



Published in final edited form as:

J Am Geriatr Soc. 2019 January ; 67(1): 9–10. doi:10.1111/jgs.15688.

Living Wills – One Part of the Advance Care Planning Puzzle

Daniel David, PhD, MS, BSN^{1,2}, Ryan D. McMahan, BA, BS³, and Rebecca L. Sudore, MD^{1,2,3,4}

¹Department of Medicine, Division of Geriatrics, University of California, San Francisco, San Francisco, CA

²Veterans Affairs Medical Center, San Francisco, CA

³UCSF School of Medicine, San Francisco, California

⁴Innovation and Implementation Center in Aging and Palliative Care, University of California, San Francisco

Historically, the measure of advance care planning (ACP) success has been the documentation of the living wills or advance directive forms (LWs). These documents outline individual preferences, often in check-box fashion, for life sustaining treatments such as cardiopulmonary resuscitation and mechanical ventilation. In addition, advance directive forms allow individuals to designate a surrogate decision maker in case of decisional incapacity. However, the definition of ACP over recent years has broadened.^{1–3} This broadened ACP paradigm, defined by international expert consensus, is a *process*, rather than a singular *moment* or document, that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.¹ This approach also focuses on preparing both patients and surrogates for decision making by supporting communication skills and helping individuals define their own values in addition to completing living wills or advance directives.

LWs likely became the metric of successful ACP because, unlike ongoing communication, they are relatively easier to measure.⁴ In the U.S., the 1990 Patient Self-Determination Act mandated that institutions provide written information on policies related to LWs, and as such, they have been adopted as a key quality metric in many models of care.⁵ Yet, many have called into question the efficacy of solely focusing on LW documentation^{6,7} and even propose an outright elimination of the practice.⁸ Such sentiments beg the question: does documentation of a LW effectively signify that quality ACP has taken place?

In this edition, Higley et al. investigate if the presence of a LW in the medical record impacts end-of-life (EOL) outcomes.⁹ The authors of this systematic review include 28 studies and ask two important questions: 1) Does the presence of a LW impact EOL care, mitigating

Please send all correspondence to Dr. Daniel David: Daniel David, PhD, MS, BSN, Veterans Administration Medical Center, 4150 Clement St (181G), San Francisco CA 94121, daniel.david@ucsf.edu, Cell phone: 781-201-0530, Work phone: (415) 221-4810 X22673.

Author Contributions: Dr. David had full access to all the materials and takes responsibility for the integrity of the accuracy of manuscript. David, McMahan, Sudore: Critical revision of the manuscript for important intellectual content.

Conflict of Interest: None of the other coauthors have conflicts to report.

outcomes suggestive of more aggressive care? and 2) Does the state of ACP science reflect studies that are rigorously conducted in a way that minimizes bias? There were a number of elements that made this review compelling. First, it only included studies with well-defined parameters for LW documentation. LWs needed to reflect the patient's wishes for the management of their EOL, not just surrogate designation, and required the document be drawn up by the patient, not a surrogate. Second, the authors approached these questions from a global perspective and included studies from multiple countries in a number of different languages. Lastly, they used the Risk of Bias in Non-Randomized Studies of Interventions (ROBINS-I¹⁰) tool to critically evaluate the presence and extent to which multiple forms of bias may color the findings.

The authors conclude that they cannot universally demonstrate a significant impact of LWs on outcomes related to EOL care (place of death, hospitalization, ICU care, life-sustaining treatments, and receipt of less aggressive medical treatment). Furthermore, 93% of the studies that were reviewed demonstrated a serious risk of bias. These findings point to inherent challenges within the field of ACP research.

One interpretation of these findings may be that LWs are, at best, ineffective and at worst, a waste of precious resources. Fagerlin and Scheider methodically identify fatal flaws of using LWs including, among other issues, that most patients fail to complete them and that LWs are often not available when needed; LWs contain vague language that is not applicable to future health states; LWs are signed by individuals who may not be truly informed, and surrogates often don't know they were chosen and are often unprepared. In addition, other work has demonstrated that many legal requirements have created overly complex forms that are difficult to read and execute.¹¹

However, it would be an error in the interpretation of these findings to equate the inadequacies of LWs to the broadened process of ACP. As described above, LWs are often limited to a check-box approach of life sustaining treatments that fail to address the goals and values behind those choices.⁶ The forms are also, on average, 5 years old and may not represent current medical wishes.¹² As above, ACP should be a process of identifying one's values and goals and communicating these over time. As the authors point out, LWs have the potential to improve psychological and emotional outcomes for patients and families. These types of outcomes may be just as important to quality of life for patients as well as downstream outcomes for surrogates, who have to live with their decisions and have subsequent interaction with the healthcare system. The broadened paradigm of ACP emphasizes the importance of not only naming a surrogate decision maker but also preparing them to advocate for the individual.¹³ In the current article, studies with surrogate involvement were excluded and, therefore, it was not possible to investigate the role of surrogates in EOL outcomes. In addition, communication-based ACP, not just form-based ACP, has been shown to have a range of benefits including an increased likelihood that patients' wishes will be honored at the end of life, as well as decreased stress for surrogate decision makers.¹⁴⁻¹⁶

