Decision-Making for Pediatric Patients: When Clinicians and Parents Disagree

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Presenter

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Objectives

At the end of this presentation, participants will be able to:

1. Analyze and differentiate surrogate decision-making for pediatric patients and adult patients
2. Apply the Harm Principle to assess decision-making in children
3. Distinguish between consent and assent in the context of pediatric decision-making
4. Define key principles of pediatric ethics and explain how they guide clinical decision-making in complex cases

Case #1

- Fifteen-year-old female with Neurofibromatosis, large plexiform neurofibroma of the head and neck
- Presented with worsening headaches
- Admitted to inpatient oncology service for evaluation
- Thought unlikely to be malignant
- Significant airway compromise from tumor

Family Background

- From a small village in Mexico
- Came to the local area for evaluation/treatment
- Father works intermittently in the U.S.
- Staying with family nearby
  - Living in a converted shed without running water
- Spanish-speaking
- Two adult older siblings (both in college)

Outpatient Workup

- Full medical and surgical consultation initiated (through multidisciplinary Craniofacial Clinic)
  - Pediatrics, Plastic Surgery, Neurosurgery, Otolaryngology, Social Work
  - Contrast computed tomography (CT) scan and magnetic resonance imaging (MRI) obtained to evaluate tumor, airway and vasculature
- Team conference
  - Suggested radical surgical resection of the tumor
  - Recommendation for perioperative tracheostomy and gastrostomy in preparation for surgery to reduce risk of postoperative complications

Meeting with Family

- Family met with Providers and Social Work from Craniofacial Clinic
- Family concerned that team was suggesting a cosmetic surgery → had been told in Mexico that she would be paralyzed or die if she had surgery
- No apparent concerns about need for perioperative tracheostomy/gastrostomy
- Decided to move forward with surgery

Surgery

- Radical debulking of right facial plexiform neurofibroma
- Apparent complete resection of circumscribed lesions
- Ten-day pediatric intensive care unit (PICU) stay
- Pathology diagnosis: malignant peripheral nerve sheath tumor
- Positron emission tomography (PET) scan two weeks after resection → residual tumor at skull base
- Prognosis: death in 3-4 months without treatment; 50% five-year survival with resection and radiation therapy
- Family asked team not to share diagnosis with child and wanted to return home to Mexico ("if you tell her she will die") to think about further treatment (parents divided)

Primary Team Consults Ethics

Case #2

- Two month well child check
- Uncomplicated pregnancy, birth, newborn stay
- Healthy child, eating and growing well
- Parents declining vaccines
  - You REALLY tried to convince them, but they still say no

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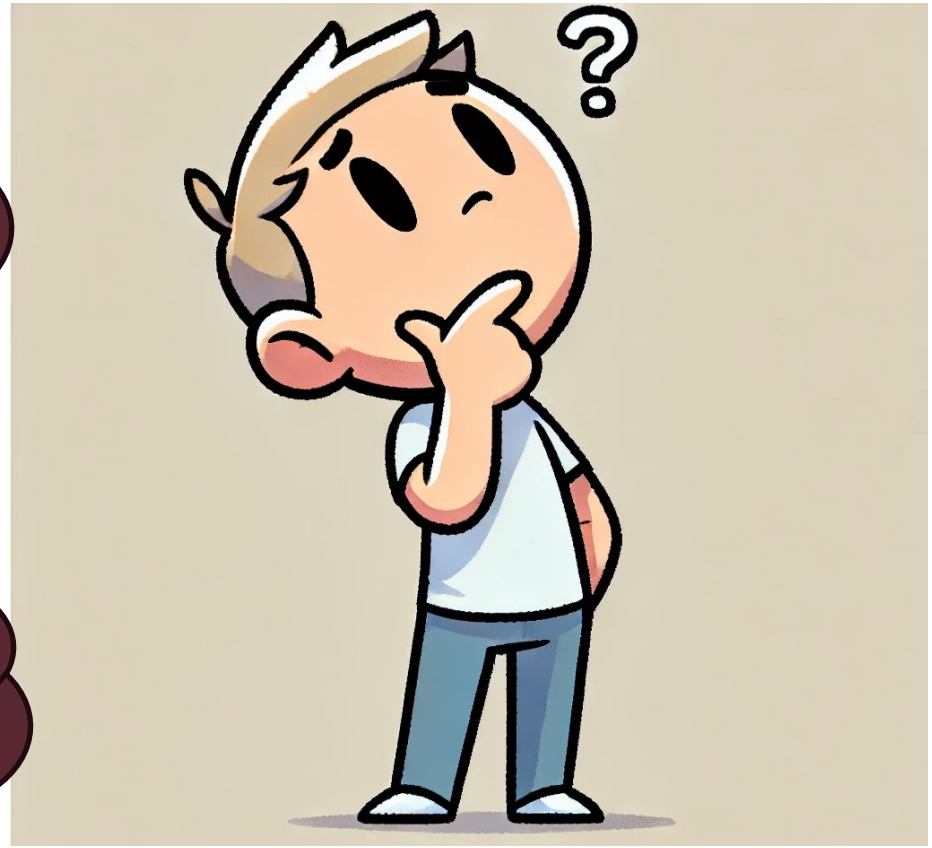
Polling Question #1

What would you do?

