RESEARCHERS CONTINUE TO SEARCH high and low for evidence that advance directives do any good. Skepticism about the relevance and helpfulness of instructional advance directives, and about the ability of surrogates to represent patients’ preferences accurately, rumbled through the professional literature even before the disheartening findings of the SUPPORT Study.\textsuperscript{1–5} Despite the fact that discouraging evidence continues to accumulate—to the effect, for example, that advance directives have little effect on the use of resources or on the costs of care,\textsuperscript{6–11} and that even after explicit conversations with patients, surrogates do not accurately predict the patient’s choices in hypothetical situations\textsuperscript{12–13}—advocates for increased use of advance directives have redoubled their efforts.

To make their uphill case, advocates have resorted to three somewhat inconsistent strategies. The first strategy has been to build longer and ever more complex advance directive forms. From the basic insight that the terminology in the earliest Living Wills—e.g., “terminal illness,” or “no heroic measures”—was too vague to be of practical use, treatment checklists, decision-trees, hypothetical scenarios across the spectrum of illness and disability, multipart values histories, and statements of philosophies of life have bloomed—all designed to give surrogates the evidentiary basis from which to extrapolate an incommunicative or mentally incapacitated patient’s real-time treatment preferences.

The second strategy has been to devalue the advance directive form, and to emphasize the importance of the advance care planning process. In this view, even if the advance directive document itself is of scant help when decisions have to be made, prior conversations will have conveyed enough of an impression of the patient’s attitudes and values that surrogates will know what treatment decisions they should make.

The third strategy has been to redefine the goals of advance care planning, and to redefine “success.” This approach is exemplified in the work of Peter Singer and colleagues,\textsuperscript{14} and most recently in the pages of this Journal by Bernard Hammes.\textsuperscript{15} Here we begin to depart from the notion that advance care planning is about “getting it right,” where “getting it right” means that surrogates make the specific treatment decisions that the patient would have made were he or she in a position to deliberate and communicate his or her real-time preferences. Singer emphasizes the importance of preparing not only for death but also for incapacity, relieving burdens on others, and solidifying relationships. Hammes suggests that advance planning “succeeds” when appropriate surrogates are identified and their scope of authority is clearly delineated.

I think Singer and Hammes are on the right track in their movement away from replication of the patient’s specific treatment preferences as a justification for advance care planning. In the rest of this paper I would like to argue that they do not go far enough.

“GETTING IT RIGHT”: A USEFUL FICTION

In a recent critique of the studies that have called the effectiveness of advance directives into question, Degenholtz and Rhee\textsuperscript{16} offer a ray of hope. They point out that most of the discouraging findings, including the SUPPORT Study, come from hospitalized patients and are therefore neg-
atively biased. When Degenholtz and Rhee analyzed the location of death for a broad population sample of community-dwelling elderly, they found that having an advance directive appears to reduce the likelihood of dying in the hospital. On this basis they conclude that advance care planning can affect this basic choice of where to receive care, even if—as the other studies suggest and Degenholtz and Rhee’s data do not refute—patients who do come to the hospital find that their advance directives are worth little once they arrive there.

Although for many seriously ill patients avoiding the hospital may be no small accomplishment, it is a very crude way to influence the medical treatments one receives near the end of life. And it is a far cry from the way advance care planning has been advertised to the general public. The reigning premise of advance care planning—and the basis on which it has been urged on patients and doctors alike—is that critically ill patients should be able to receive the medical treatments they prefer (and only those treatments) even when they are mentally incapacitated or unable to communicate their preferences directly. Proponents of advance care planning encourage people to fill out advance directives in order to “take charge” of their medical care near the end of life or, with respect to some dreadful twilight state in an intensive care unit (ICU), to “make sure this can never happen to you.” Even if they are incapacitated, people are encouraged to believe, if they plan in advance and get their documents in order, the treatment decisions that will be made for them will match the decisions that they themselves would make if, miraculously, they could be restored to full capacity, process all the currently relevant medical information, and then decide which treatments should be applied.

This is a fiction. Not only does the preponderance of the empirical evidence throw our ability to fulfill this expectation into serious question, the expectation that with sufficient advance care planning surrogates will “get it right” is also conceptually incoherent. It assumes that there is a clear and unambiguous “right” decision to be made for the critically ill patient.

