**Background:** Advance care planning (ACP) aims to guide health care in the event of decisional incapacity. Interventions to promote ACP have had limited effectiveness. We conducted an educational and motivational intervention in Department of Veterans Affairs outpatient clinics to increase ACP use and proxy and health care provider understanding of patients’ preferences and values.

**Methods:** We recruited 23 providers and up to 14 of each of their patients; the patients were randomized to the control or intervention group. Eligibility criteria included a preexisting relationship with the provider, age 55 years or older, chronic health condition(s), and no recorded advance directive. The intervention group (n=119) received an ACP workbook, motivational counseling by social workers, and cues to providers to discuss ACP. The control group (n=129) received an advance directive booklet.

**Results:** The intervention patients reported more ACP discussions with their providers (64% vs 38%; \(P<.001\)). Living wills were filed in the medical record twice as often in the intervention group (48% vs 23%; \(P<.001\)). Provider-patient dyads in the intervention group had higher agreement scores than the control group for treatment preferences, values, and personal beliefs (58% vs 48%, 57% vs 46%, and 61% vs 47%, respectively; \(P<.01\) for all comparisons). The agreement scores for the proxy-patient dyads did not differ between groups for treatment preferences and values, but were higher in the intervention than the control group for personal beliefs (67% vs 56%).

**Conclusion:** This intervention demonstrates mixed results and highlights the ongoing challenges of helping health care providers and potential proxy decision makers represent patient preferences and values.

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ADVANCE CARE PLANNING (ACP) is an iterative process in which individuals think about and communicate their preferences for medical care in the event of future decisional incapacity.\(^1,2\) Individuals often formulate their preferences on the basis of considerations of the quality of life in their current situation and/or predictable future states of health (eg, terminal illness) and the potential benefits and burdens of life-sustaining treatments. These values and preferences are then communicated to close family members or other potential surrogate decision makers and health care providers. The final step in ACP is documentation of these values and preferences through advance directives.

Many barriers exist to ACP, including a general societal reluctance to think about dying.\(^3,4\) Interventions to address these barriers have included educational materials and workshops to complete advance directives\(^8,10\) and research staff, prompts, clinical reminders, and scheduled appointments to encourage clinicians and patients to discuss directives.\(^11-13\) A few interventions have demonstrated success, particularly those that focus on completion of directives.\(^14-16\) Critics of living wills argue for a shift from legalistic documents toward a comprehensive, ongoing dialogue and process.\(^17-19\) We endorse these recommendations because none of the interventions ensured comprehensive ACP or improved the more important outcome of shared understanding of the patient’s values and wishes by the providers or the proxies.\(^8,12,13,20-22\)

The starting point for our intervention was the development of an ACP workbook, *Your Life, Your Choices*.\(^23,24\) The goal of this study was to evaluate the effectiveness of a comprehensive, systems-oriented ACP intervention that included this workbook.
METHODS

STUDY PARTICIPANTS

Our goal was to recruit 24 primary care providers at the Veterans Affairs Puget Sound Health Care System, Seattle, Wash, from a sample of clinics where providers, including specialists, have primary care assignments with patients. We sent invitation letters to 2 to 3 randomly selected providers from each of the general internal medicine teams and specialty clinics (geriatrics, pulmonary medicine, renal medicine, and oncology). Fifteen physicians and 8 nurse practitioners accepted, representing a 72% participation rate.

For each provider, patients were randomly selected and screened for eligibility criteria. Patient recruitment and the intervention were tied to an upcoming office visit with the provider that was scheduled 4 to 6 weeks in the future. Providers sent a cover letter endorsing the study, along with an information statement and consent form, to patients in their clinics who were 55 years or older; did not have an advance directive in their medical record; could speak, read, and hear English; and did not have severe cognitive impairment. Study staff made follow-up calls to explain the study and obtain verbal informed consent. Interested, eligible patients were enrolled in the study and randomly assigned to the intervention or control group. Patients mailed the signed consent forms to the study office. Recruitment efforts continued until 14 patients per provider were enrolled, unless the study ended before that goal was reached. Figure 1 shows the results of the block-design randomization.

