

BEST PRACTICES

Advance Care Planning

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Advance care planning (ACP) and the use of advance directives are considered to be key elements in end-of-life care. The goals of ACP are to improve shared understanding of patients' values and preferences, improve patient-centered decisions, alleviate the burdens on surrogate decision makers, and avoid over- and under-treatment. Unfortunately, to date there is a lack of consistent evidence of the effectiveness of ACP. A multitude of factors that create obstacles to the success of ACP need to be addressed before ACP can become truly effective.

One fundamental obstacle is a lack of clarity about the difference between ACP and advance directives. ACP is a three-stage process intended to facilitate decision-making for the patient who lacks decision-making capacity. The stages include having the competent patient (prior to losing decision-making capacity) (1) think about relevant values and preferences, (2) communicate these reflections to loved ones and health care providers that would be involved in future medical decisions, and (3) document the relevant values and preferences in an advance directive document. Therefore, advance directives are only a *part* of proper ACP: they provide the means to complete stage three.

There are two formal mechanisms for this documentation: instructional directives such as the living will, and proxy directives such as the durable power of attorney for health care. By contrast, a do-not-resuscitate order is not an advance directive; it is a physician order concerning treatment.

The difficulty in determining which patients should be encouraged to complete ACP presents another obstacle to success. Although awareness of ACP is recommended by JCAHO for all patients, it seems reasonable to focus educational efforts on people who are at the highest risk for losing the capacity to make their own health care decisions.¹ Who might fit into this group? Consider the following examples: terminally ill patients who often lose decision-making capacity near death, frail elderly patients who are at risk for delirium, patients with strokes or a history of transient ischemic attacks, those with early dementia, those who engage in risky behaviors, (such as riding motorcycles), and those with recurrent bouts of severe psychiatric illnesses. Recent demonstration projects trying to improve end-of-life care in the VA have shown marked increases in having patients complete advance directives. These data suggest that targeting appropriate patients may have beneficial effects.²

The third problem area concerns a lack of knowledge about the appropriate content of ACP discussions. No one questions the importance of identifying who

should be the surrogate decision-maker if the patient loses decisional capacity. This is particularly important for people who are not part of a traditional family unit. Beyond this element, however, the content of ACP discussions becomes rather murky. For years scholars have debated the relative merits and limitations of discussions that focus on values versus treatment preferences.³ Recently, VA-funded research has illuminated the importance of focusing on unacceptable health situations.⁴ These are the situations people desperately want to avoid, and that inspire them to sign advance directives. Three common situations that qualify as "states worse than death" are being kept alive indefinitely in an ICU, being unable to care for oneself and burdening others, and being unable to interact meaningfully with others. When individuals consider a health state to be worse than death, they tend to refuse the vast majority of life-sustaining treatments in the event they reach that state. Thus, two reasonable questions in an ACP discussion are, "Have you ever heard or read about, or seen on TV, any situations in which you said to yourself, I would never want to live like that?" and "Why? What is it about that circumstance that makes you reject it so completely?"

Other elements of meaningful ACP discussions include sharing of personal beliefs and values. Rather than vague questions that have questionable validity in the clinical setting (e.g., "How much do you value your independence?"), more specific questions can provide meaningful information. *Your Life, Your Choices* is an ACP workbook developed by the VA through the ORD that contains the following useful items (for which patients respond with "yes," "not sure," or "no"):

- I believe that it is **always** wrong to withhold (not start) treatments that could keep me alive.
- I believe that it is **always** wrong to withdraw (stop) treatments that could keep me alive after they've been started.
- I believe that it is wrong to withhold (not provide) nutrition, and fluids given through tubes, even if I am terminally ill or in a permanent coma.
- I do not wish to receive a blood transfusion or any blood products, such as plasma or red blood cells
- I would like to have my pastor, priest, rabbi, or other spiritual advisor consulted regarding any difficult health care decision that must be made on my behalf.
- I believe in other forms of treatment, such as healing through prayer, acupuncture, or herbal remedies. I want the following treatments included in my care: _____.
- I believe that controlling pain is very important, even if the pain medications might hasten my death.
- I believe that my loved ones should take their own interests into consideration, as well as mine, when making health care decisions on my behalf.
- I believe that it is acceptable to consider the financial burden of treatment on my loved ones when making health care decisions on my behalf.

- I believe that my loved ones should follow my health care directions as closely as possible.

My colleagues and I recently completed a randomized controlled trial of ACP using the workbook, *Your Life, Your Choices* as a centerpiece of the intervention. The workbook was developed to motivate, educate and facilitate ACP discussions. The goals of the study were to increase (1) documentation of ACP discussions and advance directives, and (2) proxy and health care provider understanding of patients' treatment preferences and health care-related values. The research occurred at the VA Puget Sound Health Care System.

Twenty-three health care providers were recruited (72% participation rate). Up to 14 patients were randomized to the control or intervention groups for each provider. Eligibility criteria included a pre-existing relationship with the provider, patient age ≥ 55 with chronic condition(s), and no advance directive in the medical record. Thirty-seven percent of patients agreed to participate. The intervention group received the ACP workbook, *Your Life, Your Choices*, social work counseling, and cues to providers to discuss ACP. The control group received the standard information packet about the importance of ACP and copies of the advance directive forms.

The results showed a marked effect from the intervention. The intervention patients reported significantly more ACP discussions with their providers (64% vs. 38%), and had many more directives filed in the medical record (47% vs. 27%). The intervention group also showed greater shared understanding of treatment preferences and values between patients and health care providers ($p < .05$). Unfortunately, the intervention did not increase shared understanding of treatment preferences or values between the patients and their surrogates, nor did it improve the surrogates' sense of confidence in their potential role as decision maker. Thus, this large treatment effect among participants who were willing to consider ACP suggests that an intervention aimed at motivating, educating and facilitating can substantially increase meaningful ACP activity. Future interventions, however, will have to focus attention on facilitating patient-surrogate discussions.

For more information or questions about this study you may contact Dr. Pearlman by [email](#). *Your Life, Your Choices* can be reviewed and downloaded for free. It is available at:

<http://www.hsrp.research.va.gov/publications/internal/ylyc.htm>.

1. Joint Commission on the Accreditation of Health Care Organizations. Accreditation Manual for Hospitals. Vol. R1.1.1.3.2.1. Oak Brook Terrace, IL: Joint Commission on the Accreditation of Health Care Organizations;1993:106.

2. Personal communication with Daniel Tobin (from the recent Pain Management Conference/ End of Life in Alexandria, Virginia).

3. Pearlman RA. Advance directives research: are we asking the right questions of the right people in the right circumstances? *Hastings Cent Rep.* 1994;24:S2-S5.

4. Patrick DL, Pearlman RA, Starks HE, Cain KC, Cole WG, Uhlmann RF. Validation of life-sustaining treatment preferences: implications for advance care planning. *Ann Intern Med.* 1997;127(7):509-17.