

# UC San Francisco

## UC San Francisco Previously Published Works

### Title

Authors' Reply to Swetz et al.

### Permalink

<https://escholarship.org/uc/item/5h62x5m6>

### Journal

Journal of pain and symptom management, 47(3)

### ISSN

0885-3924

### Authors

McMahan, RD  
Sudore, R

### Publication Date

2014-03-01

### DOI

10.1016/j.jpainsymman.2013.12.228

Peer reviewed

Department of Medicine  
Program in Professionalism and  
Ethics  
Mayo Clinic  
Rochester, Minnesota, USA

<http://dx.doi.org/10.1016/j.jpainsymman.2013.10.010>

### References

1. McMahan RD, Knight SJ, Fried TR, Sudore RL. Advance care planning beyond advance directives: perspectives from patients and surrogates. *J Pain Symptom Manage* 2013;46:355–365.
2. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010;362:1211–1218.
3. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association between advance directives and quality of end-of-life care: a national study. *J Am Geriatr Soc* 2007;55:189–194.
4. Singer PA, Robertson G, Roy DJ. Bioethics for clinicians: 6. Advance care planning. *CMAJ* 1996;155:1689–1692.
5. Perkins HS. Controlling death: the false promise of advance directives. *Ann Intern Med* 2007;147:51–57.
6. Teno JM, Licks S, Lynn J, et al. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc* 1997;45:508–512.
7. Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep* 2004;34:30–42.
8. Aging with dignity. Five wishes. 2013. Available from <http://www.agingwithdignity.org/five-wishes-resources.php>. Accessed October 21, 2013.
9. Menkin ES. Go Wish: a tool for end-of-life care conversations. *J Palliat Med* 2007;10:297–303.
10. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476–2482.
11. Singer PA. Disease-specific advance directives. *Lancet* 1994;344:594–596.
12. Swetz KM, Kamal AH, Matlock DD, et al. Preparedness planning before mechanical circulatory support: a “how-to” guide for palliative medicine clinicians. *J Pain Symptom Manage* 2013 [Epub ahead of print].
13. Lampert R, Hayes DL, Annas GJ, et al. HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm* 2010;7:1008–1026.
14. Mendelssohn DC, Singer PA. Advance directives in dialysis. *Adv Ren Replace Ther* 1994;1:240–250.
15. Singer P. Advance directives in COPD. *Monaldi Arch Chest Dis* 1995;50:62–63.
16. Benditt JO, Smith TS, Tonelli MR. Empowering the individual with ALS at the end-of-life: disease-specific advance care planning. *Muscle Nerve* 2001;24:1706–1709.
17. Mueller LA, Reid KI, Mueller PS. Readability of state-sponsored advance directive forms in the United States: a cross sectional study. *BMC Med Ethics* 2010;11:6.
18. Nishimura A, Mueller PS, Evenson LK, et al. Patients who complete advance directives and what they prefer. *Mayo Clin Proc* 2007;82:1480–1486.

### Authors' Reply to Swetz et al.

To the Editor:

With regard to the letter “Advance Directives, Advance Care Planning, and Shared Decision Making: Promoting Synergy Over Exclusivity in Contemporary Context,” by Swetz et al., we agree that any form of preparation that helps patients engage in the process of advance care planning is worthwhile, including advance directives. The goal of our qualitative study was to describe patients’ and surrogates’ experiences with serious illness, medical decision making, and advance directives. Our goal was not to review advance directive developments, and therefore, we appreciate the thoughtful review provided in the letter by Swetz et al.

We agree that there have been several improvements to advance directives, including the Five Wishes<sup>®</sup> and an easy-to-read advance directive we designed for culturally diverse patients with low health literacy.<sup>1</sup> However, our qualitative study demonstrated that although statutory advance directives are important, they often, in and of themselves, do not provide the support and skills training that patients and surrogates need to prepare for complex medical decision making. This is especially true for vulnerable and low-literacy populations who have been shown to be at risk for poor understanding of advance directives—forms that are often written at a postgraduate reading level.<sup>2</sup> Many patients report not being able to complete these documents on their own,<sup>3</sup> and even when they can complete them, they are often uncertain about their choices.<sup>4</sup> The patients

and surrogates in our focus groups expressed the need for more support than advance directives could provide. They also discussed the components needed to prepare for decision making: “choose surrogates wisely and verify that they understand their role (a complex task participants felt that they needed additional support to do), identify values based on past experiences and quality of life, decide whether to grant leeway in surrogate decision making, and inform other family and friends of one’s wishes to prevent conflict.”<sup>5</sup>

As stated previously, we are in favor of any educational tool or program that can help patients and surrogates engage in advance care planning and prepare for medical decision making. In addition to improvements to recent advance directive forms, there are several communication-based programs that help to facilitate advance care planning discussions, help patients to identify their overall values and goals, and provide a framework for iterative discussions over time. These programs include the Go Wish Cards,<sup>6</sup> The Conversation Project,<sup>7</sup> and the markedly successful, facilitator-based Respecting Choices<sup>®</sup> model.<sup>8,9</sup> In addition, the focus group study discussed in our article<sup>5</sup> directly informed the creation of a communication-based advance care planning website called PREPARE ([www.prepareforyourcare.org](http://www.prepareforyourcare.org)). PREPARE provides communication and decision-making skills training through videos and has been shown in a recent pilot study<sup>10</sup> to help patients engage in advance care planning. Although some people may be helped by advance directives alone, to be fully prepared, many people may need more support through communication and decision-making skills training, such as the support provided in the aforementioned communication-based programs.

Ryan D. McMahan, BS, BA  
Rebecca Sudore, MD  
Division of Geriatrics  
San Francisco Veterans Affairs  
Medical Center

University of California at  
San Francisco  
San Francisco, California, USA  
E-mail: [rebecca.sudore@ucsf.edu](mailto:rebecca.sudore@ucsf.edu)

<http://dx.doi.org/10.1016/j.jpainsymman.2013.12.228>

### References

1. Sudore RL, Landefeld CS, Barnes DE, et al. An advance directive redesigned to meet the literacy level of most adults: a randomized trial. *Patient Educ Couns* 2007;69:165–195.
2. Ott BB, Hardie TL. Readability of advance directive documents. *Image J Nurs Sch* 1997;29:53–57.
3. Schickedanz AD, Schillinger D, Landefeld CS, et al. A clinical framework for improving the advance care planning process: start with patients’ self-identified barriers. *J Am Geriatr Soc* 2009;57:31–39.
4. Sudore RL, Schillinger D, Knight SJ, Fried TR. Uncertainty about advance care planning treatment preferences among diverse older adults. *J Health Commun* 2010;15(Suppl 2):159–171.
5. McMahan RD, Knight SJ, Fried TR, Sudore RL. Advance care planning beyond advance directives: perspectives from patients and surrogates. *J Pain Symptom Manage* 2013;46:355–365.
6. Menkin ES. Go Wish: a tool for end-of-life care conversations. *J Palliat Med* 2007;10:297–303.
7. The Conversation Project. Available from <http://theconversationproject.org/>. Accessed December 20, 2012.
8. Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *J Am Geriatr Soc* 2010;58:1249–1255.
9. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345.
10. Sudore RL, Knight SJ, McMahan RD, et al. A novel website to prepare diverse old adults decision making and advance care planning: a pilot study. *J Pain Symptom Manage* 2013 Aug 21. [Epub ahead of print].