Clinical Bioethicist Megan Wanzo Discusses Her Experiences, and Racial Disparity in Access to Care and in the Experience of Clinical Care

Jennifer Cohen and Megan Wanzo

Camille Castelyn 0:04

Welcome to the Voices in Bioethics podcast. I'm Camille Castelyn and it is my great pleasure to welcome Megan Wanzo today. Megan, thanks for joining us.

Megan Wanzo 0:15

Thanks for having me, Camille.

Camille Castelyn 0:17

So, Megan Lonzo is currently a clinical trial manager at the Bristol Myers Squibb and she is also the adjunct professor at the University of Health Sciences and Pharmacy for Ethics. Megan, we are very happy that you are here with us today. It's clear from your work that patient centered care and promoting quality and equitable health outcomes are really important to you. Would you please tell us more about why that's an issue that you're so passionate about?

Megan Wanzo 0:46

Absolutely Camille, thank you so much for asking me this question. I grew up in a rural area. I grew up in Central Illinois, which is about 60 miles east of St. Louis, Missouri. In rural America, we have a lot of unique health issues. The first one is we are an underserved population. We do not have a lot of medical access. So, I knew going into this career in ethics that I wanted to create more access, not only for people in rural communities, but also for people who look like me. So African Americans, especially African American women, which already have lower health outcomes than other populations.

Camille Castelyn 1:29

Oh, yeah, no, that is very important. Why specifically, would you feel that African American women are especially important group of people, when considering these issues? You mentioned that there are certain barriers as well to equitable health care specifically for this group.

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Megan Wanzo 1:48

You know, Camille, there was a study in 2016 that found that 40% of first- and second-year medical students believed that black people didn't feel as much pain as their white counterparts. This was especially true when it came to black woman. We saw that they were coming to emergency rooms across the United States and they were not being treated for their pain. They were being sent home. They were being told that their pain was not real and that they could take over the counter medications to heal their perceived sickness illness pain. These black women were actually suffering from quite complex issues that should have been caught by medical professionals and some of them even ended up dying from the lack of care they receive.

Camille Castelyn 2:43

Yeah, well, no, that is horrific. I think this is just one example of so many structural injustices that are present still to this day. If we think of past transgressions as well, we would have hoped that it was something of the past but unfortunately, that is the reality that we have also seen during the COVID pandemic.

Megan Wanzo 3:06

Absolutely. We have to remember that bias is a two-way street, especially when it comes to the black woman in the American healthcare system. You know, black women have bias from previous transgressions such as Henrietta Lacks, and how her cells were used without consent. Now there is a major profit off of HeLa cells, as they're called, but she did not consent and her family did not consent. Now it is a major profit for the industry. But where is the justice for her? We also have medical providers who hold their own internal biases from outside sources. From where they grew up, from media that places unfair stereotypes on black woman, in particular.

Camille Castelyn 3:56

Yeah. I'm so glad that you also raised the issue of bias. I really appreciated reading the book of Henrietta Lacks. I could actually advise our listeners also, if they haven't read it, to really read it. I know the woman who wrote it as well and she really delved into the story. She went to go meet her family and it was such an important story to tell. I'm still surprised, even today, sometimes people that I talked to in the bioethics field don't know who she is. Yeah, that kind of just always surprises me. But it also comes to show that these discussions need to be had more often as well. Are there any, in your experience, specific cases that raise some ethical issues pertaining to black woman in healthcare?

Megan Wanzo 4:43

I can think of one in particular, that happened in St. Louis, Missouri. It was not a case I was on but it is a case that I often talk about with my students and people I know. It's the story of Anna Brown. She was a resident of St. Louis. Missouri, and she had gone to several different area St. Louis hospitals complaining of intense intractable pain in her calves and legs. Anna Brown at this time was homeless, which should not have mattered, but clinicians kind of

wrote her off as drug seeking and possibly seeking illegal sexual activity.

Eventually, when she presented to the ER for the third time and doctors looked at her, Anna refused to leave. She was screaming that she was in so much pain but she couldn't walk. The doctors called the police on her and they said she was trespassing. Police agreed with the doctor's assessment that she could be drug seeking that she could be into some illegal activity and they carried her off to jail. Anna was in such pain complaining she couldn't walk, that police officers carried her by her arms and legs into her jail cell and left her on the floor.

Even though there were beds there, they left Anna Brown, a black woman on the concrete floor of her jail cell. Anna was left there moaning, kind of weeping, and officers stood by and watched. Anna died shortly after she was brought to that jail cell. An autopsy later revealed that she had blood clots in her leg that had gone to her lung. So in this case, it tells a powerful story of a black woman who sought out care for pain she was having and didn't receive that care.

