



**END-OF-LIFE DECISION-MAKING
AND DISABILITY**

Ethics: Autonomy and Health (Spring 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
- 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)**
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THE CASE OF BB

○ Similar case: Elizabeth Bouvia

- Both sought death by refusing life-sustaining treatment
- Desires to die based on perceived low quality of life associated with disability

○ Unlike Bouvia's condition, BB's impairment was the result of a recent catastrophic injury

- “the onset of impairment is sudden and unexpected; the symptoms and inabilities are foreign and frightening. The dependency that ensues is often complete, following fast on a life with no knowledge of physical limitation” (Powell & Lowenstein 56)



PATERNALISTIC INTERFERENCES AGAINST ACTING ON DESIRE TO DIE

- **“because newly disabled patients have limited experience with disability and lack information about their options and outcomes” (Powell & Lowenstein 57)**
 - **Rehabilitation can be crucial in stabilizing sense of self, readjusting life plans, evaluating new possibilities and abilities**
 - **For how long can the emergency overriding of autonomy be justified?**
 - **Can paternalism be justified for the sake of preventing a poor standard of care (e.g., non-treatment) for disabled persons generally?**
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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? BB’s? What is analogous and disanalogous in these two cases?





QUESTIONS? COMMENTS?