

Routine Discussion of Advance Health Care Directives: Are We Ready?

An Affirmative View

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On the night of January 11, 1983, a 25-year-old woman was driving down Elm Road in Jasper County, Missouri. An accident occurred, causing her car to overturn into a ditch. Paramedics were called to the scene and discovered the injured driver without detectable respiratory or cardiac function. Cardiopulmonary resuscitation (CPR) succeeded in restoring both breathing and a heart beat at the accident site, and the patient was transferred to a local hospital in an unconscious state. The attending physician diagnosed closed head and anoxic brain injuries. The patient remained comatose for approximately 3 weeks, at which time a gastrostomy feeding and hydration tube was placed with the consent of her family. Subsequent rehabilitation, however, yielded no improvement. The patient continued to have motor reflexes, but remained in a persistent vegetative state with no indication of cognitive function. Her respiration and circulation were not artificially maintained. Diagnostic imaging of her brain revealed massive enlargement of her ventricles and cerebral atrophy. After it became clear that the patient's neurologic function was irreversibly impaired, her parents requested that her physicians terminate artificial nutritional support. Believing that a removal of such support would cause her death, hospital employees refused to honor this request without a court approval.

The patient in this case is Nancy Beth Cruzan. On June 25, 1990, the United States Supreme Court announced its opinion in the case of *Cruzan vs the Director of the Missouri Department of Health*. In a 5 to 4 decision, the court upheld a state supreme court ruling that prohibited

the removal of nutritional support from this patient. In the case of an incompetent patient, Missouri state law requires that "clear and convincing evidence" must exist that the patient would refuse consent for supportive care before such care can be withdrawn or withheld. In the absence of "clear and convincing evidence," the Missouri law assumes that the patient would consent to such treatment. In trying to determine Nancy Cruzan's wishes, the court had two pieces of evidence. Her parents, having known Nancy all of her life, stated that she would be unwilling to consent to further nutritional support given her irreversible neurological state. The second piece of evidence was a statement made by the patient to a former housemate several years earlier that she would not want to be kept alive if so disabled. There was no living will or written statement from the patient indicating her wishes. The lower court ruled, and the Supreme Court upheld, that the opinions of Miss Cruzan's parents and housemate do not represent "clear and convincing" evidence of her wishes in this situation.¹

Most states either have adopted or are working to adopt legislation regarding the withholding or withdrawal of life support from mentally incompetent patients. A law in New York, which became effective in April 1988, presumes that any patient who has not consented to a do-not-resuscitate (DNR) order is presumed to consent to CPR. The law lays forth conditions under which a surrogate decision maker may consent to a DNR order for an incompetent patient. If a patient lacks decision-making capacity, the attending physician and at least one consulting physician must certify in writing the cause and permanent duration of the patient's incapacity. This statement must be given to the patient's surrogate decision maker, who should be either a legal guardian or next of kin. The surrogate may consent to a DNR order if the two physicians have determined that the patient's condition is terminal and irreversible and that resuscitation would be

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medically futile.² A more recent development in New York was the enactment in July 1990 of the Health Care Agents and Proxies Act, which permits New Yorkers to appoint a person to make all health care decisions, including decisions about life-sustaining treatment, on behalf of the appointer in the event of incapacity. As noted above, the law in the state of Missouri has now been interpreted to require a higher standard of proof than the opinion of the next of kin to guide decision making in such cases.

If Nancy Cruzan had visited her primary care physician 1 month before her automobile accident, what issues would have been discussed? Her physician might have discussed the importance of eating a healthy diet and exercising regularly. The importance of avoiding tobacco use and wearing seat belts might have been covered. They might have discussed measures such as Papanicolaou smears and blood pressure screening. Unfortunately, Ms Cruzan's attitudes regarding death, dying, and disability, or her wishes for care in the event of incapacity would not have been elicited. Who would have imagined that such a young and healthy patient would be in such a dire situation so quickly?

Writing in the *New England Journal of Medicine* 3 months before the announcement of the Cruzan decision, Dr Bernard Lo and colleagues said, "In one way or another, [the Cruzan decision] will affect nearly all of us, because it will influence profoundly the extent to which life sustaining treatment is seen as optional, not only for our patients, but for our family members and ourselves."³ Physicians often discuss advance directives with patients who have terminal illness or who are elderly. The issue sometimes comes up at the time of hospital or nursing home admission. Table 1 summarizes several studies that have addressed the frequency of patient counseling regarding CPR and DNR orders. Evidently, most patients who undergo CPR have not discussed their wishes on this subject with their physicians. The question now is whether the issues brought forth in the Cruzan case should effect a change in the standard of practice regarding when physicians discuss advance directives with patients.

