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ETHICS CASE

How to Communicate Clearly about Brain Death and First-Person Consent to Donate

Commentary by Stuart J. Youngner, MD

Michael is a healthy 21-year-old man who is brought by ambulance to an emergency department after a motor vehicle accident. His family is devastated when he falls into a coma, is put on a ventilator, and, three days later, is declared brain-dead by two physicians. Dr. Allen, the attending trauma physician on service in the intensive care unit that week, explains to Michael's parents the unlikelihood of his recovering and initiates a discussion about whether and for how long the family would like to continue life-sustaining care. Michael's parents are distraught over the idea of stopping it. His mother says, "How can you even suggest discontinuing care? His heart is still beating, he still has life energy inside of him, and you want us to kill him?"

Later that afternoon, a nurse taking care of Michael, Rhana, learns that he had registered to be an organ donor on the state's donor registry and lets Dr. Allen know. She asks whether he would like her to inform the local organ bank so it can send an organ procurement representative to speak with the family, as is expected of hospitals when a patient has either died or is in critical condition *and* is a potential organ donor [1]. Rhana and Dr. Allen know that such involvement of organ procurement organizations (OPOs) is standard practice in the US, in order to ensure that all potential donors' families are eventually approached by someone trained to speak to them in a thoughtful manner. However, although OPOs must be notified, organ procurement coordinators may not directly speak with families until death is declared. Although Dr. Allen could follow the regulations strictly and contact the local OPO, he thanks Rhana but says that he will revisit the issue in the next day or so after the family has had more time to process what's happening to Michael.

After several days with no change in Michael's reflexes or vital signs, Dr. Allen again brings up the issue of continuing life-sustaining care, this time to a slightly more amenable, and extended, family. He also tells the family that Michael has listed himself as an organ donor on the state's registry. The family is shocked by this news and questions Dr. Allen about the procedures by which organs are actually taken from a donor. Some family members respond with agitation when they learn the answers: Michael would be left on a ventilator until being taken to surgery for organ retrieval and would die after the organs are removed from his body and the ventilator is turned off. Michael's father is the first to speak. "Wait. We had no idea that the retrieval procedures

would interfere with Michael's dying process so much. That's not what we've envisioned for him. We're not comfortable with that."

Afterward, Rhana asks Dr. Allen whether she should still call the organ bank. He explains that the state's first-person consent law—as established in Illinois, for example, in 2006—prohibits one's next of kin from overriding a documented decision to donate [2]. Every state in the country has such a law [3]. Rhana asks, "Can the patient's family override Michael's decision if he would have declined to be an organ donor?" He nods and starts to emphasize the extent of the organ shortage crisis, but she says, "I don't understand. How can respect for patients' autonomy apply only if they made the 'right' decision according to the state and the OPO? Especially in a case like this one, when the state's and the OPO's priorities are really different from the family's?"

Commentary

This case raises two major classes of ethical issues. First, it prompts us to wonder about organ donation under a first-person consent law and about the ethical relevance of states' support for a legal climate that seeks to increase the numbers of available organs without considering consequences for patients' death processes. The Illinois law, for example, mandates that a patient's wish to donate, as expressed in a state registry, *must* trump any family wishes to the contrary [2]. Second, it prompts our consideration of ethically relevant consequences—including confusion among Michael's family members—of Dr. Allen's poor communication about brain death.

Confusion

Dr. Allen is compassionate and probably wise to give the family a limited time to come to terms emotionally with Michael's situation, but his communication causes problems that are ethically relevant. For example, he gives the family a mixed message that could both confuse them and make them feel guilty. When he says that Michael will "die after the organs are taken," Dr. Allen seems to be giving and taking away hope at the same time by presenting the idea that Michael is simultaneously not yet dead and already dead. Michael's family might wonder, "Is he dead or isn't he?"

Michael has been pronounced dead by neurological criteria after a motor vehicle accident. In all states, such a determination meets legal criteria of death [4]. Michael is legally dead. Yet, Dr. Allen, the attending trauma surgeon, tells a devastated family about the "unlikelihood" of Michael recovering as a prelude to a discussion about withdrawing supportive care. The fact is that Michael's recovery is not unlikely; it is impossible. His prognosis is as certain as any in medicine [5]. The law in every state gives as the clinical criteria for declaring the death of a person that he or she has suffered either: (1) irreversible loss of cardiopulmonary function or (2) irreversible loss of all brain function. There is widespread agreement that any clinical criterion of death must have a sound conceptual definition that supports it [6]. A definition of death must answer the

question, which function of the human being is so critical that, without it, a person would be dead (not irreversibly dying but actually dead)? In 1981, James Bernat and his colleagues offered the first definition supporting brain death as the cessation of the functioning of the organism as a whole. By “functioning of the organism as a whole” they meant:

the spontaneous and innate activities carried out by the integration of all or most subsystems (for example, neuroendocrine control), and at least limited response to the environment (for example, limited response to light and sound) [7].

