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Original Article

A Novel Website to Prepare Diverse Older Adults for Decision Making and Advance Care Planning: A Pilot Study

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Abstract

Context. We have reconceptualized advance care planning (ACP) as a multistep process focused on preparing patients with skills needed for communication and in-the-moment decision making.

Objectives. To operationalize this paradigm, we created an easy-to-use ACP website (prepareforyourcare.org) based on a theoretical framework of behavior change and pilot-tested its efficacy to engage older adults in ACP.

Methods. At baseline and 1 week after viewing the PREPARE website, we assessed behavior change in ACP by using a validated survey that includes Process Measures (knowledge, contemplation, self-efficacy, and readiness, 5-point Likert scales) and Action Measures (yes/no whether an ACP behavior was completed). We also assigned participants into behavior change stages (i.e., precontemplation, contemplation, preparation, action, maintenance) and determined the percentage of participants who moved from precontemplation at baseline to higher stages at 1 week. We also assessed PREPARE ease-of-use (10-point scale, 10 being the easiest). Changes were assessed with Wilcoxon signed rank sum tests and McNemar's tests.

Results. Mean age of the participants was 68.4 years (SD 6.6), and 65% were nonwhite. Behavior Change Process Measures average Likert scores increased from 3.1 (0.9) to 3.7 (0.7), $P < 0.001$. Action Measures did not change significantly. However, precontemplation significantly decreased for most actions (e.g., talking to doctor about desired medical care, 61% to 35%, $P < 0.003$), with

Preliminary findings of this pilot study were presented at the National Palliative Care Research Center Foundation meeting, Park City, Utah, October 2012.

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a mean decrease of 21% (range, 16%-33%). PREPARE was rated a nine of ten (± 1.9) for ease-of-use.

Conclusion. A new, patient-centered ACP website that focuses on preparing patients for communication and decision making significantly improves engagement in the process of ACP and behavior change. A clinical trial of PREPARE is currently underway. *J Pain Symptom Manage* 2014;47:674–686. Published by Elsevier Inc. on behalf of U.S. Cancer Pain Relief Committee.

Key Words

Advance care planning, medical decision making, aging, technology

Introduction

Advance care planning (ACP) traditionally has focused on asking patients to make decisions about whether they would want to receive medical procedures, such as cardiopulmonary resuscitation (CPR) or mechanical ventilation, and to document these wishes in a written advance directive form.¹ However, advance directives often are not completed, especially by minorities and patients with lower education and literacy skills.^{2,3} Furthermore, advance directives typically are written with vague, legal language that can be hard to understand and, even if completed, often are not entered into the medical record.⁴ A growing body of literature demonstrates that focusing on a one-time written advance directive and hypothetical decisions about aggressive medical procedures does not adequately prepare patients or their surrogate decision makers for real, complex, and often unforeseen medical decisions that typically occur over the course of serious medical illness, such as weighing the risks and benefits of beginning a new medication, having surgery, or deciding on nursing home care.¹

We and others have argued that ACP should not merely focus on asking patients to make decisions about aggressive procedures. ACP also should focus on preparation for medical decision making and development of the skills needed to engage in multiple ACP behaviors. Therefore, we and others have reconceptualized ACP as a process consisting of several discrete behaviors that include identifying a surrogate, identifying one's values, and communicating these values and preferences with the surrogate and the physician, in addition to an advance directive.^{1,5,6}

Behavior change plays a role in engaging in each of these discrete ACP behaviors.⁵ Behavior

change theory is the most well-established theory for how people change behavior and posits that individuals proceed through a series of steps before acting, including precontemplation, contemplation, preparation, and then on to action and maintenance.^{7,8} As people engage in ACP, they proceed, at different times, through varying behavior change stages.⁵

To operationalize this new paradigm of ACP, we developed a step-by-step, web-based guide to teach people the skills needed to identify their life goals and preferences for medical care within their current clinical and social context and to communicate these preferences to their surrogate decision makers and to their physicians. Here, we first describe the development of a novel, evidenced-based website called PREPARE (prepareforyourcare.org). PREPARE is based on behavior change theory and the new paradigm of ACP that focuses on preparing patients and surrogates for complex medical decision making. We then describe a pilot study to assess the ability of PREPARE to engage older adults from racially and ethnically diverse backgrounds in ACP and the feasibility of using the PREPARE website among diverse populations.

Methods

Development of the PREPARE Website

The novel content of the PREPARE website builds on extensive previous research by others and on our previously published conceptual framework of ACP focused on preparing patients and surrogates for informed medical decision making.¹ PREPARE content also is based on 13 focus groups of diverse, English- and Spanish-speaking older patients and surrogate decision makers with experience making serious medical decisions. Participants in these

focus groups were asked to “give their advice” about how individuals can prepare for medical decision making.⁹ PREPARE constitutes a paradigm shift away from merely focusing on whether to receive specific medical treatments, such as CPR or mechanical ventilation, and toward preparing patients with the concrete skills needed to identify which treatments are most consistent with their current goals and circumstances and to communicate these beliefs effectively to surrogate decision makers and clinicians. The focus of PREPARE, therefore, is on preparation for in-the-moment medical decision making.

