Using CIRUPA to Help Foster Communication with Families about Brain Death in Sub-Saharan Africa

Sir,

Brain death, with a functioning cardiovascular system, remains a difficult issue to grasp for most families. Furthermore, conversations about brain death remain challenging even for the most experienced physicians. We developed an acronym, CIRUPA, to further improve the goals of care conversations in patients diagnosed with brain death. To our knowledge, this is the first acronym within Sub-Saharan Africa, which helps provide a structured method on how to foster conversations centered around brain death.

CASE REPORT

A 53-year-old Ethiopian female with a long-standing history of hypertension was air evacuated to our institution after suffering a syncopal episode. A review of her initial head computed tomography (CT) showed a massive intracranial parenchymal bleed. On arrival, the patient was nonresponsive and intubated requiring maximum ventilator support. Her physical examination revealed absent pupillary reflex to direct and consensual light and no corneal reflex. She remained unresponsive to painful stimuli with no spontaneous breathing. A repeat head CT at our institution showed progression of her bleed with midline shift and tonsillar herniation. Our neurosurgical team was consulted and, after much discussion, felt that surgical intervention would provide no useful outcomes. Brain death testing performed by two experts confirmed brain stem death. The family was notified, but insisted that the intensive care unit team continue with artificial ventilation and hemodynamic support. She finally succumbed to an episode of cardiac arrest 2 weeks later, with multiple, but unsuccessful resuscitation efforts.

LESSONS LEARNED

Effective communication remains a key in empowering patients and families to make not only the right choices but also the decisions they are comfortable with. A lack of communication has been shown to results in care that might not be consistent with a patient's specific goals in life.[1] Furthermore, poor communication has been shown to result in both physical and psychological suffering including the higher use of interventions, poor quality of life, worse bereavement outcomes for families, and physician burnout.[2,3]

Effective communication can be challenging and is often hindered by many barriers. Patient-related barriers include anxiety, denial, and a desire to protect one's family members from distressing information. Disagreement between family members has been noted to hinder effective communication.[1,4] Medical providers, on the other hand, usually express more unease and discomfort in initiating and having such discussions than patients do. Medical providers lack adequate training, competency, and the comfort to carry out effective communication, especially at the end of life. Some medical providers are not comfortable with the strong emotions that are expressed during such difficult discussions. In addition, deciding the right time to initiate such discussion remains challenging for many medical providers. The lack of accurate prognostication tools and adequate training also add to clinician discomfort in fostering such discussions.[1,4,5]

Brain death is defined as the irreversible loss of all functions of the brain, with brain steam function being the cornerstone. The three key findings usually include coma, absence of brainstem reflexes, and apnea.[6]

Unlike cardiopulmonary death, the concept of brain death remains challenging for most families to fully understand and accept. The presence of a beating heart and other possible signs of life, such as a blood pressure and spinal reflexes, can sometimes cause much confusion and agony for a family trying to grasp the concept of brain death. Hence, the role of open-ended, honest communication with family members remains crucial in helping them prepare, grasp, and understand the consequences of brain death.[7]

Sub-Saharan Africa remains a tapestry of diverse cultures with enormous heterogeneity in cultural practices and religious beliefs. These factors greatly influence how individuals handle death and dying, and this is particularly true for brain death. Many countries in Sub-Saharan Africa lack laws recognizing brain death. Specific standards and protocols to help make an accurate diagnosis of brain death are also lacking.[8,9] Conversations about brain death have never been explored and training in this specific area remains virtually nonexistent. Understanding the origins and depth of both physical and nonphysical suffering and how individuals and family members perceive and process brain death remains crucial in promoting effective communication.[9]

At our institution, we came up with an acronym CIRUPA, to help foster better communication specifically regarding brain death. The acronym includes:

a. Confirming the diagnosis of brain death using the standard commonly used protocols
b. Informing the family members. A family meeting with key medical providers should be arranged within 24 h of confirmation of brain death. An understanding of the family's grasp of the medical situation should be sought. The medical team including the intensivist, the palliative care team, the neurologist, and the providers conducting the brain death testing should, in simple terms, explain to the family the outcomes of the test and what this means
c. Reinforcing the diagnosis and providing an update to the family on a regular basis remains key. Our palliative care team meets such patients every 24–48 h. We allow ample time to discuss questions and concerns. Questions on prognosis remain difficult to answer, but a daily update can help provide a realistic picture
d. Understand the cultural, educational, and religious barriers that may exist in accepting the diagnosis. We have learned to gradually introduce a goals of care conversation when the family understands that continued medical intervention remains futile and they are ready to move on
e. Providing educational, spiritual as well as psychosocial support as the family comes to term with the diagnosis
f. Allowing the family time and space to spend with the patient and to make a decision about the future care.

This method, to our knowledge, remains the first of its kind in Sub-Saharan Africa focusing on improving communication centered around brain death. This method also provides medical providers a systematic manner on how best to prepare and foster such difficult conversations to help families deal with this important.

Sincerely,

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Conflicts of interest

There are no conflicts of interest.

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