ABF Scholar Sheds a Light on Life-and-Death Decisions in Intensive Care
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Improving the understanding of law as it relates to everyday life is vital to the research mission of the American Bar Foundation (ABF). In a new book, Speaking for the Dying: Life-and-Death Decisions in Intensive Care, ABF Research Professor Susan P. Shapiro uncovers the complex decision-making process and the role of law in end-of-life care. The book draws on the most extensive observational study to date of how loved ones navigate life-and-death decisions for patients who are unable to speak for themselves.

Seven in ten Americans over the age of sixty who require medical decisions in the final days of their lives lack the capacity to make them. For many people, the most significant life-and-death decisions of their lives will be made by someone else. Loved ones act as surrogate decision makers, negotiating medical decisions on a patient’s behalf when the patient lacks decision-making capacity.

These decision makers will decide whether patients live or die, whether they receive medical interventions seeking cure or comfort, and whether they die in a hospital or at home. They will determine whether wishes are honored and choose between fidelity to the patients’ interests and what is best for themselves or others. Yet despite their critical role, little is known about how surrogates make decisions for their loved ones.

Speaking for the Dying draws on daily observations for over two years in two intensive care units (ICUs) in a large urban hospital. Shapiro and a medical social worker studied approximately 1,000 interactions between doctors, surrogate decision makers, and families of patients brought into the ICU. These observations document how physicians communicate with family members about life-and-death choices and how families respond and make decisions about care for their loved ones.

The book examines the medical decision-making process from all angles. It reveals how decision makers are selected, the interventions they weigh in on, the information they seek and evaluate, the values and memories they draw on, and the criteria they consider. It also explores the outcomes they choose, the conflicts they become embroiled in, the challenges they face, and the role of health care providers in this process.

In her work as a sociologist, Shapiro has focused on the intersection of law and asymmetric relationships of trust in which an agent acts on behalf of a more vulnerable other. In her past work, she examined trust in other areas such as the stock market, the news media, and conflict of interest in legal practice. It was her interest in these trust relationships that led her to the ICU to study how surrogates act as trustees on behalf of vulnerable patients without cognitive capacity.

Speaking for the Dying is a culmination of Shapiro’s rich ethnographic research on this subject, which she credits to the intellectual opportunities afforded by the ABF. “This sort of pathbreaking and intensive research, conducted from dawn to the wee hours of the night over several years, is only possible at a place like the ABF,” notes Shapiro. “I am grateful to work at such a unique place that permits the sort of commitment required to pull this off.”

The Limitations of Advance Directives

Americans have been encouraged for decades to prepare advance directives. These legal documents state treatment preferences or specify a person to make health care decisions should one lose capacity in the future. Advocates maintain that advance directives will help protect patients and their loved ones when patients can no longer speak for themselves. However, Shapiro’s findings cast light on the limitations of advance directives.

In Shapiro’s observations, not quite half of the ICU patients without capacity reportedly had completed advance directives. But in examining more than 1,000 medical discussions on their behalf, she found that families and health care providers rarely asked about or described the treatment preferences expressed in the document.

For almost half of the patients with advance directives in the hospital record—and whose treatment preferences were
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known—Shapiro found that the directives made no discernable difference in helping ensure that decisions were consistent with these preferences. Moreover, she found that for every advance directive that seemingly helped honor patient wishes by providing guidance, clarification, or closure; fostering consensus; or assuaging guilt—another directive seemingly failed to do so or even undermined the patient’s wishes. Across almost three dozen aspects of the decision-making process, outcomes, or impacts, 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 them. Aside from that, treatment decisions for patients with and without directives were not different, were made no faster, weighed similar criteria, and appeared to be no less burdensome for families.

Making Treatment Decisions

It is extraordinarily difficult for healthy individuals to anticipate the medical crisis that might land them in a hospital one day and the difficult choices their loved ones might face. They may also not realize that these decisions may be challenged by vague, ambiguous, or inconclusive prognostic information that surrogates receive or by mixed messages delivered by different specialists or teams of physicians. As a result, scripted instructions and boilerplate advance-directive documents drafted when patients are healthy rarely provide guidance for the unexpected, nuanced, and equivocal choices their surrogates often encounter.

Many reprised and followed the patient’s written or verbal instructions, sometimes expressed years or decades earlier. Others delayed decisions in the hope that patients would regain capacity in the future, and either be able to make decisions themselves or provide guidance. Many stood in the patient’s shoes to try to decide as the patient would decide if he or she knew the relevant facts. Others tried to maximize the patient’s welfare and advance his or her well-being. Some left the outcome up to a higher power. Others focused on their own interests and desires. Finally, some opted out of making any active decisions because they were in denial about the patient’s condition or distrustful of physicians.

