

The Ethical and Legal Framework for the Decision Not to Resuscitate

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Practicing physicians are frequently faced with the question of whether or not to institute cardiopulmonary resuscitation in case of cardiac or respiratory arrest in a patient in hospital. Medical training has usually not included any systematic analysis of this issue from either an ethical or a legal standpoint. Many physicians may be unaware that ethical and legal principles, as well as professional guidelines, exist to guide such decision making. In practice, physicians make this decision without the benefit of training in ethical analysis. The problem is especially acute in teaching hospitals when young physicians unacquainted with formal ethics or the law must often make decisions emergently. Studies show some discrepancy between ethical and legal principles and the actual decision making by physicians. For this reason, we recommend an approach that will enable physicians to make and implement decisions not to resuscitate that are consistent with current ethical and legal standards.

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AFTER EFFECTIVE METHODS of cardiopulmonary resuscitation (CPR) were developed in the 1960s, it became standard practice to resuscitate any patient in hospital who had no pulse or respirations.^{1,2} By the mid-1970s, however, there was increasing concern that attempting resuscitation of some in-hospital patients might be unduly invasive and offer little hope of altering their prognoses.³ Several studies have shown that the fraction of resuscitated patients who are ultimately discharged from hospital ranges from 8.2% to 24%.^{1,2,4-11} Because of the morbidity of CPR, the cost of subsequent intensive life support and the low long-term survival rate for certain patients, the routine application of these techniques in hospital has been called

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into question. Simultaneously there has been active discussion of a patient's right to die without technological intervention in the setting of terminal illness.¹² The National Conference on Cardiopulmonary Resuscitation and Emergency Cardiac Care has expressed this concern:

The purpose of CPR is the prevention of sudden, unexpected death. CPR is not indicated in certain situations, such as in cases of terminal irreversible illness where death is not unexpected. . . . It has even been suggested that resuscitation in some circumstances may represent a positive violation of a person's right to die with dignity.^{13(p508)}

Physicians frequently face the problem of deciding for which patients it is advisable to withhold CPR. Medical education has in the past not included formal instruction in ethics or case law regarding these issues. As a result, many physicians feel uncomfortable and may not deal effectively with these situations.¹⁴ We review the ethical and legal principles relevant to decisions not to resuscitate (also known as "no-code orders") and recommend a clinical approach to this problem derived from these principles.

Ethical Considerations

The principle of autonomy underlies the tradition, both ethical and legal, that rational persons have a right to self-determination based on their values and life plans. The principle of beneficence underlies physicians' fiduciary charge to do what, in their professional judgment, is best for patients.¹⁵ Treatment that will reverse illness or restore health is considered best for a patient and therefore necessary. In a discussion of the ethics of the no-code orders, reversibility of the underlying illness is thus the basic medical question. Once a clinical judgment is made that a patient's death from the primary disease is inevitable, all treatments become, in a sense, elective.^{15,16}

Competent patients may refuse treatment, including resuscitation, even when a physician feels that the underlying illness is reversible.¹⁷ It is important to determine whether patients are in full command of their judgment when expressing these wishes. Patients who are severely depressed or in pain might wish for death but be thankful for life once the pain or depression is treated. We are not using "competence" in the legal sense of the term, but rather as a description of patients' ability to understand and to judge in a clinical setting. Determination of competence must often be made clinically because legal proceedings are often not possible nor are the subtleties of fluctuating consciousness included in adjudicated competency hearings. A careful examination of mental state, with attention to memory, mood, evidence of judgment and ability to abstract is regarded by many as enough to ascertain whether a person is mentally capable of consenting or refusing, if a question exists. If doubt remains, a psychiatrist should be consulted.¹⁸ When a competent patient requests that resuscitation attempts be withheld, that wish should be honored, even if physician or family disagrees. If a condition is deemed medically

irreversible but the competent patient requests that full resuscitative efforts be made, an order to withhold CPR should not be written. If major disagreements persist between patient and doctor or family, further discussions should ensue, in an attempt to resolve disagreements. In the end, however, the wishes of a competent patient should be honored.¹⁹ If a physician feels that he or she cannot carry out the patient's wishes, it is advisable to help the patient find another provider. Rarely a patient with terminal illness in whom death is imminent may be in such psychologic distress that a discussion of CPR would be inhumane. In such a case, a physician may ethically decide to withhold CPR because it is contraindicated.

