COMMENTARY

Universal Advance Directives—Necessary but Not Sufficient

Brian L. Block, Alexander K. Smith, and Rebecca L. Sudore

Over the past several decades, clinicians, estate planners and policymakers have taken steps to increase patient involvement in medical decisions. The old model of the doctor-patient relationship — which emphasized physician knowledge and authority — has been replaced by a construct that prioritizes patient autonomy and consent. Informing patients, weighing options, and making medical decisions together is now favored because it promotes individualized, respectful, patient-centered care.

But what happens when a patient lacks the capacity to choose? How do we respect such patients' individuality and personhood, or more concretely, their autonomy and right to self-determination? Are written advance directives (AD) sufficient?

In the present issue of the *Journal of Law, Medicine & Ethics*, Charles Sabatino reviews the potential reach of universal advance directives (AD).[1] By examining each state's health care power of attorney laws, he determined that a universal AD could feasibly be implemented in 41 of 50 states and the District of Columbia (five more than in 2005). He describes six barriers to a universal AD; some surmountable (e.g., witness requirements, execution requirements, and effectiveness triggers) others, insurmountable (e.g., mandatory forms, mandatory disclosures, and specific language regarding certain decisions, such as withholding nutrition). His study offers an important opportunity to applaud the increasing harmonization of state AD laws. At the same time, it is important to remind readers that ADs do not, in isolation, adequately prepare surrogates to make decisions. Nor do they guarantee that a patient will receive goal-concordant care. A more comprehensive type of advance care planning is needed.

According to a 2017 international panel of 52 experts convened to develop a consensus definition,[2] "Advance care planning is a process 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." The goal of advance care planning, it follows, is to "ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness." Notably, this expert panel — which included legal experts — did not mandate that living wills or health care power of attorney forms be included in the definition of advance care planning. Why?

Unfortunately, prior studies indicate that legal documents alone do not adequately prepare patients or their surrogates for medical decision making.[3] This is unsurprising, given that ADs are known to poorly anticipate the decisions that surrogates face. Beyond their limited ability to inform surrogates' decisions, ADs also do little to protect surrogates from the psychosocial distress and decisional regret that often befall surrogates who make difficult decisions.

Given the limitations of ADs — whether or not they include a living will in addition to a proxy component — high quality advance care planning cannot

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be accomplished with forms alone. Rather, advance care planning is best understood as a *process* — often iterative — of appointing and preparing surrogates to make decisions through a series of conversations over time.[4] Conversations help surrogates develop an intimate knowledge of a patient's values, goals and preferences, which surrogates can bring to clinical situations that require in-the-moment decision making. Discussions are ideally documented in the medical record, where they can be referenced to support and explain why patients made the choices they did on ADs, and why they chose their health care power of attorney. Both conversations and documentation are important. Neither are sufficient in isolation -- particularly given that verbal, undocumented wishes may not have legal standing in some jurisdictions.

Tools exist to facilitate high quality advance care planning, such as the online PREPARE program (www.prepareforyourcare.org), which is available in multiple languages, includes video instructions, and has been shown to promote advance care planning in a randomized trial.[5] Individuals and their family or friends can complete PREPARE on their own, or with the help of a clinician, lawyer, or other trusted adviser. PREPARE meets the needs articulated by patients and surrogates;[3] helping them describe their values, choose surrogates with attention to their ability and willingness to serve, and providing instructions for how to tell others about their wishes. It also generates both an AD and non-legal "Summary of My Wishes" to document discussions.

Inevitably, even when using a tool such as PREPARE, discussions between patients and surrogates cannot anticipate all clinical situations. Even so, a surrogate who understands a patient's overall beliefs and values can be of tremendous help to the medical team, providing clinicians with information that personalizes and contextualizes treatment decisions and prior legal ADs. This helps clinicians assess what outcomes and quality of life would be acceptable to patients, increasing the likelihood that they receive goal-concordant care. Knowing patients' goals, values and preferences also lessens the burden on surrogates, who become reporters of patients' beliefs, rather than being asked to make wrenching decisions on their own.

So what should we make of Sabatino's finding that universal ADs are now feasible in five more states than 2005? Given that ADs are only one component of advance care planning and the field is moving towards a model of ongoing conversations, this incremental legal progress may be of limited clinical significance. Technologic developments have also made state variability in health care power of attorney laws less consequential. As Sabatino acknowledges, customizable forms can now seamlessly adapt to meet different state laws, while presenting a simple patient-facing experience. While this may be an untidy legal work-around, this technologic evolution is nonetheless helpful at the bedside, at least while state laws differ. In fact, other pitfalls of Ads — such as mandatory legal language written at too high a reading level, or AD's failure to account for cultural and religious differences — are now perhaps of more significance than variations in state law.

Ultimately, a static AD with checkboxes is only as good as the preparation of the individual and surrogate holding it. ADs are necessary but not sufficient. For this reason, advance care planning is best understood as a process, anchored around conversations between individuals and surrogates, which prepares surrogates for complex, in-the-moment decision making. Medicare has recently begun reimbursing for advance care planning conversations, and we are hopeful that clinicians will increasingly leverage this opportunity to discuss and document goals, values and preferences. Doing so will allow us to deliver the most authentic care, while minimizing patient and surrogate harms.

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Note

The authors have no conflicts to disclose.

References

1. C. P. Sabatino, "Overcoming the Balkanization of State Advance Directive Laws," *Journal of Law, Medicine & Ethics* 46, no. 4 (2018): 978-987.
2. R. L. Sudore, et al. "Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel," *Journal of Pain and Symptom Management* 53, no. 5 (2017): 821-832.e1.
3. R. D. McMahan, S. J. Knight, T. R. Fried, and R. L. Sudore, "Advance Care Planning Beyond Advance Directives: Perspectives from Patients and Surrogates," *Journal of Pain and Symptom Management* 46, no. 3 (2013): 355-365.
4. R. L. Sudore and T. R. Fried, "Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making," *Annals of Internal Medicine* 153, no. 4 (2010): 256-261.
5. R. L. Sudore, et al. "Effect of the PREPARE Website vs. an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trial," *JAMA Internal Medicine* 177, no. 8 (2017): 1102-1109.

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