

Ethical Bargaining and Parental Exclusion: A Clinical Case Analysis

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To Begin

- ▶ *The views presented here reflect the authors' only and not their affiliated institutions, William Paterson University or Washington Hospital Center.*
- ▶ Based off of forthcoming publication:
 - ▶ Guidry-Grimes, Laura and Elizabeth Victor. “Ethical Bargaining and Parental Exclusion: A Clinical Case Analysis.” *Journal of Clinical Ethics* (2015).

Case Details

- ▶ 4-month old, diagnosed with rare genetic condition
 - ▶ Ultrasounds, blood tests needed every 3 months to check for tumors (standard of care)
 - ▶ Currently stable
- ▶ Father dominates decisions, discussions
 - ▶ Mother cannot understand English
 - ▶ Father worries she will become “bad mother”
 - ▶ Resists standard of care

The Compromise

- ▶ Medical team's worries:
 - ▶ Child becoming lost to healthcare system until medical crisis
- ▶ Bargain after informal ethics consult:
 - ▶ If father agrees to standard of care, clinicians will withhold information from the mother
 - ▶ Goal: Inform the mother over time to reduce likelihood she will become overwhelmed or depressed

Ethics Committee Debrief

- ▶ Heritability concerns w/ future reproduction decisions
- ▶ Perpetual deception
- ▶ Level of father's understanding
- ▶ *All* information about the mother came exclusively from the father
- ▶ Interpreter never contacted
- ▶ No legal basis for withholding information from mother

Moral Problems of Parental Exclusion

- ▶ Case of de facto asymmetrical parental authority
- ▶ AAP: family-centered care and decisional leeway
 - ▶ Compromises are permissible insofar as they do not sacrifice child's basic needs
- ▶ *Medically optimal* decisions are not always *morally optimal*
- ▶ When do clinicians have an obligation to *solicit* viewpoints from caregivers?
 - ▶ Should not abide by a policy of strict non-interference

Parental Exclusion: In this Case

- ▶ Range of medically & morally permissible options were narrow
 - ▶ Standard of care is safe, effective, and non-invasive
- ▶ Ensuring the pediatric pt receives the standard of care:
 - ▶ Notice damaging family dynamics
 - ▶ Enable autonomy of all relevant caregivers
 - ▶ Ultimatum counts as evidence that the father may not have the patient's "good enough" interest at heart

Overcoming Parental Exclusion: Enabling Autonomy

- ▶ No evidence was given that the mother chose to defer decisional capacity
- ▶ Deeper Concerns:
 - ▶ Need to create conditions for autonomy against backdrop of structural coercion and marginalization
 - ▶ Delaying action could perpetuate harmful family dynamics
- ▶ Strategizing to minimize moral risk-taking without overstepping

Ethical Bargaining

- ▶ *Ethical bargain (EB)*: Choosing not to pursue morally preferable outcome for the sake of coming to a resolution
 - ▶ Type of compromise
 - ▶ Suboptimal, but might be necessary
- ▶ When confronted with EB:
 - ▶ Can EB be avoided?
 - ▶ Baseline for these negotiations? - range of what is ethically permissible determined first

Ethical Bargaining in this Case

- ▶ Medically uncontroversial recommendation
- ▶ Father's ultimatum prevented the other parent's involvement in the decision-making process
 - ▶ Directly affects the degree to which the mother can care for her son, short- and long-term
 - ▶ Will likely lead to host of morally problematic decisions
 - ▶ Impediment to family-centered care
- ▶ Result: Ethically **impermissible** bargain

Preventive Ethics

- ▶ Ensure information is available
 - ▶ Reach out to all appropriate consultants and services
- ▶ Mitigate the effects of implicit bias
 - ▶ Institutional initiatives to raise awareness about implicit bias
- ▶ Record problematic family dynamics
 - ▶ Indicate in chart notes when one parent dominates/remains silent
 - ▶ Enable institution to track pattern which may be necessary for future actions (legal, ethics review, etc.)

Thank You!

▶ Discussion

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