Advance directives and life-sustaining treatment: a legal primer

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Technologic and therapeutic advances in clinical medicine have greatly enhanced the ability of physicians to treat patients and to prolong their lives. Such advances, however, have challenged the ability of the legal system to respond effectively to the issues that can arise in the context of the care and treatment of patients at the end of life. These advances have enabled physicians to sustain the bodily functions of dying patients without "curing" them, thus increasing the likelihood of a lingering death. As a result, considerable debate and commentary have focused on the rights of terminally or incurably ill patients to make controlling decisions with respect to their treatment and the time and manner of their deaths.

This article focuses on the use by patients of written documents known as "advance directives" to express their preferences regarding life-sustaining care and who should make decisions for them if they become incapacitated. For physicians, a sound working knowledge of advance directives is critical for several reasons. First, it is likely that a physician will be asked by a patient at some point to assist or advise in the preparation of an advance directive. Indeed, it is often appropriate for the physician to initiate with a patient discussions about preparing such a document. Second, it is also likely that in caring for patients, a physician will encounter an advance directive and be asked to implement its provisions [1]. Finally, particularly for patients seen by hematologists and oncologists, advanced directives offer important clarity for end-of-life decision making for the physicians who attend these patients and the patients' families.

The right to make medical decisions

A central tenet of contemporary medical-legal doctrine is the notion of patient autonomy, that is, the right of a competent adult to determine what shall be done
to his or her body [2]. This right emanates, in part, from common law (i.e., judge-made) principles of autonomy and self-determination that underlie the consensual nature of the physician-patient relationship [3–5]. Physicians and other health care professionals are familiar with this concept in the context of the “informed-consent” process with patients in making treatment decisions and the potential tort liability risks associated with this process [4]. “The informed consent doctrine has become firmly entrenched in American tort law” Chief Justice Rehnquist of the United States Supreme Court observed [6]. “The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment” [6].

Beyond this common law informed-consent basis, however, the right of patients to make medical decisions and refuse care is also rooted in certain constitutionally protected rights, namely, the rights of privacy and liberty [3–5]. Historically at least, some courts have looked to a “right of privacy” embedded in the US Constitution and in state constitutions as the predicate on which to recognize a patient’s right to decline medical care [7–9]. More recently, however, the United States Supreme Court has voiced its view that a patient’s right to refuse treatment is a protected liberty interest under the Fourteenth Amendment [6]. In addition, a patient’s refusal of care, in some instances, may also be a protected religious right under the First Amendment’s free exercise provision [10,11]. In any event, it is clear that a competent patient’s right to reject unwanted medical care, even if that decision will result in the patient’s death, has both constitutional and common law support.

The law, however, has been less clear with respect to the withdrawing or withholding of life-sustaining treatment from patients who are incapacitated and, thus, unable to make known their own choices. The law has now come to take the position that the right of patients to make decisions regarding their care is not lost simply because they have become incompetent [3,6,12]. At issue, however, has been the manner by which these rights may be exercised. Today, all states recognize that patients have the right, while competent, to express their desires regarding medical care in the future, and that these wishes should be honored if and when the patient becomes incapacitated [12,13].

Advanced directives generally

An advance directive, as that term is used here, refers to a written statement or document executed by a competent adult that is designed to provide medical personnel, family members, and others information as to the person’s wishes regarding the nature and extent of medical care to be provided in the future should he or she lose decision-making capacity [1,13]. As such, an advance directive can apply to any medical care decisions; however, they are generally associated with life-sustaining treatment and end-of-life care [1].

Although this discussion of advance directives is limited to written statements, it is important to keep in mind that oral statements made by a patient before
incapacity “may be used to assess what the patient would have wanted in the particular disease and illness circumstances” [13]. Oral statements, therefore, cannot be ignored. Oral statements, however, can raise an array of issues. They may be unclear, misunderstood, or forgotten [1]. Further, it may become necessary to offer sufficient proof of an oral statement to a court should a dispute arise. Although the standard of proof in such a situation is a matter of state law and may vary, courts generally have required that proof of what medical care the incompetent person would have desired or refused under the circumstances is to be shown by “clear and convincing evidence” [6,13,14]. This heightened proof standard may pose problems and frustrate the patient in achieving the desired result [13]. Finally, in the absence of a written directive, questions may arise as to who should act as the decision maker for the patient, what factors should be considered, and what standards should be applied in making treatment choices [15]. For these reasons, patients should be encouraged to clearly express their wishes regarding life-sustaining care in an appropriate written form.

