Pulling the Plug on Living Wills*

A Critical Analysis of Advance Directives

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The recent emphasis placed on patient autonomy within medical ethics has had a profound influence not only on the practice of medicine, but on the concept of autonomy itself. As medical practice has evolved from an ideal of the beneficent physician, practicing with little guidance from the patient, toward the acceptance of a nearly absolute right of patients to control the means and manner of their health care, the very boundaries of personal autonomy have been met and forced back. Autonomy is currently seen as so integral to medical decision making that it is advocated as a guiding principle even in individuals who are no longer autonomous. The assertion that the right of self-determination is not lost in incompetent, and therefore nonautonomous, patients has required the creation of means by which such a right can be exercised. These tools for extending personal autonomy in medical decision making are generally referred to as advance directives. The instructive directive (ie, living will) aims to direct future medical care by outlining preferred courses of action, including the refusal of specific therapies, in the event that an individual is no longer able to participate directly in decision making. The proxy directive (ie, durable power of attorney for health care) designates a surrogate, chosen by the patient, to make medical decisions in the event of future patient incompetence. Combinations of these two types of directives are available.1

Surveys of both patients2 and physicians3 have found widespread support for these instruments. The federal government has voiced its approval by enacting the Patient Self-Determination Act, implemented in December 1991.4 The Act explicitly requires all Medi-care-certified hospitals to inform patients of the availability of advance directives at the time of admission, a practice implicitly designed to encourage their use. State legislatures have provided further support, as advance directives now have a statutory basis in all 50 states.5 Despite this apparently broad-based support, a relatively small number of patients have actually written such documents.2,6 In addition, clinicians have begun to note that advance directives, however well intentioned, are often unavailable or not applicable in many situations involving critically ill patients.7

The attempt to define the scope and application of these documents has raised awareness within the medical community of the value of patient autonomy. It is time to also acknowledge the limits. The ethical argument in support of advance directives has, in large part, been simply an assertion that autonomous patient decisions should guide virtually all medical practice. Such an assertion, however, is not sufficient to justify the use of these documents. Challenges to advance directives can be made on the basis of personal identity theory and practical limitations on their use. In addition, there is a growing body of evidence demonstrating that these documents fail to influence outcomes.

Many of these criticisms apply to both instructive and proxy directives, while others are specific to one or the other. This article attempts to analyze systematically these challenges and concludes from such an evaluation that instructive directives have virtually no value in decision making for the incompetent patient while proxy directives remain practically useful, but do not represent a true extension of patient autonomy.

Autonomy in the Nonautonomous Individual

Both the popular and scholarly ethical support for advance directives spring from the increasing value placed on the autonomy of patients. Patients have asserted, and courts have supported, the competent adult’s right to obtain all relevant information regarding a proposed treatment (informed consent)8 and to refuse any treatment, even if it is expected to be beneficial or life sustaining.9 Such assertions have implic-
ently or explicitly contained within them the notion of the patient as an “autonomous agent.” This concept of personhood enjoys a long history in western philosophical and political thought, perhaps best exemplified in the works of Immanuel Kant and John Stuart Mill, and has been widely adopted in modern medical ethics. Inherent in any understanding of autonomy is the requirement of agency, the capacity for intentional action.10 Advance directives, however, apply only after a person’s capacity for intentional actions is lost, as an attempt to project autonomy into the future. But whether this can or should be done depends on theories of identity and personhood that may not be uniformly agreed on.

As human beings, our interests are not immutable. Few of us still find as important what we valued as children or adolescents. However, the narrative theory of personhood underlying advance directives claims that our decisions now should be binding even when we enter a state when our values and interests will be very much changed. Severe illness and loss of cognitive function would certainly change the interests of any individual and personal values may cease to exist at all, but the ability to comprehend and communicate these changes is lost. The theory of personhood underlying advance directives demands that previous wishes, based on past interests and values, bind the future person despite this profound change.

