

The Ethics of Surrogate Decision-Making

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Philosophy

- Philia - Disinterested affection for
- Sophia - Wisdom

Ethics vs. Morality

- **Ethics:** One of the three philosophical disciplines; a systematic process for discovering and critically examining morals.
- **Morality:** A particular society's system of particular beliefs about right and wrong; how a society justifies its actions.

Dialectical Reasoning

- Virtue
- Feminist Ethics
- Principlism
- Medical Ethics / Pluralistic Principlism
- Utilitarianism / Consequentialism
- Rights-based
- Casuistry
- Theology and Judeo-Christian Ethics

Medical Ethics

A set of moral obligations which are derived from and are particular to the patient-physician relationship.

Objectives

- Define a surrogate for medical decision-making.
- Understand the ethical process for justifying surrogate decision-making.
- Discuss surrogate duties and their implications.

What is a Surrogate?

Designated - A person named by the patient to make healthcare decisions for them when they are unable to do so.

Default - Healthcare decision-maker when the patient has not designated a surrogate or the designated surrogate is unwilling/unable to perform the role. Legal order prescribed in many states.

Premise

- The patient's right to accept or refuse treatment is fundamental.
- When the patient is competent, the patient decides.
- When patients lack the ability to direct their own medical care, surrogates ensure that patients' desires are communicated and honored via consenting or withholding consent to proposed treatments and procedures.

Why Fundamental?

Liberal Individualism \leftrightarrow Respect for Individuals

“The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.”

John Stuart Mill, On Liberty

Medical Ethics: Pluralistic Principlism

- **Autonomy: Sovereignty over “self”**
- **Autonomy Extended**
 - Living Will
 - Durable Power of Attorney for Health Care
 - Other written or oral statement
 - Substituted judgment
- **Medical Utility: Beneficence/Nonmaleficence**
- **Justice**

Surrogate Duties: Informed Consent

Preconditions:

1. Competence
2. Voluntariness

Inform:

3. Disclosure
4. Recommendation
5. Understanding

Consent:

6. Decision
7. Authorization

Surrogate Duties

To comprehend the worldview, values, goals, fears, and explicit instructions of the patient and thus act in the patient's best interest by making decisions consistent with those the patient would make if capable.

“Even if Terri had left written instructions to the contrary we would insist on maintaining the feeding tube and all life support.”

Deposition of Robert and Mary Schindler

Case 1

- 89 y/o, female transferred from SNF for cachexia, altered mental status, and sepsis.
- No Advanced Directive/Designated Surrogate
- Four children in ICU waiting room.
- 2 Children want comfort care approach.
- 2 Children prefer aggressive, life-prolonging interventions.

Default Surrogates

Order of Priority

- Who gets to make decisions when no one is designated?
- Depends on your state.
 - Legal order prescribed - go down the list
 - No order named in statute
 - Not a legal question
 - Healthcare team decides
 - Who best represents the patient's wishes?
 - Who will act in the patient's best interest?

Default Surrogates

- Who makes decisions when no one is available to act as surrogate and patient lacks capacity?
 - Some states (e.g. AZ, FL) provide a mechanism for appointing a surrogate.
 - Some states (e.g. GA, IA, MN, WI) provide no guidance.
 - Institutions need to develop standard processes.
 - Court appointed guardian ad litem.

Proactive Measures

“An Ounce of Prevention...”

- Ask “who do you trust to make decisions for you” as early as possible.
- Make AD discussions a regular part of outpatient visits.
- Encourage naming just ONE surrogate.
- Ensure advanced directive documents are accessible via the medical record.

Conflict Between Surrogates

- Some states provide guidance in resolving conflict between surrogates of equal rank.
 - FL= majority rule
 - IA= consensus
- Some states give no guidance.
 - Attempt consensus
 - Negotiate compromise
 - Judicial recourse.

Bioethics Mediation

“As long as disparate values exist within families and between patients, families and the health care system, conflicts are inevitable. And if conflicts are inevitable, strategies for managing them are required.”

Nancy N. Dubler & Carol B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions*.
United Hospital Fund of New York, 2004, pg. 8.

Origins of Conflict

- Fragmentation of care teams
- Complexities of prognoses
- Nuanced jargon
- Reluctance to deliver bad news or discuss death
- ?Technology

Mediation Is *Not*...

