

ADVANCE DIRECTIVES: THE ELUSIVE GOAL OF HAVING THE LAST WORD

By Susan P. Shapiro, PhD

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I. INTRODUCTION

One of the more controversial elements of the debate over health care reform in the United States concerned a rather benign proposal to compensate physicians for conversations held at most once every five years, if requested by Medicare patients, about advance directives¹ and patient preferences regarding future medical treatment. It is curious that crit-

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1 Advance directives are legal documents in which competent adults give instructions regarding their health care in the event they lose decisional capacity in the future. There are generally two types of directives: proxy directives designate one or more persons to make health care decisions on a person's behalf; instructional directives provide guidance about the type and amount of care desired. Instructional

ics were so fearful that this would inevitably lead to “death panels” in which infirm or elderly patients would be coerced into ending their lives. Existing research and theory have repeatedly demonstrated the extraordinary difficulty of affecting end-of-life decision making. For example, a massive social experiment undertaken 20 years ago involving 9,000 seriously ill patients across five hospitals found that an intervention: 1) enhanced communication between patients, families, and medical staff; 2) supplied greater prognostic information to each of them; and 3) provided ongoing opportunities for patients or their spokespersons to articulate their wishes and preferences regarding treatment with treating physicians, made no difference. With great surprise, the investigators reported that:

[P]atients experienced no improvement in patient-physician communication... or in the five targeted outcomes[:]... incidence or timing of DNR orders... physicians’ knowledge of their patients’ preferences not to be resuscitated... number of days spent in an ICU, on a ventilator, or in a coma before death... or level of reported pain... . The intervention also did not reduce use of hospital resources... .²

They concluded that the “study certainly casts a pall over any claim that, if the health care system is given additional resources for collaborative decision making in the form of skilled professional time, improvements will occur.”³

Despite repeated campaigns for decades, coupled with regulations that require all hospitals to offer advance directives to patients upon admission, a substantial majority of Americans have not executed advance directives.⁴ Moreover, comprehensive reviews of the empirical and theoretical literature have documented the failure of instructional directives such as living wills as effective means of guiding medical decision making for patients unable to speak for themselves.⁵

In short, the prospect of giving patients the last word about their goals of medical care has received little empirical support. However, an article recently published in the influential *New England Journal of Medicine*⁶ finds advance directives both prevalent and

directives are sometimes referred to as living wills and proxy directives as durable powers of attorney for health care. In practice, proxy and instructional directives may be combined in various hybrid documents, depending on jurisdiction.

2 SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)* 274 J. Amer. Med. Assn., 1591, 1591 (no. 20, 1995).

3 *Id.* at 1596.

4 Pew Research Center for the People & the Press, *Strong Public Support for Right to Die: More Americans Discussing — and Planning — End-of-Life Treatment* (Jan. 5, 2006), <http://people-press.org/report/266/strong-public-support-for-right-to-die>; AARP, *AARP Bulletin Poll: Getting Ready to Go* (Jan. 2008), http://assets.aarp.org/rgcenter/il/getting_ready.pdf; ABA, *ABA-Commissioned Poll Finds More Than Twice as Many Americans Talk About Planning for Healthcare Emergencies than Take Action* (May 14, 2008), https://www.abanet.org/abanet/media/release/news_release.cfm?releaseid=345.

5 Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 Hastings Ctr. Rpt. 30 (No. 2, 2004), http://www.thehastingscenter.org/pdf/publications/hcr_mar_apr_2004_enough.pdf.

6 Maria J. Silveira, Scott Y.H. Kim & Kenneth M. Langa, *Advance Directives and Outcomes of Surrogate Decision Making Before Death*, 362 New England J. Med. 1211 (2010), <http://www.nejm.org/doi>

effective. The authors make three primary claims based on a large representative sample of U.S. adults 60-years-old or older who had died between 2000 and 2006:

1. “Among subjects who needed surrogate decision making, 67.6% had an advance directive. ...The fact that so many elderly adults complete advance directives suggests that they find these documents familiar, available, and acceptable. Moreover, it suggests that elderly patients, their families, and perhaps their health care providers think that advance directives have value.”⁷
2. “Patients who had prepared advance directives received care that was strongly associated with their preferences.”⁸
3. “Both a living will and durable power of attorney for health care appear to have a significant effect on the outcomes of decision making.”⁹

The authors conclude that “advance directives are important tools for providing care in keeping with patients’ wishes”¹⁰ and that their “findings support the continued use of advance directives.”¹¹ The study was cited in short-lived Medicare regulations that authorized compensation for advance care planning in wellness visits for Medicare patients.¹²

Unfortunately, the *New England Journal of Medicine* study (the “Proxy Study”) is compromised by four methodological limitations, some of them acknowledged by the authors,¹³ which call these findings into question. First, researchers had no independent measures of whether the subjects had actually ever executed an advance directive, what was contained therein, or the nature of their end-of-life medical care.¹⁴ Data were obtained from family members (called “proxy respondents”) on average 13 months after the subjects had died. As the authors themselves concede, the proxies were “subject to recall and social-desirability biases, especially with regard to subjective details such as patients’ preferences.”¹⁵ Proxy respondents were not asked how they knew the subject had an advance directive or whether or when they had ever seen it or even whether their recollections were of legally documented instructions. Investigators simply took their word.

These proxy respondents were usually (80 percent of them)¹⁶ the same persons who had made medical decisions on behalf of patients lacking capacity before they died. Over-

full/10.1056/NEJMsa0907901#t=article.

7 *Id.* at 1216–1217.

8 *Id.* at 1211.

9 *Id.* at 1218.

10 *Id.*

11 *Id.* at 1211.

12 75 Fed. Reg. 73170, 73406 (Nov. 29, 2010).

13 Silveira et al., *supra* n. 6, at 1217–1218.

14 *Supplementary Appendix* to Maria J. Silveira, Scott Y.H. Kim & Kenneth M. Langa, *Advance Directives and Outcomes of Surrogate Decision Making Before Death*, 362 *New England J. Med.* 1211 (2010), http://www.nejm.org/doi/suppl/10.1056/NEJMsa0907901/suppl_file/nejm_silveira_1211sa1.pdf.

15 Silveira et al., *supra* n. 6, at 1217.

16 *Id.* at 1214.

whelmingly (94 percent),¹⁷ these proxy respondents chose to forego measures to prolong life. In essence, the interviews asked those charged with following the advance directive whether they did. The finding that these directives “have a significant effect on the outcomes of decision making” is not persuasive when there is no independent measure of either variable other than proxy reports. Rather, it appears that those who had responsibility for ending the life of a loved one remember, 13 months later, that this is what their loved one wanted.

Second, the Proxy Study’s classification of advance directives does not correspond to real-world choices. There is a plethora of legal statutes, forms, and options across the 50 states through which patients are able to express their preferences for care at the end of life. In some states, these advance directives include complex check lists and flow charts through which patients pick and choose different treatment options for different diagnoses and prognoses, expand or limit the discretion of decision makers, and allow for decisions to change over time or even by cost. Unfortunately, these detailed instructions do not correspond to the categories that the researchers gave proxy respondents to classify patients’ written directives. Rather, the Proxy Study used the following three categories, a desire to:

1. “... receive all care possible under any circumstances in order to prolong life,”
2. “... limit care in certain situations,” or
3. “... keep [her/him] comfortable and pain free but to forego extensive measures to prolong life.”¹⁸

Presumably, investigators came up with these categories as least common denominators that capture the enormous diversity in advance directives across the 50 states. In doing so, however, they may have inadvertently created the very findings they observe. The fact that interview categories were broader than the actual options available on advance-directive forms, capturing so many distinct and sometimes inconsistent contingencies, may explain why the study found that care was strongly associated with patient preferences. For example, if the advance directive indicated that life support be removed only if in an irreversible coma and life support was subsequently withdrawn from the non-comatose patient because of concerns about future quality of life, proxies would report both preferences and treatment as “limiting care in certain situations,” despite the fact that the situations are by no means equivalent.

Third, the Proxy Study’s analysis only pertains to decedents whose proxies indicated had executed advance directives. Since aggressive care is the legal default, living-will-type directives in many states only allow for requests to withhold or withdraw treatment. Those opting for full treatment to prolong life, therefore, have no reason (and in some states, no legal document in which) to make written instructions. The Proxy Study exhibits a profound selection bias that over-represents those whose goals of care are to limit treatment and under-represents those who want aggressive care. This is exacerbated by the fact that there is a correlation between the desire for aggressive care and certain de-

17 *Id.* at 1217 (calculations from Table 3).