Shapiro’s findings underscore that a would-be patient is best served by carefully selecting and documenting well in advance a surrogate decision maker to entrust with making life-or-death decisions on his or her behalf.

The effective surrogates were good advocates and engaged health care providers to gather information and ask difficult questions. They were willing to devote considerable time to visit the hospital repeatedly, observe the patient, and meet with varied teams of physicians. They knew how to stand up to doctors and family members when necessary, but also how to build consensus and inspire trust. They were sensitive about separating their interests from those of the patient.

The selection of a decision maker to speak on a patient’s behalf should not be taken lightly. Shapiro’s observations show that decision makers who lacked the attributes of effective surrogates risked relying on insufficient data or misunderstanding it. This could lead them to make...
The ABF is pleased to reprint chapter one of *Speaking for the Dying: Life-and-Death Decisions in Intensive Care* by Susan P. Shapiro.

**Holding Life and Death in Their Hands**

It is 6 A.M. The critical care resident checks on one of his patients before morning rounds and encounters ten angry family members encircling the unresponsive patient’s bed, livid that he had been intubated (had a breathing tube inserted into his airway) and attached to a ventilator in the middle of the night. The patient, a seventy-six-year-old white man and former purchasing agent, had been admitted to the hospital for a relatively minor stent (drainage tube) procedure and to explore his eligibility for a liver transplant. He had previously designated his wife power of attorney for health care and documented that he did not want to be resuscitated or intubated.

The previous day, tests had revealed that the patient had liver cancer and would probably not be eligible for a transplant. Late that night, the patient experienced breathing difficulties, and the medical team asked for his consent to be intubated and placed on a ventilator. At 3:25 A.M., the patient, alone in his room, was intubated.

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**CRITICAL CARE ATTENDING:** I’m going to look at his heart and lungs, and then I know you have concerns about the vent [ventilator].

**WIFE:** Pull the plug.

**DAUGHTER-IN-LAW:** This is not what he would have wanted.

**CRITICAL CARE ATTENDING:** Would he feel differently if he was able to potentially get a transplant?

**DAUGHTER-IN-LAW:** No.

**CRITICAL CARE ATTENDING:** If the cancer is confined to his liver, they wouldn’t rule him out as a transplant candidate. It’s a long shot, I’ll be honest. But they haven’t ruled him out yet.

**WIFE:** I thought they found fluid in his abdomen and so he can’t get a transplant.

**DAUGHTER-IN-LAW:** They haven’t told us that he’s definitely not a candidate.

**WIFE:** Just pull the damn plug!

**CRITICAL CARE ATTENDING:** See, we’re in a bit of a bind. He told the nurses last night that he wanted to be intubated, and in effect retracted his living will. But sometimes when people are in distress, they’ll make decisions differently. You don’t think this is what he wanted?

**WIFE, DAUGHTER-IN-LAW, DAUGHTER, AND TWO SONS:** [In unison] No.

**DAUGHTER-IN-LAW:** He talked about this at length with me in the last three months. He told me in detail what he wanted. It’s not this.

**WIFE:** I think he was just frightened.

**DAUGHTER-IN-LAW:** Yes, I think he was scared. He thought he was
The critical care team then consulted the chair of the hospital ethics committee to determine whether the patient’s wife was permitted to reverse the patient’s decision made just hours earlier. The physicians and nurses who had cared for the patient overnight and had secured his consent to be intubated were here as soon as possible to get their thoughts. Unfortunately, during the night, things sometimes are complicated because the primary team and the family aren’t around.

The second patient is a fifty-five-year-old Middle Eastern man from a Christian denomination who immigrated to the United States in his late teens. He works in real estate. While doing pushups at home, he collapsed and had a seizure. He was taken to a small neighborhood hospital, which found that an aneurysm (a weak bulging in the wall of an artery that supplies blood to the brain) had ruptured, initially talking and moving, the patient suffered another seizure and lost consciousness. He was airlifted to a second hospital, which administered life support and other interventions, but an exam suggested possible brain death. The neurologist inserted the water into the patient’s ear to see if his eyes move. He explained that they didn’t. He said that he will pinch the patient’s fingers to see if he responds to pain. He noted that the patient didn’t. He explained that he will put some cold water in the patient’s ear to see if he is brain-dead. The neurologist inserted the water and said that it can take as long as a minute. Everyone in the room was riveted, staring at the patient’s eyes, but they don’t move. The patient’s mother began shaking her head no. The neurologist put cold water in the other ear, again with no response. He then sat down beside the patient’s wife and explained that, once again, the exam indicates brain death.

