]. The outcome measures pertained to ACP outcomes, and family and patient outcomes:

3.3.1. ACP outcomes

Three studies reported that the intervention led to an increase in the documentation of EOL care preferences [37,41,42]. One study reported an increase in the rates of completion of durable powers of attorney [30] and another study reported an increase in those completing a standardised ACD [41].

3.3.2. Patient and family outcomes

One study reported an increase in patient knowledge of ACDs and life-sustaining treatments [44,45]. Concordance between patients EOL wishes and treatment received, was increased in two studies [38,42]. Only one study reported a significant reduction in hospitalisation rates from the nursing homes and a significant

Table 3
Characteristics of the Interventions and Reported Outcomes.

Study	Intervention Personnel	Intervention and Follow-up	Outcomes Measured
Brown et al. (1999)[37]	Postal but contact details for a study nurse were provided	A mailed 10-page cartoon-illustrated educational pamphlet on patient choices, a selection of Colorado ACDs and a guide to their completion, and a 20-min videotape on ACDs. Follow-up postal questionnaire and review of medical records after 3 months	Proportion of subjects who placed a directive in their medical record for the first time
Detering et al. (2010)[38]	Trained facilitator (nurse or allied health worker)	Formal ACP using the Respecting Patient Choices model which aimed to assist patients to reflect on their goals, values, and beliefs; to consider future medical treatment preferences; to appoint a surrogate; and to document their wishes. Follow-up immediately after discharge, 3 and 6 months post enrolment.	Doctors' knowledge of, and compliance with, a patient's EOL wishes Patient and family satisfaction with care Levels of stress, anxiety and depression in bereaved family members
Ditto et al. (2001)[39]	Research team	Four interventions: No-discussion intervention with a scenario-based ACD and surrogate review of the ACD. No-discussion intervention with a values-based ACD and surrogate review of the ACD. Discussion intervention in the presence of the surrogate with scenario-based ACD. Discussion intervention in the presence of the surrogate with values-based ACD. Follow-up over 2 years	Accuracy of substituted judgement Perceived benefits of ACD completion
Grimaldo et al. (2001)[40]	Anaesthesiologists Admitting counsellor Research team	Short information session emphasising the importance of communication about EOL care between patients and their proxies. Follow-up over 8 months	Discussions about EOL care between patients and their proxies Quality of communication Treatment preferences Durable power of attorney completion rates SF-36 Health survey Previous experiences with EOL discussions ACD completion rates, residents' and families' satisfaction with health care, health care services utilisation over 18 months and location of deaths.
Molloy et al. (2000)[41]	Clinical nurse managers, hospital staff, nurse health care facilitators	The Let Me Decide ACD programme which included educating staff in local hospitals and nursing homes, residents, and families about ACD and offering competent residents or next of kin of mentally incompetent residents an ACD that provided a range of health care choices for life-threatening illness, cardiac arrest, and nutrition. Follow-up at 6, 12, and 18 months.	ACD completion rates, residents' and families' satisfaction with health care, health care services utilisation over 18 months and location of deaths.
Morrison et al. (2005)[42]	Social workers Research associate	Baseline education in ACP for intervention social workers; structured ACP discussions with residents and their proxies on admission, after any change in clinical status, and at yearly intervals; formal structured review of residents' goals of care at pre-existing regular team meetings; 'flagging' of ACDs on charts; and feedback to healthcare providers of the congruence of care they provided and the preferences specified in the ACP process. Follow-up for 6 months post enrolment	Nursing home chart documentation of ACDs and do-not-resuscitate orders Preferences for artificial nutrition and hydration Experience of sentinel event (e.g. CPR, tube feeding, intravenous antibiotics, or hospitalisation) and the outcome of the event Concordance of treatments received with documented preferences
Sampson et al. (2010)[43]	Clinical team Independent researcher	Two-component intervention: palliative care needs assessment of patient leading to the documentation of a management plan; and discussions with carers based on the needs assessment. Follow-up at 6 weeks and 6 months.	Carer outcomes: -Level of distress -Health status and quality of life -Uncertainty and difficulties in decision making -Satisfaction in decision making -Intensity of angry feelings -Life satisfaction -Satisfaction with EOL care -Experience of care planning and formulation of an ACP Patient outcomes: -Pain and distress
Schwartz et al. (2002)[44]	ACP facilitator	Respecting Choices intervention: 2 pamphlets that describe ACP with questions that prompt patients to consider what factors affect their personal goals for EOL care, and vignettes about situations in which ACP would be beneficial. Meeting and discussion with the ACP facilitator. Follow-up at 2 months	Congruence between patient and healthcare agent in reporting patient goals of treatment in each scenario Knowledge of ACDs Treatment preferences Patient conceptualisations of quality of life Self-reported pain, anxiety, and alertness
Yamada et al. (1999)[45]	Clinical team	A hand-out about ACDs, an additional hand-out describing procedural aspects and outcomes of CPR, and a videotape about ACDs. Follow-up 2–4 weeks following study entry	Knowledge of ACDs Knowledge of CPR Outcomes of CPR Attitudes and preferences regarding ACDs and CPR

reduction in use of health resources [41]. Two studies reported improved understanding among surrogates of patient EOL preferences [39,44]. Discussions regarding EOL care between patients and proxies increased in a single study [40]. Levels of stress, anxiety, and depression among bereaved family members were reduced in two studies [38,43]. Patient and family satisfaction with care increased in one study [38]. Another study reported increased life satisfaction, and reduced levels of distress and decisional conflict among carers of people with dementia [43].

