

Researching

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**THE FELLOWS CLE RESEARCH SEMINAR: Your Voice in the Future:
The Role of Advance Directives Near the End of Life**

The Fellows CLE Research Your Voice in the Advance Directives

A recent study found that 70 percent of Americans who require decisions about medical treatment in the final days of life lack decision-making capacity. Studies of intensive care units, where patients are much sicker, have found that of all decisions to withhold or withdraw life support, only 3 or 4 percent were made by the patients themselves; the others lacked decisional capacity. In short, the most important life-and-death decisions of many of our lives will be made by someone else. The implications of this stark reality were addressed in a recent ABF Fellows Research Seminar.

The seminar was held on February 4, 2012 in New Orleans, Louisiana, during the Fellows Mid Year Meeting. ABF Research Professor Susan P. Shapiro presented her research on end-of-life decision making to an audience of Fellows and other interested ABA attendees. Rachel Billow, a social worker who worked closely with Dr. Shapiro gathering data in the field, joined in the presentation as well. A panel of commentators including attorney Robyn S. Shapiro (no relation to Susan Shapiro), the Reverend Donald P. Owens, Jr., Ph.D., and Dominique Anwar, M.D. added their professional perspectives and experiences and stimulated an engaging and informative discussion among the audience and presenters. The seminar was moderated by Doreen Dodson, Chair of the Fellows of the American Bar Foundation.

Doreen Dodson began the session and introduced the speakers. Dodson noted that her own interest in the topic of advance directives dates back to the early 1990s when the high profile Nancy Cruzan case prompted the State Bar of Missouri to push for legislation on durable powers of attorney and advance directives. She stated that the main question to be addressed in the panel was “do advance directives actually advance anything or not?”

Like a Fly on the Wall: The Research Method

Shapiro’s research on advance directives is part of a larger ABF research project, “Surrogate Decision Making at the End of Life.” For this project Shapiro is investigating how fiduciaries who act on behalf of those unable to make decisions or

communicate preferences on end-of-life care exercise their responsibilities. By unobtrusively observing and documenting interactions between surrogate decision-makers, family members, friends and medical staff as decisions about end-of-life care were made, Shapiro has compiled a unique data set that helps answer questions about this crucially important topic. Shapiro stated that her theme for the presentation was to “explain why our best laid plans are rarely realized at the end of life, and how limited legal solutions are in that particular context.”

Shapiro began by describing the way she and associate Rachel Billow went about collecting data in two intensive care units at a major urban teaching hospital, during three years of fieldwork.

Research Seminar:

Future: The Role of Near the End of Life

“Every morning, either Rachel or I or both of us would get up very early, we would throw on a white coat and we’d race off to one of the two intensive care units in a large urban teaching hospital in Illinois that serves a very diverse population of patients. Rachel would go to the medical ICU...I would usually go to the neurological intensive care unit. Like a fly on the wall, we would go on critical care rounds every morning and then we would hang out in the hospital throughout the day to observe both spontaneous meetings, planned meetings and various encounters between healthcare providers and families, friends and significant others of patients who did not have the capacity to make their own medical decisions.

After the meetings ended, we reconstructed transcripts of what was said, who said it and how it was said. We also had access to patients’ medical records, we had documentation of whether patients had advance directives, and we examined all of the living wills and powers of attorney that were in the medical records. In the two intensive care units, we observed more than 1,000 of these meetings involving

205 patients who did not have capacity to make their own medical decisions. We observed more than 600 different friends and family members interacting with almost 300 different healthcare providers. To the best of my knowledge, research has never been done this way before at this scale, and as a result I think I have some really important findings to share with you today.”

Shapiro took time to clarify why intensive care units were chosen as the setting for the research, as they represent only one of several sites where end-of-life decisions are made. According to Shapiro, ICUs are relevant research sites because “1) 40 percent of all Medicare enrollees visit an ICU in the last six months of their lives; 2) hospitals are the most common places in which Americans die; 3) ICUs tend to collect patients who lack decisional capacity.”

What Exactly is an Advance Directive and Who Has One?

Before discussing specific research findings Shapiro explained what she means by “advance directives.” Shapiro defines advance directives as “legal documents in which competent

people give instructions regarding healthcare decision-making to be made on their behalf if they should lose capacity in the future.” Further, she explained, there are two kinds of advance directives—proxy directives in which one or more individuals are named to make decisions on a person’s behalf, and instructional directives in which the author provides guidance about the type and amount of treatment he or she would like to have in the future.

