



PREVENT. RESIST. SUPPORT.

Episode 4: Women's Access to Healthcare

with Dr. Kendall Soucie



University
of Windsor

Office of Sexual Violence Prevention,
Resistance, and Support

Prevent Resist Support Podcast

Season 2 Episode 4: Women's Access to Healthcare with Dr. Kendall Soucie

Anne Rudzinski: Hi everyone, I'm Anne and you're listening to Prevent Resist Support, a podcast by the Office of Sexual Violence at the University of Windsor.

Music: I got your back my dear and I know that you got mine. I feel that hope and fear but I know we'll hold the line. Keep your head up. Keep your hand out when your breath is feeling short. Prevent, Resist, Support.

Anne: So today we're chatting with Dr. Kendall Soucie about women's access to health care, and specifically some of her research on PCOS. PCOS stands for polycystic ovarian syndrome. And Kendall does that research here at the University of Windsor in the psychology department. So we're really grateful to have her today chatting with us about her research, and about some pieces around advocacy in the healthcare system. So as always, we just want to give you a reminder that we will have an accessible transcript available for you for this episode. And we'll also provide links to all of the things we talked about today in our episode descriptions. So you don't have to worry about writing those down. And then I just like to remind folks too, about the support options we have available on campus. So if you would like support and you're a member of our user community, you can reach out to us at svsupport@uwindor.ca. Or check out our website www.uwindor.ca/prevent-resist-support. And then if you're not in our UWindsor community and you want to find some support, you can

check out the Ontario Coalition of Rape Crisis Centres, their website is sexualassaultsupport.ca. Thanks very much for listening. And we're going to get right into our interview with Kendall.

All right, so we have Kendall, here with us today to chat about PCOS and access to health care for women. Welcome, Kendall.

Dr. Kendall Soucie: Hi, Anne. Thank you for having me. I'm really happy to be here. And I'm happy to have this conversation with you today.

Anne: I'm so excited to chat about the work that you've been doing. And I think before we get into it, we wanted to give just a bit of a disclaimer about the way that gender is going to be talked about in the episode. So did you want to chat about that?

Kendall: Yeah, we can take a moment to talk about that. So when we think about you know, gender, I want to kind of make the argument that anybody with ovaries, for example, can have PCOS. So we tend to be more inclusive and diverse. And when we're thinking about women's experiences, managing PCOS, and also navigating the healthcare spaces. So the work that we're trying to get into is more intersectional. And I think that's incredibly important. And we're starting to learn more about intersectionality. And how people's social positions and locations impact their lived experiences and their experiences within different contexts. So for example, within the healthcare system.

Anne: That's awesome. So I think we're going to be using the term women a lot when we talk about health care access, but it sounds like this experience is more wide reaching than just women.

Kendall: Absolutely.

Anne: Awesome. So my first question that I always love to ask is, you know, you do a lot of really cool work around PCOS and access to health care. And you're teaching at the university. And so I would love for you to tell our listeners how you got into your line of work.

Kendall: So one of the things that I've been interested in for a really, really long time is women's health. I kind of got into this work in a couple of different ways, which I'll share with you. So the first thing that I will mention is that when I was 27 years old, I was diagnosed with PCOS. And I had a really tough diagnosis experience. It was really challenging to get a diagnosis. I actually got diagnosed in the States when I was completing grad school over in Michigan. And so I, you know, I started to kind of think about PCOS. And actually, I'll start by saying PCOS stands for polycystic ovarian syndrome. And we'll learn a little bit later that that name is actually kind of a misnomer. Because not all women, and not all folks with ovaries have cysts on them. So there's been some controversy around the syndrome in that way. But, you know, just reflecting on my diagnosis experiences and, and thinking about, you know, other women, other folks who might have PCOS and are kind of living with it and managing it, um, if they've had similar experiences, and if they, you know, even kind of know about the syndrome, and if they know about kind of the biomedical stuff behind it if they know, you know, kind of what's happening with their bodies and so, you know, having that personal experience when I when I started teaching, and I started teaching at Wayne State University in grad school, and I started teaching as a sessional at the University of Windsor I would always include in the courses I taught, so they were courses initially, like child development. For example, I teach adolescents now, I teach stats and methods, but in the Child and Adolescent courses or in those units, I would always include a section on PCOS or something to do with like pregnancy or fertility. And I would talk about it and I would talk about what PCOS is, how it impacts fertility, how it impacts, you know, women's health, how it impacts, you know, physical health, mental health, and I would just include, like, some general information about it. And at the end of some of those lectures, I would have women come forward, like students would come forward and say, you know, that was the first time anybody has ever, you know, taught me anything about PCOS. And I would also bring in endometriosis and some other like pelvic pain and those kinds of issues as well. But like, I would definitely spend, you know, time talking about PCOS. And they would come up after and they would say, that was really cool. Like, nobody's ever explained it that way before. I didn't know how common this was, I was diagnosed with PCOS. And, and nobody's really told me this

