**Episode 60: The Ethics of Breastfeeding With HIV**

Dr. Joe Chappelle: Hello everyone, and welcome back. I’m Joe Chappelle and you’re listening to Episode 60 of the OB/GYN Podcast. Today, we have a new voice and a new topic. The new voice is Dr. Mariel Gross and the topic is breastfeeding in HIV positive women. Dr. Gross is an author on a recent paper on that topic. What really got me interested is that it’s not a randomized controlled trial or even a meta-analysis. Rather, it takes the existent data and looks at the question through the lens of bioethics. I really enjoyed this conversation and I hope you do too. So, let’s get started with Episode 60: The Ethics of Breastfeeding in Women With HIV.

Hi, everyone. I’m here with Mariel Gross who is a practicing Ob/Gyn and a fellow at the Berman Institute of Bioethics at Johns Hopkins. Welcome.

Dr. Mariel Gross: Thanks for having me.

Dr. Joe Chappelle: Mariel and I met at the National Perinatal Association meeting which I’ve been talking about on the show for a few weeks here. And we had some great conversations surrounding bioethics. And I had a lot of questions for her because it seems like a relatively new field, at least to me. And I didn’t know much about it. And it was so interesting that I said you should come on the show and we should talk about it. She also recently co-authored a paper about the ethics of breastfeeding with HIV and I wanted to talk about that as well. But before we get in there, Mariel, I wanted to ask you… how did you get into ethics or bioethics? And, as an Ob/Gyn how did you… I don’t want to say fall into what you’re doing, because it seems like a more proactive thing, but how did you get into this?

Dr. Mariel Gross: Yeah. It started a really long time ago. And I was… as a freshman year pre-med undergraduate philosophy major, it kind of actually happened as a result of my interest in medicine. I chose to take a bioethics course because to me, it seemed relevant to learn some bioethics if I was trying to go into medical school. And that ended up diving off the deep-end of just totally opening my mind to loving to talk about and think about these things that were the application of philosophy and bio- in real life, specifically in health. And ended up becoming a philosophy major as a result of that, so I switched out of the biology. I actually was simultaneously doing another bachelor’s degree in ethics. I actually ended up designing the major in Jewish ethics at the Jewish Theological Seminary. And my interest in philosophy and ethics and bioethics kind of went from there. And then I went on actually to do a… I thought it was so important to stay- the idea of staying grounded in humanity before going into medical training.

So, I actually ended up doing a bioethics master’s degree prior to going to medical school. And I just loved the- I had this intuitive sense that when you cut onto a person’s body and it becomes wrote in your muscle memory it’s almost like cutting into any other kind of meat. And that freaked me out. And I really wanted to have this… I think, diverse, humanities background that would enable me to really have a firm rooting in the human values as I learned how to treat human bodies in a way that was not necessarily commensurate in certain regards to their humanity. I don’t know if that makes sense.

Dr. Joe Chappelle: I think it does. We have talked a little bit on this show about… I think in the last couple episodes we talked about… I don’t want to call it depersonalization but definitely you have to disassociate sometimes between yourself and the patient because what you’re doing to them can be relatively horrific.

Dr. Mariel Gross: Yeah. Totally.

Dr. Joe Chappelle: But at the same time, it’s essential to the care that you have to provide them. And of course, I wish we could provide care that was in a less barbaric way, but it is what it is currently.

Dr. Mariel Gross: Although, we have a… I would just push back just a tiny bit and say that there’s a wide range of latitude that we have in terms of how we practice and our attention to- we don’t have to be quite so barbaric in certain ways that are common, I would say.

Dr. Joe Chappelle: Okay, fair enough.

Dr. Mariel Gross: And yeah, we could talk later about Marion Sims and all the drama and the background there.

Dr. Joe Chappelle: Yes. Absolutely. I mean, what I was going to say is Ob/Gyn, I mean, I think all of medicine can benefit from a discussion of bioethics or is kind of engrossed in that topic. But Ob/Gyn even more because we have often times two people who we are caring for. We have a fetus and a mother. And sometimes balancing those two things is difficult. And we’re going to get into a couple of those things later when we talk about your paper. But there are some ethical issues that we see there which can be quite complex. Specially if we’re trying to impose what our ethics or feelings are on somebody who doesn’t have the same notions.

Dr. Mariel Gross: Yeah. It’s interesting that you used the word barbaric. Baber was the original surgeon, right?

Dr. Joe Chappelle: That’s right. In a lot of ways in Ob/Gyn we are not that removed from 50 years ago, or 100 years ago. I mean, we know a lot more about things but we’re still doing c-sections and episiotomies although we don’t really do them where I work. But people do episiotomies, c-sections, forceps. We’re not that dissimilar to 100 years ago.

Dr. Mariel Gross: Which is not to change- I mean, I don’t want to put the cart before the horse or anything. But my entire fellowship research focuses on the use of evidence in women’s healthcare. And we’ll kind of get to that later. Just to give you the rundown of the rest of how I got to where I am. So, I sort of approached my medical training with this intense bioethics and religious background. And fully intending to go into medicine. I had nobody in my family that was a physician. And so, they kind of tell you, as a student, you’re either picking surgery or medicine. And I loved to think about things, and the investigative nature of a medical investigation, and so it seems like medicine was a natural choice. I was doing research in medical school on the HPV vaccine, trying to increase catch-up vaccination amongst unvaccinated college students in Florida. So, I had that experience. I chose, for the clinical clerkships, I chose to have my Ob/Gyn rotation last because I thought, if there’s anything I won’t do, in fact, it is that.

Dr. Joe Chappelle: Mm-hmm. That’s very common.

