

Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review

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BACKGROUND/OBJECTIVES: Advance care planning (ACP) has shown benefit in some, but not all, studies. It is important to understand the utility of ACP. We conducted a scoping review to identify promising interventions and outcomes.

DESIGN: Scoping review.

MEASUREMENTS: We searched MEDLINE/PubMed, EMBASE, CINAHL, PsycINFO, and Web of Science for ACP randomized controlled trials from January 1, 2010, to March 3, 2020. We used standardized Preferred Reporting Items for Systematic Review and Meta-Analyses methods to chart study characteristics, including a standardized ACP Outcome Framework: Process (e.g., readiness), Action (e.g., communication), Quality of Care (e.g., satisfaction), Health Status (e.g., anxiety), and Healthcare Utilization. Differences between arms of $P < .05$ were deemed positive.

RESULTS: Of 1,464 articles, 69 met eligibility; 94% were rated high quality. There were variable definitions, age criteria (≥ 18 to ≥ 80 years), diseases (e.g., dementia and cancer), and settings (e.g., outpatient and inpatient). Interventions included facilitated discussions (42%), video only (20%), interactive, multimedia (17%), written only (12%), and clinician training (9%). For written only, 75% of primary outcomes were positive, as were 69% for multimedia programs; 67% for facilitated discussions, 59% for video only, and 57% for clinician training. Overall, 72% of Process and 86% of Action outcomes were positive. For Quality of Care, 88% of outcomes were positive for patient-surrogate/clinician congruence, 100% for patients/surrogate/clinician satisfaction with communication, and

75% for surrogate satisfaction with patients' care, but not for goal concordance. For Health Status outcomes, 100% were positive for reducing surrogate/clinician distress, but not for patient quality of life. Healthcare Utilization data were mixed.

CONCLUSION: ACP is complex, and trial characteristics were heterogeneous. Outcomes for all ACP interventions were predominantly positive, as were Process and Action outcomes. Although some Quality of Care and Health Status outcomes were mixed, increased patient/surrogate satisfaction with communication and care and decreased surrogate/clinician distress were positive. Further research is needed to appropriately tailor interventions and outcomes for local contexts, set appropriate expectations of ACP outcomes, and standardize across studies. *J Am Geriatr Soc* 69:234-244, 2021.

Keywords: advance care planning; scoping review; advance directives

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INTRODUCTION

Advance care planning (ACP) has garnered enthusiasm and skepticism since several high-profile court cases in the 1970s and the Patient Self-Determination Act in 1990.¹ Patients, surrogates, and clinicians consistently rate ACP as important, especially by those who have experienced decision-making for serious illness.²⁻⁵ In addition, ACP research has seen sustained growth (Figure 1), and prominent organizations have called for its implementation and reimbursement.⁶⁻¹¹ Recent ACP studies have shown an overall benefit for patient, surrogate, and clinician outcomes; however, some results have been mixed,¹² leading some to question the utility of ACP.¹³ In balancing the reported desire for, and rated importance of, ACP by patients, surrogates, and clinicians with the mixed research findings, it has been unclear how best to move forward as a