Recognizing that many patients still do not have written directives and mindful of the other problems noted here, many states have enacted “surrogate consent” or “family consent” statutes [13,15–17]. These statutes apply in situations where the incapacitated patient has not executed an effective or applicable advance directive. For example, a family consent statute may come into play for a patient whose living will does not cover the clinical situation presented. Family consent statutes typically provide a priority list or hierarchy of persons (eg, spouse, adult children) authorized to act as the patient’s “surrogate” and make medical decisions for them. The person (or persons) highest on the list is the decision maker for the patient. These laws also set out the standards by which the surrogate is to make treatment choices for the patient [18]. Although such surrogate consent statutes provide an important decision-making alternative, to truly effectuate the patient’s desires, there is no substitute for a carefully prepared written advance directive.

Written advance directives can be classified into two potentially overlapping categories: “instructional” and “proxy” [1,19]. An instructional directive tells caregivers, family members, and others what sort of specific medical treatments and interventions the patient does or does not want in particular circumstances [19]. As discussed below, instructional directives include “living wills” and “do-not-resuscitate (DNR) orders.” A proxy directive is one in which the patient authorizes a named person or persons to make medical treatment decisions in the event that the patient is unable to do so [20]. The “durable power of attorney for health care” is a proxy directive.

All states now have statutes specifically recognizing a patient’s right to prepare an advance directive [13]. These statutes generally set out authorized advance directive forms [21,22]. Use of such forms in preparing an advance directive may have certain advantages. One particular advantage is that the state statute prescribing the form may provide some protections such as immunity from liability for physicians and other providers if the advance directive conforms to the statutory form and is executed in conformity with the statute’s requirements.
[1,13,19]. In addition, the use of the statutory form may reduce uncertainty regarding the validity of the directive, facilitate its implementation, and avoid the need for judicial approval of a decision.

Physicians and other providers, however, must be mindful of the fact that state statutes generally do not require that the statutory form be followed [19,23,24]. In fact, statutes typically specify that the statutory form is not exclusive. For example, the Illinois Living Will Act states that a living will declaration “may, but need not, be in the following form and in addition may include other specific directions” [21]. Further, this statute states that “Nothing in this Act shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of death delaying procedures in any lawful manner. In such respect the provisions of this Act are cumulative.” Thus, the statute itself recognizes that patients have common law and constitutional rights regarding medical decisions potentially more expansive than those set out in the statute.

What this means is that a physician encountering an advance directive that does not conform to the state’s model form or that includes provisions that go beyond the statutory form cannot ignore or dismiss the directive as invalid. The directive may well be a proper expression of the patient’s treatment preferences [19,24]. Still, a departure from the model form may raise uncertainties that will require careful consideration by the patient’s family and health care providers in making treatment choices.

Just as the patient has the right to make an advance directive, the patient also has the right to change or revoke that directive. Again, state statutes expressly recognize this right and may specify procedures for revision or revocation. Usually such statutes allow revocation by any means deemed to indicate such a decision by the patient [21,22].

Physicians should keep in mind that hospitals generally have written policies in place dealing with patient advance directives. Both governmental regulations and accreditation standards require this [13]. Physicians should participate in developing these policies and be familiar with them. When questions arise for the physician in implementing an advance directive, as discussed below, resources within the hospital such as an ethics committee may provide advice and guidance.

With this general overview of advance directives as a context, an examination of the most common types of advance directives—the living will, the DNR order, and the durable power of attorney for health care—can be undertaken.

**Living will**

One of the most widely used advance directives is the living will. A living will is an instructional written directive “that indicate[s] the author’s wishes for medical treatment should he or she become incapacitated and unable to participate in medical decision-making” [25]. As such, it will set out, with varying degrees of specificity, the clinical circumstances under which the patient would or would not want to receive life-sustaining treatment and the sorts of
treatments to be provided or withheld [13]. For example, a living will might state in general language, “In the event that my physician finds that I am in a terminal or incurable condition where death is imminent, I do not wish to receive any medical treatments or procedures that would serve only to delay my death.” Or, it might be narrower; for example, “If I should have another stroke and experience trouble breathing, I do not wish to be placed on a respirator” [19]. The range of conditions and treatments that a living will can be designed to cover is, in theory, very broad, depending on the patient’s individual preferences. In each instance, the living will only comes into operation when the patient is unable to make medical decisions, and then only as to conditions and treatments it covers [26]. If these circumstances are present, the physician is obligated to follow the directive or transfer the patient to the care of another physician who will [13,21].

