Do Advance Directives Direct?

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Abstract Resolution of long-standing debates about the role and impact of advance directives—living wills and powers of attorney for health care—has been hampered by a dearth of appropriate data, in particular data that compare the process and outcomes of end-of-life decision making on behalf of patients with and without advance directives. Drawing on a large ethnographic study of patients in two intensive care units in a large urban teaching hospital, this article compares aspects of the medical decision-making process and outcomes by advance-directive status. Controlling for demographic characteristics and severity of illness, the study finds few significant differences between patients without advance directives and those who claim to have them. Surprisingly, these few differences hold only for those whose directives are in their hospital chart. There are no significant differences between those with no directive and those claiming to have a copy at home or elsewhere. The article considers the implications if directives seemingly must be in hand to show even modest effects. Do advance directives direct? The intensive care unit data provide far more support for the growing body of literature that casts doubt on their impact than studies that promote the use of them.

Keywords advance directives, intensive care unit, surrogate decision making

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> *Enough. The living will has failed, and it is time to say so.*
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> *We should have known it would fail: A notable but neglected psychological literature always provided arresting reasons to expect the policy of living wills to misfire. Given their alluring potential, perhaps they were worth trying. But a crescendoing empirical literature and persistent clinical disappointments reveal that the rewards of the campaign to promote living wills do not justify its costs. Nor can any degree of tinkering ever make the living will an effective instrument of social policy.*
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> *As the evidence of failure has mounted, living wills have lost some of their friends. . . . But living wills are still widely and confidently urged on patients, and they retain the allegiance of many bioethicists, doctors, nurses, social workers, and patients. For these loyal advocates, we offer systematic proof that such persistence in error is but the triumph of dogma over inquiry and hope over experience.*
> —Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will."
>
> *Despite the prodigious effort devoted to designing, legislating, and studying advance directives, the consensus of medical ethicists, researchers in health care services, and palliative care physicians is that the directives have been a resounding failure.*
> —Muriel R. Gillick, "Reversing the Code Status of Advance Directives?"

Despite these bold indictments of living wills and advance directives published in prominent bioethics and medical journals, the debate about their efficacy has raged on for decades, even as advocates continue to encourage Americans to create them. On the one hand, numerous studies have found little effect of advance directives on a host of outcomes, from varied features of clinical care to length of hospital stay, level of pain, and health care costs (Ditto et al. 2001; Fonk et al. 2012; Halpern et al. 2011; Teno et al. 1997; Teno et al. 1994). Diverse literatures provide richer context and shed light on why positive findings are rare. They consider

- Americans' diverse attitudes regarding autonomy and medical decision making and their disinclination to prepare and challenges in implementing advance directives (Braun, Pietsch, and Blanchette 2000; Fagerlin and Schneider 2004; Kwak and Haley 2005; Schneider 1998);
- philosophical and psychological accounts of why advance directives do not always reflect our true wishes in the first place (Ditto, Hawkins, and Pizarro 2005; Dresser 1986; Emanuel and Emanuel 1992; Fagerlin and Schneider 2004; Kirschner 2005);

- the instability of our treatment preferences, even over relatively short periods of time (Chochinov et al. 1999; Ditto et al. 2006; Fried et al. 2007; Kirschner 2005; Krumholz et al. 1998);
- the preferences of many patients that the wishes of their families ought to override their own, even if they contradict their own expressed wishes (Hawkins et al. 2005; Puchalski et al. 2000);
- difficulties that our loved ones face in trying to reproduce our wishes (Shalowitz, Garrett-Mayer, and Wendler 2006);
- the elusiveness of prognostic information necessary for decision making (Christakis 1999; Drought and Koenig 2002; Russ and Kaufman 2005); and
- the social organization, rhythms, and culture of hospital care and the complicated pathways toward death that they construct, assign, and obstruct (Kaufman 2005; Shapiro 2007).

On the other hand, some recent studies have found greater use of advance directives and evidence that they affect patient care reflected, for example, in the concordance between treatment preferences expressed in directives and selected outcomes—final treatment, place of death, and so on (e.g., Degenholtz, Rhee, and Arnold 2004; Hammes, Rooney, and Gundrum 2010; Silveira, Kim, and Langa 2010; Wood and Arnold 2013). And so the scholarly literature seesaws back and forth between upbeat assessments and studies that find that directives make no difference, providing conflicting guidance about appropriate policies to facilitate medical decision making when patients are unable to speak for themselves.

Unfortunately, resolution of the debate has been elusive, at least in part, because of a dearth of appropriate empirical data. Although the studies are plentiful, many are plagued by a host of methodological compromises that include reliance on the recollections of informants (often tainted by recall as well as social-desirability biases) or on limited information available in medical records, lack of independent measures of critical variables, a static focus on the final medical decision (rather than the oscillating course of treatments that unfold near the end of life), concentrating on an individual decision maker (rather than entertaining the possibility that decisions may be a collective enterprise), overly general classifications of advance directives and medical decisions (such that they necessarily correspond), and sometimes even the confusion of correlation and cause (Shapiro 2012).

Relying on a different methodological strategy, this article illuminates two areas that have been underexplored in the literature. First, existing studies often consider outcomes in evaluating the efficacy of advance

directives—a final medical decision or the aggressiveness of medical treatment at the end of life, the number of hospitalizations, place of death, the cost of medical treatment, and other indicators that can be readily abstracted from medical records or informant accounts. But advance directives usually address the decision-making process rather than outcome—who should serve as decision maker, the criteria to be considered or values respected in medical decision making, preferences for some treatments over others, whether decisions should be contingent on medical condition or prognosis, and so on.

To understand the role of advance directives in medical decision making, it is critical to examine the process during which they are invoked, ignored, interpreted, reinterpreted, or disputed over, day after day, as a medical crisis plays out and decisions—both momentous and routine—are made and remade and shape and constrain the next set of decisions that surrogates speaking for the patient necessarily face. Few studies track advance directives, from day one of a medical crisis until the crisis is resolved. As elaborated below, this article provides a unique window on the process as well as the outcomes of surrogate medical decision making.

Second, for studies that assess the efficacy of advance directives by exploring correlations between their content and decision-making outcomes, evidence is often limited to patients who allegedly have advance directives. But as Muriel R. Gillick (2010: 1239) explains in her critique, "What we really would like to know—whether the preferences of patients were any more likely to be honored if they had a living will than if they did not—cannot be determined." This problem arises because patients without advance directives have not documented their wishes about end-of-life care. Assessing the concordance between patient wishes and treatment outcomes is, therefore, impossible for those without documented wishes.

Because of these difficulties, studies examining the concordance of wishes and outcomes often have no control group, looking only at those with directives. An appreciation of the role of advance directives is profoundly incomplete without including the majority of Americans who, as documented below, do not have them. Does the decision-making process look any different for those with and those without directives? Drawing on the experience, day to day, of all patients, this article examines this critical question and addresses the policy implications that follow.

Methods

The data come from a three-year prospective observational study of patients admitted to the neurological or medical intensive care units (ICUs) of a

large urban Illinois teaching hospital serving a demographically diverse population of patients.[1] Data on the prevalence of advance directives reflect the population of all 2,216 patients who passed through the two ICUs during the period of the study. The observational study focuses on the friends, family, and significant others who spoke on behalf of 205 of the ICU patients lacking decision-making capacity.[2] They faced a host of medical 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.[3]

Data sources include paper and electronic medical records and observations of daily critical care rounds and 1,013 conversations or meetings between almost three hundred health care providers and more than six hundred of the patients' friends and families throughout the day.[4] Data reflect the medical issues patients faced, the interventions made and refused, what transpired in meetings with their representatives, the disposition of their hospital stay, and their demographic characteristics and those of meeting participants.

To minimize reactivity, encounters were not tape-recorded, nor were notes taken. At their conclusion, the observers re-created transcripts of what was said and by whom and documented the dynamics of the interaction and characteristics of the meeting and participants. For each patient, the actual advance directives in the hospital chart were examined, the treatment decisions made were known, and the process by which and articulated reasons for which these decisions were made were observed.

Observations were conducted by me and by a medical social worker, and both of us coded the transcripts with ATLAS.ti (version 5.71). ATLAS.ti and other data were exported into SPSS (version 18), Stata (version 11.2), and Clarify (version 2.1) for quantitative analysis. The research protocol

1. As shown in table 2 below, patients are very diverse demographically, reflecting trends nationwide.

2. The observational study included all ICU patients deemed by their physicians to be unable to make medical decisions and about whom a discussion occurred regarding goals of care or consent to a medical procedure or at least three encounters between health care providers and patient representatives were observed. Many ICU patients (especially those admitted after a surgical procedure) do not lack or quickly regain capacity 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 are the focus of the observational study.

3. By a conservative count, more than half of the decision makers in the observational study were consulted or initiated a conversation about at least four major interventions or changes in goals of care.

4. Although not presented here, limited data on 699 interactions that were not observed came from physician notes or accounts from participating doctors or nurses. These encounters occurred at the same time as another observed meeting, away from the ICU or over the phone, or late at night or on weekends. Most of the significant family meetings were observed.

was approved by the institutional review boards of the university with which the hospital was affiliated as well as that of the American Bar Foundation.

Advance Directives in the ICU

Advance directives are legal documents in which competent people give instructions for medical decision making on their behalf should they lose decision-making capacity in the future. Although the particulars vary considerably across the fifty states (American Bar Association Commission on Law and Aging 2013b), there are two generic types or elements of advance directives, sometimes combined in a single document: proxy directives that designate one or more persons to make health care decisions on our behalf (often called durable powers of attorney for health care) and instructional directives that provide guidance about the type and amount of treatment desired (often called living wills).[5] For individuals who fail to name a power of attorney, state surrogacy statutes specify who on the family tree will serve as default surrogate decision maker and often limit the kinds of medical decisions these default surrogates are permitted to make (American Bar Association Commission on Law and Aging 2014).

