Nursing Ethics at the Heart of Health Care
March

Pediatrics, Genetics and Prenatal

Helpful readings/media can be found here and posted to the Ethics Resources folder in the Health Services Library. Please review before the discussion.

Consider these questions:

As a nurse, how do you balance supporting parents and protecting the patients?

What is morally distressing about supporting a patient’s choice that is not in line with your personal values? How do you provide more education while supporting your patient’s values?

When there are so many different values to consider, how do you prioritize/decide what is “most right”?

Consider the idea of how the identity of an individual can be altered by the following examples:

**Topic 1: The choices that parents have over their child’s health:**

- Discussion of a project at Brigham & Women’s hospital that offers parents the option to have the genome of their newborn tested.

- The Ashley Treatment: A controversial set of medical procedures undergone by a developmentally disabled Seattle child, “Ashley X” that inhibited her puberty and growth. Please watch for case study discussion:
  - Nursing Ethics Blog Post: [https://www.psychologytoday.com/blog/the-love-wisdom/201206/the-ashley-treatment](https://www.psychologytoday.com/blog/the-love-wisdom/201206/the-ashley-treatment)
  - Website that Ashley’s family established: [http://pillowangel.org/](http://pillowangel.org/)
● Time Magazine article:
Part 1 - http://content.time.com/time/nation/article/0,8599,1574851,00.html
Part 2 - http://content.time.com/time/nation/article/0,8599,1575325,00.html

● MSNBC commentary: http://www.nbcnews.com/id/16472931/ns/health-health_care/t/peter-pan-treatment-moral-choice/#.WKcezjgzWig

**Topic 2: Asymptomatic Genetic Testing & Modification – is it ethical or unethical to use genetic technology to eradicate disease?**

- CRISPR technology: Clustered Regularly Interspaced Short Palindromic Repeats
  - An efficient technique that allows DNA from every type of cell to be programmed to switch genes on and off and target and study particular DNA sequences.
  - Human Embryos – “Designer Babies” – permanently editing the gene pool due to editing the DNA of one in-utero or as a child, and these genes could be passed on to children. The intention is to eliminate disease.
  - Major health breakthroughs include:
    - 2015 – Elimination of HIV from living cells (in lab), major step towards using technology to cure viruses like HIV and Herpes
    - 2016 – First US clinical trial for CRISPR Cancer treatment approved for human trials. This works by editing immune cells to help them target and fight cancer. An individual’s own cells could be edited with CRISPR technology and injected back into the body.
  - Genetic Diseases – Many genetic diseases are caused by a single variation in DNA. CRISPR technology can target “fixing” the exact variation and nothing else.

Resources about CRISPR:
- https://medium.com/startup-grind/a-primer-on-crispr-and-how-to-learn-more-c1b4ca7159f6#qc8uix12av
- Patreon Video: Genetic Engineering with Change Everything Forever – CRISPR https://www.youtube.com/watch?time_continue=8&v=jAhiPd4uNFY
- TED Talk: What you need to know about CRISPR, Ellen Jorgensen https://www.youtube.com/watch?v=1BXYSGepx7Q
- http://www.nature.com/news/crispr-gene-editing-is-just-the-beginning-1.19510

**Topic 3: Prenatal/Perinatal Choice - A different way of looking at choice: What does choice mean in prenatal care? The options of abortion and Perinatal Hospice**

- Continuing your pregnancy when your baby’s life is expected to be brief. http://www.perinatalhospice.org/
Resource alert:

Registration is free, but they ask for a $50 fee for food and beverage. This fee can be waived if it’s restrictive for you.
It is on April 6 &7, which unfortunately overlaps with our April discussion group, but I will be attempting to do both. If you’d like to carpool, let me know!