

Discussion of Student Experiences, South Africa, and Ethics & Religion

Jennifer Cohen and Camille Castelyn

Welcome to the voices in bioethics podcast. I'm Jennifer Cohen and it's my pleasure to interview today, Camille Castelyn about the experiences that led her to the field of bioethics. Camille, you are the managing editor of Columbia's online bioethics journal *Voices in Bioethics*. And you're simultaneously in two academic degree programs. You're a student in the master's program in bioethics here at Columbia University. And you're a PhD candidate in health ethics at the University of Pretoria in South Africa. And that is because you are a South African citizen. Welcome, Camille.

Camille Castelyn

Hi, Jennifer. Yeah, thank you so much. I'm excited to be here.

Jennifer Cohen

Terrific. Now one of the factors that makes Columbia's bioethics program so rich is its large contingent of international students. But I think you're one of just two South African students currently in our program, is that correct?

Camille Castelyn

That's correct. Yes.

Jennifer Cohen

So how and why did you decide to pursue your education in bioethics at Columbia, so far from home.

Camille Castelyn

So basically, I had done my undergraduate degree in theology, but in my master's was about Christian ethics and genetics. And while doing this, I realized that I really wanted a more broader view of ethical principles. So basically, I was just looking at what was out there. And my family's always encouraged me to apply for anything and dream big. So when I found Columbia and its bioethics program, I was really excited because I felt that it was an amazing place to be able to learn because of the amazing history that Columbia's professors has played in genetics, specifically, if you just think about Thomas Morgan, who in 1993, actually had his fly room in one of the labs where he grew many, many flies, basically, and to understand heterogeneity and mutation. And I just really felt that it was the place where I could learn so much. And Dr. Klitzman who's the head of this program as well, he's also such a visionary in the field of bioethics. So yeah, I basically applied and then I got asked to write an essay about why I needed to fail, because that actually failed one of my courses in my second year in

genetics, and it didn't look great on my transcript, but in hindsight, it actually helped me. Yeah.

Jennifer Cohen

Wonderful. So I want to get into both of those topics - your interest in Christian ethics and your interest in genetics. But first, what is your experience been as an international student in this program?

Camille Castelyn

Oh, it's been really amazing, I have to say that I was a bit concerned about just sharing my South African experience and wondering whether it would be at all relevant for anyone there and vice versa. But really, the people at Columbia and at our program, specifically, are so just open minded, and really just remarkable people who have always encouraged me to share my South African perspective. And they really do make space for diverse voices, and are willing to listen and create a space that it's beneficial for everyone to just share their different experiences. Yeah,

Jennifer Cohen

That's wonderful. So let's turn now to your undergraduate degree at the University of Pretoria, which, as you said, was in Christian theology. So the world's religions have made long standing thoughtful, well developed contributions to ethics in general and medical ethics in particular, today, especially in the academy, bioethics has become a much more secular field. So what role has your studies in religion played in your current study of bioethics?

Camille Castelyn

Yeah, so I think that's why I wanted to study bioethics to have that broader view. And I think theology really taught me a kind of sensitivity, if I can call it like that, about people's perspective and religions. And oftentimes, people would think that, oh, you studied theology, you might be super religious and want to like shove your religion down somebody's throat, but actually just taught me how to really be able to think critically, and definitely to understand why people sometimes make the decisions that they do, based on deeply held beliefs and really understanding where people come from when they do make these decisions. Yeah. And then of course, from an academic point of view, the science and theology question is a complex one for sure. And one where I sometimes also still shy away from.

Jennifer Cohen

Do you find in general that religious values align with traditional principlism in bioethics, or do you find that those values conflict?

Camille Castelyn

I would say that, I don't know, I wouldn't look at it necessarily like it either overlaps or it conflicts. It's more, as I say, like the underlying why people make certain decisions, for example, in clinical ethics. I think Religious Studies has definitely helped me. I don't know if I'd say the principles. I don't know exactly.

Jennifer Cohen

Okay. In 2017, you became an ordained minister and the Dutch Reformed Church. Can you talk more about that decision?

Camille Castelyn

Yeah. So that was basically part of my theology studies. And when you're at the University of Pretoria, sociology faculty, you can basically choose whether you want to be part of a church, because that kind of also shapes one of the subjects that you also have to take. So you could either choose nondenominational or you can choose another religion as well. So I kind of grew up in the Dutch Reformed Church. And I also from a personal point of view, my own religion, I appreciate tradition, and, or at least just a long standing way of thinking about things, because I feel that's almost a safe way. So I basically got ordained in 2017, as part of my theology studies, and I did marry a few people, or did the ceremonies. But in the end, it was not for me to make a full time career of that. Yeah.

Jennifer Cohen

Did you ever consider working as a chaplain in a clinical setting?

Camille Castelyn

I haven't considered that. No, not really. I don't know. I don't think that's such a big thing in South Africa, even though there are chaplains. But yeah, I guess that could be option.

Jennifer Cohen

Let's turn now to your experience in genetics, your interest in genetics and ethics. As you said, your masters and doctoral theses are focusing on genetics and ethics, can you flesh out the bioethical issues you're specifically addressing in your work in genetics?