5. In Illinois, the site of this study, durable powers of attorney for health care designate patients' proxy medical decision maker, but they also have instructional components offering three optional treatment preferences that most patients check:

1. "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." [Sixty-five percent of forms in the medical record check this option.]
2. "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 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." [Ten percent of forms in the medical record check this option.]
3. "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." [Eight percent of forms in the medical record check this option.]

Illinois changed the wording of these options slightly after the conclusion of the study. The boilerplate Illinois living will states:

> 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 or sustenance or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.

Table 1 Advance Directives in the ICUs

	All Patients		Patients in Observational Study	
	(*N*)	%	(*N*)	%
No advance directive[a]	(936)	42%	(59)	29%
Claim only power of attorney (POA)	(365)	16%	(58)	28%
Claim only living will (LW)	(74)	3%	(5)	2%
Claim both POA and LW	(351)	16%	(37)	18%
Hospital did not or could not obtain information[b]	(490)	22%	(46)	22%
All patients	(2,216)		(205)	
POA and/or LW in hospital chart	(212)	10%	(47)	23%

Notes: On admission, patients or surrogates were asked whether the patient had a living will or power of attorney for health care and who was the decision maker. If patients had a directive, a family member was asked to bring it in; if they did not, competent patients were asked whether they would like information to prepare one. Throughout the hospital admission, nurses received daily reminders to ask that advance directives be brought in or that incomplete forms be completed.

[a]This category includes patients who were offered the opportunity to complete an advance directive and chose not to.

[b]In some cases (especially with emergency admissions), patients were comatose or incompetent and could not be asked about their advance directives, and no family members were around to ask. Although nurses solicited this information throughout the admission, some were not successful.

In most American hospitals, patients or the persons who accompany them are asked whether the patient has or, if competent, would like to complete an advance directive. Like Americans in general (AARP 2008; American Bar Association 2008; Pew Research Center for the People and the Press 2006; Rao et al. 2014), only a minority of ICU patients report or complete directives. Table 1 indicates that this is true of a little more than one-third of all the ICU patients; most are proxy directives. Patients included in the observational study were more likely to claim an advance directive (49 percent); this reflects the fact that they are considerably older (median age sixty-seven versus fifty-six for ICU patients not in the observational study).

Few of the reported directives ever appear in the patient's hospital chart; it is not clear that many actually exist.[6] Despite continued prodding of family members to bring in copies, by the end of the patient's ICU stay,

6. Sometimes patients misremember, misunderstand, or tell hospital staff what they think they want to hear. When they lack competence, 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. (2011) find that 13 percent of surrogates report the existence of living wills and 28 percent mistakenly report health care proxy documents that do not actually exist. (Another 6 percent and 4 percent, respectively, erroneously report that these documents were not completed.)

only one in ten has documentation in the medical record of written treatment preferences and/or a legally designated surrogate medical decision maker (almost one in four of those in the observational study).

Table 2 reveals that age is the most important predictor that an ICU patient allegedly has an advance directive. Patients over seventy-five are three and a half times more likely to report a directive than those under thirty. African American and Hispanic patients report substantially fewer directives (less than half as many) than their white counterparts. Patients residing in the poorest zip codes and with no medical insurance or on public aid have lower rates of advance directive use as well. Differences are not as large between patients with long-standing medical problems or hospitalized for elective procedures and those who are admitted to the ICU after an unexpected emergency.

Although table 2 displays data for all patients with reported directives, these relationships hold separately for those with actual directives in their hospital chart and those claiming to have directives elsewhere. Logistic regressions find no demographic differences between these two groups; they differ only on patient decisional capacity and length of stay in the ICU (those claiming directives elsewhere have shorter stays and are more likely to be consistently competent throughout their admission than those with in-chart directives). For this reason, of ICU patients reporting directives, those in the observational study are more likely to have directives in their chart (47 percent) than those ineligible (24 percent).

Analytic Strategy

One of the challenges of evaluating the efficacy or impact of advance directives arises from the elusiveness of an appropriate control group about whom comparable data are available. The ICU observations provide rich systematic data on varied aspects of the decision-making process and outcomes for all patients throughout their ICU admission. If advance directives provide authority, guidance, information, or reassurance to decision makers and health care providers, one would expect to see their footprints all over the decision-making process. Because patients without advance directives have not documented their wishes about end-of-life care, the data do not permit assessment of the concordance between preferences and treatment outcomes for all patients.[7] But they do allow us to track these footprints and evaluate whether there are any differences by

7. However, they do permit this assessment for those with in-house advance directives (see Shapiro 2012).

Table 2 Characteristics of ICU Patients with Reported Advance Directives

Characteristic (*N*)	% of Those Asked Who Claim to Have a Directive	B	SE
Gender			
Female (866)	46%	(reference)	
Male (860)	46%	0.012	0.110
Age[a], ***		0.358***	0.042
30 or under (153)	21%		
31–50 (457)	28%		
51–65 (549)	48%		
66–75 (319)	56%		
More than 75 (248)	76%		
Race/ethnicity***			
White (1,127)	56%	(reference)	
Black (377)	27%	−0.997***	0.150
Hispanic (109)	20%	−1.234***	0.265
Other (77)	32%	−0.839**	0.271
Wealth of residential neighborhood[b],***		0.007*	0.003
Poorest zip code (446)	35%		
Medium zip code (837)	46%		
Richest zip code (441)	57%		
Health insurance***			
No insurance (214)	22%	(reference)	
Public aid (104)	16%	−0.067	0.334
Private insurance (768)	43%	0.593**	0.204
Medicare (636)	62%	0.848***	0.222
Medical history***			
Unexpected emergency (502)	39%	(reference)	
General health problems (295)	40%	0.036	0.173
Long-standing problem (929)	51%	0.376**	0.140
Elective hospitalization			
No (1,446)	45%	(reference)	
Yes (280)	50%	−0.282	0.157

Notes: B = unstandardized coefficient; SE = standard error

[a]The logistic regression coefficients represent a ten-year change in age.

[b]Median household income in the 2000 census for the poorest zip codes is less than $38,500; that for the richest zip codes exceeds $64,000; the range is $14,200–$200,000. The logistic regression coefficients represent a $1,000 change in median household income of the patient's zip code.

*$p < .05$; **$p < .01$; *** $p < .001$

496 Journal of Health Politics, Policy and Law

advance-directive status in decisions made and how they are reached. The finding of a significant residual correlation, after controlling for covariates, does not necessarily indicate that advance directives have a particular impact. These "footprints" should not be confused with measures of efficacy. But the absence of difference between those with and those without advance directives in the decision-making process and outcomes would certainly raise questions about claims of efficacy. Advance directives are unlikely to be very directive when their footprints are few and far between.

The following tables display the results of logistic or linear regressions on more than thirty aspects of the decision-making process or outcomes by advance-directive status. Because variables associated with reporting an advance directive are also related to the process and outcomes of surrogate decision making, analyses control for these covariates, including the patient's age, ethnicity, and gender; income of residential neighborhood; whether illness was preexisting or came out of the blue; and whether the patient or family member is a lawyer or health care provider. Analyses also control for severity of illness,[8] which affects prognosis, treatments considered, and how decision makers think about them.[9]

Of course, running dozens of regressions to look for footprints of advance directives represents a statistical fishing expedition that increases the likelihood of committing Type I errors—falsely rejecting null hypotheses. Although there are statistical techniques to assess this "false discovery rate" (Benjamini and Hochberg 1995), they are probably overkill here.[10]

8. Most ICU-based medical research uses physiological measurements—blood count, heart and respiratory rate, creatinine, arterial pressure, and so on—to rank patients' severity of illness or likelihood of mortality; the most commonly used measure is the so-called APACHE score (Knaus et al. 1985). Unfortunately, although the ethnographic research reported here collected considerable medical history for each patient, it did not gather detailed clinical information that could generate an APACHE-like score. The measure used here of severity of illness comes from coefficients obtained from logistic regressions of patient medical history, circumstances of admission, and medical status on good (patient goes home or to rehabilitation) or bad (patient dies or is discharged to a facility) outcomes. This gross dichotomy of outcome was chosen because it is generally independent of treatment decisions made by surrogates. For example, no matter how heroic the treatment, a very sick patient will rarely be discharged home directly from the ICU. Similarly, patients on life support typically die if surrogates remove it and either die or end up in a long-term acute care facility if surrogates do not. The best predictors of good or bad outcomes from the logistic regressions are data collected throughout the ICU admission on the patient's ventilation status (i.e., whether on or not on a ventilator) and cognitive responsiveness (Glasgow Coma Scale, which is one component of the APACHE score).

9. Covariates are entered, using a forward (LR) stepwise method that retains only variables that make a significant difference to the fit of the model to the observed data. For many of the dependent variables presented in the following tables, the covariates of age and severity of illness remain in the model, but most other covariates drop out most of the time. I also tested for interaction effects, although few were significant.

10. Nonetheless, an assessment of the false discovery rate in the thirty-plus logistic or linear regressions reported below (using the Simes method in Stata 11) yields only one relationship that warrants rejection of the null hypothesis.

I seek to make a best-case assessment of the impact of advance directives. Even with the expectation that some statistically significant findings do not warrant rejecting the null hypothesis, we will see that there are relatively few traces of the footprints of advance directives in the ICU.

In table 1, ICU patients fell into four groups regarding their advance-directive status: (1) copies of directives were in their hospital chart; (2) they or their spokesperson claimed to have advance directives, copies of which were never produced; (3) they or their spokesperson claimed not to have directives; and (4) the hospital was unable to obtain or failed to record information on advance-directive status. The last three categories undoubtedly have some misclassifications.[11] Some of those reporting directives do not actually have them, and, much less often, those allegedly without directives actually do (Fried et al. 2011).[12] Although most of the patients about whom the hospital collected no information do not have advance directives, undoubtedly some do. To allow for the cleanest comparisons and therefore maximize the likelihood that footprints of advance directives, if any, will be seen in the data, the regressions differentiate all four categories, assessing whether patients with actual directives in their chart, those claiming directives that are never produced, or those with missing data on advance-directive status fare differently than those allegedly without directives at all (the reference category). For simplicity of presentation, the following tables exclude the missing-data category.