Figure 1. Results of the block-design randomization.

Patients with proxies were asked to invite them to participate in the study. Proxies were defined as those who would represent patients if they could not speak for themselves. Fifty-seven patients (20%) did not have a proxy, and 18 (6%) chose not to refer a proxy to the study. Information statements and consent forms were sent to the remaining 203 proxies. Proxies were recruited using the same procedures as with patients. One hundred thirty-two proxies (64% participation rate) were recruited (60 and 72 in the intervention and control groups, respectively).

Social workers were chosen to facilitate ACP because they routinely counsel and provide assistance with completing directives. Thirteen social workers from 10 clinics participated in the study.

STUDY DESIGN AND PROCEDURES

We used a block-randomized controlled trial to evaluate a multifaceted ACP intervention in clinical practice. The intervention was centered around the use of Your Life, Your Choices, a 52-page workbook that incorporated concepts from multiple frameworks, including stages of behavioral change, the health belief model, self-efficacy, the relationship between states/fates worse than death and patient preferences to forego lifesustaining treatment, and general guidelines about human information processing and information design. The workbook is divided into 3 parts. The first part contains case stories written to convey basic information and motivate persons in precontemplation and contemplation stages of change to engage in ACP behaviors. The second part contains case stories written to convey basic information and motivate persons in precontemplation and contemplation stages of change to engage in ACP behaviors. The second part contains case stories written to convey basic information and motivate persons in precontemplation and contemplation stages of change to engage in ACP behaviors. The second part contains case stories written to convey basic information and motivate persons in precontemplation and contemplation stages of change to engage in ACP behaviors. The second part contains case stories written to convey basic information and motivate persons in precontemplation and contemplation stages of change to engage in ACP behaviors. The second part contains case stories written to convey basic information and motivate persons in precontemplation and contemplation stages of change to engage in ACP behaviors.
Patients in the intervention group received the following co-ordinated, sequential intervention:

1. *Your Life, Your Choices*, mailed early so that they could work through it and share it with their proxy;
2. A postcard sent 1 week before their scheduled visit, reminding them to review the workbook and bring it to their appointment;
3. A 30-minute appointment with a social worker immediately before their provider visit to review the workbook, answer questions, and/or complete directives, depending on the patient’s stage of readiness in ACP; and
4. An appointment flag to remind their provider to discuss ACP.

In contrast, before their scheduled appointment, patients in the control group were mailed the hospital’s 8-page advance directives packet, which included the living will and durable power of attorney for health care forms.

Before enrolling patients, we conducted a 4½-hour training program with the social workers. The training included an overview of the study methods and procedures, definitions of ACP, a review of the workbook, and instruction in motivational interviewing.31 We also conducted 30-minute sessions with providers to review the study and provide a definition of ACP. The Human Subjects Committee of the University of Washington, Seattle, approved the consent process and study procedures.

**OUTCOME MEASURES**

Two days after the index visit, we called patients in both groups to assess whether they had discussed ACP with their providers. We collected all other outcomes data 4 months after the index visit to allow sufficient time for the ACP process and follow-up visits to occur. We anticipated that some providers would not have time to discuss ACP during the index visit because of their patients’ medical problems. Patients completed a questionnaire that assessed their preferences for life-sustaining treatments in 5 health states (Figure 2 and Figure 3; legends describe the rating scales). In addition, patients rated their quality of life under the following 5 conditions (using the same rating scale as the health states): being in severe pain most of the time; reliance on a breathing machine; inability to think clearly; inability to recognize family or friends; and causing severe emotional burden for the family. Patients also were asked about withholding medical nutrition and fluids given through tubes; controlling pain even if the medication might hasten death; leaving no record of personal beliefs, no partial credit was given. The “don’t know” responses from proxies and providers were also counted as disagreements because they demonstrate a lack of shared understanding.

