Ethics Cases and Additional Resources in Pediatric Bioethics

Introduction:
At times during the practice of Pediatrics, clinicians must make difficult ethical and moral decisions to serve the best interest of their patients. The scenarios described below are real cases, address ethical issues unique to pediatric patients and give you the chance to develop practical approaches to these problems. We have also included a list of online resources to introduce you to broader materials available in pediatric bioethics.

Group Discussion:
Your bioethical learning objective can be met by a group discussion of the cases. **Be prepared to discuss the following for BOTH case 1 and 2, as everyone is expected to participate:**
- The ethical issues raised by each case;
- How you would weigh the various sides of the conflicts/view the different arguments;
- How you would develop a plan to resolve the problem and the ethical conflicts;
- Basic ethical principles that would guide your plans.

Ethics Cases

**Case 1**
You are a primary care physician who is assuming the care of a family. Upon review of the past medical history of the 1-year-old daughter, you find that she has had no immunizations although she received several well child examinations with their homeopathic caregiver. Her current medications include Chinese herbal supplements and the family follows a vegan diet. You ask the parents why your patient hasn’t received immunizations and they state, "We don’t believe in immunizations".

**Case 2**
A 14 year-old boy is admitted to the Hematology-Oncology ward with acute lymphoblastic leukemia. He presented to the Emergency Department with pallor and dizziness and was found to have a hematocrit of 14.9%. The oncologist would like to start best available chemotherapy immediately, but the patient and his legal guardians (aunt and uncle) have made it clear both verbally and in writing that, as Jehovah’s Witnesses, they will refuse all blood products. His chemotherapy is myeloablative and will cause a further decline in his hematocrit. There is virtually a 100% chance of death with this leukemia if it is not treated and an approximately 75% chance of survival with best available chemotherapy.

**Case 3 (Optional):**
A 7-week old previously healthy full term Hmong female infant presents to your clinic with 24 hours of fever, mild cough, nasal congestion and irritability. Mom measured an axillary temperature of 104.5 degrees Fahrenheit this morning. On physical exam, you find the infant sleeping comfortably in no acute distress in her mother’s arms but who begins to whimper when you try to move her. Overall, her exam is non-focal with a full but soft anterior fontanelle. Initial labs show a normal white blood cell count but with a left shift, a negative urinalysis, and an elevated C-reactive protein. Mom declines any further work-up—including a lumbar puncture—saying she is “against any more invasive tests”.


Resources in Pediatric Bioethics

University of Washington School of Medicine

(1) Pediatric Clerkship UW
http://depts.washington.edu/bioethx/topics/index.html
This website presents core materials about ethics and professionalism for each clerkship at UW. Go to the pediatric clerkship section for specific information.

(2) Treuman Katz Center for Pediatric Bioethics
http://www.seattlechildrens.org/research/initiatives/bioethics/
The Treuman Katz Center for Pediatric Bioethics at Seattle Children’s Hospital and the University of Washington offers a number of helpful resources for pediatric bioethics. You may also access past conferences and videos of the presentations. Check the calendar for grand rounds presentations on ethics, guest speakers, and other educational activities.

National Resources in Pediatric Bioethics:

(3) American Academy of Pediatrics
https://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Section-on-Bioethics/Pages/Bioethics.aspx
American Academy of Pediatrics has been at the forefront of ethical policy development for the Pediatrics profession. While AAP policy statements are not legally binding, they reflect the considered wisdom and consensus of leadership in the profession. The ethics policy statements and full length articles from the membership are some of the most thoughtful ethical discussions among professional statements in medicine. The site is also the best place to go to see a comprehensive list of both classic and current articles on issues in pediatric ethics. Click on “current articles”, “classic articles”, and “policy statements” to access these documents.

(4) American Medical Association’s Journal of Ethics is a terrific resource sponsored by the AMA. It offers case scenarios, brief discussions and helpful presentations. Enter: “child” as the search word to bring up additional discussions in pediatric ethics.

Immunization Information

(5) Information for providers from the CDC: http://www.cdc.gov/vaccines/
AAP Policy Immunization Hesitancy: http://pediatrics.aappublications.org/content/138/3/e20162146
Ethics and Professionalism Benchmarks for Pediatrics

Many of the ethical principles that apply to caring for adults also apply to caring for children. These benchmarks outline several topics unique to pediatric patients that are highlighted in your clerkship. This is not an all-inclusive list. Useful links to additional cases are also included in the final section of the document.

ETHICS:

Parental rights to guide care

Know

Parental rights:
Society has given the right of making medical care decisions to parents because they are viewed as uniquely capable of determining the child’s best interest. This included authorizing treatments AND refusing treatments (even life sustaining treatments).

Limitations to parental rights:
If the parents’ actions appear not to be in the child’s best interest, the parents’ rights can be challenged. You have the ethical responsibility to advocate for the patient if you believe the parents’ actions are imminently dangerous, neglectful or abusive.

