Refusing Needed Treatment: Ethics in Rehabilitation Medicine

Arkansas Trauma Rehabilitation 2017

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The Consensus

- The goal of treatment is to find the best balance of benefits over burdens in the available and acceptable alternatives
  - Limited by patient preferences
  - Limited by available resources
  - Limited by the needs of others
- The goal is the same at the end of life
- Treatments may be withdrawn if they no longer achieve the goal

Who decides?

- The patient with decision-making capacity
  - Patient usually either does or does not have capacity
- Advance directives should be honored
- Oral directives are acceptable (document)
- Family members or close personal friends decide for incapacitated patients
  - What would the patient want?
  - What is best for the patient?

I. What about Rehab?

- Choosing goals of treatment
  - Decision-making may be impaired by stroke, trauma, or other long-lasting causes
  - Partial capacity may fluctuate according to mood, setting, time of day, influence of drugs
  - Goals must frequently be adjusted to accommodate lasting impairment
  - Despondent patients may not "buy into" ambitious but realistic goals (<paternalism?)

Elizabeth Layton, Stroke (1978)

Increased Paternalism?

- Persuasion of the despondent patient
- Permanent impairment produces depression (rational vs. irrational, treatable vs. untreatable)
- Overriding patient's rejection to enhance or restore competence: autonomy as a goal rather than a principle
- Creating a new self
  - Developing new values and goals in partnership
  - *(Whose Life Is It, Anyway?)*

Role of the Family

- Acute care: turn to family only if patient is unable to decide; consider only patient preferences and interests
- Rehabilitation: family centrally involved
  - Helping compromised patient set goals
  - Encouraging to work toward goals
  - Providing care in home afterward
    - Level of recovery necessary for home setting
    - Resources available to care for patient

Implications of greater family role

- In acute care, patient welfare is dominant
  - Interests of others are relevant but less compelling
- In long-term care and rehab, family interests assume greater importance
  - Balancing of legitimate interests (e.g. job)
  - Assuring cooperation to achieve goals

Confidentiality

- Rule in all professions
  - Wrong to tell secrets
  - Consequences
- More information needs to be shared in setting goals and matching to resources
- Privacy still a basic value
- HIPAA still operative; so permission needed
- Inform client of any limits

Advance Directives in Rehabilitation Setting

- Hope for progress, not anticipation of reversal
- Nevertheless, all patients should consider ADs
  - Not only for frail elderly (Quinlan, Cruzan, Schiavo)
  - Some rehab patients at risk for further, more acute stroke or infarct (rush to ICU?)
  - Many suffer from multiple problems (e.g. diabetes, cardiac insufficiency)
  - Perhaps at exit interview, if not before
  - If discharged to home, someone should have power of attorney for health care

II. Institutional Ethics Committees

- Hospital ECs
  - AMA – 1985
  - AHA – 1986
  - JCAHO – 1992

- Membership
  - Medicine
  - Nursing
  - Pharmacy
  - Allied health
  - Social work
  - Ethics
  - Law
  - Ministry
  - Administration
  - Community

Hospital EC Functions

- Education
- Policy
- Consultation
  - Whole committee
  - Individual consultant
  - Team

Code of Professional Ethics for Rehabilitation Counselors

- Adopted September 2016
- Serves as guide to assist rehab counselors in resolving ethical issues
- Available at www.crccertification.com
- Or by calling (847) 944-1325

