Variability of Brain Death Policies in the United States
Greer DM, Wang HH, Robinson JD, Varelas PN, Henderson GV, Wijdicks EF
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Welcome to another installment of the SNACC Article of the Month. This March edition deals with a topic faced by many of us in the neurocritical care unit, namely the accurate and appropriate declaration of brain death as designated by the 2010 AAN guidelines. As indicated by this paper and by our expert this month, the reality is that these guidelines are still not adhered to with the desired consistency across much of the United States. Internal policies can differ considerably, as can the implementation of these policies, and this can have dire medico-legal and ethical consequences, as well as consequences regarding the appropriate procurement of donated organs. To help us sort through this article, as well as to give us some insight into the problem, we have enlisted the help of Dr. Souter from the University of Washington. Dr. Souter is a long-time SNACC member and a national leader in the field of brain death and organ procurement for transplantation, and his insight is truly thought-provoking and beckons us to improve our practice. We hope you will enjoy this Article of the Month offering and ask you to let your thoughts be known on SNACC LinkedIn feed the Twitter feed, or the Facebook page.

~John F. Bebawy, MD

Commentary
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Back in 2008, David Greer and his co-authors published a concerning study illustrating significant variability in protocols for diagnosis of brain death used by 50 major neurological centers in the USA. It illustrated poor adherence with many aspects of the then guidelines promulgated by the American Academy of Neurology. The impact of that was not lost on many in the associated world of organ donation, where real concerns arose on variability of practice offering opportunities for inadequacy and mishap, coupled with a loss of public confidence. Fueled by this concern for misdiagnosis, most of the authors then undertook a systematic review of practice and presented new guidelines from the AAN in 2010, designed to be straightforward and easy to implement.

After waiting two years, they then secured around 500 hospital protocols for diagnosis of brain death, with help from US organ procurement organizations. This group of hospitals constitute around 85% of the medical centers
in the US, and capture the majority of the country’s organ donation practice. The protocols were then analyzed in a similar fashion to the 2008 study, looking at who undertook diagnosis, when it was appropriate, how it was done (including apnea and ancillary testing) and how long it took.

Their results in the current study make sobering reading. While there is evident improvement upon the 2008 paper, there is still significant variability in the protocols used to declare death by neurologic criteria. For those who dismiss the protocols as not being illustrative of actual practice, I can confirm (as the medical director of an organ procurement organization) that many physicians outside of large academic neuroscience centers depend on such protocols to guide them through a practice that may be unfamiliar to them, either by reason of inexperience (many exams are still done by residents – borne out in this paper) or by inadequate frequency of practice (the on-call neurologist may be a specialist in movement disorders, or the neurosurgeon on call is a spine specialist.)

Without clear statement of necessary steps in hospital protocols, there’s opportunity for inadequate examination, ignorance of confounding conditions, as well as use of inappropriate testing and imaging modalities – all of which may provoke uncertainty and concern of misdiagnosis of brain death, within medical teams, families of patients and the lay press. (Google Dick Teresi or Jahi McMath if you don’t think people are interested in this.)

The authors do consider what gives rise to this seeming inertia of medical culture, which resists incorporation of what was clear advice into protocols of practice. There may be assumptions that if there’s nothing actually gone wrong in your hospital, then everything is okay. This Rumsfeldian approach (not knowing what you don’t know) is not tenable when under the scrutiny of regulatory bodies such as the Joint Commission. But therein lies the rub – there is really no ‘interested’ regulatory agency driving an agenda of change here. In the absence of that drive, cultural shift within medicine takes some considerable time. In the interests of abbreviating that glacial process, I would encourage all reading this paper to go and dig out their own hospital policy on brain death diagnosis, reviewing it for concordance with the 2010 AAN guidelines. If there are differences, bring them to appropriate forums within your hospital, and ask questions… ignoring the problem is not an acceptable solution.