Conceptual Framework of Behavior Change and ACP

The theoretical framework of PREPARE is based on Social Cognitive Theory, the Interpersonal Communication Competence Model, and Behavior Change Theory (Fig. 1).^{7,8,10,11} PREPARE includes both training and goal-setting components that have been shown to be effective in changing outpatient behaviors.¹² Moderator variables, which may affect the ability of PREPARE to have an effect on ACP and on decision making, include factors such as race/ethnicity, health literacy, and desired role in decision making (Fig. 1). These factors have been addressed in the PREPARE content (see below). PREPARE also was designed to address modifiable mediators that must be improved to affect behavior change: knowledge, by describing the importance of preparation; outcome expectations, by describing how preparation can

decrease emotional burden for patients and surrogates and create a sense of control; perceived barriers, by providing examples of how to overcome typical barriers to ACP communication¹³; and skills and self-efficacy, by modeling communication behavior (through videos) and by including action plans to make small, realistic commitments to engage in ACP. Once adequate training has been provided and mediating factors have been positively affected, we hypothesize that people will begin to contemplate, prepare, plan, and then become activated to engage in ACP behaviors.

Content of the PREPARE Website

On the basis of previous work,^{1,9} we included five overarching steps in PREPARE to help patients prepare for ACP and medical decision making: 1) choose a medical decision maker and ask them to serve in that role; 2) decide what matters most in life and for medical care (i.e., contemplating health experiences that would be worse than death and whether individuals want to focus on trying to live as long as possible regardless of the quality of life; try aggressive treatments for a period of time, but stop if suffering; or focus on their quality of life and comfort, even if it results in a shorter life); 3) decide on leeway for the surrogate decision maker (i.e., permission to modify the patient’s previous decisions based on new clinical information and what is in the patient’s best interest at that current moment); 4) communicate wishes with surrogates, clinicians, and other family and friends; and 5) ask doctors

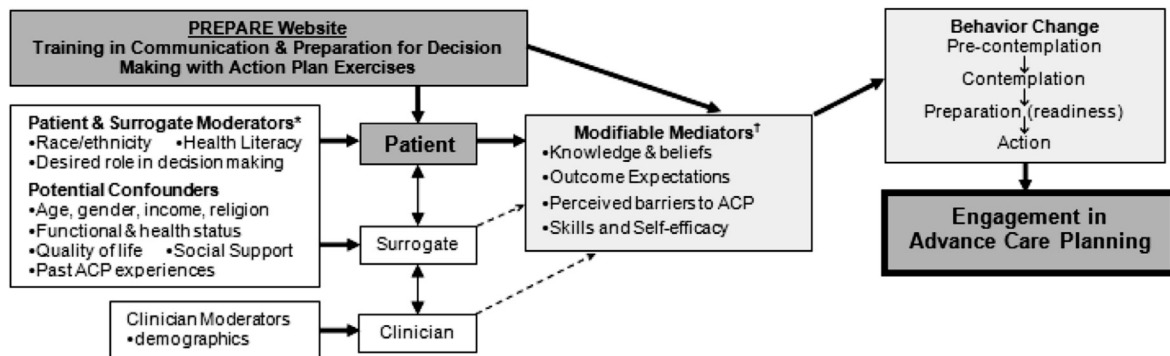


Fig. 1. Theoretical framework of factors hypothesized to influence behavior change and engagement in ACP. *Moderator variables may affect the ability of PREPARE to have an effect on advance care planning (ACP) and decision making. †Modifiable Mediators are important behavior change factors that may mediate the relationship between PREPARE and engagement in ACP. Dashed lines: PREPARE is patient-centered and does not currently include content for surrogates and clinicians in this preliminary version.

the right questions to make informed medical decisions. The specific content for each step can be found at prepareforyourcare.org and was reviewed extensively by experts in geriatrics, palliative care, health literacy, and health behavior change. In addition, 12 cognitive interviews concerning the website were completed with adults 65 years of age or older (mean age 73 ± 11 years), 42% of whom were women, 50% white, 33% African American, 17% Asian/Pacific Islander, and 50% of whom self-reported low health literacy and computer literacy skills. Serial edits were made to PREPARE content, functionality, and interface based on input from these experts and interviews with the target audience.

As discussed under the behavior change theoretical framework (Fig. 1), a cornerstone of PREPARE includes modeling behaviors through videos and interactions between actors from diverse backgrounds. Videos have been found to be powerful modes of educating patients and influencing behavior.^{14,15} Instead of merely telling patients what they should do, the videos show individuals *how* to do it, such as how to ask someone to be a medical decision maker. These videos model cultural norms for engaging in these behaviors and decrease activation energy by providing a clear road map and the exact words participants can use to engage in ACP. We used several strategies to ensure that the videos and modeling of behaviors were culturally relevant. For instance, when creating the video narratives, we attempted to balance the race/ethnicity and gender of the actors (five Latino, four white, three African American, three Asians/Pacific Islander, and eight women and seven men). We also included scenarios that we obtained from previous focus groups among diverse patients and surrogate decision makers.⁹ In addition, we balanced scenarios to reflect individuals who wanted full, aggressive treatment, those who wanted to focus on comfort care, and those who wanted to try treatments for a period of time but not indefinitely. The content of the website and videos also is tailored based upon data provided by each user while using PREPARE, including whether someone has a potential surrogate decision-maker (up to 20% of patients in previous studies lack a potential surrogate),¹³ whether someone wants to be involved in their own medical decision-making,¹⁶ and whether participants have other family

and friends who may be involved in medical decision making.