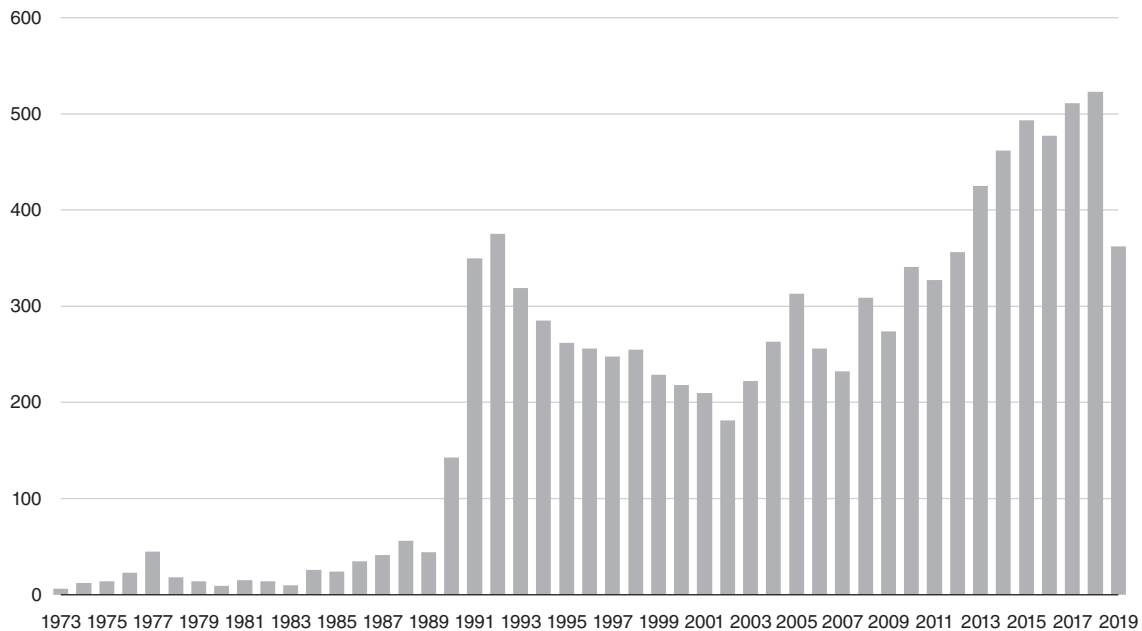


Figure 1. PubMed articles under medical subject heading (MeSH) “advance care planning.” Data from a PubMed MeSH search of “advance care planning,” which includes the previously used subject heading “advance directive.” Note, MeSH indexing not complete for 2019.

field. Therefore, the goal of this article is to describe the existing ACP landscape, conduct a scoping review of recent randomized trials in the past decade to describe current ACP interventions and outcomes, and provide recommendations for future research.

The ACP Landscape

ACP has evolved over time²; however, it was not until 2017 that a large Delphi panel agreed on a consensus definition as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.”¹⁴ This definition reflects the shift in focus from advance directive (AD) documentation to ongoing, individualized support and preparation for communication and in-the-moment decision-making.¹⁵

The inherent complexity of ACP is well documented.¹⁵⁻¹⁷ It involves many behaviors (e.g., values identification, communication, and documentation),¹⁸⁻²⁰ targets (e.g., patients, surrogate, clinicians, and health systems), and settings (e.g., inpatient, outpatient, and nursing home).²¹ The myriad ACP behaviors are also influenced by one’s readiness to engage,¹⁸⁻²⁰ health trajectory,²² community barriers, and health disparities.^{23,24}

Although improving over time, ACP engagement among older adults is approximately 50%, with one-third having documented their wishes and only 10% to 20% having discussed their wishes with clinicians.²⁵⁻²⁷ Rates of ACP have been shown to be even lower (20%) among racial/ethnic minority populations and those with limited health literacy,^{25,28-30} and ACP disparities persist for LGBTQIA, homeless, and incarcerated populations.³¹⁻³³ ACP can be complicated by lack of trust and negatively impacted by experiential racism in health care.³⁴⁻³⁶ Furthermore, some

individuals may hold nonautonomous views on decision-making (i.e., prefer others make medical decisions).³⁵⁻⁴⁰

Despite potential barriers, qualitative and other research demonstrates that patients, surrogates, and clinicians view ACP as important, particularly those individuals with previous experiences with end-of-life decision-making.²⁻⁵ Although there may be many cultural and logistic barriers to ACP,^{20,41} many patients report wanting to talk to their medical providers about ACP,^{42,43} preferably while they can still engage in decision-making,^{44,45} and report expecting their providers to initiate ACP conversations.⁴⁶⁻⁴⁸ In addition, patients view ACP as a way to prepare their families and surrogate decision makers, decrease their loved ones’ decision-making burden,^{49,50} and ensure their own wishes are honored.^{51,52} Multidisciplinary clinicians also view ACP as an important part of their job and a way to help patients and families prepare for decision-making.^{52,53}

However, a well-run trial and other studies in the 1990s showed no improvements in patient-clinician communication, ACP documentation, or utilization.^{54,55} A recent overview of 80 ACP systematic reviews published in 2018 demonstrated some improved patient, surrogate, clinician, and healthcare system outcomes, and also some mixed findings.¹² However, over 95% of the reviews were rated as poor quality, only 39% included trial data, and the majority of review recommendations were based on older, observational data conducted before the evolution of ACP definitions and outcomes.¹² Furthermore, the extreme heterogeneity of prior studies has made it difficult to make global recommendations.

