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WEBINAR SERIES

Medical & Legal Aspects of Family Conflict with the Medical Team at End-of-Life

February 11, 2020| 2-3pm ET

Speakers: Thomas A. Nakagawa, MD, FAAP, FCCM | Alexandra Glazier

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WEBINAR SPEAKERS

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“I’m sorry your loved has died.” Medical and legal aspects when families disagree with the medical team at end-of-life.

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Conflict of interest

- The presenters for this webinar have no reported conflict of interests

AP / December 3, 2015, 11:17 AM

Nevada court to decide fate of woman on life-support

Washoe County District Court Judge Frances Doherty listens to attorneys argue on whether or not to maintain support for 20-year-old Aden Hally, Wednesday, Dec. 2, 2015, in Washoe County District Court in Reno, Nev.

Seven-year-old Allen Calloway

Steve Weatherbe

NEWS | END OF LIFE Fri Sep 30, 2016 - 1:07 pm EST

Mother intervenes to keep 'brain dead' Montana boy alive

Udpate: LA Children's Hospital Removed Brain Dead Toddler From Life Support

And here's how the parent's reacted to the devastating news.

A symptom of a greater problem within our medical community

- When families disagree with the medical team

Objectives

- This webinar will provide information to participants about the medical and legal consideration when families disagree with the medical team at end-of-life including determination of death by neurologic criteria.

Objectives

- Key objectives will include issues related to the ethical, legal, and medical challenges the medical team faces:
  - When a family does not want specific tests performed to make a determination of death
  - When the family does not agree with termination of medical support after declaration of death
  - State accommodations regarding determination of neurologic death
  - Strategies to help families and the medical team when disagreement occurs

Is the primary issue defining death, determining death, or both?

Defining death

- Uniform Determination of Death Act (UDDA)
- Legal standard for declaring death: Irreversible cessation of neurologic or circulatory function
- Diagnosis of death: in accordance with medical standards

Determination of death

- The determination of death indicates an irreversible point in the dying process, not that the dying process has ended
- Determination of death does not guarantee that all bodily functions and cellular activity, including that of brain cells, have ceased
- Circulation can be maintained for hours or days to enable recovery of organs for transplantation
    - *There is no clinical or imaging study that can establish that every brain cell or every cell in the body has died.*

SPECIAL ARTICLE

AMERICAN ACADEMY OF NEUROLOGY

Evidence-based guideline update: Determining brain death in adults

Report of the Quality Standards Subcommittee of the American Academy of Neurology

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Panayiotis N. Varelas, MD, PhD
Gary S. Gronseth, MD
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Special Pediatric Neurologic Critical Care Article

Guidelines for the determination of brain death in infants and children: An update of the 1987 Task Force recommendations*

Thomas A. Nakagawa, MD, FAAP, FCCM; Stephen Ashwal, MD, FAAP; Mudit Mathur, MD, FAAP; Mohan R. Mysore, MD, FAAP, FCCM; Derek Bruce, MD; Edward E. Conway, Jr, MD, FCCM; Susan E. Duthie, MD; Shannon Hamrick, MD; Rick Harrison, MD; Andrea M. Kline, RN, MS, FCCM; Daniel J. Lebovitz, MD; Maureen A. Madden, MSN, FCCM; Vicki L. Montgomery, MD, FCCM; Jeffrey M. Perlman, MBChB, FAAP; Nancy Rollins, MD, FAAP; Sam D. Shemie, MD; Amit Vohra, MD, FAAP; Jacqueline A. Williams-Phillips, MD, FAAP, FCCM; Society of Critical Care Medicine; the Section on Critical Care and Section on Neurology of the American Academy of Pediatrics; and the Child Neurology Society

Objective: To review and revise the 1987 pediatric brain death guidelines.

Methods: Relevant literature was reviewed. Recommendations were developed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system.

