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Lessons about Law at Life's End: Rethinking Advance Directives in the Shadow of a Pandemic

I Susan P. SHAPIRO

Desde que fueron introducidas en los Estados Unidos hace medio siglo las directivas anticipadas han sido adoptadas en varios países alrededor del mundo. Sin embargo, cabe la pregunta por el impacto de dichos instrumentos en la práctica. La primera investigación empírica que mide a gran escala el uso de directivas anticipadas a favor de pacientes sin capacidad para decidir revela que su impacto, cuando lo tienen, es menor. Este artículo describe estos hallazgos, considera sus implicaciones para la vida profesional y personal de abogados y analiza cómo pueden responder mejor aquellos a los retos de dichas directivas.

"This is so difficult. I tell people to do powers of attorney all the time. I didn't know how difficult this is. I don't want to kill her, but – I am flummoxed. What keeps me up at night – We have been talking about this pretty much nonstop since this happened. That is pretty much all we talk about... I never realized what a burden it is to be a power of attorney."

This tortured lament comes from a lawyer serving as power of attorney for health care for her elderly mother who had suffered a traumatic brain injury after a fall. She knew her mother well, lived nearby, had frequent conversations about her mother's end-of-life treatment preferences, and had reviewed the instructions documented in her mother's advance directive. She was about as prepared for this responsibility as anyone I can imagine. And yet even she was flummoxed, distraught, and overwhelmed.

Advance directives are legal documents in which we provide instructions regarding medical decision making on our behalf should we lose capacity in the future. Although the laws, terminology, and forms vary from jurisdiction to jurisdiction, advance directives generally have two components: proxy directives (sometimes called durable powers of attorney for health care) that name the decision maker to speak on our behalf, and instructional directives (sometimes called living wills) that specify

the type or amount of treatment we desire. In the half century since advance directives were first introduced in the United States, this legal innovation has been adopted in many – but by no means all – countries across the world. Just as the particulars vary across the states in the U.S., they vary considerably from country to country as well. Perhaps what these disparate jurisdictions have most in common is the disinclination of their citizens to take advantage of advance directives, despite considerable efforts (at least in the U.S.) to convince them to do so.

But is the effort worth it? In the throes of a pandemic, will our failures to encourage the preparation of advance directives result in even greater harm to those whose lives hang in the balance? Was this an opportunity lost? The answer requires assessing whether patients without advance directives fare any differently than those who prepared them. And whether loved ones armed with these documents have an easier time bearing the daunting responsibility to speak on patients' behalf, as advocates of advance directives promise.

findings I would later gather that cast doubt on the value of advance directives. For more than two years, a medical social worker and/or I spent our days in two intensive care units (ICU) in a large urban hospital that serves a very diverse population of patients. There we observed medical decision making on behalf of patients without decision-making capacity, day after day, from admission to discharge. Observations over the course of each patient's ICU stay tracked when anyone asked about or referred to an advance directive, how the directive was used in conversations or decisions day-to-day, and the correspondence between the patient's treatment preferences expressed in the directive and the host of decisions made on his or her behalf.

About half of these ICU patients without capacity reportedly had prepared an advance directive, though for only a quarter was a copy available. (The percentages were far lower for other ICU patients still able to decide for themselves and therefore excluded from the study.) Yet, in more than 1,000 encounters and

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The first large-scale empirical investigation of how advance directives are used day-to-day in medical decision making on behalf of patients without capacity suggests that their impact, if any, is small.¹ In this article, I describe findings of the very limited role of advance directives, at least in two intensive care units in the U.S., and explain why this is likely to be the case in other national and institutional settings as well. I then address the implications for lawyers – in their personal and professional lives – and how they might best address these challenges.

Perhaps the anguish of the daughter quoted above should have prepared me for the

family meetings that we observed between almost 300 health care providers and more than 700 patient friends and family, for only a quarter of patients who reportedly had advance directives did anyone ever ask about treatment preferences expressed in the document, let alone describe them – ever. And for every directive that helped honor patient wishes – providing information, clarification, corroboration, or closure, fostering consensus, or assuaging guilt – another failed to do so – its instructions flouted, ignored, misunderstood, providing insufficient guidance or directions inconsistent with patient preferences.

Of course, advance directives do not have to be invoked, described, or even mentioned to affect medical decisions. But, if instructional directives, or the conversations their completion occasions, provide information, guidance, authority, reassurance, or absolution to decision makers or health care providers, one would expect them to play a role in the decision-making process, even if no one ever mentioned them. Yet the study found little difference (holding constant patient characteristics and severity of illness) in how decision makers armed with directives and those without them proceed.

Across almost three dozen aspects of the decision-making process, outcomes, or impact – from whether and how participants reprised patient wishes or spoke about their personalities or values, to the decision criteria considered, how quickly decisions were reached, the amount of conflict that ensued, the emotional burden experienced by family members, responses of health care providers, even the decisions themselves (from refusing an intervention to withdrawing life support) – only one significant difference could be found. Family members of patients with directives were more likely to initiate discussions of goals of care, although they were no more likely to have such conversations. In all other respects, the two groups were indistinguishable. Treatment decisions were not different; they were made no faster; they weighed similar criteria; they triggered no less conflict; and they appeared to be no less burdensome for families.