information before. And I thought, oh, my gosh, really, like I was kind of moved by that. And, you know, I thought I need to do that more, I need to integrate women's health more into my lectures and into my research, and I just kind of want to understand. And so that's kind of where it started, like having that personal connection, and then bringing it to the classroom, and then realizing like, whoa, you know, the response that I'm getting from students is so touching and so powerful that I need to do that more. And then I thought, you know, maybe I can do some research on on Canadian women's experiences with PCOS. Because again, we have a universal, you know, healthcare system. The healthcare context, you know, affords some kind of interesting dynamics to kind of understand that most of so when I started to actually get into the literature on PCOS, I noticed that a lot of it was really biomedical. None of it was done in Canada. They talked about all of the risk factors, like PCOS is associated with diabetes and infertility, and heart disease and all kinds of different things. But, but I realized that in the literature, this the socio cultural, the social science, part of it was really missing. And I started to kind of look at diagnosis experiences, and found that, you know, holy smokes, women with PCOS, have a lengthy, lengthy diagnosis experiences, like we're talking, you know, four years, five years for some folks to get a conclusive diagnosis. And as you're sitting and waiting and waiting and waiting, you feel like you're not really making any progress, and you don't really know what's up with your body. And so and so I thought, Okay, what's accounting for those delays? What's, what's the deal? Right. And when you read into this literature, you know, some of it has to do with a very, you know, controversy of diagnosis, you know, there's like, and we'll get into this a little bit later. But, you know, there's several criteria at one point, like four different organizing bodies had a different way to diagnose PCOS, there was a lot of confusion around the criteria, a lot of confusion around the name. But then there was this, this emerging body of literature that really focused on on patient provider communications, and things like incivility and like women being treated poorly. And so the delay wasn't necessarily, you know, completely due to the misleading name and the the poorly constructed or poorly coordinated diagnostic diagnostic criteria. But it was because of how women were being treated, when they would go to a healthcare provider and try to figure out what was causing their symptoms. And

then I started to say, okay, you know, what's going on there? How can we how can we further zero in on the diagnosis experience to see where that breakdown is? And to see what's happening? And the more that I got into it, the more than I thought, okay, Canada is misrepresented. We don't know anything. There's really nothing out there about Canadian women's experiences in a universal health care system. We also, you know, don't know about, you know, like, why these delays are happening, why they're happening right now, why, what the history is behind a lot of that, you know, which we've learned is because Women's Health was never prioritize, you know, physicians don't know what PCOS is, I don't know much about endometriosis, because women's health just wasn't something that that was in all the textbooks and that people talked about. So it's a larger systemic issue that we're really starting to kind of deconstruct so those are, I guess, the three main things, the personal experience, the including it in the units, and then diving in deeper into the literature to see what was going on. That made me think, okay, I want to I want to learn more. And I want to understand, you know, where these these disconnects are and why it's taking women a large portion of their lives actually, to really figure out what's going on and why they've been neglected and why they've been dismissed and what's what's going on and how do we fix it? So.

Anne: That is incredible. I can't wait to hear more about the work that you've been doing. And, you know, to hear some of the intricacies about how PCOS is affecting, you know, the lives of folks that have it. So let's start with like, what is PCOS? For those who are listening that are not familiar, what is PCOS? What are some of those diagnostic criteria that you talked about? Um, and you know, why is diagnosis so difficult?

Kendall: So that's a really, really great question. So. So again, PCOS stands for polycystic ovary syndrome. And it is the most common endocrine condition in women. It affects one in 10 women worldwide. And it's a syndrome that affects like the entire person. It's also a chronic health condition. So it has a lot of comorbidities attached to it. So it's also lifelong, there's no cure for it, but it can be managed. And that's why early diagnosis is so important, right? So if you can get diagnosed early, you can get on a treatment plan. You can see what works for you, then it can prevent any potential long term complications. And so because

it's a syndrome, there's this constellation of symptoms that fall into three domains. And so the first domain is reproductive. So women with PCOS experience irregular periods, that's often the first sign in young women is they, you know, haven't had a period or if they have had a period, it's like, you know, it's every four months or once a year or once every couple of years. And they realize, okay, that's sort of odd. So, you know, irregular period is usually one of the first signs that women report, they're often prescribed birth control to kind of regulate their period. Some women have cysts on the ovaries that prevent ovulation. One of the diagnostic criteria is on points that you had to have 12 cysts lining your ovaries and on an ultrasound, so in order to see them, you'll you'll get a transvaginal ultrasound so it'll show like it looks like a string of pearls around around your ovary, almost like a necklace around there. So it's one of those diagnostic markers. Again, not all women, and not all folks with PCOS have them but it is a common, a common thing that you generally see in terms of a diagnostic marker. And so when you have cysts on your ovaries, it does make it difficult to ovulate, which then impacts fertility and pregnancy. Also, in terms of reproductive symptoms, high testosterone, so high androgen levels is also pretty common. So in terms of your physical appearance, women might produce more oil on their skin, they're more prone to acne, they might also have excess hair growth on the body called hirsutism. So in places like having excess hair grows in places, you know, like your face, your face, your chest, your upper lip, but then they have something called androgenic alopecia which results in hair loss on the front of the scalp, so they're losing their hair pretty much on the top of their head, but then they're growing it in other places. They also experience you know, chronic inflammation, higher rates of cholesterol, that kind of thing. So so the reproductive part is one kind of dimension and then there's also metabolic issues. So 70% of women with PCOS have insulin resistance, and they struggle with weight gain, particularly around the the abdomen, which is referred to as central obesity. There's the potential for type two diabetes, that is there. There's also you know, high risk for for other comorbidities like you know, like obesity or non alcoholic fatty liver disease, sleep apnea. There's PCOS is also a risk for endometrial cancer. There's links to potential heart disease. So again, it's it's some of those same connections with metabolic syndrome, kind of more globally. Also, too, there's been some recent research that just came out