Prior Outcomes

In prior studies, ACP has been associated with increased knowledge about treatment choices, self-efficacy, and readiness, and increased ACP documentation.^{23,56,57} It has also

been associated with improved communication between patients, surrogates, and clinicians^{58,59} and improved satisfaction with clinicians who initiated conversations.^{2,60} In some studies, ACP has resulted in improved satisfaction with medical care,⁶¹ increased patient-surrogate congruence, and goal concordant care.^{27,62} Furthermore, patients reported a greater sense of control,⁶³ decreased decisional regret,⁶⁴ piece of mind,¹⁹ and improved quality of life.^{62,65} Benefits for surrogates have included decreased burden and conflict among loved ones¹⁹; reduced stress, anxiety, and depression in surviving family members⁶²; and increased satisfaction with patients' medical care and surrogate reports of goal concordant care.⁶⁶ Health system outcomes have included decreased unwanted intensive medical interventions, hospitalizations, and in-hospital deaths,⁶⁵ and increased earlier palliative care consultations⁶⁷ and hospice utilization.^{68,69}

However, ACP has inconsistently improved patient-surrogate agreement, goal concordant care, and satisfaction with medical care. Data on reduced costs and healthcare utilization have also been mixed.^{24,70,71} Furthermore, studies of different singular intervention modalities, combined intervention modalities, and implementation strategies have resulted in varying outcomes.¹² For example, interventions that focus only on written educational materials have not been as beneficial as those combined with videos or facilitated discussions.^{58,61,67} In addition, studies of palliative care services that included an ACP component have not always resulted in increased ACP documentation or decreased healthcare utilization.^{72,73}

Given the complexity of prior ACP research and heterogeneous outcomes, through another Delphi process, experts created an ACP Outcomes Framework in 2017: Process (e.g., readiness), Action (e.g., communication), Quality of Care (e.g., satisfaction), Health Status (e.g., anxiety), and Healthcare Utilization.²¹ Although panelists rated goal concordance as the gold standard, they and others noted the difficulty in measuring this outcome.^{74,75} For example, preferences may change in the moment, and therefore, reliance on retrospective chart review or AD documentation may be inaccurate. Additionally, panelists noted that without equitable access to health care, it may be asking too much of ACP, by itself, to affect quality of care, goal concordance, and healthcare status and utilization outcomes.

Given the field's evolving understanding of the complexity of the ACP process and new efforts to categorize and standardize ACP outcomes,^{14,15,76} it is important to gather current and high-quality evidence to help direct the next steps in ACP research. Therefore, we conducted a scoping review of ACP randomized controlled trials (RCTs), conducted within the past decade, to describe the study characteristics, intervention modalities, outcomes used to define successful ACP,²¹ and the relative statistical findings.

METHODS

Study Design

We used the standardized Arksey and O'Malley and Preferred Reporting Items for Systematic Review and Meta-Analyses frameworks.⁷⁷

Search Strategies

With a health sciences librarian, we developed a search strategy across MEDLINE/PubMed, EMBASE, CINAHL, PsycINFO, and Web of Science, and manual searches (Supplementary Appendix S1).

Selection of Studies

We restricted publications to RCTs published between January 1, 2010, through March 3, 2020, English-language articles, and adult populations. We excluded pediatrics populations; pilot RCTs with primary outcomes related only to feasibility or acceptability; palliative care trials that did not include ACP as an intervention or primary outcome; studies focused only on code status interventions and outcomes (due to the expanded definition of ACP); subgroup analyses unrelated to intervention efficacy; and conference abstracts, reports, and other gray literature. One author (R.M.) reviewed titles and removed duplicates. Two authors (R.M., R.S.) reviewed and selected abstracts for full data extraction. Discrepancies were resolved by consensus.

Data Extraction and Analysis

We created a data extraction tool to chart: article characteristics (authors, journal, and year published), population and setting, intervention, exposure target (e.g., patients, surrogate, or clinician), primary and secondary outcomes, and relative statistical findings. Interventions were categorized by primary method of information delivery (e.g., video or written material). Using the standardized ACP Outcomes Framework, primary and secondary outcomes were categorized into five domains: Process (e.g., behavior change and readiness), Action (e.g., communication and documentation), Quality of Care (e.g., goal concordant care and satisfaction), Health Status (e.g., quality of life and anxiety), and Healthcare Utilization.²¹ We used descriptive statistics (percentages) to describe the study characteristics and statistical findings. Results were defined as "positive" if there were statistically significant differences between study arms ($P < .05$). Two independent raters (R.M., R.S.) rated trial quality using the standard Jadad scale.^{78,79}

RESULTS

Of 1,464 articles identified, 69 met eligibility criteria (Figure 2), 70% were published in or after 2017 (Supplementary Table S1), and 65 trials (94%) were rated as high quality. A total of 49 (71%) studies included only patients, 2 (3%) included only surrogates or families, 12 (17%) included patient-surrogate dyads, 5 (7%) included patient-clinician dyads, and 1 included nursing home physicians and nurses.

