

## Ethical Issues in Brain Death: Lessons Learned from High-Profile Recent Cases

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## Note on Terminology

- New move to "rename" brain death. Emphasis on "death" rather than on "brain"
  - Death by neurological criteria
  - Death by circulatory criteria  
ATS/ISHLT/SCCM/AOPO/UNOS. Gries *et al.* Am J Respir Crit Care Med. 2013 188(1):103-9. PMID:23815722
- "Brain dead" used to describe other states
  - PVS (Terri Schiavo)
  - Minimally conscious state
  - Someone who isn't very bright

## HIGH PROFILE CASES

### Jesse Koochin

- 6-year-old boy with brain cancer
- Declared dead by neurological criteria in October 2004 at Primary Children's in Utah
- Family disagreed and argued that Jesse was still alive
- Court ordered the doctors to not submit a death certificate and to release the body to the parents



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## Outcome

- Jesse's body remained on a ventilator at the family's home for about a month, at which point his heart failed
- Parents called 911, and ambulance brought Jesse to St. Mark's Hospital
- Attempts at cardiac resuscitation in the Emergency Department were unsuccessful, and Jesse was declared dead by circulatory criteria

## Key Lessons

- Courts often try to placate all parties
  - Doctors were not forced to care for patient
  - Family was allowed to take patient home
- Death has become a legal construct, and courts may overrule doctors in determining who is actually dead

## Jahi McMath



- 13-year-old girl
- December 9, 2013 admitted to CHORI for T&A and uvulectomy for OSA
- Post-operative complications
- Declared dead by neurological criteria Dec 12
- Death certificate completed and submitted
- Court ordered body released to family and transferred to Saint Peter's University Hospital in New Brunswick, NJ

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## Current Events

- Family seeking to overturn death certificate
- Videos of movement
- Examination by two individuals
- Reviewed by court-appointed expert

## Key Lessons

- Courts often try to placate all parties
- Some facilities will accept patients even after they have been declared dead
- Only qualified experts should determine death by neurological criteria
- Dead patients don't have healthcare insurance
- Where the patient presents can have major implications

## Death and the Delaware River




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### Exceptions to Death by Neuro Criteria

- New Jersey statute forbids declaration of death by neurological criteria if it would violate the patients "personal religious beliefs"
- New York also allows religious or moral exceptions
- Cooper University Hospital (in New Jersey) is only 6 miles from CHOP (in Pennsylvania)
- Child declared dead at CHOP might still be alive at Cooper

### Marlise Munoz



- 14 weeks pregnant
- November 26, 2013 found unconscious on kitchen floor (possible pulmonary embolism)
- Admitted to hospital in Fort Worth, TX
- Death by neurological criteria determined on November 28
- Hospital unwilling to remove mechanical ventilation without a court order

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### Texas Law

- Texas law forbids removal of life-sustaining treatment from any pregnant patient regardless of a request for DNAR status
- Hospital unwilling to place itself at risk
- Family argued that patient was not on life support because she was already dead
- Court agreed with family and ordered discontinuation of mechanical ventilation

### Confusion in the News


- On January 26, 2014 NBC news reported: "A pregnant woman who lapsed into a brain-dead state late last year was removed from **life support** on Sunday after a Texas hospital complied with a judge's order to disconnect her from the machines **keeping her alive**."

<<http://www.nbcnews.com/news/us-news/brain-dead-pregnant-woman-taken-life-support-n16761>>

### Key Lessons

- Tremendous confusion broadly
  - Lay public
  - News
  - Doctors and hospital staff
- Words matter
  - A dead person cannot be on "life support"
  - A dead person cannot be "kept alive"

### Zack Dunlap



- 21-year-old man in Oklahoma
- ATV accident November 2007
- Admitted to hospital in Wichita Falls, TX
- Declared dead by neurological criteria by local surgeon

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## Zack's "Recovery"

- As he was being wheeled to the OR to donate organs, family member ran pocket knife over Zack's foot and saw him move
- Eventually made near-complete recovery
- Talk show appearances:  
I was dead, but I feel much better now
- Multiple media stories (Dateline, Today Show, etc.) of "miracle"

## Key Lessons

- Miracles sell better than medical errors
- Only highly qualified specialists should perform neurological examinations and interpret studies
- Even one mistake is too many
- This case has lead many families to not believe doctors when death by neuro criteria is declared
  - Doctors make mistakes
  - "Miracles really do happen"

## Pediatric Guidelines 2011

- AAP, Society of Critical Care Medicine, and Child Neurology Society
- Nakagawa *et al.* Clinical report—Guidelines for the determination of brain death in infants and children: an update of the 1987 task force recommendations.
  - Pediatrics. 2011 128(3):e720-40. PMID:21873704
  - Crit Care Med. 2011 39(9):2139-55. PMID:21849823
  - Ann Neurol. 2012 71(4):573-85. PMID:22522447

## Timing

- Delay 24 to 48 hours post CPR or other severe acute brain injuries if any concerns or inconsistencies
- 2 neurological examinations, each including an apnea test
  - <30 days post-term: 24 hours apart
  - >30 days post-term: 12 hours apart

## Ancillary Studies

- Not required
- Ancillary studies may eliminate need for delay in second exam
  - Cerebral angiography
  - EEG
  - Radionuclide cerebral blood flow

## Examiners

- Two different attending physicians
- Both with specific training in neurocritical care
- Both familiar with infants and children
  - Pediatric Critical Care
  - Neonatology
  - Child Neurology
  - Pediatric Neurosurgery
  - Pediatric Trauma Surgery
  - Pediatric Anesthesiology with Critical Care Training

## CONTROVERSIES

### What is Death by Neuro Criteria?

- Uniform Determination of Death Act
  - Irreversible cessation of all functions of the entire brain, including the brain stem
- Distinct from cortical “death” (PVS)
- but...Can a patient be dead without having DI?
- Some discussion of irreversible cessation of the brain as a whole (integrated functions)

### Legal Death vs Biological Death

- Similar to blindness
  - My be legally blind but not *completely blind*
- Is it okay for someone to be legally dead but not *completely dead*?

### Abandon Death by Neuro Criteria?

- Some have argued that brain death is fallacy
- Brain death manufactured to get organs
- Abandon dead donor rule and allow alive individuals to donate their organs based on the principles of respect for persons and nonmaleficence
  - Patients who are imminently dying
  - Patients who are permanently unconscious
- Former nomenclature “irreversible coma”

### Summary

- Death by neurological criteria remains confusing and controversial
- Many members of the lay public and the media have major misunderstandings
- Many clinicians do not fully understand
- Even seemingly minor misstatements can lead to significant confusion
- Only pediatric neurocritical care specialists are qualified to determine death by neuro criteria