The neurosurgeon on call explained to family members that an intervention was not appropriate and that another brain-death exam would be administered in the morning. The next morning the senior neurosurgeon on the case explained to the patient’s family that the results were consistent with brain death.

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The patient is brain-dead. It is destroyed. There is no blood going into the brain... If there was a one in a million chance, I would do something. Twenty to fifty percent of people with aneurysms do not survive. I do aneurysms, hemorrhages, brain trauma. This is what I do. If there is anything I could do, I would do it. If there was a one in a billion chance, I would do something.

WIFE: I believe in miracles.

NEUROSURGERY ATTENDING PHYSICIAN: I believe in miracles too. But I deal in facts. His brain is completely dead.

WIFE: They said something about a nuclear flow study [a scan that measures the amount of blood flow in the brain].

NEUROSURGERY ATTENDING PHYSICIAN: If you want that, we can do that.

WIFE: If there is even minimal flow, there is still hope. I was a doctor for four years. I know that things can happen. You don’t always know what will happen.

About a half hour after the meeting ended, a senior neurologist arrived to perform a different kind of brain-death exam in the presence of the family. As he performed each step, he told the witnesses what he was doing. He shined a flashlight in the patient’s eye and explained that he didn’t see any reaction to light. He asked for permission to turn the patient’s head to see if his eyes move. He explained that they didn’t. He said that he will pinch the patient’s fingers to see if he responds to pain. He noted that the patient didn’t. He explained that he will put some cold water in the patient’s ear to see if he is brain-dead. The neurologist inserted the water and said that it can take as long as a minute. Everyone in the room was riveted, staring at the patient’s eyes, but they don’t move. The patient’s mother began shaking her head no. The neurologist put cold water in the other ear, again with no response. He then sat down beside the patient’s wife and explained that, once again, the exam indicates brain death.

As they await the results from the nuclear flow study, fifteen family members begin filing in and out of the patient’s room. Many are in tears. Others are screaming at the patient to wake up and commanding, “Don’t do this to us!” As the hours tick away, visitors continue to implore the patient to wake up and open his eyes. “C’mon, it’s time to wake up!”

The results from the flow study finally come back. The critical care attending physician escorts the family to a conference room. He hands a copy of the report to the patient’s sister, who passes it to her brother and then to the patient’s wife. They each slowly read the report. The physician explains that the report is absolutely clear; you can see it for yourself. “The scan shows that there is no flow to the brain. It is unequivocal. This confirms what we have known all day from the various tests that we have done—that he is brain-dead. Brain death means that we can no longer treat him.” Family members begin to protest that they need more time, and the patient’s brother explains that they believe everything the physician said, but they need to be sure. They need to know that they have done everything that they can for him. As the resistance continues, the neurosurgery attending enters the room and declares, “I have just reviewed the last set of scans. The brain is entirely dead and the blood vessels in the brain are all empty.” As the family files out of the room, the critical care attending tries negotiating with the patient’s wife: the team will continue to treat the patient, but there will be no escalation of treatment, including resuscitating the patient if his heart should stop. The wife agrees.

The next morning the patient’s sister arrives to rescind the do-not-resuscitate agreement, request that physicians give the patient Ambien (a sleeping pill touted on the Internet to reverse brain damage), ask for the name of the hospital’s lawyer, and explain that the family hopes to transfer the patient to another facility and a better neurosurgeon. The nurse manager of the ICU responds that he will arrange a family meeting.
the patient alive while they locate another specialist or institution that can perform a lifesaving intervention, a miracle. They will not give up until they find someone—whether at the Mayo Clinic or in London—able to do the intervention of which physicians in this hospital are incapable. They bring a lawyer to the hospital to ensure that physicians do not remove the patient’s life support before they have an opportunity to transfer the patient elsewhere. Dubious that the family can arrange a transfer, the medical team nonetheless agrees to give them time to try to do so, although nurses and other physicians privately complain to one another about their discomfort and moral distress in treating a dead patient.

The next day, to the amazement of the health care team, an outside neurosurgeon agrees to treat the patient, and a local facility agrees to a transfer. (Just hours earlier an ICU nurse had confidently declared to his colleagues that, if any facility agreed to take a dead patient, he would quit his job.)

ICU doctors prepare the brain-dead patient, and a local facility agrees to the transfer. A few days later, a death certificate is issued. In the ICU doctors prepare the brain-dead patient, he would quit his job. Colleagues that, if any facility agreed to take a dead patient, he would quit his job. Many of you probably cannot imagine yourself standing in the shoes of a member of either of these two families—deciding as they decided, as quickly or resolutely, or for the reasons they expressed. Some of you may not ever realize how very likely it is that someday you too will stand at the bedside of a loved one facing wrenching life-and-death decisions on his or her behalf. And perhaps others of you are horrified to think that what happened to one or both of these patients could happen to you.