For participants who are not ready to engage in ACP behaviors, the website provides tailored content based upon participants' self-reported barriers to each ACP step, such as preferring to "leave their health to God" or being afraid to think about ACP. The website includes the most common barriers to engaging in ACP identified from previous literature and our own research.¹³ On the basis of the barriers endorsed, participants are shown videos of how other individuals overcame the same barriers and were able to engage in ACP. In this way, individuals who may not be ready to engage in ACP will be given information to help them develop concrete skills to overcome their barriers and move along the behavior change pathway.

To promote interactivity and to solidify learning, participants also are asked questions about their decisions and preferences (e.g., the name and relationship of a surrogate decision maker) at the end of each of the five ACP steps. Participants also can answer that they are not ready to engage in a particular step. This information is then placed into a summary for the individual, and, if ready, the participant is then asked to create an action plan based on one of the five steps in the PREPARE program. Action plans have been shown to be effective motivators of behavior change within the clinical setting.¹² After the participant creates an action plan, they have the ability to print out a summary of their responses to questions asked throughout the program and their action plan. They also can print out a pamphlet that reiterates the five points of the PREPARE program and the salient "how to do it" content. The participant is then encouraged to give their loved ones and medical providers a copy of their summary, action plan, and pamphlet to help stimulate conversations and the documentation of preferences into the medical record.

To enhance usability, we created PREPARE to be easy-to-read and understand and created the interface to be easy to use for individuals who are not frequent computer users.¹⁷ To follow low literacy health education principles, the website is written at a fifth-grade reading level, contains a font size of 14 point or larger, and is written in a "how to" active voice.¹⁷ For

each web page, we used as few words as possible, extensive white space, pictures, and the use of bright contrasting colors and intuitive buttons. For the individuals with low literacy and/or visual impairment, we include voice-overs of all the text. For the hearing impaired, we include closed-captioning of all video content. The website also comes with video instructions on how to use a computer and how to use the PREPARE website. On the basis of previous cognitive interviews and pilot testing in different individuals from the current pilot study, we discovered that even with extensive teaching, some individuals may not be able to navigate the website. For these individuals, we included the ability to select a “play the website as a movie” option, which allows participants to view the website in video format without having to navigate between website pages. Our development decisions were driven not by website conventions, but rather by the special needs of the target audience.

Pilot of the PREPARE Website

Participants. To pilot-test the feasibility and efficacy of the PREPARE website to engage older adults in ACP, we recruited a cohort of racially and ethnically diverse, older adults, by using study fliers, from three low-income senior centers in San Francisco. In response to the fliers, potential participants could call study staff or approach staff directly in the senior centers. Eligible participants had to be English-speaking and 60 years of age or older. We excluded individuals who self-reported being deaf, blind, or did not possess a phone for follow-up scheduling. Potential participants were screened with the Short Portable Mental Status Questionnaire¹⁸ and were excluded if they had severe cognitive impairment (≥ 8 errors of 10). Participants who scored in the mild-to-moderate cognitive impairment range (3–7 errors) were further screened using the Mini-Cog¹⁹ and were excluded if they were unable to recall at least one item on the three-item recall and/or were unable to perform a normal clock draw.

This study was approved by the Institutional Review Boards at the University of California, San Francisco and the San Francisco VA Medical Center, and all participants gave written informed consent using an informed

consent process designed for vulnerable populations.²⁰

Intervention. All participants were asked to attempt to review the PREPARE website in its entirety on their own in the senior center. Participants could take as many breaks as necessary and were told they could stop viewing the website at any time if they wished. Research staff was present to standardize the viewing process by logging participants into the website with unique login codes and redirecting participants who may have accidentally skipped a step in the program. The “movie version” of the website was not made available during pilot-testing.

Measures

Primary Outcome. The primary outcome, engagement in ACP, was measured with the ACP Engagement Survey.²¹ The ACP Engagement Survey assesses Process Measures of factors known from Social and Behavior Change Theory to affect behavior such as knowledge, contemplation, self-efficacy, and readiness, using five-point Likert scales (Process Measures Cronbach alpha = 0.94 and 1-week test-retest intraclass correlation = 0.70).^{7,8,10,11} The survey also includes Action Measures, using yes/no response options, of multiple ACP behaviors: 1) choose a medical decision-maker, 2) decide what is most important in life and for medical care, 3) choose flexibility for the decision maker, and 4) ask doctors questions to make informed decisions (1-week test-retest intraclass correlation of the total action score [0–17] = 0.86). Engagement in ACP was measured in person both at baseline before the subjects viewed PREPARE and 1 week after they viewed PREPARE. Behavior change Process Measures (subscales include knowledge, contemplation, self-efficacy, and readiness) are reported as an overall average five-point Likert scale score; Action Measures are reported as dichotomous yes/no responses and an overall 0- to 17-point score also was created.

Secondary Outcomes

Stage of Behavior Change. For the Action Measures questions, we also categorized participants into behavior change categories (precontemplation, contemplation, preparation, action, and

maintenance) based on methods previously described by Fried et al.⁵ Because participants were only given 1 week to act on information given in PREPARE and because the intervention was not coupled to an upcoming physician visit, we did not expect to see a significant difference in yes/no Action Measures. However, we did expect to observe improvement along the behavior change trajectory for ACP behaviors. For all ACP behaviors or action items, participants were asked to rate whether they had never thought about it before or they had thought about it but were not ready to do it (precontemplation), they were thinking about doing it in the next 6 months (contemplation), they were definitely planning to do it in the next 30 days (preparation), or they had already done it within the past 6 months (action) or longer than 6 months (maintenance). We dichotomized this variable into the precontemplative behavior stage of change (i.e., never thought about the ACP action before) vs. higher stages of change. We present the proportion of individuals who were in the precontemplative phase at baseline and 1 week later. A lower percentage of individuals in the precontemplative phase at 1 week compared with baseline would mean that PREPARE helped move individuals out of the precontemplative stage to higher behavior change stages.

