Ethics of Vulnerability in Diverse Pediatric Populations: Implications for Clinical Practice

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Learning Objectives

At the conclusion of this activity, participants will be able to:

1. Identify the ethical challenges in pediatric clinical care
2. Explain the sociocultural factors that are important for ethical pediatric clinical care
3. Select clinical practices that can improve inclusive and ethical pediatric care

Case 1: Mary

- 15 year old (yo) with advanced metastatic cancer
- Not responding to conventional treatment
- Has tried experimental treatment but there was no response
- Mary says that she wants to stop additional treatment. She understands that it is likely she will die and also that the options for her treatment are limited.
- Mother wants to keep going and continuously suggests new experimental treatments and therapies for Mary to try.

What should be done?

Adapted from Unguru, (2011)

Poll: What should be done with Mary's request?

- Answer Choices:

a. We must do whatever the mother asks for as she is the decision-maker

b. We must abide by Mary's wishes as she is the patient

c. We should engage in shared decision-making

Decisions in pediatric care

- Children are not just mini-adults
  - Physiology is different
  - Psychology is different
  - Cognitive ability is different

- Adult care→
  - One is expected to ask a capacitated patient to make decisions about oneself

Different ethical assumptions

Adult Care Ethical Presumptions	Pediatric Care Ethical Presumptions
Patient *autonomy*	Patient incapacity
Persons with insight into patient's values	Presumption of *parental authority*
Greater potential conflict between *respecting autonomy* and "best interests"	Potential for conflict between *parental authority* and "best interests"

Adapted from Diekema, Douglas, & Hester (2021)

Capacity

- Ability to
  - **Communicate** a stable choice
  - **Understand** relevant information
  - **Reason through** proposed treatment/procedure in relation to alternatives
  - **Appreciate** the situation and its context

Appelbaum & Grisso (1988)

Consent vs. Assent

- Consent
  - Requires an **autonomous** and **capacitated** choice

- Assent
  - **Active agreement** to participate in a diagnostic or treatment regime
  - Assent must be **voluntary**
  - How active that child will be depends on a variety of contexts

Assent

- Respect children's emerging autonomy
  - National Health Commission (1978)
- Respect developing capacity
  - Assisting them in understanding their condition and treatment options
  - Involving them in appropriate decision-making tasks
- Shared decision-making
  - Empowers them at the extent of their capacity

How to achieve assent?

- Help achieve cognition→ Don't rule out a child because of age
- Tell patient what to expect
- Assess patient's understanding
- Assess factors contributing to patient's responses
- Solicit patient's willingness for care

All pediatricians should assess ability to assent in *all patients*
(American Academy of Pediatrics, 1995)

Bartholome (1995)

How might bias influence assent?

- Implicit bias
  - Attitudes or stereotypes that might influence assessment

- Preferences of caring for specific children (Puumula et al. 2016)
  - "Easier" to understand
    - ✓ E.g., pain management
  - Assuming abilities because of a diagnosis
    - ✓ E.g., children with disabilities

Shared-decision making model

- Physicians must ensure assent
  - Some parents may not be aware
    - ✓ Must emphasize reasons for sharing-in decisions
- Provides choices to child based on abilities
  - Being able to choose an arm for a blood draw
  - Time of day a medication is taken

Benefits of shared decision-making

- Clarifies values and behaviors
- Allows children to feel respected
  - Listening
- Education
- Provides parents and physicians an opportunity to gain insight on developing preferences

Coming back to the case

- Mary
  - 15 yo with advanced metastatic cancer
  - Not responding to conventional treatment
  - Has tried experimental treatment but there was no response
  - Mary says that she wants to stop additional treatment. She understands that it is likely she will die and also that the options for her treatment are limited.
  - Mother wants to keep going and continuously suggests new experimental treatments and therapies for Mary to try.

Mary

- Key questions:
  - Is she mature enough to understand her treatment (tx)?
  - Does she understand the proposed risks and benefits?
  - What are the areas of contention?

Case 2

Grace is a 15 yo girl with developmental delays and is able to attend and participate in special education classes at school. She also experiences heavy menstruation with fibroids and has been treated with oral contraceptive pills, medroxyprogesterone and most recently an Intrauterine Device (IUD). The heavy bleeding is particularly concerning to Grace and her mother because Grace has difficulties remembering to change her pad and often stains her clothes. According to Grace, the IUD has been successful at managing her pain but she is still experiencing some bleeding that leads to her bleeding on her clothes. Later, Grace's mom, Mrs. R speaks with the gynecologist (Dr. H) privately and asks about taking Grace's uterus out because of this bleeding.

