



Treatment Refusal, Guardianships, and Advance Directives

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Disclosures

“Neither I nor my spouse/partner has a relevant financial relationship with a commercial interest to disclose.”



Introduction

- “Every human being of adult years and sound mind has a right to determine what shall be done with his own body.”
Justice Cardozo, 1914
- Individuals have:
 - Ethical claims to self-determination and respect
 - Legal entitlements (negative) to be free of unwanted interventions
- Informed consent is the process by which a patient gives permission for care
- Informed refusal is the process by which a patient asserts lack of permission for care
- Capacity is the threshold determination for informed consent
 - Capacity – clinical determination
 - Competency – legal determination

Outline

- Elements of Capacity Assessment
- Clinical Assessment
- Legal Approaches to Lack of Capacity
- Summary

Capacity: Elements

- Express a preference
- Factual understanding
- Appreciation of the seriousness of the condition and consequences of accepting or refusing?
- Able to manipulate the information in a rational fashion?

Appelbaum et. al.; See e.g. NEJM 2007

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Clinical Reality

- Capacity for **what**?
 - Specific medical decision?
 - Unsafe?
- Capacity rarely questioned if the decision is in the patient's best interests as viewed by:
 - Treators
 - Family
 - Others
- Treatment refusal over the objection of treatment team or family is a common reason for questioning capacity

Assessment , cont'

- Why does the individual lack capacity?
 - Neurologic/ Psychiatric Status
 - Neurocognitive assessment
- Is the condition reversible?
- What is the anticipated duration of incapacity?

Sliding Scale

- Physicians are often criticized for assessing capacity only for treatment refusal
 - i.e. only when the patient disagrees with the physician or treatment team
- Clinically, physicians approach capacity as a sliding scale involving a risk-benefit analysis
- In general, capacity to refuse a recommended medical intervention is higher risk than to accept

Risk–Benefit Analysis

| | Low Risk | High Risk |
|------------------|------------|------------|
| Refuse Accept | | |
| Low Benefit | + + | + +++++ |
| High Benefit | +++++ + | +++ +++ |

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Legal Framework

- Adults are presumed competent
 - Includes all activities/ tasks
 - Including medical decisions
- Incompetent (incapacitated) individuals require an alternate decision-maker
 - Capacity: clinical
 - Competent: legal
- Various mechanisms of appointment
 - Advance Directive (HCP)
 - Court appointed (Guardian)
 - Statutes (not in MA)

Mechanics of HCPs

- Since 1990, all 50 US states
- Terminology
 - Principal
 - Agent
 - HCP is the document
- Appointment/ Execution of a HCP
 - Low level of capacity
 - No automatic effect
 - Revocable at any time

HCP Mechanics, cont'

- Invocation
 - Time of future incapacity
 - “Springing clause”
- Revocation
 - *At any* time
 - Disagreement with agent revokes
 - If lack of capacity at time of revocation, may ask for Affirmation or Confirmation

HCP Mechanics, cont'

- Clinically, capacity to designate a SDM is considered a low threshold – low risk
- MA example
 - Revocable at any time
 - “Of sound mind and under no constraint or undue influence”
 - Adult witness (layperson)
 - “sniff test”
- Relevant data
 - Who has helped you in the past?
 - Who do you trust?
 - Why?
 - NOT an understanding of specific treatment needs

SDM Statutes

- Mechanism to identify and legally authorize a SDM where no prior directive exists
- Hierarchy approach
- Limitations
 - Objective rather than subjective
 - Risk of discordance with what the patient would have wanted
- 44 states

Guardianship

- Protective intervention for incapacitated individuals
- Generally a last resort
- Formal legal proceeding
 - vs. clinical capacity determination
 - triggers legal protections
- Cases that do go to court:
 - Treatment refusal
 - Chronic conditions
 - No/ feuding/ unsuitable surrogates
- Clinical and Legal Views of Guardianship

Summary

- Capacity determination
 - Preference
 - Factual Understanding
 - Appreciation
 - Rational Manipulation
- Surrogate Decision Making
 - Health Care Proxy
 - INFORMAL LEGAL MECHANISM
 - Low threshold to execute/ designate
 - Any authority the principal (patient) had when competent
 - Statutes
 - Guardianship
 - Formal mechanism (court required)
 - Burdensome and intrusive – tradeoff for protections

Selected References

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Additional references upon request