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New Website Launched to Help Patients Prepare for Complex Medical Decisions

Research Team from the San Francisco VA Medical Center and UCSF Develops User-Friendly Online Tool for Advance Care Planning

A new useful and patient-friendly online resource called PREPARE (www.prepareforyourcare.org) has been developed to help prepare people to make complex medical decisions. The website was developed by clinical researchers from the San Francisco VA Medical Center, UCSF, and NCIRE - The Veterans Health Research Institute.

The innovative aspect of PREPARE is that it provides concrete examples through videos of how to identify what is most important in life, how to communicate that with family and friends and doctors, and how to make informed medical decisions when the time comes. The website text is also written in plain language and is easy-to-use.

The resource is being launched on the heels of new research published in the November 27 issue of the *Journal of Pain and Symptom Management*. The paper, entitled *Advance Care Planning Beyond Advance Directives: Perspectives from Patients and Surrogates*, investigates gaps in planning for decisions about serious illness identified by a culturally diverse group of patients and surrogate decision makers, or individuals who have made medical decisions for others. This study identified key themes critical to successful advance care planning that go beyond completing an advance directive form. Additional key elements include successful surrogate selection and communication, determination of the surrogate role, and communication with family and doctors.

The PREPARE website incorporates content directly from this study to address all key patient- and surrogate-identified aspects of preparing for advance care planning and decision making with a no-cost, engaging, comprehensive and interactive web-based tool. This audio-visual interface is tailored to typically underserved populations (including users with low health or computer literacy and/or visual or hearing impairment) and aims to incorporate a patient-centered, comprehensive and manageable approach.

“There are few resources which can adequately prepare patients and their families to face serious illness or a medical crisis – situations which often involve complex decisions over time,” said lead

(more)

author Rebecca Sudore, MD, SFVA geriatrician and palliative medicine physician and associate professor in residence at the UCSF School of Medicine. “Advance directives are important, but they are just one piece of the puzzle. We wanted to develop a value-driven, easy-to-use tool to prepare people to make medical decisions that reflect their values and needs and prepares them to effectively communicate these wishes with others.”

The PREPARE website is written at a fifth-grade reading level, includes voice-overs of all text, closed-captioning for the hearing impaired, and large font for the visually impairment. In preliminary pilot testing, older adults from diverse backgrounds rated PREPARE a 9 out of a 10 point scale for ease of use, according to Sudore.

“We wanted to make the website free and easy-to-use by everyone,” she said. “We made sure to take advice given to us by patients and surrogates and made sure the site didn’t merely ask people to do advance care planning, but actually shows people, through videos and a step-by-step process, how to actually have the conversation and make informed medical decisions.”

The study included 69 English and Spanish-speaking patients and surrogate decision makers who reported having to make serious medical decisions for themselves or loved ones. The mean age of patients was 78 years and 61 percent were non-white. The mean age of the surrogate decision makers was 57 years, and 91 percent were non-white. Qualitative analysis revealed that advance directives were not enough to prepare patients and surrogates for medical decision making. Many participants stated that solely focusing on treatments, such as mechanical ventilation, was not sufficient to help with the “many decisions” with which they were facing.

Co-authors of the study include Ryan D. McMahan, BS, of SFVAMC and UCSF; Sara J. Knight, PhD, of the Department of Veterans Affairs; and Terri R. Fried, MD, of the VA Connecticut Healthcare System and Yale University School of Medicine.

The study was supported by funds from the Department of Veterans Affairs, the National Palliative Care Research Foundation, The Hellman Family Foundation, and the SD Bechtel Jr. Foundation.

SFVAMC has the largest medical research program in the national VA system, with more than 200 research scientists, all of whom are faculty members at UCSF.

UCSF is a leading university dedicated to promoting health worldwide through advanced biomedical research, graduate-level education in the life sciences and health professions, and excellence in patient care.

The authors have reported that they have no relationships relevant to the contents of this paper to disclose.

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