Camille Castelyn

Yeah, so I'm basically looking at people's perceptions on genome technologies, and the underlying values. So I basically did about eight interviews with people with open ended questions about their opinions on why would gene editing be right or wrong or good or bad. But I specifically focused on gene editing for enhancement purposes. Because, as I think, in some of our previous podcasts, we've seen that therapeutic gene editing is most people agree that if we have the safe means to cure disease, then we should do it, however, where the questions are, where is the line between therapeutic and enhancement purposes? So that's what really interests me.

Jennifer Cohen

That's fascinating. And can you give us a preview of what those interviews produced? And what were people's general views towards enhancement, and genetic screening these so called slippery slope of the CRISPR cas breakthrough that also happened to Columbia and is ongoing there. And how that might be incorporated into a future that includes as Dr. Klitzman's new book is entitled, "Designer Babies."

Camille Castelyn

Yeah, so I think it varied in the responses. But something that I feel quite strongly about is if we look at past experiences of what has happened in gene editing, I feel very strongly that we should find a way to manage it in a safe way. And that prohibition is not necessarily the best way forward. And rather to encourage discussions with all stakeholders, including the public, especially the public, so that it's not just the experts high up there, or a scientist somewhere, making these decisions. But because these decisions that we do make, especially if we do germline editing has an impact on the whole human genome.

Jennifer Cohen

Fascinating. So you've been careful to draw this distinction between therapeutic gene editing and enhancement. You have some personal experience with medical decision making and genetics. Can you speak a little bit about the decision you made in your own life?

Camille Castelyn

That's right. So my mom had breast cancer when she was quite young, 28 years old. And we've had the discussion in our family, whether we are two daughters, whether we should be tested or not. And it's still an ongoing discussion, but at the moment, we have chosen not to be tested. Yeah, so my mom doesn't want us to be tested. However, me being in the field that I am, I feel that knowledge might be power, but it's a complex decision because if I get tested or if my sister gets tested, and I don't, then we'll basically know either way, so Yeah, we've had the discussion about it. And I think genetic counseling is really valuable as well in these decisions that need to be made.

Jennifer Cohen

So that's a great example of your private life reflecting your intellectual academic work, where you recognize that a discussion around genetic enhancement needs to be one that includes much more than the people specifically involved. Because in your own case, you realize an individual decision will have effects beyond just your own person, it will affect other people in your family.

Camille Castelyn

Yeah, definitely

Jennifer Cohen

Fascinating. So let's turn now to bioethics in South Africa, and specifically to the pandemic. South Africa has its own bioethics journal, South African Journal of Bioethics and Law. And you have an article in the latest edition on resource allocation and vulnerable populations during the pandemic. How has the pandemic affected South African? Can you speak a little bit about your most recent article?

Camille Castelyn

Yeah. So basically, the main concern was when the World Health Organization also announced, this pandemic was specifically about, firstly, our healthcare system, which is at best of times, thinly spread. And then the second was about our vulnerable populations, we have a lot of people who have comorbidities. If I can give you some numbers, we have 7.7 million people living with HIV, and 2.5 million with tuberculosis in a population of 59 million people. So that's quite a big chunk of our population. And as we've seen with research, comorbidities really does make your risk of having a serious case of COVID-19 more. And then the other factor pertaining to the public health care system is the socio economic factors that should be factored in. So for example, 13% of our citizens live in informal settlements. And that really makes a lot of the precautionary measures such as social distancing and basic hygiene makes it quite difficult to do those things. So we were really concerned about our vulnerable populations, and their access to health care institutions, should they become sick. But luckily, our President has made a very responsible decision right at the beginning, when we had our very first case of COVID-19, which is on five March, he announced the national state of disaster on the 15th of March. So it was really playing it safe. And he has been criticized for this because our economy basically came to a grinding halt because we were placed on what we call lockdown in

one of the highest levels, prohibiting our movement. But I still think that it was the right decision at the time, even though there has been some serious economic repercussions of that.

Jennifer Cohen

South Africa is sometimes referred to as the rainbow nation because it has a very culturally and ethnically diverse population with 11 official languages, whole range of religious traditions, how do you think this diversity plays into the ways bioethical issues are tackled?

Camille Castelyn

Well, I think it's a really interesting place to do bioethics, for sure. Because of this diversity, we have to take into account a lot of different perspectives and cultures. And also in South Africa, 80% of people actually do claim that they are Christians. So definitely all of that factors in when we face any bioethical issue, from euthanasia to even just basic ethical issues like gender based violence, which is a very concerning and ongoing problem for us at the moment.

Jennifer Cohen

So let's finish up by talking about the future. Where do you hope to make the biggest contributions to the field of bioethics?

Camille Castelyn

Wow, Jennifer, what a big question. So yeah, I'm really excited to see what the future holds. And I'm hoping to definitely stay involved in the global community, and see where I can make a contribution and a difference in the end. At the moment, I'm really passionate about the genome technologies and also the values that make people say either it's wrong or right. So I was thinking I would even maybe one day want to work for I don't know if you've seen the Social Dilemma. But Tristan Harris, who started the Center for more humane technology, was thinking maybe that would be a great place to work as well somewhere in the future.

Jennifer Cohen

Well Camille Castelyn, thank you for a fascinating discussion and best of luck as you finish your degrees and continue your career in bioethics.

Camille Castelyn

Thank you, Jennifer. Appreciate it.