Beyond Cruzan: When, and to What Degree, Should Non-Decisional Patients Make Their Own Medical Decisions?

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Conflicts of Interest

We have no financial relationships with ineligible companies to disclose.

Objectives

By the end of this presentation, participants should be able to:

1) Explain the key finding of the *Cruzan 1990* decision and how it fails to help us with certain kinds of non-decisional patients.

2) Explain the role of the *reasonably prudent person standard* as the unifying feature of these proposed guidelines.

3) Name at least two of the proposed criteria for when and how to allow cognitively aware but non decisional patients *more choices* around medical decisions.

4) Be able to distinguish between competency and decisional capacity.

REASONABLY PRUDENT PERSON STANDARD

Refers to the range of choices a **reasonably prudent person** (i.e. most people in general) would make given a particular medical condition.

- Considered semi-objective: does not (normally) take a person's subjective experience into consideration
- Related to **Best Interest Standard** *but* with a wider array of options than a single best interest

Primarily used:

- When we have no one to speak for patient wishes regarding time-critical treatment
- As a "check" for when to investigate further decisional capacity

If the patient's wishes are within the reasonably prudent person standard, might that not be a situation where we should consider their wishes, even if, technically, they are considered non-decisional or incompetent?

WHAT IS DECISIONAL CAPACITY?

The ability of a patent to **communicate understanding** of the risks, benefits, burdens, and alternatives to a proposed intervention.

Components:

- Demonstrate **understanding** of the relevant information provided
- **Appreciate** the alternatives, burdens, risks, benefits, and consequences
- **Deliberate** based on own values
- **Communicate** a consistent choice

HOW IS THE DIFFERENT THAN COMPETENCE?

Decisional Capacity	Competence
• Clinical	• Legal
• Determined by health care provider	• Determined by judge
• Situational	• Single point of time
• On a spectrum	• All or nothing
• Self/surrogate as decision-maker	• Guardian as decision-maker

CRUZAN 1990 PRIMARY FINDING

Competent adult patients,
either directly or via their surrogates,
have the right to refuse medical treatments,
even if that refusal leads to their death.

BEYOND CRUZAN

What of a patient, still somewhat cognitively intact,

…who has been non-decisional for decades?

…or who was never decisional?

…or whom, now non-decisional, wishes
to change their mind?

CASE STUDY 1: LONG TERM SCHIZOPHRENIA, ADVANCED COPD, DECADES OF STATEMENTS AGAINST HOSPITALIZATION.

Patient: *Is in the ICU suffering from end stage COPD, partly due to years of smoking. One of his sons serves as caretaker and legal guardian.*

When the son brought his father to the ER, he authorized his intubation, despite telling the ER doctors that, "he'll be furious with me when he wakes up, he's repeatedly said that he wanted nothing to do with doctors and never wants to be hospitalized again."

What ethical issue does this appear to raise?

Context: *Due to a diagnosis of schizophrenia and bi-polar disorder, he was ruled incompetent decades previously. He is otherwise cognitively intact.*

The patient has three children. Two have jobs and live in other states, one has served as his legal guardian and caregiver.

The Pulmonologist gives the patient about a 10% chance of coming off the ventilator.

This person has not been a patient here in the past. We do not know whether other, perhaps newer, treatments have been tried that might have allowed him to be ruled competent.

DISCUSSION: ETHICAL ISSUES AND CONCERNS?

- Once the son realized that his reporting of the patient's wishes might be a factor in deciding against what he wanted for his father, he changed his story. After reporting, both in the ER and the ICU, that this would never have been acceptable to his father, he reversed his position.

Additional family information:

- There were two other siblings who lived out of town. They maintained the same position as was initially held by their brother--that their father would never have wanted such an extensive and invasive treatment. When the brother tried to change his story in their presence, they admonished him for being deceitful. They strongly supported shifting to comfort measures. The son with guardianship reverted to his original story when his brothers were present, but changed it whenever they were not.
- Away from their brother, the siblings explained that the son caring for their father had never been very functional. He had never held a job. This meant that when it came to appointing someone as caretaker (guardian) for dad, he was the one available. It seemed like a win-win, Dad got the supervision he needed, their brother got income and a place to live. They felt that their brother was keeping their father alive for the brother's benefit, not the father's.
- Discussion?

INITIAL GUIDELINES

Guideline One:

Incompetent or non-decisional persons, who are somewhat cognitively intact, and who are consistent in their statements of what causes them suffering or distress, should have a say in medical decisions which cause them distress.

***Suffering is subjective*. Think about the patient's experience.**

Guideline Two:

If, near the end of life, a patient, even if deemed incompetent or non-decisional, is asking to be kept comfortable and allowed to die in circumstances where we would *not* normally question the decision of a person who was decisional, we should follow their request.

