Chapter 4
On the Scope and Limits of Advance Directives and Prospective Autonomy

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4.1 Introduction

Most patients near the end of life die after a decision is taken to withhold or withdraw life-sustaining interventions, such as cardiopulmonary resuscitation (CPR), a ventilator or a feeding tube. It has been estimated that in the US more than one million hospital patient deaths each year (70 % of all hospital deaths) occur after a decision to forgo life-sustaining interventions (Prendergast 2000). When the ravages of illness, disease or injury have stolen the patient's ability to decide for oneself, others must make these difficult decisions on behalf of incompetent loved ones. The ethical and legal consensus across the US holds that, when called upon to bear the burdens of decision, families and healthcare providers should seek, first and foremost, to determine what the patient would choose for him- or herself, and should also act in the patient's best interests. Every day in hospitals across the country, families, friends, physicians, social workers and others face the challenge of constructing a narrative of the patient's wishes, drawing on their understandings of the kind of person the patient has been over a lifetime, the patient's past statements, personal stories and experiences, and other information about the patient. In order to make patients' wishes count when we cannot speak for ourselves, and to ease the psychosocial and emotional burdens on family members, the widely adopted public policy response has been to encourage and empower individuals to write advance directives for healthcare to direct and control treatment decisions in the event of future decisional incapacity.

Focusing on the US experience, this chapter discusses key features of advance directives, and the scope and limits of their authority, from both ethical and legal perspectives. Some common ethical, legal and practical challenges for honouring directives are examined—in particular, dilemmas where ethics and law may not

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agree on the duty to honour patients' advance directives. Whether advance directives should be understood as binding documents is also considered.

There are generally three types of advance directives. A *proxy directive* (also known as a "durable power of attorney for healthcare") designates a trusted family member, friend or religious adviser to make healthcare decisions on the patient's behalf. The *living will* (also known as an "instruction directive") states with some specificity the person's wishes and instructions for care. The third approach is to designate a healthcare proxy and provide the proxy with further written instructions for future treatment and care, often called a *combined directive*. Most state statutes recognize both proxies and living wills and allow for combined directives; three US states recognize by statute only the healthcare proxy (American Bar Association 2009). The legal and policy landscape across Europe and other countries similarly recognizes both proxy directives and living wills as instruments for planning ahead for end-of-life decisions (Brauer et al. 2008), though looking to patients' previously expressed wishes as a basis for decision has been unusual in most European countries until recently (Andorno et al. 2009).

This chapter is primarily concerned with the designation of a healthcare proxy, the preferred and most widely used form of advance directive in the US. Among the reasons for the prevalence of the proxy directive are the fact that it is simple to use and permits the proxy to engage in an informed-consent dialogue with the physician and respond prudently to the patient's current circumstances and treatment options. Healthcare proxies avoid many (not necessarily all) of the well-documented problems that arise with interpretation of living wills, which too often prove ambiguous and unhelpful because they were written years ago and may not adequately anticipate the patient's current condition and treatment options.

4.2 Background and Legal Context

In the US, all 50 states and the District of Columbia recognize the legal right of competent adults to write advance directives to direct and control healthcare decisions near the end of life, at a time of future decisional incapacity. Advance directive laws have been strongly influenced by American case law, where the right to refuse life-sustaining treatment was first established. In the seminal case of Karen Ann Quinlan (*In re Quinlan* 1976), Joseph Quinlan was appointed legal guardian for his 21-year-old daughter and was granted permission to request removal of the respirator sustaining her life in a persistent vegetative state (PVS). This is a condition in which all cognitive functions of the brain have been lost, resulting in complete unawareness of self and the environment. PVS patients retain some of the brainstem functions that regulate autonomic activities of the body, such as breathing, but when properly diagnosed, there is virtually no hope of recovery to a cognitive, sapient state (Multi-Society Task Force on PVS 1994). The New Jersey Supreme Court's opinion was the first to recognize a constitutional right to refuse unwanted bodily interventions, including life-sustaining treatment, and to hold that when patients are unable to exercise that right, family members may forgo life support on behalf of incompetent loved ones, on the basis of the patient's wishes and best interests (often referred to as "substituted judgment"). In the ensuing two decades, states across the country had their own much-publicized cases requiring judicial resolution. Though not bound to follow *Quinlan*, courts in other states consistently found the *Quinlan* opinion's reasoning persuasive and most often reached the same essential conclusions. Over the next 15 years, a judicial consensus emerged supporting patients' rights and the authority of family members to make end-of-life decisions for incompetent loved ones. Some courts ground these rights in the federal or state constitution, others look to the common law right of self-determination. A number of these cases, like *Quinlan*, involved PVS patients; others involved patients who were terminally ill (Cantor 1993; Olick 2001). The US Supreme Court's decision in the case of Nancy Beth Cruzan (1990), a young woman in PVS, reaffirmed the legal-ethical consensus. *Cruzan* also held that states may establish their own rules for end-of-life decisions, provided they do not unduly infringe upon patients' constitutionally protected rights to control their own healthcare (*Cruzan* 1990).