The problem with claiming that previous choices should be enforced even when counter to the clear best interests of an individual who has lost decision-making capacity is illustrated by the case of the pleasantly demented patient. Perhaps prior to losing his faculties of reason a retired mathematician with Alzheimer-type dementia held those cognitive powers in the highest regard, cultivating them for both work and leisure and stating, quite unequivocally and even in writing, that he would prefer not to exist rather than live without them. But as his disease progressed reason left him, initially frustrating him but eventually leaving him in a state without recollection of his former talents and skills and, hence, without grief at having lost them. His day-to-day life is filled with simple activities which prior to the demise of his intellect would have left him bored and unfulfilled. But now the same activities seem to leave him content, if not actually bring him pleasure. He smiles frequently and when asked if he is happy he responds in the affirmative. Clearly his interests and values have changed. Those who knew him before may recognize only traces of his former personality or wit, lamenting the fact that he is “Not the person he used to be.” Honoring such a patient’s previous willful preferences requires, at a minimum, withholding care and, perhaps, even intentionally ending his life. Yet this clearly ignores the person he has become, subjugating his current interests and desires to those of a person who no longer exists and never will again. Personal identity depends, at least in part, on psychological continuity, and philosopher Derek Parfit argues that when the strength of connectedness falls below a certain minimal threshold there are philosophical grounds to claim we are, in fact, dealing with a different person.11 If this is the case, then the prior person who expressed his desire to forgo treatment if ever he became demented has little authority to determine how the pleasantly demented patient should be treated, since the relationship between the two has been lost. If they have become, indeed, different persons altogether, then the preferences of the competent mathematician may have no more moral weight in decisions about the care of the demented patient than those of a complete stranger.

Certainly this philosophical view of personhood can be challenged and the commonly accepted narrative view of identity may remain compatible with the execution of advance directives.12 One need not endorse Parfit’s complex view of personhood, however, to oppose the implementation of the preferences of a previously competent person on his or her current incompetent self. All we need to recognize about such a patient is that his or her interests have changed radically and now have diverged from those served by the preferences incorporated into the advance directive.13 To honor the advance directive, then, may require actions that run counter to the current interests of the patient. By following the dictates of an advance directive in such a situation, the physician clearly values past competent choice over the current interests of the incompetent patient.14 Such an approach violates the oft espoused ethical duty of the physician to always act in the best interests of the patient.15,16

**Practical Concerns**

Advance directives are also severely limited by practical concerns about their use.17,18 In the case of instructive directives, three limitations appear to be particularly problematic.

First, those who formulate advance directives, even with the aid of a medical professional, can have only incomplete information about the risks and benefits of any future medical treatments they might possibly face after becoming incompetent. The informed portion of the notion of informed consent will thus be missing. Supporters of advance directives argue that this limitation can be overcome by improving physicians’ skills at counseling patients about likely future medical scenarios and life-sustaining therapies.19 Better-crafted documents, it is asserted, would aid in producing more thorough and reasoned discussions between physicians and patients, enabling patients to express their pref-
ferences in a manner that would be meaningful at the
time the advance directive takes effect.\textsuperscript{20} But as all
physicians are aware, every medical decision is unique
and no amount of foresight or discussion can anticipate
all relevant features of a particular case. Attempting to
educate patients adequately enough to make credible
decisions about three or four possible treatments for a
few common medical conditions would be extremely
time consuming and most likely never actually become
relevant. One can only wonder what level of informed
consent is possible in the 14 min that supporters of
these documents claim is necessary to complete one
with the aid of a counselor.\textsuperscript{2}

Furthermore, advance directives are currently avail-
able in stationery stores and law offices present them
to persons completing property wills. It is quite possi-
ble, then, for these documents to be completed with-
out any conversation ever having taken place with a
health-care professional. Although often espoused as a
means for improving patient-physician communica-
tion, it seems quite likely that many patients will view
the living will they complete at the attorney’s office or
senior center as obviating the need for discussing
end-of-life issues with their physician. If the expecta-
tion is that a written legal document is more effective
than verbal communication with medical practitioners
at ensuring that wishes are followed, the latter practice
may be viewed is redundant and unnecessary.

How patients are best aided in formulating advance
directives is, of course, also open to debate. Clearly,
the description of possible scenarios and treatments
profundely affects the supposedly autonomous deci-
sions of patients.\textsuperscript{20} Advocates of advance directives
propose their own presumably more value-neutral
approaches,\textsuperscript{1,2} but to our knowledge, there is currently
no method to ensure that physicians are effective
communicators able to facilitate the making of auton-
omous decisions. Even before they take effect, then,
advance directives may undermine, rather than en-
hance, patient autonomy.

