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Ask a different question, get a different answer: why living wills are poor guides to care preferences at the end of life.

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Ask a Different Question, Get a Different Answer: Why Living Wills are Poor Guides to Care Preferences at the End of Life

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Abstract

Context: Living wills have a poor record of directing care at the end of life, as a copious literature attests. Some speculation centers on the questionable correspondence between the scenario described in living wills versus the real-life circumstances that typically arise at the end of life.

Objective: To assess the strength of association between responses to a standard living will question and preferences for treatments in six end-of-life scenarios.

Design: Cross-sectional.

Setting: Telephone interviews.

Participants: Two hundred two community-dwelling men and women 70 years of age or older in the greater Philadelphia area.

Main outcome measures: Strength of preferences for four life-sustaining treatments in each of six poor-health scenarios.

Results: Associations between responses to the standard living will question and preferences for treatment (means across the four) in six specific scenarios were statistically significant but modest in size, accounting for 23% of variance at most. The association for the worse-case scenario (severe stroke with coma) was significantly stronger than for any other association.

Conclusions: The modest correspondence between living will responses and wishes for life-sustaining treatment in specific scenarios helps to elucidate the living will's poor performance. Presentation of more realistic end-of-life scenarios should improve the living will's ability to guide care, as well as preparing patients and families better for the end of life.

Introduction

ADVANCE CARE PLANNING has been advocated since the passage of the 1990 Patient Self-Determination Act (PSDA) as a means of improving decision making at the end of life. The goal of such planning is to ensure that patients' preferences guide future medical care in the event of their incapacity.[1–3] Advance care planning includes written advance directives such as living wills, which specify the medical treatments patients would or would not want, and/or durable powers of attorney for health care.

Unfortunately, advance care planning in the United States is still suboptimal despite the PSDA.[4] Even when living wills have been prepared (no more than 21% of patients complete them), they may not be available in the setting where death occurs,[5] and even when available, care preferences recorded in living wills are often discarded when patients approach the end of life.[1,2,6–8] Some investigators have concluded that living wills are ineffective and should be abandoned.[9–10]

Why have these documents performed so poorly? One issue is that preferences may change over time or with a decline in patient's health status.[11] Sicker patients, compared to healthier, tend to regard aggressive treatment as more acceptable.[12] Another possible explanation is that the scenario described in the living will does not correspond well to clinical circumstances that typically arise at the end of life.[4,6] For example, in Pennsylvania and elsewhere, the living will declaration is worded as follows: "Would you direct your physician to withhold or withdraw life-sustaining treatment that serves only to prolong the process of dying, if you should be in a terminal condition or in a state of permanent unconsciousness?"[13] The life-sustaining treatment is described as

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futile and is associated with prolonged dying. The alternative to this treatment is not named. In effect, this living will question poses the choice, "If you knew you were dying, would you want futile treatment?"

Underlying this declaration is the assumption that patients will know they are dying. This is a fundamental problem for two reasons. First, as the NIH Consensus Conference on Improving End of Life Care[14] concluded, the interval known as end of life is seldom identified as such while the patient is still alive. Evidence does not support a definition of the interval referred to as the end of life until after the patient's death. Another problem concerns prognostication. Christakis and associates[15] have described and documented multiple problems surrounding prognostication, including the absence of physician training and the reluctance of physicians to provide prognoses.[16] As a consequence, few patients are informed that their condition is terminal or given prognoses. Thus, the circumstances that emerge when the patient is dying will probably not resemble the scenario described in the living will because the patient (1) may not have received a prognosis and (2) will not recognize that he/she is in a terminal condition.

To what extent do responses to such living will questions correspond to wishes for care in specific and more realistic end-of-life scenarios? The present study explored a possible explanation for the disappointing performance of the living will by examining associations between responses to questions asked during the same interview, eliminating the possibility that changes in preference over time might explain any weak association. Thus, the present study contributes to the advance care directives literature by pinpointing a single issue: the possible mismatch between end-of-life scenario described in the living will and specific and common end-of-life circumstances. A related question concerns whether some scenarios may correspond better to the living will question than others. If so, living wills might be better guides to treatment preferences in some circumstances than in others.

Method

Subjects

Two hundred two elderly men and women (70 years of age or older) were recruited through a variety of sources selected to provide a representative sample of elders. Letters of invitation were mailed to patients 70 or older at two family medicine practices, members of two senior centers, residents of two retirement communities in suburban Philadelphia, and residents of two Philadelphia senior housing facilities. In addition, display ads were placed in two Philadelphia newspapers. Participants' mean age was 77.4 years (standard deviation [SD] = 5.6), and 72.3% were female. Whites constituted 65.5% of the sample, and most non-whites were African American. Individuals of Protestant affiliation constituted 49.0%, Jews 25.7%, Catholics 16.3%, 3.0% "other," and 5.9% stated "none" in response to religious affiliation. The majority (71.8%) had attended college, graduated, or received postgraduate education. All were cognitively intact as measured by the Mini-Mental State Examination (MMSE) telephone version.[17]

Measures

Standard living will question. Each participant was asked, "Would you direct your physician to withhold or withdraw life-sustaining treatment that serves only to prolong the process of dying, if you should be in a terminal condition or in a state of permanent unconsciousness?" Possible responses were "yes" (would *not* want life-sustaining treatment), "no" (*would* want life-sustaining treatment), or "I don't know."