When considering a living will, however, state law must be taken into account. As noted above, state statutes typically now provide a general, nonexclusive model form for a living will. State living will statutes may also seek to limit the conditions under which a living will is effective (eg, only in the case of a terminal illness), address situations under which a living will may not be given effect (eg, if the patient is pregnant), and limit the sorts of treatments or procedures that can be withheld (eg, prohibit the withdrawal of nutrition and hydration). Further, state law may require certain formalities in the execution of a living will such as that it be witnessed, notarized, and so on [13,21].

It should be kept in mind, however, that a living will that does not meet these statutory requirements is not necessarily ineffective. As discussed previously, an individual’s right to make decisions regarding his or her health care is not dependent on any state statute but, in significant part, derives from common law and constitutional rights. A state’s living will statute does not, in itself, necessarily limit the exercise of constitutional rights [19]. Thus, a patient’s written declaration that “In the event I am in a persistent vegetative state, I do not wish to receive artificial nutrition and hydration” is not automatically invalid, even in the face of a state statute that says nutrition and hydration may not be withdrawn pursuant to a living will [19,27]. Still, the physician faced with such a situation will need to consult legal counsel, and judicial approval of the decision may be necessary.

A living will has several advantages. As one commentator observed, the “great strength” of a living will is that it “actually puts [a patient’s] choices on paper” [19]. Thus, the use of a living will permits patients, while still able to do so, to state for themselves the sorts of care they do or do not want and to establish for their care givers the conditions under which they wish to die. Further, by doing so in a living will, patients can avoid burdening family members with having to make such decisions for them [28].

There are, however, significant potential shortcomings to living wills, even when well drafted. “Because living wills expressly declare the exclusive types of medical treatment to be administered or withheld, the directives of living wills are often effective in a very narrow set of anticipated circumstances” [28]. One
simply cannot predict all clinical conditions that might arise for a patient. When a
condition not addressed is encountered, a patient’s living will may be of little
value in guiding health care providers [13,19]. On the other hand, a living will
may be written so broadly as to offer the physician little or no meaningful
guidance in a given clinical situation. Thus, a living will that states, “In the event
my condition is hopeless, I do not wish to receive any heroic measures” does not
offer the physician much help in knowing what the patient would truly wish [13].
In such cases, the physician will need to seek guidance from others including the
patient’s family, colleagues, legal counsel and, perhaps, the court.

DNR orders

One form of instructional directive that all physicians are familiar with,
although they may not view it as an advance directive, is the DNR or “no
code” order [29]. Such an order is designed to specify that medical personnel are	not to administer cardiopulmonary resuscitation (CPR) to a patient who experi-
ences cardiac or respiratory arrest [28]. In the absence of such an order, it is
expected that CPR will be initiated for a patient who arrests [30–32]. Consent to
CPR is generally presumed because in such an emergency, the patient ordinarily
cannot communicate treatment preferences and, without CPR, death is certain. A
DNR order is specific to resuscitation in cardiopulmonary arrest situations. It is
not an authorization to discontinue other forms of care appropriate for the patient
under the circumstances [28].

A patient may include, as part of a living will, for example, specific directions
concerning CPR. If so, those directions should be honored. Unlike other written
advance directives that are prepared and executed by the patient, however, the
DNR order is typically entered by the physician on the patient’s chart in the
hospital after discussion with the patient (if competent) or the patient’s legal
representative (if the patient is incapable of making a decision). For a patient with
an irreversible or terminal illness, particularly when the risks of arrest are
significant, it is appropriate for the physician to discuss CPR and the possibility
of a DNR order with the patient or the surrogate in order to ascertain the patient’s
desires [30,32]. In doing so, it is important for the physician to explain CPR
procedures so that an informed decision can be made. This is important for
several reasons. The term CPR may mean different things to the physician and
the patient [13]. Does it include, for example, intubation? Further, the patient
needs to understand that CPR is a “desperate, invasive procedure” that may be,
for many patients, undesirable [32]. The clearer the understanding of what the
patient does and does not want in this context, the more certain medical personnel
will be when particular circumstances present themselves.