ACP Definitions

Definitions included ACP being a "process" (41%), making end-of-life treatment preferences (28%), communicating goals of care (7%), ordering life-sustaining treatments (4%), and completing ADs (4%). Sixteen percent gave no definition (Supplementary Table S1).

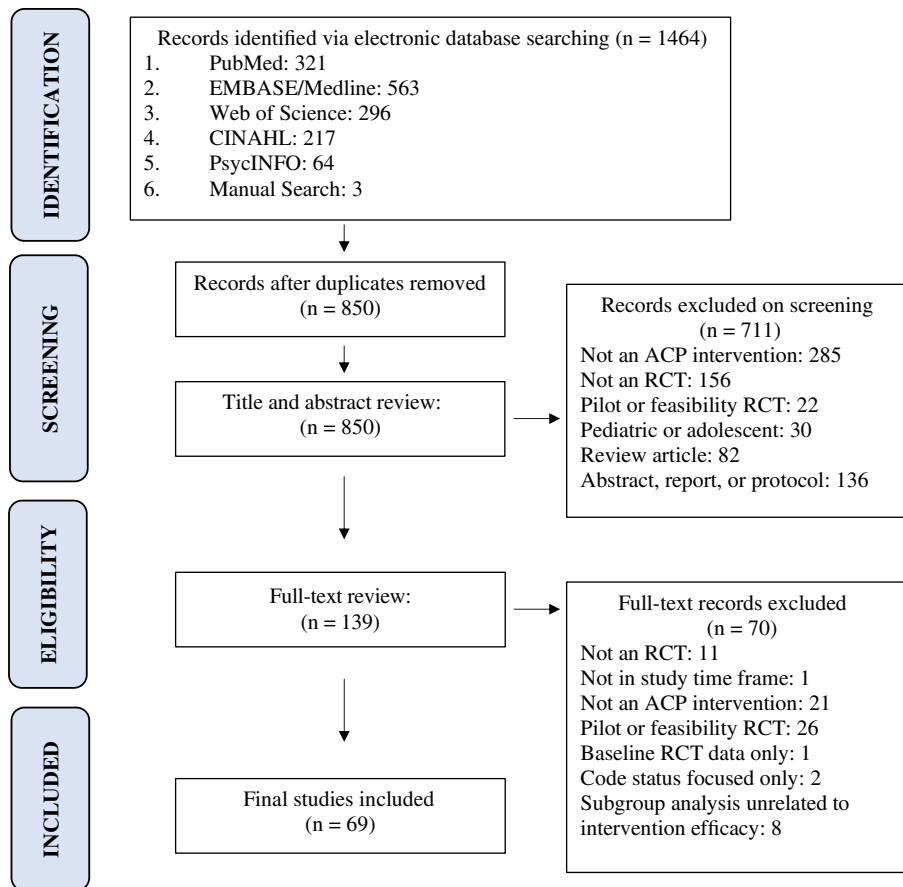


Figure 2. Preferred Reporting Items for Systematic Review and Meta-Analyses diagram. ACP, advance care planning; RCT, randomized controlled trial. [Color figure can be viewed at wileyonlinelibrary.com]

Settings and Populations

Studies were conducted in 12 countries, with 62% in the United States, and included outpatient settings (71%), nursing homes (19%), the community (7%), and inpatient settings (3%). For age, 44% had inclusion criteria that included adults 18 years or older, 31% included adults 60 years or older, 6% included adults 70 years or older, one study included adults 80 years or older, and 18% did not mention age criteria. Participants included adults with noncancer illnesses (e.g., heart failure) (29%), cancer (25%), primary care populations (20%), terminally ill (12%), nursing home residents or staff (12%), and surrogates/families (3%). Limited prognosis was an inclusion criterion for 26% of studies, and patients with dementia or surrogates were included in 9 (13%) studies. A total of 38% of studies enrolled at least a quarter of underrepresented minorities, and 23% enrolled at least half; one study included homeless participants; 43% included participants with limited health literacy/education; and among the 43 U.S. studies, 9% included Spanish speakers.

Intervention Modalities

Intervention modalities for the 69 studies included: facilitated discussions (42%), video only (20%), interactive, multimedia/multimodal online or educational programs (17%),

written-only materials (12%), and clinician training for physicians, nurses, or nursing home staff (9%).