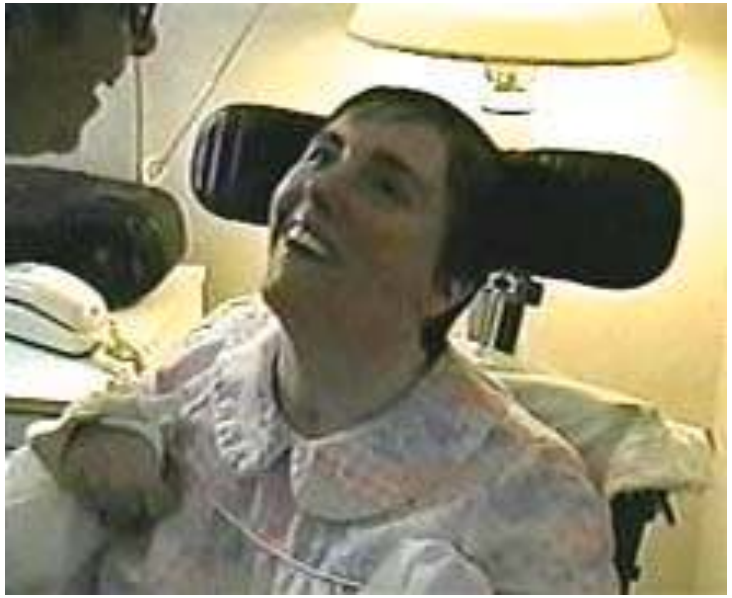
Some issues in Code

- Conflict of business and professional interests
- Sexual misconduct with clients or students
- Fraudulent use of credentials
- Failure to act as a client advocate
- Disparaging remarks about a client
- Inappropriate billing practices
- Use of an illegal substance
- Improper supervision techniques

CCMC Code

- Council for Case Management Certification Code of Professional Conduct
- https://ccmcertification.org/content/ccm-exam-portal/code-professional-conduct-case-managers

III. Challenge to Rehab: the Minimally Conscious State



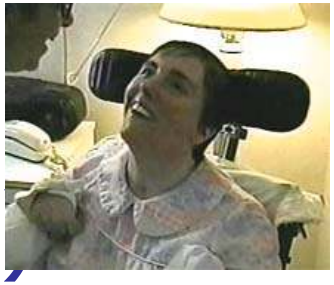
Consensus in Law and Ethics

- Competent patient may refuse treatment in an advance directive
- Family may exercise choice on behalf of incompetent patient with no directive
- Family should:
  - Decide as patient would decide
  - Choose what is best for the patient
- Life-sustaining treatment can be withdrawn from a permanently unconscious patient

Terry Schiavo

- 1990: heart attack (hypo-K), severe brain damage from lack of oxygen
- Neurologists diagnose persistent vegetative state
- Husband is surrogate under FL law; he testifies she would not want feeding tubes
- Parents reject PVS diagnosis, insist on continued feeding
- 2001: Fla. trial court agrees with husband; appeals court affirms decision; Fla. Supreme Court refuses to hear further appeal

Terry Schiavo (cont.)



- 2003: Feeding tubes removed second time; Fla. Legislature passes "Terri's Law"; Governor Jeb Bush signs bill; tubes reinserted
- Fla. Supreme Court invalidates law as violating separation of powers
- 2005: Feeding tubes removed third time on March 18; U.S. Congress passes "emergency measure;" President Bush flies in by helicopter to sign bill, making a "federal case" of it
- U.S. District Court in Florida denies emergency request to reinsert feeding tubes; says courts decided properly; U.S. Supreme Court refuses to review
- March 31, 2005: Terry Schiavo dies 13 days after feeding tubes were removed

A similar case?

Terry Wallis at home in Harriet, Ark.

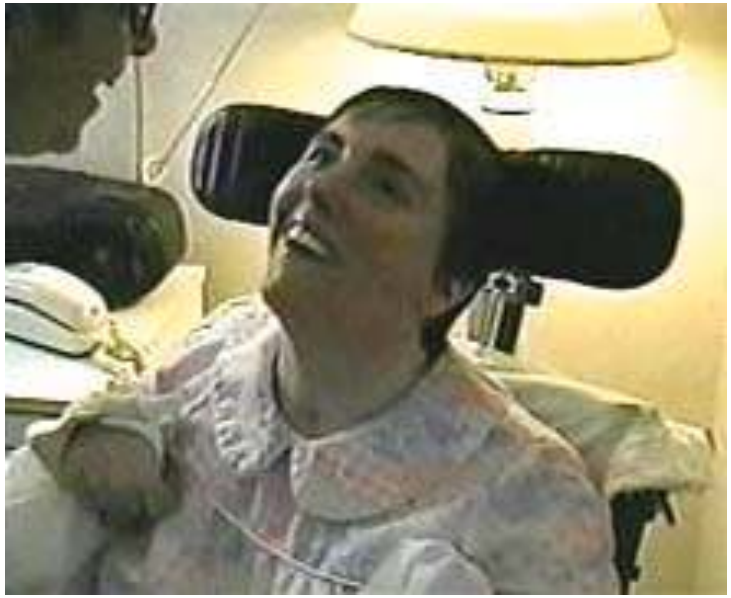
Terry Wallis speaks with his mother Angilee before a doctor appointment on June 8, 2005 in Little Rock (ABC News file photo)

