Published in final edited form as:
Am J Bioeth. 2010 April ; 10(4): W1–W2. doi:10.1080/15265161003697552.

Doing What We Can With Advance Care Planning

Benjamin H. Levi and
Penn State College of Medicine

Michael J. Green
Penn State College of Medicine

Except for the claims by Dawson and Wrigley (2010), we are largely in agreement with the views expressed in the commentaries to our article describing a computer-based decision aid for advance care planning (Levi and Green 2010). The thoughtful critiques are all the more appreciated since reviewers did not have access to our entire program and had to rely on our written description along with selected video-clips. With the publication of this article, we anticipate that the online version of our program will be available to subscribers of AJOB, and when it is, we invite readers to work through the program themselves and provide us feedback about both its usefulness and its shortcomings. We genuinely welcome your comments.

To begin, we agree with David Barnard's (2010) caution against over-confidence that there exists a hidden, genuine patient wish waiting to be uncovered. As Barnard says, when faced with weighty medical decisions, people are often confused, overwhelmed, and ambivalent, and medical decision-making under such circumstances can be difficult, especially when the outcomes are uncertain and the stakes high. We know from experience that patients often wish to rely on others (including physicians) for help in choosing which options to pursue. For this reason, we sought to design our program to 1) emphasize education—with the goal of helping individuals gain a better understanding of both the components and dynamics of critical medical decision making should there come a time when others must make decisions on their behalf; 2) encourage reflection—through values clarification exercises as well as helping users imagine future states of disability; and 3) promote communication—not simply to convey one's wishes to others, but to engage others to explore what matters to them and why, and develop a shared understanding of such matters (Green and Levi 2009).

We also agree with Berger's (2010) admonition that with regard to advance care planning, attention to "process" deserves equal footing with the specific content of individuals' wishes; so, too, we share Gastman's (2010) concern about advance care planning that occurs in isolation, without input from relatives, friends, and caregivers. Our approach to advance care planning is grounded in both a relational interpretation of respect for patient autonomy and the recognition that dialogue is the preferred method for carrying out this respect (Levi 1999a; 1999b)—where dialogue is understood as an activity that engages individuals in a deep and reciprocal interaction whose goal is to develop mutual understanding and establish meaningful interconnections between individuals.

As such, part of our research involves examining how well our decision aid fosters discussion between individuals and their relatives, friends, and caregivers. In previous studies, we showed that decision aids can help patients better understand their medical options and ask better, more informed questions of caregivers (Green et al. 2004; 2005). We

---

Address correspondence to Benjamin H. Levi, Penn State College of Medicine, Humanities & Pediatrics, 500 University Drive, Hershey, PA 17033, USA. bhlevi@psu.edu.

agree that it is both naïve and risky to propose that individuals use our program in isolation. Not only do we regard optimal advance care planning as a shared exercise, but also believe that engaging others in such discussions has significant potential to enrich one's relationships.

In ongoing research (involving the use of our decision aid among patients with advanced cancer), we have been encouraged that many individuals wish to have family members present and engaged as they work through our program. Additionally, we are currently designing a study to more fully investigate how individuals process these issues with others, depending on whether they complete our decision aid alone or in the company of their designated surrogate.

Already built into our computer program are exercises that prompt individuals to reflect on the role and impact for family and friends of their wishes vis-à-vis advance care planning. In fact, a significant part of the MAUT algorithm for translating individuals' responses into an advance directive involves using the priorities and weights that individuals assign to various concerns for others. By combining this with a "General Wishes" statement as well as a listing of issues that the individual considers "important" and "extremely important," we have tried to illuminate the "whys" and document important process-based components of individuals' decision-making.

There is no question in our minds that the program we created is highly imperfect. It does not address the needs of children for surrogate decision-making that Barfield and colleagues (2010) quite appropriately raise. So, too, our decision aid cannot coax out of individuals a definitive answer where none exists, nor can it address every eventuality that will arise (—taking an average of 106 minutes to complete, the program likely is already too time-consuming for many).

But it is an honest attempt to help patients (and others) be better prepared for the eventuality of medical decision making at times when individuals cannot speak for themselves. In no part of our current or past work have we ever suggested (as Dawson & Wriggley mischaracterize) that respect for personal autonomy should stand as a totalizing theory trumping all other concerns. As we have written elsewhere, "[o]ther principles and motivations are not displaced by… respect for autonomy. Caring and beneficence will find their way into virtually all… interactions with patients; so, too, principles such as justice, non-maleficence, utility, mercy, and so forth will have their application" (Levi, 1999b, 12).