Facilitated discussions used trained facilitators, including lay health navigators.^{62,80-86} Some discussions incorporated ADs,⁸³⁻⁸⁶ question prompts,^{87,88} or videos.⁸³ Discussions often had end goals, such as to complete an AD⁸⁴ or to assess goals or illness understanding.⁸⁹⁻⁹¹ These discussions ranged from 45 to 90 minutes, took place in the clinic, hospital, nursing homes, by telephone, or in patients' homes,^{46,84} and often over multiple visits.^{87,88,92,93}

Video-only interventions varied in length from 3 to 20 minutes,^{94,95} and some included accompanying questions.⁹⁶ Some depicted medical situations, such as simulated resuscitation,⁹⁴ health trajectories of long-term care residents,⁹⁷ and specific dementia, heart failure, and other serious illness content.^{64,98-100}

Interactive, multimedia/multimodal online programs included videos, interactive values questions, and/or written materials, such as ADs, booklets, pamphlets, or workbooks.¹⁰¹⁻¹⁰⁵ Three programs were designed for low-literacy populations^{102,106,107} and two for non-English-speaking participants.^{23,108} One study included patient and surrogate interventions,¹⁰³ and one included patient and clinician interventions.^{89,109}

Some written-only interventions included questions about values (i.e., not ADs) designed to initiate conversations with clinicians¹¹⁰⁻¹¹³ or included in nursing home records.¹¹⁴ Others included traditional ADs,

preset ADs, and ADs with expanded treatment options.¹¹⁵⁻¹¹⁷

Clinician training interventions included communication and shared decision-making training and conversation pocket guides.^{109,118-121} One study included electronic health record templates and a family discussion guide.⁸⁹

Study Follow-Up

Follow-up of the 69 studies ranged from immediate post-intervention (12%),^{64,115} to a few weeks (10%),^{90,111} 3 months (37%),^{86,122} 6 to 9 months (21%),^{85,123} 1 year (24%),^{23,124} and 2 years (3%).^{91,125}

Outcomes Types

Overall, there were 170 outcomes (79 primary and 91 secondary) across the 69 studies, including 29 Process, 56 Action, 43 Quality of Care, 30 Health Status, and 12 Healthcare Utilization outcomes (Table 1).

Interventions with Positive Primary Outcomes

Of the primary outcomes, 10% were Process, 47% were Action, 30% were Quality of Care, 9% were Health Status, and 4% were Healthcare Utilization outcomes. Six of eight outcomes (75%) for written materials only were positive, as were 9 of 13 (69%) for multimedia programs; 24 of 36 (67%) for facilitated discussions, 10 of 15 (59%) for video-only interventions, and four of seven (57%) for clinician training (Supplementary Table S1).

Results of Primary and Secondary Outcomes by Category

For Process outcomes, 21 of 29 (72%) were positive, including 20 of 27 (74%) for behavior change processes (e.g., readiness) (Table 1).^{17,23,46,92,101,126,127} For Action outcomes, 48 of 56 (86%) were positive, including seven of nine (78%) for patient reports of communication with surrogates^{118,128} and clinicians^{84,126,129} and 38 of 44 (86%) for ACP documentation.^{17,80,120,125,127,130}

For Quality of Care outcomes, 23 of 43 (53%) were positive. Although one of 10 outcomes were positive (10%) for goal concordant care,^{62,89,91,131,132} seven of eight (88%) outcomes for congruence between patients and surrogates or clinicians were positive^{46,83,85,100,122,133,134}; as were seven of seven outcomes (100%) for satisfaction with communication (including three for patients,^{84,111,125} three for surrogates,^{62,85,118} and one for clinicians¹¹²); five of 11 (45%) for satisfaction with decision-making (including three of eight (38%) for patients^{64,93,128} and two of three (67%) for surrogates)⁸²; and three of seven (43%) for satisfaction with medical care (including one of five for patients (20%)⁶² and three of four (75%) for surrogates).^{62,82,123}

For Health Status outcomes, 11 of 30 (37%) were positive. None of the 10 quality-of-life outcomes were positive (0%). However, nine of 15 mental health outcomes were positive (60%), including two of seven (29%) for decreased patient anxiety and depression,^{89,129} and seven of seven (100%) for surrogate depression, anxiety, posttraumatic stress disorder (PTSD), and complicated grief and caregiver

burden.^{46,62,86,97,135} One of one outcome was positive for reduction in clinician distress,¹¹⁸ and one of four (25%) mortality outcomes showed improved survival.¹³⁶

For Healthcare Utilization outcomes, five of 12 (42%) were positive, including one of one for decreased transfers from nursing homes to the hospital,⁸⁵ and in one of two outcomes for emergency department visits or hospitalization,^{114,137} hospital length of stay,^{114,138} and preferred place of death.^{86,139} In one trial, ACP did not decrease costs⁸¹; however, in another study, ACP did not increase the length of clinic visits.⁸⁸

