

Ethical Challenges in Neurologic Rehab

Refusing Life-Sustaining Care: Liberty or Suicide?

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Course Objectives

- Understand how **values** drive moral decision-making and behavior
- Outline legal framework for understanding **ethical principles** related to the right to refuse
- Define **informed consent** and **competency**
- Differentiate between **refusing medical intervention** and committing **suicide**
- Recognize **quality of life** judgments made regarding individuals with disability
- Participate in a **discussion** of potential evaluative strategies for determining informed consent after acquiring a disability

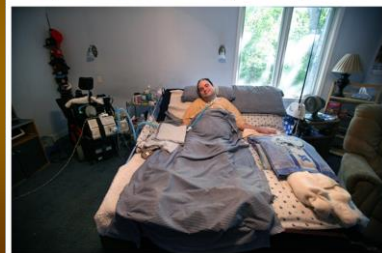
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Have you ever had a noncompliant patient?



Is that the problem with the Dan Crews case?

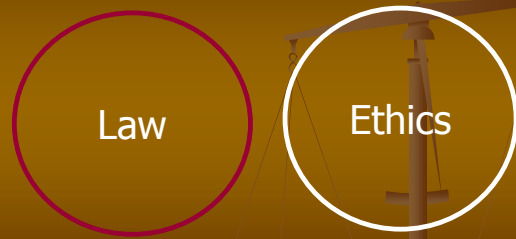
Paralyzed accident victim fights for right to die



What guidance do we have to help us evaluate these situations?



Legal vs. ethical



Law

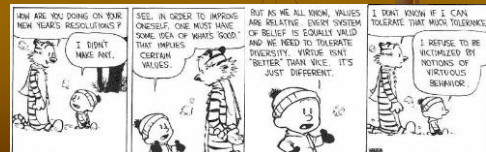
Ethics

- | | |
|---|--|
| <ul style="list-style-type: none"> ■ "Must" ■ Defined by gov't ■ Based on concepts of justice and equality ■ Formal rules ■ Public protection ■ Minimum standard ■ Enforced by regulatory authorities and courts | <ul style="list-style-type: none"> ■ "Should" ■ Defined by individual and community ■ Based on "good" life ■ Informal guidelines ■ Public trust ■ Ideals or aspiration ■ Based on customs, professional standards |
|---|--|

Purtillo '11

Where do ethics come from?

- Morals
 - Social conventions about right / wrong human behavior
 - Guided by **values**



Values → ideas / beliefs → behavior

Purtillo '11, Sim '97

Codes of Ethics

- Provide guidance by articulating the backbone of moral understanding that informs the **profession**
- Represents professional consensus
- Shared voice of the profession about responsible conduct
- Official statement of professional commitment to promote public good
- Promotes **public trust**

Gabard '03

Professionalism in PT: Core Values

Accountability
Altruism
Compassion / caring
Excellence
Integrity
Professional duty
Social responsibility

APTA '03

What are our ethical responsibilities in these cases?

- Code of Ethics, Principle:
 - 2A: PTs shall adhere to the core values of the profession and act in the best interests of the pts over the interests of the therapist
 - 2C: PTs shall provide the info necessary to allow pts to make informed decisions about PT care
 - 2D: Pts shall collaborate with pts to empower them in decisions about their health care

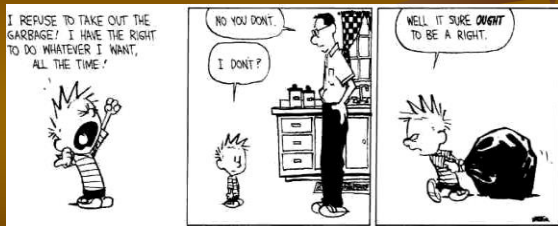
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Do patients have the right to refuse?

- Principle of **Autonomy**:
 - "Every human being of adult years and **sound mind** has a right to determine what shall be done with his own body"
 - Justice Cardozo in *Schloendorff* (1914)
 - Includes
 - Positive right of ensuring access to something
 - Negative right of not being interfered with

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Are there any limits on what a patient can refuse?



Do they have a right to die?

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When does patient autonomy create a conflict for us?

- When what they want isn't in their best interest
- **Beneficence:** what is best for each person is what should be done – provide a benefit
 - Positive obligation to do that which is good
 - Negative obligation to do no harm (nonmaleficence)

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What are our ethical obligations in providing a benefit?

- Principle 2A: PTs shall adhere to the core values of the profession and act in the **best interests** of the pts over the interests of the therapist
- Principle 3A: PTs shall demonstrate independent judgment in the pt's **best interest** in all settings

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Who gets to decide what is in the pt's best interest?