Special problems arise in the cases of patients unable to express their wishes because of coma, mental retardation, dementia or other alterations of consciousness caused by acute illness or drugs. Reversible causes of altered mental state should be sought and treated before consideration of an order not to resuscitate. If the mental incapacity cannot be treated, reversibility of the underlying illness, or medical prognosis, should be determined. This assumes a careful diagnostic evaluation, including appropriate consultations, before the decision regarding CPR can be made. A patient's clergyman or the hospital chaplain may be a useful consultant in this situation. Once the diagnosis and prognosis are determined, a physician must be guided by the duty to do those things that are likely to be of benefit to the patient.

Another ethical construct is the distinction between ordinary and extraordinary means to preserve life. Custom and common law require physicians to provide patients with reasonable and ordinary care consistent with contemporary standards of the medical profession. There is no common law duty to provide patients with extraordinary care, and such treatment may be withheld.¹⁶ The distinction between ordinary and extraordinary has been debated at some length in medical, legal and philosophical literature, but one of the clearest accounts remains that of Kelly:

Ordinary means of preserving life are all medicines, treatments, and operations, which offer reasonable hope of benefit for the patient and which can be obtained and used without excessive expense, pain, or other inconvenience. . . .

Extraordinary means of preserving life . . . mean all medicines, treatments, and operations, which cannot be obtained without excessive expense, pain or other inconvenience, or which, if used would not offer a reasonable hope of benefit.^{16(p122)}

Ordinary care, in this sense, does not mean customary care or community standard. Similarly, extraordinary is not synonymous with heroic. Rather, these definitions include nonmedical value considerations in the judgment of what differentiates ordinary versus extraordinary measures. In particular, it is a *patient's* determination of "reasonable" and "excessive" that carries the greatest weight. The controversy about whether CPR constitutes ordinary or extraordinary means of preserving life will be discussed.

Medical futility is a judgment involving considerable

uncertainty. Reference to the literature and consultation with other physicians may help in establishing an accurate prognosis. Conditions that might be considered terminal and irreversible include untreatable cancer, end-stage cardiac, pulmonary or hepatic disease, progressive neurologic disorders and other progressive diseases for which therapy is ineffective and death is imminent.¹⁵ An ethical problem arises because a physician's judgment of medical futility may be confounded by his or her evaluation of a patient's quality of life, value to society, age or cost of care. From an ethical standpoint, advanced age, mental disease or retardation and chronic disease that can be palliated should not, of themselves, be grounds for withholding CPR.¹⁵ Life judged to be of poor quality by an observer may be quite satisfactory to a person living it. Such discrepancies may be especially great if an observer is young, healthy and able-bodied and the patient older, with chronic disease and mental or physical disabilities. In addition, a patient's own evaluation may change over time, as depression resolves or pain is relieved. Some authorities assert that quality of life can only be a decisive factor in the decision to withhold CPR if a patient's wishes cannot be known, the underlying condition is irreversible and all cognitive, sensory and interactive functions are absent or extremely deficient.¹⁵

The decision regarding resuscitation is further complicated by the family's wishes and the costs of medical care. These factors involve a potential conflict of interest. For example, the family may ask that a do-not-resuscitate order be written because of the emotional or financial burden of prolonged illness. Alternatively, they may request heroic measures to appease feelings of guilt or other psychologic needs arising from long-standing interpersonal dynamics. The family's wishes should be considered, but a physician's primary obligation is to the patient's welfare. There is pressure on physicians to function as "gatekeepers," to contain the cost of medical care to society by deciding who should and should not receive expensive care. Opinions on appropriate professional roles in this regard vary.^{15,20} We are persuaded by the argument that a physician caring for an individual patient should offer to that patient those resources that are medically indicated.^{15,16} Decisions limiting access to aggressive or intensive care because of age, diagnosis or other criteria are policy decisions that if necessary should be made on a societal level, where considerations of equity and justice apply.²¹