that shows that that PCOS has so women with PCOS, PCOS are at an increased susceptibility to COVID-19 infection and to more severe COVID-19 disease because of the cardio metabolic profiles. And then there's also the third domain is mental health impacts. So women with PCOS do have higher levels of depression, anxiety, body image disturbances eating pathology, and one of the things that we've learned is that physicians do not broach mental health with women well at all. They tend to be quite dismissive of it, they tend to not really, you know, talk about it much or engage with it with it much. And so most of the treatment plans focus on weight loss or they focus on restoring fertility. Those are kind of the two main kind of, you know, treatment plans. So there's obviously medication there's, you know, birth control is very common to regulate periods and cycles. And there's Metformin that helps with insulin resistance. It's just the type of diabetic medication that helps you that part of the syndrome. And generally there's a kind of like medication and weight loss or like lifestyle change kind of component to it. But in terms of mental health, there's not really, you know, a lot of even research on kind of what avenues are good for women with PCOS. You know, the focus generally is on, again, just restoring fertility and losing weight, those seem to be the big ones. And of course, preventing any long term, you know, comorbidities so, so it's when you think about it, you know, women with PCOS, it's a constellation of symptoms that affects your entire life, like every part of you from the way that you feel, to the way that you look, to your relationships to, you know, pretty much anything you can think of. And there were actually two recent papers that came out that were qualitative papers. And women refer to the syndrome as all encompassing with those words, and also as the whole package deal. So it's something that affects every, every part of your life. And, you know, it's, it's something that is particularly challenging that we found for younger women who have a new diagnosis and are trying to figure it out and navigate it. Some of our data suggest that, that women, young women in particular feel very abnormal, they feel defective, they feel different from other girls their age, and they pick up on that difference so quickly. And they're also hyper vigilant and concerned about their weight, they're concerned about finding a partner that will accept them, you know, for who they are, they're worried they can't have kids in the future. We had one participant in our study, say that

she was worried that if she found a partner, and that partner wanted children that she wouldn't be able to deliver that she didn't know if she'd be able to give her partner that. So being young and trying to figure this out, is incredibly challenging. Because they don't quite know what's gonna kind of happen, like, they don't know, it's like, what's it? Can I get pregnant? Can I not get pregnant? Am I gonna get diabetes? Am I gonna get heart disease? Am I gonna live a long healthy life? Am I not gonna do that? How do I tell my partner? How do I tell my family? How do I tell my friends? How do I broach this conversation with them? What do I do? And we've also noticed that I research that kind of more midlife women, so you know, women who are who are not young, they're a little bit older, they're really kind of concerned about, you know, like, just what's going to happen in the future. Really, that's a big concern right there. They're not necessarily concerned about body image, per se. But it's more about, you know, what do I have to worry about in terms of risk, right? Like, am I at risk for those things to right, am I at a closer risk in terms of heart disease and, and stroke and those those kinds of things, but then they're also really concerned about if they have children, whether they can pass it on? Like, like one participant said, you know, am I going to have to sit my daughter down and tell her when do I do that? And tell her what this is? Because nobody really knows what causes it? There's a potential genetic link, but nobody knows. So it's like, am I gonna have to how do I have that conversation? And how do I how do I kind of do that? And so, and then across the board, you know, women really do report that even when they get a diagnosis, after many years of searching, they're just left in the dark. They don't know what they're supposed to do. Like, you're pretty much given a pamphlet, sometimes you're given a script for medication, you walk over to the pharmacy, you fill that script, and then you're like, Okay, what do I do? Do I take birth control forever? Do I take you know, Metformin forever? What are the long term impacts of that? How do I get off of it? How do I, if I decide, you know, I want to stop taking this medication? What does natural functioning look like? Right? That's what a lot of folks said, What does that even look like? And am I gonna have the rebound of symptoms? And that's generally what happens, you know, it's, um, they stopped taking medication, because maybe they want to have kids or maybe, you know, they want to just not take medication forever. And then it seems like everything just just

comes back so quickly. Like, it's just all of their original symptoms that were it was sort of like they make the argument or they say that birth control was masking it, right, it was not really fixing the issue, it was just kind of delaying this explosion of, of symptoms. So it's, it's again, I think, in terms of how it affects them, it's, you know, it's, it's everywhere, and it's constantly, you know, on their minds, and they're constantly worried about the impacts of it on every part of their lives, you know, from, like I said, from their identity, to their relationships to their body, their relationships with their body, to their femininity to their mental health. I mean, it's like, I think that it's challenging in that way because it affects so many parts of, of who you are and your life, you know. So.

Anne: Wow, it just sounds like incredibly disheartening to navigate that system. And I think, you know, as I'm listening to this, I think something that's really interesting is that so many of these symptoms relate to like our stereotypic gender roles for women.

Kendall: Mhm.

Anne: So I know when you were talking about like feminism, and like some of the body image pieces, you know, we have this concept that like, you know, along with PCOS might come like hair growth, or acne or hair loss and, and weight gain. And like, I think that those are things that young women struggle with already. But to have like this, this other layer of, you know, having to navigate, like, how does the like level of hair on my body relate to like my perception of myself as like, a woman, like, you know what I mean, there's like, so much within that there's so much tied into the weight piece. Acne, I know, is a huge struggle for folks. And so it's just really stark that it has, you know, affected folks in so many different ways that relate to, like, what we expect women to be and perform in our society.

Kendall: Mhm.

Anne: Does that makes sense?

