Advance Care Planning Workshop

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Disclosures

- No financial conflicts of interest
- Dr. Hook's comments are solely his own and do not necessarily reflect the views of the Mayo Clinic or Foundation

Objectives

- To review the elements of good advance health care planning
- To assist in the preparation of a personal health care directive
- To understand the importance of, and prepare an action plan for, communicating the contents of an advance healthcare directive with their designated surrogate and healthcare professionals

What is the purpose of advance health care planning?

Why do we need it?

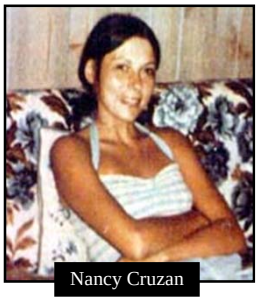
Matter of Quinlan

70 N.J. 10 (1976), Supreme Court of New Jersey

- Patients have the right to refuse treatment, even if doing so results in death
- If patients are incompetent, a surrogate may exercise the patient's right for them; such decisions are better made by families, not courts
- The state's interest in preserving life can be overridden by the patient's right to refuse treatment

Cruzan *v.* Director, Missouri Department of Health

- 1983: MVA; never gains consciousness
- 1988: parents seek removal of feeding tube
- Hospital refuses without court order
- Trial court orders removal of tube



Nancy Cruzan

CRUZAN: Missouri Supreme Court

- Must have clear and convincing evidence of a patient's wishes before removal of feeding tube
- Nutrition and hydration are not medical treatments
- State's interests in preserving life outweighs patient's interests
- Therefore, the tube could not be removed

CRUZAN: United States Supreme Court

- Competent adults have a constitutional right to refuse treatments
  - "Liberty interest" under the 14th Amendment (not the "privacy interest" under the 1st Amendment)
- Nutrition and hydration are medical treatments

CRUZAN: United States Supreme Court

- U.S. Constitution does not prohibit states from adopting a "clear and convincing" evidentiary standard
  - Each state may establish its own standards and criteria for these decisions
  - Upheld Missouri's requirement for clear and convincing evidence to permit withdrawal of treatment

Nancy Cruzan

The rest of the story

- Cruzan died in 1990
- Her death occurred 12 days after a state court allowed withdrawal of her feeding tube (the decision was based on new evidence of her wishes)

Vacco v Quill

Supreme Court of the United States

June 26, 1997

- **Chief Justice Renquist, for the Court, rejected the "Equivalence Argument" which invoked the Equal Protection Clause to state that patients who had life support to refuse had an unfair opportunity to end their lives that those not requiring such measures were denied.**
- **"The distinction comports with fundamental legal principles of causation and intent. First, when a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication….[In Cruzan] our assumption of a right to refuse treatment was grounded not…on the proposition that patients have a general and abstract "right to hasten death", but on well established, traditional rights to bodily integrity and freedom from unwanted touching."**

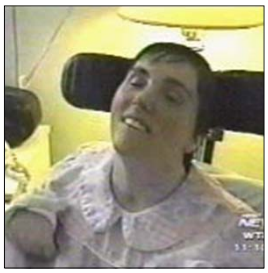
Withholding and withdrawing LSTs, physician assisted suicide and euthanasia: What are the differences?

	Withhold LST	Withdraw LST	Palliative sedation and analgesia	Physician-assisted suicide	Euthanasia
Cause of death	Underlying disease	Underlying disease	Underlying disease‡	Intervention prescribed by physician and used by patient	Intervention used by physician
Intent/goal of intervention	Avoid burdensome intervention	Remove burdensome intervention	Relieve symptoms	Termination of patient's life	Termination of patient's life
Legal?	Yes†	Yes†	Yes	No*	No

LST = life-sustaining treatment
‡Note "double effect"
†A number of states limit the power of surrogate decision-makers regarding LSTs
*Legal only in Oregon, Washington, and Montana

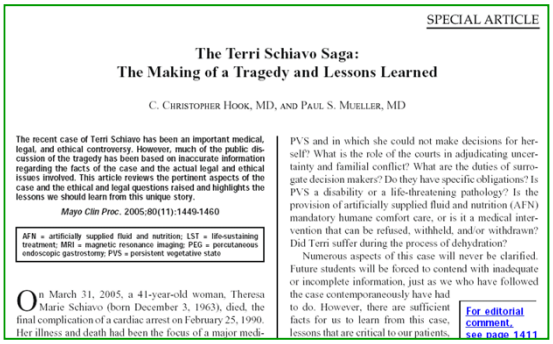
Patient Self-Determination Act (PSDA)

