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Authors' Reply to Swetz et al.

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Journal

Journal of Pain and Symptom Management, 47(3)

ISSN

0885-3924

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Publication Date

2014-03-01

DOI

10.1016/j.jpainsymman.2013.12.228

Peer reviewed

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

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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[®] and an easy-to-read advance directive we designed for culturally diverse patients with low health literacy.¹ 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.² Many patients report not being able to complete these documents on their own,³ and even when they can complete them, they are often uncertain about their choices.⁴ 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.”⁵

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,⁶ The Conversation Project,⁷ and the markedly successful, facilitator-based Respecting Choices[®] model.^{8,9} In addition, the focus group study discussed in our article⁵ directly informed the creation of a communication-based advance care planning website called PREPARE (www.prepareforyourcare.org). PREPARE provides communication and decision-making skills training through videos and has been shown in a recent pilot study¹⁰ 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.

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

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