

Communicating About Resuscitation: Problems And Prospects

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Abstract: Background: The Patient Self-Determination Act of 1991 implicitly encourages physicians to discuss advance directives and no-code orders with their patients. The medical literature to date, however, has done little to place resuscitative decision making in the context of how physicians, patients, and families communicate with one another. This paper investigates how interactions between involved parties affect the process and outcome of this decision making.

Methods: Participant observation and open-ended interviews were conducted with patients, their families, resident physicians, and family medicine faculty members.

Results: This report describes three social and cultural issues that commonly influence and shape the process of do-not-resuscitate decision making: judging competency and capacity, dealing with uncertainty, and recognizing attitudes toward death.

Conclusions: Improved understanding of the communicative process can facilitate the establishment of meaningful, therapeutic alliances between physicians, patients, and families at an influential juncture in the family life cycle. (J Am Board Fam Pract 1993; 6:137-141.)

With the December 1991 enactment of the Patient Self-Determination Act,¹ medical care institutions are required to inform incoming patients of their rights to forgo life-sustaining treatments. This bill implicitly encourages physicians to discuss advance directives and no-code orders with their patients. The medical literature to date, however, has failed to place resuscitative decision making in the context of how physicians, patients, and families actually communicate with one another,²⁻⁴ which leaves physicians with little guidance in addressing this complex interaction.

While bioethicists have previously offered guidelines regarding resuscitative decision making^{5,6} and the conduct of discussions,⁷⁻⁹ these guidelines are normative, describing how things should be done rather than reviewing how they are done in actual practice. Researchers have focused on quantitative assessments of do-not-resuscitate decision making using survey questionnaires,¹⁰⁻¹⁴ descriptive epidemiology,¹⁵⁻¹⁹ hypothetical sce-

narios,^{20,21} and meta-analyses.²² What ethicists and researchers alike have neglected is how the interaction between involved parties affects the process and outcome of this decision making.

In my experience as a community physician, researcher, and residency faculty member, I have witnessed a variety of issues, among them personal histories and values, social expectations, human emotions, and individual coping behaviors, that influence and shape communication about resuscitation. Three issues in particular recur frequently: judging competency, dealing with uncertainty and ambiguity, and attitudes toward death and dying. Each of these issues is illustrated below, using responses to open-ended interviews that I conducted with patients, their families, resident physicians, and family medicine faculty members involved in end-of-life discussions.

Judging Competency

Competency is of primary concern for physicians when discussing resuscitation. Traditionally patients are competent to make specific treatment decisions when they are aware of their current medical situation, understand the proposed treatments, including potential risks and benefits, and are able to discuss the pertinent issues and arrive at a decision.²³ In their day-to-day work, however, physicians frequently translate

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the determination of competency into one question: Can patients be trusted to make informed decisions that are rational?

Even before they consider the issue of mental status as a starting point,²⁴ physicians often use a variety of subjective means to determine competency. Physicians can evaluate the patient's physical status and actions, e.g., whether the patient looks alert or restless, or they can evaluate whether the patient responds appropriately to inquiries. They might assess the patient in relation to situational information, such as the patient's response to a physician walking into the room, or note whether the patient agrees with them. A consulting psychiatrist once stated:

As long as patients agree with clinicians, they're competent. I've never been called to question a patient's competency when the patient agrees with the clinician. I've been called all the time when the patient disagrees.

Physicians also assess whether a patient's coping style is both consistent with previous behavior and appropriate for the situation.²⁵ In one example, resident physicians readily discussed code status with a lonely 79-year-old Italian-speaking immigrant who seemed to withdraw emotionally and hope for death upon his admission for treatment of pneumonia. His capitulation to disease mimicked his long-present feelings of loss regarding homeland and family. In contrast, these same physicians declined to bring up resuscitative issues with a 65-year-old man with a long history of progressive multiple sclerosis who was currently depressed about his admission for treatment of pneumonia. He had previously expressed that he was "not unhappy" with his life in the face of chronic disability. The resident physicians believed any decision about resuscitation at this time would not be valid; the patient was judged to lack capacity based on an acute depression.

