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Are we equal in death?

Avoiding diagnostic error in brain death

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THE HISTORY OF BRAIN DEATH For thousands of years, the term “death” meant the permanent stopping of the heart and breathing. However, when Bjorn Ibsen from Denmark invented the artificial respirator in the 1950s, breathing and heartbeat could be continued when people were in a deep coma. This invention and the rise of better medicine and medical care forced doctors to rethink the old definition of “death.” In 1959, French doctors Mollaret and Goulon first described what is now called “brain death.” In 1968, the rules for deciding “brain death” were first put in place with guidelines called the Harvard criteria. These were developed by anesthesiologist and early bioethicist Henry K. Beecher. Following Christian Barnard’s first transplant of a human heart in 1967, Beecher wrote that organ donation from those who were “hopelessly unconscious” would be beneficial.

HOW DO PHYSICIANS DECLARE A PATIENT BRAIN DEAD? In a study reported in this issue of *Neurology*[®], Greer and co-authors studied this question by looking at the top 50 US neurology and neurosurgery programs. They compared the official medical guidelines from these top hospitals against guidelines used by the American Academy of Neurology (AAN) published in 1995 (see the table).

WHAT DID THE AUTHORS FIND? The good news is that doctors in most of these programs closely followed the AAN guidelines in the examination of brain death. All hospitals correctly defined brain death as irreversible coma with absent brainstem reflexes (such as reactions of the pupils to light and other “automatic” reflexes). However, many centers’ policies did not follow AAN guidelines on rules for testing. Programs were not the same in the attention they paid to low body temperature (hypothermia), sedative or paralytic medicines, or the presence of severe metabolic disorders that might confuse the diagnosis of brain death.

Although careful and standardized testing of the absence of breathing—called apnea testing—is needed for the diagnosis of brain death,

Table “Gold standard” guidelines for the diagnosis of brain death as published by the American Academy of Neurology (1995)

- Demonstration of coma
- Evidence for the cause of coma
- Absence of confounding factors, including hypothermia, drugs, electrolyte, and endocrine disturbances
- Absence of brainstem reflexes
- Absent motor responses
- Apnea
- A repeat evaluation in 6 hours is advised, but the time period is considered arbitrary
- Confirmatory laboratory tests are only required when specific components of the clinical testing cannot be reliably evaluated

the centers were a bit different in how they did apnea testing. Programs were also different in the number of required examinations and the required time between them, the use of extra tests, and in deciding who makes the diagnosis. The best person to make the diagnosis should be a trained and experienced neurologist, but the medical staffing at many US hospitals might make this difficult.

WHY IS THIS STUDY IMPORTANT? This study is important because it provides facts about current practices that can help improve the 13-year-old guidelines from the AAN; in addition, the authors mention areas where there are too many differences between current practices and the AAN guidelines. We need to make practices more similar so that doctors can keep the trust of patients and their families. Also, a definite assessment of death is needed for organ donation so that organs are taken at the right time.

All of these things together are needed for the successful continuation—and growth—of organ donor programs. Finally, studies like this one also give families better information about potential outcomes from coma. By better understanding the future—both good and bad—of patients in coma, families can make informed choices about continuing or stopping life-sustaining therapy. By

improving the diagnosis of brain death, doctors can provide strong proof in cases when further treatment would not be helpful or ethical.

WHERE DO WE GO FROM HERE? Doctors should make every effort to make the correct diagnosis for patients in coma. A patient who is brain dead or who will always be in a “vegetative state” should be correctly diagnosed. Also, doctors should not make a mistake when saying that a patient will always be in a “vegetative state.” A patient who is “vegetative” is in a state of “wakeful unresponsiveness” in which the eyes are open but there is no awareness of self or others. Such patients have reflex movements, including random eye movements, but are unconscious (Laureys S. Eyes open, brain shut: the vegetative state. *Scientific American* 2007;4:32–37).

Here, doctors need to make all efforts to make sure there is no consciousness left and also exclude the diagnosis of a minimally conscious state (MCS). MCS patients show limited and changing signs of awareness as evidenced by occasional but inconsistent purposeful movements such as following a command or speaking. These responses are not simple reflexes. However, MCS patients cannot reliably communicate (spoken or nonspoken) their thoughts and feelings. We also need to improve our understanding of how the different types of injury (from trauma, or from lack of oxygen to the brain) influence how the brain moves from coma through the vegetative state and onto MCS.

Another diagnosis that should not be missed is that of the locked-in syndrome (LIS). Here patients awaken from their coma, fully conscious, but are unable to move or speak; they can communicate only by blinking or moving their eyes. Jean Dominique Bauby (whose book *The Diving Bell and the Butterfly* just appeared in US theaters) probably was the world’s best-known locked-in patient. His book and movie are about the importance of doctors not missing this diagnosis and how a meaningful life can be missed through misdiagnosis.

All physicians have an ethical obligation to

make correct diagnoses in brain death. We thank Greer and co-authors for pointing the way toward the improvement of these clinical assessments through careful study.

FOR MORE INFORMATION

Coma Science Group

www.comascience.org

American Academy of Neurology

http://aan.com/professionals/practice/pdfs/pdf_1995_thru_1998/1995.45.1012.pdf

American Medical Association

www.ama-assn.org/ama/pub/category/8457.html

United Network for Organ Sharing

<http://www.unos.org>

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