**STATISTICAL ANALYSIS**

The primary analyses focused on shared understanding of preferences and values between patients and their providers and proxies. Additional analyses included documentation of ACP components, including discussion and completion of advance directives. We chose shared understanding and proxy preparedness because they are critical components to ensure high-quality surrogate decision making and ACP documentation because it provides a record of preferences to revisit or use to guide future decision making.31,16

We used Fisher exact tests to determine differences between the groups for categorical variables. For the analyses determining patient-proxy and patient-provider agreement about treatment preferences, we collapsed response categories into “want treatment” (including “definitely yes” and “probably yes”) and “do not want treatment” (including “probably no” and “definitely no”). Proxies and providers had an additional response category of “I don’t know how the patient would answer.” Agreement scores are reported as the percentage of treatment decisions for which both parties had the same answer. The κ statistics are included to control for chance agreement. We counted the “don’t know” responses from proxies and providers as disagreements because they demonstrate a lack of shared understanding.

For the analyses determining patient-proxy and patient-provider agreement about health state ratings and quality-of-life values, we gave partial credit (half a point) when pairs differed by a single response category. Full credit was given to absolute agreement, and no credit was given when differences were greater than 1 response category. For the questions pertaining to personal beliefs, no partial credit was given. The “don’t know” responses from proxies and providers were also counted as disagreements for these analyses.

For analyses in which a provider effect might influence the results, we used analysis of variance and logistic regression to test for treatment effect while controlling for provider as a fixed effect. We detected a significant provider effect for only some of the analyses determining patient-provider agreement. For analyses that did not control for provider effect, we used unpaired t tests (2-tailed) to compare the groups on interval variables such as agreement score and χ² tests for categorical variables. Analyses were performed using SPSS 10.0 (SPSS Inc, Chicago, Ill).

**RESULTS**

There were no significant differences between the groups in their demographic characteristics. The patients were mostly older, educated, white men (Table 1). Figures 2 and 3 show the distribution of patients’ health state ratings and treatment preferences. There were no significant differences between the groups for any of these data except for the distribution of preferences to forgo short-term ventilation in current health (P = .04).

**PATIENT-PROVIDER AGREEMENT**

Table 2 gives the percentage agreement and κ statistics for treatment preferences between patients and providers. For every treatment, the intervention patient-provider dyads showed greater agreement than the control patient-provider dyads. When all treatments were...
considered together, the intervention showed a 10% positive effect. However, only the following 3 treatments demonstrated significant differences representing improved agreement by 15% or more: cardiopulmonary resuscitation in the dementia and terminal illness scenarios, and short-term mechanical ventilator use in current health.
Moreover, agreement was poor when controlling for chance ($\kappa$ statistic).

We also examined the patterns of agreement and disagreement to further understand the agreement scores regarding treatment preferences (data not shown). Among the disagreements, providers believed that patients wanted treatments more often (overtreatment) or less often (undertreatment) than their patients reported, or simply did not know how to answer. In the current health scenarios, the disagreement scores were fairly evenly divided across these 3 categories for both the control and intervention groups. In the dementia, coma, and terminal illness scenarios, providers were more likely to undertreat or say they did not know their patients’ wishes. For the nursing home scenarios, providers were more likely to overtreat. In all cases, the disagreements and “don’t know” responses were lower for the intervention group than for the control group. However, the $\kappa$ statistics for these comparisons were generally low ($<.07$), indicating that the agreement scores were not much different from chance.

Table 3 shows agreement scores between patients and providers pertaining to patients’ values. For quality-of-life assessments and personal beliefs, intervention patient-provider dyads showed greater agreement than control dyads, although again, the $\kappa$ statistics were low.