You are in good company. This book shares the very different stories of roughly two hundred other intensive care unit patients and how their families and friends negotiated medical decisions on their behalf. Like the first patient, many had preexisting medical problems, some of very long standing. Some patients were in the ICU for an elective procedure or second opinion; a few flew across the country when local physicians offered little hope. Others experienced complications— infections, respiratory problems, cardiac arrests, strokes—from unrelated medical procedures performed elsewhere in this or another hospital. And, like the second patient, for many the symptoms came out of the blue. They were at home, at work, in a public place, or engaged in sports when they collapsed, suffered a seizure or the worst headache of their life, or exhibited slurred speech, weakness on one side, or confusion. And others were transported to the ICU after a fall, accident, or assault.

The unfortunate patients in these stories are current or former doctors, nurses, lawyers, teachers, bus drivers, farmers, bookkeepers, construction workers, factory workers, business owners, musicians, performers, security guards, architects, salespersons, homemakers, honor students, and likely drug dealers. They are celebrities and street people. They are young and old, male, female, and transgendered, rich and poor, gay and straight, someone’s parent and another’s child. They are black and white, Hispanic and Middle Eastern, East and South Asian, Protestant and Catholic, Jewish and Muslim, Jehovah’s Witness and Hmong, evangelicals and agnostics. Some live blocks and others thousands of miles away. Some are attended by round-the-clock vigils of family and friends; others languish alone in their room, day after day, without a single visitor.

The patients are as diverse—literally—as the American census. Yet what they have in common is so much more fundamental than mere demographics or the circumstances of their visit. Whether comatose, nonresponsive, unconscious, sedated, or suffering cognitive deficits or dementia, they cannot speak for themselves. Denizens of intensive care units offering the highest-tech interventions that modern medicine has invented, they lack the capacity to direct their care—to embrace or refuse surgeries, procedures, medical devices, medications, or life-sustaining treatments that might cure their disease or relieve their symptoms, extend their lives or their suffering, restore their quality of life or destroy it, cheat death or sentence them to a fate worse than death. The biggest life-and-death decisions of their lives—literally—had to be made by someone else.

Hospital records will tell you that more than half didn’t make it out of the hospital alive—nine in ten of them, because someone directed physicians to stop aggressive measures. They will document what procedures were performed or tally the many millions of dollars collectively paid for that care. This book will tell a different story. I look beyond the hospital bed and goggle of white coats administering to unresponsible bodies secured with a tangle of lines, tubes, and monitors—the activities methodically documented in the medical record and in many other books and articles—to the anxius faces of loved ones hovering nearby, and to waiting rooms and conference rooms and hallways. I tell the stories of these others, without the white coats, who also hold life and death in their hands, however reluctantly. It is easy to forget, in the drama of saving lives, that their stories are often the most decisive. After all, for every patient who died despite their doctors’ best efforts, nine others did so at the behest of their loved ones. Loved ones hold life and death in their hands because Americans’ constitutional rights of autonomy and self-determination to make decisions regarding medical treatment are so sacred that they are extended by law to proxies or surrogates authorized to decide on patients’ behalf when the latter cannot. Intensive care units represent ground zero for surrogate medical decision making because of the gravity of the illnesses and injuries they attract and the aggressive interventions they offer. Two studies found, for example, that because so few ICU patients have decision-making capacity, 96–97 percent of decisions to withdraw or withdraw life support were made by someone else. Although impaired capacity may be commonplace in intensive care units, it is not uncommon elsewhere, especially near life’s end. One study found that 70 percent of Americans aged sixty or over requiring decisions about care and treatment in the “final days of life” lack capacity to make these decisions. Because these numbers are so large, most of us will someday be called on to act as a health care surrogate on behalf of another and perhaps need one ourselves.

These surrogates who make treatment decisions on patients’ behalf often determine the trajectories of life’s end: whether patients go to a health care institution at all and what kind; the level of risk or suffering to assume in the hope of a cure; the appropriate tipping point between length of life and quality of life; whether they receive routine treatment, cutting edge interventions, aggressive care, life support, or hospice care, and for how long; whether they receive comfort care or heroic measures in their last hours; whether they die at home or in a hospital; the disposition of their bodies (organ donation, autopsy, cremation, etc.); and whether their wishes (if they ever expressed any) are honored, forgotten, or betrayed. And they choose between fidelity to patient interests and what is best for themselves or others. Surrogates also control many of the expenditures on health care near the end of life, much of it, studies find, for unwanted treatment.