If the patient decides not to have CPR, then a DNR order should be
documented in the patient’s record. Hospitals and other facilities generally are
required by licensing and accreditation organizations to have specific policies and
procedures pertaining to DNR orders, including requirements for proper docu-
mentation [33]. These policies may specify a standard DNR order form to be used by physicians. They may also provide that the patient or the patient’s representative must sign the order to evidence consent. Consistent with the right of patients to make their own health care decisions, if a competent patient does not consent to a DNR order, then it cannot be written [30].

The setting in which a DNR order is to be implemented can raise problems for caregivers. Arrest is an emergency condition in which the initial impetus is to rescue the patient who is about to die [29]. Yet, physicians and others should implement the patient’s preferences and not let their own value judgments and personal beliefs influence them. At times, however, this can be very difficult. Within the hospital setting, there may be great reluctance to implement a DNR order when the patient is in surgery or is receiving some other therapeutic or diagnostic care. After all, it seems inconsistent for a patient to elect to have surgery and at the same time decline CPR if necessary during surgery. Although commentators have tried to address these concerns, many hospitals include within their policies and procedures provisions suspending DNR orders while patients are in surgery or are receiving other therapeutic or diagnostic treatment in the hospital [18,34]. In contrast, other hospitals have established specific procedures to follow to determine whether a DNR should be suspended or not. Under such policies, the patient or the patient’s representative makes the final decision about whether the DNR should remain in effect during surgery or in other settings [34].

The discussion here has been of DNR orders within the hospital or other facility setting; however, a DNR order may also apply outside of a hospital or nursing home (e.g., for a terminally or irreversibly ill patient living at home and receiving hospice or home health care) [29,34]. In these situations, the out-of-hospital DNR is designed to direct health care personnel such as emergency medical technicians as to the patient’s desires regarding CPR in case of cardiopulmonary arrest. There have, however, been some concerns regarding such out-of-hospital DNR orders. Although a patient has the right to decline CPR whether or not they are hospitalized, emergency personnel are understandably reluctant to withhold CPR when they encounter an arrest situation. As a result, many states now have statutes and regulations authorizing out-of-hospital DNR orders and specifying their preparation and implementation by emergency personnel [34].

**Durable power of attorney for health care**

A durable power of attorney for health care is a proxy form of advance directive. It identifies and designates a named person or persons to make decisions about the patient’s care if and when the patient is incapable of doing so [13,19,28]. The patient as “principal” authorizes the identified person as the “agent” or “attorney in fact” to act for the patient in making medical treatment decisions. The agent’s discretion, unless limited by the patient, broadly covers all
manner of medical issues and decision making for the patient. Unlike a living
will, which instructs medical personnel and family members as to the patient’s
treatment preferences with respect to particular medical conditions, the durable
power of attorney empowers someone of the patient’s choosing to make such
decisions for him or her when he or she is unable to do so. Thus, the agent can
make treatment choices for the patient in the wide array of unforeseen circum-
stances that might arise, even in the face of disagreement with those choices by
others such as family members. When it is a choice the patient could legally make
for him or herself, the agent can make that choice.

A key concept underlying the durable power of attorney for health care is that
the agent will exercise “substituted judgment,” that is, the agent will make
decisions that are consistent with what the patient would have decided for himself
or herself under the circumstances [12,13]. For the durable power of attorney to
function in this manner, it is critical that the agent know and understand the
patient’s moral and religious values, attitudes regarding life, death, and medical
care generally, as well as any specific preferences the patient has concerning
particular treatment scenarios [19]. Thus, the patient should appoint as agent
someone who knows them well, who can be trusted to reflect the patient’s values
and preferences in making decisions, and who has the ability to make difficult
decisions [13,28].

There are a number of mechanisms, both formal and informal, whereby the
patient can offer the agent as well as the physician, assistance in this regard. The
patient may, in addition to preparing a durable power of attorney, also prepare a
separate living will with specific instructions to guide the agent in certain
situations. Because the agent enjoys the same authority as the patient, however,
the agent may elect not to follow specific provisions of the living will.
Alternatively, the patient may include in the durable power itself instructions
as to the sorts of treatments to be used or withheld from the patient should the
need arise. The agent would be bound by such limitations, unless the durable
power provided otherwise [19].