INITIAL GUIDELINES CONTINUED

Guideline Three:

The weight of patient preferences should increase as:

1) The invasiveness and discomfort of the medical intervention, including the recovery, *increases*.

2) The likelihood of a return to an acceptable baseline for the patient *decreases*.

3) The time between repeat incidents *shortens* even if there is a return to baseline.

4) Their decision is consistent with the *reasonably prudent person standard*.

CASE STUDY 2: NON-DECISIONAL PATIENT LIVING INDEPENDENTLY WITH FAMILY SUPPORT

Patient: *64 y/o woman in good health. Schizophrenia. New NSTEMI requiring stent plus dual antiplatelets for a year after and then single antiplatelet lifelong.*

Context: *Lives alone. Fiercely values independence. Poor compliance with medication. Significant social anxiety.*

Should the family authorize the stent?

If we decide that the ethical choice is to go with the patient's wishes, does that mean the need to discard the *reasonably prudent person standard*?

The problem is the condition of recovery (need for compliance with antiplatelet(s) and other heart protective medicines causing loss of independence) not just the procedure itself.

DISCUSSION: CONSIDER TOLERABILITY

Even if the procedure is relatively safe and benign, if the result was to live the rest one one's life in a situation one found intolerable, would it then be within the range of a reasonably prudent person to refuse the procedure?

GUIDELINE

Guideline Four:

When applying the reasonably prudent person standard to non decisional patients, it's important to incorporate key elements, if known, of the *patient's subjective experience* and issues that will be faced not only during the immediate procedure and recovery but also as a long term result of the procedure in question.

This also takes us back to part of Guideline #3, where the weight of the patient's preference changes

…with *increase* in the invasiveness and discomfort of the intervention.

…with *decrease* in a potential return to acceptable baseline.

CASE STUDY 3: NON-DECISIONAL PATIENT WANTS TREATMENT SHE WOULD HAVE REFUSED WHEN DECISIONAL

Patient: *76yo woman with emphysema and major depression now with pulmonary embolism*

Context: *fiercely independent, no family, two friends of 50 years, PCP of 7 years, psychiatrist*

Treatment: *Intubated, mechanically ventilated, permanent cognitive loss*

PCP and Friends	*ICU Staff*
Extubate	Patient indicates do not extubate
Keep comfortable	No overt signs of suffering
Allow to die	OK with her change in cognition

Hastings Center Report: Jan-Feb 1988 28-30

GUIDELINE

Guideline Five:

If a person becomes permanently non-decisional, but appears to want to make a decision in opposition to what they would likely have made from when they were decisional, they should be allowed to change their mind if that decision is within the realm of what a *reasonably prudent person* might choose.

CASE STUDY 4: WOMEN, AGE 20, SEVERE ANOREXIA

Patient: *80 lbs. Cannot lift herself out of bed. Multiple hospital admissions. Refuses transfer to a hospital specializing in eating disorders. Denies suicidal intent.*

Context: *Patient eats, just not enough to sustain life. Claims eating more is intolerable. Psychiatrist rules her decisional.*

Should we follow her wishes or force her to undergo treatment?

This may include a feeding tube and/or transfer.

Are there additional medical considerations?

Does age matter here?

On the surface, Cruzan would say to follow her wishes. On what grounds might we disagree?

CASE STUDY 4: CONTINUED

Additional Context: *(Dr. Laine Ross, U of Chicago)*

Patients with anorexia tend to fall into three roughly equal groups:

1. *Patients who pretty much overcome the condition and go on to live normal lives.*
2. *Patients who experience periodic flare ups of anorexia, but are still fine most of the time.*
3. *Patients who spend their lives lurching from crisis to crisis, always struggling, very few periods of remission.*

At age 20, we don't know which group she will fall under.

Can she be decisional in some ways, but not with respect this specific condition?

CASE STUDY 5: PATIENT REFUSING BLOOD

Patient: *35 y/o male suffering from a gunshot wound to the abdomen. Willing to be treated, but states that he will not accept blood due to religious reasons.*

Context: *ER assessment is that he appears decisional. The patient tells us that his sister should make decisions for him if he becomes non decisional. Unable to reach her before surgery. Initial surgery is done without blood or blood products.*

Patient: *Patient is now unconscious and on a ventilator. It becomes apparent that he still has a slow bleed. He needs to go back to surgery.*

If the patient now needs blood to survive the surgery, should we override his wishes?

If so, on what grounds?

Are there other things we need to know?