Why do physicians not discuss advance directives more often with their patients? With healthy patients, sudden and unexpected incapacity is unlikely, but physicians routinely discuss unlikely outcomes such as cervical cancer (Papanicolaou smears) and breast cancer (mammography). Some physicians may believe that advance directives can be discussed at a later time, when it becomes clear that the patient has a potentially terminal illness. Available evidence in the medical literature suggests that physicians are not compulsive in discussing advance directives even with these patients.⁸ Several common causes of death, such as cardiovascular disease and trauma, may have sudden and unpredictable onset.

Perhaps the two most important reasons why advance directives are not discussed more frequently are physicians' lack of knowledge about the outcome of medical interventions and lack of skill in counseling patients. Medicine lacks an adequate knowledge of how likely it is that a given medical intervention will succeed in prolonging or improving the patient's life. Some data are available for cardiopulmonary resuscitation. Five to 23% of patients who receive in-hospital CPR survive long enough to be discharged.⁹ This outcome clearly varies depending on the patient population. A recent study examined 503 patients aged over 69 years who received CPR in five Boston hospitals revealing that only 3.8% survived to be discharged.¹⁰ Data about the outcomes of other interventions in terminally ill patients are often not available.

A second important reason why advance directives are not discussed is that many physicians lack counseling skills and are uncomfortable discussing these issues. Stolman et al⁸ interviewed 97 competent patients who had DNR orders at a hospital in Summit, New Jersey. Fifty-eight percent of these patient said that they had discussed resuscitation with their physicians, whereas 73% of their physicians said that they had discussed this issue with the patients. The patients in this study were ill and may have forgotten the discussion, but another possible explanation is that physician discomfort leads to brief and superficial discussions.

Why should standards of care change to include discussion of advance directives with patients as a routine part of office practice? There is substantial evidence in the literature that patients want these discussions. In a study published in 1986, Lo and colleagues at the University of California, San Francisco, found that while 6% of the patients in their study had discussed life-sustaining treatment with their physicians, 68% desired such discussions.⁶ Finucane and colleagues⁷ randomized 72 elderly patients into two study groups. The intervention group had a discussion with their physicians regarding advance directives and their care plans regarding terminal or serious illness. All of the 34 patients in this group stated that they believed it was a good idea for physicians to talk to their patients about this issue. Surely advance directives and terminal care must be easier issues for physicians to raise with patients than for patients to raise with physicians.

A compelling reason to discuss advance directives with patients is that evidence exists that both physicians and next-of-kin family members are less than perfect in their ability to predict patient wishes. Bedell and Delbanco⁴ interviewed 25 patients who were survivors of in-hospital cardiopulmonary resuscitation. Eight of these 25 patients stated unequivocally that they had not desired CPR and did not wish to be resuscitated in the future. Only one of the 16 physicians who were caring for these 8 patients was

TABLE 1. STUDIES ADDRESSING FREQUENCY OF PATIENT COUNSELING REGARDING CARDIOPULMONARY RESUSCITATION (CPR) AND DO-NOT-RESUSCITATE (DNR) ORDERS

Reference	Location	Patient Population	Percent of Patients Who Discussed Advance Directives With Their Physicians
Bedell and Delbanco ⁴	Beth Israel Hospital, Boston, Mass	154 patients who had received CPR in the hospital	19
Bedell, et al ⁵	Beth Israel Hospital, Boston, Mass	Medical record review of 521 patients who had a cardiopulmonary arrest in the hospital	22*
Lo, et al ⁶	General Internal Medicine Practice, University of California, San Francisco	152 ambulatory patients who were aged either over 65 or under 65 years with 1 of 7 chronic medical diagnosis	6
Finucane, et al ⁷	General Medicine Clinic, West Virginia University, Morgantown	74 mentally competent ambulatory patients over the age of 65 years	1†
Stolman, et al ⁸	Overlook Hospital Summit, NJ	97 mentally competent, hospitalized patients currently classified as DNR	58

⁴Based on documentation in the medical record.
[†]Forty-four percent reported having discussed this issue previously but only 1 of 74 patients reported having done so with his or her physician.

aware that the patient had not desired resuscitation. Uhlmann and colleagues¹¹ studied 402 patients who were older than 65 years and had at least one chronic disease, but who were neither demented nor terminally ill. These patients were given a self-administered questionnaire that asked several questions regarding their preferences for resuscitation under several clinical scenarios. The patients' responses on this questionnaire were compared independently with the prediction of their answers by their physician and their spouse. In addition to stating their predictions, physicians and spouses were asked to rate their degree of certainty that the prediction was correct. Although more than three out of four of the physicians and spouses believed their predictions to be correct, the accuracy of predictions by both physicians and spouses did not exceed chance for more than one half of the scenarios.

