

5-9-22

What do I think about genetic modification?

I'm on the fence. When I consider health issues, and the ability to make people healthy, I'm all for it. I don't think we should allow people to suffer with their affliction if there is a "cure". But when it comes to enhancing "healthy" individuals, to make them "better," I'd say the idea is morally wrong. Where that line can be drawn between someone who needs it, and someone who doesn't, I don't know. I'm not sure how you can morally allow it for some people and not for others, but I know it wouldn't be impossible to distinguish a sick person who needs help and a healthy person who doesn't.

JUNE 9, 2022

Our meeting ~~is~~ with Jennifer Puck and MORTON COWAN was a really cool experience. I have not interacted with many doctors who have the same relationships w/ their patients that they do. It's evident through so many things that they both really care, + really have a connection. Why is that missing from most other medical professionals? What makes them different? I can imagine their care, their disposition impacts their kids so much. They're using a gene therapy that has had success in completely curing kids. With that, we know that enhancement on the germline level is overwhelmingly necessary. If we can use gene therapy, why focus on / use any thing other than that? ~~Their~~ their presentation was really informative - I hope they get their clinical trial off the ground and it becomes widely available. We need more medical professionals like them; more people that care and love for their patients and will do all that they can for them. I was inspired by them, and I'm thankful for their example.

June 10, 2022

Today we met w/ Dr. Ashley and his team of scientists. This was a really interesting experience for me. It was a tad overwhelming at some points during the presentation to hear the ~~the~~ advances in diagnosing undiagnosed diseases. My own sickness had no known diagnosis, so the presentation was cool, but also slightly overwhelming. I hate the thought of people suffering with illness, and the success Dr. Ashley has achieved has been nothing short of incredible. This meeting definitely opened my eyes to the fact that science is advancing at a very rapid speed. We can do so many things now - like read the genome! What once were far off concepts are now simple + affordable. We have come so far. This experience really solidified that I am pro- using enhancement for medical purposes. I'm not sure about germline editing, but I'm definitely in favor of genome editing. No one should have to suffer or be left undiagnosed if we have the technology to find and heal so many things.

My first journal entry of the entire course begins with the statement “I’m on the fence.” From the start, I struggled to find where I stood on the entire debate. I definitely felt strongly about sick people being able to make use of genetic enhancement, in that I felt the services should be available to those who need it most. In a world full of sickness, why wouldn’t we make use of enhancements to bring about healing? I was also of the mind that healthy individuals would not and should not need to make use of enhancement. I struggled then to find where the line could be drawn between unhealthy people who need the services, and healthy people who don’t, and I have to say I still struggle to find that line. It’s a tough call. As time went on, the more I learned, the more questions came up. For example, I felt strongly that genetic enhancement should be used for people who are sick, but after our conversations and discussions with stakeholders, I now had to decide where I stood on the debate of germline editing versus genome editing.

I do not agree with germline editing, but I fully endorse genome editing. I say this because I feel any medical decisions should be left fully up to the patient, or the patient's immediate loved ones at the time of the sickness. I feel that eradicating certain genes for generations to come could have so many unknown consequences, and it takes away an individual’s freedom of choice. For example, in one of our first viewing assignments, there was a boy with a disease who said he wouldn’t have changed his past when it came to his condition. He felt it made him who he was; he had grown as a person from it. I feel the same way about my sickness that I experienced. It was terrible, and I suffered, but I wouldn’t go back and change it. I grew from it, and as weird as it sounds, we all have the ability to grow and become better people from health related adversities. I feel it makes people more empathetic, and much more in tune

with their own emotions. Those people should have the ability to make their own choices to edit their genome to experience the healing they may need, at the time they feel is best fit.

As every conversation came and went with our stakeholders, I slowly discovered that my personal opinion was being affirmed. I am completely for people's ability to use enhancement for medical purposes, but people shouldn't be able to enhance for fun or personal gain. In the beginning I struggled with the concept of how this would be managed, but from my own experience, I know that medicine is already very highly regulated, and I believe it will continue to be so. Unfortunately, in our current scenario, some people who desperately do need medical help still do not receive it. That said, the concern from a medical or even a governmental standpoint is that they will overregulate enhancement. My concern would be, the technology is available, but now people who can and should receive it, can't. I do agree regulation could be a problem but I am on the opposite end of the spectrum. I don't think there would be a problem ensuring people don't abuse the service; it's not like it is something people can buy off of the rack at the store. But I can definitely see our government abusing enhancement, and keeping people who need it from getting it, which is a scary thought.

One thing I struggled with was where I felt about the course content from a religious perspective. This is one thing I wish we had more time to discuss from the course, especially having two people with such a deep theological background. I grappled with the question "Is this moral?" But I also grappled with the question of whether or not enhancement was Biblically "okay." In my heart I feel this entire field can easily be spun as the answer to so many prayers. How many parents have prayed for solutions to their children's disease, and now we have that solution. There are many moral dilemmas with this subject, but I felt from the beginning that it had the opportunity to produce so much more good in the world than bad.

The main question of our course was "In a world where genetic engineering and embryo selection may (sooner or later) mean that we have immense control over the genome of our species, what does "Being Human" mean, and how will modern human genetics alter that meaning?" Over the course of this class, I found out my answer to this question. I do not feel that our control over the genome will take away our humanity. Being human is so much deeper than our DNA. Humanity is rooted in our emotions, in our thoughts, and in our relationships with other people. Enhancing the genome will not make someone any less human, in the same way that someone taking a Tylenol to get rid of a headache won't make them less human. In fact, I would argue that enhancing the genome of sick individuals will make society more human. People with certain conditions will be able to suffer less. They will experience healing, and in that, they will be able to truly discover and enjoy a different side of life that will allow them to be even more in touch with their humanity.

Change is scary, and I feel like the first thing we do is quickly address and promote all of our fears and worries. This isn't necessarily a bad practice in of itself; conversation is good so we can prepare ourselves for the next phase we enter. But when we let the fear of the unknown completely cloud our judgment, we close the door to so many amazing opportunities. The thought of a child being able to live his or her life free of their genetic condition fills me with so much joy and hope. I am extremely thankful for this course because it introduced me to this entire world I knew nothing about. Each stakeholder, each conversation, and each experience added to my thoughts and helped me form my own opinion that was rooted in fact. I am excited for what the future holds in the realm of genetic enhancement, and I cannot wait to be the biggest supporter of medicine's newest ways to bring people healing.