Decisional Balance, Beliefs, and Processes of Behavior Change. At baseline and 1 week later, we also used the only other validated behavior change survey of ACP that measures decisional balance (12 items about pros and cons of behavior change, Cronbach's alpha = 0.86), ACP values and beliefs (seven items about medical misconceptions, religious beliefs, etc., Cronbach's alpha = 0.89), and processes of change (15 items about behavioral and cognitive processes used to foster participation in ACP, Cronbach's alpha = 0.93) on a five-point Likert scale (strongly agree to strongly disagree). We considered even small changes on this scale, such as 0.1 to 0.2, to be clinically significant. This survey is described in detail elsewhere.²²

Satisfaction. To understand participants' experiences using PREPARE, immediately after viewing the website at baseline, we assessed satisfaction with PREPARE with one question ("On a scale from 1 to 10, with 10 being the

easiest, how easy was it for you to use the website?") and previously validated scales to assess ease-of-understanding (10 questions) and usefulness in ACP (nine questions) measured and reported on an overall average five-point Likert scale.²³ To minimize the potential for bias, research assistants emphasized at great length that study participants should answer questions as honestly as possible. To measure potential adverse outcomes of viewing PREPARE, we also assessed pre- and post-levels of anxiety and depression using the Patient Health Questionnaire-2 and the Generalized Anxiety Disorder-2 scale.^{24,25}

Participant Characteristics. To describe the cohort, we obtained self-reported socioeconomic and demographic information such as age; race/ethnicity; education (<high school vs. high school or higher education); acculturation (birthplace outside of the U.S.); religiosity (five-point Likert scale dichotomized to very-to-extremely vs. somewhat, a little, not at all); spirituality (five-point Likert scale dichotomized to very-to-extremely vs. somewhat, a little, not at all); social support (married or long-term relationship vs. not and the presence of adult children vs. not); financial status (not enough money to make ends meet vs. enough to make ends meet or to save); and health status (five-point Likert scale dichotomized to fair, poor vs. good, very good, excellent). The Control Preferences Scale was used to assess how patients preferred to make their medical decisions with their doctors (i.e., making all decisions on their own, sharing decision making, or having the doctor make all decisions).²⁶ Participants also were asked whether they had any family or friends who could serve as a surrogate decision maker. Previous experience with ACP was assessed through self-report yes/no questions such as: "Have you ever made out a will? Made funeral arrangements? Filled out an advance directive? Made life-threatening medical decisions for yourself? For someone else?"²³ We included the validated Short Test of Functional Health Literacy in Adults (STOFHLA), and categorized participants as having limited health literacy with a standard cutoff of ≤ 22 of 36.²⁷ We also calculated the mean (SD) of how long it took participants to review PREPARE in its entirety.

Statistical Analyses. Demographic and other participant characteristics are described with percentages and means \pm SD. Change from baseline to 1 week later were assessed with the Wilcoxon signed rank sum test for continuous variables and McNemar's test for dichotomous variables. Comparisons of the percentage of participants in the precontemplative phase of behavior change at baseline and 1 week later were assessed using McNemar's tests. A decrease in the percentage of precontemplation at 1 week was considered an improvement as this would signify that more participants were in higher phases of behavior change and moving toward action. Given the small samples size, we did not stratify our results by participant subgroups. A *P*-value of 0.05 was used to indicate statistical significance. Because this was a pilot study, we did not adjust for multiple comparisons because tests were of highly correlated endpoints and because we were more concerned with minimizing type I error (false negatives) than type II error (false positives).

Exploratory Analysis. It is a well-known psychological phenomenon that individuals may think that they have completed a task or engaged in a particular behavior, but after receiving education about that behavior, realize they have not.^{28,29} Therefore, it is possible that some of the Action Measures could decrease 1 week after viewing PREPARE. To explore whether and why this occurred, if any action item decreased from baseline to 1 week later, we asked participants in open-ended questions during the 1-week follow-up interview why they thought this was the case. We used thematic content analysis to analyze these responses.

Results

A total of 43 participants were enrolled in the pilot study. All participants who were enrolled were able to view PREPARE in its entirety and provided both baseline and 1-week follow-up data. No participants were lost to follow-up. The mean age of study participants was 68.4 ± 6.6 years, 51% were women, 65% were nonwhite, 33% had limited health literacy, and 28% had fair-to-poor health status.

In addition, 16% preferred physicians to make all their medical decisions for them, approximately a quarter of participants had previously engaged in some form of ACP, and 16% reported not having any prospects for a potential surrogate decision maker (Table 1). Six participants (7%) required redirection from study staff because they skipped a step in the program. The mean age of these six participants was 74 ± 8 years, two were men, four were women, four were white, one African American, one Latino, and two had limited health literacy.