Dr. Mariel Gross: I feel like people have- Some people come in with an idea that they want to do it, but I think there’s a lot of things in our society, culture of medicine, and just, the nature of some aspects of our job that are incredibly intimate or really personal that people would think that they wouldn’t want to do. And certainly, I felt that way, And I was already applying for my residency… Actually, a combination. I was very interested in a combination of medicine and preventive medicine. And I took my Ob/Gyn rotation at the beginning of fourth year. And I started to be like, this is interesting. Because I knew so much from the HPV vaccine work I had done. I knew a lot about that. And my master’s work had involved a lot of ethics of IVF and different things. And in that field, my undergraduate honors thesis was on the Octomom.

Dr. Joe Chappelle: Okay.

Dr. Mariel Gross: And so, I knew a lot about these things for some reason. I knew more than I did naturally about the other fields that I visited on my rotations. And then I went to my first delivery and it just really struck me how all we- it was a para 5. It was me and the resident running into the room catching the baby and wiping it off and handing it back to them.

Dr. Joe Chappelle: Yep.

Dr. Mariel Gross: It just really struck me how happy of an event that was and acknowledging fully that all we were doing was at best facilitating a process that was already happening. But at the time I was very interested in HPV and cancer and I was thinking about infectious disease and the intersection of infectious disease and oncology, and maybe I will do fellowships in infectious disease and oncology after my medicine/preventive medicine fellowship in residency. And so, I’m coming from that perspective and I just thought, even if I cured somebody’s cancer, I don’t think they would’ve been as happy as that woman was and all we did was hand her her baby. And when you go through medical school, especially if somebody, for me like, didn’t have any real background in that, we encounter so much suffering. And so much heaviness. And there’s- basically everyone we take care of is worse off than you are. And there’s an oppressive feature of that that makes the job, the work really oppressive, emotionally, psychologically oppressive. And I was really inspired by this idea that there could be a part of my job that was inherently light and would offset that. And then I started to think, well, wait a second. But then I want to do preventive medicine. Well, a lot of Ob/Gyn seems to be preventive medicine.

Dr. Joe Chappelle: Right. It should be.

Dr. Mariel Gross: Should be. Because many women of reproductive age only have an Ob/Gyn if they have a doctor at all.

Dr. Joe Chappelle: Yep.

Dr. Mariel Gross: And then started reflective on all of my HPV- I’m like HPV and- like, wait a second. It’s like Occam's razor. It would be a lot easier as an Ob/Gyn and more of a direct path to take care of HPV-related disease as an Ob/Gyn than as a medicine/preventive medicine/infectious disease/oncologist.

Dr. Joe Chappelle: Absolutely.

Dr. Mariel Gross: It kind of seems silly that I had… And then when I started to think about my master’s degree work and all of that experience of my Octomom piece and was like, it’s amazing to me how I had never- it was so obvious that it was amazing to me that it had never occurred to me because of my biases about what it meant to be an Ob/Gyn.

Dr. Joe Chappelle: We had an episode, Episode 50, where we all talked about how we got into Ob/Gyn and you basically just told the same story that we all told. We all wanted to do something else and then did our Ob/Gyn rotation and said, oh my God, this is it. Like, why did I ever want to do anything different. It checks all my boxes for me.

Dr. Mariel Gross: And it’s so amazing too, because I thought that medicine was the most diverse and broadest field and I’m the kind of person that has a lot of ideas and gets bored easily. And so, I like the idea of being able to do all sorts of different kinds of things. And I thought about that, and actually, Ob/Gyn is more broad because the nature of the work that we do ranges from psychiatry to surgery and everything in between. And it has so many components of so many other fields in it that we can do more for any one woman than almost any other physician could do for any other patient.

Dr. Joe Chappelle: Yeah. I mean, we are basically one of the last general doctors that exist. We just happen to be only for women.

Dr. Mariel Gross: Yeah. Right, that was the one thing. I was like, do I feel okay giving up men as patients except in the public health as partners capacity. I was like, you know what? Yeah. I could go without some of the…

Dr. Joe Chappelle: I felt the same way.

Dr. Mariel Gross: Those things… And so, yeah. That was my story of how I got into it. But bioethics became this theme in residency where I would continue- my research sort of followed these bioethical tracks. And that’s what led me to wanting to find my career that way. And I mean, I could go on, but…

Dr. Joe Chappelle: Well, I mean it’s interesting because there may be people out there who had never really thought about bioethics as an Ob/Gyn and I’d never really consider it. I know bioethics exist, but I haven’t really seen Ob/Gyns go into that. And so, I think people may be interested to hear what you do and how you got there. And so, let’s take that and segue into your paper because I think it’s really interesting. And you’re right, it absolutely takes… comes from the beginnings of evidence-based medicine and then moves into a question. What I think is interesting about this question that you asked, which basically is about breastfeeding with HIV and should we recommended or not recommended. But we… in medicine, Ob/Gyn especially but I’m sure general medicine as well, we get stuck doing something that started for a good reason and we just keep doing it without necessarily going back and looking at should we still be doing it? This happened with episiotomies and thankfully I think in most academic centers at least, episiotomy is not really routinely done anymore, but it is in some places. There are other things as well though, that… In New York, we have this Medicaid form for tubals, has to be signed like 90 days in advance and if it’s thirty days… you know, within 30 days and whatever it is. And it was designed because people were doing unindicated- and I don’t want to say unindicated by unrequested tubals on people-

Dr. Mariel Gross: Mississippi Appendectomy.

Dr. Joe Chappelle: Right. There you go. And- I like that I haven’t heard that one before.

Dr. Mariel Gross: It’s horrifying.

Dr. Joe Chappelle: People… And this was a response to that to prevent women from being preyed upon, essentially. And it made sense in 1970s when it came out. But now it’s 30, 40 years later and now what it does is actually make a barrier to women getting a tubal.

Dr. Mariel Gross: Yep.

Dr. Joe Chappelle: And I personally believe we should go back and revisit that, because it’s having- I don’t want to say unintended consequences but I guess they are, they’re unintended consequences from something that started out in good faith. And so, what you looked at is sort of similar, where when the HIV epidemic was probably at its peak, and we told women that they should not breastfeed if they had HIV regardless of whether they had control or not because there was a decent chance of transmission.