PATIENT-PROXY AGREEMENT AND PROXY PREPAREDNESS

The intervention had no effect on agreement between proxies and patients for any of the treatments or quality-of-life assessments. The agreement scores between the intervention and control groups for the 16 treatment preferences were 61% and 63%, respectively. However, the intervention improved patient-proxy agreement with regard to personal beliefs. When all 4 belief statements were considered together, the intervention vs control proxy-patient dyads demonstrated 67% vs 56% agreement scores ($P=.04$).

The intervention also did not affect proxies’ feelings that they had greater knowledge of patients’ wishes, or were more comfortable making decisions on their behalf (4.1 vs 3.8 and 4.3 vs 4.1, respectively).

ACP DISCUSSION, ADVANCE DIRECTIVE COMPLETION, AND DOCUMENTATION

The intervention was successful in increasing ACP discussion, all aspects of directive completion, and filing of advance directives in the medical record. The intervention patients reported more ACP discussions after the index visit with their providers (64% vs 38%; $P<.001$). During the medical record reviews, we found ACP-related notes written by the providers in 47% vs 24% of the charts for the intervention and control groups, respectively ($P<.001$). Figure 4 shows additional results for livings wills; the results for durable power of attorney for health care were similar (not shown). These results also demonstrate that the effect of the intervention increased as the measure became more objective, ie, from patient self-report to verification of advance directives in the medical record.
Table 1. Respondent Characteristics*  

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Control (n = 129)</th>
<th>Intervention (n = 119)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD, y</td>
<td>69.5 (8.3)</td>
<td>68.5 (7.5)</td>
</tr>
<tr>
<td>Sex, % male</td>
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<td>95</td>
</tr>
<tr>
<td>Race, %</td>
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<td></td>
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<tr>
<td>White</td>
<td>88</td>
<td>89</td>
</tr>
<tr>
<td>African American</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
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<td>3</td>
</tr>
<tr>
<td>Marital status, %</td>
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<td></td>
</tr>
<tr>
<td>Married/living with partner</td>
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<td>48</td>
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<tr>
<td>Divorced/separated</td>
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<td>38</td>
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<tr>
<td>Widowed</td>
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<td>8</td>
</tr>
<tr>
<td>Never married</td>
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<td>6</td>
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<tr>
<td>Religion, %</td>
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<tr>
<td>Protestant</td>
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<td>60</td>
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<tr>
<td>Catholic</td>
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<tr>
<td>No preference</td>
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<td>18</td>
</tr>
<tr>
<td>Other</td>
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<td>5</td>
</tr>
<tr>
<td>Education, %</td>
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<td>Did not finish high school</td>
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<tr>
<td>High school diploma</td>
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<td>Some college</td>
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<td>37</td>
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<tr>
<td>College graduate or more</td>
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<td>29</td>
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<tr>
<td>Self-rating of health at baseline, % fair or poor</td>
<td>39</td>
<td>38</td>
</tr>
<tr>
<td>Physical health score, mean ± SD†</td>
<td>39 ± 11</td>
<td>39 ± 11</td>
</tr>
<tr>
<td>Mental health score, mean ± SD†</td>
<td>47 ± 11</td>
<td>51 ± 9</td>
</tr>
<tr>
<td>Depressive symptoms, %§</td>
<td>29</td>
<td>20</td>
</tr>
</tbody>
</table>

*Control and intervention groups are described in the “Study Design and Procedures” subsection of the “Methods” section.  
†Measured by the 12-item Short-Form Health Survey. Scores are normalized to a 100-point scale, with higher scores representing better functioning. The mean score for the general US population for ages 65 to 74 years is 43.65; for ages 75 years and older, 38.68.  
‡Measured by the 12-item Short-Form Health Survey. Scores are normalized to a 100-point scale, with higher scores representing better functioning. The mean score for the general US population for ages 65 to 74 years is 52.10; for ages 75 years and older, 50.06.  
§Measured by the Center for Epidemiologic Studies–Depression Scale.  
Per centages shown are those with scores of 16 or higher, indicating probable depression.