There are compelling reasons to consider a change in the standard of medical practice regarding when and how physicians discuss advance care directives with patients. Americans have an astounding tendency to deny their mortality and avoid discussing death and dying. Physicians are as affected by this societal bias as patients. Medical decision making should be guided by the patient's right to choose, provided the patient is in a competent mental state to make such decisions. Unfortunately, decisions about life support and resuscitation too often are made at a time when patients lack the mental capacity to participate. Under these circumstances, the physician-patient relationship must be expanded to include family members and, in some cases, ethics committees or courts. The only way to prevent the unfortunate circumstances of the Cruzan case is for each patient to

discuss and document his or her preference regarding resuscitation and supportive care. As patient advocate, the family physician is in the best position to discuss these issues sensitively and meaningfully with patients.

Encouraging patients to think about such scenarios may have other benefits as well. If the physician can succeed in getting the patient to consider his or her own mortality, it should be easier to discuss the importance of seat belt use, smoking cessation, and other health promotion and disease prevention activities. Barriers, such as physician discomfort and lack of training, can be overcome with efforts to enhance continuing medical education and public education. The Cruzan case makes it clear that the only way patients can be assured a role in decision making is to document their choices while alert and competent. Surely it is a part of the responsibility of a primary care physician to facilitate this discussion and documentation.

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An Opposing View

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Advances in medical technology have enabled physicians to support physiologic processes at the margins of life. These advances have been embraced by both the medical profession and the public as consistent with a primary goal of medical practice: to prevent death. These same advances, however, have brought a vast array of unforeseen dilemmas. Society now painfully questions the costs of these new powers, costs measured in human suffering, in dollars, and in public distrust of physicians' motives for so aggressively postponing death. The Quinlan case was the first legal test of an emerging social debate. The Cruzan case now represents the first US Supreme Court ruling on the "right to die."

In the wake of the Cruzan decision, many are advocating widespread discussions of advance health care directives by physicians with their patients. Dr Bernard Lo recently stated: "Physicians should make sure to discuss life-sustaining treatments with patients while they are still competent. Such discussions have been recommended previously, the stakes are higher now. . . . Such discussions may consume a substantial amount of time, but the alternative may be to spend even more time in court or to be required to provide treatments that conflict with physicians' professional judgment and the wishes of patients and families. If the physicians do not encourage patients to give directives in advance, the courts may assume medical roles for which they are poorly suited."¹

Should the routine discussion of advance health care directives be prioritized as highly as Dr Lo recommends?

It is at best an uncertain investment of the valuable time physicians spend with their patients. It would not have altered Nancy Cruzan's tragic entanglement with the courts. A review of the tenuous legal status and limitations of advance directives will explain why.

THE LEGAL STATUS OF LIVING WILLS

In the wake of the Quinlan case and the California Natural Death Act in 1976, 41 states and the District of Columbia have passed "living will" legislation to protect individuals from unwanted death-prolonging medical care. Living wills generally specify when and under what conditions medical procedures can be forgone. Unfortunately, the circumstances under which living wills apply can be quite limited, and implementation has had limited success. After a decade of legal recognition, only 5% to 15% of Americans currently have completed living wills. Hospitals do not routinely inquire about their existence when important medical decisions are being made.²

The details of the automobile accident that led to Nancy Cruzan's institutionalization at the Missouri Rehabilitation Center in Mount Vernon, in a persistent vegetative state and fed by gastrostomy tube, have been extensively described. The initial Missouri trial court review, noting the consensus among Nancy's family, a court-appointed guardian ad litem, and her physicians, ordered the tube feedings stopped. The court also praised the "caring compassion of the respondents and their associates."³

The Missouri Supreme Court reversed the trial court ruling, not on the basis of any factual concerns, but on the assertion that (1) the common law right to refuse treatment cannot apply to incompetent people, (2) a constitu-

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tional right to privacy does not establish a "right to die" or abrogate the State of Missouri's unqualified interest in the preservation of life, and (3) Missouri state law limits a guardian's authority to make such decisions. The radical conclusions of the Missouri Supreme Court conflict with the trend in all other state courts except New York.