Ask more questions

Spend more time trying to convince them



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Respect their decision

Call Child Protective Services

Vaccine Hesitancy in the Pediatric Population

- For more about vaccine hesitancy in the pediatric population, here are some further (optional) resources:
  - Pediatric Ethics podcast on language used to describe vaccines: https://www.childrensmercy.org/health-care-providers/bioethics-center/bioethics-webinars-and-podcasts/bioethics-podcast-series/
  - Pediatric Ethics podcast on vaccine hesitancy (specifically with the COVID vaccine): https://www.childrensmercy.org/health-care-providers/bioethics-center/bioethics-webinars-and-podcasts/bioethics-podcast-series/
  - Material from the Children's Hospital of Philadelphia on addressing vaccine hesitancy: https://policylab.chop.edu/evidence-action-briefs/addressing-vaccine-hesitancy-protect-children-and-communities-against

Case #3

- 10-year-old male status post motor vehicle crash
- Massive blood loss, hypotensive shock
- Needs surgery
- Family is Jehovah's Witness, refusing blood products

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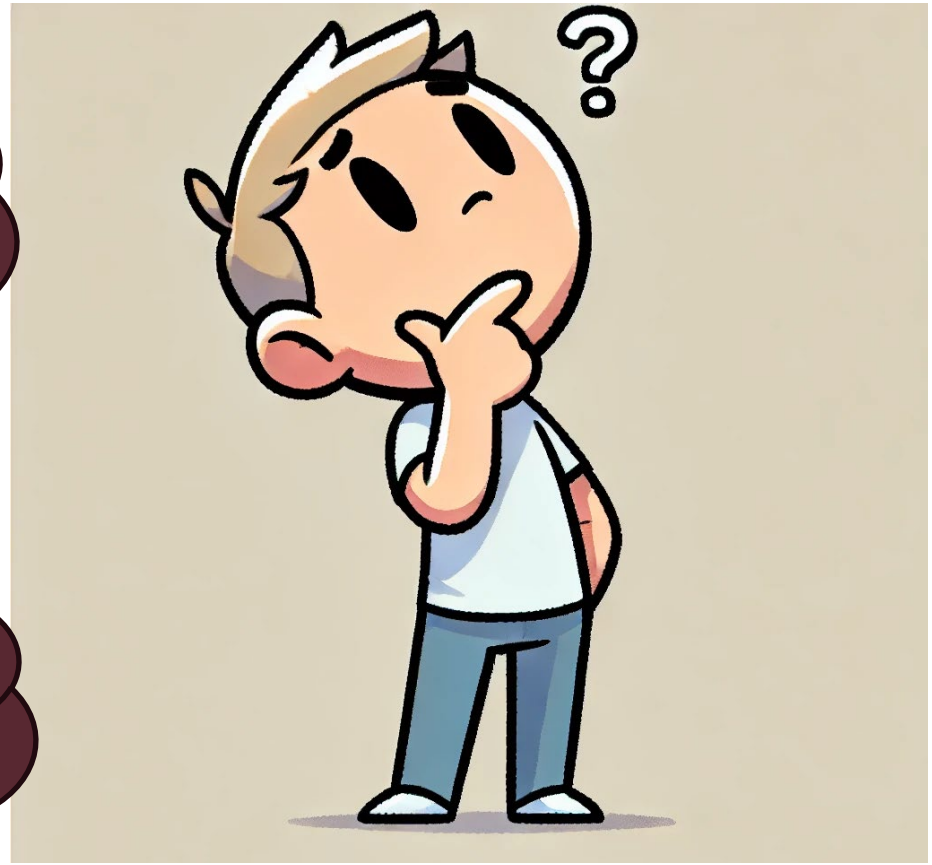
Polling Question #2

What would you do?

Ask more questions

Spend more time trying to convince them



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Respect their decision

Give blood products

Refusal of Blood Products for Children

- For more about refusal of blood products for children, here are some further (optional) resources:
  - Review article: Smith ML. Ethical perspectives on Jehovah's Witnesses' refusal of blood https://www.ccjm.org/content/ccjom/64/9/475.full.pdf
  - Pediatric ethics podcast on ethical decision making in pediatric emergencies: https://www.childrensmercy.org/health-care-providers/bioethics-center/bioethics-webinars-and-podcasts/bioethics-podcast-series/

What makes these cases different?