Instructional directives are often called “living wills,” Shapiro explained, while proxy directives are often called “power of attorney.” In practice, however, Shapiro noted, in many jurisdictions “these two documents are combined in all sorts of different hybrid documents.” In many states also, state statutes specify who shall be the default decision maker, when no power of attorney is named. Finally, Shapiro noted, in some states, “there are limitations that are placed on the kinds of medical decisions the default decision-makers can make—limitations that are not faced by patients themselves and limitations that often are not faced by powers of attorney, either.”

What was the prevalence of advance directives in the study sample? Shapiro explained that, like most American adults, only a minority of patients or their spokespersons—about 36 percent—claimed to have an advance directive, most often a power of attorney or power of attorney combined with a living will. However, in some cases these purported advance directives did not exist or could not be located. “For only about 1 in 10 patients is there ever a copy of an advance directive in the hospital record, specifying who the patient wants their decision-maker to be or specifying the treatments they prefer and want to have provided for them,” Shapiro stated. Shapiro found that “even when the documents are in the medical record, many physicians do not read them,” nor have many family members read or discussed advance directives with their loved ones.

Shapiro also discussed the demographics of those in the ICUs most likely to have an advance directive. Her research revealed, not surprisingly, that older patients are much more likely to have an advance directive than younger patients. A second important factor was wealth—patients from more affluent neighborhoods were more likely to have an advance directive than those from poorer neighborhoods. Similarly, patients with private health insurance were more likely to have directives than patients who were on public aid or who had no health insurance at all. When race and ethnicity were examined, Shapiro found that white patients were more likely to have an advance directive than Hispanic or Black patients. Finally, Shapiro pointed out, her data showed that health status was far less important than demographics in predicting the

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presence or absence of an advance directive. Patients who were very sick and who had experienced multiple hospitalizations were only slightly more likely to have an advance directive than patients who had generally been healthy. Again, patients who had gone to the hospital for an elective procedure were just barely more likely to have an advance directive than those admitted to the hospital for other reasons.

What Role Did Advance Directives Play in Actual Day-to-Day Conversations between Family and Hospital Staff?

Shapiro found that in 70 percent of cases where the patient had a power of attorney in their medical chart, the person who was designated as power of attorney did, in fact, make all medical decisions. (In 3 percent of cases the designated decision maker made no decisions, and in 25 percent of cases the designated person made some of the medical decisions, or it was unclear who was making the decisions.) The evidence was less compelling, however, when Shapiro examined the role advance directives actually played in day-to-day conversations between families and hospital staff.

For about one third of patients with advance directives in their charts, “the topic of their advance directive was never, ever mentioned once,” Shapiro reported. Further, Shapiro stated, “for patients who claimed to have directives that never came to the hospital, there was no discussion of it for three-quarters of the patients, where you might expect a discussion like ‘Where’s the power of attorney? Are you going to bring it in? What does it say?’”

How useful were advance directives in implementing patient preferences for end-of-life care? Shapiro reported that in about one quarter of patients with advance directives it seemed that the directives did help ensure that patient wishes were honored. Most often when this occurred “the decision-makers knew what the patients’ wishes were, they knew what the patient wanted them to do, but they decided to reread the power of attorney, to reread the advance directive, to talk about it themselves. And they described that doing that gave them a sense of reassurance that they were doing the right thing. It provided closure for them; it tended to assuage their guilt, it made it a little easier for them to make the decision.” Advance directives also helped when

something else.” Finally, a patient’s preferences can change. On occasion, while a patient is still competent he or she will express to the physician that they want something different than what they had initially said in the directive, but they “don’t bother to change the advance directive and they don’t bother to tell their family members. And so what is written in stone are wishes that no longer apply to the patient,” Shapiro stated.

Finally, advance directives can also be counter-productive when the directive itself “stands in the way of making the right decision,” Shapiro noted. Sometimes this happens when the physician misunderstands the directive; at other times, “the surrogate hides behind the directive and refuses to make any decision at all,” Shapiro found. Shapiro and Billow read aloud from another dialogue between a physician and a patient’s family:

NEUROLOGY FELLOW: *She’s having another episode requiring chest compressions. There’s blood coming out of her trach, the chest*

compressions are very aggressive. It’s up to you, as her family, but my recommendation would be to just have them stop doing the compressions and stop trying to resuscitate her. It’s a very painful process and the chances that she would have any neurological functioning after a third cardiac arrest and resuscitation are very low.

