AWAKENING (MIS)CONCEPTIONS ABOUT BRAIN DEATH

By Richard H. Savel, MD, and Cindy L. Munro, RN, PhD, ANP

The headlines above, all making reference to the same event, appeared on various Internet stories in late December 2011, but similar headlines appear frequently atop stories in the popular media. Such miraculous accounts certainly entice readers, and of course they are great news for the people figuring in them who presumably earn a new lease on life. But to those of us who care for critically ill patients day in and day out, such sensationalism can be frustrating. Often the journalists who report these stories recycle misunderstandings and misconceptions about brain death. When misunderstood, such accounts can confuse families, leaving them with a sense that critical care practitioners don’t know what we’re doing—or worse, that the members of the multidisciplinary care team cannot be trusted. These unfortunate misunderstandings create a false sense that the intensive care unit (ICU) team and the patient’s family are at odds with one another, with families protecting and speaking for patients at their most vulnerable while ICU teams seem interested only in withdrawal of support to reinforce a hastily made and seemingly incorrect diagnosis of brain death. What can we as members of multidisciplinary critical care teams do to repair such damage?

Background

Let’s begin with the case itself. The patient in these stories was a young college student brought to the hospital with severe traumatic brain injury following an automobile accident. He was airlifted to a regional medical center where surgery was performed for a life-threatening aneurysm.

"As hospital officials began palliative care and broached the subject of organ donation with his family," we are told in one of the written accounts, "the patient began to respond, holding up two fingers on command." Yet another passage in the same story suggests a slightly different angle: "So while the family was given a realistic picture of the patient's poor chances for survival, [the surgeon] ordered one more MRI to see if the critical areas of the brain had turned dark, indicating brain death."
Families listen to our words, and we must be cautious about how we speak. We … [must] be clear and honest and try to offer hope where we can.

Later in the story the patient’s mother is quoted as saying that “no one ‘specifically’ asked if her son would be a donor,” but she hints that “[the caregivers] subtly talk to you about quality of life.” According to this account, the MRI came back with encouraging news during the day and, by evening, “[the patient] inexplicably followed the doctors’ commands.” We’re told that now the patient “feels fine.” The patient’s father is quoted along the same lines as the mother above: “It seems like we were being led down a path to plan for the worst and that things were not going to work out,” he says. “The miracle, to put it bluntly, was that in a matter of 7 days, we went from organ donation to rehab. What a roller coaster it was.”

The Importance of Communication

Putting aside the specifics of this case, we can make an important generalization: there tends to be a self-fulfilling prophecy with these kinds of patients; that is, if there is documentation in the chart that the patient has a poor prognosis, patients tend to have a poor prognosis. As a practicing neurointensivist (R.H.S.), my first concern in a case like this would have been to inform the family that we cannot say with certainty how things will turn out in the long run, and that—at least during the patient’s first couple of weeks in the ICU—the care team’s focus ought to be on aggressive attempts to minimize elevated intracranial pressure, working closely with neurological colleagues to evaluate and treat any lesions that may be amenable to surgery.

Indeed, a multidisciplinary team’s job is to do everything possible to prevent iatrogenic complications that often emerge in a patient who is critically ill, including, first and foremost in this case, infection and venous thromboembolic disease.

Families of critically ill patients naturally find such a time arduous and challenging. Their loved one may have been completely healthy prior to admission to the trauma ICU, yet here are strangers on an ICU team presenting the family with the need to perform multiple simultaneous interventions (intubation, placement of invasive venous access, and, potentially, multiple surgical procedures) with no clear promise of positive outcomes.

During such a sensitive time, it’s essential that critical care practitioners on multidisciplinary teams do 2 things: (1) choose our words carefully whenever we communicate with families, and (2) do everything we can to speak with one voice.

Families listen to our words, and we must be cautious about how we speak. We have a professional obligation to be clear, to be honest, and to try to offer hope where we can. Unfortunately, we’re usually the ones who must break the news to families when hope is lost. Navigating such terrain is never easy.

Diagnosing Brain Death

Next we ought to consider some of the confusion and controversy about the term brain death.7,9 Talking about brain death is perhaps the ultimate example of the need to choose words carefully. As a construct, brain death is at best difficult, so the term should never be tossed around carelessly. Most health care institutions have key clinicians or even groups of clinicians who are comfortable performing the brain death examination and working with families during this challenging and often confusing process.

How we diagnose brain death has shifted in recent years. Until recently, neurological examinations were performed consisting of detailed neurological examinations designed to document that the patient is in a coma, has no response to external stimuli, and shows no evidence of brain stem reflexes. These examinations are separated by at least 6 hours and include an apnea test.

Based on recent recommendations and other important research, in the United States the protocol for determining brain death now typically involves only 1 neurological examination and an apnea test.10,11 Given such a change, it has become more important than ever to ensure that the exams are performed carefully, with excruciating attention to each detail, and that all members of the multidisciplinary team reach consensus before the diagnosis of brain death is made and shared with the family. And all these things must be done in addition to...
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Equally important decisions about whether to pursue donation after cardiac death or determining the appropriate wait time for a brain death examination when a patient has received therapeutic hypothermia. Given how cardiopulmonary resuscitation is often portrayed on television—with positive outcomes much more common than they are in real life—ICU clinicians face an uphill battle to properly educate families about these complex and often counterintuitive end-of-life issues.12

Conclusion

Our duty should be to focus on what we can do to alleviate the fog of confusion and improve the situation. Families are looking for healthcare providers who care and are skilled, knowledgeable, and confident. We must be able to communicate devastating information in a sympathetic way, even when the circumstances are made that much more difficult because family members take out their anger and frustration on the care team.

Again, the most important thing we can do is to choose our words carefully. As critical care clinicians we all work in a setting that has its fair share of unpredictability, but using phrases such as “nearly brain dead” or “almost brain dead” is never appropriate. These confusing non-prognoses only make matters worse. Families easily become confused, and confusion leads to mistrust. The problem is even more acute in a training hospital. We ought to emphasize to trainees that it is basically impossible to “un-say” things once they’re said. It’s always preferable to use concrete and straightforward language such as “your loved one has suffered severe brain injury,” thereby allowing us to stay together as a team. Such careful phrasing rarely needs to be retracted.

As members of a community, critical care practitioners must take a stand when we see something in the media as misleading as the story described above. As professionals we need to educate patients and families about terms like brain death and what they really mean, not to mention how damaging they can be when used incorrectly. Many of us pray for miracles for our critically ill patients, but sometimes—unfortunately, oftentimes—those miracles never happen. By failing to convey the facts and subtleties of such emotional stories accurately, journalists in the popular media risk poisoning the very important relationship between critical care practitioners and their patients and families, sowing mistrust and anger where there should be warmth and mutual respect. If we take a stand and educate when we see these stories in the media, we can begin to undo the damage. Then what awakens will be the truth, and we can lay these misconceptions to rest.

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