In short, it was difficult to find evidence that advance directives made much difference in the two ICUs. Perhaps directives are keeping patients out of hospitals altogether. But once patients have been admitted to an intensive care unit, loved ones – like the daughter who opened this essay – face a torrent of complex decisions about a host of interventions, not only for the problem that brought patients to the ICU, but for all of the complications that develop along the way. Many of these choices are nested in technical, nuanced, probabilistic, inconclusive, bewildering information – or none at all – and mixed messages offered by different specialists. These decisions could hardly be anticipated in a menu of boilerplate checkboxes or scripted instructions in an

advance directive written in better times when many would-be patients could not envision the medical crisis that would bring them to an ICU or the excruciating choices their loved ones might someday face.

These limitations of advance directives that I observed have little to do with the particulars of legal doctrine or the drafting of forms or even differences in local culture or values. Instead they reflect universal challenges—the impossibility of anticipating or planning for complex unforeseen events as well as the difficulty of making life-and-death decisions with imperfect information or of preparing decision makers to negotiate the agonizing choices that they face. For that reason, I expect that the findings limited to these two ICUs in a single U.S. city will generalize to many locations and legal systems across the globe.

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What, then, can one take away from these findings? Should lawyers be completing or advising clients, family, or friends to complete the instructional directive forms that failed, betrayed, or proved irrelevant for so many of the patients in the ICU study? Moreover, do we want to send the message to healthy individuals that writing instructions with the blessing of their lawyer or physician is all they need to do to ensure fidelity to their wishes and protect their loved ones at life's end? As citizens of the world face the terror of a pandemic bearing down, is this the time finally to complete those boilerplate forms they have avoided for years?

Scripted instructions can play an important role when patients face a known imminent terminal illness.² But the rest of us – lawyers, their families, and their clients alike – must eschew writing scripts for events we cannot foretell and that might lock those who speak on our behalf into inappropriate and unwelcome treatment decisions. Instead, we ought to reflect with loved ones on process: What decision criteria are most important; how should they be weighed, and tradeoffs balanced? How to evaluate probability, risk, or prognostic uncertainty? How long to pursue aggressive interventions before changing the

goals of care from cure to comfort? How much suffering along the way is tolerable? What constitutes an acceptable quality of life? What fates are worse than death? How much weight to give to the needs of the family?

Perhaps most important, how should we choose the most effective proxy decision makers and prepare them for what many characterize as the most difficult role of their life? Because so much of speaking for another is not about following instructions but about asking questions, analyzing complex information, drawing inferences, exercising judgment, improvising, forging consensus, and simply being there, the importance of choosing an effective proxy cannot be overstated.

The most effective decision makers I observed knew the patients really well, had communicated frequently with them in

recent years, and understood their values, preferences, and fears. But knowing the patient's wishes is far from enough. Effective decision makers were also good listeners and communicators, were intelligent, had an open mind, were decisive, could process complex, incomplete, sometimes conflicting information, and were able to see the forest as well as the trees. They were effective advocates and took the initiative to engage health care providers, gather information, and ask difficult questions. They were not easily intimidated or distracted; they stood up to doctors and even family members, when necessary, but were also consensus builders. They were sensitive about separating their interests from those of the patient. They were willing to take on these responsibilities and able to devote considerable time to visit the hospital repeatedly, observe the patient, and meet with varied teams of physicians, often waiting long stretches for the latter to show up. And they inspired trust among the patient's significant others.

Lawyers should assist their clients in identifying who in their circle of friends or family best meets this job description, ensure that he or she is willing and up to the task, document the choice of proxy in an advance

directive, and encourage them to grapple together and with other friends and family on the sorts of questions about process raised earlier.³ And lawyers should do the same for themselves and for those they love. Fortunately, there are numerous free online resources available that lawyers might pass along to help jumpstart these difficult, awkward conversations among their clients' friends and family as well as their own.⁴ In moments of collective vulnerability, as we draw close to those we love, what better time to begin these conversations?

A national study found that, among Americans over age 60 who required treatment decisions in the final days of life, 70% lacked decision-making capacity. So the probability that the biggest life-and-death decisions of our lives and of those we love will be made by someone else is very real. And so are the incentives to prepare ourselves, our clients and our loved ones for this demanding responsibility.

Susan P. SHAPIRO
Research Professor
American Bar Foundation
Chicago, IL, United States
sshapiro@abfn.org

1. The findings presented in this article come from Shapiro, Susan P., *Speaking for the Dying: Life-and-Death Decisions in Intensive Care* (University of Chicago Press, 2019).

2. Patients close to death know better the sorts of end-of-life medical interventions they face and about which they can leave instructions. Therefore, many states in the United States have adopted the POLST (Physician Orders for Life Sustaining Treatment or variations on this name) paradigm. POLST forms are not legal documents like advance directives, but medical orders prepared by physicians or other health care providers that specify the patient's treatment preferences. The orders are limited to patients facing life-threatening illness or are so frail that health care professionals would not be surprised if they died within a year (<https://polst.org>). For analysis of the possible adoption of this paradigm outside the U.S., see Vania F.S. Mayoral, et al., *Cross-Cultural Adaptation of the Physician Orders for Life-Sustaining Treatment Form to Brazil*, 21 *Journal of Palliative Medicine* (2018).

3. For resources on how lawyers can counsel their clients effectively on these matters, see American Bar Association Commission on Law and Aging, *Advance Directives: Counseling Guide for Lawyers*, 2018. https://www.americanbar.org/content/dam/aba/administrative/law_aging/lawyers-ad-counseling-guide.pdf.

4. Id.