Yet despite their critical role for so many near life’s end, we know remarkably little about these surrogates, the decision-making process they follow, the choices they make, and the challenges they face. Other researchers have employed various methods to answer some of these questions. Many have presented hypothetical scenarios to healthy would-be patients and would-be surrogate decision makers. Some have abstracted data from medical records. Others have conducted retrospective interviews or surveys of varied informants—decision-makers,
family members, physicians, and others. And a few have collected snapshots of a meeting or a final decision. Some of the most powerful work has been done by journalists and documentary filmmakers who eschew the scientific method altogether. Typically cherry-picking a handful of compelling stories, too often about white middle-or upper-middle-class families, their accounts necessarily ignore the experience of many. In appendix A, I elaborate on these varied approaches and describe their blinders, limitations, and biases, which led me to look elsewhere to understand how surrogates navigate what could be the end of another’s life.

This book offers a very different window on how these end-of-life trajectories take shape and change course—by systematically observing them, day after day, for more than two years. Early each morning, a medical social worker and/or I rushed off to a neurological or medical intensive care unit in a large urban Illinois teaching hospital serving a very diverse population of patients. Like flies on the wall, we went along on critical care rounds and then hung out in the ICUs throughout the day to observe health care providers instigate, frame, and change course—their role and responsibilities. Now familiar with the setting and the participants decide? And why do some decision makers authorize one aggressive intervention after the next while others do not—even on behalf of patients with similar problems and prospects?

In this book I tell their stories, drawing on the most extensive observational study of surrogate decision making undertaken to date. The transcripts that I will share throughout the book take you to the private bedides, hallways, and conference rooms to hear, in their own words, pulsing with raw emotion, how physicians really talk to families and how loved ones respond, inquire, ignore, argue, justify, plead, or disagree. Their words will often be more instructive than my own, and I encourage you to spend time with them. Still, however exhaustive the portrait I share, this book does not—and cannot—report on all of the many sites and settings in which end-of-life decision making unfolds. But it does open an expansive window on that private world and exposes an extremely diverse collection of participants. The window opens on the ICU itself, where you will become familiar with the rooms, technology, actors, sights, sounds, rhythms, and routines. Looking behind the privacy curtains, you will meet health care personnel, patients, and especially their significant others. Drawing on examples from the experience of hundreds of patients and families, you will learn of the misfortunes that brought patients to the ICU and the worlds from which they traveled. You will see the arrangements, if any, that they made in advance to prepare for medical decision making on their behalf. You will get to know the friends and family who visit or maintain the occasional vigil at the bedside, the complex tangled family trees from which some travel, the sometimes challenging or contentious struggles to determine who gets to speak on behalf of the patient, and how decision makers come to understand their role and responsibilities.

Now familiar with the setting and the actors, the book turns to the medical decisions themselves that physicians and significant others negotiate. You will hear physicians describe in their own words the varied medical interventions appropriate near life’s end; the risks, benefits, uncertainties, and other considerations they disclose as they discourage or seek consent to these procedures; and how loved ones respond and the ways the dialogues unfold—with emotions, misunderstandings, and conflicts on display. Considerations of prognosis—the likelihood that the patient will recover, become disabled, or die—course through these conversations and often play a significant role in how surrogates respond. The book explores prognosis—how it is avoided, framed, conveyed, even negotiated, with loved ones—and reveals the silences, accuracy, consistency, and biases to which prognosis is often subject. The central question of the book can now be addressed. How do loved ones and others make decisions on the patient’s behalf? I present the legal and bioethical norms about surrogate decision making and the difficulties of following these norms in the real world, even as so many participants don’t even know that they exist. One of these difficulties results from the impossibility of truly knowing another’s wishes, another from the conflicts of interest that arise at the bedside and are inevitable when loved ones, who have the most to gain or lose, are entrusted with life-and-death decisions. Yet another reflects the cognitive biases that compromise the judgments of physicians and decision makers alike. Given that decision-making norms are often unknown or difficult to follow, I reveal how surrogates and other friends and family improvise and the decision-making criteria they fashion, sometimes in collaboration with health care providers, sometimes in opposition to them. Again in their own words, I show how loved ones struggle with and justify the excruciating medical decisions they are called on to make on behalf

This book offers a very different window on how these end-of-life trajectories take shape and change course—by systematically observing them, day after day, for more than two years.
In short, what and how did participants decide? And why do some decision makers authorize one aggressive intervention after the next while others do not—even on behalf of patients with similar problems and prospects?

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