Love, Justice, & Humility: Reflections on Bioethics and Medicine

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“Ethics at its best is only bad poetry—that is, it seeks to help us see what we see every day but fail to see rightly... If ethicists had talent, they might be poets, but in the absence of talent, they try to make their clanking conceptual and discursive claims do the work of art.”

--Stanley Hauerwas
100 Years of Leadership
100 Years of Leadership
Ashley

6.5 year-old female with profound neurologic and cognitive disability

1 year history of pubic hair and 6 month history of early breast budding

Length and weight were at the 75\textsuperscript{th} and 50\textsuperscript{th} percentiles for age (3 ft 11 in/45 lbs)

Chief concern:  Rapid growth
• Ashley was a 6.5 year old girl with profound developmental disability who will cognitively remain at the level of a 3 month old for the rest of her life and will never walk, talk, or care for herself.

• Parents approached general pediatrician about restricting her growth, performing a hysterectomy, and removing her breast buds. Pediatrician contacted CHRMC endocrinologist.

• Ethics consult requested

• Involvement of Medical Director
Treatment of Constitutional Tall Stature in Adolescent Girls

- First report by Goldzieher in 1956
- Reports of over 700 girls
- Few serious adverse effects reported

High Dose Estrogen

- Transdermal Skin Patch
- Reduce Height from projected 5’4” to 4’6”
- Nausea, headache, weight gain—all mild
- Rapid advancement of breast development and uterine bleeding
- Deep Vein Thrombosis (increases with age and immobility)
Two Additional Requests:

- Hysterectomy
- Breast bud removal
Hysterectomy risk must be compared to alternative

- Breast bud removal and hysterectomy
  - Mitigate risks of estrogen
  - Reduce anticipated discomforts for this child after puberty

- 30 years of some form of estrogen/progesterone treatment to control menstrual bleeding and protect from pregnancy.
  - Oral Treatment
  - Injectable treatment
  - Endometrial ablation?
The Ethical Question:

Is this the right thing to do...?
Ethics Committee

- Full Committee Convened
- Parents and Ashley present for 1st part of meeting
- Ashley’s primary pediatrician and developmental pediatrician both present at meeting
- Father presented the family’s request
- Committee deliberated for 2-2.5 hours
Ethics Committee

• Considered each request as separate and independent

• Focus on
  – Benefits and risks to child
  – Role of parents in clinical decision making

• All three procedures raised ethical issues, but there was reason to believe Ashley would benefit and would be unlikely to experience harm
Ethics Committee
Recommendations

• Recommend allowing the parents to proceed

• Recommend Legal opinion regarding necessity for a court order for hysterectomy given lack of clarity in Washington State Law

• Develop process for independent review of future requests
Outcome

• Treatment included a surgical procedure to remove uterus (ovaries preserved) and breast buds

• High Dose Estrogen Treatment for two years resulted in 12-18 inch reduction in ultimate adult height

• Gunther and Diekema submit article to Archives of Pediatrics and Adolescent Medicine with permission of parents
“Everything has both intended and unintended consequences. The intended consequences may or may not happen; the unintended consequences always do.”

—Dee Hock, Founder and CEO emeritus of Visa International
Timeline cont.

- **2004**: Treatment begins
- **Oct. 2006**: ARCHIVES article published
- **Jan. 3 2007**: LA TIMES article published
- **Jan. 3-12 2007**: Media onslaught begins
- **Feb. 2007**: Protestors outside AMA headquarters

- **11/19/06**: Bend Bulletin publishes well-balanced story
- **01/12/07**: CNN: Larry King Live
- **01/22/07**: People Mag. 1/22/07 Time Mag.
To Seek the Truth

A Christian Duty
Step 1

Identify the Question
What were the questions?

• Is this in Ashley’s Best Interest (in comparison to available alternatives)?
  – Growth Attenuation
  – Hysterectomy
  – Breast Bud Removal

• Who ultimately should be able to decide?

• Are there limits to what kind of decision should be tolerated?
Micah 6:8

He has shown you, O man, what is good; and what does the Lord require of you but to do justly, to love mercy, and to walk humbly with your God?
Beneficence

• “To Do Good”

• Obligation to seek the good of others
  – Avoid inflicting harm
  – Prevent harm
  – Promote good
Beneficence

Medicine is a form of applied beneficence

...so is parenting
Beneficence and Decision-making: Values and Best Interests

• Best Interests encompass spheres other than the medical:
  Total Well-being vs. Medical Well-being

• Trade-offs between competing medical goods: i.e. comfort
  vs. life extension vs. cure

• Balancing benefit and harms of a given therapy

RM Veatch, J Med Phil 2000; 25: 701-722
This case was about making one little girl’s life and one family’s experience a little better.

This was not about setting a precedent or creating an policy.
Are there Policy Implications?

- Is this in Ashley’s Best Interest (in comparison to available alternatives)?
  - Growth Attenuation
  - Hysterectomy
  - Breast Bud Removal

- Who ultimately should be able to decide?

- Are there limits to what kind of decision should be tolerated (Harm Principle)?
Purpose of Decision-making Standards

• Provide Guidance to Decision-makers?
  – Patient Preference
  – Best Interests

• Identify the limits of surrogate decision-makers?
  – Harm Principle
In Cases where reasonable people disagree about what is in a child’s best interest:

Parents should be able to decide
Eligibility Criteria & Process

- Profound Developmental Delay
- Non-ambulatory
- Prognosis near certain
- Agreement on multiple evaluations by different providers
- Willing Provider
- Ethics Committee Review
- Review of outcomes
“Those are my principles. If you don’t like them I have others”

--Groucho Marx
Objection 1: This is not natural

• Neither is almost everything we do in medicine

  – Immunizations
  – Antibiotics
  – Surgery
  – Transplants
  – G-tubes, tracheostomies
Objection 2: You are playing God

• We are “playing God” nearly every time we intervene medically

• We are “playing God” when we decide *not* to offer someone treatment

• Stewardship
Objection 3: The Slippery Slope

• The Slippery Slope: Even if this was justified for Ashley, there is great potential for misuse

• There is more than one response to a slippery slope
  – Avoid it (and it restricts your options)
  – Place protection and use care
Objection 4:
This benefits the parents, not the child

• It benefits both

• Sometimes interests may be so intertwined that they may be difficult to separate

• Parental interests should carry some weight
Objection 5: This violates her dignity

- This represents an assertion without any content.

- What is the meaning of dignity?

- Why is this intervention for this child undignified?

- Treating people with dignity may require treating them as individuals with individual needs
Ashley Today

- 10 years old
- 4’5” tall
- 63 pounds

Photos from:
Tragic Choices

• No clearly “Good” choice

• Moral Ambiguity

• Humility

• Courage
The demands of living morally are hard....We do not wish to face the truth that we live in a world where honesty and faithfulness do not always lead to good results and consequences, but sometimes to tragic choices.

--Stanley Hauerwas, Truthfulness and Tragedy