DISCUSSION

This review included 69 high-quality RCTs from the last decade, the majority of which have not been summarized in prior reviews.¹² ACP is complex, and trial characteristics were heterogeneous in their ACP definitions, populations, life trajectory, settings, intervention modalities, follow-up time points, and outcomes. For all intervention modalities, the majority of outcomes were positive. Using the standardized ACP Outcomes Framework, Process (e.g., readiness) and Action outcomes (e.g., communication and documentation) were consistently positive, whereas Quality of Care outcomes were mixed (e.g., the majority of congruence and satisfaction with communication and care outcomes were positive, but goal concordant care was not). Findings were also mixed for Health Status (e.g., the majority of surrogate distress and grief outcomes were positive, but patient quality-of-life outcomes were not) and for Healthcare Utilization.

Study heterogeneity as well as mixed findings for some ACP outcomes have been previously described.¹² In contrast to older studies, recent studies have embraced the broader definition of ACP as a process, with only 4% equating ACP with completion of an AD. Recent studies have expanded in participant diversity; however, attention to inclusion of underrepresented populations should continue to be a focus for future research. For intervention modalities, written-only materials, interactive, multimedia interventions, and facilitated discussions were consistently positive, followed by video-only and clinician training interventions. Newer written materials appear to perform better than those studied in the past.¹² This may be due to their attention to patients' values, preferences, and health literacy, rather than standard, difficult-to-read ADs,¹⁴⁰ or to the selection of more appropriate outcomes for this intervention type. For Quality of Care outcomes, congruence outcomes appear to have improved over time and studies continue to show positive findings for satisfaction with communication but no benefit for goal concordance. Mixed results for Health Status outcomes, such as negative findings for quality of life with consistently positive findings for surrogate and clinician distress, have also been described.¹² For Healthcare Utilization, data remained mixed, and the trials did not assess increased palliative care consultation or hospice, as has been previously shown.¹⁴¹

Where Do We Go from Here?

Given patient, surrogate, and clinician desire for ACP, especially those with previous decision-making experience,²⁻⁵ it

Table 1. Primary and Secondary Outcomes by Outcome Domain

Outcome domain	Subdomain	Outcome details	Outcomes, No.	Positive, No. (%)
Total			170	108 (64)
Process	Overall		29	21 (72)
	Behavior change		27	20 (74)
	Knowledge	ACP importance, ¹⁰¹ CPR, ^{100,108} intubation, ⁹⁴ prognostic awareness, ¹²⁸ surrogate knowledge of patient decision control preferences ¹³⁵	10	8 (80)
	Self-efficacy	Comfort in decision-making, ⁹⁰ confidence in decision-making, ^{46,92,126} preparedness ^{103,104}	10	5 (50)
	Readiness	Intention to complete documents, ^{95,120,134} comfort with AD completion ¹⁵⁸	4	4 (100)
	Composite survey	Knowledge, self-efficacy, readiness ^{17,23,127}	3	3 (100)
	Attitudes	Of ACP, ¹⁰⁸ shared decision-making ¹¹⁹	2	1 (50)
Action	Overall		56	48 (86)
	Communication	Patient reported communication with surrogate ¹²⁸ or clinician, ^{84,126,129} or family reported ¹¹⁸	9	7 (78)
	Documentation of values and preferences	AD completion, ^{116,122,123,127,159} documents or discussions, ^{17,80,120,125,127,130} DNR, DNI, do not hospitalize orders ^{86,94,160}	44	38 (86)
	Composite survey	Surrogates, values, and preferences, and decision-making ^{17,23,127}	3	3 (100)
Quality of Care	Overall		43	23 (53)
	Congruence	Treatment preference between patient-surrogate ^{46,83,90,133} or patient-clinician ^{85,100}	8	7 (88)
	Goal concordant care	Via medical record review alone ^{62,89,96,99,128,161} or also surrogate report ^{91,131,132}	10	1 (10)
	Satisfaction		25	15 (64)
	Communication	Quality of patient-clinician conversations, ^{84,111,125} surrogate-family satisfaction with communication ^{62,85,118}	7	7 (100)
	Decision-making	Patient decisional conflict ^{64,90,93,116} or surrogate ^{46,82}	11	5 (45)
	Medical care	Patient compassion assessment of clinician, ³⁶ patient or family assessment of quality ^{62,82,125,137}	7	3 (43)
Health Status	Overall		30	11 (37)
	Quality of life	Patient QOL, ^{80,121,162} spiritual well-being, ⁹⁰ surrogate well-being, ^{123,132} symptom management, ⁸⁰ peacefulness ⁸⁹	10	0 (0)
	Mental health	Anxiety, depression, PTSD, ^{46,62,86,129,134} burden, stress, ^{86,97,135} complicated grief ⁹⁷	15	9 (60)
	Clinician distress	Nursing home staff distress ¹¹⁸	1	1 (100)
	Mortality	1-y survival ¹¹⁴	4	1 (25)
Healthcare Utilization	Overall	Hospital admissions or ED visits, ^{114,137} length of hospital stay ^{114,139} or clinic visit, ¹¹² nursing home transfers to hospital, ⁸⁵ place of death, ¹³⁹ hospice utilization ⁸⁰	12	5 (42)