Dr. Mariel Gross: Well, we didn’t just- The history’s so important. I have just become so much even more convinced of this, about how much the history of our practice and our society influences the ethics and the practice of what we’re doing now. So, we didn’t use to just tell women not to breastfeed, we used to tell women to terminate their pregnancies if they had HIV.

Dr. Joe Chappelle: There you go.

Dr. Mariel Gross: And we used to tell them to get- We would use to tell them to get a tubal so they would never get pregnant again. And so that’s really the background context of HIV care for gynecologic/obstetric HIV care, especially once we learned that it was something that was transmissible to an infant, that was the stance. And we came such a far way from that, and then it seemed to sort of abruptly stop with breastfeeding. So, I think that context is really important to keep in mind.

Dr. Joe Chappelle: Agreed. And so, what you did in your paper, I’m going to help you- I’m going to ask you to walk me through it a little bit, is, you said, okay let’s go back and look at the actual data, especially now when we’re in 2019, where we have good access to good antiretrovirals and really proven regimens now that can make viral loads undetectable for years, decades at a time. Should we reevaluate our breastfeeding recommendations? Because also, in that intervening 10 or 20 years, we have really come to learn how good breast milk is for babies. And you do break it down a little bit in the beginning between developed and under-developed countries. I think that most of your paper is talking about developed countries like the U.S.

Dr. Mariel Gross: Yeah.

Dr. Joe Chappelle: But certainly, the calculus may be different in under-developed countries.

Dr. Mariel Gross: Yeah. We have this- what you were describing, it’s really gone even beyond that we have effective treatment for HIV, because there’s this new movement called “U=U” which means “undetectable equals untransmissible,” and there’s this extensive, you know, hundreds of thousands of years of data between couples that are sexual partners that with the person who has HIV having an undetectable serum viral load, even with unprotected intercourse their partners are not getting HIV. And so that has dramatically changed the landscape, in addition to the fact the now, with HIV, it can be well controlled, and you live a normal lifespan. So, it’s a completely different context, and what captures my imagination about this issue is that, actually, because of similar evidence in Africa, the WHO, for breastfeeding, the WHO actually recommends since 2009 that women living with HIV take antiretroviral medications and breastfeed because they found that the children of those women who had HIV who breastfed had better survival than the infants of the same women who didn’t breastfeed, or had either combination of breast milk and formula. And so, with all of that context, the question I set out to answer was is this an evidence-based recommendation or is this a stigma or prejudice-based recommendation. And that’s the question I was seeking to answer, and this paper was the entrée into what I ultimately developed as this concept of prejudice-based medicine.

Dr. Joe Chappelle: Okay. So, there’s your question. It’s a good question. What was your framework for trying to answer this?

Dr. Mariel Gross: The first thing I had to do was just the deep dive into all of the evidence that’s available. What is the evidence that informs the WHO recommendation that women in low-resource settings should breastfeed? What is the evidence about breast milk in terms of infant health in developed nations? Because I’m really- and the paper is about the U.S. context specifically, and other developed nations, because the recommendation is worldwide to breastfeed in this setting. But the exception is any high-resource setting, it doesn’t have that policy. They’re the reverse. And so, my first task was to really critically evaluate the evidence that exists about breastfeeding, and about perinatal HIV transmission, and about breastfeeding also as a women’s health issue and break that down. As I was saying to you before, my first question to really answer was, for the infant, are the risks outweighing the benefits? First, we have to discuss- because the concern, of course the theoretical concern is HIV is a harm to an infant. And so, the concern was whether… I think the first thing I wanted to address is, does this make infants better off or worse off? And after extensively reviewing the evidence, one, I think that you can say, although it’s controversial, I do believe the evidence supports U=U for breast milk as well as for sexual intercourse purposes.

Dr. Joe Chappelle: Okay.

Dr. Mariel Gross: And so, we also know about the insane amount of benefits to infants from breastfeeding that we’re constantly haranguing on in every other setting, and shoving down everyone’s throat even if they don’t want to or have good reasons for not wanting to. In that setting… Of course, it’s difficult to apply some of the evidence to high income settings because the harms that infants face in low-resource settings related to mortality such as infectious disease-related death like from gastroenteritis or pneumonia mainly, which we know is offset by breastfeeding, that benefit, because child mortality in the U.S. is so much lower, that benefit was less pronounced. But there are a number of other benefits like were relevant, like decreased SIDS, decreased necrotizing enterocolitis and other diseases, potentially mortality-causing diseases that affect newborns in the U.S. In addition to the long-term health consequences, such as diabetes and obesity, asthma, leukemia, things that get thrown in there. But to me, there is a clear mortality benefit for infants, and so I started thinking about, well, there’s this one risk and on the other side there’s the risk, I would say, of formula. Because we treat breast milk as the normative feeding method. So, to do formula is an intervention.

Dr. Joe Chappelle: Agreed.

Dr. Mariel Gross: There’s risks of that intervention. And in the setting of a woman with an undetectable viral load that’s been consistently undetectable, I think… My conclusion was that we at least have equipoise clinically in terms of that infant. And once I established that I felt you could make the argument for at least equipoise if not that maybe infants with mothers who have an undetectable viral load probably benefit more than they are harmed… But once we had that, I sort of took that position and then analyzed it from- ethically, from the perspective of respect for persons, like we talked about, or autonomy-related considerations. I also talk about this approach that’s been proposed which is a harm-reduction approach to this issue. And then also justice-related concerns. And I can kind of walk you through how each of those shake out.

Dr. Joe Chappelle: Yeah. Why don’t we start with what did you find in the evidence that is the… For women with an undetectable viral load, taking their medications successfully, what is the transmission rate if you could find any data on this, for those infants?