Study participants significantly increased their engagement in ACP during the week after viewing the PREPARE website. Mean \pm SD overall behavior change Process Measure scores increased significantly from an average

Table 1
Participant Characteristics, *n* = 43

Characteristic	<i>n</i> (%)
Age, yrs, mean \pm SD, range	68 \pm 6.6, 61-86
Gender	
Women	22 (51.2)
Race/ethnicity	
White, non-Hispanic	15 (34.9)
African American	19 (44.2)
Latino or Hispanic	4 (9.3)
Asian or Pacific Islander	3 (7.0)
Multiethnic, other	2 (4.7)
Education	
Not a high school graduate	12 (27.9)
Religious	
Very-to-extremely	19 (44.2)
Spiritual	
Very-to-extremely	27 (62.8)
Acculturation	
Born outside of the U.S.	7 (16.3)
Social support	
Married/in long-term relationship	8 (18.6)
Have adult children	26 (60.5)
Finances	
Not enough to make ends meet	11 (25.6)
Limited health literacy	
s-TOFHLA score \leq 22	13 (32.5)
Health status	
Fair-to-poor	12 (27.9)
Decision control preferences	
Patient makes decisions	28 (65.1)
Patient-doctor share decisions	8 (18.6)
Doctor makes decisions	7 (16.0)
Surrogate decision maker	
Has potential surrogate	36 (83.7)
Previous care planning	
Completed a will	12 (27.9)
Made funeral arrangements	12 (27.9)
Completed an advance directive	11 (26.2)
Made life/death decisions for self	12 (29.3)
Made life/death decisions for others	11 (25.6)

s-TOFHLA = Test of Functional Health Literacy Assessment, short version.

Table 2
Process Measures of ACP Behavior Change (n = 43)

Score	Description	Baseline Likert ^a (SD)	One-Week Likert (SD)	P-value ^b
Total process measure score	Total Behavior Change	3.1 (0.9)	3.7 (0.7)	<0.001
Behavior change subscales				
Knowledge ^c	Total Knowledge Score	3.7 (1.0)	4.3 (0.8)	<0.001
	Knowledge of Decision Maker	3.9 (1.1)	4.3 (0.9)	0.003
	Knowledge of Flexibility	3.2 (1.4)	4.2 (0.9)	<0.001
	Knowledge of Questions to Ask	4.0 (1.1)	4.2 (1.0)	0.08
Contemplation	Total Contemplation Score	2.6 (1.0)	3.4 (1.0)	<0.001
	Contemplate Decision Maker	2.9 (1.1)	3.6 (1.1)	<0.001
	Contemplate Quality of Life	2.4 (1.4)	3.6 (1.3)	<0.001
	Contemplate Flexibility	2.3 (1.2)	3.1 (1.3)	<0.001
	Contemplate Questions to Ask	3.1 (1.5)	3.5 (1.2)	0.01
Self-efficacy	Total Self-Efficacy Score	3.7 (1.1)	4.2 (0.7)	<0.001
	Self-Efficacy with Decision Maker	3.8 (1.4)	4.3 (1.1)	0.004
	Self-Efficacy with Quality of Life	3.6 (1.4)	4.1 (1.1)	0.04
	Self-Efficacy with Flexibility	3.1 (1.7)	4.3 (1.1)	<0.001
	Self-Efficacy with Questions to Ask	4.0 (1.0)	4.3 (0.9)	0.02
Readiness	Total Readiness Score	2.8 (1.2)	3.4 (1.0)	<0.001
	Readiness for Decision Maker	2.8 (1.4)	3.5 (1.1)	<0.001
	Readiness for Quality of Life	2.5 (1.3)	3.0 (1.1)	0.003
	Readiness for Flexibility	2.6 (1.3)	3.2 (1.1)	<0.001
	Readiness for Questions to Ask	4.3 (1.4)	4.4 (1.2)	0.21

ACP = advance care planning.

^aAverage Likert on 1–5 scale.

^bP-values calculated using Wilcoxon signed-rank sum test.

^cKnowledge subscale did not ask about knowledge of quality of life, as this is a personal determination.

Likert score of 3.1 ± 0.9 at baseline to 3.7 ± 0.7 1 week later, $P < 0.001$ (Table 2). In addition, scores on all of the Process Measure subscales, including knowledge, contemplation, self-efficacy, and readiness, increased significantly, $P < 0.001$ for all (Table 2).

None of the Action Measures in the ACP Engagement Survey changed significantly (Table 3). The mean Action Measures score

(0–17) was 7.7 ± 4.8 at baseline and 7.7 ± 4.3 1 week later, $P = 0.56$. However, we observed statistically significant decreases in the percentage of participants who were in the precontemplative phase of behavior change from baseline to 1 week later for most ACP behaviors, indicating transition to higher phases of behavior change such as contemplation, planning, action, or maintenance. This included a decrease