In the immediate aftermath of *Quinlan*, California enacted the first advance directives law, the California "Natural Death Act" (1976). In the ensuing years extending into the early 1990s, state after state responded to this problem of reconstructing a reliable account of the patient's wishes, to court decisions, and to the clarion call for expansion of autonomy-based rights of patients and families, by enacting advance directive laws. The oft-recited legal principle grounding advance directive laws is that incompetent patients have the same rights of self-determination as competent patients. Only the means for exercising these important rights should differ. To effectuate control over the dying process, advance directive laws establish the right to put one's wishes for future care in writing and impose obligations on physicians, hospitals, families and others to honour the patient's wishes. Advance directives are typically used to appoint a healthcare proxy and to direct withholding or withdrawal of life-sustaining treatment when irreversible disease or injury brings a severely diminished quality of life, marked by incapacity, loss of control, dependence on medical interventions, pain and suffering. Recognizing that for some individuals longevity itself is valued despite severely impaired quality of life, most states also allow use of directives to request continued life support.

The deeper grounding of advance directives resides in the ethical principle of prospective autonomy. This principle recognizes that future-oriented actions are integral to the moral life of autonomous persons. To take actions and decisions now that affect one's future, or the future of family, colleagues, co-workers and friends, to commit to personal projects and goals—in short, to think and plan ahead and make an investment in the future—is an essential feature of living the moral life. Buying insurance, seeing the doctor regularly, having health-conscious diet and habits, and making important decisions about medications or surgery all involve a view to shaping and promoting our interests in good health, both for its own sake and for the critical instrumental importance of health and well-being in the pursuit of projects, commitments and goals that matter to us. In contrast to contemporaneous autonomy, the concept of prospective autonomy holds that it is an expression of our moral agency to make plans and take actions now that are intended to control our healthcare in the future, including when we can no longer make decisions for ourselves. When we commit to writing a personal plan for control of the dying process, to guide the course of care and treatment in the face of future incapacity to make contemporaneous decisions, this is an exercise of prospective autonomy. Taking charge of the dying process in this way is a defining feature of what is meant by "the pursuit of death with dignity". Directing one's personally selected healthcare proxy to carry out one's wishes extends autonomy beyond one's ability to make contemporaneous informed decisions and asserts control and dignity in the dying process. Moreover, the importance of future-oriented plans and commitments for how we die (or the legacy we leave our families) survives loss of capacity to appreciate whether those plans and commitments are respected. It still matters whether our wishes, values and decisions near the end of life are honoured or disregarded, even if we can no longer know what decisions are taken by our proxy, family and physician (Olick 2001).

4.2.1 Advance Directives Versus Physician Orders

Advance directives are sometimes confused with do-not-resuscitate (DNR) orders and with physicians' orders for life-sustaining treatment (POLST). One source of this confusion is that although DNRs and POLST are designed primarily to document and give effect to contemporaneous treatment decisions, they can also be used to provide direction for treatment decisions taking effect in the near future (thus, in advance), if patients' decisional capacity is lost. The key distinction is that, as the terms imply, both DNR and POLST are physician orders. In addition, both are intended to implement the patient's wishes.

DNR orders direct that resuscitation efforts be withheld should the patient suffer a cardiac arrest. They are for the most part contemporaneous orders, typically for hospitalized patients (out-of-hospital DNRs are also recognized), and are sometimes time-limited—that is, the DNR order may need to be revisited and renewed periodically. A DNR/DNI (do-not-intubate) order adds that in the event of cardio-respiratory distress the patient is not to be intubated. By contrast, advance directives specify the patient's wishes in anticipation of future ill health, are expressly designed to encompass a wide range of choices (not limited to DNR) and are personal documents with no requirement that a physician be involved in the crafting process (though communicating with one's physician is recommended); they remain valid indefinitely unless changed or revoked by the patient. When the proxy refuses resuscitation in accordance with the patient's wishes, the DNR order implements this decision.

POLST has emerged as a recent complementary mechanism for making patient and family wishes count at the bedside. The POLST form records in a single, multi-page document all physician orders for end-of-life care, including DNR/DNI, feeding tubes, dialysis and whether the patient should have comfort measures to ease the dying process or aggressive interventions to prolong life. In this way, it combines features of both advance directives and DNR orders. But like DNR orders, POLST is primarily designed to document orders for the hospitalized patient's condition and treatment options now and in the near future, based on patient and proxy (or other surrogate) decisions (Hickman et al. 2008; Sabatino 2010). POLST is sometimes used to implement advance directives and proxy decisions, but these documents are not legitimated or governed by the advance directive laws summarized here.

