Ethical Perspectives on Paternalism and Autonomy in Living Donor Acceptance Criteria

Laura Madigan McCown, DBE, MSW, MTS, HEC-C
Clinical Ethicist, MaineHealth
ILDA, Maine Transplant Program
Assistant Professor, Tufts University School of Medicine
Learning Objectives

- Increase participants’ understanding of paternalism in living donation
- Increase participants’ understanding of autonomy in living donation
- Facilitate participants’ comfort level with balancing ethical principles in service of LD autonomy and best interests
Outline

Overview of Living Donation, Paternalism and Autonomy in Bioethics

How Paternalism and Autonomy Relate to Living Donation

Balancing Interests
MaineHealth

- 12 Hospitals
- 200 Specialty and Primary Practices
- Serves 1.1 million Maine & NH residents
Maine Coon Cat
New England LKD 2022

Living Kidney Donors

- Brigham & Women’s Hospital
- Lahey Hospital And Medical Center
- Boston Medical Center
- Beth Israel Deaconess Medical Center
- Rhode Island Hospital - Lifespan
- UMass Memorial Medical Center
- Yale New Haven- York St. Campus
- Massachusetts General Hospital
- Hartford Hospital
- Maine Medical Center - MaineHealth
- Baystate Medical Center
Living Donor Acceptance

Shared Decision Making → Transparent → In Practice: Complex
Donor Centered Shared Decision Making

(Thiessen et al., 2015)

• A donor-centered approach to declining a donor would entail informing the donor about the extent to which medical uncertainty persists. Discretionary donors should be advised that other centers may use different criteria for accepting living donors.

• Possibility of Optimizing for donation

• Example: Non-ideal donors with BMI > recommended could be coached in optimization of diet, exercise, lifestyle as in DonateWell at USC.
First successful living donor transplant
1954

“I’m here, and I’m going to stay, and that’s it,” Ronald wrote to his brother on the eve of the surgery when Richard urged him to back out.’

(Boston Magazine; AP photo)

• Side note: Ronald spent his life in Maine as a math teacher and farmer until his death in 2010 at age 79.
Paternalism and Autonomy: Practical Considerations in Tension (Thiessen et al., 2015; Chen et al., 2019)

- Respect for Living Donor Self-Determination
- Recipient Need
- Potential impact of poor donor outcomes on center certification status
- Public opinions about living donation
- Professional standards
- Provider conscience
Is LD ever morally or ethically obligatory?

(Beauchamp & Childress, 2019)

- Living Organ Donation is a **supererogatory** act

Supererogatory: beyond what is obligatory

*From a medical ethics perspective, living organ donation is not a moral obligation; “praiseworthy but optional”*

*From Tuesday Keynote: Donor shortage/ethical imperative to find LD*

Response: yes but careful to not conflate ethical imperative to find qualified LD with an ethical imperative to donate
History of Paternalism (fatherly, paternal)

Intentional overriding of one person’s preferences by another. The action appeals to the goal of benefiting the person or preventing or mitigating harm.
Paternalism in Medicine: tends toward power imbalance

Paternalism in medicine is the tendency to view the medical provider as possessing greater knowledge, training, expertise and experience thereby granting authority on what constitutes a patient’s “best interests”
Karen Ann Quinlan 1976

4 Bioethical Principles
(Beauchamp & Childress 1979)

- Beneficence
- Autonomy
- Nonmaleficence
- Justice
When do we have an ethical dilemma?

- 2 or more principles/values in conflict
- Evidence equally compelling about "rightness" or "wrongness" of options
Respect for Autonomy  
(Beauchamp & Childress 2019)

Includes BOTH the obligation to establish that necessary conditions are present for autonomous action AND acknowledge right of the person to hold views, make choices, and take actions based on their beliefs and views.
What Guides Us? Conditions Necessary in Autonomous Decision Making

- The action is intended
- Understanding (informed consent)
- Free of undue pressure (internal and external)
### LD Exclusion Criteria

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undue Pressure/Inducement</td>
<td>• persuading someone to donate by using incentives/pressure that distort a person's judgment</td>
</tr>
<tr>
<td>Exploitation</td>
<td>• person who bears the risk is in a weaker or more vulnerable position and receives unequal benefits for the burdens undertaken; the recipient clearly benefits at the expense of the donor</td>
</tr>
<tr>
<td>Coercion</td>
<td>• a threat that makes you worse off no matter which outcome you choose</td>
</tr>
</tbody>
</table>
Obligations to respect autonomy do not extend to persons who cannot be rendered autonomous because they are:
Hard vs. Soft Paternalism in Bioethics
(Beauchamp & Childress)

**Hard Paternalism**
- Usurps autonomy
- Restricts information
- Overrides decisions that are:
  - informed
  - voluntary

**Soft Paternalism**
- Intervenes on grounds of Beneficence or Nonmaleficence
- Goal: prevent nonvoluntary conduct
Can We Balance These Considerations? The “non-ideal donor”: 2 perspectives

“Donor consent and autonomy is [sic] necessary, but not sufficient, to proceed to kidney donation. Medical evaluation and concurrence is essential. Donor autonomy does not overrule medical judgment and decision-making” (Thiessen et al., 2015)

“The magnitude of the harm [to donor] to be prevented does not outweigh the benefits to recipients to a degree that would permit the overruling of the non-ideal donor’s autonomy.” (Weightman, Coghlan, & Clayton, 2022)
Balancing of Ethical Concerns

**Autonomy**
- Must be informed, have capacity, not under duress
- Goal: Ensure Robust Consent

**Soft Paternalism**
- Intervenes on grounds of Beneficence or Nonmaleficence
- Goal: Prevent nonvoluntary conduct
Acceptance Criteria and the “non-ideal donor”

Amy is a 23 year old electrical engineer working at her first job at Ford Motor Company in Detroit. Her twin sister Abby is a nurse in Boston. Abby has ESRD due to acquired cystic kidney disease and will likely need to start dialysis soon. As soon as Amy heard of Abby’s need she describes feeling an immediate and profound desire to donate a kidney to her sister. Amy contacted 3 transplant centers who told her that their minimum age requirement for living donation is 25.

Is the policy a form of Paternalism? Hard or Soft? Is Amy capable of making an autonomous decision?
How Can We Balance Autonomy and Harm Avoidance/Paternalism?  
(Weightman, Coghlan, & Clayton, 2022)

- Empower LD to participate in SDM
- Understand individual risk threshold: leave room for case-by-case
- Understand how LD balances risks with motivations

Tensions will and should remain
Thank You!

Questions?
References


References


References