Life-sustaining treatment preferences. Treatment preferences were operationalized using questions about 4 life-sustaining treatments (antibiotics, gallbladder surgery, cardiopulmonary resuscitation [CPR], tube feeing) in each of 6 poor-health scenarios, for a total of 24 questions. This followed the approach used in the Life Support Preferences Questionnaire (LSPQ[18,19]). The scenarios varied in cognitive impairment, physical impairment, and presence or absence of pain (Alzheimer's disease, severe shortness of breath, severe stroke with coma, moderate stroke, cancer with no pain, and cancer with pain; see Appendix A). Thus, for each scenario (e.g., Alzheimer's disease) participants were asked how much they would want antibiotics ("If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?"), CPR ("If your heart stopped beating or you stopped breathing, would you want to receive CPR?"), gallbladder surgery ("If your gallbladder became inflamed and infected, would you want to have surgery to remove it?"), and tube feeding ("If your condition becomes such that you lose the ability to take in food or water by mouth, would you want to have artificial feeding and fluids?"). For each treatment in each scenario, participants responded on 0–4 scales (0 = definitely would not want, 1 = probably would not want, 2 = unsure, 3 = probably would want, 4 = definitely would want). Appendix A presents the treatments and scenarios.

Cognitive status. Cognitive status was assessed using a telephone version of the MMSE,[17] which excludes items that must be administered face to face. Possible scores range from 0 to 23, with 23 indicating no errors. All participants scored 17 or higher, with a mean of 21.4 (SD = 1.6).

Other variables. The questionnaire also included demographic characteristics (age, race, gender, years of education, occupation, financial difficulty, and marital status), health status (activities of daily living operationalized by seven basic activities of daily living [ADL[20]]) and seven instrumental activities (IADL[21]), a religiosity measure,[22] and an end-of-life values scale.[23] These variables were not pertinent to the present study.

Procedure

Interested elders contacted the research office at Jefferson by calling or mailing in a postage-paid return envelope provided in the mailings. Prior to the interview, the study was explained further, eligibility and willingness to participate were established, and an Institutional Review Board-approved verbal Informed Consent was obtained for each participant. The interview was conducted on the telephone at that time or on a subsequent date. It took approximately 35 minutes. Because the topic of the study was end-of-life decision making, it was natural to ask the living will question ("Would you direct your physician to withhold or withdraw life-sustaining treatment . . . ?") early in the interview.

TABLE 1. MEAN (SD) PREFERENCES FOR LIFE-SUSTAINING CARE AND ASSOCIATIONS (POINT BISERIAL COEFFICIENTS)
WITH ADVANCE DIRECTIVE RESPONSES, BY SCENARIO

Scenario	All (n = 202) mean[a] (SD)	Those not wanting life-sustaining care (n = 177) mean[a] (SD)	Those wanting life-sustaining care (n = 25) mean[a] (SD)	Point biserial correlation coefficient[b]
Shortness of breath	2.44 (1.46)	2.28 (1.49)	3.49 (0.64)	0.272
Moderately severe stroke/arm and leg paralyzed	1.64 (1.60)	1.47 (1.54)	2.88 (1.53)	0.396
Colon cancer that has spread to the liver, no pain	1.49 (1.59)	1.29 (1.51)	2.78 (1.56)	0.307
Alzheimer's disease	1.44 (1.56)	1.25 (1.49)	2.84 (1.37)	0.337
Colon cancer that has spread to the liver, with pain	0.94 (1.44)	0.75 (1.30)	2.34 (1.68)	0.366
Severe stroke, in coma	0.55 (1.16)	0.34 (0.92)	2.04 (1.55)	0.484

[a]0–4 scale: 0 = definitely do not want/1 = probably do not want/2 = unsure/3 = probably want/4 = definitely want.
[b]All were statistically significant at $p < 0.0001$.

The Life-sustaining Treatment Preferences were asked toward the end. Thus, we presented elderly individuals with both types of questions - the living will question and a set of questions about four type of treatments (e.g., tube feeding) in 6 specific scenarios. The administration of the two types of questions during the same interview minimizes the possibility that changes with time could explain any weak associations between responses to the two types of questions.

