

Ethical Perspectives on Paternalism and Autonomy in Living Donor Acceptance Criteria

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14th Annual Living Donation Conference

Presented by the American Foundation for Donation and Transplantation

Learning Objectives

Increase participants' understanding of paternalism in living donation

Increase participants' understanding of autonomy in living donation

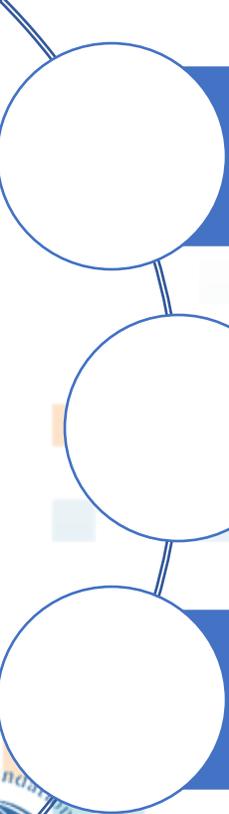
Facilitate participants' comfort level with balancing ethical principles in service of LD autonomy and best interests



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Outline



Overview of Living Donation,
Paternalism and Autonomy in Bioethics

How Paternalism and Autonomy Relate to Living Donation

Balancing Interests



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POPULATED PLACES

25,000 – 99,999 • Portland
 24,999 and less • Millinocket
 State capital ★ Augusta

TRANSPORTATION

Interstate; limited access highway 
 Other principal highway 
 Railroad 
 Ferry 

PHYSICAL FEATURES

Streams 
 Lakes 
 Highest elevation in state (feet) +5267
 The lowest elevation in Maine is sea level (Atlantic Ocean).



MaineHealth

- 12 Hospitals
- 200 Specialty and Primary Practices
- Serves 1.1 million Maine & NH residents



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Maine Coon Cat



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New England LKD 2022

Living Kidney Donors



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Living Donor Acceptance

Shared
Decision
Making



Transparent



In Practice:
Complex



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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.



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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.



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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



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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



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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



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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"