SISTER IN LAW: *[in tears]: Just let her go.*

PATIENT’S HUSBAND: *(who is her power of attorney): It’s all on the paper. It’s out of my control. Look, I don’t want her to suffer any more than anyone in this room. Look, you’re the doctor. Just read it. You’re the doctor, you figure it out. Is she gonna be brain-dead?*

NEUROLOGY FELLOW: *I can’t tell you.*

PATIENT’S HUSBAND: *Read it!*

NEUROLOGY FELLOW: *I read it, and I’m very familiar with these forms. Unfortunately they’re very obscure in practice. They rarely translate well to actual situations. I can’t definitively say whether she’ll be in a coma. She has brain stem functioning, so she’s*

not brain-dead. Brain death only occurs when there’s no brain stem functioning even. She could have brain functioning, but be in a persistent vegetative state. I can’t give you any numbers, but I would say that if her heart stops again, the chances of her having any neurological functioning would be next to zero. I think the important thing to think about is this: if she were able to sit here with us and understand what was happening to her, do you think she would want this?

What Happens When a Patient Has No Advance Directive At All?

Shapiro then discussed the experience of the vast majority of patients—those that have no advance directive at all. When looking at patient outcomes, impact on the patient, and characteristics of decisions that were made, Shapiro found no significant differences between those who had advance directives and those who did not. She also found that families of patients who lacked advance directives spent just as much time during the medical decision-making process talking about the “patients’ wishes, their fears, their values, their personalities, their experiences,” as those who did have advance directives.

Shapiro also discussed the Healthcare Surrogate Act, which in Illinois (the state in which the study hospital is located) and in a number of states, denies default decision makers the right to withdraw life support unless the patient meets one of three very narrow conditions—a limitation that is not faced by the power of attorney. Though there were a significant number of default decision makers in the study group, Shapiro found that it



Susan Shapiro and Rachel Billow

“Decision-making in a hospital setting is not easily subject to control—either legally or otherwise. To believe that it provides a false sense of security and probably increases the likelihood that a client or a family member or your own wishes will be undermined. The impulse should be to have less law, less formality, less specificity.”

was very rare for default surrogates to be refused the option of withdrawing life support. Specifically, Shapiro found that 40 percent of families without advance directives in the hospital record withdrew life support (this was true of a little more than 50 percent of those with directives in the hospital record).

Shapiro found many reasons why families were so rarely denied the option of withdrawing life support. Often, she said, “patients meet the requisite conditions of the law, or their medical condition is devastating—even if not precisely what is delineated in the law.” Additionally, Shapiro noted, “many physicians don’t know the law or don’t know the difference between a power of attorney and a default surrogate.” Finally, Shapiro found, “physicians don’t insist on seeing the advance directive document and follow whatever the family says is in the document,” nor will they stand in the way of the “wrenching decisions made by grieving families.” “But when the law is followed,” Shapiro concluded, “it is tragic and so easily avoidable. That is reason enough to execute a power of attorney.”

Put as Little in Writing as Possible

Shapiro closed by sharing some takeaway points for the audience. First, she noted, “Decision-making in a hospital setting is not easily subject to control—either legally or otherwise. To believe that it provides a false sense of security and probably increases the likelihood that a client or a family member or your own wishes will be undermined. The impulse should be to have less law, less formality, less specificity.” Second, when appointing a medical decision maker one should determine who one trusts most to have power of attorney. Shapiro recommended that this be someone one is in frequent contact with, who understands one’s values and preferences, someone who will be able to visit the hospital and confer with—and stand up to if necessary—doctors and family members. The power of attorney should be someone who listens well, who can process complex incomplete information, who can see the forest for the trees. This person should be a consensus builder, Shapiro advised, someone who is able to separate his or her interests from that of the patient. Lastly, as time

goes by, one should evaluate whether this person is still the best choice for power of attorney.

As the excerpts of patient dialogue should make clear, Shapiro recommended “putting as little in writing as possible” in order to avoid boxing one’s power of attorney into a corner or even having the opposite of what one intended carried out. “Only write down what is absolutely non-negotiable” and about which one could “never envision a situation in which the exercise of discretion would be better,” Shapiro advised. “For most of us, such a situation does not exist,” Shapiro believes. Most importantly, we should “talk, talk, talk” with our power of attorney and others who may one day be at our bedside. It is important to talk in specifics, not in platitudes, Shapiro noted. The conversation should be revisited when major life events occur, when one receives a new diagnosis, when the prognosis changes, as quality of life changes. Finally, patients or powers of attorney should ask for an ethics consultation in the hospital if they ever reach an impasse with physicians or relatives, Shapiro concluded.