Legal Considerations

Many discussions of this issue appear in the legal literature, but few cases have actually addressed the question of orders not to resuscitate. One extreme view is that taken by Levin and Levin.²² They argue that a person is not dead immediately after cardiopulmonary arrest in those states that recognize the brain death criterion and, therefore, that CPR initiated immediately after a cardiopulmonary arrest is ordinary and not extraordinary care in those states. They would hold physicians subject to criminal and civil liability for

depriving their patients of ordinary means of preserving life if they order that CPR be withheld without a patient's signed informed consent. This view is not generally accepted, however. Other legal authorities consider CPR to constitute extraordinary care in the case of a terminally ill patient and to fall outside the realm of care that a physician is required to provide.²³

We have chosen three cases to illustrate the impact of court decisions upon this issue. Only the last, the case of Shirley Dinnerstein, directly addresses the legality of do-not-resuscitate orders. The other two cases have established relevant legal principles.

In 1976, the family of Karen Quinlan, a young woman in chronic vegetative state but being maintained on a ventilator, asked the court whether the patient could be disconnected from the ventilator. The New Jersey Supreme Judicial Court ruled that the ventilator support could be discontinued. This decision (1) affirmed the patient's constitutional right to refuse life-sustaining therapy, based on the right to privacy; (2) established the medical prognosis criterion—that is, the ventilator could be discontinued if there was no reasonable possibility of the patient returning to a cognitive, sapient state, and (3) designated the physician, the family and the guardian as the appropriate agents to apply the medical criterion. The court further stated that if the hospital ethics committee concurred with the prognosis, all parties involved would be immune from civil and criminal liability.^{24,25}

The following year, a Massachusetts Supreme Judicial Court decision caused considerable controversy within the medical community. Joseph Saikewicz, a 67-year-old mentally retarded resident of a Massachusetts state hospital was found to have acute myeloblastic monocytic leukemia. He was a ward of the state. The court was asked whether chemotherapy should be administered to this person unable to give informed consent. The ruling was that chemotherapy, a life-prolonging but not life-saving treatment, should be withheld in this case. The decision affirmed the right of competent persons to refuse treatment, but stated that when a patient is terminally ill and incompetent, therapeutic decisions should be based on a judgment of what the patient would have wanted (substituted judgment). It upheld the withholding of extraordinary measures when there is no hope of recovery from the illness. Most controversial was its naming of the state's probate courts, rather than physicians or families, as the proper decision-making agents in such cases.²⁶⁻²⁸ A number of articles in the medical literature criticized this mandate for court involvement in such therapy decisions.²⁹⁻³³ The legality of ordering that resuscitation be withheld without a court sanction was unclear after the Saikewicz decision.³⁴ The following year, a case filed in Massachusetts tested that question.

Shirley Dinnerstein, a 67-year-old woman who resided in a nursing home, had progressive Alzheimer's dementia, a left hemiparesis as a result of a stroke, hypertension and coronary artery disease. She suffered from incontinence of urine and stool and inability to

swallow without aspirating. Her personal physician recommended that she not be resuscitated in the event of a cardiopulmonary arrest. The physician and the patient's family asked the court whether a doctor might enter a "no code" order in a chart without judicial authorization, and if authorization were required, that it be given in her case. The court ruled that do-not-resuscitate orders may be written without approval of probate court in the case of an incompetent, terminally ill patient, and that the decision could be made by the physician and family. In the words of the court, "the law does not prohibit a course of medical treatment which excludes attempts at resuscitation in the event of cardiac or respiratory arrest and the validity of an order to that effect does not depend on prior judicial approval."³⁵ Some authorities insist that because of this ruling the family must agree to a "no code" order for an incompetent patient.³⁶ The Dinnerstein case is the only one to date specifically addressing the legality of no-code orders³⁷ and it has not been overturned. A case currently being investigated by a grand jury in New York challenges the withholding of CPR from two elderly in-hospital patients (R. Sullivan, "Medical aspects of decision making in resuscitation and life support," *NY Times*, September 19, 1982, p 1).