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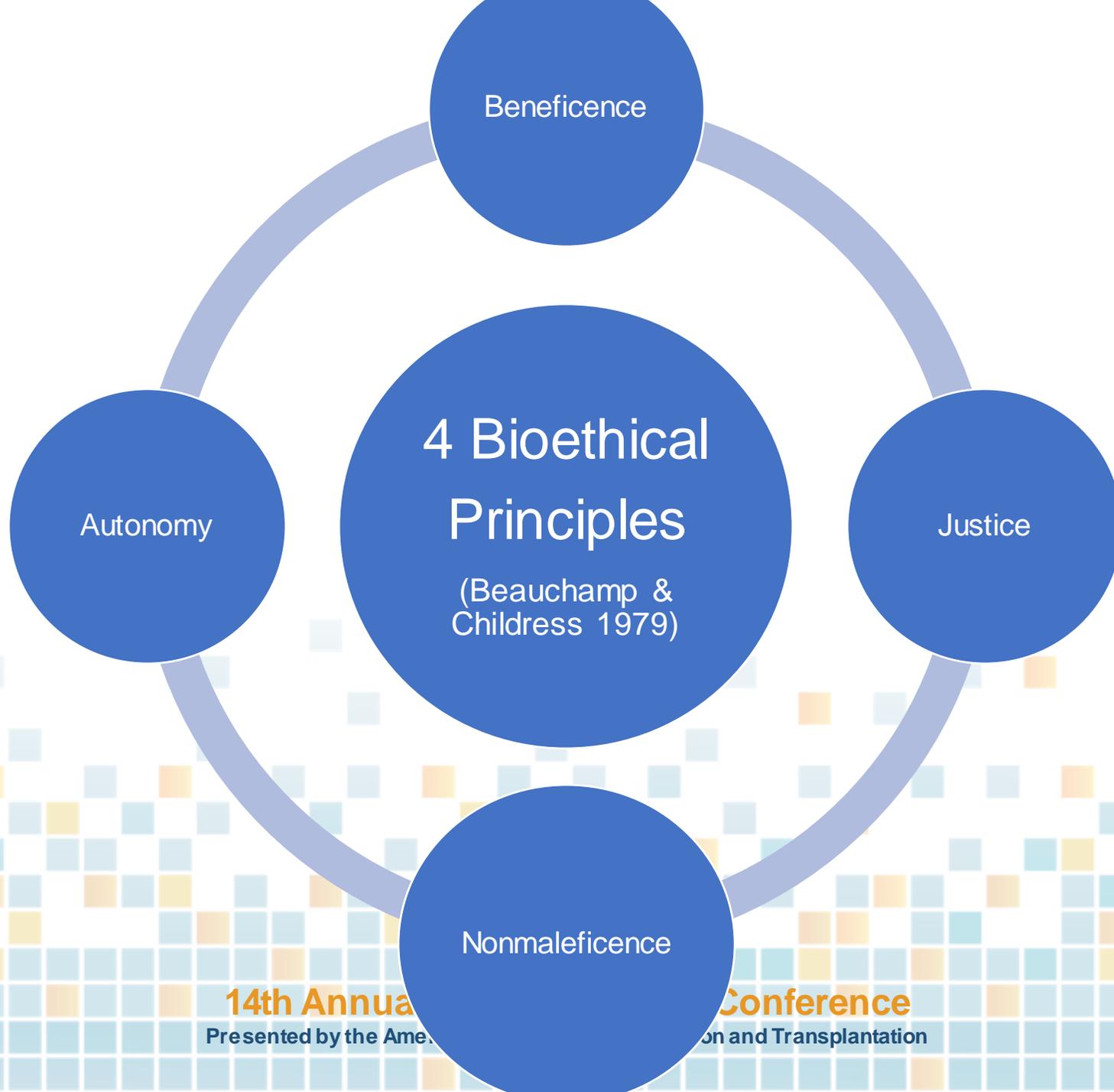
Karen Ann Quinlan 1976

(Photo used with permission: Fair use, <https://en.wikipedia.org/w/index.php?curid=7659862>)