4.2.2 *Synopsis*

The balance of this chapter describes in more detail many common features of advance directives and the supporting laws, with emphasis on the scope and authority of advance directives at the bedside. The next section discusses the determination of patient incapacity that triggers the role and authority of advance directives. I then address the rights and duties of healthcare proxies, physicians and other healthcare providers. Next, the two most significant differences among state laws that shape and limit patient and proxy rights and the authority of advance directives are explained. The first concerns forgoing of life support for patients who are neither terminally ill nor permanently unconscious (the medical-condition limitation); the second, the rules for forgoing of feeding tubes (the feeding-tube limitation). Also discussed is a third and increasingly common dilemma on which the law is often silent—whether a proxy's insistence on continued treatment can be overridden on grounds of "medical futility". Patient care dilemmas involving any of these three scenarios can create conflict between ethics and law, and can put those responsible for the patient's care in the difficult position of asking, "Although it's ethical, is it legal?" Finally, this chapter addresses in what sense advance directives are or are not *binding*, and goes on to discuss the problem of the rebel proxy who fails to fulfil their fiduciary duty to honour the patient's wishes. Because my focus is on bedside decisions, I assume for the sake of discussion a properly executed proxy directive and do not set forth the formal requirements (such as signing and witnessing) for writing directives or their practical limitations.

My focus here is on the use of advance directives under state law, but a further feature of the legal landscape should be noted. The Patient Self-Determination Act (PSDA) is a federal law, applicable across the country. This procedural law imposes obligations on hospitals and other healthcare facilities to ask patients and families if the patient has a directive, to document patients' "advance directive status", and to provide information about patients' rights and advance care planning. The PSDA is silent on matters of substantive rights; it defers to the states as the source of substantive rights and rules for end-of-life decisions (Ulrich 1999). There is no national law in the US that establishes uniform rights and duties of patients, proxies, physicians and hospitals. Because law and practice can differ from one state to the next, it is important for patients, families and practitioners alike to be familiar with the law of the state in which they live, and receive and provide healthcare.

4.3 Scope, Authority and Limitations of Advance Directives

4.3.1 Decisional Incapacity: A Triggering Condition

Competent patients have the right to control their own healthcare; all adults over the age of 18 are presumed competent (to have decisional capacity). Because advance directives are intended to take effect only when the patient lacks capacity, the law typically prescribes a process for assessing capacity when the patient's ability to make informed decisions is in question. Initially, the attending physician bears this responsibility, and is to evaluate and document in the medical record the nature, extent, cause and likely duration of the patient's incapacity. A second, confirming opinion is often required, especially if the patient has a history of developmental or intellectual disability (New York Health Care Proxy Law 2007). If the patient lacks decisional capacity, the locus of authority to make treatment decisions shifts to the proxy.

Though not often expressly stated in law, it is common clinical practice to employ a decision-specific approach to capacity assessments. Patients may be able to make one sort of decision, but not another; for example, the patient may be able to choose a spouse or adult child to serve as healthcare proxy, but at the same time cognitive deficits impair the ability to understand and reason about his or her medical condition and the risks, benefits and burdens of refusing dialysis, surgery or other recommended treatments. Also, some patients have fluctuating capacity, meaning that they may be unable to make certain decisions today, but with improving cognitive skills or reduced need for pain control can engage in decision making the next day (Ganzini et al. 2005). A physician determination of incapacity triggers the authority of the healthcare proxy, but for patients who are interactive, with some capacity for reasoning, this should not categorically exclude them from the decisional process. Patients retain the authority to decide when they regain capacity, and respect for autonomy encompasses enhancing opportunities for patients to make their own decisions. On this decision-specific approach, widely endorsed in medical ethics, the power and right to decide may shift between patient and proxy, depending on the patient's condition and the nature and complexity of the decision to be taken. Once the proxy's role has been established, it is generally advisable to continue to involve proxies in the decisional process even when patients are able to and do make certain decisions for themselves. The proxy should be considered both partner and (potential) decision maker in the care of the patient.

4.3.2 Rights and Duties of Healthcare Proxies

The rights, duties and responsibilities of healthcare proxies and healthcare providers shape bedside decisions involving advance directives and are at the heart of advance directive laws. Both law and ethics uniformly establish that the designated proxy's first obligation is to make decisions consonant with the patient's own wishes and values. Secondarily, the proxy should act in the patient's best interests. This fiduciary responsibility is recited in advance directive laws across the country and in the standard text of proxy forms. In practice, the decision-making process often involves consideration of the written document *and* other evidence of the patient's wishes (sometimes called subjective factors) as well as the patient's best interests (sometimes called objective factors), collectively forming a narrative of the patient's values, interests and intent to support a treatment decision. The patient's personally selected and trusted proxy is generally accorded substantial deference in the evaluation and interpretation of the written document, other information about the patient's wishes and values (for example, past statements made to family or friends), and how well this construction of the patient's wishes and interests fits his or her current medical condition and supports a treatment decision (for example, to refuse a respirator). In the event of significant conflict or inconsistency between the written document and reported past verbal statements, the written directive would presumptively take priority. As noted below, only in certain narrow circumstances would there be ethical ground to challenge the proxy's authority.