Principles of Biomedical Ethics

Beneficence

Non-maleficence

Respect for Autonomy

Justice

Autonomy and Decision-Making in Adults

- Adults with capacity able to make decisions for themselves
- Very few limits
- If lacking capacity, surrogate decision-maker
- Surrogate must act as a patient would have decided for themselves
  - Substituted judgement

Parental Autonomy/Authority

- Parents - legal and moral authority to make decision for their child
- Understand special considerations for their family
- Will live with the outcomes

Parental autonomy → Authority

- Autonomy → ability to practice self-rule
- Cannot have self-rule over someone else
- Parental autonomy? Authority?
- Can autonomy have limits? Authority can…

Best Interest (1 of 3)

- Best Interest Standard
  - Based in legal standards (UN Convention on the Rights of the Child)
  - “The best interests of the child shall be a primary consideration”
  - Includes all aspects important to decision
    - Child’s views and aspirations
    - Care, protection, and safety of child
    - Well-being of child
    - Family environment of child

Best Interest (2 of 3)

- Best Interest Standard
  - Used by surrogate decision-makers to determine “best” course of action
  - Must consider and weigh all relevant factors
  - Often used to determine appropriate treatment options to offer to parents by providers
  - Used by providers when no surrogate available
  - Proponents: Beauchamp/Childress, Brock/Buchanan

Best Interest (3 of 3)

- Best Interest Standard- challenges
  - Difficult to assess weight of different factors
  - Hard to separate child and family interests
  - Not made to determine when to intervene

Harm Principle

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.

- John Stuart Mill

Popular Science, Vol 3, July 1873

Harm Principle, continued

- Focuses on setting a threshold at which to seek state intervention against parental decisions
- Sets thresholds where decisions are clearly contrary to best interests of child
- Needs careful reflection
- Proponent: Diekema

Harm Principle – Eight questions

- By refusing to consent, are the parents placing their child at significant risk of serious harm?
- Is the harm imminent, requiring immediate action to prevent it?
- Is the intervention that has been refused necessary to prevent the serious harm?
- Is the intervention that has been refused of proven efficacy and, therefore, likely to prevent the harm?
- Does the intervention that has been refused by the parents also place the child at significant risk of serious harm and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?

Harm Principle – Eight questions, continued

- Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
- Can the state intervention be generalized to all other similar situations?
- Would most people familiar with the situation agree that the state intervention was reasonable?

Our cases

Back to Opening Case…

- Pathology diagnosis: malignant peripheral nerve sheath tumor
- PET scan two weeks after resection → residual tumor at skull base
- Prognosis: death in 3-4 months without treatment; 50% five-year survival with resection and radiation therapy
- Family asked team not to share diagnosis with child and wanted to return home to Mexico (“if you tell her she will die”) to think about further treatment (parents divided)

What do you think?

- Do you think this case crosses the Harm Threshold of placing the child at significant risk of serious and imminent harm?
- Why or why not?

- By refusing to consent, are the parents placing their child at significant risk of serious harm?
- Is the harm imminent, requiring immediate action to prevent it?
- Is the intervention that has been refused necessary to prevent the serious harm?
- Is the intervention that has been refused of proven efficacy and, therefore, likely to prevent the harm?
- Does the intervention that has been refused by the parents also place the child at significant risk of serious harm and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?

- Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
- Can the state intervention be generalized to all other similar situations?
- Would most people familiar with the situation agree that the state intervention was reasonable?

Polling Question #3

Do you think this case crosses the Harm Threshold ?

- By refusing to consent, are the parents placing their child at significant risk of serious harm?
- Is the harm imminent, requiring immediate action to prevent it?
- Is the intervention that has been refused necessary to prevent the serious harm?
- Is the intervention that has been refused of proven efficacy and, therefore, likely to prevent the harm?
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Opening Case – Harm Principle

- By refusing to consent, are the parents placing their child at significant risk of serious harm?
- Is the harm imminent, requiring immediate action to prevent it?
- Is the intervention that has been refused necessary to prevent the serious harm?
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- Does the intervention that has been refused by the parents also place the child at significant risk of serious harm and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?

Opening Case – Harm Principle, continued

- Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
- Can the state intervention be generalized to all other similar situations?
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Harm Assessment

- Prognosis
  - Death in 3-4 months without treatment
  - 50% five-year survival with resection and radiation therapy
- Survival
  - Multiple surgeries
  - Ongoing treatment
  - Separation from family/friends
  - Continues to worsen after five years
- Ethical analysis → not sufficient to override parental authority

Adolescents and Decision-Making

- When can adolescents make decisions for themselves?
- On what issues can adolescents make decisions for themselves?
- What about privacy and confidentiality for adolescents?

Decision-Making Capacity

- Ability to understand and communicate relevant information about a medical condition
- A framework of values that provide a context for value judgements
- The ability to reason about all available options and appreciate their effect, including risks and chances of success

Adolescents and Decision-Making, continued

- Cognitively and physically maturing
- “Developing capacity”
- Assent
- Consent
- Rule of Sevens

Case Wrap-Up

- Meeting with patient and Craniofacial team
- Determination of decision-making preferences
  - Decision-making about hearing information
- Honored parental wishes
- Passed away three months later after readmission to hospice service for pain control

Key Takeaways

- Adult vs. Pediatric decision-making
- Parental authority vs. Parental autonomy
- Harm Principle
- Adolescents- developing autonomy, rule of 7s
- Consent vs. assent

References

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Pediatric Ethics podcast on vaccine hesitancy (specifically with the COVID vaccine): https://www.childrensmercy.org/health-care-providers/bioethics-center/bioethics-webinars-and-podcasts/bioethics-podcast-series/

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Questions?

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