Kendall: 100%. And, yeah, I completely agree. We we've had, you know, in our lab, we've had these conversations as well, right? Where, you know,

those impacts on what women are supposed to look like, what bodies are supposed to do, and what the you know, what body forms are supposed to look like, right? Like you're supposed to be thin and hairless and, you know, like, and to be able to be fertile, and all of those things. Right. And PCOS directly contradicts that for some folks. And, and it's a challenge. And I think, you know, I had a student Kenzie, who's amazing, who, for her honours thesis, did a feminist post structural discourse analysis on women's narratives are like young women's lived kind of experiences with PCOS. And they used words like defective, like abnormal, like broken, you know, because they see that misalignment, like, between what they're supposed to look like, with their bodies, they're supposed to do, what the society says their bodies are supposed to do and look like, and then what they perceive their bodies are doing and looking like, right. And, and that misalignment is is distressing, especially to young women. And I was surprised to see how horrified like, like, women were with these symptoms, because they they directly challenge femininity, and, and identity and in a lot of ways, and so, and one of the things she found too, is like weight gain, you know, was another one, so a lot of, or several women have reported young women that they were kind of like the big girl, you know, or like the odd one out or something like that. And they sort of had that label held on to that label for a long time. And, you know, as as we get a little bit older, we start to kind of accept our bodies and those kinds of things. So we start to see a shift a little bit. But one other thing, too, that she found in her thesis, it was interesting, as women, young women with PCOS were all about body positivity, they were all about, like, you know, body, the body movements around, you know, self acceptance and body acceptance. But simultaneously, like they were projecting that image of like, you know, body positivity and all those things, but simultaneously, we're having that internal struggle still, even though on the on that kind of outward presentation, they were, they were 100%, you know, in favor of all of those movements. But they were they were still, you know, focused on appearance and focused on, you know, what their bodies could or could not do. And I found that to be really interesting, but you're 100% correct in that. I mean, there's that misalignment there. And that dissonance there. And so how do you make sense of that dissonance? Well, you engage in body management practices, you engage in body surveillance, right, so you wax, you pluck, you, like, you

know, you pay a ton of money for, you know, for hair loss treatments, right, laser hair removal, and those kinds of things, you spend a ton of money on weight loss programs, to conform to what you're supposed to look like. And so women would pay out of pocket for really extensive weight loss programs that wouldn't work, and that wouldn't be sustainable, that they couldn't afford. There were there were intersections with socioeconomic status, right? Like how can you afford, you know, these, these new wave, you know, things that might may or might not work? You know, fertility treatments, right, like, those are really, really expensive. And so, women who were in a more privileged position to be able to do that, you know, may or may not have had success doing that, but, you know, those things were kind of important and like other folks were in other privileged positions where they were able to, to advocate stronger for their, their health, right, like, we had some participants who were nurses who kind of knew the biochemistry behind all of it, that could use that knowledge to challenge authoritative, not like knowledge from providers that just were not listening to them, or they would, you know, use those positions. But, but most women, you know, weren't necessarily, didn't have those same privileges. So it it does, you know, get quite complicated. It is interesting, because I, I think, you know, given those those socio cultural pressures, I 100% agree, you know, it's like you try to find ways to fix that misalignment. And then you end up devoting a substantial portion of your life and your time trying to manage the way that you look or manage weight or, you know, pay out of pocket for all of these these things. And it's, it's hard, you know, and that came up quite a bit has come up quite a bit in our in our data, as well.

Anne: Wow. Yeah, I just feel like it's, like you said, it's all encompassing. There's just so much inside of this. So I know we talked a little bit about it already. But why is diagnosis so difficult? What makes it so difficult to be diagnosed?

Kendall: Yeah, that's a good question. Because this is something that I've struggled with as well, like, what the heck, like, like, this is this is ubiquitous. I mean, this is like, if we're saying 1 in 10 women have it, that diagnosis criteria should be solid, right. And so historically, it was a very contentious diagnosis criteria, in the sense that there were there were

several, like, I think, four different organizing bodies, like the Androgen Excess Society, NIH was one of them, National Institutes of Health. They all each have their own criteria. And so there wasn't really any consensus. You know, it was like, hey, what are the commonalities across all of these criteria that we could kind of use as a set of international like evidence based guidelines for the diagnosis and management and PCOS? So for a long time, it was just all of these kind of like, bodies that were operating in silos, and they weren't, you know, communicating with each other. And so GPs would use NIH, the NIH criteria. Specialists would use the Androgen Excess Society criteria, there was another criteria that other folks would use in different countries. So that was part of the reason why was this inconsistent diagnosis criteria, nobody was talking to each other. So nobody quite knew. You know, how to how to diagnosis and how to diagnose it. And so the argument from a biomedical point of view was that this diagnosis is tricky. The name is misleading. It was called Stein Leventhal Syndrome before it was called PCOS. Now it's called PCOS. This whole point about having cysts on your ovaries as a diagnostic criteria is kind of a misnomer, because many folks without or with PCOS don't have cysts on the ovaries. If you're under the age of 18, it gets really complicated in terms of diagnosis, because the argument is that some of the clinical features of PCOS overlap with just puberty like normal pupil pupil development. So that's kind of part of it. So I think about, you know, the fact that yes, diagnosis criteria was all over the place. Nobody used it consistently. And so it was challenging. But then I think about, you know, medicine, I think about medical education, I think about male bodies as being the norm and the reference point. So we know a lot about, you know, heart disease and heart attacks in men, for example, but we don't know, and we've only recently learned about heart attack heart attacks and women, right. And so the symptoms kind of manifest themselves differently. So conditions, you know, women's health conditions, were, you know, underfunded, they were poorly understood, they were seen as kind of elusive. So it's a sort of history of women, women's health, just being neglected and not prioritized and not understood, like women were not included in clinical trials for a very long time. So conditions like endometriosis and PCOS and, you know, premenstrual dysphoria were unheard of. And nobody really, you know, talked about them. And if you compound that, with