Dr. Mariel Gross: The biggest studies and the most recent studies have a .3% vertical transmission for 6 months of breastfeeding and in women living with HIV who are… undetectable.

Dr. Joe Chappelle: Okay.

Dr. Mariel Gross: Now, there’s some complicated factors, because this evidence is not based in a high resource setting. So, the viral load data, for example, is not always perfectly matched up with the timeframe. So, for example there might be reason to believe that those transmissions that occurred in that setting, maybe they weren’t actually undetectable at that point.

Dr. Joe Chappelle: Okay. So, that will be our… ceiling I suppose, .3, the highest that we think it would be in a high resource setting like here in women who we know have an undetectable viral load. Maybe lower than that, but the highest it’ll be is .3?

Dr. Mariel Gross: I mean, it’s certainly… I mean, I don’t want to say that either, because when you think about… those are clinical trials. And so, obviously clinical trial participation may involve more control than just the postpartum life of women in the U.S. now, like in the fourth trimester, if you will. So, I don’t want to say it’s higher or lower definitively, it’s just extremely low to the point where it approaches the same level of elimination that we assert with pregnancy itself. And I think that the same things seem to apply.

Dr. Joe Chappelle: Okay. And then on the other side... Actually, I should state back with that, that even if an infant does get HIV from the mother, these days it is not a lethal diagnosis anymore. And that with proper treatment and maintenance, they could live a full life, like we were talking about before, where it’s really become a chronic disease as opposed to a lethal disease.

Dr. Mariel Gross: Right. Which is kind of the frame that we discussed at the outset. I’ve heard many clinicians say I’d rather have HIV than diabetes, for example.

Dr. Joe Chappelle: Okay. Fair enough.

Dr. Mariel Gross: For whatever it’s worth. But yeah. Exactly, and I do look at that data as well because unlike in the settings where HIV is much worse- for an infant in Africa to get HIV than it is for an infant to be born with perinatal HIV in the U.S. because of the resources we have. For example, there was- from all children with HIV in the U.S. under 13 in the year, I think it was 2015 was the most recent data I had at the time, there was one death in all of those kids. And it was less than 1 in 100 child years.

Dr. Joe Chappelle: Okay. So, it’s really low.

Dr. Mariel Gross: Really low.

Dr. Joe Chappelle: Right. And then you get into your data on the breastfeeding for infants, and you already talked a lot about what the different things are. And that we obviously know there is a benefit to babies receiving breast milk over formula. Now, I think no one would argue that… It’s not like there’s a 50% decrease in mortality or something dramatic like that. But there are a whole bunch of little things that combine to decreasing overall morbidity for infants who are breastfed as opposed to not. And there’s probably more things we’re going to learn about breast milk as we’re studying it more now. So, then how do you go about weighing those two things? You have the benefits from the breast milk, which, again, are usually about morbidity or otitis media or things like that as opposed to death. And then you have, on the other side, you have three out a thousand babies being breastfed who may get HIV. So, how do you… and we’re talking about ethically, a framework for this, how do you try to balance those two things?

Dr. Mariel Gross: Yeah. Well, just like I chose to focus on the infant first, I chose to focus on actual mortality first. Because I think that that’s the most impressive thing that we have to really worry about, right? And it’s the most clear. And so, as we just discussed, mortality, even for HIV in the U.S., for a child with HIV in the U.S., is extremely low. And so, I wanted to look at what the mortality was for infants in the U.S. who as a result of- like, risks of mortality that they might incur as a result of not breastfeeding. And like I was saying, the biggest ones that are sudden infant death syndrome, which is more than, you know, it’s two and a half times more common if you don’t breastfeed. Things like infection, specifically sepsis and necrotizing enterocolitis, especially in the premature infant population, actually cause mortality and, even though the scale is different than in other countries, because our overall child mortality is lower, I think you could really make… start to crystalize this idea that actually the mortality for infants of women who live with HIV in the U.S. who don’t breastfeed might actually be higher because they’re not breastfeeding than it would be if they were. And the really important thing that comes in here is the racial disparities. And so, when you start to think about okay, wait a second, let’s think about who are the women in the U.S. who are living with HIV? And it’s 20 times more common among Black women. And you know what also is more common among Black infants? SIDS, necrotizing enterocolitis and other diseases of prematurity that are- SIDS is by definition fatal.

Dr. Joe Chappelle: Right.

Dr. Mariel Gross: So, when you’re comparing the risks, we really have to ask ourselves, like, these are health risks. Is there a reason why we’re looking at HIV as a risk and counting it differently than other things that are potentially equally risky in terms of mortality? And I really try to stake the conversation about the infants’ risk in the risk of mortality-causing agents. And then there’s also all these other considerations about chronic diseases that it might be harder- you know, higher or lower risk of… And that’s why I think the easiest position was to land on the idea of equipoise. And we know… ACOG is always saying, okay, disadvantaged women, women of color, them and their infants would disproportionately benefit from breastfeeding.

Dr. Joe Chappelle: Right.

Dr. Mariel Gross: And the rates of breastfeeding are disproportionately low.

Dr. Joe Chappelle: Correct.

Dr. Mariel Gross: And so, part of our charge as Ob/Gyns and other women’s health/infant health providers is to narrow that gap. And so, really, I started to ask why are we treating this differently when it might be causing more harm than good? And then when you start to think about well, what about the woman? If I can’t say one way or the other for the infant, just to be safe and say, well I’m not sure. But what about the woman? Women are clearly at greater health risk if they don’t breastfeed.

Dr. Joe Chappelle: Yes.

Dr. Mariel Gross: The data on this is becoming more and more compelling and not just cancer –breast, uterus, ovarian cancer– but diseases or metabolic syndromes, so hypertensive diseases, stroke, heart attack, coronary artery disease, diabetes, all higher in women who don’t breastfeed in a dose-based fashion. And then women who don’t breastfeed are also at higher risk of obstetric complications from subsequent short-interval pregnancy. Which can be especially bad in the case of a woman who had a c-section. So, you have things like accretas and uterine rupture that are more common in those short-interval pregnancies and we know breastfeeding decreases the risk of that.