It is commonly stated that proxies may make any and all healthcare decisions the patient could make if competent, subject to any limitations set forth by the patient in the proxy document (such as that the proxy must consult with a sibling or is not to put the patient in a nursing home). Generally, proxies may make decisions to provide or forgo life-sustaining interventions (the animating purpose of advance directives); consent to hospice care, out-of-hospital DNR orders, or discharge to home or a nursing home; carry out the patient's intent to donate organs; request a consultation; choose a physician; and make other choices that belong to competent patients. Because authority to consent to healthcare also entails control over personal health information, proxies control access to otherwise confidential patient information.

Yet taken literally, the "any and all" formulation can be misleading. US law generally holds that in the exercise of the right of informed consent, competent patients may refuse any unwanted bodily intrusions, including any form of life-sustaining interventions, regardless of their medical condition. By contrast, advance directive laws sometimes impose significant limitations on the scope of permissible patient choice, and hence on the proxy's power. First and most important, with respect to their application to life-threatening medical conditions, advance directive laws uniformly apply to patients who are terminally ill or permanently unconscious, but only sometimes expressly include those facing progressive, irreversible but currently non-terminal diseases (such as earlier stages of cancer or Alzheimer's disease). Statutes often define a "terminal condition" to mean "death within a short time" or within approximately 1 year; clinical practice often mirrors hospice reimbursement guidelines—a prognosis of 6 months or less to live. Narrow definitions of terminal illness or condition can effectively exclude patients with chronic, progressive, but not currently life-threatening disease from the rights that belong to terminally ill patients, unless state law expressly encompasses those with non-terminal conditions who nonetheless face an inevitable decline. The medical-condition limitation in many advance directive laws is heavily influenced by the fact that precedent court cases most often involved end-of-life decisions for patients who were either terminally ill or in PVS. It also reflects a legislative (and political) balancing between societal interests in preserving life and patient and family rights to decide when enough is enough.

Second, several state laws impose restrictions on the right to refuse artificially provided fluids and nutrition (the feeding-tube limitation). For example, in a small number of states, the patient's directive must provide specific authorization or direction to forgo a feeding tube, intravenous fluids or like modalities, or there must be some reasonable evidence that this is consistent with the patient's wishes (American Bar Association 2009). If this legal requirement is not met, the presumptive approach is to insert or continue use of a feeding tube. The position that special rules are needed to withhold and withdraw feeding tubes and intravenous fluids rests on the view that artificially provided fluids and nutrition are akin to food and water, constituting basic human caring that holds cultural, religious and symbolic significance, and that feeding tubes must therefore be provided unless the higher standard of evidence of the patient's wishes is met (Lynn 1986). This view held significant currency in the 1980s, arguably the period of most intense debate on this issue, but is clearly a minority position today. It is a distinct departure from the judicial consensus that uniformly has made no distinction between the patient's right to refuse a feeding tube and the right to refuse other medical modalities such as a ventilator, dialysis or antibiotics (Meisel 1992).

The medical-condition and feeding-tube limitations can present ethical-legal dilemmas for patients, proxies, physicians and hospitals—situations at the bedside where it is proper to ask, "Although it's ethical, is it legal?" The nature of this tension between ethics and law is explored further below, with illustrative case examples. (Other notable legal limitations on patient choice and proxy authority include restrictive rules in some states on forgoing treatment during pregnancy. Secondly, patients have no right to physician-assisted suicide pursuant to an advance directive once they have lost capacity to make their own informed decisions. Both of these circumstances are, however, extremely rare in practice).

4.3.3 Rights and Duties of Physicians and Other Healthcare Providers

When we appoint family or friend as proxy, we expect that physicians, hospitals and others will respect the proxy's authority and will honour their decisions.

Advance directive laws uniformly impose obligations to respect advance directives and contain specific provisions that shape both duties and rights of physicians and healthcare facilities. To promote compliance, physicians, hospitals and others are commonly granted immunity from liability and from professional discipline so long as they act in good faith, in accordance with the patient's wishes and with accepted medical standards. In fact, in the more than 30 years since California enacted the first advance directive law, there have been very few lawsuits brought by grieving family members concerning removal of life support, and fewer still claiming a directive was ignored or overridden (Lynch et al. 2008). Under "reciprocity" provisions in force nationwide, documents written in another state are to be honoured, so long as they are validly executed under the law of the patient's home state or the state where care is delivered. Typical requirements are that the document be signed, dated and witnessed (American Bar Association 2009).

Physicians and hospitals should give proxies substantial deference in the interpretation and application of advance directives and other information about the patient's wishes. But healthcare providers have no obligation to comply with requests that are outside the bounds of the proxy's powers. Nor can physicians be compelled to engage in behaviour contrary to law. A clear illustration is that physician-assisted suicide is expressly proscribed in advance directive laws and is illegal in most US states. The practice is legal in four states—most notably Oregon, where it is permitted solely on the basis of informed consent given by a competent, terminally ill patient (Ganzini et al. 2001). Thus, such a request from a proxy could and should be refused by the physician, even if based on an express statement in the proxy document.