Beyond such instructions, the patient should, either orally or in writing, offer
the agent insights into the patient’s values and attitudes that may help guide the
agent’s choices. One example of this is commonly referred to as a “values
history” [3,35]. The values history is a written document that sets out the
patient’s attitudes and personal values so that someone reading the history is
better able to determine what the patient would have decided under the
circumstances. It is not designed to direct treatment decisions but rather “to
provide the patient with an opportunity to be introspective about personal
desires, beliefs and goals in life, which then may provide insight into what
kinds of care are appropriate” [13]. In addition to giving this values history to
the agent, the patient should also provide it to the physician. This will give the
physician the opportunity not only to be familiar with the values history but also
to converse with and counsel the patient about these matters in a meaningful
way, so that when the time comes, the physician can better effectuate the
patient’s wishes [35].
Even in the best of circumstances, the agent under a durable power of attorney for health care may not be in a position to know with certainty what the patient would have wanted. Indeed, this may often be the case. In such cases, the agent is expected to make decisions that are in the “best interests” of the patient, taking into account what they do know about the patient’s desires and whatever other information is available, including insights from family members, medical personnel, and others, as well as pertinent medical information regarding the proposed treatment [12,13].

As with other advance directives, physicians and other caregivers are expected to abide by a valid durable power of attorney. The agent is entitled to receive all pertinent information regarding the patient just as the patient would be. Further, the informed-consent decision-making process should be fully implemented with the agent acting on behalf of the patient [36]. Finally, when a decision is made by the agent, health care providers must, acting in good faith, implement that decision in a manner consistent with applicable professional medical standards. If the physician is unable or unwilling to comply with the agent’s decision, then the physician must inform the agent of this and work with the agent to transfer care of the patient to another physician [22]. If the physician is convinced that the agent’s decision is contrary to the patient’s wishes or not in the patient’s best interests, the physician or the hospital may initiate legal proceedings to have a guardian appointed for the patient or to otherwise override the agent’s decision [36].

States generally have specific statutes authorizing and regulating the making and implementing of durable powers of attorney for health care. Typically, these statutes provide that the physician who relies in good faith on the agent’s decision is in the same position as if the patient had made that choice [22]. When the decision is not clearly inconsistent with the provisions of the power of attorney, and when the choice is one that the patient could legally have made, the physician and other medical personnel are not subject to any criminal or civil liability or any professional disciplinary action. Furthermore, state laws generally provide that withholding or discontinuing life-sustaining treatment in compliance with an agent’s directive under a durable power of attorney is not suicide or homicide [22].

State durable power laws also may set out other important provisions. For example, the Illinois statute restricts who can be designated as the patient’s agent, excluding as agent the patient’s attending physician [22]. Furthermore, state law may seek to define or limit the agent’s powers in various ways. The Illinois statute specifies that the agent may direct that an autopsy be performed on the patient and whether the patient’s organs will be donated [22]. Finally, the state’s statute may set out technical requirements for an effective durable power, such as notarization and witnesses, and may provide a model form to be used. As discussed previously, such forms are nonexclusive so that patients remain free to craft their own documents that meet their needs. Typically, such nonstandard forms still must be executed in conformity with the statute’s technical requirements.
Patient Self-Determination Act

The Omnibus Budget Reconciliation Act of 1990 adopted amendments to the federal law governing the Medicare and Medicaid programs, which included provisions referred to as the Patient Self-Determination Act (PSDA) [37]. The purpose of the PSDA is to enable patients to be better informed participants in decision making about their health care, even after they lose the ability to voice their wishes.

The PSDA requires designated health care organizations to inform all adult patients about the patient's common law and statutory rights to make health care decisions, "including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives" [38]. Included in the organizations covered by the PSDA are hospitals, nursing homes, home health care and personal care providers, hospice care programs, and health maintenance organizations [38]. The requirements established under the PSDA apply to health organizations and not to individual physicians or other medical personnel [13]. When an organization fails to comply with the PSDA, it may face termination from participation in the Medicare program [39].

States are required by the PSDA to provide a written description of state law concerning advance directives and patients' decisional rights to PSDA-covered health care organizations [40]. These organizations must, in turn, distribute this written description to patients. In addition to this written description, health care organizations are required to develop and implement written policies and procedures regarding the following [38]:

1. To provide written information to each adult patient about an organization's policies concerning the exercise of decisional rights.
2. To document in the patient's medical record whether or not the patient has executed an advance directive.
3. To insure that the provision of services to a patient is not based on the existence or absence of an advance directive.
4. To provide educational programming to staff and to the community regarding advance directives.