It is indeed beyond the scope of either our target article or this response to refute the claim that "it is a best interests judgment that must ultimately govern all decisions where a person is unable to make them for themselves" (23). However, there are sufficient bioethical treatises, professional policy statements, and legal precedents over the past 40 years to effectively counter such bald paternalism (Abram et al. 1983; Buchanan 1979; Faden & Beauchamp 1986; Orentlicher et al 1982).

Throughout our work we stress the developmental value of advance care planning and the instrumental (rather than authoritative) role of formal advance directives. As Aultman (2010) suggests, our decision aid and the advance directive it generates can be viewed as a (hopefully) useful adjunct for helping make medical decisions that must get made.

At the end of the day, an advance directive is just a piece of paper. But if that piece of paper is the end result of a well-designed educational and reflective process, it can be very useful —not just for documenting patients' values and wishes, but for facilitating meaningful dialogue about things that really do matter.

Acknowledgments

The project described was supported by grant 1 R21 NR008539 from National Institute of Nursing Research, National Institutes of Health. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the National Institute of Nursing Research or the National Institutes of Health. The project also received support from the American Cancer Society (grant RSGHP-08-005-01-CPHPS), and various funding from Penn State University (the Social Science Research Institute, the Woodward Endowment for Medical Science Education, and the Tobacco Settlement Fund Award). The author acknowledges the support and assistance of Dr. William Lawrence for his contribution to the MAUT model used in this program, Dr. Cheryl Dellasega for her leadership in focus-group activities, Charles Sabatino for his review of legal aspects of the program, Dr. Robert Pearlman and his collaborative team for use of the advance care planning booklet "Your Life, Your Choices," Joanne Caulfield for assistance in grant preparation and project organization, and the Instructional Media Development Center at the University of Wisconsin as well as JPL Integrated Communications for production and programming of the decision aid.

References

Abram, MB.; Ballantine, HT.; Punlop, GR., et al. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. U.S. Government Printing Office; Washington, D.C.: 1983.

Aultman J. Ethics of translation: MOLST and electronic advance directives. American Journal of Bioethics. 2010; 10(4):30–32. [PubMed: 20379917]

Barfield D, Brandon D, Thompson J, Harris N, Schmidt M. Mind the Child: Using Interactive Technology to Improve Child Involvement in Decision Making about Life-Limiting Illness. American Journal of Bioethics. 2010; 10(4):28–30. [PubMed: 20379916]

Barnard D. Living with Doubt. American Journal of Bioethics. 2010; 10(4):27–28. [PubMed: 20379915]

Berger J. What about process? Limitations in advance directives, care planning, and noncapacitated decision-making. American Journal of Bioethics. 2010; 10(4):33–34. [PubMed: 20379918]

Buchanan A. Medical Paternalism. Philosophy & Public Affairs. 1978; (4):370–390. [PubMed: 11664929]

Dawson A, Wrigley A. A dead proposal: Levi and Green on advance directives. American Journal of Bioethics. 2010; 10(4):23–24. [PubMed: 20379913]

Faden, RR.; Beauchamp, TL. A History and Theory of Informed Consent. Oxford University Press; New York: 1986.

Gastmans C, Denier Y. What if patients with dementia use decision aids to make an advance euthanasia request? American Journal of Bioethics. 2010; 10(4):25–26. [PubMed: 20379914]

Green MJ, Levi BH. Development of an interactive computer program for advance care planning. Health Expectations. 2009; 12(1):60–69. [PubMed: 18823445]

Green MJ, Peterson SK, Baker MW, et al. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. Journal of the American Medical Association. 2004; 292(4):442–452. [PubMed: 15280342]

Green MJ, Peterson SK, Baker MW, et al. Use of an educational computer program before genetic counseling for breast cancer susceptibility: effects on duration and content of counseling sessions. Genetic Medicine. 2005; 7(4):221–229.

Levi, BH. Respecting Patient Autonomy. University of Illinois Press; Champaign, Illinois: 1999a.

Levi BH. Patient Autonomy: A Dialogical Approach. Medical Humanities Review. 1999b; 13(2):7–27.

Levi BH, Green MJ. Too Soon to Give Up? Re-examining the Value of Advance Directives. American Journal of Bioethics. 2010; 10(4):3–22. [PubMed: 20379910]

Orentlicher D, Mcmurray RJ, Clarke OW, et al. Decisions near the End of Life. Jama-Journal of the American Medical Association. 1992; 267(16):2229–2233.