In the tables presented below, the patient is the unit of analysis. To allay concern about whether the patient sample size has sufficient power to yield significant relationships, I also ran parallel analyses that reproduce the tables but use the one thousand plus observed meetings as the unit of analysis.[13] These analyses revealed no additional significant relationships other than those below reporting on the patient as the unit of analysis.

11. Though there may be some overlap, these groups are distinctive. Compared with patients without advance directives, logistic regressions find that patients claiming to have an advance directive that is never produced are significantly older, wealthier, more likely to be white, and more likely to have Medicare or private insurance—all characteristics as well of patients whose advance directives are in their medical chart. (Recall from the discussion of table 2 that those producing directives and those claiming they are elsewhere are indistinguishable demographically.) Compared with patients without advance directives, logistic regressions find that patients for whom the hospital never recorded advance-directive status are older, less likely to be black or Hispanic, less likely to have preexisting medical problems, and less likely to have private medical insurance.

12. See note 6.

13. Most dependent variables reflect aspects of the decision-making process that occur during meetings between patients' significant others and health care providers. Analyses consider whether these aspects of the decision-making process are more or less likely to occur in meetings concerning patients with or without advance directives. A few dependent variables—about the passage of time or about patient outcomes—are patient-specific and cannot be included in analyses with meetings as the unit of analysis.

The Process and Outcomes of Surrogate Decision Making in the ICU

Talk of Advance Directives

Do health care providers or patients' family and friends talk about advance directives? Not very often; in not even one in ten of the observed encounters does anyone mention them. One might assume that references to advance directives would be more common for patients who have them than those who do not. However, talk of advance directives, whether initiated by physicians or family members, is almost twice as often to concern logistical matters that pertain to all patients—

- *Does the patient have a living will or power of attorney?*
- *It is important that you bring in a copy.*
- *We brought it in yesterday; did you see it?*
- *Which of you guys is the power of attorney?*
- *My brother will be here tomorrow; he is the power of attorney.*

—than to concern substantive matters that pertain only to those with a directive:

- *What does the directive say?*
- *Which boxes on the form did the patient check?*
- *I read his living will, and it said that he never wanted heroic measures.*
- *It said she wanted everything done.*

One of the most significant footprints of advance directives in the decision-making process is simply whether parties explicitly ask about or refer to them. In table 3 and subsequent tables, dependent variables reflect whether anyone ever—over the course of all meetings and encounters—raised a particular issue.[14] The table presents logistic regressions, controlling for demographic variables and severity of illness, regarding advance-directive talk about patients with no directive (reference) and those with directives in their chart (middle column) and those claiming directives elsewhere (right column). Patients with known advance directives in their hospital chart are significantly more likely to experience

14. Because patients may be subject to anywhere from one to dozens of meetings of very different import and with variable numbers of participants, and because some speakers and dialogues are much more succinct and others verbose, counting the numbers of times that a theme arises or even the number over some denominator does not provide meaningful comparisons across patients. Even though a patient "gets credit" for a single remark made over many conversations, the relatively small number of "yeses" across the tables suggests that measuring variables in this way ("ever"/"never") still differentiates the patients.

Table 3 Advance Directives Mentioned

Directive Mentioned	Directive in Chart		Alleged Directive Elsewhere	
Attribute (number of patients "yes")	B	SE	B	SE
Mentions directive (61)	1.280**	0.428	−0.001	0.452
Logistical (48)	0.772	0.450	−0.567	0.507
Substantive wishes (26)	2.546***	0.792	1.114	0.854
Total cases (199)	(47)		(53)	

Notes: Reference category is "no advance directive" ($N=59$). Missing data category ($N=40$) is not presented. Logistic regressions control for the patient's gender, age, and ethnicity; income of residential neighborhood; severity of illness; whether illness was preexisting or came out of the blue; and whether the patient or family member is a lawyer or health care provider. Covariates are entered, using a forward stepwise method. Regressions are computed with SPSS 18 and Stata 11. B = unstandardized coefficient; SE = standard error.

*$p<.05$; **$p<.01$; ***$p<.001$

advance-directive talk—substantively ($p<.001$) and overall ($p<.01$)—than are those with no advance directive.

Figure 1 depicts these relationships graphically. This and subsequent figures draw on simulations of the parameters derived from the logistic regression models to yield more easily interpretable and substantively meaningful results (King, Tomz, and Wittenberg 2000; Tomz, Wittenberg, and King 2003). Specifically, the figures display differences in predicted probabilities and associated measures of uncertainty around these estimates by advance-directive status. Holding all covariates at their mean, the predicted probability that someone will mention an advance directive is twice as likely (54 percent) with a directive in the chart than with no directive at all (24 percent); it is eight times more likely (32 percent vs. 4 percent, respectively) that someone will address the patient's substantive treatment preferences expressed in the directive.

Both table 3 and figure 1 show that comparisons between patients without any directives and those claiming to have a copy elsewhere are not significant; even where their predicted values differ somewhat, the confidence intervals surrounding them overlap considerably. It is not unexpected that the two groups do not differ significantly on logistical talk—questioning and nagging about the existence and location of directives, identity of the legal decision maker, and the like—which is appropriate for both groups. More surprising, once it is established that patients have directives elsewhere, there is no more questioning or talk about the substantive wishes expressed therein than for patients who have no directive at all. Since the alleged documents

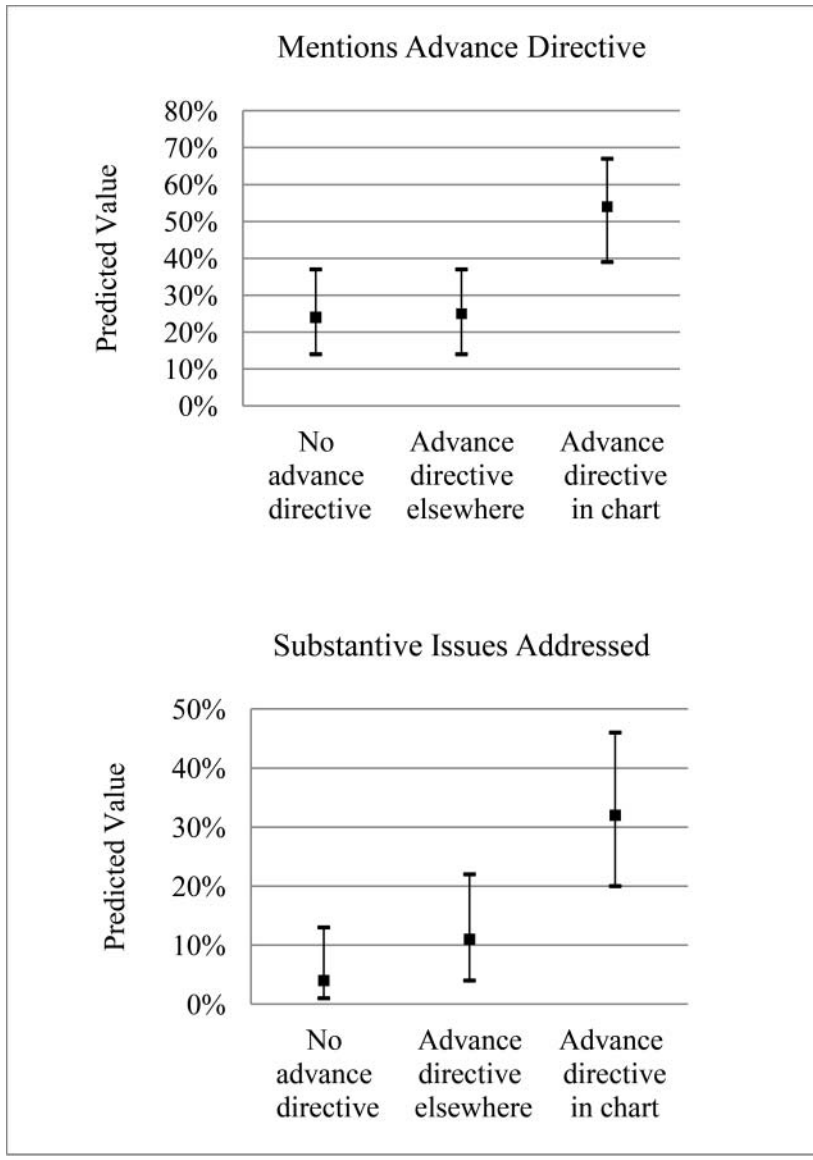

Figure 1 Advance Directives Mentioned

Notes: Plot shows predicted mean likelihood and 95 percent confidence intervals that advance directives ($p < .01$) or substantive wishes contained therein ($p < .001$) are mentioned. See table 3 for the logistic regressions from which these estimates are calculated. Number of simulation draws (M) = 1,000. Covariates are set at their mean; advance directive status is set at "no directive," "directive elsewhere," and "directive in chart." Predicted values estimated using Clarify 2.1 (King, Tomz, and Wittenberg 2000; Tomz, Wittenberg, and King 2003) and Stata 11.

are unavailable for physicians and others to read, one would have expected more questioning and asserting of what these elusive documents contain than even for patients whose directives are in the chart and available for examination. That is not the case. In fact, those claiming a directive elsewhere are significantly less likely to talk about wishes expressed in these documents than patients for whom the directives are in hand. This "out of sight, out of mind" phenomenon—advance directives seemingly leave footprints only when they are available in the hospital record—will become apparent through many of the analyses presented below.

