

A Question of Consent

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HDMH Weekly Rounds - April 29, 2026

Objectives

- List examples of difficulty in obtaining truly informed consent
- Describe ethical principles in dealing with those patients who may have difficulty providing consent
- Describe how best to manage difficult cases where consent needs to be obtained

I have no relevant declarations

Figure 1. The four principles of healthcare ethics.



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Neonatal Intestinal Obstruction (NIO)

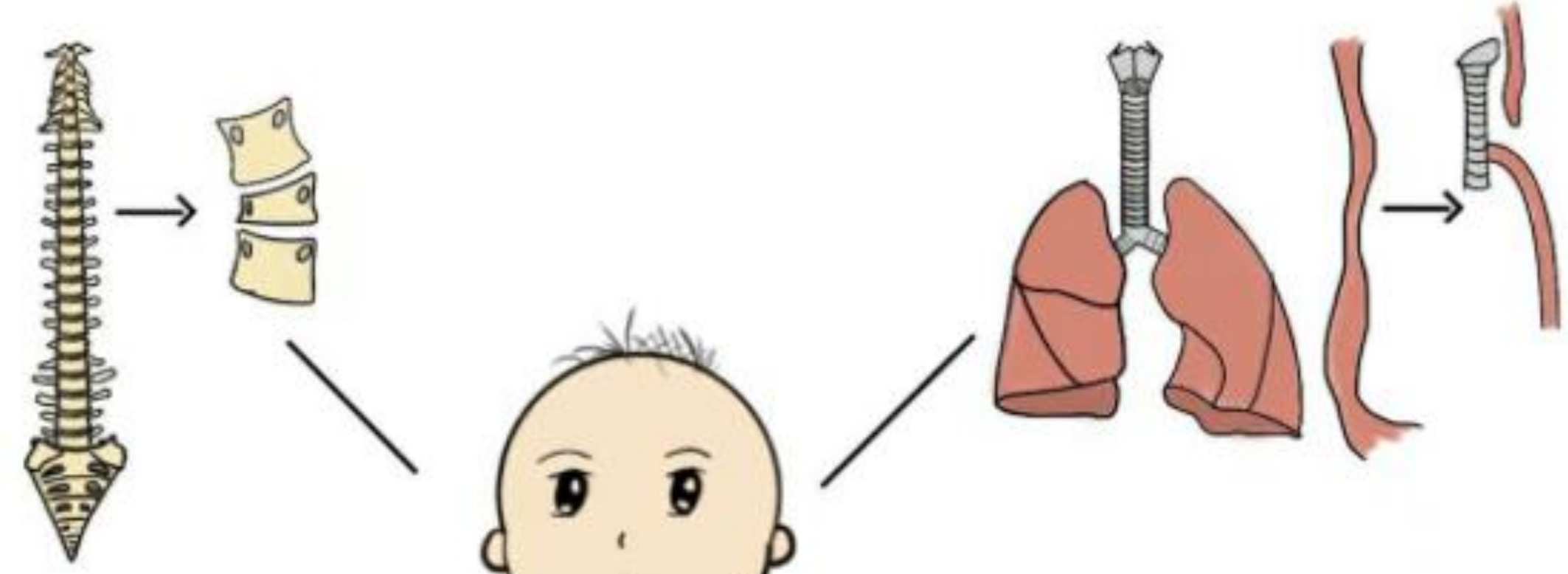
Hirschsprung's Disease

Anorectal Malformation





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Key Embryological Concepts:

- **Hindgut Development (Weeks 4-7)**: The cloaca acts as a common channel for both digestive and urogenital systems.
- **Urorectal Septum (Week 7)**: The urorectal septum, a mesenchymal fold, should descend and divide the cloaca into the anterior urogenital sinus and the posterior rectum.
- **Cloacal Membrane Breakdown (Week 8)**: The cloacal membrane should break down and combine with the proctodeum (ectodermal invagination) to form the anal opening.

- **Abnormalities:**

- **Impaired Septation:** Failure of the urorectal septum to fully divide the cloaca, often leaving a fistula (connection) between the rectum and the urogenital sinus (rectourethral, rectovaginal, or rectovestibular).
- **Cloacal Membrane Failure:** The anal membrane fails to break down, resulting in a covering or complete absence of the anus.
- **Atresia/Stenosis:** The rectal pouch ends blindly or is too narrow, often because the hindgut did not reach the proctodeum. [➤ National Institutes of Health \(.gov\) +5](#)

Things to Know

300,000 Born Every Year with Congenital Anomalies Requiring Surgery

- Anorectal Malformations and Hirschsprung's Disease Occur in 1/5,000 Births
- In Hospital Mortality for ARMs and Hirschsprung's = 39.8% in LMICs vs. 5.6% in HICs
- Low Anomalies May be Treated by Perforation of Cloacal Membrane or Anorectoplasty
- High Anomalies Require 3 Stage Procedure -> Colostomy, Anorectoplasty, Closure of Colostomy
- 2017 Study in Uganda -> 68% of Neonates with Colostomies for NIO Never Underwent Reversal and 50% Developed Serious Stoma-related Complications Within a Year

- **BENEFICENCE & NON-MALEFICENCE**

- Act for the Patient's Benefit / Do No Harm

- Benefit - Stabilize Critically Ill Neonate, Prevent Death from Perforation or Sepsis

- Maleficence - Commit Child to Lifelong Health Burden & Chronic Suffering

- Ethical Care Can't Focus Solely on Immediate Benefit Without Considering Foreseeable Long Term Harm

Autonomy

The Right to Make Informed, Comprehended and Voluntary Decisions

Difficulty to Have Time to Build Trust and Adapt Consent Process to Local Language

Health Literacy

Emotional Stability

Is Consent Defined by Fear of Death of the Child or With Clear Understanding of Short and Long Term Implications of the Surgery?

Justice

Fair and Equitable Distribution of Health Resources

Disparity of Outcomes in HICs and LMICs Due to Inequities in Workforce Capacity, Infrastructure, and Access to Care

3% of All Global Surgical Funding Is Directed To Paediatric Services

70 - 90% of Surgical Costs in LMICs Are Out of Pocket For Families

Progressive Supranuclear Palsy



Progressive supranuclear palsy (PSP) is a rare, fatal neurodegenerative disorder causing severe, rapid declines in balance, movement, vision, and speech. As an atypical parkinsonism, it involves tau protein accumulation in brain areas controlling movement and cognition. There is no cure; management focuses on symptom relief. [National Institute of Neurological Diso... +4](#)



- 75 year old man
- Symptoms since 2017, initially thought to be Parkinson's Disease
- No response to L-dopa
- PSP diagnosed - Rx @ Toronto Western and with Dr. Baker
- Last able to walk unassisted in 2024, now bed -> chair

- Falls, pressure sores, aspiration
- Weight 100kg -> 66kg
- "Just shoot me"

Laugh
Grimace
Hand Squeeze

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 **Dementia patient gets MAID after family member brought forward the request**



The MAID provider deemed the woman had given her final consent, based on her ability to repeat a question and squeeze the provider's hand



Speech Pathology Consultation



Beneficence

- To act for the patient's benefit
- Attempted to improve communication
- Didn't respect previously stated wish to die
- "Only realized if the intervention ultimately contributes to sustained well-being"

Nonmaleficence

- “First do no harm”
- Obligation to avoid inflicting needless suffering
- Obligation to minimize risk

Autonomy

- The right to make informed, comprehended and voluntary decisions
- Substitute Decision Maker “What would this person want if he or she could decide for himself or herself?”
- Previously expressed wishes

Justice

- Fair, equitable and adequate allocation of resources

Discussion