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A Legal Perspective—Explicit Advance Directives Count (or Do Put Everything in Writing)

Shapiro’s remarks were followed by commentary from the three panelists. Attorney Robyn Shapiro began by stating that while, in principle, she agreed with Susan Shapiro that “less law” is better, in many states it may be “too late” for that, and in those places “advance directives may be critically important, and the more specific the better.” She focused her discussion on the legal issues surrounding end-of-life decision-

making in Wisconsin, recounting details of two State Supreme Court cases. Robyn Shapiro emphasized that there is much legal support for the notion that a person has a right to refuse treatment, and legal support for the idea that an individual doesn’t lose that right when he or she becomes incompetent or incapacitated. “But we have two problems in that situation,” Robyn Shapiro commented, “who speaks for you, and on the basis of what?” Robyn Shapiro stated that, though flawed, advance directives—the more explicit the better—are

the best mechanism we have at the moment to ensure that a patient’s wishes are met.

Power of Attorney and Advance Directive: Choose Wisely, Review Periodically

Father Owens shared some stories involving powers of attorney and advance directives that he had witnessed in his work on the hospital level and as Chair of his hospital’s ethics committee. He stressed the importance of making a very careful choice of power of attorney, choosing a trustworthy person who will honor your values and decisions.

In her remarks, Dr. Anwar drew on her twelve years of experience working in palliative care and serving on hospital ethics committees. She emphasized that in order to avoid unnecessary suffering for patients and families, advance directives and powers of attorney “must be addressed as early as possible with our patients, not waiting until they have developed a severe condition and are not able to talk.” Because patients’ views and wishes can change, doctors should review advance directives with them periodically. Physicians, and hospital or residential staff should know where advance directives are kept. Physicians should also take care to explain fully terms and treatments that may come up in end of life care, such as “cardiopulmonary resuscitation,” “coma,” “tube feeding.” What do these terms mean, what does the treatment consist of, what are the risks and benefits?

Western medicine has developed very potent tools to extend life, Dr. Anwar commented, but we should be asking, “what is the quality of life that results?” Overall, healthcare providers need to

communicate better with patients and families and among themselves. Dr. Anwar ended her remarks by stressing the importance of educating the public about advance directives and powers of attorney, while at the same time teaching medical students from the very beginning of their training about end-of-life issues.

Concluding Thoughts

At the end of the formal presentations the panelists and audience engaged in a question and answer session that led to more discussion. Susan Shapiro in particular noted that the differences in perspective between herself and Robyn Shapiro reflected the differences between a sociologist and a lawyer. “It’s the difference between someone who looks at the top of the legal spectrum and someone who looks at the bottom,” she remarked. “And the problem is that lawyers have to deal with both sides—you have to protect yourself if you’re unlucky enough to end up in the Supreme Court, but the truth is almost no one ends up in the Supreme Court.”

In three years of observations in the two ICUs “a lawyer showed up in the ICU once, in an extraordinarily bizarre case in which the patient was dead and the family didn’t believe it,” Susan Shapiro recounted. “There were no lawsuits, there were no court appearances...law is absent in the ICU.” And so, Susan Shapiro concluded, “law has this very difficult responsibility that, on the one hand, it needs to protect us if we end up in court, but on the other hand, it has to do things that don’t hurt us

because we’re not going to end up in court.” Shapiro advised that people be realistic about what law can and cannot do at the end of life, and that “your most important allies are the people who are going to speak for you” when you yourself are unable.

In further discussion Robyn Shapiro agreed with Susan Shapiro about the

tension inherent in the role of law at the end of life. However, Robyn Shapiro stated that in her work as a lawyer on hospital ethics committees she feels it is her “professional obligation to talk about the law” regardless of whether her comments are ultimately given great weight.



Advance directives and powers of attorney “must be addressed as early as possible with our patients, not waiting until they have developed a severe condition and are not able to talk.”

These and other research findings will be presented in Dr. Shapiro’s article “Advance Directives: The Elusive Goal of Having the Last Word,” forthcoming in *NAELA (National Association of Elder Law Attorneys) Journal*.

If you are interested in supporting research on end-of-life decision making or other important ABF initiatives, please contact Lucinda Underwood at 312.988.6573.

Participant Biographies



Susan Shapiro is a sociologist and Research Professor at the American Bar Foundation in Chicago. She is conducting research in two intensive care units observing how families and others make medical decisions for patients who are unable to speak for themselves. Shapiro is the author of *Tangled Loyalties: Conflict of Interest in Legal Practice*, winner of the Distinguished Book Award of the Sociology of Law Section of the American Sociological Association, and *Wayward Capitalists: Target of the Securities and Exchange Commission*. She has written numerous articles on the role of law at the end of life, surrogate decision making, the legal profession, ethics, conflict of interest, fiduciary relationships and trust, securities fraud and regulation, white-collar crime, and the regulation of “truth” in the news media. Her research has received support from the American Bar Foundation, National Science Foundation, M.D. Anderson Foundation, Gannett Center for Media Studies, Russell Sage Foundation, and National Institute of Justice. Shapiro is a 2012 awardee of a Robert Wood Johnson Foundation Investigator Award in Health Policy Research.