Terry speaks to his daughter

Popular misunderstanding

- “As more and more is learned about how the human brain 'regenerates' itself, I believe that more people will come to realize just how evil, and heartless, the public execution of the innocent brain-injured Terri Schiavo really was.”
  - From a web log dated Jan 9, 2007

The difference is the diagnosis: Permanently unconscious vs. minimally conscious



Degrees of Loss of Consciousness

- Death: Permanent loss of consciousness and brain stem function
- Coma: eyes closed, no response to stimuli
- Vegetative state: wakeful, but no evidence of
  - Reproducible or purposeful response
  - Language comprehension or sense of self
- Minimally conscious state: responses that are
  - Episodic, inconsistent, unpredictable
  - Capable of increasing quality and consistency

Sequence of recovery

Coma (2-4+ weeks) =>

Persistent vegetative state =>

Permanent vegetative state

o*r*

Minimally conscious state =>

Functional communication =>

?????

Multi-society Task Force on PVS
N. Engl. J. Med. 330(21): 1499-1508 (1994)

- Coma lasting longer than 30 days = Persistent Vegetative State
- Becomes Permanent Vegetative State
  - With anoxic injury: after 3 months
  - With traumatic injury: after 12 months

Joseph J. Fins, CONSTRUCTING AN ETHICAL STEREOTAXY FOR SEVERE BRAIN INJURY: BALANCING RISKS, BENEFITS AND ACCESS *Nature Reviews Neuroscience* **4**, 323-327 (2003); doi:10.1038/nrn1079