18 *Supplementary Appendix, supra* n. 14.

mographic characteristics — race, for example — which, in turn, are correlated with the absence of formal legal directives. The Proxy Study's focus on only those allegedly with directives may thus under-represent important demographic groups.

Fourth, interviews assume a single decision point. Proxy respondents were asked, "Did those last decisions involve a desire to give all care possible unconditionally in order to prolong life; involve limiting care in certain situations; rest largely on keeping the patient comfortable and pain free without taking extensive measures to prolong life?"¹⁹ Many respondents could have answered, "yes" to all three questions. As described below, dozens of medical decisions are made in the last days or weeks of life, especially for hospitalized patients, and it is not at all unusual for decisions to shift from one category to the next, sometimes back and forth. Is fidelity to the patient's wishes measured by what decision is ultimately made or how long it took to implement these wishes or how many interventions were pursued along the way to comfort care? The Proxy Study interviews provide no guidance.

What the Proxy Study does tell us, however, is something about how those responsible for the death of a loved one remember the end of their lives. It tells us far less about whether, how, or under what conditions advance directives have an impact on how they die or how others survive.

II. METHOD

This paper reexamines these questions about the impact of advance directives with data that do not share the methodological limitations of the Proxy Study.²⁰ The data here come from a multi-year observational study of more than 2,000 patients who passed through either the neurological or the medical intensive care units (ICU) of a large urban teaching hospital in Illinois serving a demographically diverse²¹ population of patients from early 2007 until late 2009. The neurological ICU houses patients experiencing brain trauma, hemorrhages, strokes, seizures, brain cancers, and spinal cord injuries. Patients in the medical ICU suffered from organ failures, sepsis, respiratory distress, other cancers, bleeding, and so on. Two-hundred five of these patients lacked capacity to make medical decisions;²² observations focused on those who spoke on their behalf. These surrogate decision makers faced a host of decisions, ranging from whether to undertake surgery or other medical procedures to whether to withhold or withdraw life support or donate the patient's organs.

From daily rounds with the critical care team, observations of more than 1,000 en-

19 *Id.*

20 The Proxy Study certainly has important strengths. It is based on a very large national representative sample of all deaths of Americans 60 years of age or older, not only those that occur in hospitals. Limitations of the study reported here are assessed in the conclusion of this article.

21 As shown in Table 2, patients are very diverse, reflecting demographic trends nationwide.

22 Specifically, the observational study included all ICU patients deemed by their physicians to be unable to make medical decisions and about whom at least three interactions between health care providers and patient representatives or a discussion regarding goals of care or consent to a medical procedure were observed. Many ICU patients (especially those admitted after a surgical procedure) do not lack or quickly regain competence or are discharged from the ICU in a day or two before any treatment decisions are made; for others, families never visit and there are no encounters to observe. That is why a relatively small proportion of all ICU patients were the focus of the observational study.

counters between almost 300 health care providers and more than 600 patient families and friends throughout the day, and both paper and electronic medical records, data were gathered on patient medical histories, the medical issues and decisions they faced, the interventions made on their behalf, the disposition of their hospital stay, their advance directives (if any), their demographic characteristics as well as those of other participants in the decision-making process, and what transpired in meetings and conversations with their representatives regarding their medical care.²³

Observations were conducted by the author and a social worker. To minimize the risk that the act of observing might influence the activities being observed, encounters were not tape recorded nor were notes taken. At their conclusion, the observers recreated transcripts of what was said, by whom, and documented the dynamics of the interaction and characteristics of the meeting and participants. Excerpts from a few of the 1,000-plus transcripts are presented throughout this article. For each patient, the actual advance directives in the hospital chart were examined, the actual decisions made on behalf of the patients, day after day, were known, and the process by which and articulated reasons for which these decisions were made were observed.

III. FINDINGS

In the following sections, I describe the prevalence of advance directives and the characteristics of ICU patients who have them, the content of legal directives, the verbal instructions and expressed wishes of patients reported by their significant others, the difficulties interpreting and following these written directives and verbal instructions, and the impact of advance directives on the decision-making process and outcomes, especially the likelihood that patient wishes are honored.

A. Prevalence of Advance Directives

When patients are admitted to the ICU, the patients or the persons who accompany them are asked whether they have or the patient would like to complete an advance directive — in Illinois, a power of attorney for health care, naming a proxy decision maker and possibly optional instructions, and/or a living will.²⁴ For the majority of patients in the two ICUs in the study, the answer to both questions is “no.” Table 1 demonstrates that a little more than a third of all the patients who passed through the two ICUs or their spokespersons report an advance directive or complete one during the hospitalization.²⁵ Powers of attorney are most common among those who do; 91 percent claim to have powers of attorney and 54 percent living wills. Despite continual prodding of family members to bring in copies of these advance directives, few ever appear in the patient’s chart; it is not clear

23 The research protocol was reviewed and approved by the hospital’s Institutional Review Board as well as that of the American Bar Foundation.

24 For the wording of Illinois power-of-attorney and living-will documents, see *infra* nn. 32 and 33.

25 The percentage of patients with directives among those from whom hospital staff were able to obtain such information is higher (46 percent) than that for all ICU patients; however, this is not really the relevant number. Missing information (whatever the reason) means no directive. When medical decisions invariably need to be made, only a third of patients have a legally authorized decision maker and/or legally documented wishes.

that many of them actually exist.²⁶ Only one in ten of the patients have any documentation in their medical record of their wishes and/or of their legally designated medical decision maker.

TABLE 1: ADVANCE DIRECTIVES IN THE ICUS

No Advance Directive (AD) ¹	936	42%
Only Power of Attorney (POA)	365	16%
Only Living Will (LW)	74	3%
Both POA and LW	351	16%
Hospital did not or could not obtain AD information ²	490	22%
All ICU Patients	2,216	
POA and/or LW in Chart	212	10%

- 1 This includes patients who were offered the opportunity to complete an advance directive and chose not to.
- 2 In some cases (especially with emergency admissions), patients were comatose or incompetent and thus could not be asked about their advance directives and no family was around to ask. Although nurses were reminded to ask for this information throughout the admission, some did not or were not successful in obtaining this information.

These data are not especially reliable in the best of worlds, and even less so in an intensive care unit where many patients arrive comatose, confused, intubated, or heavily sedated. Members of the patient's entourage may not know whether the patient had any advance directives and, if so, what the patient specified. It may depend on which member of the patient's entourage is interviewed by hospital staff or even who conducts the interview. Significant others sometimes report their assumptions rather than actual knowledge; while other patients have no significant other to question. When asked about advance directives, patients and others are not always given explanations of the categories and frequently pick the wrong ones. Many, for example, assume that a presumptive decision maker is a power of attorney and do not realize that a witnessed and signed document is needed; others assume that a power of attorney for financial matters is the same thing as

26 Patients may misremember, misunderstand, or tell hospital staff what they think staff want to hear. When patients lack capacity, as ICU patients often do, advance directive status is reported by significant others who are even less likely to have correct information. Fried et al. found that 13 percent of surrogates report the existence of living wills and 28 percent report the existence of health care proxy documents that patients did not complete. (Another 6 percent and 4 percent, respectively, erroneously report that these documents were not completed.) Studies that rely on anyone's account of the existence of a directive undoubtedly overreport the prevalence of completion. Terri R. Fried, Colleen A. Redding, Mark L. Robbins, John R. O'Leary & Lynne Lannone, *Agreement Between Older Persons and Their Surrogate Decision-Makers Regarding Participation in Advance Care Planning*, 59 J. Amer. Geriatrics Socy. 1105 (2011).

one for medical decisions.²⁷ In some unknown number of instances, a legal document may exist, but may not reflect the wishes of the patient. For example:

Attending Physician: I see that you brought in the power-of-attorney document. It was from 2001.

Patient's Son: She was at [a different hospital] at the time. I believe that a chaplain brought the form in. He read it to us. She could barely understand it.

Attending Physician: I've looked over the form. You see here, your mother checked this box that says that she wants to have aggressive care unless she is in an irreversible coma.

Patient's Son: Yes. I never really read the form. That's what she is now.

Attending Physician: Unfortunately, a coma is a medical term with a very precise meaning. Your mother is not in a coma. She may experience some cognitive limitations — severe cognitive limitations — but they are not a coma, and not an irreversible coma. This hospital has a strict policy that if this box is checked, we have to provide aggressive care, even if that's not what the patient would have wanted or even told their family...