The first source of difficulty is prognostic uncertainty. The shortcomings of the hospice benefit’s requirement that patients’ survival be 6 months or less have been thoroughly documented, especially in the increasingly common context of lingering, uncertain trajectories in chronic disease. The problem is no less significant when physicians apply probabilistic statistical estimates of the likely benefit of life-sustaining treatments for a particular patient. Moreover, it is impossible to predict how, in the moment of truth, a particular patient will respond to any given probability estimate when the alternative to trying the treatment is likely to be imminent death. The desire for a gentle death, free of tubes and machines, coexists in most of us with the powerful desire to stay alive, as illustrated by the New Yorker cartoon of the curmudgeonly fellow in a hospital bed, whose doctor is commenting to the man’s wife, “He’s one tough cookie. I’ve never seen anyone bounce back from an autopsy before.” The difficulty of extrapolating patients’ real-time choices from previous discussions is compounded by the “framing effect,” in which those choices will be strongly influenced by the way the alternatives are actually described.

There is little basis, either in empirical evidence, or in the nature of the predicament of the person facing death, to expect that surrogate decision-makers, acting in accordance with a patient’s previously expressed preferences recorded in an advance directive, are going to “get it right” at the level of particular choices for life-sustaining treatment, with the possible exception, according to Degenholtz and Rhee, of the decision whether or not to be hospitalized at all. And yet the fiction persists, because all of us have strong motivations to believe in it. The fiction relieves survivor guilt (“We authorized the doctors to withhold treatment, but we were simply following Mama’s previously stated wishes”). It relieves doctors and hospitals from the fear of legal liability (“Yes, we could have kept your mother alive, but you can see right in this document that she did not want us to provide the treatments that would have enabled us to do so”). It relieves survivors, doctors, and patients alike from the awful feeling of helplessness in the face of death, the feeling that important issues of personal destiny are beyond our control (“We can’t prevent Mama from dying, but we can make sure she dies the way she wanted to”).

These benefits redound almost entirely to the survivors. In fact, I believe that the emphasis on “getting it right” is the result of projecting onto patients the anxieties and desires for a clear and distinct treatment plan that are felt most acutely by the health care team.
WHAT'S THE HARM IN THAT?

There would be no reason to abandon the fiction of "getting it right" if it were not causing any harm. But I believe it is causing harm.

1. Patients and families feel betrayed and misled when they present physicians with an advance directive only to be told that it does not apply to the situation at hand or that there are important medical reasons why they should not let their actions be guided by the document.

2. Health professionals feel pressured to conduct off-putting, technically focused interrogations of patients so they can fill out the limited support sheet. This produces such tableaux as the harried house officer brandishing a treatment checklist in front of the confused patient or relative, or the young and otherwise healthy patient, admitted to the hospital for a completely benign procedure, enduring a Patient Self-Determination Act (PSDA)-required inquisition about advance directives.

3. Patients or families are stigmatized if they do not want to participate in advance planning discussions, or if in the eyes of the health care team they make the wrong treatment choices (i.e., they want "everything done"). The team says of such patients: They are "difficult." They "don't get it." They are "in denial."

4. Health professionals who learn from hard and frustrating experience (or from reading the empirical literature cited above) that patients' advance directives are rarely helpful in the clinical moment, disparage the process of advance care planning entirely, and fail to engage patients in meaningful conversation about serious illness or the possibility of dying.

This last danger is especially significant because conversations with patients and families who are living in the shadow of death are often very important, not only as part of excellent palliative care, but as part of being human. I simply do not believe that having these conversations will lead us to make better treatment decisions, if by "better" we mean that we will have a greater probability of "getting it right." We should be open to having these conversations for a completely different reason, and the skill set we should cultivate in health professionals to facilitate them looks somewhat different from the skill set we are currently focusing on as medical educators.

IT IS ALTOGETHER FITTING AND PROPER THAT WE SHOULD DO THIS

The purpose of having conversations with patients is not to enable us to make the same decision about a treatment that the patient would have made—that is a fiction—but to give patients and families the opportunity to say things that matter to them in the face of critical illness or impending death. This is a patient-centered standard, rather than the survivor-centered standard that prevails at present. It acknowledges that for many people the likelihood of death calls for reflection about ultimate things and expressions of meaning and hope. Some people may construe meaning and hope as including efforts to direct their future medical care. Yet there would be no stigma attached to people who prefer not to talk about these things, as there is now when we tell them that without their participation we won't be able to make the "right" decision. And the skill set for professionals will shift from filling out limited support documents to genuinely engaging a human being in the face of death.