Dr. Joe Chappelle: I think you made a very important point there, which is, yes, when you talk about the absolute number, the absolute number of deaths that breastfeeding is going to prevent is small. Maybe it’s one in a thousand. Maybe it’s even a little less than that. It’s not a huge number. But, also, if three out of a thousand babies are getting HIV and one out of a thousand of those babies is going to have a mortality, that number is even smaller than that. And I think you’re right. There is this cultural… I guess I’ll call it cultural or societal bias against HIV and it still is engrained I think in the- at least the American psyche, probably worldwide psyche, that HIV is terrible and you should do anything you can to avoid it because it’ll kill you, and it’s scary. It’s like a modern-day boogie man, right?

Dr. Mariel Gross: Yeah. It’s a moral panic.

Dr. Joe Chappelle: Right. It makes that seem worse than it really is in our heads. So, I think the absolute number there is an important thing. And until you went through that I’d never put that connection together.

Dr. Mariel Gross: Yeah. And in the paper- I mean, you could look at the paper and specifically there’s a supplementary… There’s so much research on HIV it’s impossible to actually be on top of all of it. So, I ultimately made this data table that I’d be happy- it’s in the supplementary file. But it has some of the numbers, which I think, just like, looking at the numbers, and I walk through a little bit of it in the paper but the numbers are impressive when you think about it, especially when you start contextualizing it with the racial disparities. But what you’re bringing up about... You’re bringing up my point about harm reduction. There have been- there’s been acknowledgement of the fact that telling a woman not to breastfeed can be difficult for them and specifically in certain cultural settings. And there began to be this awareness that well, maybe women are breastfeeding… that are just giving us lip-service saying that they’re not going to breastfeed. Maybe they’re doing it anyway. And maybe as a result they’re not doing it as safely as they could be if they actually had provider support. And this led to one provider in particular, Judy Levison, in Huston, she’s at Baylor, to start trying to support women who decide to breastfeed against recommendations, to use their terminology. It’s pretty amazing because they got this language, because they sit on the perinatal HIV guidelines committee, she and other people that began doing this. They got that language, the harm reduction language added within the past year. I think it was actually just about a year ago, in maybe March or so, April, March of 2018, where they added language even in the guidelines of what to do if you tell a woman, for all these reasons, “we recommend that you don’t breastfeed,” but what if she’s going to do it anyway? And making some strides in terms of giving providers an approach to reduce harm.

Dr. Joe Chappelle: Right.

Dr. Mariel Gross: And my problem with that whole… Which was great, and I couldn’t be having the discussion that we’re having today without what they were doing. However, my point was that that is viewing HIV as the only harm that we’re trying to reduce. And what is the classic use of harm reduction as a strategy for public health is clean needles for IV drug users. And breastfeeding is not a clean needle. It is an inherently good thing that we think, like, all things being equal, all women and babies benefit from. And so, to use that framework seemed inappropriate. And seemed to maintain a lot of… while trying to reduce the force of a hardline stance, and trying to make a therapeutic gap, the fact that in bold they still say, “breastfeeding is not recommended, and if despite exhaustive counseling,” or whatever the exact language is –literally they say like, exhaustive counseling– “a woman insists on breastfeeding despite our recommendations,” that gives you an idea of how this might still perpetuate some of the same problems that having a hardline stance is. That a woman would just tell you what you want to hear, or maybe even worse, withdraw from care. And these are patients that have a very high risk of loss to follow up, especially postpartum. And then maybe they’re off in the world breastfeeding and everything without that.

And so, I think we really… Again, going back to the evidence, the whole charge here is that our recommendations for women need to be based on evidence where possible and informed by ethics and reason where there’s lack of evidence. And if you think that it’s at least unclear for an infant whose mother is virally undetectable, and you know this, we see our patients many times in pregnancy. So, you actually have a good sample. This is not some person off the street. This is somebody you probably say in high risk OB many times. If you talk about her infant and you can’t decide for sure whether you think her infant is harmed or benefited by breastfeeding, you have that state of equipoise, then the appropriate framework really is shared decision making and using what evidence we have to have a conversation with that woman in assessing her own risk tolerance and concerns. Does she have breast cancer run in her family? Well, maybe she would be more inclined to want to breastfeed. Did she use IVF, even though she’s been undetectable for ten years, did she use IVF because she didn’t want to have unprotected intercourse with her partner to conceive? Well, maybe she’s going to say, no way, I’m not doing anything that could even theoretically increase the risk. But that’s her, and that’s on her and that’ her- Her body, it’s her child. To me it’s crazy that we would tell women not to do this.

Dr. Joe Chappelle: Well, you’re getting into an interesting junction, and there’s two things to talk about in your paper anyway. But one of them is patient autonomy, or just autonomy in general. And the other one is informed consent, which is something I’ve talked about a lot in this show before. And those two things go together, because hopefully, people make autonomous decisions based on good recommendations. But I have a big problem with informed consent, because how long did you spend researching this paper?

Dr. Mariel Gross: Oh my God. Years.

Dr. Joe Chappelle: Years. Okay. So then, how are you- so, I’m going to call you an expert on this topic, all right?

Dr. Mariel Gross: This is one topic I am an expert on, yeah. I’ll take that.

Dr. Joe Chappelle: Okay. So then- Now, you have this woman in front of you and you have 5 or 10 minutes in a private practice setting, maybe longer in a specialty center, call it an hour. And you have to distill everything you know about this subject that makes you an expert to give her the information she needs to make this choice. And, number one, I think that’s an impossible goal, because more than likely this person does not have your undergraduate degrees, your master’s degree, your medical degree, your residency or your ethics training to even have the framework to discuss the things that you’re trying to discuss with her. So, how do we go about really doing informed consent and allowing that woman to then have the autonomy to choose what she wants to do?