Finally, the question of when an advance directive
takes effect would seem to place the physician in a
position of ultimate power, just the place the propon-
tents of patient autonomy do not want the physician
to be. Even after the removal of some vague language,
living wills continue to contain wording such as
“terminal condition,” “incurable illness,” and “serious-
ly incapacitating,” leaving the interpretation of such
phrases to individual physicians. The aggressive on-
cologist, however, may recognize nothing short of
death itself as a terminal condition while an unscrup-
ulous intensivist could use rheumatoid arthritis as an
incurable illness that would meet the criterion to sup-
port the withdrawal of care. Attempts to rigidly define
terms in order to prevent such abuses invariably lim-
its the situations in which the advance directive is ap-
licable. A clear definition of terminal condition, such
as survival less than 6 months regardless of medical
therapy, excludes patients with a massive, but nonfatal
stroke or acute respiratory distress syndrome with
other organ failure. The living wills of such patients, if
they exist, do not apply in their current, nonterminal
state. Any attempt to make instructive directives more
resistant to variation in interpretation will necessarily
make them less likely to ever be applicable.

The evaluation of a patient’s decision-making ca-
pacity, loss of which is necessary for the advance
directive to take effect, is also generally left to medi-
cal caregivers. When there is agreement between the
physician and the patient, it seems there is rarely a
challenge to the patient’s competence. Physicians may
fail to invoke an instructive directive that is applicable
so long as the patient remains “cooperative” with
therapy. The presence of advance directives, then, may
fail to limit unwanted treatment and leave the patient
subject to the will of the physician.\textsuperscript{21} By ceding to
physicians the power of determining if and when ad-
vance directives are going to be applied, patient
autonomy is not protected against the paternalistic
practitioner.

\textbf{The Problem of Proxies}

The problems with instructive directives have led
some to argue that proxy directives, such as the dura-
ble power of attorney for health care, are preferable for
most patients.\textsuperscript{22} Proxy directives are generally sup-
ported with the same ethical argument as instructive
directives: they offer a tool for the continuance of au-
tonomous choice for nonautonomous patients. To ful-
fill this goal, the decisions of surrogates must be con-
sistent with those that would be made by the now
incompetent patient. This method of surrogate deci-
sion making, in which the proxy attempts to choose as
the incompetent patient would have if he or she had
remained competent, is generally referred to as the
substituted judgment standard.\textsuperscript{23} It is this principle
which has most commonly, although not universally,
been mandated by courts\textsuperscript{24-26} and ethicists.\textsuperscript{10,23} It is the
primary method dictated by proxy directives.

How well surrogates are able to perform this task can
be measured. In several published studies it is clear
that surrogates, even when designated by the patient
and confident about their ability to do so, were unable
to choose consistently treatment options conforming to
the preferences of the patient.\textsuperscript{27-29} Given these tests of
concordance, substituted judgment appears to be an
illusory ideal. At best, the poor concordance between
patients and their surrogates makes proxy decisions
based on the presumed wishes of the patient the
practical and moral equivalent of an educated guess
and, at worst, a flip of a coin. Although some have used this discordance to call for more communication between patients and surrogates, it remains to be seen whether significant improvement is possible and whether the execution of these documents actually facilitates such discussions.

Given the apparent inability of surrogates to predict accurately the preferences of their charges, the only valid justification for proxy directives lies not in the assertion that they provide an extension of individual autonomy, but in the practical realization that someone has to make medical decisions for the incompetent. Although tradition and law assign decisional authority for incompetent patients to members of the immediate family, the moral authority to make decisions may lie elsewhere. In the current framework of substituted judgment, that authority would seem to lie with the individual who best understands the desires and preferences of the patient; if the best interests standard is being utilized, the individual in the best position to evaluate those interests should have authority. This person may not always be the legal next of kin. The proxy directive allows the patient, who presumably is in the best position to judge, to select the individual who best meets these qualifications. The durable power of attorney for health care may solve the very real problem of who will decide for the incompetent patient, but it falls far short of providing a meaningful extension of patient autonomy.

**Effectiveness**

Advance directives are put forth primarily as a method of ensuring patient autonomy. How well they serve this function can be investigated and several studies have attempted to assess whether patients’ wishes are more likely to be followed if they have written advance directives. Given the inherent difficulty of trying to measure directly whether individual preferences are followed, some studies looking at the impact of these documents have focused on indirect measurements of their effects.