Establishing Guidelines

A physician is expected to exercise "the degree and skill of the average qualified practitioner, taking into account advances in the profession."³⁸ Uncertain about how the courts will treat do-not-resuscitate orders in the future, many medical groups, including hospitals and medical societies, have recently established formal guidelines for decisions not to resuscitate. These guidelines vary from institution to institution, but consistently address three issues: the competent patient, the incompetent patient and the procedure for implementing the decision.³⁸⁻⁴¹ Most guidelines affirm the need to follow a competent patient's wishes. They differ in the approach to the incompetent patient—that is, some hospitals require department chairpersons or hospital committees to be involved in the decision. Most require family concurrence if a patient is incompetent, but some state that the family's wishes are not legally binding unless a family member is legal guardian or conservator. Almost all guidelines require documentation in the progress notes of the factors leading to the decision, as well as conversations with consultants and family. All require a written doctor's order to withhold CPR.

The approach to orders to not resuscitate for physicians in training is slightly different than in practice. In a teaching hospital, where many providers care for a patient, responsibility for decision making is often diffuse. Guidelines developed for the University of Minnesota teaching hospitals recognize this distinction and require that an attending physician or chief resident be involved in the decision not to resuscitate.⁴⁰

One common practice has been for physicians to tell nurses that a person is not to be resuscitated, but not

to write it as an order. This presents nurses with a significant communication responsibility, and no legal documentation. The "slow code," as it is called, poses a related problem for nurses. The clinician feels that resuscitation attempts would not benefit a patient, but is unwilling to make an explicit statement to that effect. The nursing staff is told to page the physician immediately rather than begin CPR or announce a full code. If nurses are not given a do-not-resuscitate order, they must initiate resuscitation attempts.⁴² The likelihood of a good outcome is severely decreased by any delay in beginning CPR, thus a "slow code" cannot be justified. There is a substantial amount of literature on nursing malpractice and ethics establishing reasons why such practices are no longer acceptable in many hospitals.

Physician Factors

Although we may be guided by a sincere desire to follow a patient's stated or presumed wishes, there are many pressures that may interfere with adherence to our principles. It is often difficult to discuss a bleak prognosis with a patient. It is even more difficult to talk about a person's imminent death and to ask what his or her feelings are regarding CPR, defibrillation, intubation and mechanical ventilation. Our discomfort with such discussions may prevent us from exploring a patient's wishes.¹⁸ Similar inhibitions may exist in discussing these questions with a family if the patient is unable to express his or her wishes. Strong feelings either for or against a no-code decision may be expressed by nursing staff or other people involved in caring for a patient.¹⁸ Such feelings may be expressed verbally or nonverbally, and may influence our decision making. A physician may be tempted to withhold resuscitation attempts without consulting patient, family or other physicians.¹⁸ Older patients and those with functional impairments may be more likely to receive a do-not-resuscitate order, as suggested by studies of physician behavior.^{11,43,44} (See also the article by Uhlmann, McDonald and Inui in this mini-symposium.)

