End-of-Life Decision-Making and Disability

Ethics: Bioethics (Fall 2014)

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Thresholds for respecting decisions

: main sources of concern when newly/chronically disabled individual wants to end life-sustaining care

Actually autonomous:
Acts from reflective values and beliefs without undue coercion, etc.

Informed consent/refusal:
Voluntary, free, informed

Verified capacity:
Communication, understanding, reasoning, appreciation

Legal competence:
Of age, etc.

What might the motive / desire be?

To die?

Problem solve:
Waiting period?

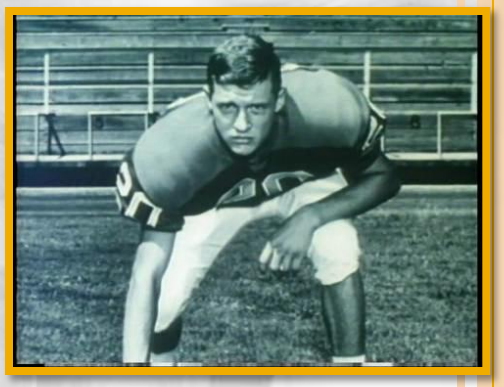
Not to suffer from disability?

Problem solve:
Increase social supports?

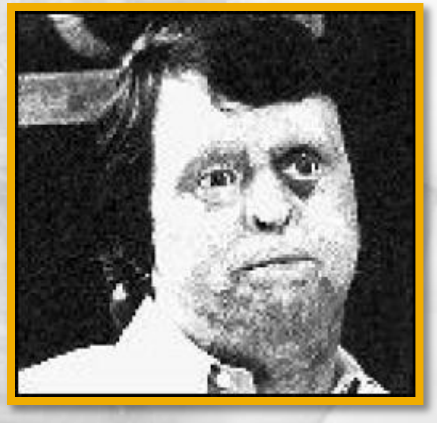
For pain to end?

Problem solve:
Better pain management?

The Case of Dax Cowart: Dax's Point of View



- Video of Cowart speaking at UVA:
  - Part 1 and Part 2



- Stated reasons for wanting to die:
  - Primary reason: Extreme, constant pain with minimal pain management
  - Secondary reason: Could not imagine sufficiently worthwhile quality of life

The Case of Dax Cowart: Dax's Point of View

- Pain issue
  - Can result in long-term distress
  - Dax nonetheless declared competent after psych evaluations
- Disability issue
  - Former physical prowess was source of pride, life goals
  - "If I felt that I could be rehabilitated to where I could walk and do other things normally, I might have a different feeling about it" (15)

The Case of Dax Cowart: Physician's Point of View (Burt)

- Concern with autonomy running amuck, consumer model taking over medicine
- How should physician respond to patient insisting on death and refusing to discuss options?
  - "'No, no, it is my business, and not because I'm a doctor but because I am another human being who is necessarily involved in your life'" (15)
- If physician asks patient to endure pain and/or disability, then the physician has a serious obligation "to spend time with this person—respectful time, extensive time" (19)

Patient's Choice at the "End of the Day"…But When Is That?

- When time for remonstrations, persuasions, presentation of arguments and evidence has passed
  - There needs to be at least *some* discussion of options, other viewpoints (Burt and Cowart agree on this!)
- When is the decision to refuse treatment because of a disability sufficiently autonomous, informed, and voluntary?
  - Especially given biases, imaginative and empathic barriers, how bodily abilities and limitations affect self-conception and life planning
- Primary goal should be to advocate for the patient, not to make the physician feel comfortable with the decision (Cowart and Burt agree on this too!) (see pg. 21)

The Case of Elizabeth Bouvia

- **Uncontroversial (generally) aspect of appellate court decision**
  - Capacitated pt has right to refuse any and all medical interventions
  - Years of life left does not determine quality of life
- **Controversial aspects of decision**
  - Quality of life determination as "essential" to respecting her wish to die
  - Asch: Bouvia treated differently in virtue of her disability (e.g., minimal efforts for increased social, emotional supports)

The Case of Elizabeth Bouvia

STATE INTERESTS

- Preserving life
- Preventing suicide
- Maintaining ethical professional standards
- Protecting innocent parties

PATIENT INTERESTS

- Own wishes, values, preferences for medical care
- Own determination of quality of life

Do you agree this was not a case of suicide, and the physicians "are not assisting in their patients' deaths" when they withdraw/withhold life-sustaining medical care?

Discussion Questions

- *Do you agree with Dax Cowart that "when the act is self-regarding in nature, the individual should be left to make his or her own decisions" (17)?*
- *What factors are relevant for determining when the "end of the day" is?*
- *What do you think the medical staff should have done in Dax's case? Bouvia's? What are some crucial similarities and dissimilarities in these cases?*

Questions? Comments?