Case adapted from *AMA Journal of Ethics (2016)*

Poll: What is the major ethical concern with this case?

- Answer choices:

a. Grace's behavior needs to be managed

b. The request for sterilization may violate Grace's future autonomy

c. Grace won't understand the reasons for her uterus being removed so we don't need to talk with her

Soliciting patient's concerns

- Ethical issues
  - Must balance risks and benefits of menstrual suppression
    - ✓ How does hormonal treatment impact her health?
    - ✓ How does hormonal treatment impact their metabolism of other drugs needed to care for other health concerns (e.g., antiepileptic drugs)
    - ✓ Are there behavioral interventions that can be therapeutic adjuncts for menstrual hygiene? (e.g., alarms)
  - Balance risks of sterilization
    - ✓ Permanent and irreversible
    - ✓ Fibroids are necessarily an indication for hysterectomy

Disability bias

- Assumptions surrounding persons with mental delays
- Disability is not reason for sterilization
  - United National Conventions→ fertility as a human right
  - Illegal to use federal money for involuntary sterilization
- Importance for sexual education

Points in Shared-Decision Making	Strategy	Case 2
Before a decision needs to be made	a. Get to know the patient b. Set expectations c. Engage patient in choices	Understand what Grace views as important for her menstruation & fertility
Making a decision	a. Define options b. Discussion decision c. Make a recommendation d. Honor medically reasonable decisions e. Acknowledge emotions	Continue as it, IUD with behavioral intervention, sterilization (?)

Sayer& Rosenberg (2020)

Case 3:

- Shaun 3 yo with dog bite
- Told by ID that needs a rabies shot
- Also needs reconstructive surgery
- Parents decide that they will pray for their son but are unwilling to consent to rabies shot because of their beliefs

Poll: What to do with Shaun's care?

- Answer choices:

a. There is nothing we can do as we must always abide by parent preferences

b. We should give Shaun the rabies shot without telling his parents

c. We should give Shaun the rabies shot while attempting to engage his parents in collaborative communication

What about collaboration?

- Collaborative communication requires
  - Establishing common goal
  - Exhibiting respect
  - Developing sufficiently complete understanding of our various perspectives
  - Assuring clarity in communication
  - Managing of inter and intra professional processes

Feudtner (2007)

Ways of creating collaboration

- Ideas for promoting collaboration, case 3

- Why does the family believe prayer would work? What does that look like to them?
- Why is the rabies vaccine something that they're against? Are there other treatments that would fit better within their belief system?
- What other compromises can we make?

Family beliefs and care of children

- Parental authority
  - When can parents refuse life-sustaining measures?

Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children

(Prince v. Massachusetts 1944)

Do I still need collaboration then?

- Law may provide ways of ensuring children are not harmed
- Collaboration creates and build trust
- Necessary for continued health care relationships
- Allows us to recognize our own biases

Role of Harm

- Despite our best efforts of collaboration, does decision of parents significantly increase the likelihood of harm compared to other options? (Diekema 2004)
  - If no, parental authority
  - If yes, state should intervene

Harm principle

- Does refusal place child at significant harm?
- Is the harm imminent?
- Will the intervention prevent the harm?
- Do projected benefits of tx outweigh the harm?
- Would other options prevent serious harm that are more acceptable?
- Can state intervention be generalized to others?
- Would most parents say that it is reasonable?

Diekema (2004)

Poll: Shaun's case and the harm principle

- Poll 1: Does refusal place child at significant harm? y/n
- Poll 2: Is the harm imminent? y/n
- Poll 3: Will the intervention prevent the harm? y/n
- Poll 4: Do projected benefits of tx outweigh the harm? y/n
- Poll 5: Would other options prevent serious harm that are more acceptable? y/n
- Poll 6: Can state intervention be generalized to others? y/n
- Poll 7: Would most parents say that it is reasonable? y/n

Key Takeaways

- Pediatric populations should have the ability to assent to treatments
- Our implicit biases may impact how we engage in shared decision-making
- Collaborative communication may be a more effective way to overcome barriers to care than simply using policy or law to override parental authority

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