Notes and summary of themes from March 2, 2017 – Nursing Ethics at the Heart of
Health Care Discussion Group

Our clinical focus this month was, “Pediatrics, Genetics and Prenatal Care”. Our group
was comprised of nurses and genetic counselors, with moderation from Baystate’s
clinical ethicist, Dr. Peter DePergola.

My reflections from this discussion:

For each session, my professional goal is to provide a forum that allows us to discuss our
decision-making concerning these highly complex topics. I’m very proud that this past
session had a robust dialogue and most people spoke up about what our case study
evoked in them, what their thinking was about it and what from their own lives
influenced that decision-making. Again, I do not have a formal background in ethics, but
I’ve learned that the ethical perspective needs to consider all angles of a situation, and
being aware of what influences our own values is critical for being able to appreciate
someone else’s perspective.

What I hope to promote through each session is using this dialogue to promote an ethical
decision-making framework amongst us. This may sound like a simple thing, but there is
an enormous wealth of research from psychology, sociology, medicine, etc., that studies
this process and if it has proven anything, it’s that there is no simple path for these
decisions. So, it is important that we consider the logic behind these decisions, the way
they are executed, and who & what are to benefit or lose. The culture of our hospital will
greatly influence how we approach this, but I’m hopeful, that we can also have a great
influence on our culture.

This subject matter in particular strikes me because it concerns our most vulnerable
population. Deeply rooted in human nature is the instinct to care for and protect our
young, and so examining a case study concerning an extremely vulnerable child is
important because it puts a sharp focus on that instinct. Equally hard, is to question that
instinct and examine where it comes from and what it means when we extrapolate it out
to other situations. How does our thinking about these kinds of decisions change once we
age and develop, and why?

During this discussion I focused greatly on my own “gut” reaction and considered what
influenced, and what it means that someone else’s “gut” reaction might different from my
own. I’ve always considered that this feeling could only lead me in the right direction,
and that it was somehow intrinsic to my own identity. Questioning my instinct has been
incredibly difficult, but also greatly rewarding. I’d encourage everyone to reflect on your
own instinct in a deep way, and to challenge that instinct so that we may uncover our own
cultural, social, emotional biases. It’s been important for me to remember that just
because I have a strong emotional reaction, doesn’t mean that I’m right about it. By
challenging my own assumptions, I’ve been able to develop and foster the process that
helps me to think deeply about difficult situations, rather than accept an easy answer.
What I’m trying to say, is that learning to not “trust your gut” has been a valuable lesson
for me because I’ve been able to see how subjective and variable it can be. When I’ve
challenged my instincts, I’ve been able to formulate a justification for my values and
defend them with all of my confidence. Sometimes they’ve remained in line with my initial instinct, and sometimes they’ve changed. It’s a difficult and rewarding process.

I know that it may seem like we have some unfinished business related to some of the topics from this discussion, and I think that speaks to just how deep the subject matter is. Fortunately, although the clinical areas change, the topics will frequently overlap. I think that in particular, when we discuss informed consent and “Inpatient Ethics”, we will see some of these themes re-emerge. I look forward to those discussions!

I did my best to capture the notes from this meeting so that we can all revisit this on our own time and reflect. Here’s what I was able to get to paper…

Topic 1: A case study of “The Ashley Treatment”

