

Sociology of Law: Speaking for the Dying

Susan P. Shapiro, American Bar Foundation

Perhaps the most poignant image of the coronavirus pandemic captures desperate family members, with tears streaming down their faces, their noses pressed against hospital doors, barred from entry to visit their loved ones. But families are not just tragic icons at life's end; they are often its choreographers. A large national survey that predated the pandemic found that 70 percent of Americans over age 60 who required medical decisions during the final days of their lives lacked the capacity to make them. And while my own research found that more than half of Intensive Care Unit (ICU) patients — even under normal circumstances — do not survive their admission, for 9 in 10 of them, loved ones decided to limit their treatment. None of the horrific COVID-19 death statistics disclose whether this ratio applies to these patients. Still, for many of us and those we love, the biggest life-and-death decisions of our lives — literally — will be made by someone else.

As a sociologist of trust, I was intrigued by how others make these life-and-death decisions on behalf of patients who cannot speak for themselves, patients who may not have selected their decision makers, cannot fire them, may have left no information about their treatment preferences, and with whom decision makers cannot confer. As a sociologist of law, I was also curious about the role of law and advance directives in the decision-making process.

To explore these questions, I was fortunate to gain access to two intensive care units in a large urban teaching hospital serving a demographically diverse population of patients. For more than two years, a medical social worker and I spent our days in these ICUs where the coronavirus tragedy is unfolding today. There we embarked upon the most extensive ethnographic study of how loved ones navigate complex, end-of-life medical

decisions, observing more than a thousand conversations and meetings between almost 300 different health care providers and more than 700 family and friends of patients unable to speak or make medical decisions for themselves.

Fewer than a third of all patients, even those sick enough to be admitted to an ICU, had advance directives documenting their treatment preferences or who should make medical decisions on their behalf. Yet, I could find little evidence that directives alone made much difference. Comparing patients with and without directives (controlling for demographics and severity of illness), treatment decisions were no different and were based on similar criteria. Decisions were made no faster, there was no less conflict, and the process was no less emotionally burdensome for loved ones. The handful of loved ones who had confidently embraced documents that they assumed would take care of all the hard decisions discovered that directives rarely provide guidance for the nuanced, equivocal, and unexpected choices they faced. Only one in 20 ICU patients in our study had directives that actually helped honor their wishes.

When scripted directives provided no direction or when they did not exist at all, loved ones turned to improvisation to respond to the myriad choices they faced. Many reprised conversations with patients sometimes decades earlier, reflected on their personalities and values and tried to make the decisions they thought the patients would make for themselves.

Others deferred decisions in the hope that patients would regain capacity in the future, a waiting game that was rarely successful. Some refused to consider any life-limiting decisions that might be seen as playing God and demanded heroic interventions until God decided whether treatment would be successful. Some decision-makers focused on their own interests or those of others. A daughter insisted, "We want everything done." When asked whether that is what the patient wanted, the daughter responded, "It doesn't matter. This is what we want." Some opted out of decision-making altogether, distrustful of physicians, unwilling to hear bad news, and in denial about the patient's precarious condition. These patients received protracted aggressive treatment, the legal default. And others worried about the patient's quality of life or sought to minimize their pain and suffering.

Because few patients regained capacity in the ICU, I do not know how they felt about the improvisations performed on their behalf. I do know that most families were ill-prepared to decide for those whose lives were in their hands.

Coronavirus has undoubtedly altered the rhythms of life in the ICUs that I observed — from the suddenness and capriciousness of its choice of victims; to shortages of resources that may result in rationing of equipment, procedures, and physicians; to limited understanding of the disease or effective treatments; to barring family members from the ICUs, impeding communication with already overstretched health care staff. All of these factors will make advance directives even less helpful and decisions on behalf of patients even more excruciating.

COPYRIGHT © AMERICAN SOCIOLOGICAL ASSOCIATION