Data analysis

Mean preferences across all 4 treatments were computed for each scenario (e.g., Alzheimer's disease), yielding 6 scores ranging from 0 to 4.0. For the living will question, "I don't know" responses were combined with the "no" responses (would *want* life-sustaining care), following the reasoning that the provision of life-sustaining care is the default option in the U.S. health care system. Therefore, patients who do not say "Yes" to the withhold/withdraw option are likely to receive life-sustaining care.[24] Thus, living will responses were treated as a dichotomous variable.

We first examined differences in treatment preferences by scenarios using analysis of variance (ANOVA) with *post-hoc* pair-wise comparisons. In addition, we computed mean preferences for those elders who agreed that they would direct their physician to withhold life-sustaining treatment versus those that said they would not or were unsure. Point-biserial correlation coefficients were used to assess strength of association between the dichotomous living will responses and the preferences for life-sustaining care. Low associations between these responses would support the proposition that living wills perform poorly because they fail to describe realistic circumstances.

To examine whether some scenarios correspond better than others to the living will question, the significance of the difference between pairs of associations with living will responses was calculated using Pearson product-moment correlations and applying Cohen's formula for significance of the differences between dependent *r*'s.[25]

Results

In response to the living will question, 87.6% said yes, indicating that they would direct their physician to withhold or withdraw life-sustaining care; 8.9 % said no (i.e., they would want life-sustaining care), and 3.5% said they did not know.

Preferences for life-sustaining treatments per scenario

Table 1 presents mean preferences for life-sustaining care in the scenarios, representing the mean across the four treatments. The six poor-health scenario differed significantly from each other in strength of preferences for life-sustaining treatment ($F[6,196] = 152.74.27$, $p < 0.0001$). *Post-hoc* pair-wise comparisons showed that all pairs of scenarios differed significantly except Alzheimer's disease, cancer with no pain, and moderate stroke (p's ≥ 0.096). This indicates that participants distinguish among scenarios in their wishes for life-sustaining treatments.

Strength of association between living will responses and treatment preferences

Point biserial correlation coefficients between living will responses and mean treatment preferences in the six scenarios ranged from 0.27 to 0.48 (Table 1). Thus, at most these two measures share 23% of variance. The strongest correlation was for the "severe stroke with coma" scenario, arguably the most similar to the living will question. For the other scenarios, the living will response accounted for only 7%–15% of variance. This association for the severe stroke scenario was significantly stronger than associations between living will responses and treatment preferences in all other scenarios (t's ≥ 3.0, p's < 0.05). Other scenarios did not differ from each other (t's ≥ 1.32, p's > 0.05).

Discussion

Responses to a standard living will question were significantly associated with preferences in each scenario but associations were modest. At best, the living will responses accounted for 23% of variance (for the severe stroke with coma scenario). For other scenarios associations were significantly weaker. Thus, most variance in scenario-based preferences was not explained by responses to the standard living will question. This may help elucidate the disappointing performance of living wills in predicting patients' treatment preferences at the end of life. The standard living will question describes an extreme and clear-cut hypothetical scenario, one that is relatively easy to respond to but unlikely to approximate the circumstances that most patients face at the end of life. As noted earlier, the absence of prognosis and the fact that the end of life will probably not be recognized as such insure that the patient will not recognize that he/she is terminally ill.

Thus, end-of-life circumstances are unlikely to resemble the standard living will scenario. It is telling that standard living will responses best predicted treatment preferences for severe stroke with coma, an association that was significantly stronger than all others.

This study contributes to the current understanding of advance care planning by underscoring a specific problem: the mismatch between the scenario described in a standard living will and scenarios that more accurately approximate circumstances that emerge at the end of life. By administering both types of questions in the same interview, study findings distinguish this mismatch from other possible explanations for the poor performance of the living will, such as the time lapse between living will completion and the actual end of life.

Limitations and directions for future research

The present research was limited by reliance on a sample of volunteers, who may not be representative of the elderly population. The study should be replicated with a probability sample or at least a larger and more geographically diverse sample. The present study also did not examine preferences for individual treatments described in many living wills. It would be interesting to know how well living will preferences for specific treatments (e.g., feeding tube) correspond to the preferences for those treatments in specific end-of-life scenarios. Finally, whether participants fully understand descriptions of health states and treatments is always a concern in advance directives research (as it is in practice). Several considerations should provide confidence in the data, however. The fact that the LSPQ questions are administered one-on-one by a trained interviewer allows participants to express confusion and misunderstandings and to seek clarification. In addition, numerous studies based on the LSPQ report little missing data or inconsistencies in responses. It should also be noted that the LSPQ is considerably more detailed and informative than the standard living will, and more time is allocated for it than is generally provided for administering a living will.[26,27]