Would a living will executed in January 1983 have prevented the current tragedy of Nancy Cruzan's existence? Probably not. First, the Missouri Supreme Court questions the basic premise of living wills. It categorically states, "it is definitionally impossible for a person to make an informed decision—either to consent or to refuse—under hypothetical circumstances; under such circumstances, neither the benefits nor the risks of treatment can be properly weighed or appreciated."³ The court cites state law to assert that the state's unqualified interest in the preservation of life is based on "the principle that life is precious and worthy of preservation without regard to its quality."³ Finally the court notes that the Missouri living will statute specifically excludes nutrition and hydration from procedures that can be considered death-prolonging and that Nancy's condition is not terminal. These two elements—death-prolonging and terminal—are necessary conditions in Missouri for a living will to authorize the withdrawal of treatment. The Missouri Supreme Court decided the state's unqualified interest in life could be countervailed only by "clear and convincing evidence" of Nancy Cruzan's wishes, but made those wishes procedurally impossible to express.

In a narrowly worded majority opinion, Chief Justice Rehnquist cast the US Supreme Court decision: "In this Court, the question is simply and starkly whether the United States Constitution prohibits Missouri from choosing the rule of decision which it did. Missouri requires that evidence of the incompetent's wishes as to the withdrawal of treatment be provided by clear and convincing evidence. . . . The question, then, is whether the United States Constitution forbids the establishment of this procedural requirement by the state. We hold that it does not."⁴ The US Supreme Court did not directly address many of the central tenets of the Missouri court's reasoning, but in a tantalizing passage stated that "for the purposes of this case, it is assumed that a competent person would have a constitutionally protected right to refuse life saving hydration and nutrition"⁴ (emphasis added). In a concurring decision, Justice O'Connor went even further to state, "I agree that a protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions, and that the refusal of artificially delivered food and water is encompassed within that liberty interest."⁴ How one can gain access to this right in Missouri is not clarified.

ADVANCE DIRECTIVES: NEW AND IMPROVED

In an effort to improve on the limitations of traditional living wills, Emanuel and Emanuel⁵ have created what they term a *new comprehensive advance care document*. Twelve medical procedures are presented in the context of four clinical scenarios. The effort is designed to provide greater flexibility and specificity, with the opportunity to request or deny specific procedures given each clinical scenario. While providing greater clarity, the directive could not be completed by the majority of individuals without a medical interpreter. Its use would involve an enormous investment of physician time. Its complexity dramatizes the dilemma noted by the Missouri Supreme Court: Can such discussions of hypothetical situations lead to truly informed decisions? A survey of Arkansas physicians found their major concern about advance directives was that "patients could change their minds about heroic treatment after becoming terminally ill."⁶ Such indecision in the face of suffering is familiar to physicians. A study of women's attitudes toward anesthesia during childbirth found that 1 month before labor they preferred to avoid anesthesia but during active labor their preferences suddenly shifted toward avoiding pain. The author concludes that "patients may make inherently less reliable value assessments of abstract outcomes they have never experienced."⁷

Exclusive focus on details of specific medical procedures may divert physicians from ways in which they can better understand patients' values. Kohn and Menon⁸ have found elderly outpatients and physicians had different frameworks for approaching decisions about life-prolongation issues. While both groups took a pragmatic approach, the elderly weighed more heavily issues of dependency, suffering, and the role of fate and faith. The life-prolongation issue had been faced on an intimate level by nearly every elderly informant interviewed, whereas health professionals responded from a more distant professional perspective.⁸ New, but untested, approaches to help physicians bridge this gap include structured formats for taking a "medical future"⁹ or "a value history."¹⁰