An important limitation on the duty to comply with the patient's/proxy's decision concerns rights of professional conscience. Building on well-established ethical-legal consensus, advance directive laws commonly permit physicians and other healthcare professionals to decline to participate in the forgoing of life support on the ground that this would violate sincerely held professional, personal or religious commitments and values. To illustrate, when such conflicts arise, they may be based on the physician's strong belief that forgoing treatment is not in the patient's medical best interests or that compliance is contrary to the standard of practice, or perhaps the physician's principled objection to withdrawal of feeding tubes. Though couched in terms of professional rights of conscience, the approach is to balance the rights and interests of both patients and professionals. Physicians (and others) asserting a conscientious objection bear responsibility to notify patient and proxy and to facilitate a transfer of care to another clinician. An appropriate transfer is, by definition, to another physician who does not have this same objection and is prepared to honour the patient's/proxy's choices. Pending appropriate transfer, care must continue to be provided and patients may not be abandoned, but there would be no duty to comply with the decision to which the physician objects. Similar rights of conscience have been extended to private healthcare institutions, most often those with religious affiliations (such as a Catholic nursing home). Where recognized by law, the exercise of institutional conscience must often meet requirements that the institution have written policies, must provide notice of its policies to patients and families prior to or at the time of admission, and will arrange for transfer of care should a conflict arise after admission (Cugliari and Miller 1994).

4.3.4 Ethical-Legal Dilemmas: Some Case Illustrations

To show how legal limitations on permissible patient and proxy choice sometimes conflict with and constrain the ethically justified treatment decision, consider Anna, a 71-year-old mother of two adult children, who has been living for several years with the progressive decline associated with Alzheimer's disease. She appointed her husband as healthcare proxy a year before her diagnosis, giving him authority to make treatment decisions in accordance with her wishes and best interests. In their long discussions over the past decade, Anna has been firm in her views. She does not want to have her life prolonged through the inevitable decline of long-term chronic illness if she can no longer interact meaningfully with her family. In her husband's judgment, that time has come. Anna has now been hospitalized for a life-threatening pneumonia. Acting as her proxy, her husband refuses antibiotics. However, the physician's view is that the pneumonia is easily cured and is not caused by Anna's underlying Alzheimer's disease. Believing it his duty to advocate for his patient's medical best interests, he insists that antibiotics must be provided. Since Anna is not at this time dependent on a respirator or feeding tube and her pneumonia can be cured, she is deemed not to have a terminal condition.

Taking into account the proxy appointment, her husband's statements about Anna's wishes, and their close relationship over many years, we can posit a strong argument that Anna would not want antibiotics to treat her pneumonia, and that her husband's decision should be respected. Indeed, many of us would agree that to be sustained in this condition with an inevitable downward path and diminishing quality of life would be an undignified existence, imposing undue burdens on ourselves and our families. But if this state's advance directive law expressly authorizes withholding of life-sustaining interventions only when the patient is terminally ill (or permanently unconscious), the physician and hospital may well refuse to comply on the ground that withholding antibiotics under these circumstances is not legally permitted. There is a strong argument that the husband-proxy's decision is ethical, but those responsible for complying with the decision have an argument that it is not legal to do so, or at least that the law does not require compliance. By contrast, many advance directive laws take a broader view of patient rights, and expressly authorize refusal of treatment when the patient has a "progressive illness that will be fatal and is in an advanced stage", or when the patient has a progressive, irreversible condition and the burdens of aggressive treatment outweigh the benefits (Olick 2012). Under these laws, the ethical-legal conflict is anticipated and resolved in favour of patient rights and proxy authority.

Where embodied in law, the feeding-tube limitation also can create an ethical-legal dilemma. Consider Joseph, a 59-year-old man with a history of lung cancer. Two days after admission for an oncology follow-up, he suffered a serious stroke that left him minimally responsive and unable to make decisions for himself. A year earlier, Joseph had designated his sister as healthcare proxy with power to “make any and all healthcare decisions for me, except to the extent I state otherwise”, using the standard short form popular in his home state. The attending physician believes Joseph is terminally ill but could live another 6 months with a nasogastric feeding tube. Joseph’s sister refuses the feeding tube, stating that this is not what her brother would want. She recounts several conversations in which her brother spoke of not wanting to be maintained on machines if he were dying, in pain and unable to communicate meaningfully with others. And she describes him as a very active person, who valued his freedom and abhorred dependence on others. But she cannot recall any specific conversation with her brother about feeding tubes, and there is no reference to artificially provided fluids and nutrition in the proxy directive.

Under some advance directive laws (again a minority), the physician and hospital may well object that, absent any reasonable evidence Joseph had specifically contemplated and formed an opinion about forgoing a feeding tube, there is no legal authority to do so, and further that there is a duty to insert and maintain the feeding tube. (For the occasional physician who holds a principled objection to withholding artificial feeding, believing it to be ordinary and obligatory care, professional conscience further buttresses the refusal to comply, with a correlative duty to transfer care.) Joseph’s sister may well have a compelling ethical argument to refuse the feeding tube, but the feeding-tube limitation gives the physician and hospital legal ground to object. It creates an ethical-legal dilemma that limits patient rights and proxy authority. By contrast, on the (majority) rule where no such distinctions are drawn and there is no such limitation, the proxy’s decision should be honoured without conflict, respecting Joseph’s wishes.