Abbreviations: ACP, advance care planning; AD, advance directive; CPR, cardiopulmonary resuscitation; DNI, do not intubate; DNR, do not resuscitate; ED, emergency department; PTSD, posttraumatic stress disorder; QOL, quality of life.

is incumbent on the field to make sense of ACP's complexity. As recommended by others, one holistic approach is to consider the innate heterogeneity and complex interplay between several ACP stakeholders and intervention targets: patients, surrogates, communities, clinicians, health systems, and ACP policy⁵⁸ (represented as "pillars" in Figure 3). In this context, a single ACP intervention would

not be expected to positively affect all outcomes, which may be influenced by several other pillars. For example, a patient's ACP wishes may be moot if his/her surrogate is unprepared, community social norms do not support ACP, he/she lacks access to medical care, clinicians are untrained, health systems are not optimized to store and utilize ACP documents, and legislation is not optimized to help patients

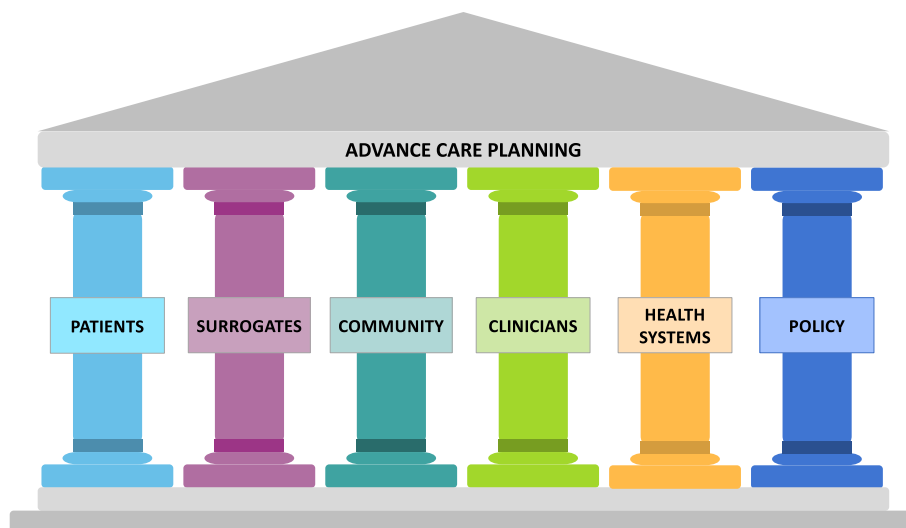


Figure 3. Six pillars of advance care planning. Pillars refer to key stakeholders or potential intervention targets.

execute care plans.^{58,140,142} Desired ACP outcomes may also be unattainable without standardized validated measures. Each “pillar” may need its own tailored interventions and outcomes for which the intervention can reasonably be expected to affect, but this paradigm must be further explored. Furthermore, testing of combined interventions and implementation strategies is needed to improve care in real-world contexts.

The novel use of the standardized ACP Outcome Framework allowed us to uncover nuanced findings.²¹ First, Process and Action outcomes were on the whole positive and may be helpful for studies aimed at engaging individuals in the ACP process. For Quality of Care, 88% of outcomes that assessed patient and surrogate/clinician congruence were positive^{46,83,85,90,93,100,133,134}; as were 100% of outcomes assessing satisfaction with communication for patients, surrogates, and clinicians^{62,84,85,111,112,125} and 75% of outcomes assessing surrogates’ satisfaction with patients’ care.^{62,82,123} However, only 10% of goal concordance outcomes were positive⁶²; all were assessed by retrospective chart review, with three studies augmenting with surrogate/family input.¹³¹⁻¹³³ However, it was unclear whether the trials used standardized postdeath surrogate questionnaires or follow-up time frames, which may have introduced recall bias.