We ask ourselves as ethicists, she went to three different St. Louis area hospitals. She came in contact with police officers, people at the police station. What if one person would have believed Anna? What if one person would have said, "Let us run one more test?" What if one person who would have said, "You know, I looked at her chart and she has been to the ER three different times in a short period and they we not prescribing her any medications." They could have run a drug screen, but they didn't. Now Anna's dead. She was someone's mother. She was someone's daughter. She was someone's sister. She was someone's friend. Anna was a black woman who was somebody. Because of these biases that we have in the American medical system, no one came to help Anna.

Right now, in that moment, it's too late for Anna. We can save other black women from this terrible mistake of not believing them, by believing them. By standing up for them. By saying, "Maybe we need to look at this a little longer." So many of our hospitals, admit patients for observation. Why are we not submitting black woman for observation? Again, with Anna we also see black women kind of suffering in the maternal mortality world. In the fourth trimester, which we have coined that as the time after labor and delivery, we see black women coming to the emergency rooms. Coming to their follow up visits and they are complaining of dizziness, of lightheadedness, of symptoms that they should not be having after giving birth. We found that black women are more likely to have preeclampsia after childbirth, during childbirth and preeclampsia after childbirth.

They are also more subject to the risk of embolisms. So black women are three to four times more likely to die from a pregnancy related complication than white woman. We just have to remember that black women are not medical mysteries. They are not a medical rarity. We have to believe black women and their stories and what they come to us and tell us.

Camille Castelyn 9:15

Yeah, definitely, Megan. I think that is such an important and powerful story that you just shared with us as well. It

is such an important question as well. Everyone can ask themselves, “What if one person were just to care more, just do the basics that they need to and that they needed to do with Anna?” You have also been a panelist and a speaker on the ethics of black lives in health care. Do you think that speaking at these kinds of events puts the right issues on the table and encourages these kinds of discussions? Do they actually bring about eventual change?

Megan Wanzo 9:56

Absolutely, Camille. I think it is very important that we take our work, our mission, our purpose to academic conferences, such as the Annual Conference of the American Society of Bioethics and Humanities. These conferences are extremely important. So is the one that the American Public Health Association holds. But we also have to remember that a lot of people that come to these conferences are like minded. They think like us. They believe like us. They see the same patterns we see. So, while it is important to speak at these conferences, it is also important to take that same message out into your community, into your workplace, to your friend groups and to your church groups. It is just as important to spread your message at a community level as it is at an academic base level.

Camille Castelyn 10:49

Oh, yeah. That is definitely true. I like that. So, what would be other ways, as you said, going to the community to bring about change and ensure justice and equity for specifically black women in healthcare? For example, if you had unlimited time and resources to improve health and health care in rural America, what would you do?

Megan Wanzo 11:15

This is such an important question Camille. I think that there is a couple of things we need to understand about black women in particular. First, one of the things is that black women are often the matriarch of their family. Black women take on a really strong role in their family. They are often really involved, not only in their families, but also in the community, to make a way for their families to guide a path for their families.

The second thing is that in the black community, the church is a very important pillar. These two combinations, I think it is important as people in healthcare, as ethics professionals, as clinicians, we find opportunities to speak to the black church. We find their church picnics, their church activities, and we ask, “Can we set up a booth?”, “Can we provide healthcare advice?” “Can we take your blood pressure”, “Can we check your oxygen?” Those basic health care needs that we find that sometimes black women are not getting because of the lack of trust of the medical system and the fear of the medical system.

We find ways that we can do this in a community aspect. One that is non-threatening, a non-white coat environment, a non-hostile environment, so we can introduce ourselves and establish a relationship with black women that we can carry on. One of the things I really advocate for is preventative care and for black woman to get a general practitioner or a primary care provider because we see, especially with black woman, cancer rates, such as breast cancer, there is a late diagnosis. So black women have lower survival rates, they have a higher death

rate and we know that we can get black woman in to see a primary care provider or a general practitioner where they can be diagnosed earlier. Where they are getting their scheduled mammograms. We can diagnose them sooner and we can provide a better treatment for them that will produce better outcomes.

Camille Castelyn 13:14

Wow, that's amazing. Just comes to show how important preventative care is. Also, how impactful actually building relationships and going into the communities is and how important that is. That could definitely be a very impactful and important way to do it in the future. So, let us move now to your career path. How has your family and your upbringing actually helped shape your passions and influenced your career path?