We should be open to having these conversations because it is the fitting thing to do. Consider an analogy with voting. Why do people object to being disenfranchised? The mischief in Florida in the 2000 election aside, it is not, I think, because people believe that their one vote is actually going to determine the outcome of the election. People know that the likelihood of that is vanishingly small. Rather, the outrage of being disenfranchised stems from the belief that not to be allowed to vote is to be treated with fundamental disrespect as a citizen in a democratic society. Choosing leaders and policies in a democratic society involves citizen participation. At the point when public policies are to be decided, it is fitting and proper that citizens make their voices heard. Something is seriously askew, something that calls into question the very meaning of a democratic society, when citizens are prevented from voting. And the disrespect, the wrong perpetrated on the disenfranchised voter, has nothing to do with the likelihood that his or her vote would have controlled the outcome.

I believe the same is true with advance care planning conversations. They are important for reasons that have nothing whatever to do with control. Not having the opportunity to speak of one's feelings, thoughts, hopes, and values in the face of death is wrong because that which is fit-
tung and proper has not been allowed to occur. It treats the dying person—or, to say it better, the person who may be at a potential turning point in the course of his or her disease, where the balance between health and decline may be tilting toward decline—with fundamental disrespect.

This attitude is consistent with a long sweep of recorded history, in which human beings have attached great importance to ritualizing and sacralizing the process of death and dying.\textsuperscript{18–20} For many people in pre-Civil War America, for example, the paradigm of the bad death was the sudden, unanticipated death far from home. Such a death was feared because it precluded the self-conscious preparations for death that were interpersonally and spiritually required: putting oneself right with God and solidifying relationships with important people with thanks and forgiveness.\textsuperscript{21} This same history confirms, however, that human beings’ movement toward death is culturally patterned, and there is no single way to die well. In our own time this cultural and individual variation extends to preferences for truth-telling,\textsuperscript{22} aggressive use of life-prolonging treatments,\textsuperscript{23} and receptivity to hospice care.\textsuperscript{24}

A SPIRITUAL–EXISTENTIAL, NOT A CLINICAL–TECHNICAL, ORIENTATION

Our preoccupation with specifying the exact nature of the medical treatments that the dying person will receive reflects the technologization and professionalization of dying that took place in the mid to late 20th century. Not only do dying people have more treatment options to choose from (or reject), but the shift of responsibility for caring for the dying from family and community to health professional and hospital has led the latter to elevate their needs for unambiguous guidance in their treatment decisions, and the optimal management of symptoms, over other aspects of dying that are more spiritually or existentially significant.

Of course, patients and families are part of this cultural transformation, too. We all collude with medicine (as Daniel Callahan\textsuperscript{25} has put it) in translating existential and spiritual concerns into hopes for technical triumphs over death. So it is not a question of medical personnel simply imposing their technologized agenda onto patients. Moreover, the two dimensions—spiritual–existential and clinical–technical—need not be mutually exclusive. Why shouldn’t we be able to recognize and respect spiritual and existential dimensions of end-of-life care and manage symptoms expertly? After all, the latter is often a prerequisite for the former.\textsuperscript{26,27} And while we are at it, can we not also make treatment decisions for patients that at least approximate their values?

True. These dimensions need not be mutually exclusive. Nevertheless, the obsession with “getting it right” encourages particular approaches to patients and families that detract from environments of meaning and spiritual significance—and with no net gain in accurate decision making. I can make this point most clearly by contrasting two skill sets. The first is the one that currently receives the most emphasis. It will be familiar to anyone who has recently perused a training manual for facilitating advance care planning:

- Prognostication
- Communication of information about the illness
- Eliciting the patient’s values and goals for treatment
- Identification of a surrogate
- Documentation

These are unquestionably valuable skills to have, and when they are deployed with sensitivity they serve many patients well, even though we have little reason to think that they improve our chances of getting end-of-life treatment decisions “right.” Moreover, patients’ satisfaction with their doctors’ ability to communicate near the end of life is presently so poor, that broadly inculcating these skills would be an enormous achievement all by itself. There is another skill set, however, that does not receive the emphasis it deserves. It is related primarily to encouraging conversations that acknowledge the spiritual and existential significance of dying. I believe these skills, while certainly not antithetical to the first set, can help prevent some of the harms associated with our obsession with “getting it right.”

- Recognizing “nodal moments” or possible turning points in an illness trajectory

The term “nodal moments” (for which I am indebted to Jeffrey Burack at the University of California at Berkeley) refers to encounters between a doctor and patient when new information be-
comes available, either through the patient’s report of symptoms or as a result of a diagnostic test, that suggests that the patient’s health status may be changing significantly. It is at such a moment that the experienced clinician will recognize (possibly later than the patient) that the balance between health and decline has shifted toward decline. The patient may not be imminently dying, or even reliably within hospice’s magic threshold of 6 months survival. Nevertheless, something is happening that deserves recognition, and it may serve as an occasion for doctor and patient to think together about the patient’s goals and hopes for the future.