the fact that physicians still bring in hysteria, like hysteria narratives, and women who do advocate and do push back and fight for a diagnosis and fight for better care are kind of labeled as overly emotional, hysterical, right, their symptoms are on their head. So we see a lot of medical gaslighting in women's health and women's struggle, and folks' struggle to be heard, and they're told over and over again, nothing is wrong with you, nothing is wrong with you, right. And if you take into you know, even that context of women are socialized to be passive, you're, you know, to sort of not really advocate, you know, to not, you know, fight as much. And so we're starting to kind of see a lot of that change, but there's a lot of reasons why, like, does I know I talked about a lot to kind of summarize, it's like, you know, tricky diagnosis criteria, history of women's health not being prioritized. Women in the consultation room being told that nothing's wrong with you. It's all in your head you're fine. Missed periods are normal, right? But you know, you challenge that authoritative knowledge you know, that's not true. That's not my body is does not feel right. My body is not performing the way that it's supposed to. Something feels wrong. So your challenge and to challenge that authoritative knowledge is something women don't do, right. And women are socialized. Like no, no, you just be polite. You just sort of, you know, this is the authority and this is this the power dynamic and you know, you don't confront and you don't, and so it's flipping that and saying no, no. Like you need to challenge you need fight back, you need to, you need to hold, you know, these these interactions, these these folks accountable. Right? And, and, you know, because what happens is, you know, women and folks with with PCOS report feeling completely defeated after leaving a medical appointment, you know, they feel just not heard, they feel invalidated, they feel exhausted, they don't want to go back. And so we see in our research connections with health avoidance and health anxiety, right, like, if you are mistreated, and even subjected, we have many, many folks talk about being subjected to invasive procedures without really being told what that procedure was. So it's like, you know, so you have to get this particular, you know, procedure done. And then you go to get the procedure done. And your physician said, Oh, it's fine. It doesn't hurt at all. The technician says, Oh, it's fine, doesn't hurt at all, and you get in there, and it's excruciatingly painful. You know, would you go back to that doctor? Probably not, right. So we start to see healthcare

anxiety, we see healthcare avoidance, where folks are, are not going to get their regular screenings. So pap smears and cervical, like, you know, those types of things. They're just not doing that, because they're afraid like that, they're going to be mistreated again, that something's gonna be really painful. So that's one of the connections we're starting to see. And women doubt themselves, they doubt their bodies, they doubt their experiences. And they think, Well, if this physician says nothing is wrong with me, then maybe nothing is wrong with me. Maybe it is in my head, maybe it's stress, maybe it's my hormones, and they sort of say that ambiguous word, like maybe it's my hormone. And so, you know, all of those things are working against you, when you're trying to figure this out, and you're trying to get, you know, a conclusive diagnosis. Because, again, if you go online and google PCOS, it's terrifying. You see all of the things that that could potentially happen to you if you don't get this treated and under control, and you're not, you know, you don't have some sort of plan. The more the longer you wait, right to get a diagnosis, the more at risk you are at of some of those, those long term comorbidities, you know, so it's important to get that diagnosis early.

Anne: Yeah, wow. I'm just like, struck by some of the parallels between what you're telling me about your work and some of the things that we tackle in our work around sexual violence. And I think the piece that I'm seeing is just, you know, it is so pervasive that as women, we are taught to be nice, and that we are taught to be polite. And that really hinders us in these medical settings, it sounds like but you know, in my work, I see how much that hinders us in our sexual violence settings, right? If we're not feeling comfortable, if somebody is being gross to us, there's still this like, pull to be polite. And the other piece that I'm seeing that is just like such a big tie in is the piece around trusting yourself and trusting your feelings and your gut reaction. And like, you know, if you're feeling like, this person is not listening to you, if you're feeling like this person is not, you know, hearing you, when you say things, if you feel like you can't get the words in that you need, if you feel uncomfortable, or intimidated, or like any of these things that you've discussed, you know, you can trust your gut, and you can sit in that knowledge of like, that was not a great medical interaction, I'm not going to go back to that doctor or like, that was not a great date, I'm not going to go out

with that person, again, like whatever that is, I think it's just the ways that as women, we are taught to be polite and nice and not trust our guts is so pervasive. And so I think it's, it's so interesting to see how that's coming up within your field.

Kendall: I agree. And that was the one thing I actually when when we were, we were collecting these narratives, and we collected narratives from a woman's diagnosis experiences from 2017 to 2019. So we collected about 72 interviews with women that basically chart their entire diagnosis experiences. And these things kept coming up repeatedly. Right, it was sort of theme and I'm going to get into in a second because I think that the point you made just makes me jump into power and resistance. Because whenever we see power, and hierarchies we see resistance to there's sort of like this interesting juxtaposition. Right? So a lot of the work that I'm moving into is sort of feminism and advocacy work, you know, but also Foucault and power and like thinking about forms of resistance, right? But you're absolutely right, we see, you know, women, it's the same story. It's the same kind of thing. It's like, you know, women and folks, they have this reoccurring issue like this health issue. They see a physician doesn't really go anywhere they see another physician doesn't really go anywhere. They spend years navigating the healthcare system to try to figure out why do I feel like this, what's going on with my body? This doesn't feel normal, right? Um, only to be dismissed and dismissed and dismissed until something big happens usually, like within women with PCOS, sometimes a cyst will burst and they're like, they pass out from the pain and they end up in the emergency room and then they have, you know, somebody that says to them, you know, okay, so we did all of these diagnostics, and here's what you have. And it's like, all along, I knew I knew all along that something was was not okay. That something was misaligned. And I was off, and nobody helped me. And then this, this traumatic thing happens to me. And finally, finally, after all of those years of doubting myself and, and not trusting my gut, it's like, I feel the sense of relief, like finally now I know, but then also anger, like what the heck, you know, and sometimes there's a supporting character, like a partner or something that comes with them, that helps to advocate on their behalf when they're in, you know, such pain. But it's like that, that story comes up over and over and over again. And it's like, you know,

