Summary: Ethics for Lunch, 17 December 2018

Issues of Distrust around Neurological Death, Organ Donation and Role of Spiritual Care

<https://www.youtube.com/watch?v=gSjEgir3dbw&t=2s>.

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The December 2018 Ethics for Lunch considered the ethical and moral issues surrounding family distrust in cases involving Neurological Death and Organ Donation, with particular focus on the role of spiritual care. The panel discussion created a forum for attendees to contextualize and become familiar with the current practices, policies and protocols in the declaration of death by neurological criteria. In addition, the panel reviewed strategies to proactively engage families who are emotionally distraught, in denial, potentially in conflict with medical teams, and resistant to the neurological death prognosis. Recent updates to the Brain Death protocol and evaluation process were reviewed and a case was presented. The attendees and panel members discussed pertinent issues in relation to the content and case.

The primary focus of the session was on ways that chaplains mitigate emotional, spiritual or existential distress in their work with families, particularly those experiencing and expressing their grief reactions.

1. Facilitating the family’s decision-making process involves a two-step approach:

1. The Family Advocate (FA) / Chaplain’s spiritual assessment includes an extensive review of psychosocial issues, while being sensitive to the family’s socioeconomic, political, religio-cultural contexts, so as to understand their pathos and unresolved issues of grief. The FA / Chaplain explores ways that the family makes meaning in the loss they are experiencing, including their understanding of the present situation and their relationship with the divine / God. Further, the FA /Chaplain identifies the hopes, aspirations, and ways the family members wish to remember their loved one’s life.
2. The Chaplain’s assessment is shared with clinicians and interdisciplinary teams, which is helpful in the team’s explanation of the medical reality to the family members. The family is educated in terms of the differences between coma, brain death, and persistent vegetative state. Brain death is framed as a legal definition of death (“the patient is pronounced dead at …”), with no decisions for the legal next of kin / surrogates to make when the patient has met neurological death criteria. Ethically it is not permissible to treat someone who is dead, and to do so may contribute to the suffering of their loved one.

2. The Chaplain and interdisciplinary tem should recognize potential challenges in suspected brain death situations and identify ways to help family members understand that the neurological injury is irreversible and death is imminent.

3. To maximize family trust, the team may encourage family to be present for the physical brain death exam. Also, teams might be encouraged to utilize visual materials of CT Scans and other aids such as Cerebral Flow Study and/or Cerebral Angiogram, in appropriate situations, in explaining neurological death.

4. It is important to educate family members about the brain death testing process, which may require stimulation that may be perceived as pain and suffering, especially in pediatrics.

5. The Neurology team should explain the initiation of brain death process and educate families about voluntary and involuntary movements if the patient displays spinal cord reflexes.

6. Members of the health care team should remain focused in the present moment and refrain from undue negative emphasis on possible negative or positive outcomes when the family is approached for organ donation. It should be recognized that care is family-centered, and it is patient/ family choice to donate organs or decline to consent.

7. Decoupling is an essential and important aspect in the organ donation process, so that there is a clean boundary between the Medical team / Attending Physician and the Organ Procurement Organization (OPO). Ideally, the brain death confirmation communication and the approach for organ donation conversations by the OPO representative are separated.

8. The process should strive to safeguard open, transparent communication. If possible, the team may need to accommodate / encourage the family to seek a second opinion. The team should consider the option of involving a care provider who has trusted relationship with the family. Also, it may be helpful to collaborate with the patient’s longitudinal provider/ PCP.

9. Involve the Chaplain / faith leader and/or community clergy from the very beginning of a case for focused provision of emotional and spiritual support of families and staff.

10. The states of New York, California and Illinois mandate accommodations for religious objections to brain death but these states leave the nature of the accommodation to the discretion of individual hospitals. New Jersey allows an exception to brain death criteria and imposes a duty statewide to accommodate patients who reject brain death. (This issue was raised by a physician after the session, therefore it does not appear in the video recording.)

**References:**

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