

Ethical Issues in Pediatric Palliative Care



Erin Flanagan M.D.
Medical Director
Pediatric Palliative and Supportive Care
Advocate Children's Hospital

The
Coleman Palliative Medicine
TRAINING PROGRAM

Ethics

- Concerned with “the good”; what is “right” action/conduct
- Based on values of a community and/or individual
- Values based on principles
- Values CAN be sanctioned into laws
 - (but not always)

Principles of Medical Ethics

For patients of all ages

- Autonomy
 - *Respect for patient integrity and wishes*
- Beneficence
 - *Relieve pain and suffering*
- Nonmaleficence
 - *Avoid /minimize causing harm*
- Justice
 - *Treat patients and parents fairly*

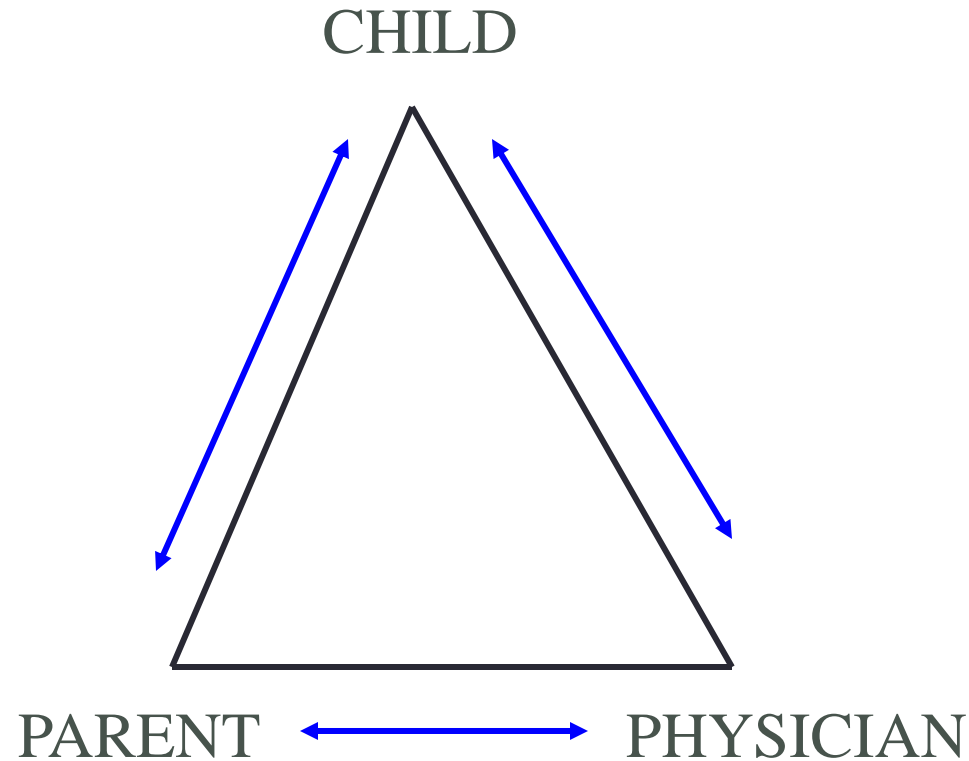
Physician-patient relationship

- Trust
- Therapeutic alliance
- Fiduciary
- Honesty
- Confidentiality

What is different about pediatrics?

- Surrogate decision-making is the model
- Developmental variation in patient participation in care decisions
- Accepted boundaries of patient/parent autonomy
- Greater role for physician paternalism
- Heightened emotions
- Advance care planning not focused on advance directives

Physician-Patient Relationship in Pediatrics



SURROGATE DECISION-MAKING IS THE RULE

Principles of Medical Ethics

Pediatrics

- Autonomy of Parents
 - ‘Evolving autonomy’ of pediatric patient
 - *Respect for patient integrity and wishes*
- Beneficence
 - *Relieve pain and suffering (of patient and family)*
- Nonmaleficence
 - *Avoid /minimize causing harm (to patient, and family)*
- Justice
 - *Treat patients/families fairly*

Conflict in the Therapeutic Relationship

- Discordant goals of care (based on values)
- Breakdown in communication
- Loss of trust
- Prognostic uncertainty
- Presence of moral distress