As previously described, there are many barriers to measuring goal concordant care,^{74,75} especially as ACP has evolved as a process, rather than a static treatment choice.¹⁵⁻²⁰ Furthermore, the retrospective methods used are subject to in-the-moment preference changes; preferred place of death and unwanted healthcare utilization experience similar measurement challenges. Although some have recommended eliminating the potentially unattainable goal concordance outcome, others have recommended new research procedures that may get us closer to the mark (e.g., categorizing goals and matching to accumulated outcomes data),⁷⁴ yet this is not yet known. It may also be prudent, as others recommend, to ask patients about their current care, rather than just end-of-life care or relying on postdeath interviews or retrospective chart reviews.^{75,143}

Given the positive findings of patient, surrogate, and clinician satisfaction with communication and surrogate’s satisfaction with patients’ care, these may be more appropriate or realistic Quality of Care outcomes until a validated, standardized method for measuring goal concordance is established.¹⁴³⁻¹⁴⁵

Health status outcomes were not positive for patients’ quality of life. However, clinician distress was reduced in the one study it was measured,¹¹⁸ and 100% of outcomes assessing surrogate depression, anxiety, PTSD, and complicated grief showed improvement and were all of high quality.^{46,62,86,97,134,135} These results suggest that ACP appears to be meeting patients’ stated goals for ACP—decreasing decision-making burden on others.^{49,50} Therefore, it is possible that these Health Status outcomes may be most affected by the ACP interventions in these trials. For Healthcare Utilization outcomes, it is unclear whether utilization represented unwanted treatment, and increases in access to palliative care, as other studies have shown,¹⁴¹ may be an appropriate outcome depending on the goal of the study.

In consideration for future intervention research, most studies in this review did not target the community, the healthcare system, or policy “pillars.” Communities are where social norms about ACP are defined and where larger educational interventions could be helpful.¹⁴⁶⁻¹⁴⁹ For health systems, electronic records and patient portals may provide additional opportunities to message patients, surrogates, and clinicians.¹⁵⁰⁻¹⁵² Furthermore, policy and legislation changes may help to simplify ACP legal requirements and help make ACP billing easier and more widespread.^{140,142} Although targeting all ACP stakeholders/pillars would be optimal, this is not feasible for many communities and healthcare systems. The results of this review demonstrate that although we continue to expand clinician training and optimize health systems and policy, there may still be benefit in targeting one or more ACP stakeholders. For example, we and others have shown the ability to engage vulnerable patients in resource poor health systems in ACP with patient-only interventions,^{23,61,102,127}

and surrogate-only interventions,^{51,153} in addition to clinician and health system interventions.¹⁴³

In consideration for outcomes research, further work may be needed to refine the ACP Outcomes Framework (e.g., goal concordant may need its own category). Furthermore, decisions about which ACP stakeholder/pillar to focus on, which populations to include, which intervention to use, and which outcomes to assess will require a tailored approach based on the needs of the local environment. That said, given the current heterogeneity of ACP outcomes, future research should consider using some standardized outcomes so that trial findings can be compared, as some studies are attempting.^{154,155} Finally, pragmatic trials measuring implementation strategies in real-world settings are needed, and several are underway.^{152,154-156} For effective ACP interventions, an impartial repository, as used in other fields,¹⁵⁷ may help disseminate the interventions to clinical champions.

Limitations

Our search strategy may not have captured all RCTs, and we did not account for research that may be in progress, feasibility trials, or gray literature. Furthermore, we did not exclude studies based on quality per the PRIMSA guidelines⁷⁷; however, 94% of included trials were rated as high quality.

Conclusion

ACP is complex, and recent ACP trials included heterogeneous populations, disease states, settings, interventions, and outcomes. Trials including written-only interventions, interactive, multimedia/multimodal programs, facilitated discussions, video-only interventions, and clinician training were predominantly positive, as were Process and Action outcomes. Although some data on Quality of Care outcomes, such as goal concordance, and Health Status outcomes, such as quality of life, were mixed, increased patient and surrogate satisfaction with communication and medical care (Quality of Care) and decreased surrogate and clinician distress (Health Status) were consistently positive and may be more appropriate ACP outcomes. A holistic view of ACP as a complex interplay between patients, surrogates, communities, clinicians, health systems, and policy is needed. In addition, further research is needed to set appropriate expectations of ACP outcomes, standardize outcomes across studies, and tailor interventions and outcomes to local environmental resources and contexts.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Supplementary Appendix S1: Search Strategies Used for Electronic Databases.

Supplementary Table S1: Overview of All Included Studies.