Patient's Son: So you are saying that she has to have a trach???? [PAUSE] You know, this document... She didn't understand it. She was pretty demented. I was sitting there while the chaplain was reading to her. Basically, I told him what to do. I thought a coma was pretty much what she is in now. I checked the box.²⁸

Attending Physician: Unfortunately we have to follow the law. This is so difficult. I'm really sorry.

Of course, if the patient's son (or the patient's daughter in the previous footnote), like most families, had not brought in the power-of-attorney form, no one would have ever discovered the problem. These sorts of scenarios are undoubtedly not uncommon. Research on the social construction of advance directive documents is sorely needed.

As indicated earlier, the Proxy Study found that proxy respondents reported that two-thirds of all decedents 60 or older who lacked decision-making capacity had an advance directive. This is quite high compared with the overall rate in the two ICUs I studied and with that documented by other researchers.²⁹ The difference could be attributed to the

27 One patient in the study had been in the ICU for two weeks. After days of wrenching conversations, the family decided to remove her life support. At the insistence of a physician, the patient's daughter brought in a copy of the power-of-attorney form; however, the document only addressed the handling of financial matters. Under Illinois law, only a designated power of attorney for health care is permitted to remove life support from a patient who does not have a qualifying medical condition, which this patient did not have. The family was stunned and infuriated by the news that the life support had to continue.

28 Indeed, on examination of the form, the check mark was strong and legible, whereas the patient's signature was a thin meandering undecipherable line across the diagonal of the page.

29 Recent studies find advance directive use ranging from 29 percent to 37 percent, Pew Research Center for the People & the Press, AARP, and ABA, *supra* n. 4.

limited demographic group considered in the Proxy Study. Using the inclusion criteria employed by the Proxy Study, among the patients in the two ICUs who were also 60 or older, lacking capacity, and who ultimately died during their hospitalization, 65 percent had advance directives (compared to 36 percent of all ICU patients). The roughly two-thirds rate in both studies reflects a very narrow slice of the adult population. The Proxy Study uses this limited demographic group to celebrate the widespread prevalence and what they infer to be the acceptance of advance directives. The ICU data — with directives reported by roughly half this proportion, even among those sick enough to be in an intensive care unit — suggest otherwise.

The ICU data reveal large differences in the likelihood of having an advance directive by a variety of demographic characteristics. As reflected in Table 2, the most important

TABLE 2: CHARACTERISTICS OF ICU PATIENTS WITH ADVANCE DIRECTIVES

Characteristic (N)	Percent of Those Asked Who Report an Advance Directive
Gender	
Female (866)	46%
Male (860)	46%
Age	
30 or less (153)	21%
31-50 (457)	28%
51-65 (549)	48%
66-75 (319)	56%
More than 75 (248)	76%
Race/Ethnicity	
White (1127)	56%
Black (377)	27%
Hispanic (109)	20%
Other (77)	32%
Wealth of Residential Neighborhood¹	
Poorest zip code (446)	35%
Medium zip code (837)	46%
Richest zip code (441)	57%
Health Insurance	
No insurance (214)	22%
Public aid (104)	16%
Private insurance (768)	43%
Medicare (636)	62%
Medical History	
Unexpected emergency (502)	39%
General health problems (295)	40%
Long-standing problem (929)	51%
Elective hospitalization	
No (1446)	45%
Yes (280)	50%

1 Median household income, as reported in the 2000 census, for the poorest ZIP codes was less than \$38,500 and for the richest zip codes exceeded \$64,000; the range was \$14,200 to \$200,000.

predictor that an ICU patient is said to have an advance directive is age: the proportion rises in a linear fashion from 21 percent of patients 30 or younger to 76 percent of those over 75. The influence of age is also reflected in the fact that patients on Medicare have the highest rates of advance directives (62 percent) among those with different health insurance arrangements. Wealth is a second predictor with patients residing in the poorest zip codes and with no medical insurance or on public aid having substantially lower rates of advance directive use. The prevalence of advance directives also varies by race and ethnicity. African American and Hispanic patients report substantially fewer advance directives than their white counterparts.³⁰ Finally, although patients with longstanding medical problems or who are hospitalized for elective procedures are more likely to have advance directives than those who are admitted to the ICU after an unexpected emergency, the differences are not as large as one might expect and certainly smaller than the other characteristics.³¹

B. Written Instructions

Limited data are available about patients' legally articulated wishes as only approximately 10 percent of all ICU patients (27 percent of those with advance directives) had directives brought to the hospital or executed directives while at the hospital. These limitations are also faced by medical staff; most of the time there is no document on hand indicating who the patient selected as the power of attorney or if written wishes were expressed and, if so, what they are.

Table 3 summarizes the content of the advance directives in the hospital record for the patients lacking decisional capacity who were the subject of the observational study. The Illinois power-of-attorney form offers optional check boxes regarding general treatment preferences.³² Eighty-two percent of patients in the observational study with a power of attorney in the chart check one of the boxes. By far, patients give their powers of attorney the most discretion, authorizing them not to prolong life if the burdens outweigh the benefits (this is

30 The relationship between having an advance directive and age, ethnicity, and wealth remains strong when controlling for the other variables.

31 Twenty of the patients had worked in the legal or medical field, where one might expect greater use of advance directives. One quarter of them had no directive, 55 percent reported having an advance directive that never made it to the hospital, and 20 percent had their directives in the hospital record.

32 The options included the following:

- "I do not want my life to be prolonged nor do I want life-sustaining treatment to be provided or continued if my agent believes the burdens of the treatment outweigh the expected benefits. I want my agent to consider the relief of suffering, the expense involved and the quality as well as the possible extension of my life in making decisions concerning life-sustaining treatment."
- "I want my life to be prolonged and I want life-sustaining treatment to be provided or continued unless I am in a coma which [sic] my attending physician believes to be irreversible, in accordance with reasonable medical standards at the time of reference. If and when I have suffered irreversible coma, I want life-sustaining treatment to be withheld or discontinued."
- "I want my life to be prolonged to the greatest extent possible without regard to my condition, the chances I have for recovery or the cost of the procedures."

Illinois Statutory Short Form Power of Attorney for Health Care, IL ST CH 755 § 45/4-10. Effective July 22, 2004 to June 30, 2011. Enacted Legislation P.A. 93-794, § 45, eff. July 22, 2004, <http://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=097-0148>. Illinois changed the wording of these options somewhat after the conclusion of the study.

TABLE 3: WISHES EXPRESSED IN ADVANCE DIRECTIVES IN THE PATIENT'S CHART¹

Wishes expressed in Power of Attorney	Percent of Total:		
	No Living Will	Wishes expressed in Living Will Terminal/ Imminent Death	Total
No Power of Attorney		(7) 15%	(7) 15%
No Boxes Checked	(7) 15%		(7) 15%
Prolong Regardless	(3) 6%		(3) 6%
Prolong Unless Coma	(3) 6%	(1) 2%	(4) 9%
Weigh Benefits/Burdens	(24) 51%	(2) 4%	(26) 55%
Total	(37) 79%	(10) 21%	(47) 100%

- 1 See Illinois Statutory Short Form Power of Attorney for Health Care, *supra* n. 32, for the exact wording of the options in the form, which are simplified in the row names in Table 3. The wording of the “terminal/imminent death” column reflects the standard language used in Illinois living wills. See Illinois Living Will, *infra* n. 33.

true of 79 percent of those who check an option on their power-of-attorney form). Substantially fewer (9 percent) ask that life be prolonged to the greatest extent possible or that it be prolonged unless the patient has an irreversible coma (12 percent). A number of patients also executed living wills. The Illinois living-will form contains boiler-plate language that states that death should not be artificially postponed if the individual has an incurable, irreversible, terminal condition and death is imminent;³³ 5 percent of the charts of the 205 patients in the observational study contained copies of living wills.

A handful of patients added additional statements to their advance directives. A fifth specified that they did or did not want to donate organs. Four percent approved of treatment only if it is likely that they will return to their current lifestyle or level of functioning. A few addressed quality of life (2 percent), nutrition and hydration (13 percent), loss of mental capacity or being in a persistent vegetative state (8 percent), eschewed specific procedures or heroic measures (6 percent), or requested cremation (6 percent). Other individuals wrote explicitly that they do not want cost to be a consideration; do not want to be in pain; do not want dialysis, surgery, or chemotherapy; want to die of natural causes, not on life support; want to be able to eat and drink without medical assistance. One penciled in that she wanted her life prolonged as long as possible, even if it meant being kept alive on machines for years; she also indicated that she does not want blood products, but

33 “If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition by my attending physician who has personally examined me and has determined that my death is imminent except for death delaying procedures, I direct that such procedures which would only prolong the dying process be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.” *Illinois Living Will, in Illinois Living Will Act*, http://www.state.il.us/aging/1news_pubs/publications/poa_will.pdf.

would consider blood fractions or medical procedures involving the use of her own blood. Four percent of the patients had a pre-existing “Do Not Resuscitate” order.

