

Craig D. Blinderman, “Commentary on ‘Last Hours of Life: Encouraging End-of-Life Conversations’,” *The Journal of Clinical Ethics* 19, no. 2 (Summer 2008): 167-8.

Commentary on “Last Hours of Life: Encouraging End-of-Life Conversations”

Craig D. Blinderman

Craig D. Blinderman, MD, MA, is an Attending Physician in the Palliative Care Service of Massachusetts General Hospital and an Instructor at Harvard Medical School, Boston. ©2008 by *The Journal of Clinical Ethics*. All rights reserved.

In this issue of *JCE*, Stump and colleagues present a novel tool, the “Last Hours of Life” worksheet, to address inadequate communication between healthcare providers and patients at the end of life. Their tool is based on a revised (*emic*) version of a 1996 worksheet completed by participants who attended seminars and lectures targeting healthcare professionals. The project identifies several themes important to individuals at the end of life: good pain and symptom management, attendance to spiritual and existential concerns, and preferences regarding where and how they would like to die. The worksheet allows the documentation of advance directives and preferences. The authors postulate that using such a worksheet may help facilitate communication at the end of life so that providers may better identify patients’ needs, values, and preferences. The result of such a process would presumably help improve the quality of life in patients’ “last hours.”

The authors attempt to tackle a formidable challenge, namely, how to honor individuals’ preferences and values at the end of life. While the worksheet may be helpful in stressing the importance of exploring several issues when patients consider their own death, there are several limitations that should give us pause before we consider the worksheet’s clinical usefulness. First, the revised worksheet is based on responses from a healthy population of mostly healthcare professionals. The bias seems obvious — healthcare professionals likely have their own conceptions of “a good death,” and this would certainly impact their own preferences. While such input from healthcare professionals is valuable, for example in guiding policy decisions or developing research questions, the themes that emerge and their stated preferences may not be generalizable. Indeed, it would be worthwhile to investigate this tool in a terminally ill population — to evaluate its feasibility (not too burdensome or harmful) and utility (elucidates the concerns of dying patients).

If such a tool is to address the disparity in patients’ preferences and outcomes at the end of life as described in SUPPORT, we should evaluate whether such a communication tool can affect things like: days spent in the intensive care unit during the last six months of life, do not resuscitate/do not intubate orders, referrals to hospice or palliative care and place of death. There is some evidence that end-of-life discussions may result in increased patient understanding of illness severity, fewer invasive procedures, and lower rates of ICU admission at the end of life.¹ Nevertheless, it may be the case that “prognostic awareness,” at least with respect to oncology patients, plays a greater role in reducing these unnecessarily burdensome treatments at the end of life. The hypothesis that improved communication around death and dying, facilitated by a worksheet, improves quality of life in a meaningful way would also need to be demonstrated in a future study.

Although it would be important to evaluate if this worksheet is clinically useful to care providers, I am skeptical that such a tool would be effective, given the complex psychological adjustments employed by terminally ill patients. Efforts by earnest clinicians who hope to explore patients' end-of-life preferences using the worksheet may be undermined by not recognizing terminally ill patients' various coping styles, which complicate such conversations. Weissman described how patients may acknowledge their inevitable death and yet maintain a sense of hope and concurrent disbelief that they will die.² Maladaptive denial, which is marked by a rigid belief that one is not seriously ill, is another coping style. Both of these coping patterns would likely constrain the utility of such a communication tool. The impact of other psychosocial factors, such as psychiatric disorders, developmental stage, family dysfunction, and financial stressors, should be addressed for effective communication at the end of life.³ In my experience working with patients with advanced illness, well-developed communication skills are required to effectively discuss preferences and concerns at the end of life; a static assessment tool will not suffice.

Finally, there is an inherent philosophical limitation to virtually any type of advance care planning. While this worksheet is not an advance directive *per se*, it serves a similar role in documenting patients' preferences for the future. The concern is that, in general, we make systematic errors in predicting our future desires. What we believe we prefer in a pre-morbid, healthy state is likely to be inaccurate compared to what we would choose when actually faced with a life-threatening illness. Research corroborates this.⁴ Thus, as one critic of advance directives points out, if we are not aware of this difficulty when we consider what we would desire in a future hypothetical scenario, we undermine the principle of autonomy we are attempting to protect.⁵ Beyond this philosophical objection, there seems to be a practical issue at stake, since seriously ill patients often change preferences over time.⁶ Given the complex medical, psychological, and social factors at play at the end of life, it is not uncommon that what was once seen as desirable for a patient and family, for example, dying at home with loved ones, can become an unwelcome option as patients approach death.

The authors have constructed an interesting tool that is meant to encourage conversations around death and dying. Presently, there is insufficient evidence to recommend its use among providers caring for the terminally ill. My sense is that a semi-structured interview with open questions tailored to the unique psychological make-up of the patient is a clinically more effective and compassionate strategy. However, this worksheet may be an effective way for patients to facilitate a dialogue between family, friends, and their healthcare agents about end-of-life wishes. Indeed, such a worksheet would be invaluable to proxy decision makers struggling with making end-of-life decisions for an incapacitated patient. Similar to advance directives, there are limitations in how one might use preferences about death and dying to make important clinical decisions. Nonetheless, this worksheet may improve the chances of discussing our values and beliefs about death and dying, an opportunity we often circumvent.

NOTES

1. A.A. Wright et al., "Medical care and emotional distress associated with advanced cancer patients' end-of-life discussions with their physicians," *Journal of Clinical Oncology* 26 (20 May 2008 suppl.): abstract 6505.

2. A.D. Weissman, *Coping with Cancer* (New York: McGraw Hill, 1979).

3. S.D. Block, "Psychological Issues in End-of-Life Care," *Journal of Palliative Medicine* 9, no. 3 (2006): 751-72.

4. D.A. Redelmeier, P. Rozin, and D. Kahneman, "Understanding patients' decisions. Cognitive and emotional perspectives," *Journal of the American Medical Association* 270, no. 1 (1993): 72-6.

5. C.J. Ryan, "Betting your life: an argument against certain advance directives," *Journal of Medical Ethics* 22 (1996): 95-9.

6. T.R. Fried et al., "Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment," *Journal of the American Geriatric Society* 55, no. 7 (2007): 1007-14; Danis et al., "Stability of choices about life-sustaining treatments," *Annals of Internal Medicine* 120 (1994): 567-73.