The latest form of advance directive has been the appointment of proxy health care decision makers. Currently 20 states and the District of Columbia have adopted durable power of attorney statutes expressly authorizing the appointment of proxies for making health care decisions. They specify how individuals may identify a person to make decisions about their health care for them if they become no longer competent to decide for themselves. Some legal authorities believe that durable power of attorney statutes, currently available in all 50 states, could encompass health care decisions. Appointment of proxy

health care decision makers allows the dynamic, situation-specific, informed consent process to continue even if the patient becomes unable to participate. Justice O'Connor, in a concurring opinion on the Cruzan case, endorses the "practical wisdom of such a procedure . . . that specifically authorize(s) an individual to appoint a surrogate to make medical decisions."⁴ Surveys have shown that while a minority of citizens have completed living wills, most have discussed their wishes concerning life-prolonging treatment with family members. The New Jersey Supreme Court observed, "Family members are best qualified to make substitute judgments for incompetent patients, not only because of their peculiar grasp of the patient's approach to life, but also because of their special bonds with him or her. . . . It is . . . they who treat the patient as a person, rather than a symbol of a cause."¹¹

ROUTINE DISCUSSION OF ADVANCE HEALTH CARE DIRECTIVES

Surveys have demonstrated that physicians discuss advance health care directives and specific issues, such as do-not-resuscitate orders, with the minority of their patients. Do-not-resuscitate discussions are frequently postponed until patients are so ill, they cannot directly participate.¹² One survey found that such discussion involved family in 86% of the cases, but patients themselves in only 22%.¹³ Advocates of early and more routine discussions point out that such discussions can improve the quality of physician-patient communication, clarify important patient values, and identify areas of agreement or conflict between the physician and patient. These advocates further emphasize studies indicating that many older citizens wish to discuss these issues routinely with their physicians.¹⁴ A survey of Arkansas physicians found wide support for the use of advance directives in clinical practice. Those physicians with the most positive attitudes reported personal experience with advance directives influencing treatment decisions in critical situations. Only 28% of the respondents, however, had ever discussed advance directives with more than 25 patients.⁷

Given the evidence that physicians do not currently discuss these issues routinely, can one assume that physicians are prepared for routine discussions with all patients? No published surveys assess physicians' knowledge about advance health care directive legislation in their own states, but Youngner et al¹⁵ demonstrated significant health care professional confusion about legal definitions of brain death. Little information exists to guide physicians on how to raise these issues in a sensitive and supportive way. Studies of the use of advance directives in the office setting have allowed exclusion of pa-

tients at risk for significant emotional harm, but predictive characteristics have not been identified.¹⁶ Indiscriminate implementation of advance directive discussions will match less carefully prepared physicians and less carefully selected patients. The poor, the uneducated, and the uninsured, groups disenfranchised from the full benefits of health care in America, may misinterpret physicians' motives for initiating discussions of advance directives. Despite generally good intentions, physicians must also recognize the potential conflict of interest in discussing advance directives with patients if they have a financial interest in the decision. A balanced discussion should offer directives for "maximal care"¹⁷ as well as traditional directives designed to stop or limit care.

Supreme Court Justice Brennan, in an eloquent dissenting opinion on the Cruzan case, observes, "Too few people execute living wills or equivalent formal directives for such an evidentiary rule to insure adequately that the wishes of incompetent persons will be honored When a person tells family or close friends that she does not want her life sustained artificially, she is expressing her wishes in the only terms familiar to her . . . to require more is unrealistic, and for all practical purposes, it precludes the rights of patients to forgo life-sustaining treatment."¹⁴ This social reality cannot be changed by even the most conscientious efforts by physicians to discuss advance directives. Only policies at the state and national levels can equitably address this dilemma.

CONCLUSIONS

The need for physicians to improve communication with their patients is clear. Discussions that help physicians understand their patients' values and wishes over the entire spectrum of health care decisions are important. The Cruzan decision has codified the primacy of state law in establishing the legal framework for health care decisions, but many unresolved legal issues remain. All physicians are obligated to understand the living will and durable power of attorney for health care statutes in their respective states. Physicians must prepare to explain and disseminate this information to interested patients.

There are potential errors physicians must avoid in discussing advance health care directives. We must not trivialize these difficult, highly personal discussions by excessive reliance on advance directive forms alone. We must not advocate the use of advance directives as a solution to social or economic issues. We must not focus exclusively on advance directives to limit care. We must not ignore the needs of individuals unlikely to have advance directives: the poor, the uneducated, or members of unique cultural or religious groups.

Physicians have no interest in providing care that is unwanted or not medically indicated. We must educate our patients and ourselves about advance directives. We must encourage patients to discuss these issues with their families. We must overcome our own ambivalence about discussing death. We must educate state legislatures and support state laws designed to protect the rights of incompetent persons. We must continue, despite an uncertain legal environment and imperfect models for advance directives, to honor our patients' wishes and protect their best interests.

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