A third scenario that puts ethics and law in tension arises when proxies and families insist on continued aggressive interventions that physicians consider “medically inappropriate” or “futile”. Consider Paul, a 39-year-old man with a history of acute myelogenous leukaemia (AML). Multiple attempts at induction chemotherapy have been unsuccessful. His condition now being refractory to treatment, his wife (who he appointed as proxy 3 years ago) has consented to a palliative treatment plan. But she insists that Paul be resuscitated in the event of cardiac arrest. Social workers believe her insistence on CPR is based partly on reluctance to let go and partly on the desire to allow time for other family members to say goodbye. Paul’s physicians believe CPR would be futile. They think it highly unlikely he would survive the attempt and implore the proxy to consent to a DNR order. Frustrated, they call for an ethics consultation in the hope that it will support such an order.

Here, it is the physicians who argue that to further limit life-sustaining interventions—to place a DNR order—is ethically justified. Many would agree this to be an ethically sound position, one that finds support in the American Medical Association (AMA) Code of Medical Ethics statement that when “further intervention to prolong the life of a patient becomes futile … [the intent of treatment] should not be to prolong the dying process without benefit to the patient or others with legitimate interests" (American Medical Association 2010). But law provides scant reason for the physician to "just say no". Advance directive laws typically state that there is no duty to provide treatment that is contrary to "accepted professional standards" or that is "not medically appropriate", but this language is widely considered to be pro forma and its application to futility cases is untested. Case law offers few examples and no consensus on the physician's asserted right to say no to life-sustaining treatment over the patient/proxy's objection. The common experience in practice is that ethical arguments of physicians and hospitals ultimately yield to legal rights of patients and families to insist on continued interventions to sustain life regardless of quality. "Futile" treatment deemed legally required though ethically inappropriate is provided.

4.3.5 Summary

To summarize, advance directives are grounded in the ethical principle of prospective autonomy, on which it is an essential feature of the moral life to take actions and make plans now that are intended to foster and secure a desired future. With respect to decisions near the end of life, advance directives exercise that moral agency by asserting control over the dying process in accordance with our own values and wishes. The legal framework and daily practice facilitate planning ahead for important end-of-life decisions, empower patients and proxies to make the patient's wishes count after capacity to make contemporaneous informed decisions has been lost, and obligate physicians, hospitals and others to honour the patient's wishes and the proxy's authority. In general, ethics, law and practice in the US take an expansive approach to patient rights and proxy power near the end of life. Commentators have proffered strong arguments that the medical-condition and feeding-tube limitations on patient/proxy choice in force under the law of a minority of states are unjustified (Cantor 1993), but—as the scenarios above illustrate—these limitations can constrain bedside decisions where ethics and law collide. The practical consequence is that sometimes physicians and hospitals feel compelled to refuse to respect the patient's/proxy's decision, asserting the absence of legal authority to withhold a feeding tube or to forgo life-sustaining treatment for a patient with a progressive, irreversible, but non-terminal condition; they thereby frustrate and override the patient's directive and deny the patient the right to control and shape a more dignified dying process. Medical futility scenarios present an opposite dilemma, where—in the absence of legal rules to support the physician's judgment—patient/proxy autonomy often (but not always) trumps the physician's ethical view that continued aggressive efforts to sustain life offer the patient no medical benefit. Of critical importance here, the resolution of ethical-legal conflicts at the bedside can hinge on one's understanding of the interface between ethics and law. For those who read such legal limitations literally and adhere to the myth that "anything the law does not expressly permit, it therefore prohibits" (Meisel 1991), such conflicts will likely be more common and patient rights more often dishonoured. On the other hand, physicians and other healthcare providers committed to supporting the patient and proxy in an ethically sound decision will often choose to ignore the law, embrace the understanding that though the law does not authorize, it does not expressly prohibit forgoing of treatment in these circumstances, or otherwise reconcile their professional judgment to respect the patient's/proxy's decision.

4.4 Are Advance Directives Binding?

4.4.1 Meaning of the Concept

Discussions of the scope and limits of advance directives sometimes pose the question, "Are advance directives binding?" In order to answer this question, it is important to distinguish different senses in which the term "binding" has been used. Sometimes families believe that advance directives must always be followed, in effect that "Whatever the proxy says goes." Some physicians believe proxy directives to be binding in this way as well; others have difficulty relinquishing control over treatment decisions and resist or show ambivalence towards the proxy's role. It should be evident from the foregoing that if what is meant by "binding" is that the literal terms of a directive must always be strictly followed, or that the proxy's choice must always be honoured whatever it is, then directives are not binding in this absolute sense. When ethics and law collide, we may hold that there is an ethical obligation to honour the patient's wishes and the proxy's authority. But it is difficult to maintain that physicians and hospitals are duty-bound to disregard the law and put themselves at risk for legal entanglement or professional discipline, even given that lawsuits involving advance directives are rare and risk of legal liability low (hence advance directives are also not binding in the sense that they are legally enforceable) (Lynch et al. 2008).