3.4. Methodological quality

The quality of the studies in the review was variable (see Table 4). Only three of the studies achieved a score of three on the Oxford Quality Scale, the remainder scored 1 or 2. Many of the studies had small numbers at the unit of randomisation level. Only three studies prospectively carried out a power calculation at the design stage [38–40]. Two studies had over 1000 participants [37,41]. One was a cluster randomised controlled trial in six nursing homes [41].

4. Discussion

The aim of this paper was to systematically review RCTs implementing ACP interventions, in older adults, in any setting. The studies sourced were heterogeneous in terms of intervention type and outcomes assessed. This made it difficult to synthesise the findings and draw clear conclusions from the review. Nonetheless, these findings demonstrate the feasibility of conducting RCTs, to evaluate the impact of ACP interventions, in older adults, with multiple outcomes in different settings. Although an abundance of literature refers to the benefits of ACDs, in terms of improving patient experience, and healthcare outcomes [38,46], few RCTs have been conducted to rigorously evaluate these proposed effects. Only one study implemented a standardised ACD [41].

The majority of studies were conducted in the USA and only one was conducted in Europe. Only two studies were conducted in nursing homes [41,42]. Reviewing the interventions used, most were informational with a goal of increasing ACD completion rates and enhancing proxy-decision making. Only one study evaluated the effect on healthcare use and cost [41] and two studies examined the effects on satisfaction with care [38,41]. In these studies, there was evidence that ACP interventions decreased hospitalisation and use of resources, increased patient and family satisfaction with care and increased the use of ACDs. The outcomes measured across studies were categorised into ACP outcomes, and patient and family outcomes. In the first category, studies reported an increase in the documentation of EOL care preferences, and completion rates of a durable power of attorney or ACD. Patient and family outcomes also improved. For example, knowledge of ACP, concordance with EOL wishes, and understanding of EOL preferences were generally improved. Additionally, more discussions regarding EOL care took place as a consequence of ACP interventions. However, patient outcomes like symptom management, quality of care at the end of life and quality of dying have not been measured in these studies and this is clearly a deficit.

The majority of the studies sourced in this review evaluated the effects of interventions on ACD completion rates, knowledge of ACDs, and proxy decision-making. These findings are important and provide some insight into the acceptability of ACDs amongst healthcare professionals, patients, and family members. However, with ACDs becoming more accepted among the general public, and in light of recent changes in policy and legislation [47–49], researchers need to include other outcomes such as quality of EOL care, healthcare utilisation, quality of death and dying, patient satisfaction, and patient self-determination. Only one study that

Table 4
Quality criteria results for included studies^a.

Author, year	Adequate sequence generation	Adequate allocation concealment	Similar baseline outcomes	Similar baseline characteristics	Incomplete outcome data addressed	Adequate blinding	Protected against contamination	Full outcome reporting	Oxford Quality Scale Score
Brown et al. (1999)[37]	Unclear	Unclear	Yes	Yes	No	Unclear	Unclear	Yes	1
Detering et al. (2010)[38]	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	2
Ditto et al. (2001)[39]	Yes	Unclear	Yes	Yes	Yes	Unclear	Unclear	Yes	3
Grimaldo et al. (2001)[40]	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes	3
Molloy et al. (2000)[41]	Unclear	Unclear	Yes	Yes	Yes	Unclear	Yes	Yes	2
Morrison et al. (2005)[42]	Unclear	Unclear	Unclear	No	Unclear	Yes	Yes	Yes	1
Sampson et al. (2010)[43]	Unclear	Unclear	Yes	Yes	Yes	Unclear	Yes	Yes	2
Schwartz et al. (2002)[44]	Yes	Yes	Unclear	Yes	Yes	No	Unclear	Yes	3
Yamada et al. (1999)[45]	No	Unclear	Yes	Yes	Yes	Unclear	Unclear	Yes	1
Studies satisfying criterion, n (%)	4 (44)	3 (33)	6 (67)	8 (89)	6 (67)	2 (22)	3 (33)	9 (100)	3 (33)

^a These criteria are taken directly from the Cochrane Effective Practice and Organisation of Care (EPoC) group guidelines available at: <http://epoc.cochrane.org/sites/epoc.cochrane.org/files/uploads/Suggested%20risk%20of%20bias%20criteria%20for%20EPoC%20reviews.pdf>.