The initial assessment of competency is based on the interaction between physician and patient. This interaction is full of nuances, evidenced by a 2nd-year resident's statement:

Part of judging competency is intuition. Competency is like a symptom complex that you put together in your head, because you've seen other things, and you make the diagnosis. In terms of code status, competency is judged in the context of the situation at the time it's obtained.

Even when patients have the cognitive abilities to suggest that they are competent, the next step physicians face is whether these patients can make rational decisions. When discussing resuscitation, however, rational goals can be replaced by emotive desires that patients and families might not be able to spell out logically. Physicians looking for rational plans and goals could find poorly articulated wishes instead.

Dealing with Uncertainty and Ambiguity

Communication and decision making about resuscitation often provoke anxiety in patients and families. Conflicting emotions and beliefs can emerge, fostering difficulties because of uncertainty. Dealing with uncertainty also causes problems for physicians.²⁶ While "good facts make good ethics,"²⁷ giving meaning to those facts in the context of the patient's situation is often difficult. For example, the typical use of percentages to give prognoses does little to diminish uncertainty. As one colleague described:

Lots of physicians talk to patients about resuscitation using numbers. Ten percent this, 50 percent that. We use numbers to sway a patient into one kind of therapy or another. It's easy to do, because numbers are "just the facts." They are part of the scientific method in which we are trained. Only it's not exactly natural. When you're walking down the street you don't think, "Well, my chance today of getting struck by lightning is 1 percent."

Many times diagnoses are presumptive. Final pathological conditions are not determined until autopsy. Thus with many hospitalized patients, physicians discuss resuscitation without having the security of an absolute prognosis. In teaching hospitals, where patients and physicians often know little of each other, this uncertainty is exacerbated. Environment and time are influential factors that contribute to the perception of uncertainty in resuscitative decision making.

Even within discussions ambiguity influences physicians' behavior patterns. These are often conditioned by patients' responses, just as patients' behaviors are conditioned by physicians' responses. One intern related the problems he faced when discussing cardiopulmonary resuscitation with the husband of an incompetent, apparently terminal patient:

I couldn't tell whether he was just reserved or whether there was denial or whether he didn't understand what I was saying. Usually when I talk to someone, I feel like I can read their responses when I say "serious illness," or "what would you like us to do?" My first reaction is not to come out and say, "If your wife's heart stops, do you want us to shock her chest?" That's something that I feel I don't have to do, because it's very, very blunt. Usually people pick up on the other cues. They will have already thought about it and say, "Oh, you know, my grandmother was on a ventilator, I never want to be on one." Or, "Don't shock her chest." Or they'll say, "Do everything you can." In this case, I felt like he didn't pick up on some of the earlier cues, and so I had to become progressively more explicit.

This kind of frustration often results because physicians, patients, and families fail to reach a common ground during their discussion. Why? First, whereas physicians talk about the biomedical aspects of disease, patients are concerned about the experiential aspects of illness and qualitative dimensions of health.²⁸ Second, just as the facts that physicians consider are tempered by their own experiences with dying patients and resuscitative measures, patients also have prototypical scenarios from their experiences that sketch their goals for resuscitative decision making. For example, in an interview shortly after his physician asked whether he would want cardiopulmonary resuscitation should the need arise, a 68-year-old man hospitalized for arrhythmias and syncope responded:

Her question surprised me. It came from left field. When the doctor mentioned resuscitation, what immediately came to my mind was when they took me to Farmdale Hospital 20 years ago. I was unconscious, and they had to use the paddles when I got in the door to the emergency room. They called it a code red or something, and I got the paddles. This friend of mine was an orderly on the team. The first thing I can remember was him saying, "Come on, Tom!" He was slapping me. "You can make it, come on, you can beat it!" I've already seen the tunnel ahead of me.