Patient Wishes

It is not necessary to explicitly inquire about, mention, describe, or invoke advance directives in order for them to have an effect. We are encouraged to prepare directives to help ensure that our preferences about treatment and who will make treatment decisions for us when we lack decision-making capacity are honored. An important place to look for an effect of advance directives is whether and how these preferences are shared in encounters between our significant others and health care providers. Whether a participant reads verbatim from the directive, summarizes it, or reprises a conversation with the patient about the document or the process of preparing it, we expect that advance directives will help bring the patient's voice and direction into the encounter. But does it?

Over the course of multiple encounters in the ICU and with different constellations of participants, the patient's directions and wishes are shared by families, friends, and physicians in many different ways. For somewhat more than half the patients (59 percent), at least once over their ICU admission, someone solicits or offers information about their treatment preferences.

Expressed wishes. Some recall specific statements made by the patient, some in recent weeks and others decades ago:

- *He said that he did not want to be intubated and on a ventilator; he did not want a feeding tube; he did not want any surgical interventions; he did not want CPR.*
- *She told me that as long as she's a viable person, she will keep fighting, but once she's not a viable person, she doesn't want any extreme measures taken.*[15]

15. When a physician asked what the patient meant by "viable," the speaker (her mother) didn't know.

- *She said, "Don't do to me what you did to your mother."*
- *Well, he told me, "Do everything you can to keep me alive."*
- *She felt that if she were unresponsive or in a persistent vegetative state or any other state, she did not want to be kept alive by artificial means.*
- *My husband told me often and very seriously that he would not want his death prolonged if he couldn't function.*
- *She said she didn't want to spend her life lying in bed and looking at the wall.*

As these examples demonstrate, some of our expressed instructions are considerably more specific or amenable to operationalization than others. Where expressed statements were never made or provide insufficient guidance, as they often do, some participants turn to other ways of bringing the patient's wishes into the conversation.

Inferred wishes. Drawing on more general or related statements, prior experiences, or the patient's values, some describe the criteria they use to make inferences about what they imagine the patient would want under the circumstances. Some family members explained why they think that the patient would want to continue aggressive treatment:

- *My mother loved life. She would want to live.*
- *She has always been really independent, and she is definitely a fighter. Everyone who knows her agrees. . . . Here, this is the best way I can explain it. Who do you look up to in your life? Who do you really admire? . . . Well, let me tell you who she most admired: Christopher Reeve.*
- *I mean, yesterday I guess someone had told him he'd had a heart attack, and he said to me, "Well can't they just put a stent in, like they did to John?" So to me, I think that would mean he wants to be saved. . . . Yeah, I agree. He said something to me about getting a stent too. So I think he wants us to do everything we can for him.*
- *He's got a fifteen-year-old son, too. . . . That's why he would want all this. He lives for his son.*

Others described why they think that the patient would want to change goals of care from aggressive interventions to comfort care:

- *She is a very active person. She is always doing something. She takes care of her appearance. Always wears makeup. Always fixes her hair. She wouldn't want this.*

- *My mother is very vain about her intellect and very upset about the losses she has experienced. She won't accept this.*
- *It sounds like your mother's wishes, based on what you told me about how she had attempted to commit suicide, were to not live like this.*
- *I know that she wanted to watch her children grow up. But she wanted to interact with them, watch it happen. Not just be alive for it.*
- *About four or five months ago, she gave [her daughter-in-law] a copy of* On Death and Dying*, written by Barbara Ross's mom. She believed in the importance of having a dignified death.*

Personality characteristics. Inferences sometimes draw on features of the patient's personality:

- *I think you ought to know that he is a fighter. His town was taken over by the Nazis. Then he served in the American army during the war. . . . What my father enjoys is fighting adversity.*
- *She wasn't a fighter. She was agoraphobic and didn't want to go outside. She was very depressed.*
- *He's just such a proud man. I don't know if he would want this.*
- *I know my brother. My brother was terrified of pain, of suffering, of death.*

Evidence. Some speakers reinforce their accounts, memories, or inferences with evidentiary authority. Some cite specific conversations:

- *Over Christmas, she told me that she never would want this. She told others too.*
- *Some time ago I spoke with him because I was asking him to serve as a backup on my estate. We had a long conversation about these issues, and he expressed the same thing to me.*
- *We really only had one conversation. It was about seven or eight years ago. It was when her sister was very sick. She was in dialysis and was in a lot of pain. My mother told me that she never wanted to be in that kind of pain. . . . That was our only conversation. Later she developed dementia and she didn't talk much.*

Others emphasize the consistency and frequency of expressions:

- *We lived with her. You didn't. She told all of us what she wanted. I asked her many times what she wanted.*

Some invoke witnesses:

- *I've heard the comment, "How could you?" And that hurts so much. This is what my son wanted. He was insistent. He said it in front of his oncologist and his mother.*
- *We know that she did not want a feeding tube. She said that, and there were witnesses.*

Others cite consensus among friends and family:

- *I've asked a lot of other people for advice on this so that it's not a biased opinion: her friend of thirty-five years and more current people, too. They all agree that this is what she would want.*

Some draw on prior conduct:

- *He didn't want an autopsy for [his mother], so that's why we know he wouldn't have wanted one.*

Others reference observations of the patient while in the ICU:

- *All I can say is that I still see the fight in her. If I didn't, I would say it's enough. But last night when she was blinking and everything, I felt like she was still fighting.*
- *If he didn't want to fight this, it would be over. He will show us what we should do.*
- *I really think she's tired. She doesn't want to suffer any more. That is why she stopped eating.*

And others cite documentary support, including the patient's advance directives:

- *He wanted to donate his organs. I have his driver's license.*
- *Organ donation was not on my mother's driver's license.*
- *Besides it's written down; it's in the papers we gave you.*

Perceived wishes. Finally, some significant others simply state what the patient would want without offering any basis for their conclusion:

I know/think that he/she would want _____.

- *everything you can do*
- *to fight for his/her life*
- *us to make him/her comfortable*
- *to pull the plug*
- *to donate his/her organs*

I know/think that he/she would not *want* _____.

- *"this"*
- *to live this way*
- *any heroic measures, aggressive care, machines, tubes, chest compressions or shocks to restart the heart, a trach, dialysis, nutrition, medications, and so on*

And some add a conditional element:

- *if he/she wouldn't improve, was in a vegetative state*
- *if there's a chance he/she could come out of this, become a normal person again*
- *if there is hope*

As the following dialogue attests, offering one's perceptions of a patient's wishes with no context, evidence, or authority risks confusing one's own wishes with those of the patient perhaps more than the other ways of sharing patient treatment preferences.

> Physician: *Knowing him as you do, do you think that this is what he would want? Some people would say, "If I can't be independent and do things for myself, or if I am on a ventilator permanently, then that is not an acceptable lifestyle for me." Other people think that life is just so precious that one more day, regardless of the condition, is worth it.*
>
> Patient's son: *The second one.*
>
> Physician: *I understand where you stand on it. I'm wondering where he would stand. You know him far better than I do. What do you think he would want?*
>
> Patient's son: *Everything. If there's a fight to be fought, then we need to do everything we can to fight. If there's even a one percent chance, then we need to try.*
>
> Patient's wife: *I don't know that that's what he would say. I just don't know. We never talked about it.*

The data. These quotations, taken from observations of encounters between families and health care providers, were made on behalf of patients with and without advance directives alike. But might the significant others of those with directives be more likely to talk about patient wishes or perhaps more likely to draw on expressed preferences over perceptions of what they might be than those of patients who never put their preferences in writing?

Table 4 Advance Directives and Discussion of Patient Wishes

Patient Wishes	Directive in Chart		Alleged Directive Elsewhere	
Attribute (number of patients "yes")	B	SE	B	SE
Any patient wishes mentioned (118)	0.928	0.512	−0.328	0.482
Patient's expressed wishes mentioned (87)	1.133*	0.495	−0.553	0.480
Patient's wishes inferred (51)	1.051*	0.498	−0.155	0.535
Patient's wishes perceived (78)	0.245	0.419	0.061	0.411
Patient's personality described (75)	−0.010	0.431	−0.177	0.434
Evidence of patient's wishes described (53)	−0.010	0.475	−0.337	0.499
Family doesn't know patient's wishes (15)	0.583	0.944	0.910	0.728
Total cases (199)	(47)		(53)	

Notes: Reference category is "no advance directive" ($N=59$). Missing data category ($N=40$) is not presented. Logistic regressions control for patient gender, age, and ethnicity; income of residential neighborhood; severity of illness; whether illness was preexisting or came out of the blue; and whether the patient or family member is a lawyer or health care provider. Covariates are entered, using a forward stepwise method. Regressions are computed with SPSS 18 and Stata 11.

Expressed wishes pertain to the patient's previously expressed wishes, instructions, or treatment preferences. Inferred wishes provide the reasoning for an inference about the patient's likely wishes (personality, values, prior experiences, related expressed wishes, etc.). Perceived wishes simply state what the patient would want without any explanation. B = unstandardized coefficient; SE = standard error.

*$p<.05$; **$p<.01$; ***$p<.001$

Table 4 provides systematic data from logistic regressions that assess whether and in what ways patient treatment preferences reprised in these encounters vary by advance-directive status (controlling, as before, for patient demographic characteristics and severity of illness). The analyses suggest that advance directives are related to how participants inquire or talk about the patient's wishes or treatment preferences, but not whether they do.

It is perhaps not surprising that the expressed wishes of patients with directives in their chart are significantly ($p<.05$) more likely to be discussed than those without directives at all, since many living wills and other instructional directives on hand in the hospital express their wishes.[16] Figure 2 shows that the predicted probabilities that the patient's expressed wishes will be discussed are 65 percent versus 38 percent, respectively. But both table 4 and figure 2 show that there is no significant difference in the

16. However, there is certainly reason to be skeptical about their influence. For example, for six patients, physicians asked decision makers what was stated in the advance directive that they had brought to the hospital. Two reported correctly; four did not know.