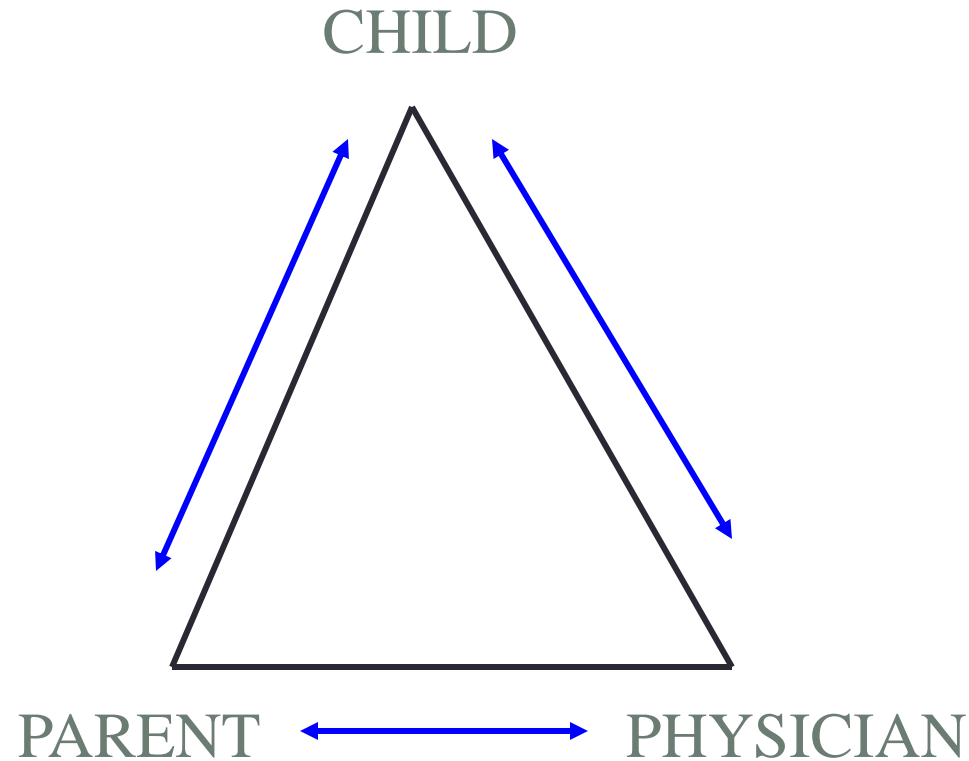
Common Settings of Conflict

when most Ethics consults are called...

- Participation in Medical Decision-Making
- Information disclosure/Truth-Telling
- Conflict over goals of medical care
 - Parent or provider promoting “futile” care
 - Parent refusal of recommended treatment
- Care at the Margins of Life
 - Neonatal Viability
 - End of Life



Physician-Patient Relationship in Pediatrics



SURROGATE DECISION-MAKING MODEL

Medical Decision-making Models

- Physician as decision-maker
 - Paternalism model
 - Insufficient information/insight about child and family well-being
- Parent as decision-maker
 - Patient rights model
 - Insufficient clinical insight and medical information

Neither extreme is good!

Shared Decision-Making

- Physician and patient/parent engage in mutual exchange of information about achievable treatment and patient goals
- When indicated, each may defer certain decisions to the other based on insight and experience