- Parent perspective: The treatment is justified, as parents have the right to make decisions for their children. What is the harm in this treatment for Ashley?
- Who paid for this? This is a huge procedure without a medical diagnosis. It turns out that the procedure received pre-approval from the insurance company.
- Another reaction: “Something just feels wrong about this”.
  - This is a major surgical procedure for someone that can’t express their own wishes.
  - Short-term problems: Surgical post-op pain, discomfort.
    - The purpose seems to be for the convenience of the parents
  - Long-term problems: Unknown? What are the risks?
  - Choices are based on precedence… so the family has a history of breast cancer, and mastectomies have become common practice for prevention.
    - Making this choice based on the “desexualizing in case of institution” doesn’t have precedence.
- Logical & Ethical Perspective:
  - Look at assumptions – does removing a uterus remove abuse? No.
- What does Ashley need to have a fulfilling life?
  - The care and love of her family – part of the triad of family, parent, child
- What about alternative therapies? If the goal is to prevent pregnancy in case of abuse, instead of removing a major organ, why not use a medication like birth control?
- To who’s benefit is this really for? Ashley, or her parents?
- The topic of Personhood. Is someone there that can appreciate what’s going on?
  - Is a procedure like this “the American way” – to keep her convenient?
  - Why not recommend a DNR?
  - At her intellectual level – she is able to experience something – she can recognize her parents voice, she can experience pain, possibly happiness.
    - This is important to consider.
  - Rights are inalienable, they exist whether or not a person can recognize them.
- The communities of disabilities was outraged by this procedure
  - This appeared to be using Ashley as a means to an end – why not try to conform society to Ashley than the other way around?
    - “The ends justify the means” is not sound ethical reasoning
• The example that Peter’s colleague uses:
  o An able-bodied 7 year old experiences a traumatic injury on the playground and becomes a quadriplegic. The parents are concerned about what will happen when the child grows larger, and they consult with a plastic surgeon to remove their extremities, as they no longer serve a purpose.
    ▪ It’s not a perfect analogy – but it highlights two important points.
      • A regular 7 year old would see the difference – whereas an intellectually disabled child cannot. Just because one is aware of the difference and one is not doesn’t mean it should or shouldn’t be done. This is part of inalienable rights.
      • Internal versus external changes. Why is there a difference? Again – why should societies perspective matter?
  • Question: What is the harm to Ashley?
    o The community of disabilities said: just because dignity doesn’t show up on an xray doesn’t mean it’s not there. This procedure uses Ashley as a means to an end.
    o Why conform Ashley to society rather than conform society to Ashley?
  • How do you measure dignity?
    o What does it matter what society thinks?
    o Right to be respected as a human being no matter the intellectual level.
    o There is something larger to consider than Ashley’s perspective of dignity.
  • Tenants of medical treatment – where does the right to provide medical treatments come from?
  • The argument that Ashley’s parents have the right to decide what’s best for her
    o However – we don’t allow parents to deny blood transfusions for their children. Parents do not have free reign over the medical decisions for their children.
      ▪ Circumcision? We allow parents to decide if a boy’s genitals will be mutilated 12h after birth. We don’t allow this for girls.
      ▪ There is a difference here in similarity versus equality.
  • Societal Perspective:
    o What are the institutional options? Home visits?
    o The risk of sexual abuse – where does this fear come from?
      ▪ However, statistically, sexual abuse is 5x more likely to take place at home than in an institution.
    o What happens to Ashley if her parents are gone?
Medical procedures are based on desire to keep Ashley out of an institution and in the home, but are based on an assumption that parents won’t die in a car crash the next day.

- One of the benefits of this procedure for Ashley: It makes it easier to reposition her, and makes it less likely that she will develop a pressure ulcer or aspirate.
- Ethical debate: Is this a proportionate means of getting to the intended goals? The debate is not really focused on: What’s best for Ashley?
- The Children’s Hospital of Seattle Ethics Committee
  - Voted unanimously, 18-0 in favor of the procedure
  - Department of Children + Families was not involved because nobody took issue with the procedure. Everyone agreed.
  - Afterwards – the hospital was sued and Dr. Gunther (endocrinologist) was fired and barred from practicing. He committed suicide relatively soon thereafter. The bioethicist at the time resigned and has kept a low-profile.
- The law tells us what we are allowed to do. Medical technology tells us what we can do.
  - We need to consider a hierarchy of values in making these decisions.

Topic 2: Genetics & CRISPR technology

- We were fortunate enough to have two genetic counselors join this discussion and give a brief overview of what CRISPR technology is and what it might be used for.
  - Human trials have begun in China, and it appears that US trials are forthcoming. Here’s a link: [http://www.genengnews.com/gen-exclusives/crispr-in-china/77900819](http://www.genengnews.com/gen-exclusives/crispr-in-china/77900819)
  - We discussed the implications of easy genetic testing and the possibility that this might contribute to the elimination of Down Syndrome.
    - Courtney discussed what some of her patients are asking her about testing, and what some of their attitudes are like towards knowing or not knowing certain genetic information.
    - Bev spoke about a conversation she had with a mother of someone with Down syndrome, and especially how upset the mother was that so much stigma is placed on her daughter’s diagnosis rather than on who she is as a person.
  - Heavy conversation regarding the community of disabilities, especially the deaf community.
    - The Deaf community regards Deafness not as a disability but instead as a culture.
      - More information: [http://www.handsandvoices.org/comcon/articles/deafculture.htm](http://www.handsandvoices.org/comcon/articles/deafculture.htm)
• Wonderful book recommendation: “Everyone Here Spoke Sign Language”, by Nora Ellen Groce
  ▪ Huntington’s Disease – approaching this disease is very difficult, especially concerning disclosure of pre-natal testing. Is it ok to get testing if the mother does not intend to tell the father, even though that would effectively “out” him if the test is positive?
    o When asked how genetic counselors protect themselves from moral distress, Bev cited that she relies on a conversation with coworkers, the resources within the Genetic Society Ethics Committee. After 30 years of working with emotionally and ethically complex situations, she has found some peace by remembering that at the end of the day, “it’s not my problem”

Topic 3: Prenatal and Perinatal Care
  o We intended to take a twist on topic of abortion and ethics by discussing perinatal hospice. We ran out of time to discuss this thoroughly, but there was much interest in learning more about what this practice might look like and what the potential risks and benefits might be.
    o Although we didn’t discuss it much, the thought on my brain is about choice. If perinatal hospice is implemented, is it essentially a late-term abortion, as it precludes the possibility of medical intervention and resuscitation? Do we define the mother as the patient, or as a vessel for the patient?