- The pt themselves, if they are **autonomous**
 - Based on the **PATIENT's** values
- What if they are unable to decide for themselves?
 - Previously competent but now not
 - Advanced directive
 - Previously stated wishes
 - Never competent

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1975 Karen Ann Quinlan

- 21 yo consumed alcohol and Valium
 - became comatose
 - diagnosed as in PVS
- Parents wanted ventilator removed
- MDs refused
- Courts granted
 - 1st "Right to Die" case
 - Substituted judgment
- She lived 10 more years



Quill '05, Fine '05

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1983 Nancy Cruzan

- 25 yo in auto accident
- Initially PNB; resuscitated
- Eventually breathing on her own
 - 1989 Parents wanted feeding tube to be removed
- MDs refused
- US Supreme Court: parents can direct care
 - "Clear and convincing evidence"



Quill '05, Fine '05

1990 Terri Schiavo

- 27 yo anoxic brain injury
- Many physicians provided clear and convincing evidence of PVS with no hope of recovery
- Parents refused to believe
- 1998 Husband wanted feeding tube removed
 - Substituted judgment or best interest standard
- Case heard in court > 20x
- 2005 tube permanently removed



Quill '05, Fine '05



Advanced directives

- Given statutory recognition
- Respected in the eventuality that one loses one's decision-making capacity
- Includes living wills, durable powers of attorney
- Following ADs respects the autonomy, individuality, and self-determination of patients

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Advanced directives

- Seldom address the exact decision at hand
- Statements may be very general or vague
- Often have been made with implicit assumptions about their status or prognosis
- Some people change their minds
 - 15-20% of people change their mind about life-sustaining rx over the course of their illness
- They may not have been **informed**

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Lo '95

Informed Consent

- Based on principle of **autonomy**
- Elements
 - Disclosure (prognosis, risk / benefit)
 - Cognition (understanding, appreciation)
 - Consent / refusal / choice
- Conditions
 - Freedom from controlling influences
 - Competence / decision-making capacity

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Freedom from controlling influence

- **Persuasion**: convinced through reasoning
- **Manipulation**: getting someone to do something (for reasons you keep secret), which they would never do if they knew what your reasons were
- **Coercion**: intentional use of credible and severe form of threat to control another

In the matter of Baby M, 537 A2d 1227 (NJ 1988)

- Payment to be the surrogate and biological mother for a baby that is given up to the biological father at birth
- Contract was considered to be invalid
 - Use of money = coercion
 - Irrevocable agreement to give up child before birth (even before conception) is unenforceable in private placement adoption
 - Agreement to surrender baby occurs only after birth and only after the birth mother has been counseled

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Competency

- Evidence a choice
- "Reasonable" outcome of choice
- Choice based on "rational" reasons
- Ability to understand
- Actual understanding

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West '91

Decisional capacity

- Preferred term indicating that such capacity will vary across decisions and over time
- Seems to support the notion that people change their minds and this is acceptable to some degree
- Stable commitment is also a strong factor

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West '91

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research

- Definition of decision-making capacity
 - Possession of a set of values and goals
 - Ability to communicate and to understand information
 - Ability to reason and deliberate about one's choices

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West '91

Assessment of decision-making capacity

- Pt makes and communicates a choice
- Pt appreciates the situation, prognosis, nature of rx, alternatives, risk / benefit, consequences
- Pt's decision is stable over time
- Decisions are consistent with pt goals and values
- Decisions should not result from delusions
- Decisions should be rational

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Lo '95

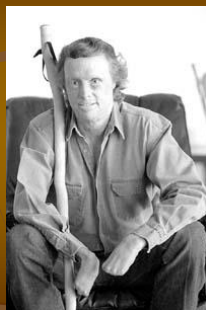
Are we always rational?



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Dax (1973)

- Donald Cowart was critically injured in an oil tank explosion
 - sustained severe 2° & 3° burns over 68% of his body
 - blind and disfigured
- Despite repeated demands to stop treatment, and being declared competent, the medical team forced him to endure painful procedures and surgeries for more than a year



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Paternalism

- Overriding a patient's autonomous decision in order to produce a good outcome for the patient
- Paternalism in the short term may be the best way to produce long-term autonomy
 - As a means to an end, not an end in itself
 - Caplan '88, Sim '98
 - Greater tolerance of paternalism may be justified when accommodation and acceptance is needed to "come to grips" with the reality of one's impairments
 - Caplan '88

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Bouvia v. Superior Court, 179 Cal.App.3d 1127, 225 Cal.Rptr.297 (1986)

- 28 yo female with CP and severe arthritis wanted her feeding tube removed
- Completely dependent, with constant pain and lack of social support prevented her from living outside the hospital
- Court upheld her right to refuse medical rx - not limited to terminal cases

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Suicide

- The State has an interest in
 - Preserving life
 - Protection of the interests of innocent 3rd parties
 - Prevention of suicide
 - Maintenance of the ethical integrity of the medical profession
- Some have argued that these countervailing interests could overcome a patient's choice

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- All states have abrogated laws making suicide a crime, but most prohibit assisting a suicide

- California Penal Code Section 401. Suicide; aiding, advising or encouraging
 - "Every person who deliberately aids, or advises, or encourages another to commit suicide, is guilty of a felony."