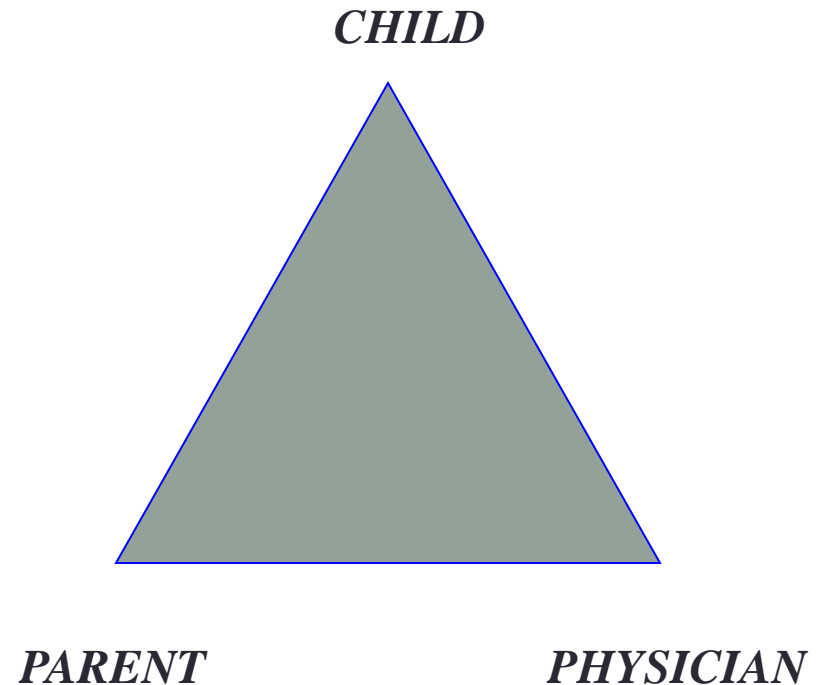
Factors in Medical Decision-Making

- Competence (kids usually don't have)
 - *Legal term implying ability to give informed consent at age of majority (18yrs)*
 - *Able to make independent personal, medical and financial decisions*
 - *All or nothing*
- Decisional Capacity (kids often do have)
 - *Cognitive and developmental skills necessary for informed decisionmaking*
 - *Can be impaired partially or temporarily*

Medical Decision-making

Informed Consent

- Flawed term in pediatrics
- Informed assent of the child
- Informed permission of the parent as surrogate decision-maker



Standards for Surrogate Decision-making

- Substitute Judgement – *surrogate puts patient stated wishes into action*
 - *Adult with advance directive*
 - *“My Wishes” and “Voicing My Choices”*
- **Best Interests** – *identified surrogate uses own judgment weighing risks and benefits on patients behalf*
 - *Most common standard for parents*
 - *Subjective interpretation*
 - *Treatment team and parent opinions may differ*

Parental Autonomy

- **Parents** are presumed to be the most appropriate decision-makers or guides for the *evolving* autonomy of their children.
- State cannot provide the intimacy, stability and emotional bonds that exist in the private family setting.
- State must balance its powers and limitations with respect to children and families
- In general, the state's goal in advancing a *child's best interest* is best served by deferring to parental autonomy.



Parental Autonomy



Parental Autonomy



Limits of Parental Autonomy

- Physical abuse/ neglect
 - Child endangerment
 - Parental incapacitation
 - Medical neglect
- *Provision of medically inappropriate/harmful interventions*

Supreme Court Ruling - 1944

Religious freedoms vs. child welfare

“Parents are 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, 321 U.S. 158 1944

Parent Refusal of Treatment

- Over last 50 yrs, case law filled with cases of parents refusing medical care for children.
- Baby Doe Regulations – 1984, C E Koop
 - Amendments to the federal Child Abuse and Neglect legislation
 - Limit circumstances in which treatment may be withheld in infant under 1 year old.
 - Do not require physicians to provide medically inappropriate treatment
 - Remain highly controversial, and poorly enforced
 - No physician or hospital has ever been prosecuted.
- Cases are handled through local court systems, and decided on a case by case basis.

Case 1

- 12 y/o female with advanced medulloblastoma refractory to initial treatment with resection, chemotherapy and XRT.
- Oncologist would like to place her on a Phase 2 Clinical trial involving additional chemotherapy.
- Parents defer this option and seek CAM in addition to Palliative Care.
- Oncologist questioning parental decision and authority

Treatment decisions for children

- EFFICACY (benefit)
of treatment

*What is the threshold
beyond which there is a
moral imperative to treat
despite parent wishes?*

- TOXICITY (risks)
of treatment

*What is the level
beyond which parent
refusal is morally
permissive?*

Case 2

- 16 y/o female with widely metastatic osteosarcoma to chest wall, mediastinum, lungs and brain at EOL at home in hospice.
- *Pt with moderate-severe bone pain, immobility and worsening agitation and delirium.*
- *During multiple goals of care conversations in past months/weeks w pt and parent, pt states “I just want to be at home”.*
- *Parent states in private, “She is to remain a full code, no matter what. And DO NOT speak to her about EOL”*
- *Pt presents to OS ED in respiratory failure, is intubated and transported to our institution*

Medical Decision-Making

The Adolescent Patient

Evolving autonomy in decision-making

Goal of patient ASSENT

Specialized consent/privacy statutes apply only for:

- Reproductive health
- STD
- Mental health
- Substance abuse

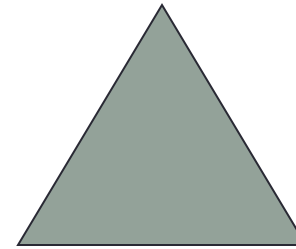
Confidentiality not absolute!

