New York Times
October 10, 2006

The Last Word on the Last Breath

By JAN HOFFMAN

The patient, only 35, had been in a persistent vegetative state for 15 years. Recently, he had developed septic bedsores and pneumonia. His kidneys were failing, and despite the feeding tube, he was losing weight. Now he was in cardiac arrest. He was dying.

But the young staff doctor had no choice. The patient's relatives, convinced that the man could communicate, had insisted that all revival efforts be made. So the doctor gave the patient a few mouth-to-mouth breaths, climbed on the bed and began vigorous chest compressions, trying cardiopulmonary resuscitation.

The patient was intubated, shocked with electric paddles and injected with epinephrine. Blood spurted as a central line was inserted into the large vein in his groin to administer medicine and fluids. EKG electrodes were placed on his arms and legs: streams of paper spilled over the floor, as the hospital room filled with people and shouted orders.

After 15 minutes, the doctors called the time of death.

"Kneeling on that bed, doing CPR, felt not only pointless, but like I was administering final blows to someone who had already had a hard enough life," said the doctor, Daniel Sulmasy, now a New York internist, medical ethicist and Franciscan friar, recalling this experience from his internship. "Why was I forced to crack this person's ribs? Why couldn't we have let the patient die in peace?"

Extreme cases like this one are rare. But the question of who has final say over whether CPR should be attempted on a gravely ill patient — the doctor, the patient or the patient's representative — is live and unsettled in law and medicine.

Many doctors believe that their medical judgment about whether CPR will be effective in a given patient's case, and their knowledge of the havoc it can wreak on a dying body, should prevail. But a patient's representative, who is often a relative, may believe that every medical option should be exercised and that a miracle could be just a chest compression away. And patients' families, spurred on by TV medical dramas, often mistakenly believe that CPR is almost always effective — a notion emphatically disproved by studies.

The debate over who makes the decision raises fundamental challenges to medical integrity as well as patients' rights and can rub feelings raw for all concerned. Hospitals around the country and some state legislatures have wrestled with how to balance these competing values, reaching different conclusions.

New York is one of the few states with a law that directly addresses resuscitation orders. In New York, even when a doctor believes that CPR would be medically futile, if the patient is incapable of indicating a preference for or against it and the patient's designated representative insists it be performed, the physician must ultimately go to court to prevail. Texas, which has a complex advance directive law that includes checks and balances, ultimately sides with physicians, immunizing them from litigation.

Hawaii passed legislation this year giving great weight to a patient's "comfort care" document, which specifies the patient's preferences in dire medical situations. Nonetheless, if the patient has indicated no resuscitation but "the provider's own conscience" dictates otherwise, a medical professional may override the document.

"The black and white of the law has significant limitations in the emotional gray area of decision making around serious illness and dying," said William H. Colby, a lawyer who represented the family of Nancy Cruzan, a patient in a vegetative state whose parents won the right to refuse medical treatment for her. Mr. Colby is the author of "Unplugged: Reclaiming Our Right to Die in America."

One side effect of state legislation has been confusion. A 2004 survey of Oklahoma judges found that many felt uncomfortable and undereducated about their state's laws about resuscitation.

In recent years, many hospitals have quietly developed policies underscoring that doctors, not family members, should have the final authority to make these medical decisions.

But to pre-empt such clashes and elicit the patient's wishes, a simple document developed in Oregon about treatments like CPR is being increasingly used in at least 14 states. When elderly invalids are rushed to the hospital, usually in no condition to discuss resuscitation, the bright pink form called Physician Orders for Life-Sustaining Treatment, or Polst, travels with them and can stand in as a doctor's order.

Many physicians and patient advocates say that casting these end-of-life conversations as adversarial needlessly provokes tensions. Instead, they say, the focus should be on achieving a goal of end-stage care that both sides can agree on.

Typically, an order on a chart is a doctor's green light to staff: give this medicine, do this therapy. A do not resuscitate, or D.N.R., order is a red light, an order not to do something. Such an order is needed because it is counterintuitive: the assumption in health care is that everyone who goes into cardiac arrest would want to be revived. Even though the success rate of CPR is poor and the likelihood great that its impact will be more burdensome than beneficial, health care providers need explicit permission not to try it.

Unlike other life-sustaining measures, like feeding and breathing tubes, which afford families and physicians a bigger window of time to make decisions, CPR is an emergency procedure. That is one reason hospitals want a D.N.R. order in place if a patient suffers a cardiac arrest.

Patients can choose not to be resuscitated, and their informed consent to a D.N.R. order is generally inviolate. But friction arises when a patient is near death and has not been interviewed about resuscitation and the doctors need to obtain that consent from the patient's representative, usually a family member. Doctors initiate these painful conversations when they believe a resuscitation effort would be "medically futile," a term whose definition is debated widely in medical and bioethics journals.

Doctors can fumble this most delicate of conversations. "With gravely ill patients, doctors sometimes foster these D.N.R. disputes by saying that a patient is getting better," said Dr. Joseph J. Fins, author of "A Palliative Ethic of Care: Clinical Wisdom at Life's End." "We focus on the minutiae of one organ system at a time, fostering hope when there is nothing but the grim reality that the patient will die. Then all of a sudden we tell the family it's futile and we're surprised that they're surprised."

Jane Greenlaw, an ethicist at the University of Rochester Medical Center, said that in New York, if neither a patient nor a representative has consented to a D.N.R. order, medical personnel have to try to resuscitate patients "because you don't have permission not to."

But she said: "It's the medical person's decision about when it's time to stop. That person can say after 15 minutes, 'This is over, we've tried.' And to some families, that means everything."