PSDA advance directive information must be individually distributed to each hospital, nursing home, or hospice patient at the time of admission. Home health care and personal care services may distribute the information before providing care at the first visit [41]. Health maintenance organizations must furnish the information to individual enrollees at the time of enrollment [42]. In situations where the individual is physically or mentally incapacitated and unable to receive the information, the organization may give the information to family members, surrogates, or other concerned persons [41,42].

The health care provider's "right of conscience," that is, the right under state law to object on the basis of conscience to implementing an advance directive, is protected under the PSDA [38]. The written policies of the organization must
clearly and concisely explain any limitations on implementing an advance directive based on the exercise of the right of conscience. These policies, at a minimum, must do the following [41,42]:

1. Clarify any differences between institution-wide conscience objections and those that may be raised by individual physicians.
2. Identify the state legal authority permitting such objections.
3. Describe the range of medical conditions or procedures affected by the conscience objection.

As a practical matter, the PSDA has been far from easy to put into effect. Uncertainties in the language of the PSDA coupled with a delay in adopting regulations initially contributed to difficulties in interpretation and implementation. Despite these considerations, studies have shown that health care organizations do comply with most formal PSDA requirements [43,44]. Whether the PSDA has increased the use of advance directives and enhanced the effectiveness of such documents is open to question.

**Impact and effectiveness of advanced directives**

In recent years, public policy as reflected in the PSDA and in an array of state laws has focused on increasing public awareness of advance directives and their use by patients. Legal and medical professional groups and patient advocacy and other interest groups have vigorously joined in these efforts. What has been the impact? To what extent do patients prepare advance directives? If they do so, are they effective? Are they implemented by health care providers in the way they were intended? What impediments remain in the effort to encourage patients to make their health care wishes known in advance and assure that when the time comes, those wishes will be put into effect by caregivers? Finally, what is the physician’s role in this regard, and how can the medical community play that role more effectively?

As previously noted, studies indicate that overall institutional compliance with the formal requirements of the PSDA has been adequate. Current evidence, however, also suggests that despite the efforts of government agencies, health care organizations, and patient advocacy groups, many patients still do not prepare advance directives. The study results vary. Some conclude that these efforts have been largely ineffective, whereas others find a modest or even a significant impact. One survey of research findings indicated that before the PSDA was enacted, the number of patients completing advance directives ranged from as low as 4% to as high as 28%, with 15% to 20% being the norm, and that since then, these numbers have not substantially changed [26]. In contrast, some studies reveal a more significant impact. For example, a study of elderly nursing home patients after the PSDA was put into effect found that 20% of the 600 patients studied had prepared an advance directive—a sevenfold increase over the number doing so prior to the
PSDA [45]. It appears that a variety of factors such as who and where a patient is may play a role in the rate of advance directive completion. Thus, the patient’s age and education and the setting in which care is being provided play a role in whether the patient is likely to prepare an advance directive [5].

Apart from the advance directive completion rate is the question of implementation. It appears that many patients who do prepare directives never tell their physician or even their family members that they have done so [13]. As a result, according to one study, only about a third of the patients who had prepared an advance directive actually had it included as part of their medical record [32].

Furthermore, even if the patient’s directive is available, it still may not be put into effect for a host of reasons. If there has been little or no prior discussion among the patient, the family, and the physician concerning the advance directive and the patient’s preferences, implementation will be impeded [46]. Further, without adequate discussion and review, the advance directive prepared by the patient may prove to be so vague or uncertain as to offer little real assistance to medical personnel and family members in making treatment decisions [13,29,32]. Disagreement among family members over implementing an otherwise clear directive may also inhibit health care personnel from doing so [13,29,47]. Concerns among physicians, nurses, and other care givers about their ethical and legal responsibilities, including fears about civil lawsuits and even criminal charges may also impact whether and how a patient’s directive is honored [13,46,48]. Finally, the physician’s own moral, professional, and social values can impact decision making regarding an advance directive [13,45,49]. Implementing an advance directive may be difficult for a physician who disagrees with the patient’s or surrogate’s choice, whether it is to discontinue treatment that seems promising or to continue treatment that seems futile to the physician [29].

