Pediatric Ethics

Nanette Elster, JD, MPH
Assistant Professor
Neiswanger Institute for Bioethics
Overview

• Key issues in pediatric ethics
• What makes pediatric ethics different?
• Informed consent v. assent
• Best interests v. substituted judgment
• Conflicts
Key Issues in Pediatric Ethics

1. Decision-making (informed consent, assent, conflicts)
2. Beginning of life issues (pre-conception, conception, in utero, birth)
3. End of life issues (life sustaining treatment, determination of death)
4. Uses of new technologies and research (transplant, genetics, fertility preservation, enhancement technologies)
5. Public health issues (vaccination, firearms, football)
6. Other issues (special needs, social media, LGBTQI)
Cases in the news
What Makes Pediatric Ethics Different?

1. 3 parties rather than 2 (Autonomy)
What Makes Pediatric Ethics Different?

2. Children lack capacity, competence and life experience, but this is a continuum.
What Makes Pediatric Ethics Different?

3. Law and ethics are inextricably intertwined. (Justice, beneficence)
   a. Parents have the right to the care, control and custody of children.
   b. The state must act on behalf of children if no parent/guardian or if parent(s)/guardian(s) are abusing or neglecting a child.
What the Law Says

• “It is cardinal with us that the custody, care and nurture of the child reside first in the parents,” (Prince v. Massachusetts, 321 US 158 (1944)).

• “the interest of parents in the care, custody, and control of their children -- is perhaps the oldest of the fundamental liberty interests recognized by this Court” (Troxel v. Granville, 530 US 57 (2000)).
Limitations on Parental Authority – Parens Patriae

“(literally, ‘father of the people’) refers to the power of the state to usurp the rights of a natural parent and act as the parent of any child who is in need of protection. It stems from the idea that the state has an affirmative duty to protect those who cannot protect or speak for themselves . . .”

(Public Health Law Center, Mitchell Hamline Law School)
Informed Consent


• The concept is “‘rooted in the fundamental recognition—reflected in the legal presumption of competency—that adults are entitled to, accept or reject health care interventions on the basis of their own personal values and in furtherance of their own personal goals.’” (President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Making health care decisions. 1982)
Assent

• “the active agreement of a minor to participate in a diagnostic or treatment regimen. The ethical principle of pediatric assent recognizes that children (especially adolescents) are capable of participating at some level in decision-making related to their care.”

(Y. Unguru, in Clinical Ethics in Pediatrics: A Case-Based Textbook)
Exceptions to Parental Consent

• Mature minors
• Emancipated minors
• Treatment for STIs, birth control, mental and substance abuse
• Treatment for sexual assault
• In most states, parents cannot choose to sterilize a child without court review
## Children’s Right to Consent

### Minors May Consent To:

<table>
<thead>
<tr>
<th>State</th>
<th>Contraceptive Services</th>
<th>STI Services</th>
<th>Prenatal Care</th>
<th>Adoption</th>
<th>Medical Care For Minor’s Child</th>
<th>Abortion Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Alaska</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Arizona</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Arkansas</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>California</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Colorado</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Connecticut</td>
<td>Some</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Delaware</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Dist. of Columbia</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Florida</td>
<td>Some</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Georgia</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Hawaii</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Idaho</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Illinois</td>
<td>Some</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Indiana</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Iowa</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Kansas</td>
<td>Some</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Kentucky</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Louisiana</td>
<td>Some</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent</td>
</tr>
<tr>
<td>Maine</td>
<td>Some</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Maryland</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
</tr>
</tbody>
</table>
Best Interests v. Substituted Judgment

**Best Interests**
- Relates to family autonomy/privacy; deferential to parents
- Parents typically in the best position to know what best meets their child’s needs
- “the essential element of preserving the integrity of the family is maintaining the autonomy of the parent-child relationship.” (Newmark, DE S. Ct., 1991)

**Substituted Judgment**
- Applied when surrogate is making a decision for an adult who has had capacity.
- What would that person have wanted if s/he currently had capacity?
- Focus is on what the patient would do in the situation
Alternative Approaches

Constrained Parental Autonomy
• Developed by Lainie Ross
• Goes beyond the essential needs of the child and considers the needs of the family unite

Harm Principle
• Developed Doug Diekema
• Considers whether decisions that are made on behalf of the child actually cause harm
Children’s right to an “open future”

• “[the child’s right] while . . . still a child is to have future options kept open until [the child] is a fully formed, self-determining adult capable of deciding among them.” (Joel Feinberg, 1980).

• “The concept of the child’s right to an open future offers a new way to resolve these issues by focusing on the autonomy of the child (present or future) as a limit on the autonomy of the parents.” (Dena Davis, 1997).
Case 1 - Adolescent refusal of tx

• Cassandra C.

• “Pathological tests showed conclusively that Cassandra was suffering from Hodgkin’s lymphoma, a type of cancer that is invariably fatal if not treated, but that has a high probability of cure if treated in a timely manner. Interrupting chemotherapy treatment of the disease can lead to resistance of the cancer to treatment. Delaying chemotherapy treatment may increase the risk of a poor outcome and may require radiation treatment, which has increased risks of harmful side effects, especially for young women.”
Case 2 – Parental refusal of diagnostic

• From Clinical Ethics in Pediatrics: A Case-Based Textbook:

3 year old brought to the ER by parents concerned with a head injury. Fell about 4ft off of monkey bars and hit his head. Did not lose consciousness and after 15 min. seemed fine. Now complaining of headache and vomiting. Has vomited 3 times since arriving in the ER. Dr. concerned about a cranial bleed and feels a CT is necessary to diagnose and intervene if necessary. Parents are concerned that previous x-rays have causes son to have learning problems and refuse to consent to the CT.

(Chapter 3, Doug Diekema)
Case 3 – Maternal/fetal conflict

“Angela Carder at twenty-five weeks of pregnancy was diagnosed with a lung tumor. A week and a half later Ms. Carder, who had chosen to fight this recurrent bout of cancer aggressively was near death and the hospital sought an emergency court order to perform a cesarean section to deliver the fetus. After a hearing in Ms. Carder’s hospital room, the order was granted and the operation performed.”

Case 4 – Genetic testing

• From Clinical Ethics in Pediatrics: A Case-Based Textbook:

Mrs. Smith has breast cancer. She is the 3rd of 3 sisters to develop BC by age 40 and she does have the BRCA mutation. She has brought her 14 year old in for her physical and has asked if she can be tested for the mutation.

(Extracted from a case study by L. Ross)
Summary

1. Parents are typically the best decision makers for children
2. There are exceptions
3. Children’s views can and should be considered
4. The interests of all involved participants in accepting or refusing treatment should be considered
5. Children will hopefully grow up to be autonomous adults
Conclusion

“Life affords no greater responsibility, no greater privilege, than the raising of the next generation.”

C. Everett Koop