The outcomes for this study are also important to put into context. For example, we do not know whether the health care utilization outcomes described in this study for life sustaining

treatments, ICU stays, hospitalization, or decision to restrict care actually reflected the care that was desired by patients and their families. Some patients and families will choose aggressive treatment options as a part of their LW and actualization of that plan, or utilization of those resources, may not represent a failure of ACP but exactly the opposite. To address the need for a consensus concerning the outcomes that define successful ACP, an international panel of ACP experts rated the relative importance of many ACP outcomes for research. The top-rated outcomes were goal concordant care as well as the identification and discussions with surrogate decision makers and medical providers. LWs were rated lower as was healthcare utilization. However, goal concordant care and communication are outcomes which are difficult to measure. Identifying metrics that evaluate goal concordant care is vital to examining the effectiveness and quality ACP interventions, yet no standardized metric is currently available.⁴ Although validated patient-reported surveys of ACP are available, it is difficult to abstract this information from the medical record, especially given the notoriously poor documentation by clinicians of these important ACP conversations.¹²

While LWs alone may be insufficient to move the needle on the healthcare utilization outcomes described in the article, this study does not confirm that the broader, consensus definition of ACP is ineffective. LW are only one piece of the ACP puzzle and are only as good as the preparation of patients and surrogates and the communication about the wishes in those documents. Therefore, this study helps to point out what is needed for future ACP research: outcomes that measure the broad process of ACP and ACP quality; outcomes that measure what matter to patients and surrogates in addition to healthcare utilization; the inclusion of surrogate decision makers into ACP research; the development of validated metrics that measure goal concordant care; and the standardization of methods to capture ACP communication in the medical record. Living wills alone do not equate to ACP quality, and, therefore, much work is needed in the field to improve ACP research and define and measure the effectiveness of the ACP process.

ACKNOWLEDGMENTS

Funding: Dr. Sudore is funded by an NIA K24AG054415 award.

Financial Disclosure: This study was supported by Grant NIA K24AG054415 from the National Institute on Aging (Dr. Sudore)

REFERENCES

1. Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage*. 2017;53(5):821–832 e821. [PubMed: 28062339]
2. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol*. 2017;18(9):e543–e551. [PubMed: 28884703]
3. Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Ann Intern Med*. 2010;153(4):256–261. [PubMed: 20713793]
4. Sudore RL, Heyland DK, Lum HD, et al. Outcomes That Define Successful Advance Care Planning: A Delphi Panel Consensus. *J Pain Symptom Manage*. 2018;55(2):245–255 e248. [PubMed: 28865870]

5. Dy SM, Kiley KB, Ast K, et al. Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *J Pain Symptom Manage*. 2015;49(4):773–781. [PubMed: 25697097]
6. Winter L, Parks SM, Diamond JJ. Ask a different question, get a different answer: why living wills are poor guides to care preferences at the end of life. *J Palliat Med*. 2010;13(5):567–572. [PubMed: 20377499]
7. Winter L Patient values and preferences for end-of-life treatments: are values better predictors than a living will? *J Palliat Med*. 2013;16(4):362–368. [PubMed: 23442042]
8. Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep*. 2004;34(2):30–42. [PubMed: 15156835]
9. Higel T, Alaoui A, Bouton C, Fournier J. Impact of living wills on adult patients' end-of-life care: a Systematic Review. *J Am Geriatr Soc*. 2018. doi: 10.1111/jgs.15630
10. Sterne JA, Hernan MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *BMJ*. 2016;355:i4919. [PubMed: 27733354]
11. Castillo LS, Williams BA, Hooper SM, Sabatino CP, Weithorn LA, Sudore RL. Lost in translation: the unintended consequences of advance directive law on clinical care. *Ann Intern Med*. 2011;154(2):121–128. [PubMed: 21242368]
12. Walker E, McMahan R, Barnes D, Katen M, Lamas D, Sudore R. Advance Care Planning Documentation Practices and Accessibility in the Electronic Health Record: Implications for Patient Safety. *J Pain Symptom Manage*. 2018;55(2):256–264. [PubMed: 28943360]
13. 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(3):355–365. [PubMed: 23200188]
14. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665–1673. [PubMed: 18840840]
15. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010;362(13):1211–1218. [PubMed: 20357283]
16. 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. [PubMed: 20332506]