Improving both the use and effectiveness of advance directives clearly involves efforts from a range of participants. Physicians play one of the most significant roles in this regard [43,50]. For the physician community to not only increase the number of patients with advance directives, but also enhance the quality of such directives as tools for effective treatment decisions, it requires education, communication, and consultation [43].

In terms of education, physicians need to inform themselves on an ongoing basis about the legal, ethical, and professional rules and standards regarding advance directives. As noted, uncertainties in these areas have been shown to inhibit physicians from addressing advance directives with their patients and from putting directives into effect.

Ethical and legal standards clearly recognize and support the good faith implementation of a patient’s advance directive by medical personnel [36]. Ethical or legal questions may, of course, arise in specific clinical situations; however, in the majority of cases, these questions can be resolved and the patient’s wishes put into effect. Courts have generally been loath to impose either civil or criminal liability for honoring, in good faith, an advance directive.
Indeed, failing to implement a valid advance directive may expose the physician to legal claims including battery [12,13,19,52].

Physicians also ought to enhance both their understanding of how and when to initiate discussions with their patients about preparing advance directives and their ability and willingness to do so [50,53]. Although well intentioned, the design of the PSDA to have the advance directive discussion at the time of admission to the hospital is clearly flawed [13,43]. Surveys indicate that patients are often reluctant to initiate discussion of advance directives with their physicians, seeing it as the physician’s responsibility to begin the dialogue. Patients also feel that this discussion should begin at earlier age and earlier in the physician-patient relationship than is usually the case [54]. To accomplish this, beyond appreciating these patient concerns, physicians need to address their own reluctance to discuss end-of-life care and advance directives with their patients. They can do so by increasing their practical experience and skills in this area.

Communication between the patient and the physician is critical in terms of the likelihood that a patient will have an advance directive and that it will be effective in guiding treatment choices [13]. If the goals of patient autonomy and decision making are to be realized in the real-world clinical setting, then this can only be accomplished through full and open communication [43]. It is not enough that the patient has an advance directive. If, in making the directive, the patient is uninformed or his or her true desires remain unarticulated, if the directive is vague or unclear, or if the physician’s own concerns and values that might limit the directive’s implementation are not addressed, then the likelihood that the directive will function effectively is greatly diminished. The quality and effectiveness of a directive is largely determined by the quality of the physician-patient dialogue that occurs in the process of preparing and, as appropriate, revising that directive [1,29,43]. Beyond communication between the physician and the patient, the physician should encourage and, when possible, facilitate communication among the patient, the patient’s surrogate, and family members.

As discussed previously, part of the difficulty encountered in putting patient directives into effect at the bedside is physician uncertainty about legal, ethical, and professional standards. In addition, the physician’s own moral, professional, and social values may be in conflict with the patient’s or surrogate’s choices. These uncertainties and conflicts can be compounded. The physician may well be encountering the patient for the first time at the bedside. The physician may be faced with deciphering and implementing an advance directive—having played no role in its preparation—with a patient and a family with whom he or she has had no prior contact. In such situations, the physician can be sorely challenged in making treatment decisions.

In this setting, opportunities for consultation are important. Clearly, consultation with other physicians and care providers can be helpful. Beyond this, a hospital ethics committee, an individual clinical ethicist, or an ethics consultation team may be available to offer valuable advice and guidance [55]. Other units
within the hospital such as pastoral care, patient education, and legal services often can assist physicians in addressing concerns and conflicts regarding advance directives. Finally, mediation may, in some instances, be an appropriate alternative in the context of disagreements concerning implementation of an advance directive [56].

Summary

Advanced directives are a natural extension of a patient's right to self-determination of what actions will be taken upon his or her body. As such, instructional advanced directives such as living wills and DNR orders represent important patient preferences that must be adhered to in the health care context. In addition, health care proxies provide the patient with an authority for decision making in the event of incapacity. Overall, advanced directives provide health care providers, patients, and patient families with control over the kinds of care they do and do not desire at the end of life. Understanding the legal status of these instruments will provide the physician with another tool to advocate effectively for the patient.

References


[18] Ill Comp Stat 755: 45/1 et seq.


[21] Ill Comp Stat 755: 35/1 et seq.

[22] Ill Comp Stat 755:45/1 et seq.


[27] DeCrella v Elston, 895 SW2d 698 (Ky 1993).


[38] 42 USC §§1395cc(t), 1396a(w) (2001).


[41] CFR §489.102.