COMMENT

This multimodal intervention was designed to remedy many of the shortcomings of previous research on ACP, such as anchoring to traditional living wills whose nonspecific language creates problems of interpretation in clinical settings. Patients’ interest in advance directives is frequently motivated by a desire to avoid health states with low quality of life. We specifically designed this intervention to include Your Life, Your Choices to help patients personalize their advance directives with their impressions of unacceptable states of health and their personal values with clear relevance to health care decisions; examples are provided in Table 3.

We drew on lessons from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) when we designed this intervention to (1) promote meaningful ACP communication, (2) minimize the input and impact of research staff to promote long-term feasibility and sustainability, and (3) maximize systems-level supports, such as social worker availability for counseling. This design meant that social workers shared the educational process about ACP, freeing some of the providers’ time so that they could review patients’ questions and check for consistency in their preferences, serving as a quality check on ACP.

However, the intervention had mixed results. It promoted more ACP discussions between patients and their health care providers and resulted in a substantial increase in ACP documentation. Nevertheless, it was less successful at improving shared understanding of patients’ wishes and values between patients and their health care providers. Although the intervention only modestly improved shared understanding between patients and their health care providers, this effect was greater than the results of previous research with instructional or values-based directives. The intervention did not significantly affect patient-proxy shared understanding or proxy preparedness. Research has demonstrated that advance directives reduce family stress associated with decisions to withdraw life-sustaining treatment. The absence of an effect on proxy preparedness may be the result of the timing of the outcome measures.

Several findings warrant further discussion. Although the rate of documentation doubled, it achieved only 48%. This may represent a ceiling effect because advance directives are not for everyone. Patients may place greater trust in family members to do the right thing at the appropriate time. Alternatively, patients may not be quite ready to commit their preferences for future action. Some patients may learn enough about ACP to distrust how other providers might use advance directives in a hospital. Because advance directives may not be appropriate for everyone, clinicians should efficiently target ACP to those who may benefit the most from it, that is, patients at risk for loss of decision-making capacity (eg, patients with dementia, terminal illness, frailty, or a previous stroke) and those with distant and/or nonnuclear families.

The finding of marginal improvement of shared understanding between patients and providers suggests that alternative methods may need to be explored. One possibility is greater investment in training to facilitate high-quality conversations repeated over time between providers and patients. Providers could initiate such conversations with a question such as: “Are there any situations you can think of when you’ve said to yourself, ‘I would never want to live like that? Why?’” If patients indicate that they have yet to consider these issues, providers could give them select exercises from Your Life, Your Choices (based on patient interest) as a catalyst for discussion. Providers and patients can access the entire workbook for free on the Internet.

We must mention several observations about this intervention. First, only about half of the eligible patients who were contacted agreed to participate, suggesting that the study participants were willing to engage in ACP. The significant differences between groups is therefore more meaningful because among those who enrolled, the control patients exhibited more ACP-related activities than did the general population.

Second, we chose social workers to facilitate ACP because it was already one of their responsibilities. This may
limit the generalizability of this particular design to other academic medical settings that employ a full complement of clinic social workers. In health care settings that do not have many social workers, the challenge will be to identify other personnel to facilitate ACP.

Third, our intervention did not have a component that was specifically aimed at promoting and ensuring quality patient-proxy ACP discussions. We left this activity to the patients’ discretion. This study suggests that specific efforts should be made to include proxies in ACP.
discussions with the patients. Because proxies are involved in about 75% of end-of-life decisions, it is important for them to be prepared for their role. Proxies in both groups correctly estimated only about 60% of patients' preferences, suggesting room for improvement. This is a prime target for future research.

Despite these limitations, this study demonstrates that systems-level processes can improve ACP discussions and documentation. However, to substantially improve ACP in a cost-effective manner, clinicians need to target this activity to those ready to engage in it and likely to benefit from it.

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