

Dilemmas in Surrogate Decision Making

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Disclosures

None

Learning Objectives

- Describe the ethical obligation of informed consent, surrogate decision making and the legal compulsion there of
- Apply the ethical frame work for surrogate decision making
- Identify risk factors that impact surrogate decision makers and utilize a script to mitigate long term impact

Definitions

- Informed Consent
- Surrogate Decision Maker
 - Proxy Decision Maker
 - MD POA vs POA
 - "All interested party"

Definitions

- Informed Consent: Arises from the ethical principle of patient autonomy and basic human rights. Patients have the right to receive information and ask questions about recommended treatments so that they can make well-considered decisions about care.
- Instrument of communication and expression of authorization
- Process: Communication between a patient and physician results in the patient's authorization or agreement to undergo a specific medical intervention
 - Assess patients capacity
 - Disclosure of information
 - The diagnosis
 - Nature and purpose of the recommended interventions
 - The burdens, risks and expected benefits of all options, including forgoing treatment
 - Document Informed Consent

Definitions – 3 Standard Decisional Hierarchy

- When a patient lacks decision-making capacity, we follow a stepwise hierarchy of three standards:
- Patients known wishes (in writing or verbal)
- Substituted judgment
- The patient's best interest.

CASE AJ

- Legal Capacity
- All adults are presumed to have capacity in the eyes of the law unless otherwise determined in a court of law.
- Four discrete abilities that are often present in legal standards for medical consent capacity: the ability to understand diagnostic and treatment information; appreciate the significance of this information; reason about the risks and benefits of treatment alternatives; and evidence a choice

Definitions Capacity vs competency

- Capacity
 - Professional clinical judgement as to whether a specific individual has the requisite cognitive, decisional, affective and practical abilities to be judge to have the ability to complete a specific task or make specific decision
 - Decisional Capacity
 - Executional Capacity
- Competency
 - Associated with a legal determination
 - "All or nothing"

Handbook of Assessment in Clinical Gerontology 2010, pg 581-618

Framework for Capacity Assessment

Decision Making Capacity Assessment Tool Date/Time Assessed:

Indication for assessment of DMC: Refusing treatment or disposition, Decisional Capacity in Question, other
 Is there an impediment that could affect my assessment of this patient's DMC?
 Language, Cultural Issues, Communication, other

Capacity – Assess the patient's understanding of the following and document findings:

A1. Ability to understand the medical problem: (DMC IMPAIRMENTS YES NO UNSURE)
 Why are you in the hospital now? What have you learned from the medical team about your illness?

A2. Ability to understand the proposed treatment: (DMC IMPAIRMENTS YES NO UNSURE)
 What is the recommended treatment for your problem? What can we do to help you?

A3. Ability to understand the alternatives to treatment: (DMC IMPAIRMENTS YES NO UNSURE)
 Are there any other treatments available? What other options do you have?

A4. Ability to understand the option of refusing treatment: (DMC IMPAIRMENTS YES NO UNSURE)
 Can you refuse the treatment? Can we stop the treatment?

A5. Ability to appreciate consequences of accepting or refusing treatment: (DMC IMPAIRMENTS YES NO UNSURE)
 What could happen to you if you have the treatment? How could the treatment help you? Could the treatment cause problems or side-effects? Could you get sicker or die without the treatment?

A6. Ability to weigh the risks, benefits and burdens of treatment options: (DMC IMPAIRMENTS YES NO UNSURE)

A7. Ability to rationally reason how to reach a decision to accept or reject treatment: (DMC IMPAIRMENTS YES NO UNSURE)
 Can you tell me how you arrived at your decision? What factors helped you come to your decision?

B. Is the patient able to communicate the above in her/his own words: (DMC IMPAIRMENTS YES NO UNSURE)

C. Is the patient consistent with her/his communication regarding the above? (DMC IMPAIRMENTS YES NO UNSURE)

Conclusion: Decision Making Capacity – Intact, Unclear, Lacks capacity
 (Consider lack of DMC if "No" was checked under sections A 1-7, B, or C above)

Definitions

- **Surrogate Decision Maker – Proxy decision maker**
 - *2016 Colorado Revised Statutes Title 15 - Probate, Trusts, and Fiduciaries Declarations - Future Medical Treatment Article 18.5 - Proxy Decision-Makers for Medical Treatment and Surrogate Decision-Makers for Health Care Benefit Decisions § 15-18.5-103. Proxy decision-makers for medical treatment authorized - definitions*
- "Interested person" means a patient's spouse, either parent of the patient, any adult child, sibling, or grandchild of the patient, or any close friend of the patient.

Case SF

Why Health Care Proxies refuse to make decisions

- Out of Love
- Out of Duty
- Out of Guilt

Bearing the Repercussions of the Surrogate Decision Maker Responsibility

- these individuals are expected to make decisions that accord with what patients would have wanted if they had been able to decide for themselves
- Highly Stressful
- Majority were satisfied with the process
- Emotional burden lasts from months to years

Table 3. Most Commonly Reported Stressors and Possible Ways to Mitigate Them

Stressors	Possible Responses
Unsure of patient's preferences	Encourage previous discussion and advance directives
Uncertain prognosis	Difficult to address
Discomfort with hospital environment	Help to familiarize and adjust to environment
Logistics of making decisions	Evaluate and address challenges to decision making
Poor communication by clinicians	Establish a contact person, hold consistent meetings, and use clear language
Insufficient time	Prepare surrogates and give time to decide
Conflict with clinicians and family	Identify and address sources of conflict
Sense of sole responsibility	Share responsibility for decisions
Uncertainty or guilt over decisions	Support decisions and offer counseling

Effect of Decision Making on Surrogates

Positive Effect	Negative Effect
Consolation Learning Protect Patient Satisfaction Support Patient	Anxiety Conflict Doubt Overwhelmed Responsible/Guilty Stress

Adapted Appendix Fig. 2
Ann Intern Med. 2011;154:336-346

Factors Reported to be associated Surrogate Experience

Positive Factors		Negative Factors	
Setting	Know patient Verbal Advanced Directive Written Advanced Directive Certain Prognosis Experienced Surrogate	Setting	No Advanced Directive Uncertain Prognosis Discomfort Setting Logistics
Process	Sufficient Time Good Communication Clinicians Surrogate Decision Maker Clinician Support Family Surrogate Decision Maker Family Consensus Family Support Religion	Process	Poor Understanding Poor Communication Insufficient Time Patient Preference/Best Interest Conflict Surrogate Role/Preferences Conflict Conflict with Family Deciding Alone
Decision	Right Decision Substitute Judgment Best Interest Did Everything	Decision	Uncertain of Decision

Adapted Appendix Fig 3 & 4
Ann Intern Med. 2011;154:336-346

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