

# Virtual Mentor

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## ETHICS CASE

### The Use of Informed Assent in Withholding Cardiopulmonary Resuscitation in the ICU

Commentary by J. Randall Curtis, MD, MPH

Ms. Rose's family had gathered in the intensive care unit conference room. Her three sons and daughter all looked haggard; their mother's advancing lung cancer had led to a long stay in the intensive care unit (ICU). This was the second conference since their mother was intubated a week before. After that meeting, she'd done well with treatments, and the breathing tube had just been removed, although she was still drifting in and out of consciousness. However, the last few days had been increasingly difficult, and, although Ms. Rose's lung function was improved, she was no longer aware of what was going on around her. Her heart had weakened, and her blood pressure had slowly been dropping despite medications.

During the first meeting, it had been easy for the siblings and the ICU attending physician, Dr. Branson, to come to an agreement about a plan. They would put her on the ventilator to see how her lungs responded and would keep her as comfortable as possible, hoping that she could soon recover and get home to enjoy her flower gardens and visits from her many grandchildren.

By 9 AM after their long week, many of the siblings were sipping coffee from styrofoam cups, as they chatted with the chaplain, social worker, and nurse who had also gathered for the meeting. As Dr. Branson entered, the room hushed a little. Despite the long course of Ms. Rose's worsening pulmonary condition, her family braced for the coming conversation.

"Thanks to all of you for making it in," Dr. Branson started. "As I've discussed with many of you day to day, your mother continues to get sicker. She did well last week after a short amount of time on the ventilator, but the cancer keeps spreading and she's getting weaker. At this point, I worry that giving her CPR will not improve her chances of ever leaving the hospital and it'll cause her a lot of discomfort. My understanding from all of you is that what matters to her is being up and busy and taking care of the people in her life. It sounds like she would not want to be resuscitated if it meant that she would likely never leave the ICU, much less the hospital." He paused and looked around the room. Several of Ms. Rose's children looked at him and nodded slightly. After allowing a few moments during which no one spoke, Dr. Branson said, "Unless anyone disagrees, I'd like to write in her chart that if her heart stops, she not be resuscitated."

After answering some questions from the family, he wrapped up the meeting. A few minutes later, the nurse who had been in the family meeting approached him. “You didn’t give the family a chance to choose,” she said angrily. “You just decided for them. What if after CPR she bounces back? It’s happened before.”

### **Commentary**

There is growing consensus on the importance of shared decision making in the intensive care unit (ICU) [1]. At the same time, however, there is an active debate over the appropriate role of unilateral decisions on the part of physicians to withhold or withdraw life-sustaining treatments because they would be medically futile [2]. The use of unilateral decision making to withdraw life-sustaining treatment has recently been brought into the spotlight in exchanges about the Texas Advance Directives Act [3, 4]. There have been cogent descriptions of the rationale for using the principle of medical futility to guide unilateral physician decision making [5, 6] and evidence that the futility rationale is used in clinical practice in the U.S. [7] and around the world [8]. However, there have also been compelling arguments made against the use of the futility principle [9-11]. In the U.S., there is not currently a consensus in medicine about the use of unilateral physician decision making concerning medical futility.

Professor Robert Burt and I have articulated an approach we have called “informed assent” that may be a reasonable alternative to unilateral decision making by physicians over the objections of family members [12]. There are specific (and relatively rare) circumstances in which some therapies that are commonly expected by family members, such as CPR, are exceedingly unlikely to provide any benefit to the patient. In these circumstances, many have argued that clinicians are not obliged to obtain informed consent to withhold or withdraw the therapies [13]. In fact, the process of obtaining informed consent may cause considerable distress for some family members: if a therapy is not indicated but we insist on requiring family members to actively refuse it, we may increase their burden of guilt.

There is compelling evidence of anxiety, depression, and posttraumatic stress disorder among family members of critically ill patients [14-17]. Observed risk factors for these psychological symptoms include any one of the following: family involvement in decision making [15], family preference for less involvement in decision making [18], and a family role that is discordant with its members’ preferences [19].

