Dell Children’s Medical Center

9TH ANNUAL PEDIATRIC CONFERENCE

Sunday, April 24, 2016
1-4 p.m.

St. Vincent de Paul Auditorium
1345 Philomena St.
Austin, TX 78723
Ethical Challenges in Pediatric Practice

Hanoch A. Patt, MD, MPH

Medical Director, Children’s Cardiology Associates
Co-Chair, Seton Network Pediatric Ethics Committee
Objectives

• Discuss basic ethical principles underlying pediatric practice
• Describe a decision making process for addressing an ethical dilemma
• Analyze the application of ethical principles using patient examples
• Discuss family communication strategies
Ethics Defined

• A systematic study of what our conduct and actions ought to be about ourselves, others and the environment; the justification of what is right and good.
  – Aroskar, 1987

• At its most basic, ethics is the study of how we make judgments in regard to right and wrong.
Ethical Principles

• Overview of Ethical Principles
  – Beneficence/Non-Maleficence
  – Autonomy/Respect for Persons
  – Veracity
  – Fidelity
  – Justice
Beneficence

• “An obligation to help others further their important and legitimate interests” – Beauchamp and Childress
  – Promoting welfare of patients (and not just avoiding harm)
    • Restore patients’ health if possible
    • Minimize pain, suffering, disability, etc.
  – Balance possible goods vs. possible harms or an action (utility)
  – Closely tied to non-maleficence
Nonmaleficence

– Hippocrates (Epidemics): “As to disease, make a habit of two things – To help, or at least to do no harm”
– The physician should attempt not to inflict evil or harm to his or her patient
– Are there some treatments that cause harm to our patients?
  • Do burdens of proposed treatment outweigh benefits?
Beneficence/Nonmaleficence

• Primary doctrine of medical ethics until second half of 20\textsuperscript{th} century
  – Ability of physicians’ to act in perceived patients’ best interests without informed consent (paternalism)
Autonomy

• Greek – *autos* (self) and *nomos* (rule)
• In medicine, suggests that the patient has the right to undergo or refuse a proposed treatment
• Informed consent
• “Autonomous actions are not to be subjected to controlling constraints by others” – Beauchamp and Childress
• Is it unlimited?
  – Harm to others, to self, to “society”
  – Presumes acting in best interest of patient
Informed Consent

• Informed Consent

• Elements of Informed Consent
  – Disclosure
  – Understanding
  – Voluntariness
  – Competence

• Assent in Pediatric Population
Surrogate Decision Making

• Substituted Judgment
  – For a formerly competent decision maker, what would he or she have decided if he or she were making the medical decision

• Best Interests
  – Surrogate acts in what he or she perceives are the “best interests” of the patient
    • Children
    • Unknown preferences of patient

• Benefits versus burdens
Veracity

• The duty to be truthful in one’s relationship with patient/family
  – Closely related to informed consent
  – Avoiding barriers to honest communication with patients/families
    • Misleading through
      – Commission
      – Omission
      – Jargon
Fidelity

• The duty to keep one’s commitment
  – Acting in best interests of patient
  – Responsibilities to patient, medical team, employer, professional society, government
  – Contractual vs. covenantal fidelity
    • What level of effort must a physician/practitioner/nurse undertake to fulfill the desires/needs of his or her patient?
Justice

• Many theories of justice in medicine
  – Egalitarian – equal access to care
  – Libertarian – create a fair system without worrying about specific outcomes
  – Utilitarian – maximize public good

• Who should get what care in a system of scarce resources?
Applying Ethical Principles in Practice

• How do we apply these ethical principles in practice?
  – Stepwise approach to challenging cases
    • Understand the facts and alternative courses of action, including the potential consequences of each potential
    • Assess each available alternative from the perspective of all of the *relevant* ethical principles.
    • Identify and consider implications of relevant ethical or legal consensus position(s)
    • Develop and justify management plan for resolving case
Easy, right?

- Living in gray areas
- In pediatrics, we both have it easier and harder
  - Patient is not typically an autonomous decision maker
  - Multiple, often conflicted surrogate decision makers
  - Best interest legal standard provides additional protections for patient
Applying ethics

• Many themes
  – Truth telling and informed consent
    • What is my obligation as a pediatrician when parents think they are acting in child’s best interests by withholding diagnosis, prognosis, etc.?  
      – Cancer diagnosis
      – Disorders of sex development
Applying ethics

• Many themes
  – Parental autonomy vs. best interests and professional integrity
    • Parental demanded diagnostic testing and treatment
      – “my teenager is taking the SAT this fall and needs ritalin”
      – Plastic surgery
    • Parental demanded undertreatment
      – “Your chemotherapy/vaccines/antibiotics are harming my child. He/she needs to stop treatment/go gluten free/no vaccines, etc.”
  – Beneficence/nonmaleficence
    • Genetic testing that doesn’t affect plan of care
    • Determination of abuse and obligation to report
Maintaining physician-patient-family relationship in difficult cases

• How do you maintain open dialogue?
• Effective communication is a procedural skill
  – Planning
  – Practice
  – Self-evaluation
• Physician-parent-child communication includes:
  – Informativeness
  – Interpersonal sensitivity
  – Partnership building
• Religious and/or Cultural sensitivity and best interests of patient
• Messaging: importance of word choice
• Levetown et al., Communicating with Children and Families
  – http://pediatrics.aappublications.org/content/121/5/e1441
Summary

• Ethical challenges are common in pediatric practice
• A structured process for ethical discernment can help the provider navigate difficult cases
• Effective communication is vital to maintaining relationship between physician-parent-child
• The Seton Network Pediatric Ethics Committee is available to assist with challenging cases
• To access the ethics committee, call 512-324-0000 and ask the operator to page the ethics first responder.