Advance directives provide one mechanism for individuals to have the last word about their medical care. But, as we have seen, they are infrequently completed and rarely available to medical staff. Even when the documents are included in the medical record, they often do not articulate the patient’s wishes or simply give decision-makers wide discretion (authorizing them to weigh benefits and burdens of treatment without articulating what they personally consider beneficial or burdensome or how these factors should be weighted). When they express the patient’s wishes, directives often provide abstract guidance not easily translated to the nuanced contingencies of real-world patient care. The following demonstrates the paralysis that ensues when the surrogate refuses to play an interpretive role and insists that the advance directive be literally followed.

Critical Care Fellow: Okay, why don't I start by giving you an update of what's going on. Earlier this morning, [Patient] needed platelets. When the nurse gave her the platelets, her blood pressure went up to the 230s, so we gave her medications to bring it back down. At that point, her blood pressure fell very low and her heart stopped. We performed CPR, including aggressive chest compressions, for about 15 minutes. She suffered during that process. We were about to call it because it didn't seem like we'd be able to bring her back. But at the last minute, she regained a pulse. We gave her the max dose of pressors to keep her blood pressure up. Then just a short time later, her heart stopped again. We did more compressions for about 8 or 9 minutes until she regained a pulse. Now, the question I know you're wondering about is what her prognosis is. That's what I would want to know, whether she would regain her neurological functioning. She does have brain stem functioning now, which is what you need to breathe, for your heart to pump blood. We have a neuro intensivist on staff who did a full neurological exam on her before I came in to talk to you folks. She does not have higher functioning capabilities now. So she can't interact, or think or any of that. It's too soon to know for certain whether that will ever come back, but given the two arrests, it is very unlikely. If you wanted us to confirm that, we could do some diagnostic tests that would determine with greater certainty, but those take three days and seven days to get the results. What we do know is that her pupils are very dilated. When her blood pressure got so high, we think there might have been a bleed in her brain.

Husband: A stroke?

Critical Care Fellow: Yes. Now we look to you, her loved ones. You know her and love her, and so it's important for you to tell us what you think her wishes would be in this situation.

Husband: She has a living will. [HUSBAND STANDS UP AND WALKS OVER TO HIS BRIEFCASE. HE OPENS IT UP, TAKES OUT

A MANILLA ENVELOPE, AND PUTS THE LIVING WILL (WHICH IS ACTUALLY A POWER-OF-ATTORNEY FORM) ON THE TABLE IN FRONT OF THE CRITICAL CARE FELLOW.] [CRITICAL CARE FELLOW READS IT.]

Critical Care Fellow: I think this is where she's at now. I'm so sorry.

Husband: I knew this day was gonna come, I just didn't realize it would be so soon. Oh, [Patient]! [HUSBAND STANDS UP AND WALKS OVER TO THE WINDOW. HE'S CRYING AT FIRST, AND THEN BREAKS DOWN AND BEGINS CRYING HYSTERICALLY, SOBBING LOUDLY.]

Patient's Brother: So are we making a decision today?

Husband: No, [Brother]. I'm not making any decisions. It's all in the living will; so don't even go there. Don't put this on me! [HUSBAND IS POINTING AT HIM AND SHAKING HIS FINGER AT HIM.]

Patient's Brother: I'm not, [Husband]. So what do we do now? Do we go home?

Critical Care Fellow: It's up to you.

Husband: We have to wait for the tests.

Critical Care Fellow: Right. Some families would say just stop. That's why I wanted to talk to you all.

Husband: They're saying she's clinically dead. But she's still hangin' on. So now we wait for the tests.

Critical Care Fellow: Would it be helpful to have the neurologist who examined her come and answer any questions you may have?

Husband: Sure.

Critical Care Fellow: Okay, I'll go get him.

.....

ABOUT 15 MINUTES LATER, AFTER THE PATIENT HAD A THIRD CARDIAC ARREST:

Neurology Fellow: She is 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.

Patient's Sister-in-law: [IN TEARS] Just let her go!

Husband: 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. [HE SHOVES THE ADVANCE DIRECTIVE FORM IN FRONT OF THE NEUROLOGY FELLOW.] 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-

Husband: Read it!!

Neurology Fellow: [GLANCES AT THE FORM AND THEN PUTS HIS HAND ON THE HUSBAND'S ARM.] 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 will be in a coma. She has brain stem functioning, so she's not brain dead. Brain death only occurs when there is 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 chance 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 that she would want this?

C. Verbal Instructions

A complementary or alternative strategy to have the last word is to express one's wishes, values, and priorities directly to one's physicians, power of attorney, loved ones, friends, and colleagues while still capable of doing so, perhaps repeatedly. There is no way of knowing how many of these conversations occur over a lifetime, with how many persons, how frequently, how recently, what provokes them, or how consistent is their message. We do know, though, how these conversations are invoked or reported at the bedside and how often families report that they never had such a conversation with the patient and are clueless about his or her wishes.³⁴

From observing hundreds of hours of interactions and formal family meetings between physicians and patient family and friends, the researchers recorded reports of the patients' expressed wishes, often made over the course of a lifetime.³⁵ Meeting participants described previously expressed wishes of 43 percent of the patients (ranging from two-thirds of those whose directives were in their chart, to 36 percent of those without advance directives). Almost three-quarters of the time, family members initiated discussions of the patient's expressed wishes (as opposed to medical staff who would ask if the patient had ever expressed any wishes). Of course, many families may not have shared the patient's wishes during meetings with medical staff, especially if they were not asked about them; this does not mean that patients had not previously expressed their wishes or that those wishes were not instrumental in the medical decisions families made on behalf of their loved ones.

Table 4 summarizes the words conveyed by those who reported these conversations with patients, along with the frequency of expressions. Patient wishes represent several themes, many of them also expressed in the statements that patients appended to their advance directives. Patients who requested that interventions be limited and that goals of

34 When asked by physicians, family members of 7 percent of the patients reported that they had never discussed the patients' wishes with them. Clearly, this failure to discuss wishes is more common, but many families were never asked about it directly.

35 Of course, these reports may be inaccurate, selective or incomplete, outdated, self-serving, or even fabricated. It is fairly rare, though, that one friend or family member disagrees with another's memory of the patient's expressed wishes or values.

care be conditional far outnumber those whose goals of care were unconditional or sought everything to be done. Goals of care were generally conditional on the likelihood of recovery, quality of life, and brain function. Few patients reportedly included a temporal dimension in their expressions — that interventions were acceptable for a brief trial, but should not be prolonged. Generally, the wishes reported by family members were consistent with instructions noted in advance directives, with one exception: Patients who had checked the box on their power-of-attorney form that everything should be done unless they are in an irreversible coma reportedly expressed wishes that were incompatible, e.g., not wanting to continue if they are in pain or if unable to function.

TABLE 4: REPORTS OF PATIENTS’ EXPRESSED WISHES¹

Reports of Wishes (Number)	Reports of Wishes (Number)
<p>Statements about medical procedures</p> <ul style="list-style-type: none"> • No surgery (1) • No life support/machines (6) • No tubes (3) • No intubation (6) • No ventilator (6) • No feeding tube (2) • No resuscitation; no “code blue” (5) • No blood transfusions (1) • Wants nutrition; does not believe in starvation (1) • No sedation (1) • Nothing invasive (1) • No aggressive care (3) • No heroic or exceptional measures (2) • Does not want to be brought to the hospital (1) <p>Unconditional goals of care</p> <ul style="list-style-type: none"> • Do everything you can to keep me alive (5) • Is not ready [to die] (1) • Wants to live (2) • Doesn’t want to be kept alive (1) • Wants to be allowed to pass naturally and peacefully (1) • Doesn’t want to continue living the way he/she is living (3) • Doesn’t want to suffer any more (1) • Patient chose this intervention; knew it was going to be tough (i.e., doesn’t want to quit) (3) • Wants hospice (1) 	<p>Contingent goals of care</p> <ul style="list-style-type: none"> • Unless about to die, wants to be brought back (1) • Does not want to live unless will recover (14) • If good chance of a “meaningful outcome” (3) • Not if prognosis is “dire” (1) <p>Statements about quality of life or functional status on which goals of care are contingent</p> <ul style="list-style-type: none"> • Wants a quality of life (8) • Ability to “function” (2) • Cognitive abilities (1) • Does not want to be in a vegetative state, does not want to be a “vegetable,” “if brain not working right” (7) • Does not want to be dependent (1) • Does not want to be impaired (1) • As long as she is a “viable” person (1) • No nursing home, does not want to end up in a facility (4) <p>Temporal contingencies</p> <ul style="list-style-type: none"> • Life support is okay, if temporary (3) • Don’t prolong things (2) <p>General statements</p> <ul style="list-style-type: none"> • Wants to have a chance (2) • No pain, never wants to be in pain like that (4)
<p>Total patients whose expressed wishes were reported (71)</p>	

¹ For many patients, more than one expressed wish was reported.