In another study decisions to discontinue CPR in emergency rooms were examined, in which 78 emergency room physicians were polled with case studies. Using age alone as a criterion, 4% of the respondents would cease CPR if the patient were older than 65 years and 9% would stop if the patient were older than 75 years of age. Regardless of diagnosis, if a patient were transferred from a nursing home, 18% would stop CPR. If a patient were senile, demented or mentally retarded, 54% would discontinue CPR. If a patient were described as having "end-stage" chronic obstructive pulmonary disease or malignancy, no further details given, 87% would stop.¹¹

Pearlman and co-workers used a case study describing acute respiratory deterioration in an elderly male nursing home patient with chronic obstructive pulmonary disease to study the factors influencing physicians to decide for or against intubation. They found that whether they chose to intubate or not, respondents cited the following considerations in decreasing order of

frequency: the nature of the acute problem; the patient's quality of life; the natural history of the disease; personal attitudes of the physician; inadequate information; previous courses in hospital; estimated survival time if intubated; impact of treatment on patient, family or society, and interpretation of patient and family treatment desires. Those who chose to intubate estimated a significantly longer life span than nonintubators. House staff withheld intubation significantly more frequently than did private practitioners.⁴³

In a classic sociologic study, by polling 3,000 physicians with both case histories and attitude questions, Crane tested the hypothesis that physicians use information other than strictly physiologic criteria in deciding how aggressively to treat critically ill patients. This investigator found that age, the probability of mental or physical disability as a result of illness and the wishes of a patient all significantly influenced physicians to pursue a less aggressive course. In Crane's opinion, these findings represented a disparity between the traditional ethic of basing decisions only on prognostic biomedical criteria and the actual behavior of physicians. She recommended that guidelines be developed that outline both physiologic and social criteria for withholding or withdrawing treatment in specified conditions.⁴⁴

The Symbolic Meaning of a Do-Not-Resuscitate Order

There is a tendency to equate deciding not to give CPR with deciding to stop all vigorous medical therapy directed at reversible processes. Some intensive care units have a policy not to accept any patients who carry do-not-resuscitate orders. A decision about resuscitation attempts can be made on the basis of the poor prognosis inherent after cardiopulmonary arrest in that patient. This does not necessarily imply that other aggressive measures are not indicated as long as a patient lives. At times it may be appropriate to withhold antibiotics or transfusions, but these decisions are distinct from the decision to withhold CPR. It also may be indicated in some patients to attempt certain limited measures in the event of cardiac arrest, but to desist promptly if they are not effective. The reversal of a relatively simple arrhythmia has a very different prognosis than more profound systems failure. This is not the same as the "slow code" because those measures used are instituted promptly in a vigorous manner and with a clear endpoint.

Even in dying patients, a do-not-resuscitate order does not imply less attentive care. One of the most unfortunate problems surrounding these decisions is the tendency of physicians to feel that a meaningful role is finished when we have decided to cease aggressive medical therapy. In fact, challenging therapeutic issues still exist. Orders should be reviewed and revised to maximize patient comfort. This may include intravenously administering fluids or giving oxygen or analgesia, or other interventions. Our involvement should be intensified by providing comfort measures

TABLE 1.—A Stepwise Approach to Deciding Not to Resuscitate

If patient is competent, honor patient's wishes

If patient is unable to understand condition or express wishes

Establish likelihood of reversing illness

 If reversible, no do-not-resuscitate order

 If prognosis unclear, no do-not-resuscitate order

 If illness irreversible, a do-not-resuscitate order may be considered

Discuss decision with other physicians with expertise in establishing prognosis; physicians in training should discuss such decisions with attending physician or chief resident

Discuss decision with family, if available

If primary physician, consultants and family agree, a do-not-resuscitate order may be written; if significant disagreement exists, further discussions are indicated before recording a do-not-resuscitate order

If strong disagreement persists, a hospital ethics committee may be helpful in reaching a resolution

TABLE 2.—Implementing a Decision Not to Resuscitate

In progress notes, document the factors considered in the decision and the content of discussions with family and consultants

Write a doctor's order in the patient chart

Discuss the decision and the reasons for it with all staff involved in the care of the patient

Continue appropriate medical therapy and comfort measures

Reconsider the decision at regular intervals; the prognosis may change and, with it, a patient's code status

and by not abandoning a patient and family at a time of suffering and loss.