Shapiro was formerly a professor at Northwestern and New York Universities. She received her A.B. from the University of Michigan and Ph.D. from Yale University.



Dr. Dominique Anwar, MD is a Board-Certified physician in Internal Medicine. She was at the head of a Palliative Care Unit and of a Palliative Care Mobile Team in Switzerland from 2000 to 2009, and also involved in education and clinical research at the academic level. Since 2009, Dr. Anwar has been an Associate Professor of Clinical Medicine of the Section of Internal Medicine and Geriatrics of Tulane School of Medicine, and the head of the Palliative Care Program. She directs a Supportive and Palliative Clinic at the Tulane Cancer Center and serves as Medical Director for two local hospice agencies. She is also very active in medical education and clinical research. After completing her certification in Clinical Ethics, Dr. Anwar served as a member of various Ethics Committees, including Tulane’s. She is a member of several medical associations and serves on the Board of the Palliative Care Institute of Southeast Louisiana.



Doreen D. Dodson is Chair of The Fellows of the American Bar Foundation. As a partner in the Stolar Partnership LLP, Doreen represents for profit, non-profit and governmental entities in a range of legal matters, sometimes serving in the capacity of outside General Counsel. For these clients, Doreen provides corporate advice, including employment and immigration counsel.

Doreen is a past President of The Missouri Bar, currently serves as one of its delegates to the American Bar Association House of Delegates and has chaired other entities in the ABA. During her year as President of The Missouri Bar, the Bar’s first legislative priority, which arose from the Nancy Cruzan case, was to pass a law providing for Durable Powers of Attorney for Healthcare and health care directives. A grass roots coalition of medical and legal professionals and representatives of various religious and senior citizen groups successfully passed the legislation.



The Reverend Donald P. Owens, Jr., Ph.D. received his undergraduate degree from Trinity University, San Antonio, Texas; Master of Divinity from Pittsburgh Theological Seminary; and Ph.D. from the University of Oklahoma in Philosophy and Psychology. He is an ordained Priest in the Episcopal Church. Father Owens is married. He and wife, Barbara, have four children. He served as the Episcopal Chaplain to the University of Oklahoma, Norman, for twenty-five years before coming to Tulane University Health Sciences Center as Chaplain in August, 2000. Fr. Owens holds two academic appointments, as Professor in the Department of Medicine and the Department of Psychiatry. He holds the James A. Knight, M.D. Chair of Humanities and Ethics in Medicine. He is the co-chair of the Tulane University and Hospital Ethics Committee. He is a Licensed Professional Counselor, and a Licensed Marriage and Family Therapist.

Fr. Owens is a Member of the American Society for Bioethics and Humanities, American Counseling Association, American Association for Marriage and Family Therapy, and Life Fellow American Psychotherapy Association.



Robyn S. Shapiro, health law partner and Regional Partner in Charge in the Milwaukee office of Drinker Biddle & Reath LLP, has significant experience in representing clients with respect to bioethics issues, research compliance issues, medical staff matters, health information privacy issues, informed consent, regulatory and licensing matters, and employment and other business issues. Attorney Shapiro's past position as Ursula von Der Ruhr Professor of Bioethics at the Medical College of Wisconsin, and her 26-year leadership as Director of the Center for the Study of Bioethics at the Medical College of Wisconsin complements her wide-ranging experience in health law. Ms. Shapiro is listed in the *Best Lawyers in America*, *Who's Who in American Law*, *Who's Who in America*, *Who's Who of American Women*, *Who's Who of Emerging Leaders of America*, *Who's Who in the Midwest*, *International Who's Who*, *Who's Who in the World*, *Who's Who in American Education*; and *Wisconsin Super Lawyers*; she was included in *Nightingale's* 2006 list of "Outstanding Hospital Lawyers" in the nation; in 2006 she was one of 12 honorees selected as a "Leader in the Law" by the *Wisconsin Law Journal*; in 2011 she was named a "Woman of Influence" by the *Milwaukee Business Journal*; and in 2011 she was named Milwaukee's Health Care Law "Lawyer of the Year" by *Best Lawyers*.



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