Families often believe that consenting to a D.N.R. order implies they are giving up on their loved one, signing a death warrant, turning their backs on hope. They can be haunted by guilt and a fear that they have betrayed their religious faith.

One woman, who did not want to be identified out of concern for family privacy, felt trapped between her medical knowledge and her family's wishes. Last year, she was the health care agent for her father, who was treated for end-stage cancer of the larynx in the intensive care unit at New York-Presbyterian Hospital/Columbia. He developed acute respiratory disease. The cancer had metastasized: tumors were punching bulges in his forehead. He was too sick to endure more chemotherapy or radiation. After he languished for nearly two months in the intensive care unit, the doctors approached the woman with a D.N.R. consent form.

The woman, a nurse in the hospital's coronary care unit, understood the implications fully. But she also had to face her grieving mother.

"My mom thought that if you'd sign the D.N.R., we would be abandoning him," she said. "My mom kept saying, 'There will be a miracle, there will be a miracle.' I felt caught in between. I am a nurse, but I am also a daughter."

She had seen chest compressions done many times. “I knew it would break my dad’s bones and that he wouldn’t make it,” she said. “The decision was so hard for me.”

After five and a half months in intensive care, her father slipped into a coma and his organs began to shut down. As doctors rushed to his bedside, the family stopped them, saying, “Enough,” and then, “Thank you for all you’ve done.” He died without a D.N.R. order in place.

The widespread misunderstanding about CPR itself can make a family’s agony worse. The technique, which has been an accepted medical procedure for about 40 years, can be successful in patients who have a sudden, unexpected heart attack or severe respiratory distress. But it was not intended to be used routinely for very sick patients, for whom cardiac arrest is expected. Some studies show that the long-term survival for hospitalized patients given CPR is about 15 percent; some find even smaller percentages. But according to a 1996 article in The New England Journal of Medicine, the long-term survival rate on TV medical dramas for patients given CPR was 67 percent.

The need for policies dealing with D.N.R. orders began to be felt in the late 1980’s. CPR-related techniques had become increasingly sophisticated. Running a code, as the process is called, became more protracted. End-of-life conundrums, ethical and legal, proliferated. At the same time, with the rise of the patients’ rights movement and its concomitant distrust of paternalistic doctors, patients and their families wanted a greater voice in decision-making.

In New York, doctors at one hospital had a casual way of indicating to staff, without informing families, which patients should not be resuscitated : purple stickers were affixed to their charts. Occasionally, stickers were placed on the wrong charts or fell off. After these and other stories came to light, New York passed a law in 1987 that addressed the conditions under which a physician could write a D.N.R. order. Patient consent was essential.

The statute did say that if resuscitation was “medically futile” and no representative could be found to consent to the D.N.R. order, a doctor could write one, if another doctor also signed it. Under these narrow circumstances, a doctor’s judgment that CPR would be useless was sufficient. But what if a “medically futile” patient’s decision-maker insisted that CPR be performed anyway? Could a doctor’s judgment prevail?

In 2003, an upstate New York hospital, seeking policy guidance, put the question to Attorney General Eliot Spitzer. Mr. Spitzer interpreted the state law to mean that even in these cases, a doctor could not enter a D.N.R. order over the objections of a family. A doctor’s only recourse was to proceed to mediation, and then, if necessary, to court.

“We have gone from one extreme to the other,” said Dr. Kenneth Prager, chief of medical ethics at New York-Presbyterian/Columbia, “from physicians making unilateral decisions to the situation where the family and the patient have all control.”

At the same time the New York statute was being enacted, stories around the country emerged of doctors going through the motions of a code for the benefit of a family. Hospital slang like “slow code” (to suggest a leisurely walk to the bedside), “Hollywood code” (in deference to TV hospital programs) or “light blue code” (an allusion to code blue, the term for a cardiac arrest resuscitation) became public.

In reaction, states passed advanced-care directive laws and hospitals drafted new ethics policies.

Certainly the goal of the legislation was to create dignity and transparency in end-of-life decisions. And in a litigation-rich era, the policies and laws were also intended to help insulate doctors from lawsuits.

Dr. Robert V. Brody, chairman of the ethics committee at San Francisco General Hospital, where the policy ultimately favors the doctor’s decision, says the task of performing CPR usually falls to the younger resident staff at a hospital rather than to an attending physician. The burden is mostly felt, he said, at smaller community hospitals, that may not have the deep pockets to withstand a lawsuit. “Nurses and doctors hate it,” Dr. Brody said. “It’s a mess.”

George Annas, a health law expert at Boston University Law School, said that in such cases, doctors wound up doing what they considered to be forced bad practice.

“We’re back to the days of light blue, slow code, Hollywood codes,” Professor Annas said.

He added that a doctor could not be successfully sued for refusing to administer CPR if the procedure would have violated good medical practice.

Dr. Sulmasy, chief ethicist at St. Vincent’s Manhattan Hospital and New York Medical College, studied a half-dozen cases in which the decision makers for a dying patient refused to consent to a D.N.R. order.

“We measured the stress of making a D.N.R. decision for someone else and found it was like someone surviving a house fire,” he said. “Before the attorney general’s opinion, we could say to some families, ‘This is it, your loved one is dying.’ And they would say, ‘All right, it’s your decision. As long as it’s not on me.’ And they could get on with the task of mourning.”

Dr. Fins thinks that the focus on D.N.R. orders is in itself misguided.

“D.N.R. is a game plan for the last 15 minutes of your life,” he said. “By planning for those last 15 minutes, we’re distorting priorities. Instead of talking about futility, we should be discussing what has utility, like pain management, comfort, closure. Recasting the discussion has led to turning irresolvable dilemmas into problems that can be addressed.”