GUIDELINE

Guideline Six:

Be attentive to the medical and contextual features when dealing with requests by non-decisional patients, particularly when those requests will result in their death.

a. **If there is a reasonable chance of getting the patient to a good long-term baseline, then that is a strong reason for denying said request.**
b. **If not, or if the process is too painful, remember that suffering is subjective. If we cannot relieve the suffering, particularly in the long term, we may need to follow the patient's wishes, even if it results in their death.**
c. **Be prepared to do a deeper dive into the question of decisional capacity when such a decision is likely to result in death or significant harm to the patient, unless the patient's medical condition is such that the decision fits under the reasonably prudent person standard.**

CASE STUDY 6: MULTIPLE SUICIDE ATTEMPTS OVER DECADES OF DEPRESSION

Patient: *54 y/o woman with a long history of depression and suicide attempts. In the ICU for a drug overdose. She is on a respirator and may have suffered some cognitive loss, the level of which is uncertain.*

Context: *She has a large extended family who clearly love her and are distressed by her condition. However, instead of advocating for aggressive treatment, they argue that, finally, it is time to let her go. Tearfully, they tell us that life has been one long burden to her. This is what she wants.*

By default, we consider most suicidal patients to be non-decisional.

Does this mean we should always force them to stay alive?

If she has suffered permanent cognitive loss, does that change the situation?

If so, how?

CASE STUDY 7: HOLD ME AND LET ME DIE

Patient: *58 y/o man who is in the ICU for an attempted suicide. At one point, the nurse calls his father, who found him and called 911, for permission to put in a central line. He replied:*

"Don't do anything. He's been trying to die for 40 years. We need to just let him go."

Context: *The son had texted his father just before he made the attempt. The father called 911.*

Does this suggest anything about the suicide attempt?

A cry for help?

Context: *He had a sister who had attempted multiple suicides. At one point, the father had found the sister, barely breathing, and decided just to hold her head in his lap until she passed.*

Could it be that the son just wanted the same?

Was what the father did with his daughter legal?

What do you think the father is likely to do the next time he gets a text?

THESE LAST TWO CASES, IN PARTICULAR, RAISE A LOT OF TROUBLING ISSUES

Are we enabling someone's suicide if we allow them to die?

Have all other resources to help the person really been exhausted?

(There are cases of people who suffered from depression for decades. For example, a person who struggled for over 50 years before finally being put on a medication that "worked" for them.")

What of new treatments?

If we were to accept this kind of approach, how do we decide whether and when such a choice should be allowed? (*#3 may require us to prove a negative.*)

1. There would need to be a long and established history of chronic suffering and suicide attempts.
2. There would need to be a well-documented history of treatment and that these had failed.
3. It should be clear that there are no other promising treatments which have not been tried for this patient.

GUIDELINE

Guideline Seven:

Patients with an extended life history of suffering and multiple suicide attempts, who have been unable to find relief in any available treatment, and for whom returning them to baseline would result in forcing them to live a life which they find miserable, should be allowed to be kept comfortable and to pass.

This is likely to be the most controversial guideline.

Even if accepted as ethical, it might not be practical.

CONTINUED CHALLENGES

- We often allow incompetent patients to make decisions.
- Health care providers are not usually comfortable with shades of grey.
- Providing information that is material to specific person making a particular decision.
- Experiences change us when the abstract becomes more concrete.
- Surrogate decision makers AND health care provides have their own biases.

ASSESSING DECISIONAL CAPACITY

- Decision making is a complex process: Initiation, maintenance, and metacognition.
- There are many tools to aid in assessment.
- There is no gold standard.
- Many measures have poor inter-rater and test-retest reliability.
- Tailored instruments are not standardized.
- Vignette-style instruments are standardized but not always relevant to decision at hand.
- Clinical gestalt is needed to synthesize pertinent information.

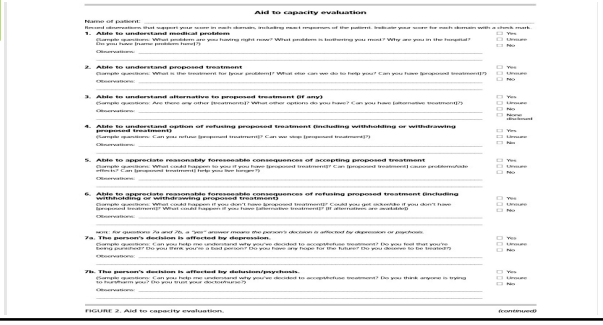
TOOLS TO GUIDE ASSESSMENT

Table 1. Legally Relevant Criteria for Decision-Making Capacity and Approaches to Assessment of the Patient.