we're supposed to trust authoritative knowledge, we're supposed to trust what physicians are telling us. But it's it misaligns sometimes, you know, with our experiences, and and we're taught, you know, you don't challenge that, though. You don't, you know, you don't, you don't do that, women don't do that women are socialized to do these things. And, you know, it's, it's, it's interesting. So when we're thinking about, you know, thinking about your work and thinking about the Bystander Initiative in the sexual violence prevention on campus, and thinking about Flip the Script and thinking about, you know, challenging and kind of resisting those things that have been ingrained in our psyche and who we are, from the dawn of time, like, right, these are things that have been part of part of our life story for so long. And it is, it's hard sometimes to challenge that way of thinking, right? Like you were saying, to trust your gut and to trust your experiences, and listen to yourself and trust your voice. And, and, and also, like, for some women, like finding your voice, and, and, you know, owning that and being empowered by that. And then we're seeing the exact same things. And women who do resist, and who do find ways to do that do have have, they get more, I will say out of their their medical appointment, which we can talk about, but I want to talk about, you know, some forms of resistance as well that we're seeing, because I think this is really cool. And, and again, we frame it within the context of, of kind of feminist methodology and epistemologies and those kinds of things. But one kind of cool thing is, you know, when you see the power, you see these power dynamics, you start to see again, those forms of resistance, and one form of resistance that has been kind of, in the literature that has been kind of really cool, is seeing women and folks banded together to do their own, it's like they're forming a movement, like this online kind of movement, where they come together through online virtual kind of communities. So there's so many PCOS communities online, like there's a PCOS support group on Facebook for Canadian women and folks. There's also like several of them that kind of pop up, where you can, you know, be part of the movement, you can raise awareness of PCOS, you can buy things and donate and, and contribute to kind of the cause there's a conference every year some, some women actually pay out of pocket to go to this conference. And at one point, it was before COVID it was it was in Washington and I believe there was like a march or something that came with it, where they went and like the like the one

of the buildings was turned teal like it was the colour teal to kind of represent the the PCOS color. And so we have this, this this group of, of awesome folks who are coming together sharing information, you know, empowering each other to get more out of their health care experiences, sharing knowledge, sharing support, ideas, advocacy work. And we see that you know, in the face of institutional sexism and oppression women band together, they organize, they advocate for better health care, and they're doing it at these larger levels. Like they're, they're changing policy, in terms of women's health. And so that's, that's on the larger scale, right, like having will actually and I'll say the, the conference is coming up in September. So September is PCOS Awareness Month. And there's a conference called PCOS con, and I'm actually speaking there. So I'm going to talk about some of our research and I'm doing a networking thing. I am excited about it, because it's another way for women to sort of connect and share and empower and be part of of that policy change to get PCOS, you know, legislation. I mean, there's like all kinds of things happening, that are really kind of large scale stuff, but then also, you know, on a smaller scale, like when you're in a consultation with a medical provider, challenge, right? Refuse to leave like I've we've had women in our sample, talk about how they'll sit there forever. I'm not leaving until you give me a script because I or for whatever diagnostics, bloodwork ultrasound, whatever, like challenge, question, resist sit there literally, will refuse to leave until there's some acknowledgement Right. Or you know, they they will choose another provider, right, like get a second opinion. And I and I understand I will say, you know, when it comes to privilege, right, like some folks are in a more of a privileged position to be able to advocate more and to be able to switch providers in some some areas you know, you're not able to do that. But there's ways in that moment where you can challenge right. And some of it involves distress tolerance, you know, like just sort of being able to kind of say, like, this is something that, that I'm not used to, it's gonna make me uncomfortable, right with that whole socialization stuff in the background, but just sort of having distress tolerance to sort of, you know, know that, that this is why you're doing it, it's important, it's important to be your own advocate, you know, and these context, so, you know, it's, it's really cool to kind of see that and the third way, and again, this moves out of the the micro consultation room, but even telling their families and friends disclosing,

this is what I have, this is what it means wearing a PCOS bracelet and saying, Hey, what does that stand for, you know, when somebody asks you, and then you, you take that as an opportunity to raise awareness of the syndrome and to talk about it, you know, to have those conversations. Other folks in our sample also, in addition to those kinds of things, they also posted online, like I do that all the time, on Facebook, I post stories about PCOS to raise awareness so people know what it is. I've had folks connect with me from all over the place to talk about how they have PCOS, they want to talk about it, they want to know what they could do to get more out of their health care, like how, you know, they also want to just I think, you know, have a conversation about it, and they feel kind of alone sometimes, you know, and I'm like, you know, absolutely, I would love to have a conversation, I booked zoom meetings and phone calls, with women, you know, who want to talk about it and want to kind of know what they can do to help manage it, or to learn about it, or to do research on it with me, you know, it's been really kind of cool. So people, you know, post on Facebook, or they, you know, use social media as a as a tool to do that. And I've also seen recipes and things being shared, you know, those kinds of things. So I think, I think there's a lot of things that that we're doing to kind of resist and to sort of push back and to reclaim some of that autonomy, over not only the diagnostic journey, you know, but also the treatment opportunities. And right, like, one of the main things I say birth control, right, that's sort of a one size fits all treatment, but but not necessarily. Like there's other avenues that folks can explore too. So challenging those those kinds of things, to do what's best for you and for your body, you know, so there's all kinds of practitioners, all kinds of folks you can connect with to just get so much information. And there's been out of Monash University. There's a whole website devoted to PCOS and information and sharing resources, I think you can connect with a nurse, if you want. Like it's connected to a women's health clinic, so you're able to get information and I can send you that link. We also have several resources on our website as well, that can help direct you to evidence based information. So they're not you know, it's it's its database. It's rooted in scientific data. And I think that that's, that's fantastic. Because there's such an issue with information and misinformation and all of those, it's important to kind of tackle that and to if women are going to go online anyway, because they're not getting

enough, you know, from those in person consultations, and they're banding together online. The stuff online has to be accurate and has to be vetted to a certain extent. You know.