Proxy directives are, however, binding in a third and very important sense. A properly executed document imposes ethical and legal obligations on the proxy, family, physician and other healthcare providers to honour the patient's wishes, and those directions may be overridden only if there is strong justification for doing so. Rephrased, advance directives are *prima facie* binding. They are to be respected unless those who question the obligation to honour the directive and the proxy's decision establish strong justification to override it. A number of European countries embrace this position as well, though the Council of Europe's Biomedicine Convention (1997) adopts a weaker position, stating that patients' previously expressed wishes "shall be taken into account" (Andorno et al. 2009). As I have argued elsewhere (Olick 2001), ethical grounds to either remove the proxy or override a particular decision arise in *the case of the rebel proxy* who fails to fulfil his or her fiduciary duty to the patient. Putting aside the prior discussion of *legal* rules that limit the scope of proxy choice, the next section summarizes the position that, in rare cases, there is a strong *ethical* argument to override the proxy. This position is generally supported in law, though not articulated in this way.

4.4.2 The Case of the Rebel Proxy

As an exercise of prospective autonomy, the writing of advance directives entails anticipatory judgment. A personally selected spouse, partner, adult child, or friend designated as a healthcare proxy is entrusted with the role of faithfully assuming the responsibility to make decisions in accord with the patient's wishes and best interests. But on rare occasion that faith and trust is violated. Most scholarly discussion points to the proxy who acts from malicious, malevolent or self-interested motives, intending to impose undue suffering or to hasten death and the path to a tidy inheritance (sometimes called a "turncoat proxy"). The proxy who not only harbours such feelings and intentions but also seeks to act on them—perhaps offering a tortured account of the patient's wishes out of ulterior motive—should be stripped of the power to decide. One may also be a *rebel proxy* in a more benign and more common way, by failing to honour the patient's wishes despite good-faith efforts to do so. From time to time, a proxy is unable to shoulder the burdens of decision; clearly contravenes written instructions or family consensus about the patient's wishes because of an inability to let go; strains too hard to rely on a hopelessly ambiguous directive, contrary to the best interests of the patient; or simply is "dead wrong" in their understanding of the patient's wishes.

A familiar example in clinical practice involves apparent conflict between a living will and the proxy's decision. Consider the patient who chooses his spouse as proxy but fails to discuss the meaning of a living will authored several years before, or whose combined directive conjoins the proxy appointment with the more detailed instructions of a living will. Critics of living wills often contend that these instructions are vague, ambiguous and unhelpful as decisional tools (Fagerlin et al. 2002). Experience with living wills that may have been written years ago in times of good health shows that we can be poor forecasters of future illness, disease and disability and of what our medical needs and options will be. Further, living wills have often used vague and ambiguous language that refuses treatment when there is "no reasonable expectation of my recovery from physical or mental disability" or simply refuses "heroic measures" (Eisendrath and Jonsen 1983). Because living wills commonly set forth with some specificity interventions that are or are not wanted in particular medical circumstances, they give the appearance of clear guidance and direction, and often this is the case. But when the patient's actual medical circumstances and treatment options differ substantially from those previously contemplated, the specificity of a living will can create ambiguity and uncertainty. A fair reading of the patient's express contemplation of a different medical situation may be that the patient did not consider his or her current condition and options. Perhaps the patient did not want to be ventilator dependent but might accept a trial of ventilation. Or, analogous to the case of Anna, the living will clearly refuses ventilator and feeding tube, but is silent about antibiotics. When healthcare providers or even other family members take the literal written word (the living will) as the controlling statement of the patient's wishes, they sometimes question the authority of the proxy who would decide otherwise. Or, those responsible for the patient's care may conclude that the document fails to provide sufficient guidance about the patient's wishes, or that the document is hopelessly ambiguous when applied to the patient in the bed before them. They may therefore question the proxy's reliance on the content of the living will, and take the position that the proxy's decision cannot be accepted.

Another scenario can also be imagined. Future-oriented refusals of treatment are rooted in today's understanding of the nature of illness, disease and disability, and the potential and limitations of medicine to heal, restore function, control pain and relieve suffering. Occasionally, new developments in medicine not previously contemplated by the patient's directive will offer significant promise of substantial benefit for the patient. Consider, for example, the promise of ongoing research into the genetic basis of common diseases such as cancer and the quest for more effective pharmacogenetic interventions; perhaps a biomedical research breakthrough to reverse the course of Alzheimer's disease is on the horizon. When what medicine has to offer has changed substantially, when there has been a *radical change in circumstances* from those previously contemplated by the patient, there is good reason *not* to honour the patient's prior refusal of treatment. Of course, medicine is constantly changing. How radical, then, must the change in what medicine has to offer be to justify overriding the patient's refusal? It must be an intervention that promises to alleviate the very unwanted conditions that underlie the refusal of treatment—incapacity, pain, suffering, dependence on others, or other conditions material to the patient's view of an unacceptable quality of life. A "new" treatment that would merely prolong life a while more does not count as offering substantial benefit to the patient.