Conclusions and Recommendations: 1) Determination of brain death in term newborns, infants, and children is a clinical diagnosis based on the absence of neurologic function with a known irreversible cause of coma. Because of insufficient data in the literature, recommendations for preterm infants <37 wks gestational age are not included in this guideline. 2) Hypotension, hypothermia, and metabolic disturbances should be treated and corrected and medications that can interfere with the neurologic examination and apnea testing should be discontinued allowing for adequate clearance before proceeding with these evaluations. 3) Two examinations, including apnea testing with each examination separated by an observation period, are required. Examinations should be performed by different attending physicians. Apnea testing may be performed by the same physician. An observation period of 24 hrs for term newborns (37 wks gestational age) to 30 days of age and 12 hrs for infants and children (>30 days to 18 yrs) is recommended. The first examination determines the child has met the accepted neurologic examination criteria for brain death. The second examination confirms brain death based on an unchanged and irreversible condition. Assessment of neurologic function after cardiopulmonary resuscitation or other severe acute brain injuries should be deferred for ≥24 hrs if there are concerns or inconsistencies in the examination. 4) Apnea testing to support the diagnosis of brain death must be performed safely and requires documentation of an arterial $Paco_2$ 20 mm Hg above the baseline and ≥60 mm Hg with no respiratory effort during the testing period. If the apnea test cannot be safely completed, an ancillary study should be performed. 5) Ancillary studies (electroencephalogram and radionuclide cerebral blood flow) are not required to establish brain death and are not a substitute for the neurologic examination. Ancillary studies may be used to assist the clinician in making the diagnosis of brain death a) when components of the examination or apnea testing cannot be completed safely as a result of the underlying medical condition of the patient; b) if there is uncertainty about the results of the neurologic examination; c) if a medication effect may be present; or d) to reduce the interexamination observation period. When ancillary studies are used, a second clinical examination and apnea test should be performed and components that can be completed must remain consistent with brain death. In this instance, the observation interval may be shortened and the second neurologic examination and apnea test (or all components that are able to be completed safely) can be performed at any time thereafter. 6) Death is declared when these criteria are fulfilled. (Crit Care Med 2011; 39:2139–2155)

KEY WORDS: apnea testing; brain death; cerebral blood flow; children; electroencephalography; infants; neonates; pediatrics

Society of Critical Care Medicine
The Intensive Care Professionals

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

CHILD NEUROLOGY SOCIETY

Medical, ethical, and legal considerations when families disagree with the medical team

State laws and neurologic death

- Every state has adapted the UDDA standard
- Some state laws provide accommodation from declaration based on neurologic criteria
  - Religious
  - Brief period of time
- No right to "treatment" after death

When families deny performance of medical tests to determine neurologic death

- Does diagnostic testing require permission? Do families have a choice to agree to have testing performed?
  - Clinical examination
  - Apnea testing
  - Ancillary studies

What happens when families deny performance of medical tests to determine neurologic death?

- Ethical and moral consequences for the medical team?
  - Maintaining somatic support for a decedent
    - Daily rounds
    - Charting
    - Laboratory testing
    - Radiographic studies
    - Treatment decisions based on laboratory and radiographic studies
  - Morale distress
  - Financial considerations
  - Appropriate utilization of resources

Strategies to help families and the medical team when disagreement occurs

Why do families disagree with the medical team?

- Lack of trust in the medical system
- Public perception about death
- News, information, and technology
- Communication between the family and the medical team

Reducing legal conflict

- Clear legal standards and hospital policies
- Medical standards and independent second opinions
- Death certificate versus brain death note
- Court as a last resort

Helping families understand

- Families in crisis
- Obligations of the medical team
- Providing a consistent message to the family
- Second opinions

Helping the medical team

- Ethics committee
- Involvement of hospital leadership
  - Administration
  - Risk management
  - Unit leadership
  - Family relations
  - Public relations
- Provider support for emotional and moral distress

The Best Escalation Plan is a De-escalation plan

- Goal: Remove the medical team from the center of conflict and allow them to continue to provide ongoing medical care while supporting the family
  - Develop a response team
    - Hospital and unit administration
    - Risk Management
    - Legal
    - Hospital community relations
  - Review hospital policy
  - Second and third opinions
  - Support of administration to intervene and have difficult conversations with the family while being supportive

Conclusions

- Legal and medical conflict may be ultimately unavoidable but there are strategies to reduce this conflict
- Resolution of the death diagnosis is primary to any organ donation discussions
- Role of the OPO as a resource to the hospital team in understanding neurological criteria standards

Alexandra Glazier and Tom Nakagawa thank all of you for being a part of this webinar and for your dedication and continued efforts to save more lives through donation and transplantation

Questions and further discussion