

VIEWPOINT

What's Wrong With Advance Care Planning?

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Advance care planning (ACP) has emerged during the last 30 years as a potential response to the problem of low-value end-of-life care. The assumption that ACP will result in goal-concordant end-of-life care led to widespread public initiatives promoting its use, physician reimbursement for ACP discussions, and use as a quality measure by the Centers for Medicare & Medicaid Services, commercial payers, and others. However, the scientific data do not support this assumption. ACP does not improve end-of-life care, nor does its documentation serve as a reliable and valid quality indicator of an end-of-life discussion.

What Is ACP?

The purpose of ACP is to ensure goal-concordant care near the end of life for patients who lack decisional capacity. It is a process to support adults in understanding and sharing their values, goals, and preferences regarding future potential medical care decisions; choosing and preparing a trusted person(s) to make medical decisions; and documenting these wishes so that they can be acted on when future medical decisions need to be made. Most approaches to ACP encourage all adults to participate in the process regardless of their health status. Advance care planning

goal-concordant care or patient quality of life. Additionally, these reviews found no association of ACP with subsequent health care use, including emergency department visits, hospitalizations, and critical care. Subsequently, 5 large multisite randomized clinical trials that enrolled patients with cancer (1117 patients at 23 hospital cancer centers),³ nursing home residents (12 479 residents from 360 nursing homes),⁴ older adults in primary care (759 patients from 8 primary care practices),⁵ adults with serious illness (515 patients from 20 outpatient clinics),⁶ and patients with heart failure (282 patients from 2 heart failure centers)⁷ could not identify meaningful differences in health care use, patient quality of life, or goal-concordant care between those randomly assigned to receive either ACP or usual care.

Why Does ACP Not Achieve Its Desired Outcomes?

The inability of ACP to achieve its desired outcomes represents the gap between hypothetical scenarios and the decision-making process in clinical practice settings. The success of ACP depends on 8 steps: (1) patients can articulate their values and goals and identify which treatments would align with those goals in hypothetical future scenarios; (2) clinicians can elicit these values and preferences; (3) preferences are documented; (4) directives or surrogates are available to guide clinical decisions when patients' preferences have not changed and they lose enough decisional capacity for their ACP views to become operative; (5) surrogates will invoke substituted judgment (make the decision the patient would make if they were able) and base their treatment decisions on the patient's prior stated preferences; (6) clinicians will read prior documents and integrate patient preferences into conversations with surrogates; (7) previously expressed wishes will be honored; and (8) health care systems will commit resources and care delivery to support goal-concordant care.

Scenarios and situations in clinical practice settings rarely reflect these conditions. Treatment choices near the end of life are not simple, consistent, logical, linear, or predictable but are complex, uncertain, emotionally laden, and fluid. Patients' preferences are rarely static and are influenced by age, physical and cognitive function, culture, family preferences, clinician advice, financial resources, and perceived caregiver burden (eg, need to provide personal care, time off from work, emotional strain, out-of-pocket or noncovered medical costs), which change over time. Surrogates find it difficult to extrapolate treatment decisions in the present from hypothetical discussions with patients that occurred in the past, piece together what the patient would have

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is distinct from "in-the-moment" decision making, in which seriously ill patients and their families engage with their clinicians in goals of care and treatment discussions at present and regarding their current situation.

If ACP led to higher-quality care at the end of life, it would make sense to continue efforts to promote it and integrate it into value-based care. However, a substantial body of high-quality evidence now exists demonstrating that ACP fails to improve end-of-life care. A 2018 review of 80 systematic reviews (including 1600 original articles)¹ found no evidence that ACP was associated with influencing medical decision making at the end of life, enhancing the likelihood of goal-concordant care, or improving patients' or families' perceptions of the quality of care received. A 2020 scoping review² that included 62 recent high-quality articles also demonstrated no link between ACP and occurrence of

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wanted, disentangle their own preferences and emotions, or challenge physicians who recommend different treatments. When a decision must be made, prior directives are often absent, poorly documented, or either so prescriptive or so vague that they cannot promote informed goal-concordant care. Moreover, treatment choices do not occur in a vacuum but are driven by financial pressures, societal capacity to support patient and family needs, and institutional/regional cultures and practice patterns.

Should Efforts to Address the Problems of ACP Continue?

Some suggest that these data do not diminish the potential positive effects of ACP. Advocates maintain that although ACP is necessary for good end-of-life care, it is not sufficient. Why not promote and incentivize conversations with patients regarding their future values, goals, and treatment choices?

The problem with accepting these arguments and continuing along the current path is the potential for unintended consequences. Encouraging the belief that ACP is essential to good end-of-life care meaningfully detracts from other initiatives. For example, health care institutions are incentivized to devote resources that promote and measure ACP and thus direct them away from equally and perhaps more important areas of clinical care. Research demonstrates that patients leave clinically based ACP sessions with serious misconceptions about life-sustaining treatments and that advance directives are often misinterpreted by physicians, families, and surrogates.⁸ In addition, the presence of an advance directive can inhibit current discussions about goals of care; this occurred in overwhelmed hospitals during the COVID-19 pandemic when treatment decisions were made according to written documents rather than discussions with patients or their surrogate.

If ACP is not essential to high-value end-of-life care, then what is? One approach is to encourage appointment of a trusted surrogate decision maker (health care proxy) in advance and to focus research and clinical efforts on improving current shared decision making between proxies and clinicians. Psychometrically valid patient-reported outcomes, including the presence and severity of symptoms and health-related quality of life, can be measured in real time; others, such as experiences of “feeling heard and understood by their clinician” and “receiving desired help for pain,” are being field tested. Surveys of surrogates after the death of the patients they have represented are now a standard quality measure within the Veterans Health Administration, have shown good linkages with health care processes, and are a more direct measure of patient and family end-of-life experience than the occurrence of an ACP discussion.⁹

The history of ACP is the story of science working. There was logic to the belief that ACP would lead to better care for seriously ill patients. During the last 25 years, studies have evaluated ACP with various methods and across large groups of patients. Despite the intrinsic logic of ACP, the evidence suggests it does not have the desired effect. Many clinicians may be disappointed that promoting conversations with patients well in advance of needed medical decisions has not improved subsequent care as hoped. New research focused on training clinicians and preparing patients and families to engage in high-quality discussions when actual (not hypothetical) medical decisions must be made is needed to achieve the outcomes that ACP has not. The clinical and research communities should learn from the evidence that does not support prior hypotheses and proceed with different approaches to improve care for seriously ill patients.

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