AMA Council on Ethical and Judicial Affairs

“Withholding or Withdrawing Life Prolonging Medical Treatment”

- Declares that the social commitment of the physician is to sustain life and relieve suffering
- Where the performance of one duty conflicts with the other, the choice of the **patient** should prevail

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- AMA Ethics and Health Policy H140.952
 - Physician assisted suicide is fundamentally inconsistent with the physician's professional role.
- AMA Ethics and Health Policy H140.966
 - The principle of patient autonomy requires that physicians must respect the decision to forgo life-sustaining treatment of a patient who possesses **decision-making capacity**. Life-sustaining treatment is any medical treatment that serves to prolong life without reversing the underlying medical condition.

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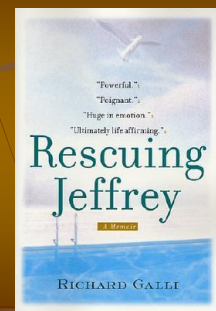
Right to refuse medical intervention: Bottom Line

- Supported by the courts, regardless of State interests or the ultimate outcome
- One has a right to exercise free choice
 - Includes freedom from unwanted interventions
 - It is a constitutionally protected right
 - Liberty interest of the 14th Amendment
- Removing life support not considered suicide in most living will legislation

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Parent deciding for child

- Jeffrey Galli
 - 17 yo C1-2 fx
 - Father was going to disconnect ventilator and not tell him
- Rudy Linares
 - 15 month old son
 - Disconnected his son's ventilator while holding hospital staff at bay with a gun



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Nov 5th, 2013: Indiana hunter paralyzed in fall chooses to end life support

Pro



Tim Bowers - victim

Con



Paul Tobin – president of Nat'l Spinal Cord Injury Assoc

"He would never walk or hold his baby. He might live the rest of his life in a rehabilitation hospital, relying on a machine to help him breathe. He'd never return to those outdoor activities that gave him such peace."



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Acquired Disability

- Newly injured (disabled) = grey zone
 - Past irrevocably gone, future hard to imagine
- Sense of self fragmented by the loss of their identity-defining roles and characteristics
 - Kirschner '06
- Incongruence between desired personal identity and assigned **social identity**
 - Brown '97

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Disability = limitations?



Disability = inspiration?



Your excuse is invalid.

"The only disability in life is a bad attitude."

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Quadruplegic Dan Crews Swamped With Letters: Don't Die

Dec. 7, 2010
By SUSAN DONALDSON JAMES via WORLD NEWS



"Keep the faith!"

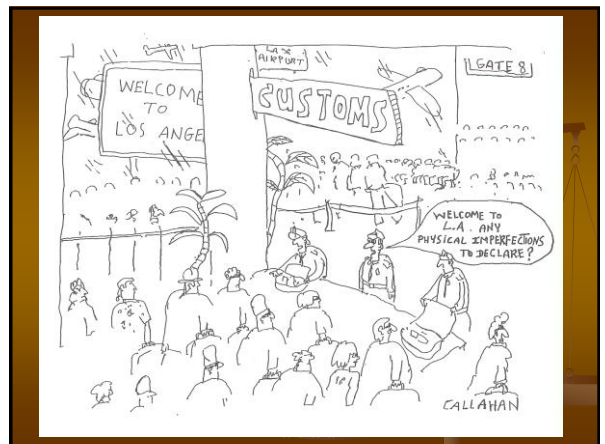
"The world needs you!"

"Please never give up hope. It's the reason you were put here on this earth."

"I really encourage you. Your life has great value beyond understanding."

"God has a purpose."

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Personhood

- Personhood = being human in a way that is valued
 - Concepts of worth
- Dilemma between an identity in flux and decision-making capacity
 - Not a position of strength from which to exercise "autonomy"

- Instad '95

- Kirschner '06

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How is truly "informed" consent ultimately determined?

- May not be possible initially after an acute disabling injury; true informed consent can only occur after understanding the potential for long term rehab
- The sooner a person can regain control over as many variables of their lives as possible, the faster this capacity will return.

- Gerhart '94

- Kirschner '06

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