In addition to promoting patient autonomy, advance directives may have several other potential “positive” effects. First, they may make it easier for physicians to withdraw support from critically ill patients who have little or no chance of recovery since such a course of action has been mandated previously by a patient. (This, of course, assumes that most people who draft living wills will opt for no treatment in such situations although many forms of such documents include an option to provide all forms of care, including cardiopulmonary resuscitation, mechanical ventilation, and nutrition, regardless of the situation.) As a result, health-care resources may be saved by allowing the foregoing of presumably expensive and ultimately futile end-of-life treatments. There are some who argue that promoting advance directives with such an end in mind would be, in itself, unethical. But there seems nothing wrong with arguing that, as a desirable side effect of advancing patient autonomy, costs are lowered and inappropriate treatments are withheld. As these goals are more openly valued by both health-care providers and society, there may be support for increased patient autonomy even if only as a means toward these ends.

How well then have advance directives performed in actual practice? From a review of the literature, the answer appears to be not well at all. The first published attempt to examine the effectiveness of advance directives was performed on a cohort of nursing home patients. Danis and colleagues recorded preferences regarding potential future treatments for about 175 patients. Follow-up revealed that although subsequent care was consistent with previously stated wishes in three quarters of patients, the presence of an advance directive did not impact on this level of consistency. Interestingly, those patients who were felt to be given care inconsistent with their previously stated preferences, only one quarter were “overtreated” while the rest received less aggressive care than they had appeared to desire. Such a finding hints that the emphasis on advance directives as a way to limit appropriately aggressive care may be misguided, with the real threat to patient autonomy coming from the side of undertreatment.

A cohort of patients from outpatient clinics was studied by Schneiderman et al. in a randomized prospective fashion, with about one half of 200 patients being offered advance directives and a control group managed without mention of these documents. An impressive 66% of the study group wrote the combination instructive/proxy directive that was offered. The authors found no difference between the control and study group in subsequent measurements of patient satisfaction and well-being or in the level of aggressive care measured by do not attempt resuscitation orders, attempts at resuscitation, ICU stay, or the duration of mechanical ventilation and artificial feeding. Survival time and length of hospital stay were also not different between groups so, not surprisingly, total health-care charges were equivalent. This study was limited by its small sample size and the fact that only “a few” patients became incompetent at a stage when patient preferences still influenced decision making.

In the largest sample reported to date, the Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments (SUPPORT) investigators looked at a cohort of more than 3,000 seriously ill hospitalized patients for differences in care between those with and without advance directives. As reported
by Teno et al, patients with advance directives had the same likelihood of having a do not attempt resuscitation order on their chart and were just as likely to undergo an attempt at resuscitation within 24 h of their death as those patients who had no formal directives. Measurements of the intensity of therapeutic interventions and patterns of resource utilization were also not changed by the presence of an advance directive. The study itself is limited by the fact that very few of those patients who claimed to have written advance directives had them actually placed in the medical chart. In addition, it is difficult to tell from the published report how many patients with advance directives were incompetent to make medical decisions before death. Still, these investigators conclude that “as far as we could tell, advance directives were irrelevant to decision making.”

Although none of these studies, either alone or together, provide incontrovertible proof that advance directives are not effective, neither do they provide any reason to justify their support. Simply put, there is no evidence that advance directives are an effective tool in advancing the cause of patient autonomy or that they have any impact whatsoever on subsequent care. The reasons for this lack of demonstrable effect could come from a wide variety of sources: unwilling physicians, inefficient hospital administrators, uncooperative family members, or patients themselves. It may be that the sense that physicians err on the side of overtreatment, which fueled the rise of advance directives, is inaccurate. Or perhaps we never should have expected these documents to influence outcomes because they do not, despite their proponents’ assertions to the contrary, carry enough ethical weight to change a patient’s care.