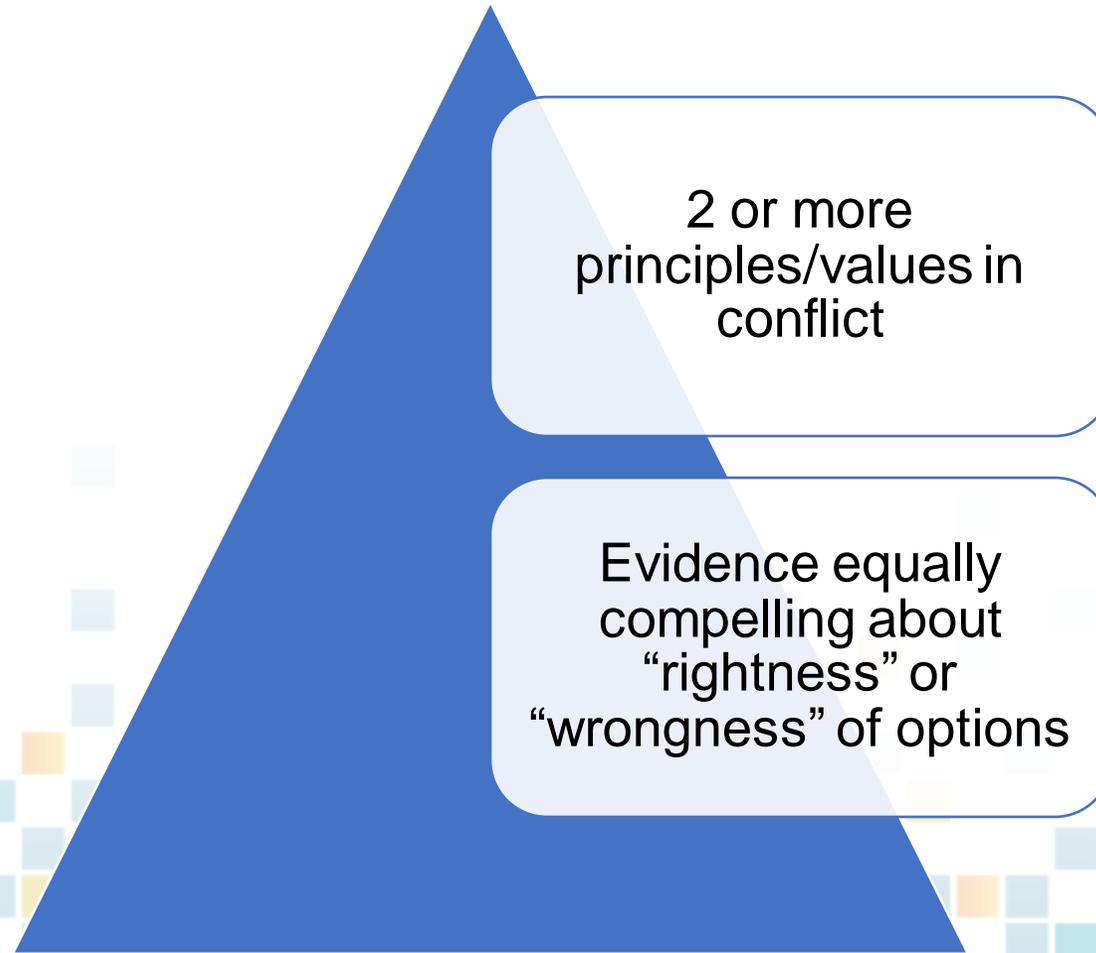


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When do we have an ethical dilemma?



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.



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What Guides Us? Conditions Necessary in Autonomous Decision Making

The action is intended

Understanding
(informed consent)

Free of undue pressure
(internal and external)



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LD Exclusion Criteria

	<h2>Undue Pressure/Inducement</h2>	<ul style="list-style-type: none">• persuading someone to donate by using incentives/pressure that distort a person's judgment
	<h2>Exploitation</h2>	<ul style="list-style-type: none">• 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
	<h2>Coercion</h2>	<ul style="list-style-type: none">• a threat that makes you worse off no matter which outcome you choose



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Obligations to respect
autonomy do not extend to
persons who cannot be
rendered autonomous
because they are:



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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



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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)



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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



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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?



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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***



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Thank You!



Questions?



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References

Aykas, A., A. Uslu, and C. Şimşek. "Mass media, online social network, and organ donation: old mistakes and new perspectives." *Transplantation proceedings*. Vol. 47. No. 4. Elsevier, 2015.

Beauchamp, T. L., & Childress, J. F. (2019). *Principles of biomedical ethics* (8th ed.). Oxford University Press.

Belisomo, R. (2015). A Call to Remove Financial Disincentives to Organ Donation. *Voices in Bioethics*, 1. <https://doi.org/10.7916/vib.v1i.6632>

Blumenthal-Barby, Jennifer S. "Between reason and coercion: ethically permissible influence in health care and health policy contexts." *Kennedy Institute of Ethics Journal* 22.4 (2012): 345-366.

Blumenthal-Barby, Jennifer Swindell, and Hadley Burroughs. "Seeking better health care outcomes: the ethics of using the "nudge"." *The American Journal of Bioethics* 12.2 (2012): 1-10.

Blumenthal-Barby, Jennifer S. "Biases and heuristics in decision making and their impact on autonomy." *The American Journal of Bioethics* 16.5 (2016): 5-15.

Butt, Z., et al. "Psychological outcomes of living liver donors from a multicenter prospective study: results from the Adult-to-Adult Living Donor Liver Transplantation Cohort Study2 (A2ALL-2)." *American Journal of Transplantation* 17.5 (2017): 1267-1277.