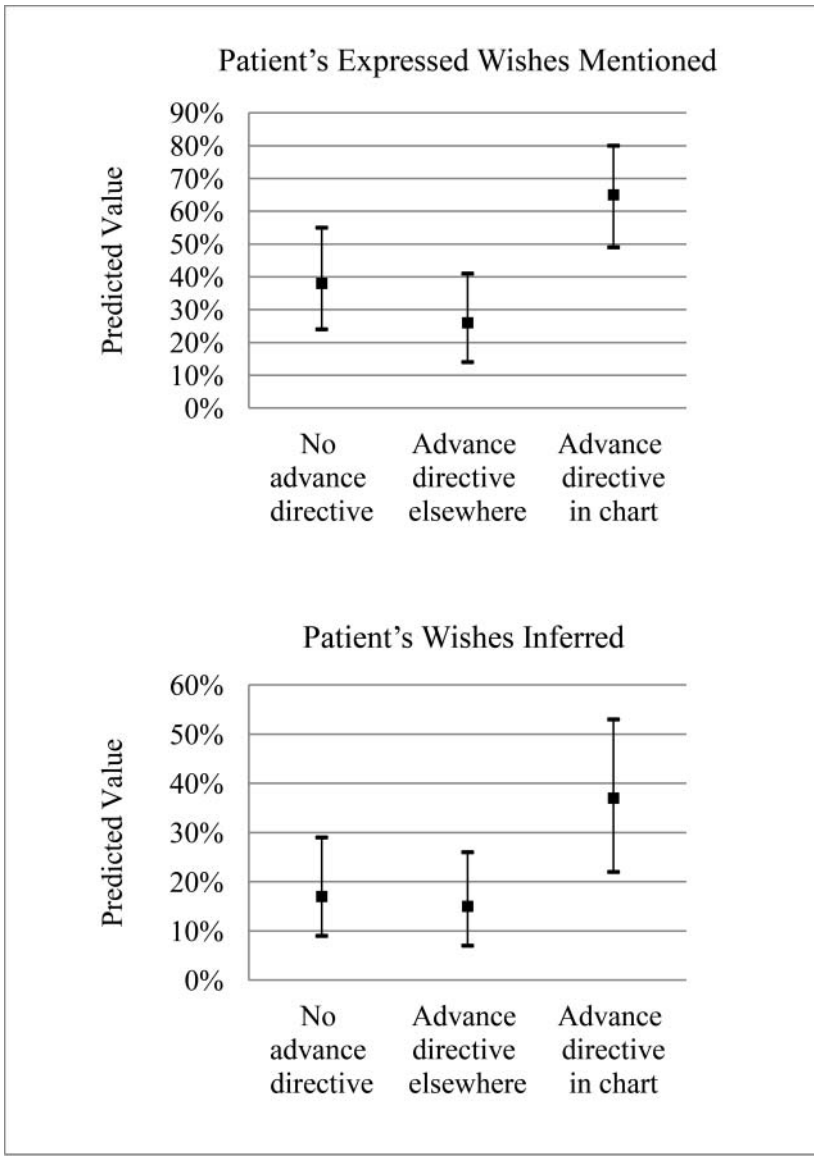

Figure 2 Advance Directives and Discussion of Patient Wishes

Notes: Plot shows predicted mean likelihood and 95 percent confidence intervals that patient's expressed ($p < .05$) or inferred wishes ($p < .05$) are mentioned. See table 4 for the logistic regressions from which these estimates are calculated. Number of simulation draws (M) = 1,000. Covariates are set at their mean; advance directive status is set at "no directive," "directive elsewhere," and "directive in chart." Predicted values estimated using Clarify 2.1 (King, Tomz, and Wittenberg 2000; Tomz, Wittenberg, and King 2003) and Stata 11.

likelihood that expressed wishes will be discussed for those who allegedly have written directives that were never brought to the hospital and those without them. Perhaps because generic expressed wishes must often be tweaked to the particulars of the treatment decision at hand, significant others of patients with in-hospital directives are also significantly ($p < .05$) more likely (predicted probability, 37 percent) than those without any directives (predicted probability, 17 percent) to offer inferences about their wishes. Again, the table and figure show that no such difference exists for patients whose alleged directives are elsewhere.

Table 4 also shows that on the sheer likelihood of any discussion of patient wishes or of other ways of reporting wishes (through personality characteristics, perceptions, or evidence), there are no significant differences between those with in-house directives or those claiming them and those who never executed directives. Moreover, the table shows that these three groups are not significantly more or less likely to indicate that they do not know the patient's wishes.

In short, if your directives are in the hospital record, it is more likely that someone may refer to your expressed directions or offer inferences about them. Otherwise, whether you executed an advance directive or not, whether it is in the hospital record or not, it is no more likely that your wishes will be known, invoked, perceived, or proved. Your doctors or loved ones will be no more or less likely to talk about them or to speculate with less direct knowledge of what you might want.

Before concluding that advance directives play a limited role in ensuring that patients' preferences are considered by surrogates in treatment decisions on their behalf, one caveat must be considered. Perhaps health care providers are overcompensating for patients who never executed advance directives by trying to bring their voice into the conversation. Maybe there is as much talk about the wishes of these patients because health care providers ask about them. For example, the dialogue above between the physician and the patient's son and wife was initiated by the physician's questioning. Had he not posed the question, perhaps the wishes of the patient may never have been considered in the decision-making process at all.

To explore this caveat, logistic regressions consider overall, expressed, inferred, and perceived wishes, but only for conversations about patient treatment preferences that were initiated by health care providers (see appendix). The table in the appendix provides little support for this hypothesis; there are no significant differences between patients without advance directives and those with directives in their chart or allegedly elsewhere in the likelihood that physicians or other health care providers will initiate discussion of their wishes.

Of course, a purported benefit of advance directives is not to ensure that others talk about our wishes but that they talk correctly about them. What of the accuracy of the statements shared, inferences made, or perceptions offered?[17] This question is, of course, inherently unanswerable, at least with these data. But one can ask about the consistency with which participants report on patient wishes and the extent to which significant others disagree about patient wishes.

It is surprising how little the significant others who surround the patient differ about the patient's expressed, perceived, inferred, or overall wishes. This finding is especially striking given that patients often confide different things in different people or that experiences shared with some but not others give rise to different memories that family members reprise. Although it was not unusual to see participants bristle, quarrel, or clash over how to implement or act on a patient's wishes—for example, whether it is appropriate to continue or to stop aggressive treatments—for only six patients (3 percent) did we ever witness even minor disagreement about the wishes themselves (ironically, disproportionately about patients with an advance directive in their chart).

Decision-Making Criteria and Process

Of course, that directives or patient wishes are often or never discussed 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. Perhaps directives have more impact on process than substance, helping to initiate or shape conversations. Table 5 displays the results of logistic regressions concerning elements of the decision-making process observed in encounters between patients' friends or family and health care providers. Again, there are few significant differences between patients without advance directives and either those with directives in their chart or those with alleged directives never produced.

The most important exception is the greater likelihood of spokespersons for patients with advance directives in their chart to initiate discussion about goals of care ($p < .001$)—whether to continue or escalate aggressive measures or to transition to comfort care, to change code (do-not-resuscitate) status, and the like—even before physicians broach these conversations. As displayed in figure 3, the predicted probability that

17. A voluminous empirical literature (e.g., Shalowitz, Garrett-Mayer, and Wendler 2006), relying largely on hypothetical scenarios considered by generally healthy research subjects, casts doubt on our ability to accurately reproduce the wishes of our loved ones.

Table 5 Advance Directives and Decision-Making Criteria and Process

Decision-Making Process	Directive in Chart		Alleged Directive Elsewhere	
Attribute (number of patients "yes")	B	SE	B	SE
Raises goals of care (170)	1.063	0.624	0.501	0.539
Family raises goals of care (89)	1.504***	0.437	0.346	0.418
Physician raises goals of care (133)	−0.015	0.450	−0.030	0.434
Who is the decision maker (50)	0.006	0.449	−0.264	0.452
Decision criteria (75)	0.889	0.486	−0.053	0.479
Best interest (20)	0.298	0.623	−0.042	0.647
Quality of life (47)	0.835	0.437	−0.542	0.499
Pain and/or suffering (140)	−0.107	0.471	−0.851	0.451
Cost (25)	1.018	0.776	0.927	0.781
What I would want for myself (14)	−0.492	0.889	−0.192	0.788
Needs of self or others (50)	0.433	0.466	−0.339	0.507
Family seeks advice (36)	−0.093	0.573	−0.267	0.567
Physician offers advice (69)	0.682	0.466	−0.276	0.460
Conflict between family and physicians (29)	0.618	0.597	−0.491	0.688
Total cases (199)	(47)		(53)	

Notes: Reference category is "no advance directive" ($N = 59$). Missing data category ($N = 40$) is not presented. Logistic regressions control for the patient's gender, age, and ethnicity; income of residential neighborhood; severity of illness; whether illness was preexisting or came out of the blue; and whether the patient or family member is a lawyer or health care provider. Covariates are entered, using a forward stepwise method. Regressions are computed with SPSS 18 and Stata 11. B = unstandardized coefficient; SE = standard error.