A Search for Relevance

The recognition that instructive directives only imperfectly represent an autonomous choice, along with the numerous practical limitations to their use, has eroded the notion that these documents must always be followed. Brock acknowledged relatively early in the debate on instructive directives that it is, at times, ethically appropriate to “trump” them. The preferences of previously competent patients can be questioned and possibly overruled when incomplete information was received to facilitate decision making, when there was an inability to anticipate their future state, when there is a conflict with the current interests of the now incompetent patient, or when they demand care that is clearly ineffective or futile. Still, Brock concludes that advance directives should be honored in “the vast majority” and that setting them aside should be contingent on negotiating institutional safeguards designed to prevent “abuse.”

This conclusion, however, does not follow from a critical analysis of instructive directives. Instead, it depends on the continued assertion of the preeminence of a severely weakened notion of autonomy over all other considerations. To say that advance directives must be “trumped” implies that they are to be considered prescriptive and binding until proved otherwise. Understanding the limitations of instructive directives leads, instead, to the conclusion that they should be challenged in every single case. The problems with incomplete information and inability to anticipate future states do not apply to only a minority of instructive directives, but to all. Uncertainty regarding meaning and intent permeates every living will. In no instance does the existence of an instructive directive give the physician permission to ignore the current interests of the patient. To determine whether there is a conflict between such interests and the advance directive, an evaluation of those interests must always be performed. Neither does the presence of an advance directive obviate the need to assess whether a particular treatment is medically appropriate. In short, all instructive directives must be validated; none can be accepted at face value. But the very process of validation makes the document itself nearly superfluous.

To interpret and validate a living will, the physician must seek information from others in an attempt to determine what the patient “really meant” when the directive was written. These discussions among physicians, surrogates, and family members are not merely concerned about the meaning of the living will, but attempt to determine the best course of action for the particular patient. The discussion will, and should, be essentially the same with the surrogate and family members of a patient who has not written an advance directive. The attempt to validate the instructive directive, if done correctly, requires seeking independent information about a patient’s past preferences and interests and weighing them against his or her current state. This is exactly what should be done when no advance directive exists. In the end, the presence of an advance directive will represent only one piece of evidence in an attempt to reach a shared conclusion about the most appropriate course of action. Physicians must not assume that the legal preference for written documents implies the ethical superiority of such evidence. Depending on the circumstances, a living will may have less moral weight than a statement made to a family member, a note written by a physician, or even the smile of the now incompetent patient.

Given that instructive directives cannot be taken at face value, a conclusion that follows from an ethical and practical analysis of these documents, it is actually reassuring that studies thus far have failed to demon-
strate that they have an effect on outcomes. This may indicate that physicians, surrogates, and families continue to address the complex and unique circumstances surrounding each particular patient when making medical decisions, rather than relying on an ambiguous legal document. With the understanding that advance directives have very limited value in making decisions for incompetent patients, it is neither surprising nor disheartening that they produce no observable effect on the care of such patients.

**CONCLUSION**

Advance directives are designed as instruments by which a competent individual can continue to exercise autonomous control over health-care decisions in the event of future incompetence. They do not appear capable of fulfilling this task. Instructive directives, hobbled by uncertainty regarding identity, intention, and meaning, cannot be accepted as binding without an attempt to verify them independently. This process of validation, involving discussions with other physicians, surrogates, and family members, may make the living will itself largely irrelevant. The lack of empirical evidence demonstrating the effectiveness of living wills is not surprising given their inherent limitations. Proxy directives remain practically useful because they answer the important question of who will decide for the incompetent patient. The apparent inability of surrogates to predict accurately the preferences of those they represent, however, limits the claim that these documents are effective instruments for extending individual autonomy.

Advance directives were developed, at least in part, as a response to the impression that medical knowledge and machinery were being employed to maintain persons when it was no longer appropriate to do so. How often this actually occurred is unknown and not relevant to this discussion. It is enough to recognize that instructive directives are, and should have been anticipated to be, ineffective at influencing such a practice. The avoidance of the inappropriate use of medical technology starts with the recognition by practitioners that it is inappropriate. The development of professional standards of medical treatment, which reflect an ethical and scientific consensus, could be used to substitute for the elusive ideal of the instructive directive. Continued attempts to salvage living wills simply distract us from this task.

Advance directives have failed because they aimed wrong. The goal should not be to extend autonomy further than reason allows any more than it is to extend life regardless of its quality and meaning. The realization that there may come a time when we will be unable to direct our own lives is frightening. But assuaging this fear with the illusion of the advance directive does the patient a disservice.

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