Frequently, friends and family described how they knew the patient's wishes. Some reported repeated conversations over the years; others, a specific formal family gathering for this purpose. Some described the context in which the conversation occurred: "I asked her what her wishes were; over Christmas; before coming to the hospital; when her sister was so sick (or triggered by some other family illness or medical procedure); the last time she was in a nursing home, she pleaded with me; we were lying in bed and she told me; we made an agreement; when I spoke with him about my estate, we talked about this; he had conversations about this with his internist; there were witnesses." And others referred to tangible evidence: "it is written down; it's on (or isn't on) her driver's license." Family members often also responded with what they thought the patients' wishes might be — inferences based on related conversations, features of their personality, or medical decisions patients had made on behalf of someone else. These inferences are not addressed in this paper, which considers only the patient's direct expressions and actions.

D. Interpretive Difficulties

The reprised wishes share some of the same difficulties as those expressed in legal documents.³⁶ First, they lack operational definitions. For example, one patient reportedly told her mother that she wants to be treated aggressively as long as she is "viable." Her mother never asked what she meant by "viable," and it occasioned many frustrating conversations as the patient, now riddled with breast cancer, swirled close to death. And what is a "meaningful outcome?" What constitutes an ability to "function" — to drive? go to work? pay one's bills? walk? eat or go to the bathroom without assistance?

Second, many instructions use medical terminology that patients do not understand and profoundly constrain treatment options when subsequently interpreted by medical staff. The term "coma" in the middle option offered on the Illinois Power-of-Attorney form³⁷ occasioned many conflicts in the ICU. Most patients and families consider the term "coma" to reflect non-responsiveness and do not realize that it must meet precise medical criteria that do not apply to many situations in which families consider the patient comatose; the use of "vegetative state" or "vegetable" presents similar problems. So does the wish about not being on a "machine" or eschewing "tubes."

Third, many patient wishes are contingent on prognosis (e.g., "unless I will recover"). But accurate prognostic information about functional status as well as survival can be especially hard to come by.³⁸ The literature documents the difficulty of generating accurate prognostic information, the cognitive barriers physicians face when applying generic scientific models to unique individuals, and the reluctance of physicians to share prognoses with their patients or those who act on their behalf.³⁹ Out of fear of being

36 For a more comprehensive review of these issues, see Susan P. Shapiro, *When Life Imitates Art: Surrogate Decision Making at the End of Life*, 14 *Topics in Stroke Rehab.* 80 (No. 4, 2007).

37 *Illinois Statutory Short Form Power of Attorney for Health Care*, *supra* n. 32.

38 Ann J. Russ & Sharon R. Kaufman, *Family Perceptions of Prognosis, Silence, and the "Suddenness" of Death*, 29 *Culture, Med. & Psych.* 103 (2005); Nicholas A. Christakis, *Death Foretold: Prophecy and Prognosis in Medical Care* (U. Chi. Press 1999).

39 Theresa S. Drought & Barbara A. Koenig, "Choice" in End-of-Life Decision Making: Researching Fact or Fiction? 42 *Gerontologist* 114 (2002).

wrong, they may offer nothing at all.⁴⁰ Few physicians, especially in the first weeks or months after injury, are willing to say that the injury is irreversible. Few will offer sufficient information to make inferences about likely quality of life or the other outcomes that are critical to honoring patients' pre-existing wishes.

Fourth, with few exceptions, wishes are expressed in absolute terms — no dialysis, no ventilator, no tubes, no heroic treatments, do everything. But sometimes very time-limited aggressive treatments are necessary to get over a small bump in the road — a pneumonia diagnosis, for example — or an iatrogenic outcome of the treatment itself (e.g., a few days of dialysis to get rid of the fluid or toxins that built up from the treatment). In other instances, a time-limited trial of aggressive treatments may be appropriate to see whether the problem will resolve itself. On the other end of the continuum of wishes, do patients truly want “everything done” when treatment is futile, harmful to the patient, or likely to cause needless suffering? What are the appropriate stopping points? When are time-limited trials acceptable? For how long? What are the criteria? Patients rarely provide this guidance.

In other cases, absolute wishes were uttered (or remembered) years or decades ago, when the state of medical knowledge or available treatments were more limited (or less benign or successful) or when the patient was healthier and could not fathom the infirmities that come with aging, illness, or disability. This raises a fifth problem, generally captured by the notion of future selves and the extent to which their treatment should be bound by the wishes of former selves. Research on affective forecasting has demonstrated that individuals are quite bad at predicting how they will feel about medical problems in the future.⁴¹ Considerable empirical research has also established the instability of patient preferences, even over relatively short periods of time.⁴² The wishes documented in an advance directive or reprised from one or more conversations may be artifacts of the moment at which they were heard and recorded as well as of the context in which the words were spoken and of the relationship between the speaker and receiver.

The various hurdles faced by proxy decision makers in interpreting a patient's wishes suggest that having the last word may well turn out to be the wrong word. It should be no surprise that instructions given long ago, in the abstract, and without medical guidance will poorly anticipate the very specific choices, interventions, risks, side effects, and

40 *Christakis, supra* n. 38.

41 Timothy D. Wilson & Daniel T. Gilbert, *Affective Forecasting: Knowing What to Want*, 14 *Current Directions in Psychol. Sci.* 131 (No. 3, 2005); Peter H. Ditto, Nikki A. Hawkins & David A. Pizarro, *Imagining the End of Life: On the Psychology of Advance Medical Decision Making*, 29 *Motivation & Emotion* 475 (No. 4, 2005).

We tend to “overestimate the intensity and the duration of our emotional reactions — our ‘affect’ — to future events. ... On average, bad events prove less intense and more transient than... predicted. ... People adapt to serious physical challenges far better and will be happier than they imagine.”

Jon Gertner, *The Futile Pursuit of Happiness*, *N.Y. Times Mag.* (Sept. 7, 2003), <http://www.nytimes.com/2003/09/07/magazine/the-futile-pursuit-of-happiness.html?pagewanted=all&src=pm>.

42 *Ditto et al., supra* n. 41; Kristi L. Kirschner, *When Written Advance Directives Are Not Enough*, 21 *Clinics in Geriatric Med.* 193 (2005).

potential outcomes faced down the road. It is for this reason that many ethicists advise patients to pick the option on the advance directive form that provides few specific instructions and empowers surrogate decision makers with the discretion to weigh the benefits and burdens of treatment and then encourage patients to talk at length with decision makers about their values and preferences. Still, in a moment of crisis and despair, a word dropped in random conversation may nonetheless turn out to be the last. The extended example below provides a poignant sense of how a conversation may become inflexibly written in stone:

Critical Care Fellow: So, last night he developed what he had before, called septic shock. The infections are over-taking [Patient's] body despite the optimal antibiotic treatments that we're giving him. Because of the tumor, the infections went into his blood stream. His blood pressures dropped to a point that is not consistent with life. We have him on three medications to keep his blood pressures up, and even still his blood pressure is pretty low. ... We're doing everything we can, but his body is not able to fight off all these infections.

I know that you love him so much. I can see how much you love him. The main reason I wanted to talk to you is because his blood pressures are dropping, and so we're concerned that his heart may stop. If he were to have a cardiac arrest, we would try to resuscitate him by doing chest compressions. This is an absurdly painful process. In situations where we think that someone could recover, we often do cardiac resuscitation. But in [Patient's] case, because so many of his organ systems are down — his blood pressure, the cancer overtaking his body, his immune system, the infections — the chances of being able to bring him back are pretty much as close as they get to the smallest chance. I would not want to put [Patient] through that pain, since I don't believe it would allow him to come back.

Mother: I don't have a choice. This is what [Patient] wanted. [Patient] told his doctor, [Oncologist]. He said, "Mama, I do not want DNR."

Critical Care Fellow: I do not want to what?

Mother: Do Not Resuscitate, or whatever. Do not Do Not Resuscitate. Well he didn't say it that way, but he said he wanted to be resuscitated. I wish that I could do it differently, but that's what [Patient] wanted.