Do

Fully elicit parents’ reasons for therapeutic decisions.
Explore perceived differences in an open and accepting manner (even if you really disagree).
Assess whether parents are capable/competent to make medical decisions
Determine (through conversations with your resident and faculty supervisors) whether there are concerns about the parents advocating for the child’s best interests.

Child abuse reporting

Know

Caregivers’ legal responsibility:
Physicians who care for children have a legal obligation to report suspected child abuse. It is your responsibility to determine whether the abuse occurred, what person may have perpetrated the abuse or any other specific details. This is a critical role to understand. There are often complicated social interaction and caring for abused children is a team effort. We work with nurses, social workers, other physicians and child protective services as a team to help determine what happened. If you do NOT report it and you suspect it you are legally liable.

Do

Be vigilant about this issue
Be non-judgmental—just because you suspect abuse doesn’t mean it happened OR you know who the abuser might be.
Be honest about what you see with the parents and ask for their explanation of your findings.
Discuss your observation with your faculty supervisor
Clearly document what you see and what you are told
You SHOULD NOT disclose your concerns to the family before discussing this with your supervisors. Discussing these issues is the faculty/attendings responsibility.
Care of adolescent patients

Know

General approach:
Adolescent patients are capable of participating and guiding their medical therapy. The extent of each patient’s ability will depend on the developmental maturation of the patient. In general, parents retain the responsibility to direct care for patients less than 18 years of age unless there is disagreement about the course of therapy.

Special considerations:
As a caregiver for pediatric patients you should be able to define the following special categories of patients:

1. Emancipated minor:
   There are specific categories of adolescents who are legally capable of directing their medical care. The categories include: 1) married, 2) pregnant/parent, 3) in the military, 4) self-supporting.

2. Mature minor:
   Courts can grant decision-making capacity to minors; this may be limited to specific categories of care (see below) or in some cases of chronic illness when the PHYSICIAN case determined that the patients is capable of informed consent.

3. Specific categories of care:
   Decision-making capacity is given to minors for the treatment/care of pregnancy, drug or alcohol abuse and sexually transmitted disease. Laws vary by state.

As a caregiver for pediatric patients you should be able to define the difference between:

1. Informed consent: requires that the patient be competent to make health care decisions, physician disclosure of relevant information, patient understanding of the information and a voluntary, un-coerced patient decision.

2. Parental permission: parents give permission for therapy provided to their children. The same standards and procedures for giving informed consent to a competent patient apply.

3. Child Assent: helps patients acquire a developmentally appropriate understanding of her condition, telling the patient what he can expect for the treatment, assessing the patient’s understanding of the situation, including determining whether they fell pressured to accept/reject the treatment. It also includes soliciting the patient’s willingness to undergo the procedure (you can see how this is probably a team effort with the parents!). This approach is not limited to adolescent patients but is appropriate for ALL pediatric patients.

Do

Use appropriate language for the patient’s developmental level when explaining medical care options.
Respect the patient’s privacy.
Discuss sensitive issues when you are alone with older patients (e.g. drug or alcohol use, sexual practices/preferences, suicide risk etc.)
Obtain parental permission about therapeutic interventions
Obtain child assent from patients about therapeutic interventions.
PROFESSIONALISM:

Admitting Mistakes

Know
A medical error or mistake is a preventable or unexpected outcome of a medical treatment. An adverse event is a side effect that may occur in a certain percentage of cases that are treated. Medical mistakes are usually not due to negligence. They arise from incomplete knowledge base, an error of judgment, lapse in attention or a “systems” error. You have a professional responsibility as a health care provider to disclose errors to your patients. Although it is difficult and uncomfortable disclosing errors, most patient appreciate honesty (wouldn’t you?). Loss of trust usually arises from nondisclosure of errors.

Do
When you identify a medical error:
- Determine the effect (actual or potential) on the patient
- Investigate/identify possible causes
- Explain in a calm, unhurried, truthful and apologetic manner that an error has occurred.
- Answer all questions the patient has and be open for additional questions in the future
- Provide information about follow up of the incident
- Accept responsibility and apologize in necessary

Balancing Learning and Care for the patient

Know
As a student it is a common dilemma and each case should be approached on an individual basis. The primary conflict in these cases is the care for THIS patient vs. the need to learn to care for FUTURE patients. Balancing the risk to the patient you are caring for presently compared to what you will learn must be determined. There is an adage “see one, do one, teach one”, that may or may not be appropriate based on the risk to the patient and your own unique abilities. You must be honest and provide adequate informed consent. An additional stressor for most students is also balancing care for the patient and being evaluated.

Do
Provide informed consent:
- You should clearly indicate who will be doing the procedure and what the level of training is. You must answer additional follow up questions (like…how many of these have you done?).
- Know your limitations
- Communicate your abilities clearly with your supervisors
- First do no harm to your patients