Table 3
Completion of ACP Actions

ACP Domain	Description	Baseline n (%)	One Week n (%)	P-value ^a
Decision Makers (DM)	Decided on DM	30 (69.8)	34 (81.0)	0.13
	Formally asked a DM	18 (42.9)	19 (46.3)	0.45
	Talked to your doctor about DM	7 (16.7)	7 (16.7)	1.0
	Signed official papers naming DM	15 (34.9)	13 (30.2)	0.63
Quality of Life	Decided whether certain health situations not worth living	23 (53.5)	28 (68.3)	0.13
	Talked with DM about health situations	14 (34.1)	13 (31.0)	0.63
	Talked with doctor about health situations	5 (11.6)	7 (16.3)	0.63
	Signed forms about kind of health care want	9 (22.0)	8 (18.6)	0.50
Flexibility	Decided on Flexibility	19 (51.4)	25 (67.7)	0.13
	Talked DM about flexibility	11 (26.8)	11 (26.2)	0.69
	Talked doctor about flexibility	6 (14.1)	6 (14.1)	1.0
	Signed forms about flexibility	9 (21.4)	5 (11.9)	0.25
Ask Doctors Questions	Asked about risks	33 (76.7)	32 (74.4)	0.90
	Asked about benefits	35 (81.4)	32 (74.4)	0.38
	Asked about other options	33 (76.7)	30 (69.8)	0.45
	What quality of life will be like	26 (60.5)	26 (60.5)	1.0
	Repeat info if not understand	38 (88.4)	35 (81.4)	0.25

ACP = advance care planning; DM = decision maker.

^aP-values calculated using McNemar's test.

Table 4
Percentage of Participants in Precontemplation for Each ACP Behavior^a

ACP Domain	Description	Baseline, n (%)	One Week, n (%)	P-value ^b
Decision Makers (DM)	Formally ask a DM	17 (39.5)	10 (23.3)	0.04
	Talk to doctor about a DM	27 (62.8)	13 (30.2)	<0.001
	Sign forms naming a DM	21 (48.8)	13 (30.2)	0.04
Quality of Life	Talk with DM about medical care want if sick or dying	20 (46.5)	12 (27.9)	0.02
	Talk with doctor about medical care want if sick or dying	26 (60.5)	15 (34.9)	0.003
	Sign forms about medical care want if sick or dying	19 (44.2)	14 (32.6)	0.18
Flexibility	Talk with DM about flexibility	21 (48.8)	14 (32.6)	0.07
	Talk with doctor about flexibility	26 (60.5)	18 (41.9)	0.04
	Sign forms about flexibility	25 (58.1)	15 (34.9)	0.02
Ask Doctors Questions	Ask doctors questions ^c	7 (16.3)	5 (11.6)	0.63

^aBehavior Change Likert responses (Never thought about it = precontemplation vs. greater behavior phases), including contemplation, preparation, action, and maintenance. A decrease in the percentage of precontemplation from baseline to one week shows improvement in behavior change to higher stages than precontemplation and movement toward action.

^bP-values calculated using McNemar's test.

^cThis question was: "How ready are you to ask your doctor questions to help you make a good medical decision?"

in precontemplation for behaviors such as asking a decision maker, 39.5% vs. 23.3%, $P < 0.04$; talking to the doctor about the decision maker, 62.8% vs. 30.2%, $P < 0.001$; signing official papers about a decision maker, 49% vs. 30%, $P = 0.04$; talking with decision maker about medical wishes, 46% vs. 28%, $P = 0.02$; talking with doctor about medical wishes, 61% vs. 35%, $P = 0.003$; talking with doctor about flexibility for the decision maker, 61% vs. 42%, $P = 0.04$; and signing forms about flexibility for the decision maker 58.1% vs. 34.9%, $P = 0.02$ (Table 4). The mean decrease in precontemplation across all ACP behaviors was 21% (range, 16%–33%).

The decisional balance (pros and cons), beliefs, and processes of change survey also showed improvement during the week after viewing the PREPARE website, with an increase in overall average Likert scores from 3.6 ± 0.5 at baseline to 3.8 ± 0.6 1 week later, $P < 0.001$ (Appendix). Although improvements in some decisional balance questions such as "ACP would help my loved ones" and "give me peace of mind" were statistically significant, most of the overall improvement was observed with the processes of change subscale with such questions as "I looked for information on ACP," "I thought about information people have given me on ACP," "I reviewed my advance care documents so I know what they say," and "I feel committed to doing ACP," P -values ≤ 0.005 (Appendix).

Participants rated their satisfaction with PREPARE a mean 9 ± 1.9 of 10. In addition, the average five-point Likert score for the

ease-of-use and understanding survey was 4.2 ± 0.5 and for usefulness in ACP it was 4.2 ± 0.8 . The number of individuals who endorsed anxiety was 10 (23.3%) at baseline and seven (16.3%) 1 week later ($P = 0.42$). Only four (9.3%) individuals endorsed depression at both time points. Study participants took a mean of 57 ± 16 minutes to review PREPARE, with a mean of 2 ± 1 minute to complete the welcome materials, 12 ± 5 minutes to complete Step 1, 12 ± 4 minutes for Step 2, 10 ± 5 minutes for Step 3, 8 ± 5 minutes for Step 4, 9 ± 5 minutes for Step 5, and 3 ± 2 minutes for the action plan.

In the exploratory analysis, 16 participants (mean age 70 ± 8 years, five men, 11 women, six white, nine African American, one Asian/Pacific Islander, and four with limited health literacy) changed their answers regarding completion of an action item from "yes" at baseline to "no" 1 week later. Eight individuals changed their answers regarding actions concerning signing "official papers," and eight individuals changed their answers regarding actions concerning having spoken to a surrogate or doctor about their wishes. When these individuals were asked why, all endorsed learning new things from PREPARE that made them realize they had not actually completed activities they initially thought they had. For instance, one person thought he had completed an advance directive but realized later it was "just a will." Another person commented that after seeing PREPARE, "I haven't talked about it to the extent that I now know I need to," and another person stated they learned, "This is

a serious topic; I want to go back and talk about it again.”