Dr. Mariel Gross: Yeah, I think this is where, one of the things I suggest is that we really need to develop tools both for clinicians and for patients to help guide them through these decisions. So that’s part of the answer, is that there needs to be decision tools. I would say that you ought to have more than 5 to 10 minutes also to discuss this, because this is a really big deal. And right now the cool thing is that as a result of this work and more patients that are coming up with HIV requesting to breastfeed, there’s sort of this wider knowledge that this is a thing, it’s going on in other countries, some women breastfed a child before they moved to the U.S. in Africa or wherever else and they’re like, “what do you mean I shouldn’t breastfeed here but I should before and my other child doesn’t have HIV and that was so important,” bla, bla, bla. These discussions need to be brought up early and what we’re developing now are guidelines for how to address the issue of infant feeding for women living with HIV at our medical centers in the United States. So, we’re trying to make that framework because it’s important also to have consistency across providers and not all providers know as much as others. And so, the one thing I would say is that women are experts in themselves and so as much as I know about this topic, and as much as I- I view my job as to inform her of medically relevant information that she could use to then make a decision based on her life. And part of our job is to guide women to the decisions that we think are in their best interest. That’s what shared decision-making is. It’s a process that we engage in together. So, I would say like I have just as much responsibility to learn what is important to her and what are the factors that guide her thinking about this as much as it is for me to share the risks and benefits. And women have a lot of ideas about whether or not they would want to breastfeed. You don’t have to… They know, in the culture, breast is best. And the reason why women experience it as a harm if you tell them not to breastfeed, the term that I hate is “not allowed” to breastfeed.

Dr. Joe Chappelle: Sure.

Dr. Mariel Gross: And that comes up often. If you tell a woman she’s not allowed to breastfeed, she experiences that as a harm because she thinks that as we tell all other women that breast milk is the best food for babies, and because she wants to be a good mom. So, when you tell someone “you shouldn’t breastfeed” or “you’re not allowed to breastfeed because of your HIV status”, it’s really like saying “you’re a bad mom because of your HIV status.” And so, I think that having that framework is really important and there’s a shared mental model. And so we have to fill women in on yes, what are the details, but- Just like we teach them and they teach us about what it means to sit and manage HIV in pregnancy in general, I feel like it’s just more of that same conversation. And it needs to be based on them.

Dr. Joe Chappelle: Yeah. I mean that kind of… We come up on that exact question I think often in Ob/Gyn. Another one I can think of off the top of my head is VBAC. Where we have people who are, you know, okay, you have a 2% chance of having a uterine rupture. And she says, okay.

Dr. Mariel Gross: What does that mean to her, right?

Dr. Joe Chappelle: Right.

Dr. Mariel Gross: What does she know about what a uterine rupture is? How could she even… Informed consent is kind of nonsense in that regard.

Dr. Joe Chappelle: It is. I mean, you say, “okay, so two out of a hundred people just like you will have a uterine rupture, and a certain percentage of those people will end up with something catastrophic.” And she says, “okay. But I still want to have a vaginal delivery.” And that goes into what they were talking about with the breastfeeding before. It was, okay, so, now what do I do with this woman who, against my recommendation is going to try to have a vaginal delivery? And we’ve had a few cases like that over the years at Stony Brook. We had one lady with three prior c-sections who wanted to have a vaginal delivery, and everyone got very up in arms about that. To which I said, “well, she’s been counseled about the risks and that what she chose to do so, what are we going to do?” You just document well. At the end of the day, we’re not going to not take care of her. So, we do the best we can for her.

Dr. Mariel Gross: Brings up a really good point, because I think the parallel issue, you know, we used to do c-sections to prevent perinatal HIV transmission. And why did we stop doing that? Well, we realized that with women who have a low, not even undetectable but women with a low viral load, the marginal risk to the infant from a vaginal delivery was not justified by the harm imposed on the woman from having a surgery that was not indicated, or indicated for that purpose. That that tiny difference for the baby wasn’t worth causing the harm to the woman. And that’s not even the same argument that I made where I was like, first let’s talk about the baby. We’re talking about baby only first and then when you add the woman to it, it’s like, well actually this may be harming both of them more than it’s helping anybody. And then it’s like, who’s that serving, the providers? Their own… You have to think about the context of a woman with HIV who is carrying a pregnancy. That’s her context of the whole thing.

Dr. Joe Chappelle: Right. I think that gets into something that I’ve been thinking a lot about recently. I’ve been trying to come up with an episode about it but I’m having a hard time making something interesting. And that is about the decision to do nothing. And in this case, it’s the decision not to do a c-section for these women. And, sure, I mean, if you do a c-section, you’re going to prevent, I don’t know, X number of babies that get HIV, whatever that number, it’s very small now, it’s actually non-detectable, but there’s still some. And then the decision to do nothing, what does that get you? Well, it gets you vaginal deliveries and you get rid of all the c-sections. But we, as humans, don’t think that way. We think through the positive consequences of doing something, but not the positive consequences of not doing something. We could apply it to a lot of things, CAT scans and blood tests and all that stuff, right? But I want to reframe the decision to not do an intervention as an active decision. As opposed to a passive.

Dr. Mariel Gross: Yeah. You’re intervening against Ob/Gyns’ behavior.

Dr. Joe Chappelle: Right. And that has its own sets off pros and cons or risks and benefits. But I don’t think we- at least in my head, I’m starting to try to change how I compare those two things as two active decisions as opposed to an active versus a passive decision.