Megan Wanzo 13:50

Growing up, I knew a lot about medicine. It seems like my family was always involved in health care in some aspect. My grandmother was a Pink Lady growing up. Pink Ladies in the US are kind of the women who work at the gift shops at hospitals. So, I remember spending a lot of time at the hospital as a kid. I would see the doctors and I would see the nurses. I thought that was so amazing. These people were helping people they were caring for. I also found medicine so interesting. When I went to college, I started off in an international studies program, which ended up being cancelled by the university. I wanted to focus on public health and global health. So, I looked for what I could do next, since that program was canceled. By sheer chance, I ended up in a bioethics class.

I cannot think of a more perfect major for me, a more perfect career path. It is the perfect combination of medicine and the humanities. It is really that social side of medicine, that understanding side of medicine that sometimes our primary clinicians, such as doctors, and nurses, do not have time to get down to. As ethicists, we get to deal with the most difficult cases. We see the most complex decisions. We kind of help not only families and patients through these decisions but we also have this unique perspective where we can help clinicians through their treatment plans, through their care plan, to really build what the patient needs in some of their last moments. I think that is really special to give people their final decision at the end of their life and to let them know that you're still the author of your story.

Camille Castelyn 15:56

Wow, that's so amazing that that is how everything happened to help bring you to this successful career path that you are actually on at the moment. Do you feel like the bioethics studies equipped you enough? Or was it a combination of the two? I guess that the practical experience in the field, as you say, in the clinical setting as well, that really helped you to address the issues that were most important?

Megan Wanzo 16:23

I think where I am at now, as a clinical trial manager, it is really a combination. At Columbia, we do research ethics, we do clinical ethics, we do organizational ethics, we do end of life ethics, and the list goes on. I would say a clinical

trial manager is really a great combination of research ethics and clinical ethics and making sure that the proper procedures are done for research. I'm also making sure that there is access to patients who need these oncology treatments. Who need these rare treatments to treat their disease and have this opportunity that they would not have otherwise. That is the amazing thing about clinical trials is that you are providing an opportunity that this patient would not have elsewise. You are extending their life or extending their quality of life into patients. That is everything.

Camille Castelyn 17:22

Yeah, wow, that sounds really important as well. What has been some of the most difficult ethical issues that you have had to deal with, as an ethics consultant?

Megan Wanzo 17:34

I would say, you know, one of the most difficult ethical issues I dealt with in Southern Illinois, where I previously worked, was mistrust of the medical system. Issues stemming from that mistrust, especially at the end of life, where I was stationed previously. It was a rural community and a lot of the physicians, clinicians, clinical staff, people at the front desk, were white Americans. When we would have black Americans come in, or Hispanic Americans come in, they automatically clammed up because they did not see people who look like them.

Representation is so important, especially in the medical system, because we are more comfortable around people who look like us. We are more comfortable when we see people that look like us, working at the hospitals, at the clinics. When we see people that look like us in these health care systems, it establishes a sense of trust. If I see someone who looks like me at a clinic, I think I can trust the system because this person trusts this system enough to work here. I would see a lot of families who did not trust what the doctor was saying. They did not trust what the nurse was saying. They ended up drawing out their loved one's illness for a long amount of time because they just could not establish that trust. Because for days, they did not see anyone who looks like them.

Camille Castelyn 19:16

Wow. What I am hearing is that ethical principles, like equitable access, trust, and justice are really important when looking at these issues. Is that correct?

Megan Wanzo 19:32

Yes, we also sometimes don't talk about some of our unknown, but latter known, principles after the four principles. But veracity and fidelity also. Truth telling and establishing trust are really important. Bedside ethical issues that we have to work with as clinicians, as physicians, as nurses. It is important that we do try to establish a rapport with our patients, so that they know that we want to do what is best for them.

Camille Castelyn 20:09

That sounds really important as well. I wonder whether doctors in training, at the moment, actually pay enough attention to those principals as well that you mentioned now. I am not sure how their training looks, but I'm sure there is room for improvement.

Megan Wanzo 20:27

One of the goals of ASBH is really to improve training for medical physicians so that they will be more aware of these issues and they will not conform to previously held biases.

Camille Castelyn 20:43

Well, that actually brings us to your other current position, which is that you have recently been appointed adjunct professor at the University of Health Sciences and Pharmacy for Ethics. Do you enjoy that position and do you think there is a lot of potential as well to bring in these important issues that you've raised?