Conclusions and Recommendations

Based on a review of the ethical and legal literature on orders not to resuscitate, we have formulated a stepwise approach for physicians faced with such decisions (Table 1). A competent patient's wishes should be honored, under all circumstances, even when the physician disagrees. If a patient cannot express competent wishes, the physician must consider the reversibility of the illness. If the illness is reversible, a no-code order is neither ethical nor legal. If the prognosis is unclear, ethical and legal standards direct that no order should be written. Only when the process is irreversible does it become ethical to consider an order to not resuscitate. Under these circumstances, a physician must discuss the decision with other physicians. Physicians in training should consult with an attending physician or chief resident. These consultations are essential to verify prognosis and re-evaluate decisions that may not be in a patient's best interest. The family's wishes should be sought. If all agree, a do-not-resuscitate order may be written. If disagreement exists, the discussion should continue. If disagreement persists between a physician and family, it is in general prudent not to write a do-not-resuscitate order, despite the opinion of some authors who consider the family's

wishes in this instance to be less binding than the wishes of a competent patient.⁴⁵

Some philosophers feel that physicians are not qualified to make these critical and complex ethical decisions, and would defer to ethics committees or to the courts.⁴⁶ While *Dinnerstein* established that physician and family concurrence justifies such a decision on behalf of a clearly incompetent patient, subsequent challenges to this precedent may occur. In the most difficult cases—either of disagreement between family and physician, or of questionable patient competence—there is no consistent legal recommendation. If significant uncertainty surrounds the decision for a particular patient, it is ethically proper and consistent with medical tradition to err on the side of attempting resuscitation.^{17,25} In especially problematic cases, or where a patient is a ward of the state, judicial intervention may be warranted.

The implementation of a no-code order must also follow ethical and legal guidelines (Table 2). It is essential to document the factors leading to the decision, as well as the content of discussions with the family and consultants in the progress notes. An order should be written. It is important to discuss the decision and the reasons for it with all staff involved in caring for the patient. The distinction between withholding CPR and withholding other forms of therapy should be addressed case by case. An order not to resuscitate should be re-evaluated at reasonable intervals. Patients may unexpectedly improve, and a no-code order may need to be withdrawn.

Once the decision has been made not to attempt resuscitation and to allow a terminal illness to take its course, a significant challenge remains to a physician: "Even when we decide that our advanced technologies are no longer indicated, we can still agree that certain extreme measures are indicated—extreme responsibility, extraordinary sensitivity, heroic compassion."^{18(p574)}

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Medical Practice Questions

EDITOR'S NOTE: From time to time medical practice questions from organizations with a legitimate interest in the information are referred to the Scientific Board by the Quality Care Review Commission of the California Medical Association. The opinions offered are based on training, experience and literature reviewed by specialists. These opinions are, however, informational only and should not be interpreted as directives, instructions or policy statements.

Noninvasive Muscle Stimulators

QUESTION:

Is the home use of noninvasive muscle stimulators for the prevention of muscle atrophy considered accepted medical practice?

OPINION:

In the opinion of the Scientific Advisory Panels on Neurology and Physical Medicine and Rehabilitation, noninvasive muscle stimulation is of proved value in retarding atrophy and promoting nerve regeneration. This procedure has been accepted medical practice for many years for such conditions as Guillain-Barré syndrome, facial nerve palsy and incomplete lesions of peripheral nerves. Its use to prevent muscle atrophy in patients with multiple sclerosis, spinal cord injuries and head injuries is still considered investigational. Whether noninvasive muscle stimulation actually improves long-term functional recovery is still undetermined.

Home use of noninvasive muscle stimulators by persons other than physicians or therapists raises some potential problems, such as the hazards of accidental electrical injury or damage to tissue. However, home use of noninvasive muscle stimulator can be considered accepted medical practice if the person operating the device is instructed in its proper use by a physician or a therapist knowledgeable in the motor points of muscles.