Ethics of Pediatric Fertility Preservation

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Talk objectives

Identify and discuss ethical considerations for different pediatric fertility preservation (FP) populations

No disclosures
General ethical considerations

- Autonomy: developing/future autonomy vs. best interest
- Beneficence: preserve potential for genetic children
- Nonmaleficence: minimize risks and harms
- Justice
  - Access and cost
  - FP vs. other medical treatments
  - Fair treatment for DSD and trans youth
Case based approach

- Examine the unique ethical considerations for:
  - Cancer patients
  - Youth with disorders (differences) of sex development (DSD)
  - Transgender youth
Collaborative publications

Features

Familial Discordance Regarding Fertility Preservation for a Transgender Teen: An Ethical Case Study
Gwendolyn P. Quinn, Amani Sampson, and Lisa Campo-Engelstein

The Ethics of Fertility Preservation for Pediatric Patients With Differences (Disorders) of Sex Development
Lisa Campo-Engelstein, Diane Chen, Arlene B. Baratz, Emilee K. Johnson, and Courtney Finlayson

Fertility Preservation for a Transgender Teenager
Leenie Nachtsheim, MD, Lisa J. Campbell-Engelstein, PhD, Amy Trosholt, MD, Gwendolyn P. Quinn, PhD, John D. Lantos, MD

Preserving the Right to Future Children: An Ethical Case Analysis
Gwendolyn P. Quinn, Moffitt Cancer Center, Health Outcomes and Behavior Program, and University of South Florida
Daniel K. Stearsman, University of South Florida, College of Medicine
Lisa Campo-Engelstein, Devin Murphy, Jonathan Jaques Children’s Cancer Center, Miller Children’s Hospital, HARBOR-UCLA

Ethical Issues in Pediatric and Adolescent Fertility Preservation
Lisa Campo-Engelstein, Diane Chen

Tough Talk: Discussing Fertility Preservation with Adolescents and Young Adults with Cancer
Angel Petropoulos, PhD, and Lisa Campo-Engelstein, PhD
### 4 box method

<table>
<thead>
<tr>
<th>Medical Indications</th>
<th>Patient Preferences</th>
<th>Quality of Life</th>
<th>Contextual Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>diagnosis, prognosis, treatment options, and goals of care</td>
<td>patient’s values or best interests of patient</td>
<td>improve, or at least address, quality of life for the patient</td>
<td>social context including family, culture, religion, SES, hospital policy, law, finances, etc.</td>
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Case 1: Oncofertility
Case overview

• Ben is 4 years old
• Brain tumor with poor prognosis
• Parents want FP
  • Testicular tissue
Who decides?

- Ben can’t consent, assent limited
- Parental paternalism justified
Reasons for FP

• Open future
• Forgoing FP = sterilization?
  • Adoption difficult for cancer survivors
• Frozen hope
Concerns with FP

- Physical
- Psychological
- Experimental procedure
  - False hope
  - Conflict of interest
Parental role and influence

- Gonadal tissue “belongs” to Ben
  - Destroyed or donated if he dies

- FP means genetic grandchildren expected
  - Parents devote time and money to expectations
• When is the prognosis too poor for FP?
  • Discussing vs. providing FP
Finances

Covered through clinical trial

Insurance coverage
Moving forward

- Risk of infertility and prognosis
- Untangle Ben’s and parents’ interests
- Recognize family unit as “patient”
Case 2: DSD fertility
Case overview

• Zoli is 13 years old and just began menarche
• Turner Syndrome
  • Diminished fertility
  • FP more likely successful at younger age
    • Egg freezing or ovarian tissue cryopreservation
• Her parents want FP
• Zoli is refusing FP
Gonadectomy

Reasons for

- Increased cancer risk
  - Difficult to monitor gonads
- Gonads lacking “purpose”
  - Not traditional hormone production and fertility
- Combine gonadectomy and FP
Gonadectomy

Medical reasons against

- Cancer risk varies among DSDs
- Surgery involves risk
- Preference for endogenous hormones
Gonadectomy

Ethical and psychosocial reasons against

• Violation of autonomy
  • “Normalizing” surgeries for DSD
  • WHO and UN human rights violations

• Damage to gendered identity
Passing condition onto children

Concerns for future children

- Obligation to minimize harm and promote good
- Duty to have the “best” children
Passing condition onto children

Treatments

• Treatments for some medical conditions associated with DSDs
• Preimplantation genetic diagnosis
Passing condition onto children

Valuing DSD lives

• Devaluing disabled lives

• Adults with DSD reject label of disordered, diseased, or disabled
Disagreement about FP

Who decides?

Parents’ paternalistic beneficence vs. Zoli’s reproductive autonomy
Assent

Importance of involving Zoli

- Zoli cannot consent, but can assent
- Subjectivity of treatment
  - Reproduction as deeply personal
Assent

Concerns with Zoli deciding
Assent

Concerns with Zoli deciding

- Reasons for refusal
  - Fear
  - Discomfort
- Not be able to predict her future wishes
- Not recognizing the potential significance of genetic reproduction
  - Most teens focused on pregnancy prevention
Negative rights

• Right to bodily integrity
  • Almost absolute in medicine
• Logistics of forcing her
Moving forward

• Conversations and even mediation
• If still refuses, don’t force
  • Non-lifesaving treatment
  • Future opportunities for FP
  • Alternative family building
Case 3: Trans fertility
Case overview

- Jackie is 16 years old
- Assigned male at birth, identifies as female
- Has been on puberty blockers since age 9
- Eager to start hormones
  - Hormones will affect fertility
Future parenthood

- Jackie is interested in FP
- Jackie is attracted to people who identify as female
- Jackie wants to have a genetic child with a future partner
Jackie’s parents

- Jackie’s parents, Jane and John, are divorced
- Jane supports Jackie’s choices
- John is concerned about Jackie going on hormones
- John believes FP is a waste of money
Who decides?

- Jackie may be able to consent
- Jackie should be involved in gender affirming care and FP
  - Both decisions very personal
- Legal and logistical barriers to FP
Positive rights

- Positive right to something
  - Entails duties from others
  - Limited in medicine
- There isn’t a positive right to FP
Parental consent

• In most states, minors need parental consent for hormones and FP

• Other reproductive services don’t require parental consent
Cost as a barrier

• FP expensive and is often not covered by insurance
  • Even supportive parents cannot afford FP
• No charity programs for FP for transgender individuals
Paths to genetic parenthood

• Delay hormones until 18
  • Psychosocial cost of delaying puberty
• Seek emancipated minor status
• Go off hormone therapy as an adult
  • Effects of cross sex hormones on Jackie’s future fertility
Alternative family building

- High costs
- Discriminatory laws and policies
How to move forward

• Providers want to be supportive of Jackie
• Providers may not want to encourage FP over John’s objections
  • Minor, financial support, parental consent
• Ideally uphold Jackie’s wishes
Legal solutions for parental discord

- Mediation
- Neutral third party
- Divorce agreement
  - Jane may have the ultimate legal authority
  - Jane can appeal for final decision-making authority
Final thoughts

• Various ethical considerations regarding FP for different pediatric populations

• Let’s continue to explore them together!

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