Criterion	Patient's Task	Physician's Assessment Approach	Questions for Clinical Assessment*	Comments
Communicate a choice	Clearly indicate preferred treatment option	Ask patient to indicate a treatment choice	Have you decided whether to follow your doctor's [or my] recommendation for your health? Can you tell me what that decision is? [If no decision] What is making it hard for you to decide?	Frequent reversals of choice because of psychiatric or neurologic conditions may indicate lack of capacity
Understand the relevant information	Grasp the fundamental meaning of information communicated by physician	Encourage patient to paraphrase disclosed information regarding medical condition and treatment	Please tell me in your own words what your doctor [or I] told you about: The problem with your health now The recommended treatment The possible benefits and risks (or discomforts) of the treatment Any alternative treatments and their risks and benefits The risks and benefits of no treatment	Information to be understood includes nature of patient's condition, nature and purpose of proposed treatment, possible benefits and risks of that treatment, and alternative approaches (including no treatment) and their benefits and risks
Appreciate the situation and its consequences	Acknowledge medical condition and likely consequences of treatment options	Ask patient to describe views of medical condition, proposed treatment, and likely outcomes	What do you believe is wrong with your health now? Do you believe that you need some kind of treatment? What is treatment likely to do for you? What makes you believe it will have that effect? What do you believe will happen if you are not treated? Why do you think your doctor has [or I have] recommended this treatment?	Courts have recognized that patients who do not acknowledge their illnesses (often referred to as "lack of insight") cannot make valid decisions about treatment Delusions or pathologic levels of distortion or denial are the most common causes of impairment
Reason about treatment options	Engage in a rational process of manipulating the relevant information	Ask patient to compare treatment options and consequences and to offer reasons for selection of option	How did you decide to accept or reject the recommended treatment? What makes [chosen option] better than [alternative option]?	This criterion focuses on the process by which a decision is reached, not the outcome of the patient's choice, since patients have a right to make "unreasonable" choices

* Questions are adapted from Grisso and Appelbaum.[21] Patients' responses to these questions need not be verbal.

TOOLS TO GUIDE ASSESSMENT



Aid to capacity evaluation

Name of patient: _____

Record observations that support your score in each domain, including exact responses of the patient. Indicate your score for each domain with a check mark.

1. Able to understand medical problem ☐ Yes ☐ Unsure ☐ No
(Sample questions: Can you tell me why you're being right now? What problem is bothering you most? Why are you in the hospital? Do you have (some problem here)?)
Observations: _____

2. Able to understand proposed treatment ☐ Yes ☐ Unsure ☐ No
(Sample questions: What is the treatment for [your problem]? What else can we do to help you? Can you have [proposed treatment]?)
Observations: _____

3. Able to understand alternative to proposed treatment (if any) ☐ Yes ☐ Unsure ☐ No ☐ None disclosed
(Sample questions: Are there any other (treatments)? What other options do you have? Can you have (alternative treatment)?)
Observations: _____

4. Able to understand option of refusing proposed treatment (including withholding or withdrawing proposed treatment) ☐ Yes ☐ Unsure ☐ No
(Sample questions: Can you refuse [proposed treatment]? Can we stop [proposed treatment]?)
Observations: _____

5. Able to appreciate reasonably foreseeable consequences of accepting proposed treatment ☐ Yes ☐ Unsure ☐ No
(Sample questions: What could happen if you have [proposed treatment]? Can [proposed treatment] cause problems/side effects? Can [proposed treatment] help you be longer?)
Observations: _____

6. Able to appreciate reasonable foreseeable consequences of refusing proposed treatment (including withholding or withdrawing proposed treatment) ☐ Yes ☐ Unsure ☐ No
(Sample questions: What could happen if you don't have [proposed treatment]? Could you get sicker/die if you don't have [proposed treatment]? What could happen if you have [alternative treatment]? (if alternatives are available))
Observations: _____

NOTE: for questions 7a and 7b, a "yes" answer means the person's decision is affected by depression or psychosis.

7a. The person's decision is affected by depression. ☐ Yes ☐ Unsure ☐ No
(Sample questions: Can you help me understand why you've decided to accept/refuse treatment? Do you feel that you're being punished? Do you think you're a bad person? Do you have any hope for the future? Do you deserve to be treated?)
Observations: _____

7b. The person's decision is affected by delusion/psychosis. ☐ Yes ☐ Unsure ☐ No
(Sample questions: Can you help me understand why you've decided to accept/refuse treatment? Do you think anyone is trying to hurt/harm you? Do you trust your doctor/family?)
Observations: _____

FIGURE 2. Aid to capacity evaluation. (continued)

CLINICAL RECOMMENDATIONS

- If the provider has emotionally-laden bias, use an assessment tool to mitigate bias.
- For patients who willfully do not engage, employ significant teach-back.
- You do not have absolute expertise for all decisions:
  - Discuss with consulting provider.
  - Recommend provider attends meeting with patient.
- There is often need for re-evaluation.
- Obtain collateral whenever possible.

Conclusion and Way Forward

Other Questions…