Discussion

PREPARE is novel, easy-to-use, interactive online tool focused on preparing people for medical decision making. PREPARE is also tailored to an individual's readiness to engage in a wide range of ACP behaviors, to their life circumstances (i.e., availability of a surrogate), and the extent to which individuals want to be involved in medical decision making. In this pilot-test, we found that PREPARE significantly increased engagement in ACP behavior change within 1 week. PREPARE also was rated easy to use and acceptable to older adults from ethnically and racially diverse backgrounds, many of whom had limited health and computer literacy.

PREPARE is complementary to several other ACP tools that are currently available and helpful to patients. Volandes et al.^{14,15} developed ACP videos that describe CPR and mechanical ventilation that have been shown to influence patients' preferences for end-of-life care. In addition, newly tailored websites help patients complete an advance directive with video instructions and explanations,^{30,31} and others include written toolkits to help individuals start ACP conversations.³² PREPARE adds to this body of work by focusing on a broadened ACP paradigm that includes values clarification, communication, and decision making skills in addition to documentation of specific treatment preferences, such as CPR. PREPARE also focuses on empowering patients by teaching concrete skills for how to identify and communicate one's values with surrogate decision makers and physicians and helps people incorporate their values into a framework to make in-the-moment medical decisions over the course of serious illness. These things are accomplished through PREPARE's easy-to-use, five-step process and the use of content that is literacy-appropriate and tailored to the cultural, visual, and hearing needs of the user.

This study demonstrates that it is possible to engage people not just in the signing of advance directive forms but also in a full range of ACP behaviors, such as identifying one's goals for medical care and communicating

with surrogate decision makers and clinicians. Results also demonstrate that, for each of those behaviors, people are in several different stages of behavioral change, from precontemplation to action, as has been found in prior research.⁵ It is not surprising that within only a one-week period, PREPARE did not significantly change actions related to ACP. However, study participants stated that they learned things from PREPARE that made them realize they had actually not completed ACP behaviors they thought they previously had, a phenomenon well described in the psychological literature.^{28,29} In addition, PREPARE clearly influenced behavior change in all Process Measure domains of the ACP Engagement Survey (knowledge, contemplation, self-efficacy, and readiness) and the processes of change subscale of Fried's behavior change measure.^{21,22} Furthermore, before viewing PREPARE, as many as 60% of participants were precontemplative about talking with their doctors about their decision maker or wishes. PREPARE greatly decreased this, for some actions halving the number of participants who were precontemplative 1 week later. Therefore, PREPARE may help individuals move along the behavior change pathway, begin to engage in ACP on their own, and prompt outpatient discussions with clinicians. The pros and cons and attitudes subscale of Fried's behavior change measure may have not been statistically significant because of a ceiling effect. In addition, it is possible that measurable changes in action items will require a multifaceted approach such as coupling review of PREPARE with upcoming primary care appointments, reminders about one's action plan, and encouragement from a clinician. In addition, a longer follow-up period that includes repeated measures may better detect the process of ACP as it unfolds over time. These studies are currently ongoing. It is important to note that previous evidence has shown that ACP requires a system level approach.³³ The patient-centered PREPARE website is a first step in an overall research program that plans to target not only patients but clinicians, surrogates, and the health care system.

This study has several limitations. It was conducted in one region of the country and participants were recruited through convenience

sampling, which may compromise generalizability. We attempted to minimize this concern by recruiting older adults from diverse backgrounds (65% nonwhite, 51% women, and 33% with limited health literacy). The study also had a small sample size, but the robust results for behavior change suggest that power was not a major concern. Because this was a pre- to postassessment, there was no control group for comparison. In addition, because everyone received the intervention, blinding of study staff was not possible and may have biased the assessments. Data collection was not anonymous and may have resulted in social desirability or reporting bias. Furthermore, we acknowledge that there are multiple comparisons in this manuscript. As such, it is estimated that 1 in 20 results will be statistically significant by chance and, therefore, the results need to be interpreted within this context. However, our consistently significant findings for measures of engagement with the ACP process minimize concern that our findings are the result of chance.

There also may be some limitations to using PREPARE in a clinical or research setting. We acknowledge that PREPARE took nearly 60 minutes to complete, although comprehensive ACP training is difficult to provide in a shorter time frame. However, given the interactive nature of the site, which is interspersed with videos and questions, patients remained engaged and rated the website easy to use. The individual steps were quite brief and, therefore, could be viewed one at a time. Furthermore, although websites make for easy dissemination of health education to consumers and health care organizations, many older adults may not possess a computer or may have low computer literacy skills.³⁴ However, PREPARE contains “how-to-use a computer” videos and was designed for the new computer user in mind. In addition, if needed, PREPARE can be made available in DVD, booklet, and pamphlet format. Currently, the pamphlet can be downloaded from the PREPARE website.

If these results are replicated in larger trials, this work may have many important implications for research, clinical care, and public health. Because PREPARE is available to the public, it has large potential to be used as a patient-centered health education modality by clinicians, health care systems, and

individuals in the community. This may allow people the opportunity to complete important ACP steps prior to clinical visits and inpatient medical encounters, potentially resulting in patients and family members who are more prepared for in-the-moment decision making. Studies are ongoing to assess this.