This way of thinking at once broadens the universe of potential conversations to include people who are realistically facing decisions (even if not imminently dying), and narrows it to exclude the obviously healthy for whom—other than identifying a surrogate, perhaps—it is likely to be as presumptuous and intrusive as it is respectful to demand a full-blown advance care discussion. In this latter context, such a demand is more a matter of imposing an ideology of planning than of genuinely patient-centered practice.

- Appreciating the range of psychological, spiritual, existential, and ritual dimensions of the encounter with death

The professionalization of end-of-life care, and the language of palliative care teams who want to “manage” the patient’s death, sometimes get in the way of respectful accompaniment of the patient who is dying. (I observed an example of this, on a palliative care unit no less, when a nurse objected to the candle on an actively dying patient’s bedside table because there was an oxygen bottle in the room.) Amid the proliferation of palliative treatments and protocols it is too easy to forget that dying is not ultimately a matter for professionals to manage. In the words of Robert Kastenbaum:

Can we sense the tides and tones, the overall shape of the deathbed scene? Can we be adept at recognizing where matters are heading, and when it is time to put everything else aside and speak? Listen? Touch? Pray? An excessive attention to details and routines could distract us from realizing what the moment requires. Can we align ourselves both with the details of care and the whole sweep of feelings and events?28

The corollary to this is the next skill, namely,

- Creating settings of privacy and calm

The palliative care unit that had the problem with the bedside candle was in better form on the day the medical director suggested to the staff that they stay out of the room of another patient—a 32-year-old woman actively dying from ovarian cancer—and allow the large group of family and friends who had been camping in the room for several days to have their privacy. It was a reminder that in the face of death an important role for the professionals is to create settings of privacy and calm, and at times this role requires modesty in the staff’s assessment of its own importance in the dying process.

- Learning the patient’s circle of significant others

The French have a word for it: l’entourage. These are the people—family members or not—who mean something to the patient, and their importance extends far beyond their role as potential surrogate decision makers. Even if caregivers do not, as some have recommended, make it one of their explicit tasks to facilitate specific deathbed interactions between the patient and his or her entourage, much can be done to anticipate and help arrange for the presence of significant others at significant moments.

- Suspending one’s own professional ideology of “the good death”

Dying patients are often caught between two ideologies. The ideology of modern medicine identifies hope with ever-more daring and innovative curative or life-prolonging efforts.29 The ideology of hospice urges patients to accept death, and to redefine hope to focus on comfort, quality of life, and the peace that can attend foregoing intensive curative treatments that only prolong suffering.30 Each of these ideologies is well-intentioned, each expresses the commitment not to abandon patients, and each serves some patients well. Rigidly applied, they can harm patients, who are usually best served when they are approached as individuals by caregivers who try to attune themselves to the nuances of the patient’s own (usually complex) definition of hope, and of “the good death.”

These skills, while compatible with the first set,
draw more attention to the personal, spiritual dimensions of the experience of dying than to its clinical management. They are summed up in one more skill, which might be called,

- Providing hospitality

“Hospitality” is pastoral theologian Henri Nouwen’s term for the essence of pastoral ministry. It was taken by Leonard Lunn, chaplain at St. Christopher’s Hospice in London, as the core characteristic of spiritual care for the dying. Lunn quotes Nouwen as follows:

Hospitality, therefore, means primarily the creation of a free space where the stranger can enter and become a friend instead of an enemy. Hospitality is not to change people, but to offer them space where change can take place. It is not to bring men and women over to our side, but to offer freedom not disturbed by dividing lines. It is not to lead our neighbor into a corner where there are no alternatives left, but to open a wide spectrum of options for choice and commitment. It is not an educated intimidation with good books, good stories and good works, but the liberation of fearful hearts so that words can find roots and bear ample fruit. It is not a method of making our God and our way into the criteria of happiness, but the opening of an opportunity to others to find their God and their way. The paradox of hospitality is that it wants to create emptiness, not a fearful emptiness, but a friendly emptiness where strangers can enter and discover themselves as created free; free to sing their own songs, speak their own languages, dance their own dances; free to leave and follow their own vocations. Hospitality is not a subtle invitation to adopt the life style of the host, but the gift of a chance for the guest to find his own.31

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