Implications: The acceptability of death, the unacceptability of dying

Although the present findings may be taken as further argument against the living will, a better approach might be to discard questions that describe circumstances like "a terminal condition or state of permanent unconscious" and treatments that "serve only to prolong the process of dying" and to substitute a description of circumstances that approximate those more likely to occur. In addition, descriptions of life-sustaining treatments (e.g., CPR) should provide probability estimates of their effectiveness in sustaining life. Patients should not be presented with a choice between treatments labeled as likely to prolong the dying process vs. an implicit, unnamed, abstract death. Their dying experience will not be an abstraction, and their actual choice will involve treatments such as CPR that may not described as futile even if their likelihood of success is in fact low.[28,29]

Given the choice posed in the living will, it is hardly surprising that most people choose death. But a dying patient, offered a treatment presumed to be effective (or why would the doctor offer it?) vs. the palpable experience of dying, may understandably opt for the treatment. Our study findings suggest that death as an abstraction (as left unnamed and undescribed in a standard living will) is acceptable, dying (in a specific scenario) less acceptable. Patient decisions may seem to change when in fact they are responses to very different questions, because the living will is irrelevant to the real-life experience of dying or the treatments offered.

A strong argument can certainly be made that advance care planning should be an ongoing process, revisited at regular intervals, because of the complexity of the issues,[30] the natural tendency of patients to vacillate,[31] and the fact that goals of care may change.[11] Yet, even with regularly updated planning discussions, standard living wills will nevertheless fall short in guiding care, because the end of life as it unfolds will not correspond to the improbable scenario described in the living will. Advance care planning may be helpful to patients and families by improving the likelihood patients will receive palliative care earlier and undergo less futile care.[32–34] But effective advance care documents must inform patients and families frankly and fully about the circumstances and treatment choices that they are likely to face at the end of life.

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Four Life-Sustaining Treatments

Antibiotics: Doctors use these medicines to treat serious infections (like pneumonia). Without antibiotics, serious infections can cause life-threatening complications or death.

Cardiopulmonary resuscitation (CPR): Doctors use cardiopulmonary resuscitation, or CPR, when a person's heart stops beating or a person stops breathing. Doctors press on the chest to help pump blood, and use artificial breathing. Artificial breathing means the doctor puts a tube in the windpipe. Then, a machine breathes for the patient through the tube. Patients usually get medicine by vein. Patients often need an electrical shock to help restart the heartbeat. Without CPR, the heart will not start beating again, and the patient will die.

Gallbladder surgery: Doctors use surgery to remove the gall bladder when it is inflamed and infected. If untreated, an inflamed and infected gall bladder can rupture and cause life-threatening complications or death.

Artificial Feeding and Fluids: Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. The food goes through a feeding tube. Usually, the feeding tube is inserted into the stomach through the left side of the abdomen during surgery. The stomach is stitched closed around the tube. Without the treatment, patients die within 7–10 days.

Six Poor-Health Scenarios

Alzheimer's disease: You have trouble remembering things and thinking clearly. You cannot recognize people you know, make decisions for yourself, or communicate. You have no chance of recovery. Your mental abilities may get worse quickly or may stay the way they are now for a long time. Your physical condition and abilities are unaffected.

Constant shortness of breath as result of a condition such as congestive heart failure, emphysema, or COPD: You are unable to climb stairs or walk more than a few feet. Your medical condition cannot improve. Your condition may get worse very quickly or slowly decline over several years. Your ability to think, reason, and remember is unaffected.

Severe stroke: You have suffered a severe stroke and have been in a coma for six weeks. In the opinion of the doctor, you have *no chance* for regaining awareness. Your current physical condition is stable but will slowly decline over time. You rely on others for help with feeding, bathing, dressing, and toileting. You may live in this condition for several years.

Moderately severe stroke: One arm and leg are paralyzed. You have trouble speaking and trouble understanding when others speak. You rely on others for help with feeding, dressing, bathing and toileting. In the opinion of your doctor, you have *a very slight chance* of improvement.

Colon cancer that has spread to the liver, no pain: You are tired and weak. Your thinking and memory are unaffected. *You are not in pain*. In the opinion of your doctor, you have no chance of recovery. Your doctor estimates that you have about six months to live.

Colon cancer that has spread to the liver, with pain: You are tired and weak. Your thinking and memory are unaffected. *You have pain that requires the constant use of medication*. In the opinion of your doctor, you have no chance of recovery. Your doctor estimates that you have about six months to live.

Sample Question

You have **Alzheimer's disease**. You have trouble remembering things and thinking clearly. You cannot recognize people you know, make decisions for yourself, or communicate. You have no chance of recovery. Your mental abilities may get worse quickly or may stay the way they are now for a long time. Your physical condition and abilities are unaffected.

If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

Definitely do not want	Probably do not want	Unsure	Probably want	Definitely want	*NA*	*Refused*
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	*-2 ( )*	*-4 ( )*

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