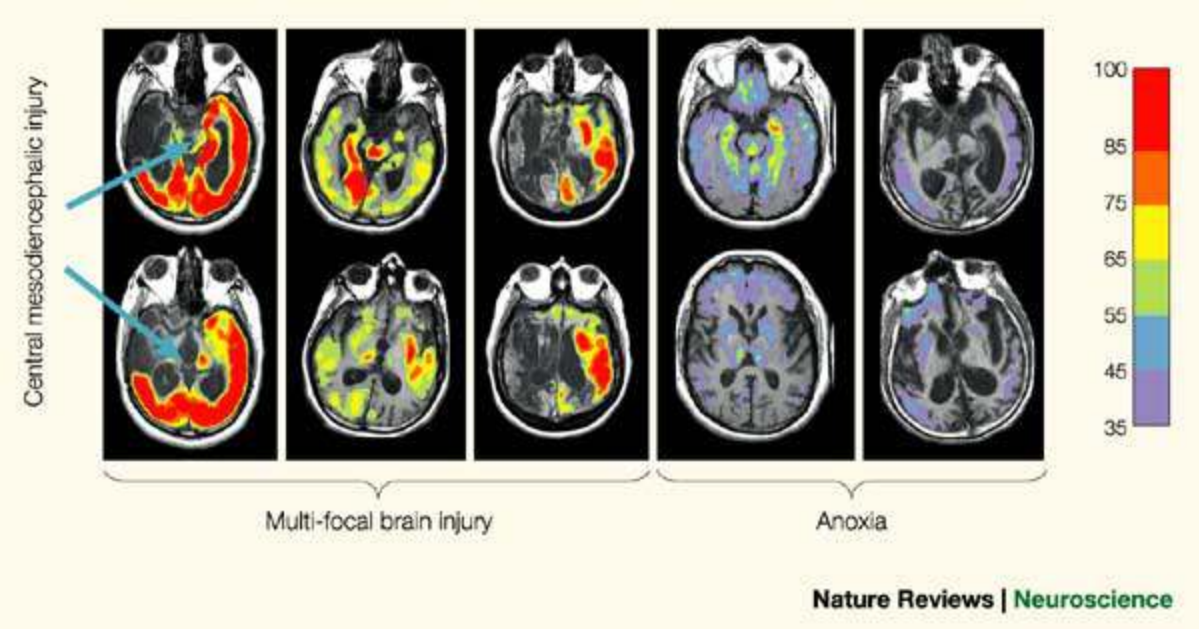
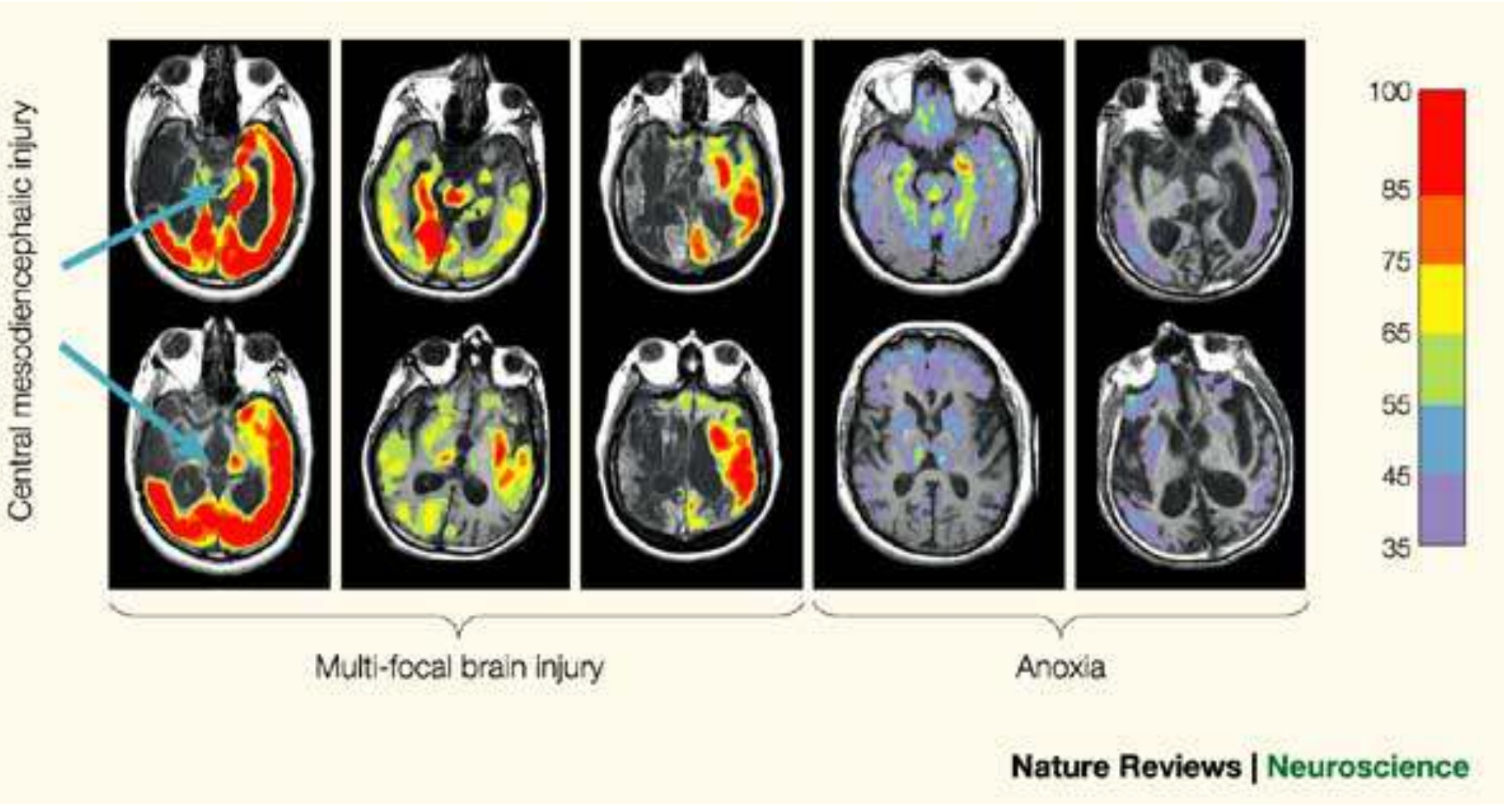
