

CHERP Policy Brief

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Qualitative research demonstrates that patients and providers think differently about life-sustaining treatment and indicates that self-empowerment drives patient use of advance directives.

Opportunities to Improve End-of-Life Care

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Context: Patients in the U.S. have the right to refuse life-sustaining medical treatment, and federal and state policies exist to ensure this right, yet hospitalized patients frequently receive unwanted life-prolonging interventions.

Background

In the event a patient becomes incapacitated, advance directives aim to provide patients some measure of control over life-sustaining treatment, through specific instructions in a living will or through a surrogate decision maker designated by a durable power of attorney. In fact, the Patient Self Determination Act requires U.S. hospitals to inform every adult patient about options for advance directives. Nonetheless, advance directives remain underutilized.

This CHERP Policy brief describes qualitative research by Rodriguez and colleagues that adds to our understanding of how patients and providers think about end-of-life care and why patients may or may not use advance directives.

Methods

- The investigators invited primary care providers at the VA Pittsburgh Healthcare System to participate in the study and the first 30 who responded were enrolled. After each provider was interviewed, the team used the VA electronic medical record to identify eligible patients from the providers' census who had appointments in the following two months.
- Thirty patients, one patient of each primary care provider, were enrolled in the research project. Participating patients and primary care providers were individually interviewed. The semistructured interviews included questions about demographics and whether respondents had an advance directive. Respondents provided their perceptions about terms used in advance directives and their reasons for these perceptions. The terms discussed commonly appear in living wills and durable powers of attorney for healthcare: "life-sustaining treatment," "terminal condition," "state of permanent unconsciousness," and "decision-making capacity."

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The patient respondents were similar to the overall VA population.

The primary care providers were typically younger, earned more, and as a group were more gender and racially diverse than the patient respondents.

Patients were more likely than providers to have written advance directives.

Patients worry that providers may place a higher value on longevity than on quality of life.

- The audiotaped interviews were transcribed, imported into a coding program, and analyzed using two common qualitative research methods: grounded theory and constant comparative technique.

Respondent Characteristics

- The majority of the 30 veteran patients who participated in the study were elderly white males and all but four had completed high school. Their average age was about 70 years old. Half were Roman Catholic and about one third were of various Protestant denominations. Most patients were retired and a little more than half were married or living with a partner. Almost all had a yearly household income of less than \$50,000.
- The provider group included nineteen physicians, ten certified registered nurse practitioners, and one physician assistant. There were more females among the providers and the group was slightly more ethnically and religiously diverse than the veteran patients.
- Eleven patients and five providers had written advance directives. However, four providers stated that they had a verbal advance directive with an immediate family member.

Table 1: Participant Sociodemographics

	Patient (n=30)	Providers (n=30)
Male	93%	36%
White	90%	86%
Average age	70.5 years	41.4 years
Religious Preference		
Roman Catholic	50%	30%
Protestant	30%	30%
Jewish	6%	6%
Other	—	6%
Agnostic/Refused	3%	3%
% yearly income less than \$50,000	96%	3%
Married/living with partner	56%	73%
Retired	80%	n/a
Have a written advance directive	37%	13%

Results

- All participants tended to discuss life-sustaining treatment in terms of goals or preferred outcomes rather than in terms of specific treatments. The investigators grouped these emergent goals into four thematic categories: extending life, improving the quality of life, maintaining or improving specific biologic functions, and assisting the body temporarily.
- A large number of patients and providers mentioned extending the length of life (26 patients and 25 providers) as a critical goal for life-sustaining treatment.
- Many patients articulated that their goals and providers' goals for life-sustaining treatment were different. These patients believed that the providers' goals for life-sustaining treatment focused on a biomedical imperative to sustain life while their own goals were based on improving the quality of life, not just prolonging life.
- Many providers used clinical terms in discussing life-sustaining treatment, emphasizing the need to maintain life as a fundamental goal of health care. However, some provider interviews revealed struggles to balance the sometimes competing goals of palliating symptoms, preventing complications and improving functional status, and the need to sustain life.

- A number of patients and providers discussed life-sustaining treatment in terms of improving the quality of life (12 patients and 10 providers) but had differing ideas about what that meant. For patients, quality of life meant being able to return to and engage in life activities that provided pleasure. For providers, quality of life meant being able to restore a patient to his or her previous state of functioning. Both providers and patients acknowledged that there is no universal agreement about what constitutes good quality of life.
- Patients were more likely to describe life-sustaining treatment as a way to assist the body for a temporary period of time (14 patients and 6 providers). Some patients and providers described such temporary assistance as a means to regain some degree of health by allowing the body to recover or as time to determine if anything more can be done to help a patient. A few providers described such temporary measures as “time given to allow for a good death.” A number in both groups emphasized that it was important to avoid the scenario of the vegetative patient who relies on technology to be kept alive.
- Patients were only slightly more likely than providers to discuss life-sustaining treatment as an acceptable means of improving specific biological functions such as breathing or heartbeat (7 patients and 8 providers). They sometimes specified that such measures be limited in duration, providing thematic overlap with the goal that life-sustaining treatment be temporary.
- Separate analyses showed that patients’ perceived control over their own health influenced their participation in planning for life-sustaining treatment. Of the 30 patients in the study, half (14) made statements suggesting that they felt empowered to make decisions about their own health. The remaining sixteen patients did not indicate any personal empowerment regarding their health.
- The eleven patients with advance directives were among the fourteen who felt personally empowered about their health.
- However, all of the 30 patients discussed one or more of the following types of external control over their health: a higher power; institutions and individuals; healthcare professionals; medical interventions; and luck, chance, or fate. Moreover, many patients identified more than one external controlling factor in end-of-life health and healthcare.

Implications

Many patients do not believe that providers share their goals about end-of-life care. The preparation of advance directives could be an opportunity to clarify the healthcare preferences and goals of patients and their family members.

Patient-provider discussions that focus on acceptable health states and valued life activities may be better suited to patients’ end-of-life care goals than discussions that focus on specific medical interventions.

Working with patients to feel empowered about their health and healthcare may increase the use of advance directives.

Elderly VA patients’ and primary care providers’ perceptions and understanding of concepts related to advance directives were framed in terms of goals rather than specific treatments.

Health care providers recognized that sustaining life may conflict with ensuring good quality of life.

Patients who were more personally empowered about their health were more likely to have advance directives.

This issue of the CHERP Policy brief was based on the following publications: 1) Rodriguez KL, Young AJ. *Elderly veterans' beliefs concerning life-sustaining treatment and the control of their end-of-life health and health care*. J Aging Health. 2006 Oct;18(5):686-706.; 2) Rodriguez KL, Young AJ. *Patients' and healthcare providers' understandings of life-sustaining treatment: are perceptions of goals shared or divergent?* Soc Sci Med. 2006 Jan;62(1):125-33.; and 3) Rodriguez KL, Young AJ. *Perceptions of patients on the utility or futility of end-of-life treatment*. J Med Ethics. 2006 Aug;32(8):444-9.

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