Dr. Mariel Gross: I think you and I may have talked about this in person. There was recently a speaker who’s interested in some aspects of data, and especially areas in medicine where we have too much data, like genetics and EFM were things that she spoke about as specific examples. And her whole position was that we should have more guidelines for how to enable Ob/Gyns to do intermittent monitoring and collect less of this data that they don’t know how to deal with or whatever, or that makes them more likely to do a c-section even though we know that the benefits on a societal level are not, you know, whatever. That we’re causing more harm than good. And, to me, I was like, both practically and ethically I don’t think- Like, I understand where you’re coming from and I agree that we do a lot of things that are not indicated. But I never see EFM, or at least some version thereof, it might change… We might be following the EEG instead of the heartrate or whatever, but we’re never going to de-implement EFM.

Dr. Joe Chappelle: Agreed.

Dr. Mariel Gross: It’s not happening. And so, my response was like, in general, data is increasing in every area of our lives. That is a losing battle to fight to make less data. What we need to be fighting is how to interpret that data better. And it also seems absurd to me that we’re using the same basic framework for interpreting EFM that we were using when it was developed or first implemented over half a century ago. That’s absurd to me. And, I loved this term, of my own, I was like, this is so clever. EFM doesn’t cause unnecessary c-sections. People practicing obstetrics do.

Dr. Joe Chappelle: That’s correct.

Dr. Mariel Gross: And so, to focus on how we- our stewardship of data was sort of my plea. The way we can maybe do more sophisticated analysis. And also, I think about the- almost like, from a virtue ethics perspective, seriously, I’m always talking to residents about my general disposition towards the EFM and that I’m aware that it’s there, but I purposefully ignore it because it’s so obvious. Like when you have one patient laboring and everyone’s bored and they’re just looking at every decel and it’s like the Wile E. Coyote, there with the scalpel and everyone’s putting their bibs on. And I’m like, just stop. She could be delivering at home, for crying out loud.

Dr. Joe Chappelle: Right. Stop looking at it.

Dr. Mariel Gross: This patient is totally appropriate to have a homebirth so… not that I’m saying she should, but I’m just saying the fact that you’re looking is making it hard not to do something. And I always love that expression “don’t just do something, stand there.” I mean, I think that that’s a fascinating topic.

Dr. Joe Chappelle: It’s a challenging thing to do. But we actually have an NIH grant at Stony Brook now looking at using machine learning on EFM to see two things. Number one is, can they come up with better criteria than we currently have?

Dr. Mariel Gross: Of course. It wouldn’t be difficult to do.

Dr. Joe Chappelle: Probably. And then second is, can we actually abstract the EFM away from us and to… A computer, essentially, that just spits out “bad”, “intermediate” and “good.” And then we can do with that as we wish. As opposed to staring at the strip the whole time. Now, that’s far in the future if ever. But it would definitely get us away from staring at the strip the whole time.

Dr. Mariel Gross: Well, yeah. It could have practical benefits just in terms of how you spend your time on the unit. But it’s so interesting, because the question about machine learning, how could machine learning do better is machine learning is learning from humans and we’ve done crappy? So, how does it not learn the same patterns that we learn?

Dr. Joe Chappelle: Right. Well, in this particular case, they’re just basically feeding it strips and outcomes. And they’re asking it to figure out what correlates to the outcomes. That’s it. And a huge data set. So, we’re not- I’m not doing the project, but my understanding is we’re not feeding it with any intentional bias. Now, there’s probably unintentional bias in there, but whatever.

Dr. Mariel Gross: Yeah. Those are the most difficult to eradicate.

Dr. Joe Chappelle: Aren’t they? Alright. Well, let’s bring it back around and finish up with your conclusions here. So, after doing your risk/benefit analysis, your ethical analysis on baby and mother, what did you come up with?

Dr. Mariel Gross: I came up with basically the view that given the benefits or potential benefits of breastfeeding for both infants and women, and the extremely low or very low risk of perinatal HIV transmission with an undetectable viral load, that women who meet that criteria should have the option of breastfeeding, and that the charge was upon us as the healthcare sector and providers to support her in doing what she prefers and that really this should be, for that patient particularly, it should be a woman-guided shared decision and that we almost shouldn’t tell them that it’s not recommended. Now, I think that we need… and I think that that’s especially important, again, given the equipoise for infants and given the health disparities that exist in this space. And so, one thing I think that could be really helpful for example is when we have long-acting heart medications. Because postpartum period is, you know, there’s concerns about adherence, and it’s a stressful time. Well, it would be great if you could give a Depo injection and those medications exist, and we really, I think should be advocating for them getting approved in breastfeeding ASAP because they could be total gamechangers. If like, imagine you don’t have to worry about pill-based adherence, they really just have to show up every month or whatever it is for their injection and you know that they’re getting their medication and therefore will maintain an undetectable viral load.

Dr. Joe Chappelle: That’s fantastic, I didn’t know that existed.

Dr. Mariel Gross: Total gamechanger. And those medications are being, you know, in clinical trials now.

Dr. Joe Chappelle: That’s crazy.

Dr. Mariel Gross: But I think that that’s important. And I think that in the interim, having decision tools to inform clinicians of what are the things that make a woman a good candidate? What are the things that make her not as good of a candidate? In terms of balancing the risks and benefits for that infant and for the woman herself. That’s kind of the conclusion that we reached, that I thought that the option to breastfeed should be included instead of the willingness to support breastfeeding despite being told not to.

Dr. Joe Chappelle: How was this received in the HIV world?

Dr. Mariel Gross: I think that it was timely. I think that it’s coming up more and more now. I’ve had more and more- Like I said, I’m part of this working group in my hospi- at Hopkins where we’re developing guidelines, active… like, as we speak, we’re developing guidelines for how to handle this issue. Whereas before, a few years ago, when I was bringing this up, there was a hardline stance. So, there’s a movement and people are starting to question whether U=U is appropriate for the breastfeeding context as well. And I think that the commentary echoes a lot of that. There was support in the commentary for this approach.

Dr. Joe Chappelle: Good. So, you think that the guidelines are going to change?

