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- Treatments may be withdrawn if they no longer achieve the goal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](http://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
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
“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

or

Minimally conscious state =>
Functional communication =>
??????
Multi-society Task Force on PVS

- 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
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.
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 Citigroup Biomedical 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
Bibliography

- John Banja, "Rehabilitation medicine" in Bruce Jennings (ed.) Bioethics (Gale, 2014).
- Guidelines for requesting an advisory opinion from the CRCC Ethics Committee (https://www.crccertification.com/advisory-opinions)
- V.M. Tarvydas and R.R. Cottone, 'The code of ethics for professional rehabilitation counsellors: what we have and what we need" (http://journals.sagepub.com/doi/abs/10.1177/003435520004300402)
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