Bernat’s formulation has been largely refuted by scholars [8, 9] and even a Presidential Commission [10]. For example, integration of subsystems is not irreversibly lost in brain death because, after the initial shock, other centers in the body take over integrative functions like temperature and blood pressure [11]. Although they will never wake up or breathe again, some brain-dead patients have been maintained at home without full intensive care for months and even years [11]. Furthermore, all integrative functions—for example, neuroendocrine control—remain but are simply not measured [12]. Brain death has largely been accepted because the diagnosis, even with the limitations described above, adequately predicts a dismal and irreversible prognosis. It is what some have called a legal fiction [8] that serves organ transplant policy well. In other words, for all intents and purposes, [brain-dead patients are dead enough](#) to donate their organs [13].

What might Dr. Allen have said to make things better? When brain death was declared, he should have told the family clearly that Michael was dead according to state law. If, for example, Michael’s family members had commented that Michael had signs of life, Dr. Allen could have empathized with them but pointed out that those signs indicated that his body was being maintained alive, but that Michael was gone, dead. He should have told them that, unlike other types of brain-damaged patients who do wake up rarely, brain death is a completely reliable diagnosis and no one has recovered from it, ever. When he brings up the possibility of donating organs, he should explain that the declaration of death is now, before organs are removed. Michael will be legally dead before organs are removed. The appearance of life has understandable emotional impact, but it is not legally or clinically determinative of death. Furthermore, it is reasonable to give the family members time to come to grips with their “cognitive dissonance” [14].

Dr. Allen should not engage Michael’s family members in a discussion of philosophical debates regarding the conceptual validity of brain death unless they bring it up and ask to him do so. (Perhaps Dr. Allen is not very familiar with these debates since they almost never, in my experience at least, occur in clinical settings.) What seems to interest

families and health professionals most is that, while a patient's diagnosis is often reliable, the prognosis is typically bleak and the law in every state says that the patient is dead.

Such confusing communications about the medical and ontological status of brain-dead patients seem to occur frequently. In my experience, it is not uncommon for health professionals and news media to refer to a patient as brain-dead but then go on to say that the patient died when the ventilator was turned off. Poor communication about brain-dead patients probably reflects underlying [confusion and ambivalence](#) about brain death that has been documented in studies [15, 16]. And no wonder. Brain-dead patients are phenomenologically very different from most dead patients—they are pink and warm with beating hearts. They digest food, produce excrement and, after a period of time, stabilize and require much less intensive care to prevent cardiovascular collapse [11, 17]. Brain-dead patients have “incubated” living fetuses for weeks or months until they can survive *ex utero* [18]. There has also been considerable scholarship [questioning the fundamental philosophical and clinical coherence of the brain death concept](#) itself, making matters even more complicated [8].

Are First-Person Consent Laws Ethical?

There is little doubt that we need more organs for transplantation. There are more than 100,000 people on the United Network for Organ Sharing (UNOS) waiting list and many die every day waiting for an organ [19]. When an organ is available, transplantation has become standard care for end-stage organ failure. The American public clearly favors organ transplantation and organ donation; in the 2012 National Survey of Organ Donation Behaviors and Attitudes, 94.9 percent of adult respondents supported or strongly supported donation [20]. Yet organs are scarce, in part, perhaps, because of the confusion surrounding brain death.

Many attempts have been made over the years to increase the pool of organs but with insufficient success. A recent effort successfully pushed by the transplant community is the adoption of first-person [consent laws](#) in every state [21]. These laws require that, if a person has registered to be a donor at an official online registry or the department of motor vehicles, her or his wish must be honored even over the objection of immediate family members [21]. When the transplant community advocated for these laws, it justified them by extolling the principle of individual autonomy that it knew is highly valued in our society [22].

However, at least in the author's state, Ohio, the online registry offers no opportunity to register a refusal to be a donor. Ohio's driver's license only allows a person to self-identify as a donor. The card is silent about a wish *not* to donate. I leave it to readers to research their own state policies, since possession of a state driver's license is often required to access the registration website. One point of ethical relevance that should be

considered is that a state's lack of process by which to register a person's wish not to donate assumes that the donation's interference with the patient's death process is irrelevant. At the very least, this assumption should be deliberated upon, considered, and recognized in clinical encounters and cases such as Michael's.

In any event, by not allowing a registered refusal, the law allows organ procurement agencies to approach families of dead persons who might not have wanted to be donors. If the families authorize donation, it will take place. Thus, the policy only supports autonomy when it serves the interest of providing more organs. This is not in itself wrong if you believe getting more organs trumps a consistent commitment to autonomy.

Conclusion

Brain death is a relatively new clinical concept and diagnosis that many believe was adopted in large part to increase the availability of organs [8, 23]. Its conceptual, clinical, and experiential inconsistencies are not without consequences. It fosters a kind of cognitive dissonance that hinders the ability of health professionals to communicate, and of families to understand, what is really at stake.

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