Megan Wanzo 21:05

Absolutely. I always say it is an honor to pour into others what has been poured into me. I think that that is one of the things I really get to do firsthand, as a professor. I get to teach students about these complex ethical issues. Of course, I go through the ethical principles, the ethical theories. The second portion of my class, I really like to do case analysis. I like to look at special topics such as ethics, reproductive health, ethics and genetics and really facilitate a learning experience for my students. Not just lecture them on autonomy and utilitarianism because they can pick up a book and they can read that. How do you apply these principles, these theories, to the real-life scenarios you are going to see?

Camille Castelyn 21:57

Well, that sounds really impactful as well. How big are your classes at the moment that you teach?

Megan Wanzo 22:02

They vary in size. I am not quite sure of the class count for this semester. I have been lucky enough to teach some RN resident students in the past, at Southern Illinois healthcare. We had anywhere from 25 to 30 students in a cohort. I think that the RN resident students really appreciated that course. So now their eyes are open, their ears are open, they know what to look for. They know the key words to look for. And they are going in to situations prepared.

Camille Castelyn 22:37

Yeah, I asked about the class size, because also doing case studies. It is really nice if you have a smaller group of students and we can discuss that really intensely as well. Then lastly, I would like to move towards the fact that we are in the Covid-19 pandemic. I would love to know more about what has been your experience, specifically in your field, at the moment you mentioned end of life care. You have also had consultations with a lot of families who have been facing some really big challenges, as well, due to this pandemic.

Megan Wanzo 23:14

Absolutely. I am happy to talk about this because I think right now it is so important. As we are kind of looking at our third wave of COVID, in the United States. First and foremost, COVID is real. COVID is affecting families. They are affecting people everywhere, especially in rural America. We were hit hard with COVID-19. Nobody expected it. Nobody was prepared. The first wave of COVID came. Our hospitals were inundated with patients. We were doing everything we could to keep them alive, to keep them in contact with their families.

Ultimately, there came a point across America, where we shut down elective surgeries and we shut down visitor policies in our hospitals. At that time, we had patients coming into the ER who were walking and talking and just presented with shortness of breath. Within 24 hours, they were intubated. That in itself breaks your heart. Then to know so many of these people, they came in without any power of attorney, without any decision maker, without any contact on file because they had never been sick before.

The next 24 to 48 hours, we were trying to identify a next of kin, a contact a point person to help make decisions for this patient. Later on, in our COVID-19 journey, we were able to get iPads set up for video chats for some families. That was how they said goodbye to their loved one. They did not have a chance to come see them. They did not have a chance to have conversations before they passed away, their final goodbye. We do not know how long it had been since some of these people had seen their families, less through an iPad. I think where we are right now, we are in a very similar situation. You do not want to see your loved one pass away through an iPad.

Right now, we have a very mixed situation where we have people in rural America who are choosing not to get vaccinated and we are seeing an influx of COVID-19, again. We are looking at we are going to be in that same situation where we are going to have to shut down our visitor policies. We are not going to be able to allow people to have visitors even for routine illnesses, or routine surgeries. I think it is an important decision that we should all do our research on. That we should make if we want to be vaccinated or not because we are watching people die again. That is really unfortunate.

Camille Castelyn 26:09

Yeah, that is very important as well. A lot of work still to be done with end-of-life care but also educating people about end-of-life care. How important it is to think about these things before it is too late as well. Megan, would you like to add anything more that I have not asked you?

Megan Wanzo 26:32

I think, once again, it is just important to really remember that advanced directives are so powerful and so important in health care. I know sometimes we sit back and we say, I am too young to have a healthcare power of attorney, I am too young to make an advanced directive. We never know what may happen. We never know when the next pandemic may roll around. We never know what really lies before us. If I could advocate for anything, it is just having the conversation with your family. Have the conversation with your loved ones about what you would want, if something was to happen to you.

You can find it at your local State's website, several different hospitals, your primary care providers often have copies of advanced directives and you can fill them out. If you fill nothing else out, you can select your healthcare power of attorney so you really have the person who you want making your end-of-life decisions or even just healthcare decisions when you are not able to make them for you. I think that is one thing we can all take from this pandemic. From everything we have seen over the last year and a half, that we never know what is ahead. It is important to have those conversations with our families and our loved ones.

Camille Castelyn 27:54

Yeah definitely, Megan. Thanks for raising that as well. For sharing that with our listeners as well. So I just like to thank you for your time today and for being with us. For just sharing your expertise and raising such important discussions that we actually should be having more about. There is still a lot of work to be done and we look forward to everything that you are going to do as well.

Megan Wanzo 28:21

Thank you so much for having me, Camille, and thank you to all the listeners. I hope to speak with you all soon.