*$p < .05$; **$p < .01$; ***$p < .001$

families will initiate such conversations for those with in-chart directives (67 percent) is more than double that of patients with no directive (32 percent). Family members may beat physicians to the punch because of their clarity about the patient's wishes. For example, in a meeting between a patient's daughters and a palliative care attending physician:

> Daughter 1: *For a week, we have been asking, what is the upside of this? What is the best we could expect? But no one would talk with us. They just keep saying that it is too soon.*
>
> Power of attorney (daughter 2): *They keep changing her antibiotics and doing interventions without consulting us. They were trying to make her better, to be where she doesn't want to be. I knew after twenty-four hours that this was not what she would have wanted, but we never had anyone to talk to about it. They sent a resident to tell us that she needed*

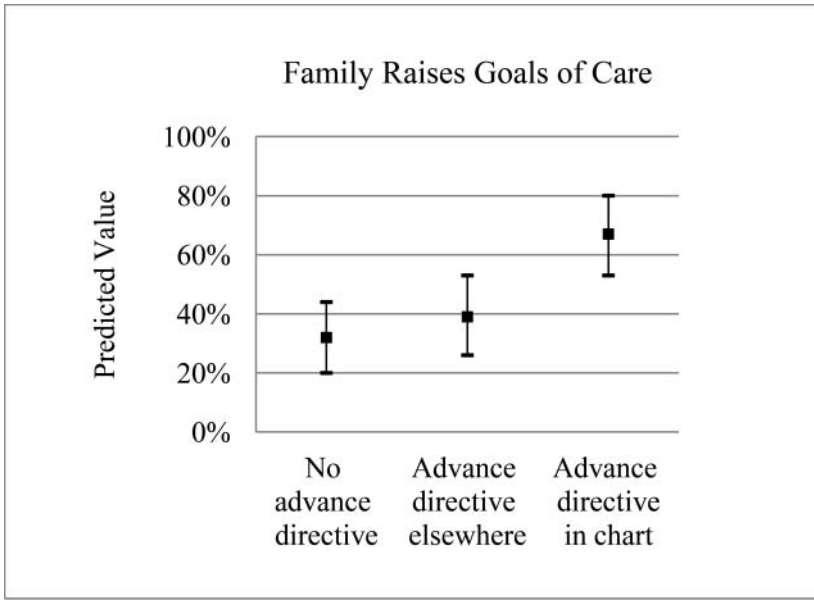

Figure 3 Advance Directives and Initiation of Discussion of Goals of Care

Notes: Plot shows predicted mean likelihood and 95 percent confidence intervals that family raises goals of care ($p < .001$). See table 5 for the logistic regressions from which these estimates are calculated. Number of simulation draws (M) = 1,000. Covariates are set at their mean; advance directive status is set at "no directive," "directive elsewhere," and "directive in chart." Predicted values estimated using Clarify 2.1 (King, Tomz, and Wittenberg 2000; Tomz, Wittenberg, and King 2003) and Stata 11.

> *a tracheotomy and a feeding tube. We told him absolutely not!!! She would not want this!*

But this impetus to initiate discussion of goals of care among families of patients with directives in hand does not extend to those with alleged directives elsewhere, who are not considerably different from the significant others of patients without advance directives. And table 5 indicates that there are no differences by advance-directive status in the likelihood that goals of care are discussed at all or that these conversations are initiated by physicians.

Similarly, table 5 shows no significant difference by advance-directive status in the likelihood of questions about, disclosure of, or discussion about who is serving as decision maker. Because this information is

unavailable when directives are not in the medical chart, one would expect more talk, not less, about the identity of the decision maker.

Physicians and family members often address the criteria by which to make medical decisions on behalf of a patient lacking capacity. Table 5 reviews the most common themes that arise in these conversations and shows that advance directives are unrelated to the likelihood that decision-making criteria are considered, either generally or specifically. Again, this finding is surprising because the directives often specify the criteria that decision makers ought to consider.

The option on the Illinois power of attorney form that gives decision makers the most discretion (and is most frequently checked) suggests that agents weigh the expected burdens and benefits and "consider the relief of suffering, the expense involved and the quality as well as the possible extension of [the patient's] life in making decisions concerning life-sustaining treatment" (see note 5). Table 5 shows no significant differences in the likelihood that participants mention quality of life, pain and suffering, cost, or the patient's best interest (the legal default when patient wishes are unknown).

Other family members elect treatments that they would choose for themselves or take account of their own interests or those of others over interests of the patient. Surrogates unsure of what to decide may solicit advice or receive unsolicited offers of advice from physicians. One might suppose that those with little advance direction from patients might be offered or grasp at one or more of these straws, but, again, there is no significant difference in the likelihood of embracing these criteria by advance-directive status. Nor are there any significant differences in the likelihood of conflict between physicians and the patients' circle of friends and family.[18]

The finding that families of those with advance directives in hand are more likely to initiate discussion of goals of care suggests that, whether or not directives affect what transpires in end-of-life conversations, they may accelerate the speed with which certain questions are raised, instructions reprised, uncertainties clarified, consensus among family members achieved, or decisions made. Table 6 presents results from linear

18. I did not examine the likelihood of a consultation with the ethics committee, often helpful to resolve conflicts or when family members have difficulty deciding or reaching consensus, because the number of patients subject to an ethics consult (nine) was too small. However, without controlling for demographic characteristics, ethics consults are almost five times more likely where they would be least expected—with advance directives in hand—than where there are no directives at all or none in the hospital chart.

Table 6 Advance Directives and Time Taken to Address

Time Taken to Address	Directive in Chart		Alleged Directive Elsewhere	
Attribute (number of patients "yes")	B	SE	B	SE
Number of days until patient wishes raised (118)	3.603	1.911	0.376	2.015
Number of days until goals of care raised (170)	2.237	1.454	0.710	1.449
Number of days goals of care raised to changed (115)	0.512	1.473	−0.362	1.441
Number of days in ICU (199)	3.069	2.207	1.339	2.174
Total cases (199)	(47)		(53)	

Notes: Reference category is "no advance directive" ($N=59$). Missing data category ($N=40$) is not presented. Multiple regression controls for the patient's gender, age, and ethnicity; income of residential neighborhood; severity of illness; whether illness was preexisting or came out of the blue; and whether the patient or family member is a lawyer or health care provider. Covariates are entered, using a forward stepwise method. Regressions are computed with SPSS 18 and Stata 11. B = unstandardized coefficient; SE = standard error.

*$p<.05$; **$p<.01$; ***$p<.001$

regressions of advance-directive status (controlling for the same variables as the logistic regressions) on temporal features of the decision-making process.

The table shows that aspects of the decision-making process that might be foreshortened by the clarity of preferences or instructions expressed in directives—how quickly patients' wishes and treatment preferences are considered, how quickly goals of care are first discussed, how much time transpires between when goals of care are first raised and when they are changed, or how long the patient remains in the ICU[19]—are unrelated to advance-directive status. Indeed, although none of these relationships are significant, the expected values from simulations suggest that, all else being equal, those with advance directives in their chart take *more* time on each of these features of the decision-making process. Of course, some goals of care are never changed because directives specify that life-sustaining treatment continue; similarly, ICU stays may be prolonged if decision makers are following directions to soldier on. However, such

19. Since almost half of all patients die in the ICU after decisions to limit life support, the length of the ICU stay is somewhat of a proxy for how long surrogates take to make this decision, if they ever do.

instructions pertain to a minority of patients; only 15 percent of directives in hospital charts dictate that life be prolonged to the greatest extent possible or unless the patient is in an irreversible coma.

Outcomes

Are advance directives associated with particular outcomes, because they request these outcomes, because they give decision makers confidence and cover to make difficult decisions, or because their instructions diverge from default outcomes (aggressive care) that apply when no advance directive exists? Although table 6 indicates that surrogates following advance directives appear to be no quicker in making these difficult decisions, one would expect them to be more likely to eventually change goals of care from aggressive to comfort measures—at least for the 85 percent of directives that do not request heroic measures under most or all circumstances. Table 7 provides no support for this expectation. Surrogates for patients with in-chart directives or with directives elsewhere are no more likely than those with no advance directive to even consider changing goals of care by consulting with palliative care physicians. Nor are they more likely to refuse an intervention or authorize a do-not-resuscitate order or the withdrawal of life support. Contrary to charges of a link between advance directives and "death panels" by opponents of health care reform

Table 7 Advance Directives and Outcome Measures

Outcome Measures	Directive in Chart		Alleged Directive Elsewhere	
Attribute (number of patients "yes")	B	SE	B	SE
Consults with palliative care (51)	0.748	0.480	0.097	0.494
Refuses an intervention (128)	−0.181	0.568	−0.864	0.556
Do-not-resuscitate order (116)	−0.561	0.552	−0.756	0.555
Withdraws life support (85)	0.166	0.558	−0.228	0.569
Total cases (199)	(47)		(53)	

Notes: Reference category is "no advance directive" ($N = 59$). Missing data category ($N = 40$) is not presented. Logistic regressions control for the patient's gender, age, and ethnicity; income of residential neighborhood; severity of illness; whether illness was preexisting or came out of the blue; and whether the patient or family member is a lawyer or health care provider. Covariates are entered, using a forward stepwise method. Regressions are computed with SPSS 18 and Stata 11. B = unstandardized coefficient; SE = standard error.

*$p < .05$; **$p < .01$; ***$p < .001$

Table 8 Advance Directives and Impact on Family

Impact on Family	Directive in Chart		Alleged Directive Elsewhere	
Attribute (number of patients "yes")	B	SE	B	SE
Conflict within family (19)	0.458	0.640	−0.434	0.756
Family emotional burden (99)	0.015	0.421	−0.290	0.412
Total cases (199)	(47)		(53)	

Notes: Reference category is "no advance directive" ($N=59$). Missing data category ($N=40$) is not presented. Logistic regressions control for the patient's gender, age, and ethnicity; income of residential neighborhood; severity of illness; whether illness was preexisting or came out of the blue; and whether the patient or family member is a lawyer or health care provider. Covariates are entered, using a forward stepwise method. Regressions are computed with SPSS 18 and Stata 11. B = unstandardized coefficient; SE = standard error.

*$p<.05$; **$p<.01$; ***$p<.001$

(Nyhan 2010), there are no significant differences between those with and without directives in the likelihood of abandoning aggressive treatment.