Conclusion

We developed a novel website grounded in behavior change theory and an evidenced-based conceptual model of ACP that is focused on providing patients with skills to identify their values, communicate with surrogates and clinicians, and prepare them for in-the-moment decision making. The PREPARE website was found to be easy-to-use by diverse, older adults, and our preliminary findings show that PREPARE positively affects behavioral change in ACP. A randomized, controlled trial is currently being conducted to assess the longitudinal efficacy of PREPARE and its effectiveness in clinical practice.

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Appendix

Decisional Balance, Beliefs, and Processes of Change Survey in Advance Care Planning (ACP), n = 43

	Baseline Likert ^a (SD)	One-Week Likert (SD)	P-value ^b
Overall score	3.6 (0.5)	3.8 (0.6)	<0.001
Pros & Cons Subscale	3.8 (0.7)	3.9 (0.7)	0.03
It would be hard to do ACP because I do not like thinking about being very ill. ^c	3.4 (1.4)	3.3 (1.4)	0.80
Doing ACP would simplify how decisions would be made if I were very ill.	4.2 (1.0)	4.3 (0.8)	0.65
It would be hard to do ACP because I do not like thinking about death. ^c	3.2 (1.4)	3.4 (1.3)	0.15
I do not want to talk with loved ones about end-of-life decisions. ^c	3.3 (1.3)	3.1 (1.4)	0.58
Doing ACP would make it easier on my close family and friends.	4.1 (1.1)	4.3 (0.9)	0.19
It would be hard to do ACP because there are too many options to consider for my end-of-life care. ^c	3.4 (1.1)	3.5 (1.1)	0.51
Understanding my wishes would help my loved ones to ensure I get the care I want.	4.1 (0.9)	4.3 (0.8)	0.05
I would feel better knowing I have done what I can to plan for my future.	4.3 (0.6)	4.4 (0.6)	0.13
ACP would go against my lifestyle of living in the moment. ^c	3.6 (1.2)	3.7 (1.2)	0.45
Doing ACP would give me peace of mind.	4.0 (0.9)	4.3 (0.7)	0.04
ACP would help me to keep control over what happens to me at the end of life.	4.1 (0.8)	4.3 (0.7)	0.28
It doesn't make sense to do ACP because my wishes for my end-of-life care might change. ^c	3.4 (1.1)	3.8 (1.0)	0.02
Attitudes Subscale	3.9 (0.9)	3.9 (0.9)	0.84
If you fill out a document such as a living will, the doctors are more likely to stop life support too soon. ^c	3.6 (1.1)	3.7 (1.0)	0.53
There is no need for me to do ACP because once you reach a certain age; the doctors aren't going to use machines to try to keep you alive. ^c	4.0 (0.8)	3.9 (1.1)	0.66
There is no need to do ACP because my doctor knows what I want for my end-of-life care. ^c	3.9 (1.0)	3.7 (1.2)	0.61
There is no need for me to do ACP because I will always be able to make my own treatment decisions. ^c	4.0 (1.0)	4.1 (1.1)	0.62
ACP would interfere with the plans that the Lord has for me. ^c	3.8 (1.0)	3.9 (1.1)	0.28
There is no need for me to do ACP because if I am made to suffer, then there must be a good reason for it. ^c	4.1 (1.0)	4.2 (1.0)	0.52
Planning for future medical care only makes sense for those who are much older or sicker than I am. ^c	4.0 (1.1)	3.8 (1.2)	0.23
Processes of Change Subscale	3.3 (0.5)	3.7 (0.6)	<0.001
I looked for information on ACP.	1.2 (0.6)	2.0 (1.3)	<0.001
I thought about information people have given me on ACP.	1.5 (0.9)	2.7 (1.3)	<0.001
I remembered information people have given me on the need for ACP.	1.8 (1.2)	2.9 (1.3)	<0.001
I reviewed my advanced care documents so that I know what they say.	1.3 (0.9)	1.9 (1.1)	0.008
There is someone I can talk to about doing ACP.	3.9 (1.0)	4.1 (1.0)	0.10
It is important that I make sure people close to me have copies of my advanced care plans with them.	3.9 (0.9)	4.0 (1.1)	0.44
Now is the right time to do ACP.	3.9 (0.8)	4.1 (0.9)	0.12
It is important that I make sure that I know where my advanced care documents can be found.	4.2 (0.8)	4.4 (0.7)	0.20
I can do ACP even if it is difficult for my loved ones.	4.1 (0.7)	4.2 (0.7)	0.18
Doing ACP makes me feel like a person who cares about my close family and friends.	3.9 (0.8)	4.2 (0.7)	0.007
I can count on my loved ones to help me with ACP.	3.6 (1.1)	3.8 (1.1)	0.35
I think of myself as someone who can reduce suffering for me and my family by doing ACP.	4.0 (0.8)	4.1 (0.8)	0.40
My loved ones will support me as I do ACP.	3.9 (0.9)	4.1 (0.9)	0.05
The thought of having an advanced care plan makes me feel good about taking responsibility for my health care.	4.1 (0.7)	4.2 (0.8)	0.42
I feel committed to doing ACP.	3.9 (1.0)	4.3 (0.8)	0.005

^aAverage Likert on 1-5 scale (strongly agree to strongly disagree).

^bP-values calculated using Wilcoxon ranked sum tests.

^cFor questions with a negative frame, we reversed the Likert scoring system such that strongly agree would be considered a 1 and strongly disagree would be considered a 5. In this way, all Likert scales represent positive attitudes, beliefs, and behaviors.