- Congressional response to *Cruzan*
- Does not create new rights for patients to make healthcare decisions
- However, it requires that patients are given information about existing rights and state law
- Effective December, 1991



Theresa Marie Schiavo

December 3, 1963 - March 31, 2005



SPECIAL ARTICLE

The Terri Schiavo Saga: The Making of a Tragedy and Lessons Learned

C. Christopher Hook, MD, and Paul S. Mueller, MD

The recent case of Terri Schiavo has been an important medical, legal, and ethical controversy. However, much of the public discussion of the tragedy has been based on inaccurate information regarding the facts of the case and the actual legal and ethical issues involved. This article reviews the pertinent aspects of the case and the ethical and legal questions raised and highlights the lessons we should learn from this unique story.

Mayo Clin Proc. 2005;80(11):1449-1460

AFN = artificially supplied fluid and nutrition; LST = life-sustaining treatment; MRI = magnetic resonance imaging; PEG = percutaneous endoscopic gastrostomy; PVS = persistent vegetative state

On March 31, 2005, a 41-year-old woman, Theresa Marie Schiavo (born December 3, 1963), died, the final complication of a cardiac arrest on February 25, 1990. Her illness and death had been the focus of a major medi-

PVS and in which she could not make decisions for herself? What is the role of the courts in adjudicating uncertainty and familial conflict? What are the duties of surrogate decision makers? Do they have specific obligations? Is PVS a disability or a life-threatening pathology? Is the provision of artificially supplied fluid and nutrition (AFN) mandatory humane comfort care, or is it a medical intervention that can be refused, withheld, and/or withdrawn? Did Terri suffer during the process of dehydration?

Numerous aspects of this case will never be clarified. Future students will be forced to contend with inadequate or incomplete information, just as we who have followed the case contemporaneously have had to do. However, there are sufficient facts for us to learn from this case, lessons that are critical to our patients,

For editorial comment, see page 1411

In re Guardianship of Browning

568 So. 2d 4, 10 (Fla. 1990)

- **"An integral component of self determination is the right to make choices pertaining to one's health, including the right to refuse unwanted medical treatment."**
- **"[A]n incompetent person has the same right to refuse medical treatment as a competent person."**

Florida Statutes, Chapter 765

Health Care Advance Directives

- **"…every competent adult has the fundamental right of self-determination regarding decisions pertaining to his or her own health, including the right to choose or refuse medical treatment."**
- **The statute provides standards for the exercise of an incompetent person's right to refuse treatment in order to "insure that such a right is not lost or diminished by virtue of later physical or mental incapacity…"**

Terri Schiavo's Saga

Summary

- 3 guardians *ad litem*
- 10 decisions by the DCA of Florida
- 4 reviews by Florida Supreme Court
- 4 times the US Supreme Court declined relief to interested parties
- Unprecedented involvement of the judicial, executive and legislative branches of the US government at all levels

You Are Never Too Young As An Adult to Create An Advance Directive!!!

Wendland v. Wendland

26 Cal 4th 519, 28 P.3d 151, 2001

- 1993: MVA; regains consciousness, but has severe brain damage, is totally dependent and requires a feeding tube
- 1995: Wife, citing prior discussions, refuses to authorize reinsertion of feeding tube claiming he would not have wanted it replaced; daughter and brother agree, but mother does not

Wendland v. Wendland

26 Cal 4th 519, 28 P.3d 151, 2001

- 2001:
  - Wendland dies of pneumonia while court deliberating
  - CA Supreme Court unanimously rules that the patient's prior oral statements were not clear and convincing because they did not address his current condition and that his wife failed to provide sufficient evidence that her decision was in his best interest

Who Speaks For a Patient When The Patient Cannot Speak?

Who Decides When a Patient Cannot?

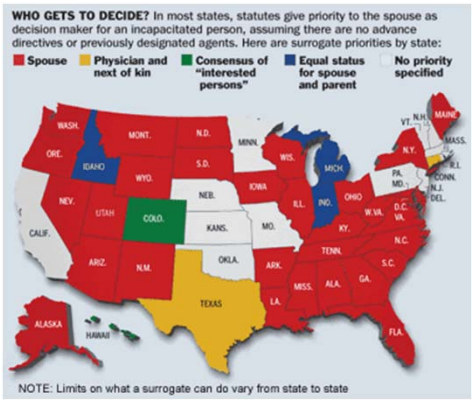
- Person designated by an advance directive
- Court-appointed surrogate
- Proxy

The Case of Mr. E.D. and the Clueless Family

Florida Statutes, Chapter 765

Health Care Advance Directives

- **765.401 The Proxy**
  - **If an incapacitated …patient has not executed an advance directive, or designated a surrogate to execute an advance directive…health care decisions may be made for the patient by any of the following individuals, in the following order of priority:**
  - **judicially appointed guardian**
  - **the patient's spouse**
  - **an adult child of the patient, or majority of children**
  - **a parent of the patient**
  - **an adult sibling, or majority of siblings**
  - **an adult relative**
  - **a close friend of the patient**



What Happens When It Is Suspected that a Surrogate May Not Be Acting in the Best Interests of the Patient?