Impact on Families

Finally, what about the impact on the patient's family, friends, and significant others? One of the reasons advocates recommend advance directives is that, by specifying treatment preferences, who should make treatment decisions, or what criteria should be followed, directives minimize the decision-making burden (and associated guilt, remorse, conflict, resentment, etc.) on family members (Martin, Emanuel, and Singer 2000). Table 8 shows that, at least with respect to expressions of emotional burden by family members or conflict among them that surfaces during encounters with health care providers—admittedly a very small window on their experience—advance directives, once again, seem to make no difference.

Choice of Decision Maker

The news is a little better about the role of proxy directives. Observational data record who made each medical decision over the course of the patient's ICU admission. For 70 percent of patients with copies of a power-of-attorney directive in their hospital chart—and, therefore, for whom their designated decision maker is known—the chosen surrogate made all medical decisions throughout their ICU stay; for 12 percent, the surrogate

made some decisions; for 3 percent, the surrogate made no decisions; and for 15 percent, it was unclear who was making some of the decisions. Of course, there is no way of knowing whom patients without directives would have chosen as their proxy decision maker; perhaps this hypothetical person and the person who actually made medical decisions on behalf of these patients corresponded even more often than for those who named powers of attorney.

Discussion

If one tried to navigate through the dense thicket of ICU decision making by following the footprints of advance directives, one would become hopelessly lost. Controlling for demographic characteristics associated with the likelihood of their adoption and severity of illness, advance directives leave relatively few footprints, at least on observable behavior in the ICUs. And even some of those are probably false positives or what statistical inference would deem "false discoveries" created by the large number of regressions from which these findings were mined. The few significant differences found, however important, are not unexpected: Compared with patients with no advance directives, families of patients with directives in their chart are more likely to talk about the directives, the wishes expressed in the directives and elsewhere, and their inferences about patients' likely preferences when wishes were not expressed or applicable and to initiate discussion of goals of care. All this talk is part of what advance-care planning is supposed to produce. But it is striking that talk is associated with no difference in process, outcome, or impact. Treatment decisions are not different, they are made no faster, they weigh similar criteria, nor do they appear to be any less burdensome for families.

Most surprising, significance tests indicate that patients who claim to have advance directives that are never produced are indistinguishable from those who have no directives at all on all the thirty-plus variables considered. As a result, had the analyses presented in tables 3–8 simply differentiated between those who report directives and those who do not, as much of the literature does, only two of the thirty-plus relationships would have been significant: discussions of treatment preferences specified in the advance directive and family members initiating discussion of goals of care.

Of course, some patients (or family members speaking on their behalf) who claim to have copies of advance directives elsewhere are undoubtedly mistaken. If some of those claiming directives do not have them and some of those denying directives actually do have copies elsewhere, the two

groups will overlap to some extent. However, as described earlier (note 11), these two groups are significantly different overall, with the demographic characteristics of those failing to produce alleged directives similar to those whose directive is in their hospital chart. Still, any overlap may account, in part, for the failure to find differences between those alleging but not producing directives and those without any directive. Nonetheless, one might have expected even more questioning by health care providers about advance directives and the wishes of patients who, hospital records indicated, had a directive that was never produced; there was no evidence of such inquiry.

In short, advance directives show even limited differences only when they are physically present in the hospital. It seems that it is not the execution of a directive or all of the talk that this process engenders that is related to surrogate decision-making processes but the availability or salience of a piece of paper, the act of bringing in that piece of paper (and perhaps reading it en route), or the availability of a document for health care providers to examine.

But availability of the document may be a proxy for something else. Perhaps patients themselves with in-chart directives and those claimed, but never produced, are somehow different in ways that cannot be observed (e.g., personality traits or social desirability bias) or that do not show up in scores of analyses that sought to assess their differences. Perhaps patients with very strong treatment preferences ensure that advance directives are in their medical record and that their loved ones are prepared to advocate these preferences on their behalf.

Maybe the patients are the same, but the families are different. Peter H. Ditto, Nikki A. Hawkins, and David A. Pizarro (2005: 497) suggest that some prepare advance directives because they worry that, otherwise, their loved ones will be "pulled" from honoring their wishes "by emotional concerns." Others may ensure that their directives are available to offer guidance or facilitate the consensus that they fear may someday be badly needed among relatives whom they know to be irresolute or contentious. Or perhaps surrogates for patients claiming directives elsewhere have never seen them; they feel empowered by the alleged document but less familiar with or accountable to its instructions. Or maybe the elusive documents name powers of attorney but provide no instructions (unlikely given that 85 percent of those in the chart include instructions).

This finding raises still more questions about the efficacy of directives if they need to be in hand to leave even a few shallow footprints. Of course, perhaps advance directives have effects that are not observable in the ICU, for example, surrogate feelings of guilt or remorse many months after the patient's death (Wendler and Rid 2011).

This statistical exploration of differences in the process and outcomes of surrogate decision making related to the execution of advance directives complements qualitative analyses that track the invocation and use of directives in these actual conversations, day after day in the two ICUs (Shapiro 2012). The qualitative findings are similarly underwhelming: for almost half the patients with advance directives in their chart, the directive made no discernible difference; for about a quarter, it probably helped to honor the patients' wishes; and at least as often, it probably failed to honor or undermined their wishes (Shapiro 2012: 228–29). But the qualitative analysis could not control for demographic differences, nor could it follow the patients with alleged directives elsewhere or none at all. However unsatisfying a statistical fishing expedition may be, it tracks the experience of all patients in the study. And it offers no better news about the apparent effects of advance directives.

Critiques of the efficacy of instructional directives or living wills usually do not extend to proxy directives or powers of attorney that designate surrogate decision makers to speak on our behalf when we lose decision-making capacity (Fagerlin and Schneider 2004). As noted earlier, most ICU patients whose power-of-attorney form was in their hospital chart got the decision maker they named most of the time. Still, as addressed below, many of these surrogates could have been better prepared for the onerous responsibilities they bore.

Policy Implications

The quantitative data illuminate the small footprint of advance directives, especially instructional directives, in the two ICUs. They do not permit assessment of alternative strategies to convey patient treatment preferences or assist surrogate decision makers. It would seem, for example, that technological advances that ensure that immediate access to directives is available in varied settings might narrow or eliminate the vast divide between decision making for patients with directives in their chart and those with directives allegedly located elsewhere. But if, as noted earlier, access to directives is actually a proxy for something else—strength of preferences, personality differences, family dynamics, and the like—uploading directives to the "cloud" or to smartphones or even implanting them in a chip under our skin may make little difference. A controlled experiment is required to evaluate the value of such an intervention.

Systematic observation of surrogate decision making, day after day, over three years among almost a thousand health care providers and friends and

family members (across the spectrum of race, ethnicity, class, age, education, and religion), though not a controlled experiment, does provide insight about how directives succeed and fail on the ground and what sorts of interventions are likely to advance patient autonomy or ameliorate the decision-making burden on those they love.

For example, as documented in note 5, boilerplate instructional directives in Illinois, where the research was conducted, tend to be relatively narrow, applying only when death is imminent, or to be extremely open-ended. Directives in some other jurisdictions as well as various advance-care-planning exercises are more specific—with long lists of various medical conditions in column A and potential interventions in column B to match up. Would surrogate decision makers have been better served with more specific directions?

My experience suggests that they would not, especially those speaking for patients who were not facing a specific imminent terminal illness when they penned their directives (Shapiro 2012).[20] First, it is impossible to foretell the precise concatenation of diagnoses, prognoses, treatment options, risks, probabilities, pain, suffering, and costs that may confront surrogates some day; real-world scenarios invariably fall between the cracks. Moreover, what seemed onerous and incurable today may be less so years hence when the directive is needed. Second, the language of medicine often means different things to patients, their surrogates, and to health care providers; the terms *coma*, *machine*, or *vegetable* are good examples. Third, prognostic information on which decisions are contingent is often unavailable or is contradictory from one physician to the next. Other medical information is rarely as black-and-white as directives demand. Fourth, when directives are in writing, patients and their significant others are less likely to talk about, interrogate, or revisit them; surrogates are more likely to hide behind them and refuse to interpret their ambiguities or gaps in application; and physicians are more likely to enforce their literal meaning rather than embrace their spirit. All of these difficulties were on display in the two ICUs.

Intensive care units do not suffer from a dearth of carefully specified written instructions. Rather, they face a deficiency of able, assured surrogates. Too little attention has been devoted to selecting an appropriate decision maker who knows the patient's priorities and values and who has the time for repeated hospital visits; the clarity to see the forest for the trees,

20. Though not available in Illinois at the time of the study, the Physician Orders for Life-Sustaining Treatment (POLST) program has shown success for patients with relatively short life expectancies (Hickman et al. 2011).

to ask the right questions, and to process complex, often conflicting, information; and the disposition to build consensus, to stand up to physicians or family members, when necessary, and to be a strong, effective advocate—assuming, of course, that such a person can be found in the patient's social circle. A minority of patients in the two ICUs I studied—or in most other studies—have bothered to select a surrogate decision maker at all, let alone one who might best take on and perform this demanding role. In observing decision makers struggle, it is clear that some patients picked the wrong significant other to speak for them and that others would have been better served if they had ensured that someone other than the default surrogate specified by legal statute was their spokesperson.

Moreover, even the most capable, diligent, and knowledgeable surrogates suffered from lack of clarity about how to adjudicate among difficult trade-offs, how to interpolate from inadequate information, and how to deal with probability, risk, and uncertainty. Much of the emphasis in the move to encourage Americans to execute advance directives focuses on achieving the right outcome. But many surrogates know the right outcome; it is the process that haunts and paralyzes them. That is one of the reasons research on how advance directives correlate with final decisions misses the space where advance directives need to do their work. How bad does the prognosis have to be? How certain does the prognosis have to be? How long to try before giving up? How much suffering along the way is acceptable? What if there is a risk that the proposed treatment might make the patient better, to where he or she "doesn't want to be," or lead to a fate worse than death? How much weight should be given to the needs of the family?