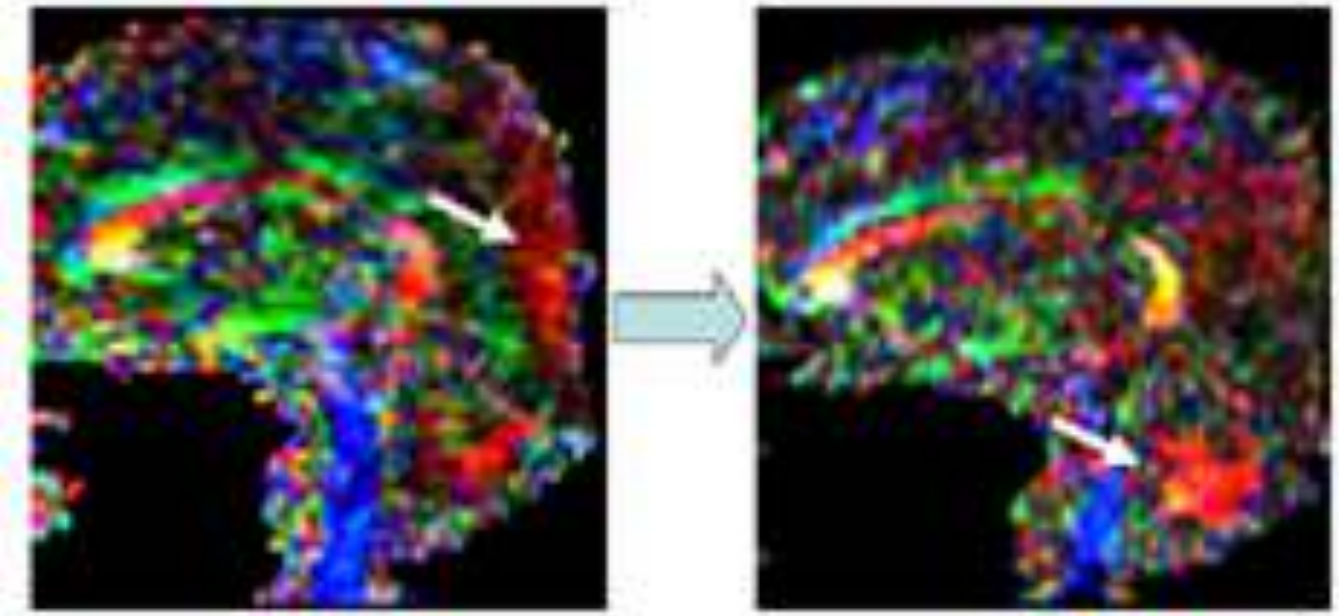