Helga Wanglie

"…the institution saw the respirator as 'non-beneficial'…In the [pt's and] family's view, however, merely maintaining life was a worthy goal, and the respirator was not only effective toward that end, but essential."

NEJM 1991;325:512-515

The Fundamental Question Before the Courts is "What Would The Patient Want?"

Quinlan:
- Family wanted to withhold LST
- Institution did not
- Court: affirmed right of families to make decisions about LST when patient cannot

Wanglie:
- Family wanted LST
- Institution, claiming futility, did not
- Court: affirmed right of families to make decisions about LST when patient cannot

LST = life sustaining treatment

Why Do We Need Advance Healthcare Planning?

- To respect each individuals values, beliefs, goals, fears and wishes concerning their life, death and treatment
  - To avoid unwanted interventions
  - To avoid technologically induced and maintained physiological limbo
- To allow these values to be expressed, even when the patient lacks decision-making capacity
- To allow the individual to declare who they would want to speak for him or her, when unable to do so for oneself
  - To empower the desired surrogate in the face of opposition from other individuals
  - To simply and clarify decision-making authority

ADVANCE DIRECTIVES

- Definition: written (or verbal) healthcare instructions for time when patient lacks decision-making capacity
  - Living will
  - Power of attorney for healthcare
  - Minnesota Health Care Directive: has features of living will and POA
  - Medical treatment directive
- All 50 states and District of Columbia

The Law and Advance Directives

- AD must be honored if requests are reasonable, legal and treatments available
- If unwilling to honor AD, physician must notify patient or surrogate and note in medical record
- Cannot deny care if no AD

What Should Be Put Into An Advance Directive - 1 ?

- Name of surrogate, as well as secondary and/or tertiary surrogates
- Goals and values; Religious beliefs
- Specific treatments
  - Desired
  - To be avoided
- Post *Schiavo*, wise to specifically address artificial fluid and nutrition (AFN)
- If have a pacemaker, ICD, etc., would specify when or if to discontinue (D/C)

What Should Be Put Into An Advance Directive - 2 ?

- "Intrusive" mental health treatments that use electroshock therapy or neuroleptic medications
- What to do if pregnant
- Consideration of time limited trials
- Place of care
- Donation of organs
- Willingness for autopsy
- Posthumous Reproduction

What Should Be Put Into An Advance Directive - 3 ?

- Specific Treatment Considerations:
  - CPR & resuscitation
  - Mechanical ventilation
  - AFN
  - Hemodialysis
  - Donation After Cardiac Death (DCD)

What Are the Duties of a Surrogate Decision-Maker?

- Must follow patient's AD (if extant)
- Substituted judgment standard
  - Not what the family (or others) wants, but what the patient would want
  - "If the patient could wake up for 15 minutes and understand his or her condition fully, and then had to return to it, what would he or she tell you to do?" (Quill T. *NEJM* 2005;352:1630-1633)
- Best interest standard

The Case of the Contrary Surrogate

The Case of the Fraudulent Surrogate

How Accurate Are Surrogates?

- Spouses over- and physicians under-estimate patient desire for CPR[1]
- Surrogates not much better than chance[1-3]
- Accuracy: education, insurance, EOL talks[3]
- No effect on accuracy: age, race[3]
- 87-90% patients believe surrogates know their wishes[2]

[1] *J Geront* 1988;43:M115
[2] *Ann IM* 1991;15:92
[3] *Ann IM* 1998;128:621

Working With Your Surrogate

- Appoint ONE surrogate, and a second and third choice if the first is unable or unwilling to perform the duties
- AVOID appointing dual surrogates or a committee
- Assume nothing - Discuss everything
- Make sure your surrogate understands your wishes, the rationale for the them, and is willing to comply
- If the individual is not willing to abide by your desires, find another surrogate
- You may need to revise your directive to clarify issues based upon the discussion

What Do I Do With My Advance Directive?

