Dead Complicated
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In a recent test case a Florida couple sued a local hospital to have their doomed newborn child declared dead. Their daughter Theresa was an anencephalic infant, born with only a brain stem, a tiny stump of a brain. Since virtually all her brain was missing, she would never be aware of her existence. In addition, her faltering heart and lungs were bound to give out in a matter of days. If she was pronounced dead, her parents would at least be able to donate her organs to help other sick infants survive.

It was a reasonable request made by well-meaning parents. But a Florida circuit court rejected it on the grounds that the baby still had a brain stem. According to state law, she was therefore alive. Ten days later, while a fierce debate raged among doctors, ethicists, and lawyers, the infant’s breathing stopped and her organs petered out for lack of oxygen, making them useless for transplantation.

As the sad case of baby Theresa demonstrates, the line between life and death is today often blurred. Once it was simple. A person was alive if his heart could beat and his lungs could breathe, and dead if they did not. It was an intuitive and satisfying definition. Who among us does not accept the lub-dub of a heart and the gentle rise and fall of a chest as reassuring signs of life? But now that machines can do the job of a heart or lung, these vital signs are no longer sufficient to define a living human being. Modern medicine has made the notion of heart-lung death increasingly inadequate, and we doctors must now rely on the much more abstract concept of brain death.

The idea was not immediately popular. Long after the first states adopted it in the early 1970s, others hung on to the traditional notion of heart-lung death, with absurd results. Ten years ago an intensive care patient being transferred from a hospital in Boston to one in Washington could have been alive in Massachusetts, dead in Connecticut, alive in New York and New Jersey, and dead again in D.C. These days, at least, there’s greater consistency. Most states, including Florida, use a whole brain concept of death: that is, the person is dead if the entire brain, including the brain stem, has ceased to function.

As in the case of baby Theresa, that has helped solve the legal dilemma of when to declare a patient dead, but it clearly hasn’t resolved the question of when life ends in a way that satisfies the soul. Whole-brain death is diagnosed by an elaborate battery of neurological tests rather than by a gut instinct of what it means to be alive. And even doctors and nurses working in the twilight world of the intensive care unit may find it deeply disturbing that patients who are legally dead look from the outside just like patients who are legally alive.

A 1989 survey of doctors and nurses in Cleveland dramatically demonstrated the point. Most could define death as whole-brain death, all right. But in a written test many did not correctly identify whether the patients described were dead or alive. A quarter of the group identified a patient whose brain had ceased to function but whose heart was still pumping on life-support systems (legally dead) as alive! About an equal number declared dead a patient who was irreversibly unconscious but whose brain stem could still orchestrate basic functions like breathing (legally alive). That people who routinely witness death have trouble applying the definition of brain death to patients shows how poorly that definition fits with our intuitions and beliefs.

Indeed, in New York and New Jersey, lawmakers, under pressure from religious groups, have been forced to write an exemption to their statutes. A brain-dead practicing Catholic or Orthodox Jew can be treated as though alive, since his religious teachings hold that a beating heart is the benchmark of life.

The source of this subconscious resistance to brain death, I think, is clear. From an emotional standpoint it goes against the grain. And from a scientific standpoint, it’s hard to define death at all when there’s no well-defined minimum standard for membership in the club of human life. Is it having 23 chromosome pairs? A heartbeat? The ability to feel or think? Just as those involved in the abortion debate struggle to decide when life begins, doctors, ethicists, and legislators are struggling to decide when it ends. And as in the abortion debate, where they draw the line is often influenced by emotion, religious and moral beliefs, and politics.
Twenty-five years ago there was no such dilemma. Patients whose heart and lungs stopped quickly turned blue and pulseless and were declared dead. If their brain was destroyed by massive head injury, bleeding, or stroke, the heart and lungs succumbed as well since the lower part of the brain helps orchestrate their function. And then along came intensive care units, cardiopulmonary resuscitation, respirators, and heart-bypass pumps. I recall one 60-year-old patient who had emphysema and severe heart rhythm problems; she needed a respirator to breathe and had an electric-shock machine implanted in her heart to reset the rhythm when the organ stopped pumping. Although her lungs were shot and her heart stopped many times, she read, knitted, and entertained guests in her hospital room. Clearly alive.

With machines to breathe and pump blood, a breathing chest and beating heart could no longer be the hallmark of life. And so doctors turned toward a brain-oriented definition of death. The advent of organ transplantation also exerted a powerful influence, since hearts, livers, and lungs for transplant must be removed from bodies with blood and oxygen still coursing through their veins. Nevertheless, defining brain death continues to engender controversy.

Scientific conservatives argue that the entire brain must die for a person to be dead, and this whole-brain concept was enacted into law. But this definition allows babies like Theresa and patients in deep, irreversible comas with just a scrap of brain function to be counted as alive. To some people this makes no sense. Anencephalics and patients in a so-called persistent vegetative state have only a brain stem, a stalk of brain that allows their bodies to perform basic, reflexive functions like breathing. But they will never be conscious, never see, feel, or think in even the most rudimentary fashion. Such functions are controlled by the cortex, the furrowed outer layer of the higher brain. Consequently some doctors argue that the death of the cortex reduces a being to a state that’s less than human—a state of death. Therefore people in persistent vegetative states and anencephalic infants should be counted as dead and their organs released for donation.