A radical change in circumstances presents a strong ethical argument for consenting to the intervention and not following a prior refusal of life-sustaining treatment. The proxy who chooses this course may justify this position on either of two grounds: first, that the patient would not have intended to refuse life-sustaining interventions had s/he known or anticipated this new and effective treatment; and second, that in this unusual case, the proxy's authority to decide in the patient's best interests trumps rigid adherence to the patient's prior wishes, which are now of uncertain meaning and application. Physicians and others ought to concur in this judgment and honour the proxy's decision. But suppose the proxy ignores or fails to take account of this radical change in circumstances. These very same arguments would support the efforts of physicians or other family members to insist on the new and beneficial treatment and to override the proxy's objection even where refusal of treatment is based on a reading of the patient's living will.

These are real, though rare, possibilities. Any of these scenarios may justifiably give pause and warrant closer scrutiny, inclining physicians and hospitals to challenge the proxy's authority. But only rarely will overriding the proxy ultimately be justified. Again, the proxy is due substantial deference and respect in his or her interpretation of the directive and of the patient's wishes. This includes insights into what the patient means by "no heroic measures", "no meaningful quality of life", or other such phrases. The proxy has been entrusted with exercising sound judgment to understand what such phrases mean to the patient, and to place them in context so as to clarify what the patient values and what the patient would find an unacceptable quality of life or an undignified dying process. Moreover, when evidence of the patient's wishes is lacking or hopelessly ambiguous, the proxy has residual authority to decide in the patient's best interests. When confronted with a rebel proxy, we may say that the patient chose unwisely. But absent extraordinary circumstances (a coerced proxy appointment), a valid proxy designation is nonetheless the patient's prospectively autonomous choice and is entitled to the strongest presumption of respect. Hence, healthcare professionals ought not simply to proceed with the course of treatment they think best for the patient and ignore or override the proxy; this would fail to take prospective autonomy and advance directives seriously. Rather, further process is in order, such as resort to an ethics consultation to first seek to resolve the dilemma, or to a court of law. To override the proxy may require formal judicial review in some states (New York Health Care Proxy Law 2007). It bears emphasis that in the case of the turncoat proxy of ill motive, removing the proxy's authority qua proxy would be an appropriate response. For the more familiar case of the rebel proxy, acting in good faith but not following the patient's wishes, it is appropriate to seek to challenge the particular decision but is often also proper to continue to involve the proxy in the patient's care and to look to the proxy to fulfil his or her fiduciary role with respect to other treatment and care decisions.

4.5 Conclusion

Since the New Jersey Supreme Court's decision in the case of Karen Ann Quinlan (1976), the right to refuse treatment has become firmly established in both ethics and law. Grounded in the ethical principle of prospective autonomy, legislation nationally has recognized the right to use advance directives to plan ahead to control treatment decisions in anticipation of future illness, disease and disability that takes away one's decisional capacity and prevents contemporaneous, informed choice. Law has played a prominent role in shaping the paradigm shift in society and medicine from a long history of "doctor knows best" to contemporary norms that put patient and proxy voice at the centre of decisions near the end of life. Strong ethical and legal support for advance directives does not mean, however, that prospective autonomy is unfettered—that any and all end-of-life decisions based on evidence of the patient's wishes and values must be honoured, or that anything the proxy decides must be done. Proxy directives are prima facie binding. Ethics and law accord substantial deference to proxy decisions and require those decisions to be honoured unless those who question this obligation establish strong justification for non-compliance. The exercise of prospective autonomy and proxy power encounters a number of ethical, legal and practical limitations. Most notably, law is not uniform across the US. A number of states limit the right to refuse treatment to conditions of terminal illness and permanent unconsciousness, and a handful impose special requirements on forgoing of feeding tubes. In those rare cases where a proxy fails to meet the fiduciary duty to decide in accord with the patient's wishes and best interests, it is justified to challenge and override the status or decisions of the rebel proxy.

Still, only about 20 % of US citizens write advance directives. This figure has not changed dramatically over time (Perkins 2007). Higher incidence of use has been reported among nursing home patients (Molloy et al. 2000), the elderly (AARP 2008), college graduates (Mueller et al. 2010) and people living with HIV/AIDS (Teno et al. 1990). A number of proposals have been made to increase the use and effectiveness of advance directives. These include reimbursing physicians for end-of-life discussions with patients (Fried and Drickamer 2010); making advance directive forms more widely available in languages other than English, removing the standard two-witness requirement, which sometimes disenfranchises the unbefriended elderly, and broadening eligibility rules for who may be chosen as proxy (Castillo et al. 2011); and making forms more readable and user-friendly (Mueller et al. 2010). All are worthy of pursuit but likely to achieve only modest gains. The psychosocial complexities of facing mortality and engaging the questions of how we die, and doing so in meaningful dialogue with family and physician, are intrinsic barriers to advance care planning. More often than not, family, friends, physicians and others are and will be called upon to decide for patients without the guidance and direction of advance directives.

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