

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

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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

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