Anne: Yeah, absolutely. And I think that's segues so well into our last question, which is just what advice would you give to our listeners, if they're having a hard time advocating for themselves in medical settings? Or they're in some kind of medical setting that is just like, not great? What are what are the like key advice pieces that you would give about how to navigate that?

Kendall: That's, that's an awesome point. And so on our website, we have a little infographic that we made that kind of, we have Jasmine, one of my research assistants, and Kenzie and a few other folks have made this infographic that has the four A's that can help you when you're in a consultation. And of course, I have other other options too, but, but you can kind of you know, there's some things like you can challenge you know, your provider, you can ask questions, you can advocate, you can you can leave, you can ask for documentation. So asking physicians for copies of notes and charts and, you know, asking for referrals, getting second opinions, finding new doctors, if it's not working for you, right, so those kinds of things can can be really, really helpful because at the end of the day, you want to have a provider who listens to you and takes you seriously and doesn't trivialize you know, your concern. So, I've known of I know, the literature actually, like some of the stuff that I've read, women's health clinics are awesome. And nurse practitioners as the point of entry is like the first the first point of entry anyway, you seem to have the most productive diagnosis and management experiences so having you know, a nurse practitioner seems to be kind of a game changer in this in this world. And then also again, like being assertive and and and finding out you know, a clinic, a provider who you trust, who's going to listen to you. In terms of the actual appointment, you can, you know, bring, bring your most urgent concerns. And, you know, documentation is really helpful. Bring lists of questions. There's been some work looking at question prompt lists. So there's an app, like the website out of Monash University has something called a PCOS app. I think it's Ask PCOS, but it's an actual app. It's like 10 bucks, I bought it, it's great. And it basically helps you come up with a list of focused

questions to bring back the control, you know, in terms of the, of the encounter, so things like that tend to be really helpful. And, you know, like, even if a doctor refuses to do something, like a request for a test or something, you you have that documented. You can also bring notepads with you, you know, stuff with you to ask questions, to take notes, some folks bring patient advocates with them. So you can actually bring somebody with you to help to make sure that your needs are being met. You know, there's also, you know, some other options like you can, you can book more time. So one thing I will direct the listeners to, which is really cool. So on our so my lab at the University is the HEAL Lab. So we're Health Experiences in Longevity lab. And we have a Facebook account associated with it like a Facebook page. And we do these little, little kind of seminars. So we're connected with a clinic, Women's Health Clinic, in Windsor, and in South Windsor. And the the primary nurse practitioner who runs the clinic does seminars with us. So we have three videos, and Anne actually you did one, you did a pot, like a little seminar with us, and it was amazing, on consent. So I would direct the listeners to check that out. Because the first one we did Christine Russette, our nurse practitioner, she has 10 tips to get the most out of your appointment. And her and I are kind of talking about that. But she has some really cool ideas about documentation and symptom journals. And you know, what types of things to report that help your provider as well like to try to narrow down some stuff. Because again, there's that bi directional component, and not being you know, afraid to ask questions, bringing any prior diagnostic records with you, like, you know, relevant medical history, those kinds of things, you can actually book a longer consultation. So normally your appointments are really short, but you can actually there's a specific thing you can say, to the receptionist, typical longer time, so you can book like an actual 45 minute consult, and then your provider will book that space for you. You know, and so, and also, I think the distress tolerance, part two I wanted to talk about again, because sometimes it can be uncomfortable. We are socialized to not talk about menstruation, there's a stigma associated periods and bleeding and menstruation all of those things, right? And so remembering, right, like, like, that's what we're socialized to do. So it's okay. It's okay. I mean, like they have, they've heard everything, and they want to know, and so it's been, you know, comfortable talking about those kinds of issues, right.

And, you know, and also kind of, you know, finding ways to just ensure that you, you ask all of your questions, and your needs are met. And so that's, these are some of the things that we see kind of at the individual level, like when we're talking about things you can do during the encounter, you know, at that time, so there's other things you can also do on a larger scale, right? Like you can do some more advocacy kinds of stuff, you can share your stories, you can speak up about it. You know, you can do all of those those kind of like awareness, kind of oriented things, because I think there's power in knowing you know, you're not alone, and that this is a pretty common kind of occurrence. And then there's some some other stuff that we find at the systemic level, like, okay, so these are some things that when you're writing a paper or something in the discussion section, like or the practice and policy implications part you would write like, here are some individual things you can do, but But ultimately, this is a systemic issue. And this is an issue that is built into power dynamics in institutions, for decades, right. So one of the things that we try to push for is education. So we push for women's health education in high school and competence building strategies, to discuss concerns around menstruation and stigmatizing kinds of things with providers, right. So having you know, some information because when we collected data on PCOS, you know, we asked women and we asked folks were like, did anybody ever talk to you about PCOS? Did you know what it was before today? Or before you were diagnosed with it? Did you know anything about it? And they're like, you know, no, I had no idea. I actually, you know, googled the symptoms, you know, like I didn't quite know. And I said, did anybody in grade school or high school like tell you anything about women's health in general? Nothing. No. So we obviously need to revamp women's health education. So we're working on on that. Christine and I have been trying to talk about ways to maybe do seminars, like some small seminars with high school students to sort of, you know, increase their knowledge and awareness of some of these these things and and also their confidence and talking about it. And we also think that, you know, more funding in terms of women's health Institute's, right, nurse practitioner funding, the those changes would be really helpful, educating physicians in terms of, you know, a curricula that is based on social justice foundations and feminist pedagogy would be crucial, because then you can attack those in, not attack, but