Therefore, we have argued that obtaining “informed assent”—in which the family is explicitly offered the choice to defer to clinicians’ judgment about withholding or withdrawing life-sustaining therapy—may be an appropriate and ethical alternative to requiring informed consent. In the application of informed assent, we believe that clinicians should provide full information about the risks and benefits of expected or requested treatments, convey specific recommendations about the medically proposed course, and clearly indicate that the patient and family are being invited to defer to the clinicians’ judgment. This is similar to the conventional conception of

informed consent—an informed patient or family member can always make an affirmative choice to accept clinicians' recommendations. But, by not asking the family to formally consent to the decision, the informed-assent approach avoids putting family members in the difficult position of feeling responsible for the outcome.

High-quality communication about withholding and withdrawing life support in the ICU does not assume that one size fits all; an important aspect of this communication is to determine the role individual family members want to play in such decisions [20]. Some want to be centrally involved in all decisions and others want to defer such decisions to the clinicians [19, 21]. There are family members who will be greatly relieved that clinicians are willing to take responsibility for decisions, for example, to withhold CPR when it is not indicated. These family members may accept a clinician's determination that CPR is not indicated, but they may find it extremely difficult to feel that they are personally deciding to withhold CPR from their critically ill loved one. There are also family members who will feel that being involved in such decisions allows them to give an important gift to the critically ill patient by taking personal responsibility for ensuring that his or her wishes are followed and best interests are advanced. It is the responsibility of clinicians to determine where on this spectrum individual family members fall and to communicate and share decision making accordingly.

In my experience, most family members have deferred to my judgment when I used an informed-assent approach. Some family members, of course, have not. Often, the latter will respect and appreciate my clinical expertise, but don't concur with my assessment that the treatment is not indicated.

When families disagree with clinicians' judgment and request the therapy that is not being offered, my approach is generally not to unilaterally refuse to offer CPR. I believe that this causes more harm than good, interfering with our relationship and undermining the trust they have in me. The American Medical Association recommends that in this situation a process be initiated to reconcile differences between clinicians and families and that the treatment be offered until reconciliation is achieved [22]. That is the approach that I tend to take for CPR and for withdrawing ongoing life-sustaining treatment. There are, however, some resource-intensive therapies, such as extracorporeal membrane oxygenation, that I may unilaterally refuse to offer if I believe they are clearly not indicated, even if the family requests it.

I argue that the informed-assent approach is most fitting when family members expect or request that we offer or discuss a particular therapy, but it would be uncommon, unnecessary, and impractical to discuss all possible but nonindicated therapies in the ICU. Routine unilateral decisions about futility are an entirely appropriate use of medical judgment and consistent with good quality care, if the clinicians are careful in the determination that the treatment is not indicated and that the family does not expect or request the treatment. However, we argue that

clinicians are obliged to discuss such interventions when they are commonly expected (such as CPR) or specifically requested by a family. To avoid creating disparities based on different families' levels of health literacy, clinicians must be careful to apply this approach only to therapies that are not indicated.

The use of informed assent is a little more complex in the *withdrawal* of a therapy that is no longer indicated than for *withholding* CPR. Although many medical ethicists conclude that withholding and withdrawing life-sustaining treatments are ethically and legally equivalent, decisions about withdrawing interventions already under way have a more powerful impact on families (and many clinicians) than decisions not to initiate therapies in the first place. Accordingly, communication with families about withdrawal decisions should account for these differences. Clinicians should assume that patients or families expect interventions to be continued and discussions should be thorough and careful.

Informed assent should not be used when clinicians are uncertain about the possibility of success or when the clinicians' convictions about withholding or withdrawing treatment are based on their value judgments about the patient's future quality of life. Such judgments are insufficient grounds for declaring that the therapy is not indicated. Consequently, clinicians may express their opinions and recommendations about the treatment options, but should make clear that these recommendations are based on value judgments and explain them.

Based on the description of the case of Ms. Rose, Dr. Branson seems to have taken an informed-assent approach. To do so ethically requires attention to the preferences and needs of individual family members; to be confident that Dr. Branson's approach was appropriate, we would want to be sure that the family understood his rationale for withholding CPR and that his communication—both verbal and nonverbal—left open the opportunity for the family to actively disagree with the order not to resuscitate. Used properly, informed assent may be an appropriate alternative and may protect some families from the potential burden of feeling responsible for a decision to withhold or withdraw a therapy that is not indicated.

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