Father: I know you probably think we don't care about him.

Critical Care Fellow: No, I absolutely think you do.

Father: I've heard the comment, "How could you?" And that hurts so much. This is what [Patient] wanted. He was insistent. He said it in front of [Oncologist] and his mother. [Patient] is very strong willed. ... He decided exactly what he wanted, where he wanted his funeral and everything. We have to do everything we can to honor his wishes,

as hard as that may be. So the question is not, "How could we?" The question is, "How could we not?" I can't be in the room; I have to walk out every time I hear the machine beeping when his blood pressure drops. I can't watch it happen. It's so hard. When I see him— [FATHER GETS CHOKED UP AND BEGINS SOBBING.]

Mother: We were talking to [Oncologist], and he was telling [Patient] that it's so painful to go through, and he should just be DNR. [Patient] said, "Mama, we talked about this. I want everything done." I wish that at this point we could just take him off the machines. But I would feel guilty for the rest of my life if I didn't carry out his wishes. I don't have a choice. I need to follow his wishes to let him keep his dignity. We understand; we really do. We know what's happening. And you know that. But this is what he wanted, and so I will fight tooth and nail to do everything I can for him, because that is what he wanted. I don't want to talk about any of this again. I just want to go back and be with [Patient]. Your mother would do the same thing for you. She'd fight for you.

The day after this conversation the patient died after four aggressive unsuccessful rounds of resuscitation. Ironically, hospital records written before the patient was transferred to the ICU suggest that he may only have wanted aggressive treatment if his cancer prognosis was good. Multiple notes in the records describe conversations between medical staff and both the patient and his girlfriend about the patient's parents pressuring him to keep pursuing aggressive treatment and his discomfort expressing his desire to change course and fear of letting them down.

In a handful of cases, families discounted, disregarded, or countermanded the patient's wishes, instructions, or consents the latter had expressed directly to medical staff. Surrogates countered that the patient tended to vacillate or observed that these wishes were colored by depression, confusion, dementia, fear, loneliness, or were predicated on misunderstandings, misinformation, or hopeful prognoses that were no longer realistic. In most instances, this reversal resulted in instructions to withhold or withdraw treatment to which the patient had consented, but occasionally in escalation of care. In a rather delicate example:

Attending Physician: I'm going to look at his heart and lungs, and then I know you have concerns about the vent.

Wife: Pull the plug.

Daughter-in-Law: This is not what he would have wanted.

Attending Physician: Would he feel differently if he was able to potentially get a transplant?

Daughter-in-Law: No.

Attending Physician: 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.

Attending Physician: They haven't told us that he's definitely not a candidate.

Wife: Just pull the damn plug!

Attending Physician: 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: No.

Daughter-in-Law: No.

Family Member #3: No.

Family Member #4: No.

Family Member #5: 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 just coming here for stents for his liver. Now he's on pressors and levo.

Attending Physician: We'll have to consult with our ethics committee to make sure that we're doing the right thing, that we're following his wishes.

Daughter-in-Law: Yes, we understand.

Attending Physician: We'll talk to ethics and the nurses who 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.

A few forthright surrogates admitted that they disregarded the patient's wishes simply because they wanted something different.⁴³

Partner: I don't mean to be dramatic, but if you were his brother or father [GETS REALLY CHOKED UP; WHISPERS THE REST OF THE SENTENCE], what would you do?

Attending Physician: I think it would really depend on what his wishes were. I know you've had conversations about that with him before. What would he want?

Partner: I'd stick around until the cows came home.

43 However, many more surrogates expressed disagreement with the patient's wishes while acknowledging that it was their responsibility nonetheless to honor the patient's wishes rather than their own. Other surrogates struggled with reconciling the patient's wishes with their own personal religious values, which would dictate a different course. See also Susan P. Shapiro, *Conflict of Interest at the Bedside: Surrogate Decision Making at the End of Life*, in *Conflict of Interest in Global, Public and Corporate Governance* (Anne Peters & Lukas Handschin eds., Cambridge U. Press 2012).

Attending Physician: Yes, but what would [Patient] want?

Partner: [ROLLS HIS EYES AND LAUGHS] He didn't want all this. I'm keeping him alive for me. I know it's selfish, but I can't help it.

In other instances, especially with domineering family members, patients express one thing when alone with medical staff and something else (or passively assent to treatments they had just refused) when family is present.

E. The Impact of Advance Directives

The Proxy Study made two related claims (one correlational and one causal) about the impact of advance directives — that “[p]atients who had prepared advance directives received care that was strongly associated with their preferences” and that “both a living will and durable power of attorney for health care appear to have a significant effect on the outcomes of decision making.”⁴⁴ Since the investigators only had data on proxy reports of outcomes and the content of directives, these claims are one and the same. Their causal claim is based solely on the correlation between or concordance of the outcomes and preferences reported. Without getting into a statistical discussion, such a causal claim could be spurious — directives and decisions may appear related because the same thing causes them both. The classic example: the fact that cities with lots of firefighters have lots of fires does not mean that firefighters are setting the fires. Similarly, it could be that being very sick or very young or very religious may affect both what you put in your directive and the decisions about your treatment, even if the directive is not directing the decisions. Indeed, the same treatment decisions may be made on behalf of very young or sick or religious patients without directives at all. In short, it is insufficient merely to observe a concordance between directives and outcomes; one needs to examine if the directive is actually playing a role to make a causal claim about a significant effect.

How do these two claims hold up to evidence about actual directives and sustained observation of the process of making treatment decisions? Although data available to the Proxy Study authors only permit the first claim — that patients with directives received care associated with their preferences — the ICU data provide insights on both claims: Do instructional directives and treatment decisions correspond? How, if at all, were directives used in the decision-making process and to what effect? Does the process look any different from that for patients without any advance directives at all?

Answers to some of these questions reflect all 205 patients in the observational study. Others, that require knowledge of the actual instructions specified in the advance directive, are based on the 40 patients with copies in their hospital chart that expressed treatment preferences. Two-hundred twenty-six of the observed meetings concerned these 40 patients. For each patient, the two observers each assessed the extent to which the patient’s written treatment preferences were followed throughout the ICU admission, the role of the advance directive in these encounters, and the extent to which the advance directive furthered the implementation of the patient’s wishes. After a first pass through

44 Silveira et al., *supra* n. 6, at 1211, 1218.

the data, assessments corresponded 85 percent or more of the time; after discussion there was 100 percent consensus.

1. Do Instructional Directives and Treatment Decisions Correspond?

Unlike the advance directive options offered informants in the Proxy Study regarding specific interventions, most of the ICU patients who expressed wishes, in asking that surrogates weigh the benefits and burdens of treatment, specify processes rather than outcomes in their preferences about end-of-life care. More than nine out of 10 surrogates for patients who checked the box on their power-of-attorney form directing decision makers to weigh benefits and burdens seemingly followed this script. They asked or opined about risks and benefits, prognosis, likely functional abilities, probabilities, pain and suffering, quality of life, likelihood of returning home, time horizons, the patient's personality, values, prior statements, and so forth. Whether mindful of the document or not (since many never referred to it), they were engaged in advocating for the patient, seeking information, asking questions, soliciting multiple opinions and expressing frustration when they were not forthcoming or were inconsistent, sorting through options, negotiating limited interventions, continually reassessing the proper course and changing course when appropriate, and trying to bring the patient's voice back into the dialogue. One or two seemed paralyzed by the process, unable to make a decision (while the patient languished in the hospital for months). Others did not seem up to the responsibility of serving as a power of attorney as demonstrated by their failure to pay attention, stay on task, distinguish the forest for the trees, or keep the interests of the patient ahead of their own.

Most surrogates charged with weighing the benefits and burdens of treatment followed the instructions. It is difficult to fail when the patient simply asks that you exercise discretion. Of course, it also means that instructional directives give surrogates very little guidance about how to exercise this discretion; a check box does not provide much of a definitive "last word." Perceptions of burdensome treatment or quality of life are highly subjective and thus there is no objective standard to evaluate whether surrogates' discretionary judgments were made well.

The evidence is mixed regarding the relatively small number of directives with specific instructions among the ICU patients. All patients with living wills asking that life support be withheld or withdrawn if they had an incurable and irreversible terminal illness and death is imminent got their wish. For some of these patients, the living will served as a mechanism for surrogates or physicians to invoke, manipulate, or settle on goals of care. For others the document remained in the background, either disregarded or consistent with what surrogates felt appropriate in any case. In none of these cases was a living will rejected or abrogated nor did the letter of the document get in the way of honoring the spirit of the patient's wishes. On the other hand, the living wills provided little direction for patients whose demise was not imminent — a substantial number even of very sick ICU patients.