dismantle, those implicit assumptions that physicians have about age, about gender, about weight, about socio economic status, right. So most of the reforms that we recommend are embedded in a social justice, feminist, you know, curricula, that that really challenges, those biases, and it's sort of similar to what the work that you do as well, right? Where you're constantly challenging the things that, you have to unlearn them, you have to be aware of them and challenge and dismantle and unlearn. So we would love to do that with medical residents, because I'm thinking about first year med students and how excited they are and how eager they are to change the world. Right? How about we harness that? Right, we harness that enthusiasm and that excitement. And then we bring in some of the the social justice reform, and I did know too, there's, um, there's one program, I think it was Wayne State, right across the border, the students actually kind of rallied together and imbued some social justice frameworks into medical education, for you know, incoming med students. So I think that that's totally doable. And, you know, I think we need to focus on how sex and gender impact healthcare and impact health care delivery, findings are intersectional. So we need to train the young people, young medical residents, we also need to bring in more diverse med students too, you know, we need to make sure we have more diversity in our in our applicant pools. You know, we need to, we had talked about also doing like continuing ed credits, continuing education credits for physicians, to have these conversations. But again, I mean, these biases are so deeply rooted, we need to find ways to do that, to make sure that, that women's health is prioritized. And I think, you know, because part of textbooks and it becomes part of curricula and and that has to incorporate corporate patients voices and patients experiences and patients narratives. So one of the things and, I know I'm talking a lot, I'm excited, I one of the things I want to do, I don't know if it's like out there. So with the next round of data that we collect, we want to take a more intersectional lens to look at women's diagnosis experiences as most of our sample were heteronormative, heterosexual, white, you know, women, we want to look at other intersections, right. And so one of the things that we want to do is we want to kind of showcase these narratives through the use of poetry. So we want to connect with Art Gallery, we want to connect with the visual arts department at the University, and do an exhibit. So when we collect this

data, I want to kind of do some sort of like, like basically these I poems that are these stanzas of like, you know, poetry 'cause I'm thinking, you know, things like, I was not heard, I was my symptoms, you know, like something that has these I poems in black and white and just sort of this exhibit, and then folks can come in and kind of resonate with with that and connect with that, and then doing some, some, some research on how that makes them feel as they're, as they're walking through this exhibit. I've connected with some folks that Montreal or we're not Montreal, sorry Bishops, well, Quebec, Bishop's University has a really cool visual arts program. And we're looking at ways to sort of intersect patients and providers through this, this sort of arts based methodology. And we also are kind of playing around with art. So having folks come in and actually design art around what what these experiences living with PCOS and managing it through healthcare spaces, what that feels like, through art and through, you know, those types of methodologies with again, having kind of a critical lens of, of the healthcare system. So that's, that's kind of where we're going. And again, our goal is advocacy, to create a dialogue to start some change to empower women to ask for more to seek for more to want more. You know, from these consultations, so that's, that's where we're sort of leading in terms of like translating this stuff out into the community. You know.

Anne: Every time we talk, I'm just floored by like the sheer amount of work that you do like you do so much, and it brings so much value and so like just the biggest thank you for talking about it with us today, I think there were some awesome really like, high level concepts about how this affects us and how this relates to culture and the structures that exist, but also some very like on the ground. Like, here are some examples of things you could do if you're in this situation. And so I think this was so wonderful. Are there any like, is there any, like last thought you would like to leave our listeners with today?

Kendall: No, thank you, Anne, for saying all that, that's so I mean, it has been wonderful talking to you today. This has been an amazing experience. And I'm grateful for this opportunity. I would you know, if anybody has any questions, or wants to learn more about the work that we do, you're welcome to check our website, you can email me, I would love to hear

from you ksoucie@uwindsor.ca, please email me, please reach out. Because I'm just, I'm just so moved by my participants, and I'm so grateful that they're sharing, you know, these intimate experiences that are really challenging for them to disclose like, they're sharing that with us and with our lab and, and we're analyzing that data and making sense of it. And we're trying to do do a justice, you know, and I think, you know, if anybody wants to get involved or just connect, please, please do reach out. I think that's probably and and also, I hope that this this conversation helps you kind of think about ways to empower you know, yourselves when you're in these, these scenarios, and in these these situations, and, you know, at the end of the day, you know, you want to be a flourishing, functioning, you know, person in the world. And hopefully, these strategies and these, these things we talked about today help you or help your listeners in some way. You know, so but thanks, thank you so much. It has been wonderful connecting with you as always.

(Transition music)

Anne: So that was our interview with Dr. Kendall Soucie from the Psychology Department here at University of Windsor. As a reminder, you can find all of the stuff that we talked about in our episode in the description, so check out their social media for the HEAL lab. And then just a reminder that we have support available if you need it. So you can check out our website www.uwindsor.ca/prevent-resist-support Or you can check out sexualassaultsupport.ca for more support options in your area. Please remember to like and subscribe folks if you're enjoying the podcast and thank you so much for joining us today.