Chen J, Bhattacharya S, Sirota M, et al. Assessment of Postdonation Outcomes in US Living Kidney Donors Using Publicly Available Data Sets. *JAMA Netw Open*. 2019;2(4):e191851. doi:10.1001/jamanetworkopen.2019.1851

Chessa, Frank. "Informed consent for living organ donation." *Living Donor Advocacy*. Springer, New York, NY, 2014. 261-274.



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References

Choudhury, Devasmita, et al. "Independent donor ethical assessment: Aiming to standardize donor advocacy." *Progress in transplantation* 24.2 (2014): 163-168.

DiMartini, Andrea, et al. "Social and Financial Outcomes of Living Liver Donation: A Prospective Investigation Within the Adult-to-Adult Living Donor Liver Transplantation Cohort Study 2 (A2 ALL-2)." *American Journal of Transplantation* 17.4 (2017): 1081-1096.

Forsberg, Anna, et al. "The essence of living parental liver donation—donors' lived experiences of donation to their children." *Pediatric transplantation* 8.4 (2004): 372-380.

Garonzik-Wang, Jacqueline M., et al. "Live donor champion: finding live kidney donors by separating the advocate from the patient." *Transplantation* 93.11 (2012): 1147.

Jackson, Whitney E., et al. "Survival benefit of living-donor liver transplant." *JAMA surgery* 157.10 (2022): 926-932.

Kaplan, Alyson, et al. "Practices and Perceptions of Living Donor Liver Transplantation, Nondirected Donation, and Liver Paired Exchange: A National Survey." *Liver Transplantation* 28.5 (2022): 774-781.

Ladner, Daniela P., et al. "Long-term quality of life after liver donation in the adult to adult living donor liver transplantation cohort study (A2ALL)." *Journal of hepatology* 62.2 (2015): 346-353.



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References

Iacoviello, Brian M., et al. "A prospective study of the reliability and validity of the live donor assessment tool." *Psychosomatics* 58.5 (2017): 519-526.

OPTN/UNOS Ethics Committee. "Ethical principles to be considered in the allocation of human organs." <http://optn.transplant.hrsa.gov/resources/bioethics.asp?index=10> (2010).

Reding, Raymond. "Is it right to promote living donor liver transplantation for fulminant hepatic failure in pediatric recipients?." *American Journal of Transplantation* 5.7 (2005): 1587-1591.

Rodrigue, James R., et al. "Altruistic kidney donation to a stranger: psychosocial and functional outcomes at two US transplant centers." *Transplantation* 91.7 (2011): 772-778.

Ross, Lainie F., and J. Richard Thistlethwaite. "Developing an ethics framework for living donor transplantation." *Journal of Medical Ethics* 44.12 (2018): 843-850.

Rudow DL, Robert SB. Evaluation of Living Liver Donors. Progress in Transplantation. 2003;13(2):110-116. doi:10.1177/152692480301300207



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References

Russo, Mark W., and Robert S. Brown Jr. "Adult living donor liver transplantation." *American Journal of Transplantation* 4.4 (2004): 458-465.

Steel, Jennifer L., et al. "The development of practice guidelines for independent living donor advocates." *Clinical transplantation* 27.2 (2013): 178-184.

Thiessen, C., E.J. Gordon, P.P. Reese, and S. Kulkarni. 2015. Development of a donor-centered approach to risk assessment: Rebalancing nonmaleficence and autonomy. *American Journal of Transplantation* 15: 2314–2323.

Truog, Robert D. "The ethics of organ donation by living donors." *The New England Journal of Medicine* 353.5 (2005): 444.

Weightman, A.C., Coghlan, S. & Clayton, P.A. Respecting living kidney donor autonomy: an argument for liberalising living kidney donor acceptance criteria. *Monash Bioeth. Rev.* (2022). <https://doi.org/10.1007/s40592-022-00166-4>



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