Only three patients requested that their lives be prolonged to the greatest extent possible. All three received treatment consistent with their instructions. Two were eventually released from the hospital after many interventions and extremely long hospital stays; the third, as noted earlier, died after four futile attempts at cardiopulmonary resuscitation

despite many entreaties in the last days by physicians to the surrogate to consider changing goals of care.

Checking the “coma” box on the power-of-attorney form, requesting aggressive care unless in an irreversible coma, proved a bit more problematic for the four ICU patients whose directives did so. One patient was not in a coma, did not require any difficult medical decisions, and was eventually discharged to a rehabilitation facility. For a second comatose patient, the directive was followed after some delay. The third patient, whose son checked the “coma” box on her behalf, misunderstanding the meaning of coma, was described earlier. Her one request of her son — that she not be in pain — could not be honored because the patient was not technically comatose and, therefore, her son was not permitted to remove life support. The fourth case was also described earlier, of the husband who absolutely refused to take any responsibility for medical decision making and insisted that the advance directive spoke for itself and that doctors implement it. As you recall, the patient’s neurologist refused, indicating that the medical situation was far more nuanced and indeterminate than the check box on the power-of-attorney form.

With the exception of these “coma” directives, the ICU data (like the Proxy Study) show a concordance between instructions and outcomes. This result largely occurs because the most common instruction permits virtually any outcome. Perhaps a more meaningful question than whether the instructions and outcomes or decision-making processes are consistent considers the second (causal) claim that advance directives actually play a role in implementing patient preferences regarding end-of-life care.

2. How, If At All, Were Directives Used in the Decision-Making Process and to What Effect?

The ICU study provides evidence of the invocation and use of advance directives in conversations about specific interventions and overall goals of care. For two-thirds of the patients with directives in their chart, the subject of advance directives was raised during one or more conversations or meetings between families, friends, and medical staff. Often parties discussed logistical matters — whether the patient had an advance directive, whether there was a copy in the hospital record, or that families need to bring it in (28 percent) or confirmed or asserted who was the power of attorney (38 percent). For 38 percent of these patients, advance directives came up as parties talked about the patient’s wishes: physicians sometimes asked what the advance directives said or what box was checked on the power-of-attorney form; families sometimes reported on prior conversations with the patients about their advance directives; physicians or families read from the documents or summarized or interpreted the patient’s wishes articulated in the documents; or parties decried the difficulties of using the documents to formulate appropriate medical decisions.

Advance directives seemed to provoke conversations only when they were physically in the hospital. Curiously, any mention of them — even logistical questions — was almost as common for patients without directives at all (24 percent) as for those claiming to have directives that were never brought to the hospital (30 percent). For only 4 percent of the former and 13 percent of the latter were the patients’ documented treatment preferences ever inquired about or described (compared to 38 percent with in-house directives). Someone asked about or described treatment preferences specified in the advance direc-

tive in only 9 percent of meetings in which goals of care were addressed (ranging from 2 percent of patients without directives to 23 percent of those with a copy in the hospital record).

The fact that the topic is never discussed or that surrogate decision making corresponds with written instructions does not mean that advance directives are or are not exerting an influence on how information is processed, how decisions are made, or who is making them. Still, for 45 percent of patients with directives in their charts (and therefore whose wishes are known), there is no evidence that directives made a difference in the process or outcomes of decision making. For these patients, there was no reference to the advance directives in any of the conversations or decision makers were adamant about knowing and honoring the patient's wishes and any reference to directives fell on deaf ears.

For a little more than a quarter of the patients, the directives seemingly helped honor the patients' wishes. The document gave authority to the person who advocated the patient's wishes when the default surrogate decision maker (had there been no power of attorney) did not.⁴⁵ In some cases, decision makers seemed clear on patient preferences, but rereading or talking about the advance directives corroborated their understanding or provided closure.⁴⁶ In other instances physicians reminded decision makers of the content of the advance directive, explained how the patient's medical condition met its terms, or affirmed the family's interpretation of the document.⁴⁷ For these patients, physician inter-

45 In one case, the patient chose her granddaughter over her children to be power of attorney. The children entreated physicians to withdraw life support; the granddaughter, who prevailed, insisted that her grandmother wanted to have a chance. When the patient did regain consciousness and began making her own decisions, they accorded with those made by her power of attorney. Had the patient not designated her granddaughter as power of attorney, the law in Illinois would have assigned her children as surrogate decision makers.

46 One patient was a Florida resident who had the longest and most complex living will I have ever seen; it was prepared by a Florida lawyer post-Terri Schiavo, one of the most famous residents of that state. The patient, who had lung cancer, had been given six months to live when she experienced a devastating stroke. The family authorized experimental surgery to remove the clot in her brain in the hope that it would restore her consciousness and improve the quality of her last few months, consistent with her wish that her life not be prolonged if she were in a permanent vegetative state. The surgery was not successful and her spouse summarized the patient's living will, which expressed her wishes that life support be withdrawn under such circumstances, to several different teams of physicians. However, before doing so, the spouse asked that the family be given time to enable his daughters to read their mother's living will, understand her wishes, and have an opportunity to talk about it. The living will, for him, was an intrinsic part of the decision-making process, a channel for the patient's voice.

47 The family of a 61-year-old woman was told that she was gravely ill. Family members explained that she would not want to be on life support if she were in a vegetative state but initially requested that physicians do everything they could until there was no more to do and see whether she would improve. On the second day in the ICU, the critical care fellow asked to meet with the family.

Critical Care Fellow: Whenever possible, we like to discuss goals of care with patients themselves. But unfortunately, your loved one is not in a position to discuss that with us. I was looking over her chart though, and I found her living will. We were reviewing it earlier as a team. As her family, you make the decisions on her behalf. But this document is a way for her to express herself, since she is not able to right now. It says:

pretations helped push surrogates along or reassured them, but didn't change their sense of what the patient wanted.

Advance directives probably failed in implementing patient wishes at least as often (29 percent of the time) as they probably helped (26 percent). Failures occurred for a number of reasons: Wishes stated in the advance directive were flouted, disregarded, or ignored by the decision maker.⁴⁸ Surrogates insisted on following their own wishes or stated that it was their decision whether or not to honor the patient's wishes. In some instances, the problem was that the advance directive did not correspond with the patient's wishes — either because the form had been filled out by someone else,⁴⁹ used medical terms that the patient misunderstood, had been completed by the patient under pressure from a family member, or because the patient's preferences, as expressed to hospital staff before losing decision-making capacity, had changed.⁵⁰ And for a few patients, the advance directive, itself, stood in the way of making the right decision — whether because it was misinterpreted by a physician⁵¹ or family member or because the decision maker hid behind the document and refused to make a decision.⁵² Failures to further patient wishes were most common for directives that seek to prolong life under all or most circumstances (67 percent vs. 25 percent for directives opting for benefits/burdens or imminent death).

My dying shall not be artificially prolonged under the circumstances set forth below, and I declare: If at any time my attending physician certifies in writing that: 1) I have an incurable injury, disease, or illness; 2) my death will occur within a short time; and 3) the use of life prolonging procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the performance or provision of any medical procedure or medication necessary to provide me with comfort care or to alleviate pain, and have so indicated below, the provision of artificially supplied nutrition and hydration.

Now, sometimes these documents can be quite obscure. But I believe that this one is quite clear:

Husband: We have a lawyer friend who came over and went through this with her. It's what her wishes were. I think it's very clear.

Critical Care Fellow: Yes. So as for the three criteria, her cancer is not curable. I don't know when she would otherwise die from it, but the oncologists have determined that it is not treatable. And now with the septic shock on top of that, the chances are very low that she would survive. I believe she would die very quickly if we were to withdraw support. And she is on artificial life support, the ventilator and the blood pressure medications. In terms of futility, is it 100 percent? No. I can never make that judgment. Just like the oncologists can never say for sure what the prognosis is for the cancer. But what I can say is that the chances of her surviving this hospitalization and going home and resuming any of her normal activities are pretty much zero.

Shortly thereafter, the family came to a consensus and withdrew life support.

48 Recall the case of the partner who said, "He didn't want all this. I'm keeping him alive for me."

49 Recall the son who checked the "coma box" for his mother, who had dementia.

50 Recall the young man who indicated to hospital staff that he only wanted aggressive care if his prognosis was good but, feeling pressure from his parents, never changed his advance directive. He died after four grueling efforts to resuscitate him because his parents felt an obligation to fight for him.