- About identifying who is to blame
- About deciding who is right or wrong
- About determining what version of events is true
- About imposing or mandating solutions

Mediation *Is...*

- Based on 3 core principles:
 - Party autonomy
 - Informed decision-making
 - Confidentiality
- Optimistic
 - Believes that most people enmeshed in conflict have the ability to consider options and select resolutions that meet their needs
- A *process* of negotiation, not a static event

Mediator's Obligations

- Mediate power imbalances
- Manage the negotiations
- Prevent staff from “ganging up” on patient and family
- Ensure that family members do not distort the medical realities and possibilities
- Identify sources of conflict
- Maximize options for resolution

Limits of Mediation

- It does not always succeed
 - Parties to mediation must *want* to reach agreement
 - Providers may have religious beliefs, value preferences, or practice patterns that conflict with the values and desires of the patient
 - Patients/families may not have the emotional strength to take responsibility for facing difficult decisions or making hard choices

Case 2

- 76 y/o, male dxed SCCA esophagus
- Initial rx with radiation and chemo.
- Esophagectomy

Postoperative Course

- Uneventful initial postoperative course.
- Day #6 transfers to ICU for
 - Mediastinitis
 - Pneumonia
 - Septic shock
- Over next month develops MOFS

Supportive Measures

- Fluid boluses and Dopamine
- PRBC and platelet transfusions
- Tracheotomy and mechanical vent.
- Dialysis
- Tube feeding and ROM exercises

Unanimous Medical Opinion

- Expected to remain transfusion, dialysis, and ventilator dependent
- Not expected to survive 6 months
- Not expected to recover decision making capacity

Advanced Directive

The Living Will

“If, in the opinion of my attending physician and a consulting physician, I should suffer from a terminal condition, end-stage medical condition, or persistent vegetative state with no reasonable medical probability of recovery, then I direct that life-prolonging procedures (including nutrition and hydration) be withheld or withdrawn when the application of such procedures serves only to prolong the dying process.”

Advanced Directive

The Durable Power of Attorney

- Appoints spouse as attorney-in-fact if cannot make own health care decisions.
- If spouse is unable, unwilling, or unavailable to act as agent then his daughter is designated to fulfill this role.

The Dilemma

- Designated surrogate/health care agent objects to the Living Will
 - is not convinced her husband's condition is irreversible.
 - was not obtained with the informed consent of the patient.
- Neither wife nor daughter have any knowledge regarding end-of-life wishes or life goals.

Florida Statute 765.104

Revoking an Advanced Directive

- Principle physically destroys the document or directs another to physically destroy in the presence of witnesses.
- Signed, dated statement revoking.
- Subsequently executes a materially different advanced directive.
- Oral intent to revoke
 - Statements inconsistent with the instructions of the advanced directive
 - Yes/No responses to leading questions

Judicial Review to Validate/Invalidate

1. Physicians may seek to have the document declared valid.
2. Surrogate may seek to have the document declared invalid based on clear and convincing evidence of impropriety.
3. Inform surrogate of intent to proceed according to the instructions of the Living Will. Surrogate then has 7 days to seek an Expedited Judicial Review.

Resolution

1. Accept wife's contention along with risk of violating the patient's autonomy.
2. Pursue judicial review and/or inform surrogate of intent to honor the Living Will
3. Create a third option.

Case 3

- 37 y/o, female from the Dominican Republic with episodes of life-threatening airway hemorrhage secondary to giant pulmonary artery aneurysm transferred for consideration of heart/lung transplant.
- Patient's mother directing medical care and insists on shielding her daughter from the dire nature of her condition.
- Mother is supported by all family members.

Question

- Familial autonomy - Is the family an appropriate autonomous unit for medical decision-making?

Key Points

- The surrogate's ability to extend the patient's autonomy requires faithfully representing the patient's wishes and acting in the patient's best interest via the informed consent process.
- Know your state's statutes governing surrogates.
- Know your hospital's policies regarding surrogates.
- Use the ethics team to facilitate communication and promote conflict resolution.

Ethics: Discovering and Justifying Right Action

References:

- Supporting Family Caregivers at the End of Life (JAMA. 2004;291:483-491)
- Discussing Do-Not-Resuscitate Status (*J Clin Oncol.* 2001;19(5):1576-1581)
- Conflict and Consensus at the End of Life (Hastings Center Report. 2005;35,no.6:19-25)