measured health care costs [41], showed a decrease in hospitalisations and less resource use. Implementation of this same programme in Ireland, outside of an RCT setting has reaffirmed these findings [50]. Future RCTs of ACP interventions should include economic outcomes simultaneously with quality of care outcomes. The delivery of each ACP intervention also varied between studies. Just over half (5/9) were conducted by trained healthcare professionals. The remainder used less interactive questionnaires or other media, which while facilitated by trained interviewers, did not incorporate a personal discussion with a trained healthcare professional with knowledge of managing end-of-life care related issues. While not ideal, this reflects clinical practice where few healthcare professionals are available and able to undertake such conversations, a key barrier in the widespread implementation of ACP [51]. The extent to which healthcare professionals are trained and prepared to support ACP is variable [52] and technical and infrastructural barriers such as time and environment are often highlighted [53,54]. The extent to which patients want to engage in ACP is also variable, and support and training are particularly important for health professionals to initiate such discussions. Evidence suggests that patients often welcome such conversations and want their doctors involved [55].

In terms of the methodological quality of studies, only three achieved a score of three on the Oxford Quality Scale [39,40,44], and all had some risk of bias according to the EPOC criteria [35]. The problem of blinding health services interventions is a problem with all of these studies. The Oxford Quality Scale, appears to be more appropriate to score drug interventions rather than complex health service interventions. For example, it is almost impossible to conceal allocation, or ensure double blinding, in these types of health service interventions [56]. Furthermore, in cluster-randomised trials, often used for complex interventions, allocation concealment is not possible. Additionally, in these types of trials clusters are usually randomised all at once, so lack of concealment of an allocation sequence should not be an issue [57]. While there is a risk of chance baseline imbalance between the randomised groups, due to the small numbers of clusters randomised, this risk can be reduced by reporting the baseline comparability of clusters, adjustment for baseline characteristics, or by using stratified or pair-matched randomisation of clusters [57]. While there are limitations to the use of the Oxford Quality Scale in the appraisal of complex interventions, some guidelines exist for quality appraisal of cluster RCTs [58]. New guidance is currently being prepared for complex interventions [59]. There is a need to adapt these appraisal tools, such as the Oxford Quality Scale, by explicitly integrating guidelines to ensure transparency and clarity in synthesising and evaluating complex interventions.

Another limitation of this review is that only papers written in English were included, possibly resulting in the omission of important studies. Additionally, only three databases were searched, which may have limited the findings of the review. Nonetheless, the findings help to elicit the current state of the art and science, in terms of ACP interventions and older adults, and highlight the huge gaps that need to be addressed in this field.

5. Conclusion

Overall, although it can be concluded that ACP interventions have many benefits for patients, family, and healthcare staff, the results of this study demonstrate a distinct lack of RCTs, particularly well-conducted RCTs that evaluate ACP interventions in older adults irrespective of setting. Research with properly conducted RCTs is urgently needed to address this deficiency. Specifically, it is important to examine if ACDs improve the quality of EOL care

for the patient, family and health care workers who care for them and to systematically study the experience of death and dying from a variety of perspectives. The economic impact of these programmes also needs to be examined as some data suggests that they may reduce acute care hospital use and, at the same time, improve quality of dying – clearly outcomes that would significantly impact care and resource use [60]. This research is urgently needed to inform practice, policy, programme development and training needs.

Although the majority of older adults would like an opportunity to discuss their EOL care, only a minority are given the opportunity [61]. ACP interventions help to elicit a person's wishes for EOL care and allow individuals to maintain control over their EOL care, ensuring that those wishes are respected. Furthermore, there is now some data suggesting that ACP interventions in nursing homes and long-term care settings can reduce unnecessary, and sometimes traumatic, hospitalisations of frail older adults [27,62] and this needs further study [26]. This review highlights the obvious need for better-designed RCTs to establish the effects of ACP interventions, in different settings and to examine their impact on patient and healthcare outcomes.

Authors contributions

Study concept and design: EW, AC, CMC, DWM. Data extraction (abstracts and full articles): EW, NC. Independent review of full articles: EW, DWM. Data analysis and interpretation: EW. Quality review (NC, RO'S). Drafting of the manuscript: RO'C, NC, EW, CF, ED. Editing and reviewing the final manuscript: RO'C, DWM, EW, TK. All authors read and approved the final manuscript.

Contributors

EW, AC, CMCg and DWM were responsible for the study concept and design.

EW and NC undertook data extraction (abstracts and full articles).

EW and DWM independently reviewed full articles.

EW was responsible for data analysis and interpretation.

NC and RO'S undertook the quality review.

RO'C, NC, EW, CF and ED were responsible for drafting of the manuscript.

RO'C, DWM, EW and TK were responsible for editing and reviewing the final manuscript.

All authors read and approved the final manuscript.

Conflict of interest

Prof. D. William Molloy is copyright holder of the Let Me Decide Advanced Care Plan and Directive. The authors report no other conflict of interest.

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Provenance and peer review

This article has undergone peer review.

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