An Intro to Medical Ethics-Part 2
based on XIII International Intensive Course in Bioethics

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Objectives

- Review the fundamental principles of ethics
- Application of ethical decision making to real cases
- Acknowledge that there are no “right” answers and that many factors may influence decision making
Fundamental Principles of Ethics

- Autonomy
  - Duty to respect the patient’s wishes
- Beneficence
  - Duty of performing actions that benefit the patient
- Non-Maleficence
  - Do no harm
- Justice (fairness)
  - Distributing benefits, risks, and costs fairly
Ethical Decision Making

1. Understand the problem
2. Identify the parties involved
3. Identify the ethical principles involved
4. Clarify the possible solutions
Ethical Decision Making

It is also important to know that there are many other influences on our decision making.
Case 1

- A 12 year old female is diagnosed with “androgen insensitivity syndrome.”

- Should a physician respect the parents’ request not to disclose the diagnosis to their adolescent daughter?
Case 1

- Androgen insensitivity syndrome (testicular feminization syndrome)
  - X-linked condition
  - 1:20,000 newborns
  - Born looking externally like normal girls.
    - Internally, there is a short blind-pouch vagina, no uterus, fallopian tubes or ovaries.
    - Testes in the abdomen or the inguinal canal
    - No pubic or axillary hair
    - Sterile and cannot bear children
  - Detected at puberty when a girl should but does not begin to menstruate.
  - The testes need to be removed and patients require estrogen replacement therapy.
Case 1 Voting

Should a physician respect the parents’ request not to disclose the diagnosis to their adolescent daughter?

A. Yes?
B. No?
C. Undecided
Food For Thought...

- What should the physician tell the parents and what should the physician say to their patient?
- Who is the doctor’s patient and to whom is he responsible?
- Who should make medical decisions for children?
  - Role of parents
  - Role of physician
Piaget’s Stages of Cognitive Development

- Sensorimotor stage
  - Birth to 2 years
- Preoperational stage
  - 2 to 6 years
- Concrete operational stage
  - 7 to 11 years
- Formal operational stage
  - 12 years to adulthood
Ethical Decision Making

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Case 1 Post Discussion Voting

Should a physician respect the parents’ request not to disclose the diagnosis to their adolescent daughter?

A. Yes?
B. No?
C. Undecided
Sheela role-playing.
Case 2

There is a 72 hr old infant born at EJ. The nurse is preparing to collect heelstick blood for a NBS.

Should the parents be consulted about the types of studies for which stored blood samples are used?
Case 2

- Since the early 1990s, hospitals have been obtaining a few drops of blood from the heels of millions of babies born each year, with the intent of saving lives and prevent permanent neurological damage.
- Parents are usually informed about the “screening tests” at the time of birth.
  - Not asked for permission to store the samples or use them for subsequent research
- These samples have been stored
  - Used primarily to validate the accuracy of newborn screening
  - Used for other types of research.
- In the US, the NIH is funding a $13.5 million five year project aimed at creating a “virtual repository” of DNA samples from around the country.
Case 2 Voting

Should parents be consulted about the types of studies for which stored blood samples are used?

A. Yes?
B. No?
C. Undecided
Food For Thought...

- Under what circumstances can the research be performed?
- Extent of medical knowledge of the parents
- What is the limit as to how many diseases we will ultimately screen for?
- Who does the blood belong to once it’s tested?
- Once the blood is screened, should it even be stored?
- Once the results return, who do the results belong to?
- Future treatment of the infant and quality of life
- Carrier status
Ethical Decision Making

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Case 2 Post Discussion Voting

Should parents be consulted about the types of studies for which stored blood samples are used?

A. Yes?
B. No?
C. Undecided
Venezia
Case 3

- J.G. is an 18 year old with a rare metabolic disease who wants to enroll in gene therapy trials.

- As a member of the Ethical Committee would you approve the experimental treatment in this patient?
Case 3

- Jesse Gelsinger, 18 years old
  - Ornithine transcarbamylase deficiency
    - X-linked genetic disease of the liver
      - Inability to metabolize ammonia—a byproduct of protein breakdown.
      - Fatal at birth
  - Gelsinger’s disease was not inherited
    - Result of a genetic mutation
    - Not as severe
      - Able to survive on a restricted diet and special medications
Case 3

- Gelsinger joined a clinical trial run by the University of Pennsylvania that aimed to correct the mutation.
  - Injected with adenovirus carrying a corrected gene in hopes that it would manufacture the needed enzyme
- He died 4 days later.
  - Massive immune response triggered by the use of the viral vector used to transport the gene into his cells
Case 3 Voting

As a member of the Ethical Committee would you have approved the experimental treatment in this patient?

A. Yes?
B. No?
C. Undecided
Food For Thought...

- How old should a patient be before they can enroll themselves into a risky clinical trial?
- The patient’s disease was under relatively good control with diet.
- Risk vs. benefit
  - Principle of research participation is altruism.
- Do people have a right to involve themselves in clinical research even if it means possible death?
  - Should the doctor accept the patient in the study?
- High investment for an unusual condition
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Case 3 Post Discussion Voting

As a member of the Ethical Committee would you have approved the experimental treatment in this patient?

A. Yes?
B. No?
C. Undecided
Case 4

- An 8 year old who has osteosarcoma of the right arm has been cancer free but has recently been found to have recurrence. She refuses treatment, but her parents insist on aggressive treatment.

- Should the physician respect the parents wishes for further treatment?
Case 4

• 8 year old girl with right arm osteosarcoma
  • s/p amputation
  • Chemotherapy
    • Cancer free x 18 months
    • Rough course with chemo-struggled violently when it was administered
  • Has an arm prosthesis
    • Self conscious
    • Sad because she had to give away her cat, “Princess,” to decrease her risk of infxn
  • Recent studies showed recurrence and lung metastases
  • Family does not want to give up hope.
  • Even with aggressive tx, chances for recovery are < 20%
Case 4

- She is determined in refusing further treatment.
- She distrusts health-care providers and is angry with them and her parents.
  - “You already made me give up Princess and my arm. What more do you want?”
Case 4 Voting

Should the physician respect the parents wishes for further treatment?

A. Yes?
B. No?
C. Undecided
Food For Thought...

- How much should an 8 year old of average maturity be aware of his/her illness and participate in the decision about treatment?
  - Piaget’s concrete operational stage by age

- Are there age limits in dealing with autonomy and self determination and if so, what are they?

- Medical futility
“Consent” vs. “Assent”

- **Assent**
  - To express acceptance of an opinion or proposal; to agree

- **Consent**
  - Agreement to an action based on knowledge of what the action involves and its likely consequences
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Case 4 Post Discussion Voting

- Should the physician respect the parents wishes for further treatment?
  - A. Yes?
  - B. No?
  - C. Undecided
Summary

• Remember the 4 principles of ethics and the 4 components to ethical decision making.

• There are many influences on ethical decision making.

• A systematic approach is helpful but it may be necessary to consider other alternatives for a possible solution.
References

- XIII International Intensive Course in Bioethics Manuals
- www.massgeneralforchildren.org
- http://psychology.about.com/od/piagetstheory/