Dr. Mariel Gross: I do. Yeah, I do.

Dr. Joe Chappelle: Good. That’s great.

Dr. Mariel Gross: Yeah. I think that we should not practice prejudice-based medicine.

Dr. Joe Chappelle: Well, I don’t think anyone would disagree with you on that. Getting there is difficult but…

Dr. Mariel Gross: Yes. Yeah.

Dr. Joe Chappelle: First, you have to recognize your own prejudice.

Dr. Mariel Gross: Right. And that was really what I… One of the goals I hoped to accomplish through this paper by going through it. I was thinking, really, getting each individual to think, what if this was me? Would I want to breastfeed? What if this was my friend or my colleague? Would I think that it would be appropriate for them? And then, really start thinking, why am I recommending against it for other women?

Dr. Joe Chappelle: I have one more question for you.

Dr. Mariel Gross: Yeah.

Dr. Joe Chappelle: This paper was published in the Journal of Law, Medicine and Ethics, which seems appropriate. But reading the paper, I’ll tell you that this could easily have been published in the Green Journal or the Gray Journal. So, why did you guys choose an ethics journal as opposed to an Ob/Gyn journal?

Dr. Mariel Gross: Well, first of all it got rejected from three other journals.

Dr. Joe Chappelle: Oh, okay.

Dr. Mariel Gross: Yeah. I mean, which is just… This was an extre- It’s very interesting. This was an extremely difficult to publish paper even though there was, since its inception, there were people that… I mean, the paper itself hasn’t changed. But it’s extremely controversial to suggest even, how dare I suggest that women in the United States would breastfeed with HIV when you could give a baby HIV that way? And the response to that really dictated my choice ultimately to aim it towards this journal. I mean, the reason I wanted- I actually wanted a more general journal, even beyond Ob/Gyn, because this doesn’t just involve Ob/Gyns, this involves public health, this involves pediatrics, infectious disease, medical communities. There’s a lot of different providers and people, stakeholders, that I felt like should be part of this discussion.

Dr. Joe Chappelle: Agreed.

Dr. Mariel Gross: And that was why I was seeking a more general audience. But I was finding that the general audience, even if I would have a “revise and resubmit” for example, and then they add a reviewer, and the third reviewer says, “oh, no, this is unconscionable.” Or they didn’t really get it. They’re just so up in arms about the mere suggestion, which kind of spoke to my theory, which is that this is not really and evidence base. This is emotional fear of HIV and stigma and moral panic about HIV based healthcare. And I think we found an audience within the Law, Medicine and Ethics community that was more willing to have this discussion.

Dr. Joe Chappelle: That makes sense to me. The other three journals that you submitted it to, they lost out.

Dr. Mariel Gross: Thank you.

Dr. Joe Chappelle: And I’m glad that we were able to sit down and talk about this. And hopefully my listeners will go out and look at this paper. I’ll put it in the show notes obviously along with the commentary that was also there. Because I think it is important, even if you don’t see that many people who have HIV in your private practice or even academic practice –we have a few at Stony Brook but not a ton– I think the overall method of going about looking at the question can inform other things that we do. And it also I think does a little bit to pull back what you said about the panic about HIV and to say, you know what? Maybe it’s not as bad as it was 30 years ago, and that is engrained in our head. We should start looking at it as something else. And so, I thought, just for those reasons alone, it is a great article to read. And also, you get into the ethic stuff. And I wouldn’t- To me, it was understandable, even though I really don’t have a background in ethics, except for what I did in medical school. But it was a, to me, I could follow your arguments and they made sense. And I was like, oh I see how I could apply that, like I said, to VBAC and I’m sure there are other things that I can apply similar reasoning to. So, I recommend everyone go read this. It’s there for you to read.

Dr. Mariel Gross: Thanks. The one context I would invite other providers to think about this work as applying to breastfeeding specifically in the setting of substance use. And so, you might not take care of the patients with HIV, but you definitely take care of patients who use substances…

Dr. Joe Chappelle: I do.

Dr. Mariel Gross: Yeah. Especially marihuana.

Dr. Joe Chappelle: It’s everywhere.

Dr. Mariel Gross: And other substances and think about whether you’re telling women that they shouldn’t breastfeed in that setting or discouraging women from breastfeeding in that setting and whether it’s appropriate. You can use the same, like you’re saying, use this same way of digesting the issue and the evidence and then looking at the different considerations to reflect on your practice and whether maybe you’re imposing more harms unintentionally with, actually with good intentions, may be imposing more harms than you’re benefiting.

Dr. Joe Chappelle: Absolutely. So, yeah. It’s all going to be in the show notes, guys, you can check it out. And then, if people want to delve further into this bioethics and Ob/Gyn, is there any place we can point people to go read more or people that they can talk to…?

Dr. Mariel Gross: Well, anybody can reach out to me. So, there’s about five Ob/Gyns that are professors in this country that are Ob/Gyn bioethicists, I hope to become the sixth one. And I am working on starting a blog. So that would be, I would say the best- I mean, there really isn’t too much of a specific forum for these kinds of discussions for people in our field yet. But I’m working on making it. So, stay in touch with me and hopefully we can circle back with a better answer. But I’m working on a blog for that.

Dr. Joe Chappelle: Alright. Fair enough. So, in the meantime, if it’s okay with you, I’ll put your contact information in the show notes.

Dr. Mariel Gross: Yeah. That would be great.

Dr. Joe Chappelle: And people can reach out to you if they have questions or if they want to get involved somehow and they have interesting things. Maybe you can guide them to the same path you’re on.

Dr. Mariel Gross: Yeah. Thanks.

Dr. Joe Chappelle: Alright. Well, Dr. Mariel Gross, thank you so much for coming on and walking us through this paper, and actually a lot of other topics as well. Really, the pleasure was mine. It was very, very interesting. So, thank you.

Dr. Mariel Gross: You’re welcome. Thanks.