- Notarize?
- DO NOT PLACE IT IN YOUR LOCKBOX!!
- Discuss contents with all pertinent health care providers to ensure understanding and compliance
  - Modify as necessary
- Discuss with other family members or significant parties, in addition to surrogate (Kitchen Table Talk)
- Provide final copies to all pertinent health care providers, chosen surrogates and pertinent significant others
- Review (and revise as necessary) every three years, or if there is a major change in health status or the status of your surrogate
- If you are chosen as a surrogate, it may be helpful to touch base with the patient every few years yourself to make sure their views have not changed

The Case of the Incompetent Advance Directive

Do Not Resuscitate (DNR) Orders

- DNR: the withholding of CPR and ACLS for cardiac arrest (pulseless patient)
- A DNR order may be compatible with maximal therapy
- Must get informed consent for DNR order

CPR on Television

NEJM 1996;334:1578

- Patients and physicians overestimate the success of CPR
- Point of reference may be TV
- Episodes of *ER*, *Chicago Hope* and *Rescue 911* reviewed
- CPR occurred 60 times in 97 episodes
- 75% immediate survival, 67% STD

What Are the Outcomes of CPR?

J Gen Int Med 1998;13:805

- Meta-analysis of 10 studies
- Immediate survival 41%
- Survival to discharge 13%
- Lower survival: sepsis, cancer, dementia, AA race, renal insufficiency
- Greater survival: CAD, CPR in ICU
- Age: no impact

CPR Outcomes by Setting

Survival to discharge:

- Cancer: 11%[1,2]
- ICU: 5-11%[3,4]
- Dialysis: 8%[5]
- Nursing home: 0-5%[7]

References:

1. *JCO* 1991;9:111
2. *Anesth Analg* 1993;76:479
3. *Chest* 1991;100:168
4. *Arch IM* 1992;52:2305
5. *J Am S Neph* 1992;3:1238
6. *Ann IM* 1989;111:199
7. *Arch FM* 1997;6:424

Who Survives CPR?

J Crit Care 1997;12:142

- 308 patients underwent CPR
- 99 (32%) resuscitated; 41 (13%) STD: all 41 previously healthy and experienced a sudden unexpected arrhythmia
- Poor performance status most important negative predictor
- Average length of CPR: survivors 9 minutes, non-survivors 27 minutes
- Greater survival: VT or VF

What Are the CNS Outcomes of CPR Survivors?

- 26-57% of CPR survivors are neurologically impaired[1]
- One year after CPR:
  - 48% moderate cognitive impairment
  - 45% depression (24% severe)[2]

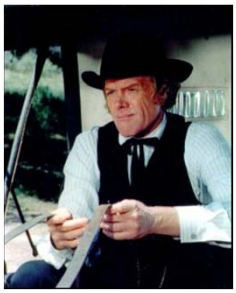
[1] *Neurology* 1993;43:2173
[2] *JAMA* 1993;269:237

Should DNR Orders Be Honored During Procedures?

- Yes: principle of double effect
- The patient may accept mortality risk of surgery and other procedures
  - Analogous to JW who declines blood, yet accepts other treatments
- Prohibiting DNR order may deny palliative surgery and other treatments
- However, cannot *force* a surgeon or anesthesiologist to operate with a DNR
- Need to assess before all procedures

Are Artificially Supplied Nutrition & Hydration Medical Therapy or Mandatory Care?

The Little House on the Prairie Test



- Requires expertise to insert and maintain a feeding tube
- Similar to other LSTs
- Complications (*J Gen Intern Med* 1996;11:287-293)
- Death of patient despite "basic" care

Tube Feeding in Patients With Advanced Dementia

Finucane, et al. *JAMA* 282:1365-1370, 1999

- Tube feedings failed to
  - Prevent aspiration pneumonia
  - Prolong survival
  - Reduce risk of pressure sores or infection
  - Improve function
  - Provide palliation of symptoms
- For severely demented patients, the practice of tube feeding should be discouraged

Is Terminal Dehydration "Barbaric and Painful"?

Comfort Care of Terminally Ill Patients The Appropriate Use of Nutrition & Hydration

McCann, et al. *JAMA* 272:1263-1266, 1994

- 32 patients over 12 months; all aware & communicative
- 63% never experienced hunger
- 34% only experienced hunger briefly at first
- 62% never experienced thirst, or only briefly at first
- In all patients, any symptoms of hunger, thirst and dry mouth could be alleviated by small amounts of food, water and/or by ice chips and lubrication for the lips

Questions & Discussion

Thank You!

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