Third, while physicians communicate about mechanistic aspects of resuscitation, including intubation, defibrillation, and chest compression, patients can base equally rational decisions on other factors, such as perceived potential suffering. The focus on objectified knowledge could inhibit involved parties from communicating important emotional issues. Fourth, ambiguity in

communication arises because of conflicts about who should be making the decision. A paradox arises when physicians, whose goal it is to maintain patients in health, want nothing to do with their patients' deaths. Conversely, patients often abdicate responsibility to physicians by requesting them to "do everything possible."

Attitudes toward Death and Dying

Patients and physicians face conflicts in their decision making about resuscitation because of their perceptions of death. Each party might wish to guarantee "a good death," but these perceptions might differ from one party to another. Each could, as well, have difficulty translating his or her image of an appropriate death to the other.

Individuals involved in discussions about resuscitation could be concerned that their decisions — based on personal beliefs and values — will later be judged by others. For example, families might assume apologetic roles and give up decision-making responsibility in an effort to mask years of unmet needs or feelings of guilt and remorse. Asked why he wanted physicians to pursue full resuscitative measures for his wife, one husband responded:

I don't think I could let her die here. I would feel responsible for her death. I blame myself for her condition, for her smoking and her drinking. I think all my 5 children would blame me, too. I just want her to get home so I won't be blamed.

Physicians, for their part, might not only be concerned about caring for a patient while alive, they might also feel responsible for how the patient dies. Management of disease can replace either restoration of health or satisfaction in dying as a primary goal. As one resident physician noted:

If a patient who has a chronic illness and a protracted hospitalization dies with a potassium of 3.0 mEq/L, there is a subtle attitude that the physician is supposed to feel guilty, an attitude of blame. Everybody works so that he or she can't be blamed for a death.

The symptoms and signs of impending death have deep cultural meanings to all parties involved, often evoking images of rescue or assault and considerations of economic, cultural, or moral costs. These symptoms and signs become symbols that guide perceptions and patterns of decision

making about resuscitation. The symbols vary from society to society: dying with or without pain, fever, thirst, suffering, or grief^{29,30}; dying only after a fight to stay alive; dying "naturally."³¹ Recognizing these symbols is an important facet of communication when the physician is dealing with patient and family, especially where the spirit of the dead is taken seriously.

Summary

Discussing do-not-resuscitate orders and advance directives with patients and families is not a simple procedure. The Patient Self-Determination Act does not ameliorate the difficulties involved. It does, however, do three things. First, this act forces family physicians to consider their roles in the determination of code statuses by prodding them to accept the responsibility for bringing up resuscitative issues early. Second, it prompts physicians to look at their patients' medical records and determine whether previous directives have been made. Third, given the emphasis of the act on patient involvement in choosing treatment options, the act encourages physicians to listen to the values that patients bring to discussions about resuscitative efforts and invites the physicians to share their own. Asking "Have you signed a living will or a durable power of attorney for health care?" is one strategy physicians can easily use to broach the topic with patients.³²

To fulfill the promise of the Patient Self-Determination Act, bioethicists and clinician-researchers need to hold up for scrutiny the actual interactions that take place. Investigation into patterns of discourse and the situational factors that affect decision making about resuscitation is important not only to break down the barriers that exist between physicians and patients but also to foster recognition of exemplary methods for sharing information, values, and emotions. Improved understanding of the communicative process can facilitate the establishment of meaningful, therapeutic alliances among physicians, patients, and families at an influential juncture in the family life cycle.

Just as they attend to different tasks in dealing with chronic disability,³³ physicians, patients, and families focus on different agendas in the context of decision making about resuscitation. Physicians primarily concentrate on medical agendas: they inform patients about prognoses and possible

therapeutic interventions in anticipation of gaining their patients' consent for clinical plans. Patients work to reconcile their current physical statuses with the perceptions they hold about the end of life. They and their families attempt to ensure an appropriate ending to the stories of their lives. These tasks are undertaken at the same time that other work is going on, developing trust, communicating uncertainty, and establishing role relationships within the interaction.

How physicians, patients, and families approach these demands is determined by personal and social factors. Participants in discussions about resuscitation bring with them individual experiences and cultural assumptions that affect the course of the ensuing decision making about resuscitation. Reaching a communicative sharing in this context begins with clarification of those experiences and assumptions.

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