Figure 1 | **Widely varying patterns of resting metabolic activity observed in patients in a chronic persistent vegetative state.** A wide range of regional variation in resting cerebral metabolic activity is observed in five patients, including a unique pattern of widely preserved metabolic activity in a patient with overwhelming injury to the central mesodiencephalon (far left). Reproduced, with permission, from Ref. 19 © (2002) Oxford University Press.


Central mesodiencephalic injury
100
85
75
65
55
45
35
Multi-focal brain injury
Anoxia
Nature Reviews | Neuroscience

Diffusion tensor images of brain at the first scan (left) and 18 months later (right). Color shows direction of white matter fibers, e.g., green for anterior-posterior fiber tracts. Large red area in second scan (arrow) shows what scientists think is growth of new neural processes in a part of the brain that controls movement.

Weil Cornell CitigroupBiomedical Imaging Center/Henning U. Voss.)



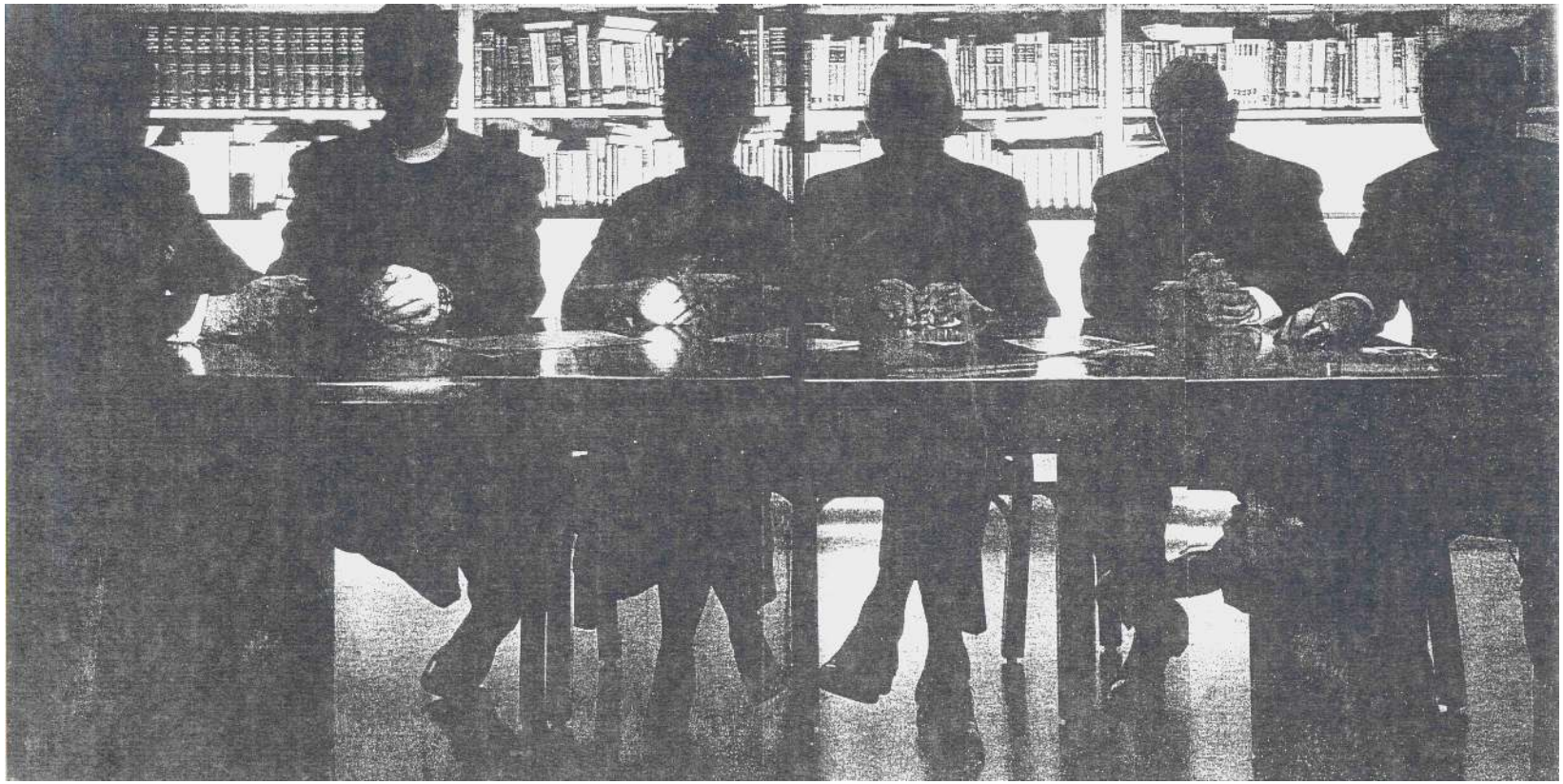
Terry in Rehab

Remaining dilemmas

- Incidence and prevalence unknown
- Estimated incidence: 56-170/million in USA sustain severe traumatic head injury *each year*
- The prevalence in USA estimated between 112,000 to 280,000 in adult and pediatric cases
- Projected average lifetime/person cost ranges from $600,000 to $1,875,000 with a single reported cost of just in-hospital cost of $6,104,590

Neurology 2002;58:349-353

Justice: allocation of scarce resources



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- Guidelines for requesting an advisory opinion from the CRCC Ethics Committee (https://www.crccertification.com/advisory-opinions)
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