Another problem with whole-brain death is that it’s tricky to ascertain. Often it takes the specialized knowledge of a neurologist to distinguish the person in an irreversible coma who is alive from the person in an irreversible coma who is dead—the key distinction being a functioning brain stem.

Many of the brain stem’s duties involve extremely primitive reflexes: insuring that we breathe, move our eyes in a coordinated manner, blink when something grazes our eye. These simple maneuvers require great ingenuity to test in the intensive care unit. Patients who are unconscious and therefore unseeing do not look around to demonstrate eye coordination. And how do you tell if a patient’s chest is moving air in a place where everyone is hooked up to breathing machines?

To test eye movements, neurologists resort to some bizarre tactics. For example, even in people who are deeply comatose, a good squirt of cold water in the ear causes the eyes to twitch uncontrollably toward the invaded ear. It is an extremely noxious stimulus (conscious patients will sense the world spinning and throw up), but it is a sure way to check that the brain stem is working.

To test breathing skill, doctors have devised an equally devious challenge called an apnea test. It is virtually impossible to tell if a person in a deep coma on a respirator can breathe just by turning off the machine. The centers in the brain stem that direct the lungs to take a breath sense high levels of carbon dioxide, a waste product of the body’s metabolism, rather than low levels of oxygen, the essential gas that we all need.

When a comatose patient’s respirator is turned off, the oxygen level begins to fall and the CO2 level climbs. Since CO2 is not terribly toxic to organs, the brain is programmed to allow high levels to build up before it panics and directs the body to take a breath. And, unfortunately, the oxygen content of blood often dips to deadly levels before the CO2 rises high enough to sound the brain-stem alarm. So—catch-22—if a doctor seeks to diagnose death by turning off a respirator, his search will become a self-fulfilling prophecy.

To avoid killing the patient in an attempt to determine if he is dead, doctors give comatose patients 100 percent oxygen to breathe through a ventilator for 10 to 20 minutes and then place a tube blowing a constant flow of oxygen into the airway leading to the lungs. They saturate the patient with oxygen, so that even if the body does not seek to breathe after the ventilator is turned off, the vital organs can survive.
Under these conditions, the body is given 10 minutes to take a breath in response to the rising CO2 after the ventilator is turned off. If it does, the patient is alive; if not, he is dead. It is a pretty elaborate subterfuge to figure out what should be obvious.

The point struck home during my training when I cared for a 50-year-old woman who had been sent into a persistent vegetative state by a ruptured aneurysm in her brain. She developed lung problems while on a ventilator and, after she came off the machine, remained prone to pneumonia. Each time a new infection imperiled oxygen flow to her brain, she came back to intensive care to be put on a respirator. And each time we called in a neurologist to determine if lack of oxygen had killed off the brain stem to render her dead. Although my patient looked exactly the same, the first three times the answer was no, but the fourth time it was yes.

Apart from the absurdity of situations like these, the insistence that every last brain cell must expire before a patient can be declared dead has also limited the supply of donor organs. A fragment of a brain stem can allow a patient to take some breaths, but (as was the case with baby Theresa) the breathing is often not sufficient to sustain vital organs.

That’s another reason why a vocal minority of doctors have suggested that a patient needs some brain function above the primitive brain stem to qualify as a living human being—and that anything less makes him dead. Logic tells me they’re right: If a beating heart does not suffice for us to be human beings, what is left but consciousness to link us all together?

Ethicists, of course, worry about a world in which a society chooses which parts of the brain are necessary to qualify an individual as human. If today we decide that a person in a persistent vegetative state is obviously not one of us, then tomorrow why not the woman who is severely retarded, or the man rendered speechless and immobile by a stroke? Having treated patients in all three states, it seems to me that there are clear distinctions. Even people who are severely retarded or paralyzed can experience something—can sense touch or taste food or feel pleasure. But in the endless coma of anencephaly or a persistent vegetative state, there is nothing.

So, were I to lapse into a persistent vegetative state or have a child born without a higher brain, I would desperately want the organs taken for donation in the hope that they might help others live. But, having said that, would I want society to allow me, as a practicing physician, to act on these instincts by declaring all patients with these conditions dead? Now I balk.

Although science and logic say these patients are dead, emotion shouts, no, they’re alive! When I touch them, they’re warm. When I place a stethoscope on their rising chests, I hear air moving and the vibrant beating of their hearts. George Annas, a lawyer at the Boston University School of Public Health, argues for a commonsense solution. Dead is when you’d bury someone, he says. To me the way to resolve the issue is to decide whether you’d bury someone with a beating heart. And the answer is no. In our society, being buried alive is the ultimate fear.

I have to agree. I just can’t see putting people whose hearts are still beating and whose lungs are still breathing six feet under in a box—no matter how hopelessly comatose they may be. And with only a brain stem, those feats can in some fashion be performed.

So, reluctantly, I conclude that baby Theresa was alive and had to be allowed to die. Too bad we lost her organs.