51 One dramatic failure was caused by a physician's misunderstanding of the meaning of an advance directive, wrongly assuming that asking the power of attorney to weigh the burdens and benefits of treatment meant that the patient wanted no life-saving measures.

52 Recall the case of the husband who brandished the power-of-attorney document and insisted that the physicians implement it.

Unfortunately, these observations are based on a very small number of cases and may not be representative, even though they reflect every patient (out of more than 2,000 passing through the two ICUs over three years) requiring a surrogate decision whose treatment preferences were in their hospital chart. Some may interpret these results as a glass half empty (they help only about a quarter of the time) and others a glass half full (they fail less than a third of the time). The latter will see justification for ongoing efforts to get more Americans to write instructional directives, the former to get them to appoint powers of attorney to speak on their behalf, given how difficult it is to have the last word.

To truly understand the role or efficacy of advance directives on end-of-life decision making, one must also look at the patients whose advance directives, if they existed at all, were never brought in to the hospital as well as the majority who had no advance directives, and track the process and outcomes of medical decisions made on their behalf. They may have fared equally well or even better in getting the last word than those with properly documented wishes. That is beyond the scope of the present paper. However, a complex statistical analysis shows that the decision-making process and outcomes are not significantly different between patients without advance directives and those whose directives appear in the hospital record.⁵³ Though surrogates for the former are less likely to mention advance directives or invoke expressed wishes, they are no less likely to talk about what they believe the patients' wishes would be. Of course there is no way to know whether these memories, perceptions, or inferences are accurate.

IV. CONCLUSION

The data regarding surrogate decision making in the two ICUs confirm the finding of the Proxy Study that patients who have advance directives receive care that is strongly associated with their preferences. The ICU study suggests, however, that this correlation arises in part because many patient preferences are open-ended and therefore allow any outcome. A more meaningful conclusion supported by the ICU data would be that, in the long run, patients whose wishes are known do not often receive medical care that is clearly antithetical to them.

The ICU data do not support the causal argument from the Proxy Study that advance directives "appear to have a significant effect on the outcomes of decision making." The

53 A logistic regression assessed whether the process of surrogate decision making differs for patients with advance directives in their chart or those claiming directives that are not in their chart and those without directives at all. The analysis considered 41 features of ICU conversations, patient outcomes, and impacts on families. They included: whether anyone ever asked about or mentioned the advance directive (substantively or logistically); whether and how representatives of patients initiated discussions about the patient's wishes or whether physicians initiated these discussions (perhaps to compensate for the disinclination of some families to talk about this); whether patient representatives initiated discussion of decision-making criteria or process or whether instead physicians initiated these conversations; how long it took for an issue to be addressed or resolved (rather than whether it was addressed); outcome measures; and characteristics of the meetings. Because demographic characteristics associated with having an advance directive are also related to the process and outcomes of surrogate decision making, the logistic regressions controlled for patient gender, age, ethnicity, income of residential neighborhood, whether illness was pre-existing or came out of the blue, and whether the patient or family member is a lawyer or health care provider. Contact the author for more information.

data are equivocal about whether advance directives do more harm than good. Proxy directives or powers of attorney alone are more benign, in that they allow patients to designate a trusted decision maker, particularly when the legal default order would assign someone who they do not believe to be up to the task. And certainly powers of attorney are desirable for patients who would ask that life support be withheld or withdrawn for infirmities short of imminent death or permanent unconsciousness. In Illinois and elsewhere, only patients or powers of attorney are permitted to make that request.⁵⁴ But the value of instructional directives is certainly debatable.

This is a limited study, of course. Although the patient population was very diverse and hundreds of medical staff were observed in interaction with families, the data nonetheless reflect a single teaching hospital in a single city in a single state. Moreover, although 40 percent of Medicare enrollees visit an ICU in the last six months of life⁵⁵ and ICUs disproportionately collect patients unable to make their own medical decisions,⁵⁶ surely what happens inside an ICU is quite different from what surrogates do outside of the hospital. Perhaps advance directives help keep some patients out of the ICU in the first place. Moreover, important variation can be expected in laws, types of advance directives available, practices and protocols, norms, values, incentives, resources, even medical issues and available technologies in other settings. Nonetheless, while we await observational research from other settings, the ICU study provides the largest and most extended and systematic look at how end-of-life decisions are made in real time, on the one hand, and at the legal documents that potentially shape that process, on the other.

Back to the death panels and the allegations by those opposed to health care reform that conversations about our wishes at the end of life would create death panels that pressure the elderly or infirm into ending their lives. It is impossible to know how many of the directives reported by patients in the ICU study resulted from the kind of counseling to which critics of health care reform objected. Still, there is no evidence in the ICU data to support the “death-panel” charge: 56 percent of patients without advance directives died or went into hospice during their hospital stay; this was true of 55 percent of those whose advance directive was in the hospital record as well as 55 percent of those whose directive never made it to the hospital.⁵⁷ Of course, the three groups are different in many respects,

54 See e.g. the case reported in *supra* n. 27. This is certainly an example in which power-of-attorney documents provide greater opportunity to maintain fidelity to a patient’s wishes. In Illinois, surrogate decision makers not designated as powers of attorney are not permitted to withhold or withdraw life support unless the patient’s medical condition meets one of three rather narrow qualifying conditions, described as a “terminal condition,” “permanent unconsciousness,” or an “incurable or irreversible condition.” (755 ILCS, Health Care Surrogate Act.) Presumably the state does not want to give broad discretion over life and death to persons who were never formally selected by patients to make medical decisions on their behalf. Powers of attorney do not face these constraints.

55 *Percent of Medicare Decedents Hospitalized at Least Once During the Last Six Months of Life, by Race and Level of Care Intensity*, Dartmouth Atlas of Health Care (2007), <http://www.dartmouthatlas.org/data/table.aspx?ind=134> .

56 John M. Luce & Thomas J. Prendergast, *The Changing Nature of Death in the ICU, in Managing Death in the ICU: The Transition from Cure to Comfort* 19, 21–22 (J. Randall Curtis & Gordon D. Rubenfield eds., Oxford U. Press 2001).

57 This is especially striking because one would expect more deaths among the advance directive group due to selection bias, even if the directives have no effect. Because the legal default is aggressive care,

both demographic and medical, that undoubtedly affect the likelihood that patients would die as well as how decision makers would choose their treatment. But, after controlling for these factors, there is still no significant difference between the three groups in the likelihood of hospital death or hospice.⁵⁸ It does not appear that keeping one's wishes to oneself increases the odds of survival, nor, for that matter, having the last word about the treatments one does or does not receive.

Perhaps because of the furor over death panels, the provision to permit Medicare to compensate physicians for discussing patient wishes about future medical treatment and/or advance directives did not make it into the final health care bill. And a provision to reinstate compensation for advance care planning through subsequent Medicare regulations⁵⁹ was introduced and then swiftly withdrawn.⁶⁰ Though my study provides little support for the paranoia envisioned by the death panel crowd, neither does it find advance directives a panacea for the inevitable and wrenching decisions that await many of us at the end of life. The Proxy Study found that 42 percent of the decedents "required decision making about treatment in the final days of life" and that 70 percent of them lacked decision-making capacity.⁶¹ Studies of ICUs, where patients are much sicker, have found that of all decisions to withhold or withdraw life support, only 3 to 4 percent were made by the patients themselves; the others lacked decisional capacity.⁶² In short, the most important life-and-death decisions of many of our lives will be made by someone else.

It certainly seems desirable for most of us to get to pick who that someone else is (or at least exclude a few potential candidates) and to talk with them and those who will seek to influence or silence them about our values, priorities, and fears. Is it possible to have the last word? Absolutely. The price, as the ICU study illuminates, is that it may be the wrong word.

advance directives are more important for patients who chose to limit care than for those who want everything done to prolong their lives.

58 A logistic regression between advance directive status and hospital death or hospice (controlling for age, ethnicity, gender, neighborhood income, whether hospitalization came from an unexpected emergency or pre-existing medical problems, and how sick the patient was) was not significant (*i.e.*, there is no difference among the three advance directive groups in the likelihood of hospital death or hospice). Contact the author for more information.

59 75 Fed. Reg. at 73406.

60 Robert Pear, *U.S. Alters Rule on Paying for End-of-Life Planning*, N.Y. Times (Jan. 4, 2011), <http://www.nytimes.com/2011/01/05/health/policy/05health.html>.

61 Silveira et al., *supra* n. 6, at 1214.

62 Luce & Prendergast, *supra* n. 56.