Because of the many difficulties that surrogates face in speaking for patients without capacity, some scholars have proposed default guidelines, based on preferences of relevant communities of patients, that remove at least some discretion from surrogates and reportedly reproduce patient preferences at least as accurately as surrogates do (Emanuel and Emanuel 1993; Lindgren 1993; Shalowitz, Garrett-Mayer, and Wendler 2007; Smucker et al. 2000). But most policy makers seek instead to improve the quality of patients' expressed preferences as well as how surrogates represent them, embracing variations on the theme of advance-care planning. In different forums—from doctors' offices to senior centers to dinner parties—and by offering varied stimulus materials and conversational tools, advance-care planning programs assist us in thinking and talking about our expectations, goals, values, trade-offs, priorities, and fears (Hickman et al. 2005; Martin, Emanuel, and Singer 2000; Rogne and McCune 2014; Sudore and Fried 2010) and, to a far lesser extent, in

selecting appropriate surrogates and preparing them for their role (American Bar Association Commission on Law and Aging 2009, 2013a).[21] Although these programs strive to extend their reach, especially to diverse populations, there is little evidence from the ICU study that any of the patients had engaged in such exercises.

Advance-care planning would benefit from several insights gleaned from the research. First, although claiming to have an advance directive is not coterminous with participation in advance-care planning, policy makers should be mindful that a significant majority of the ICU patients without advance directives (a little more than three-quarters) were relatively young (under age sixty) and/or without preexisting health problems. Given this demographic, guidance on how to select and prepare the most effective surrogate is far more appropriate than guidance on how to express and document wishes about a host of abstract medical problems and treatments that may or may not arise far down the road. And outreach efforts to prospective patients and their (usually younger) surrogates need to continue to expand beyond venues that serve the elderly.

Second, even for older and sicker patients, for whom discussion of medical conditions and related treatment preferences may be more appropriate, advance-care planning ought to devote as much attention to surrogates as it does to wishes. Patients' closest relatives, specified as decision makers in most surrogate default statutes and often the knee-jerk patient choice as health care powers of attorney, are not always the persons patients prefer to make decisions on their behalf or feel best know their wishes (Hawkins et al. 2005; Lipkin 2006). Nor do these closest relatives always possess the attributes described earlier as characteristic of an effective surrogate. Advance-care planning should help patients identify who in their circle would be the most faithful and effective advocate and how to make the best choice without offending others on the family tree. Moreover, because many of us face challenges finding or enlisting effective advocates, advance-care planning efforts should help surrogates step up to a task for which they may not be well suited.

Third, facilitating conversation between prospective patients and their loved ones is only as valuable as the quality of information shared. When understandings, terminology, expectations, wishes, and fears reflect misinformation derived from heroic television fare, gossip about the medical

21. Many of these programs conclude with documentation of an instructional directive. I argue that this is one step too far and might make matters even worse if complicated, idiosyncratic documents, which surrogates may not understand and with which physicians are unfamiliar, make their way into hospital charts.

misfortunes or miracles of others, Internet blogs, or stereotypes about the experience of disability, surrogates may take away misguided directions from those they may someday represent. Moreover, as noted earlier, conversations about process or decision-making criteria are at least as helpful to surrogates as are specific desired outcomes (which are likely to change with experience, infirmity, or the passage of time).

Each of these proposals would benefit from better stimulus materials for prospective patients and surrogates alike that correct for misinformation and convey what various procedures, medical conditions, and outcomes actually look like; what to expect from hospital routines and personnel; what sorts of information to demand; how much inconclusive or inconsistent information to expect; or how to negotiate the decision-making process. A few videos of this sort with demonstrated efficacy already exist (McCannon et al. 2012; Volandes et al. 2007), and interactive checklists, simulations, and virtual worlds could be developed with online links to advance-directive forms or advance-care planning programs or for use within hospitals when decision-making demands are imminent.

Finally, however effective the outreach, there will always be hospitalized patients without designated decision makers who have not discussed their treatment preferences with others and surrogates unprepared to negotiate the difficult challenges that lie ahead. Hospitals could do more to assist both patients with capacity and surrogates speaking for those without capacity. Hospital staff might help patients identify who in their circle is most up to the task of speaking for them; facilitate conversations between patients and their surrogate and other family members; help collect, synthesize, and translate complex medical information to decision makers; and assist and support surrogates and other family members in navigating the process.

Although physicians should receive better training facilitating end-of-life conversations and decision making, their likely efficacy in this role is limited, at least in part because they face challenges seeing the forest for the trees, especially in ICUs, where different specialists treat the patient and where physicians continually rotate on and off the unit. Specially trained social workers or ethicists assigned to the critical care team would be more effective, interacting with surrogates and family members throughout the hospitalization, as teams and specialists come and go and sometimes disagree. They would not supplant the critical role of physicians in updating patients and families, negotiating informed consent, or developing goals of care. Rather, these team members would assist patients and families

in communication; information collection, translation, and processing; decision making; group dynamics; and conflict resolution.[22]

Advance-care planning, even at its best, is no panacea. However well prepared, surrogates often face the most difficult decisions of their lives. How well these resources will enhance patient autonomy or surrogate efficacy or comfort or how many participants will partake of them remains to be seen. Some offerings will be more expensive than others. Some may promise cost savings or efficiencies as responsibilities shift from physicians to other professionals and as surrogates become more decisive with better information and support. Hospitals, insurers, regulators, legislators, and the organizations that develop and promote advance-care planning will have to decide if the expenditures and/or requirements are justified.

Limitations

The ICU study has limitations of course. First, despite a diverse pool of subjects and data on more than one thousand interactions between almost three hundred medical staff and more than six hundred friends and family of patients over three years, the resources demanded to conduct observational research significantly limit its breadth. This study was conducted in one city, in one hospital, in only two of its ICUs, about a rather modest number of research subjects. The *N*s in some of the tables presented earlier were uncomfortably small (although parallel analyses of the much larger number of meetings suggest that the sample size of patients did not depress the number of significant findings).

Second, although observations of ICU encounters provide rich, revealing detail on how treatment decisions are negotiated between surrogates, family members, and health care providers, they do not provide a window on what transpires outside the unit or what participants think but do not share.

Third, ICUs represent only one of several venues in which end-of-life medical decisions are negotiated. Even so, almost 40 percent of Medicare enrollees visit an ICU in the last six months of life (29 percent in the last month of life); roughly one-fifth of all Americans die during an ICU

22. Readers may recall the disappointing results of interventions in the well-known SUPPORT study (Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment), in which nurse specialists facilitated communication between patients, surrogates, and physicians. Many critics attributed the failure of the intervention, in part, to the possibility that nurses lacked sufficient power or status or were not sufficiently integrated into the health care team to influence physician behavior (Hastings Center 1995). In contrast, the suggestion here that social workers or ethicists join the critical care team is intended to assist patients and families, not physicians.

admission, and others do so in the weeks or months thereafter (Angus et al. 2004; Teno et al. 2013; Dartmouth Institute for Health Policy and Clinical Practice 2007). Intensive care units disproportionately collect patients unable to make their own medical decisions (Luce and Prendergast 2001). If ever one needs an advance directive, the ICU is the place. Still, perhaps directives play a different or more significant role in settings other than ICUs or even hospitals (Degenholtz, Rhee, and Arnold 2004). Indeed, perhaps their most important role is in keeping people out of hospitals altogether, a story the ICU data cannot tell.

The findings presented here do not illuminate the experience of many nearing the end of life, especially those who eschew aggressive care. Research is critical across jurisdictions with different laws and advance-directive options; for patients in for-profit, rural, community, or religious hospitals and not only in their ICUs; and especially for those whose end-of-life decisions are made outside hospitals altogether.

Conclusion

Articles reporting negative findings never attract the attention of those breaking new ground. But negative findings in a long-standing policy debate are as critical as significant correlations that lead us to squander resources implementing policies that ultimately prove to make little difference. The contribution is particularly important when the research design offers triangulated data that illuminate the policy question from an entirely new perspective—in this case, drawing on observations of all participants in the decision-making process, including observations of the actual invocation of advance directives, throughout the course of a medical crisis.

In eulogizing the death of the living will, Angela Fagerlin and Carl Schneider (2004: 30) decried that "persistence in error is but the triumph of dogma over inquiry and hope over experience." I would argue that we ought not nail the coffin shut quite yet. More inquiry and experience with triangulated data from diverse settings are still needed. But we should remain mindful of their cautionary polemic. In the meantime, it would behoove all of us to talk to our loved ones more and to document less. The ICU data provide more support for the growing body of literature that casts doubt on the impact of instructional directives than studies that promote the use of them. Unfortunately, there are few simple formulas or protocols to decisively guide our surrogates through the daunting course of life-and-death decision making, especially in an ICU. Statements to the contrary merely provide a false sense of security (Hoffmann, Zimmerman, and Tompkins 1996; Perkins 2007).

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Appendix Advance Directives and Discussion of Patient Wishes Initiated by Health Care Providers

Discussion of Wishes Initiated by Health Care Providers	Directive in Chart		Alleged Directive Elsewhere	
Attribute (number of patients "yes")	B	SE	B	SE
Any patient wishes mentioned (75)	0.751	0.465	0.665	0.458
Patient's express wishes mentioned (50)	0.481	0.463	−0.162	0.479
Patient's wishes inferred (29)	0.879	0.645	0.565	0.641
Patient's wishes perceived (44)	0.218	0.533	0.824	0.484
Total cases (199)	(47)		(53)	

Notes: Reference category is "no advance directive" ($N = 59$). Missing data category ($N = 40$) is not presented. Logistic regressions control for patient gender, age, ethnicity, income of residential neighborhood, severity of illness, whether illness was preexisting or came out of the blue, and whether the patient or family member is a lawyer or health care provider. Covariates are entered, using a forward stepwise method. Regressions are computed with SPSS 18 and Stata 11. B = unstandardized coefficient; SE = standard error.

*$p < .05$; **$p < .01$; ***$p < .001$