Emancipation status

- Must meet state criteria

The 'mature minor'

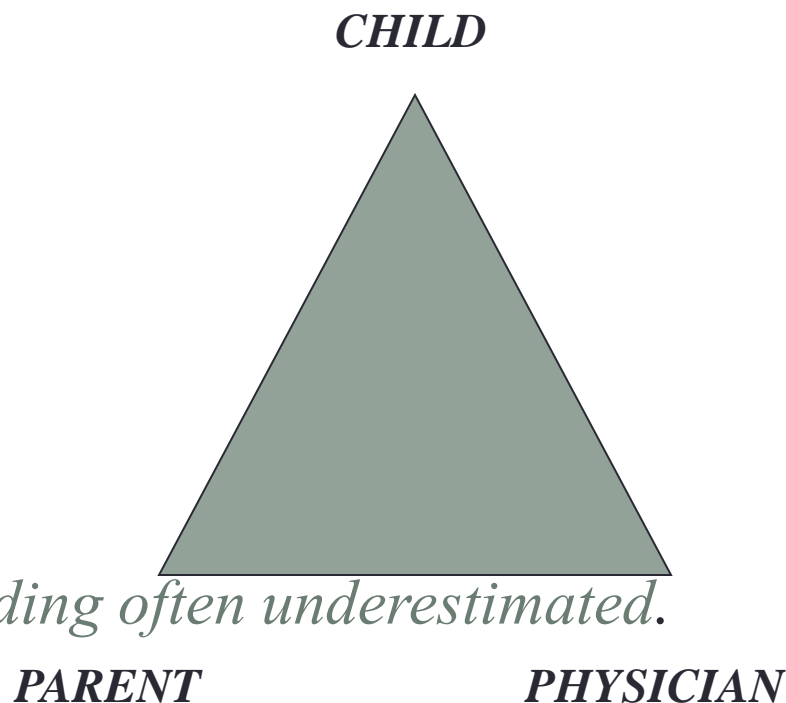
- Must involve courts



Truth telling and information disclosure

- Developmentally appropriate
- Influenced by parent's own grief and anxiety
- Family dynamic, and cultural factors

Child's knowledge and understanding often underestimated.



Case 3

- 2 y/o male s/p MVA, ejected from car found at scene in full arrest, 30 min of CPR before HR restored.
 - *TBI, severe ICH L>>R, requiring L hemicranectomy*
 - *C-spine translocation at C1-2, Halo placed*
 - *After 7 days, neuro exam notable only for unilateral corneal reflex.*
 - *Mother counseled daily, at length by multiple providers about grave prognosis*
 - *Mother wishes to proceed with VPS, spinal fusion, trach, G-tube and full resuscitation as necessary*

“Medical Futility”

- No single definition, many have tried.
 - Physiologic, *speech therapy in comatose pt*
 - Quantitative, *Phase 1 trial as curative, CPR at EOL in adv Ca*
 - Qualitative, *chronic mechanical ventilation in setting of brain death*
- Perceptions, and definitions influenced by:
 - Process of Innovation
 - Goals of patient care
 - Goals of patient and family
 - Outside influences on family

The Advance Directive in Pediatrics

- “My Wishes” – school age children
- “Voicing My Choices” – adolescents
- Very common for parents to prefer to make decisions about LST in real time as child is deteriorating, in consultation with treatment team, either in the hospital or at home.

Decisions at the margins of life

- End of life
 - Same approach to symptom management as in adults
 - Palliative sedation ok
 - Withholding and withdrawing non-beneficial interventions
 - *morally and ethically equivalent in pediatrics.*
- Beginning of life / viability
 - Perinatal palliative care
 - Competing interests of mother and infant
 - Dilemma of deciding what is “futile” with more uncertainty

Shared Decision-Making

- Parents commonly defer active role in EOL decisions involving withholding/withdrawing treatments
 - *Grief*
 - *Guilt*
 - *Life after child's death*
- Parents often look to care team for insight, experience and recommendations.
 - *Remove burden of difficult EOL decisions*

Summary

- Respect families, no matter what their belief system. Understand that they play the central role in their child's life and well-being.
- Initiate and sustain meaningful dialogue with parents and children, and advocate for 'shared decision-making' model.
- When conflicts over goals of care arise, assume role as the child's advocate rather than the parent's adversary.
- Usurping parental authority should always be a 'last resort' in preserving patients' medical best interests.
- Try to maximize the greatest 'good' for pediatric patients and their families, which may be different in each case.

Questions?

