Okay, hello.

Okay.

Thank you for participating. I just want to give you a little bit of an intro to our study my study.

In general, this will not be evaluating you in any way, but I'm just wanting to learn about your experience at PCOS. There are no wrong or right answers and you don't have to answer anything you don't feel comfortable answering. This will be mainly a discussion and pretty casual. The general outline will be I'll ask you some information on your experience with PC iOS, and then learn a little bit more about how you acquire health related information and then asking more about specifics of the certain types of activities that you do to take care of your health and to mitigate any symptoms that you experience. I encourage you to think about what is going on in your mind for examples, things you like or you don't like or feel uncomfortable sharing

So feel free to send in your bike. And don't worry about saying anything offensive or feeling silly because of being is useful information for me.

And I will be recording our session so I can go back and review things, make sure that I got all the correct information, but I will exclude the name and any other personal information in connection with the recording and the results so your information will remain confidential. That sound good to you? Yes. Okay. Perfect. Good questions for me at this point. No. Okay. Perfect. So to start off, I just wanted to learn a little bit about your experience with PCOS.

So I was diagnosed this year. I'm 23 right now. And I always suspected that I had something like something was up because I never got my period or Well, I did. But after the first time I got it.

I only got like once a year and each time I got it was like really heavy. So I always knew something was up. So then my second year college, I got my hormones tested and all my hormones get back normal so I like I kind of just like let it go. And the me progesterone pills to induce my period, but I never took that either. So yeah, it's just kind of kind of like always been on the back of my mind, but I never like took any action until this year where they look at my old hormone tests, which they kind of like disregarded because everything came back normal but because I had like two out of the like four symptoms or whatever, which is absolute periods. And they ordered an ultrasound for me for me and they found cysts on the ovaries. So that's two out of the four. So then that's when they diagnosed me.

What How? What are you feeling when you were? First start your hormones tested and then they didn't find anything? And then how are you feeling when you receive like an official diagnosis?

So when they first tested my hormones, I was relieved that everything kind of came back normal, but also at the same time. I felt kind of frustrated because it was like, it didn't give me the answer that I wanted. Like, what's wrong with me? Did you feel like you're Mr. knows, like, did you know that there was something off but I so it kind of frustrated me that like the most important hormones which were like the thyroid and the Andrew or the testosterone, they marked as normal, but I looked at the actual numbers and it was really close to being not normal. So I feel like they should investigate data that a little further especially given the I told them my other symptoms of like no period, but because like numerically

It like just hit under like the, the normal range, they just kind of like know you're normal. So that kind of frustrated me. So then, like, in the back of my mind, I knew like it's probably not hormones because it was so close. But because like it was still in the normal range, I just like let it go. And then when they officially like, diagnosed me, I felt relieved because I like, in the back of my mind I always knew like, I kind of always knew because I like googled my symptoms or whatever. So it was like a relief but also kind of just like, kind of suck that it was true. But it was like I liked that they did the ultrasound because that's a good clear. Like they could see what's going on rather than like testing based on hormones, really physical symptoms.

How much and in what ways does having PCs, the tremor affect your day to day lifestyle?

Not that much not at all actually. Like before I knew it officially what I had, like, I was just normal. I just never got my period. If anything, like it kind of made things better physically, but also give me a lot of anxiety because I felt like I was not normal. And then whenever like people will talk about their period, I would just be like, Yeah, for sure.

And then what about after your diagnosis?

I feel like after getting the, like official diagnosis, it was actually good because then it gave me like a concrete reason to be healthy, like a concrete motivation to not do stuff that was bad for me. And like to actively do stuff that was good for me, so like, like now I work out because I want to be healthy because of that. Or like, I try to eat healthier because I know that it's better for my PCOS.

Are there any other ways that you take care for him? So you’ve mentioned physical exercise and then healthier diet.

Yeah, um, well, I smoke cigarettes. And I'm trying to quit. So that's like one of the biggest things I've tried to do. Quit smoking. Yeah. And also, because of like, the mental effects of it, I think I'm more cognizant of like, when I'm feeling down, it like makes me feel better that when I'm feeling down, or when I'm feeling anxious, there's like a physical factor to it. Like, it's not just feeling sad. It's like, you know, it's like, these chemicals are making me feel this way. So it kind of makes me feel better that eventually, like, it's not kind of like it kind of takes the blame away from me kind of that makes sense. Yeah.

How public or private are usually about sharing these details about your health and lifestyle.

Honestly, before I was really private about it, because I was ashamed kind of, like, I didn't want to talk about any given period, because it's weird and embarrassing, and it kind of makes me feel like, I wasn't like a legit girl basically, or like a woman. But now I feel like because of how I felt before, like, so in the dark, and then shame. I feel like now I want to talk about it more because like, it should be talked about, especially for people who were like me who I didn't know anything that was going on, and I felt so much anxiety because of it. Like I feel like if I knew people who had it, and it was a normal thing, and it's pretty common, and it's like, not the end of your life, I would have felt a lot less anxiety because of it.

Diving into a little bit more about your PCOS background, do you often look up information about PCOS? And how often?

I probably look like now in my day to day I probably look up stuff about it around like my period of time just because at that time I'm more curious about what my body's doing. I looked I like looked up a lot of stuff when I first got diagnosed and I looked up a lot of like a lot of stuff before I got diagnosed just because like I was kind of obsessing over it and like trying to learn more about it, but now I know now that I know I have it. I'm kind of more chilled out.

How did you hear about the syndrome? What caused you to raise suspicions that you had it?

Well, I didn't ever get my period except for once a year. And I'm gonna listen to this because I know I feel like a lot of people have never heard of PCOS before. Yeah, I just googled like “no period” and then it took me to that.

Do you have regular periods cycles now?

It's so interesting because up until the point that I got diagnosed, I never ever, ever got my period. Right. But after that diagnosed, something happened and I've been getting it every month. I don't know if that helps you. So you would look up information like once a month, maybe. Now I look up information if I sense something different if I feel like something's wrong, something's like not normal. Not you like the usual. So like this month. It was longer cycle than normal.

Do you ever look at lifestyle tips or forums online?

There’s certainly communities. Yeah. So after I noticed, I like looked up because they recommended me to take birth control, but I didn't want to take birth control because it's just it just alleviates the symptoms it doesn't like actually do anything to help the syndrome. So I looked up a lot of resources online of how you can like change or alleviate your symptoms through lifestyle changes rather than birth control. I also didn't want to take birth control because I read that like it messes with your hormones in different ways and like makes you depressed and whatever. So yeah, I read a lot of blogs online of people who had in my

The lifestyle that they had to leave because of it wouldn't they eat because of it. And I read a lot of like Reddit forums to read like people who got diagnosed and like stuff like that. I also read a lot of forums about like, fertility and PCOS because I want to guess later in life and that's like my biggest concern. It was just nice to read other people's experiences. Like just to feel less alone in it. Read other people like me, the other people are feeling this too and are living normal lives. And also just like reading everyday, like real life tips of like, yeah, I work out every day, like I lost 10 pounds and my symptoms got way better or whatever.

What were some of the activities that you started implementing in your own life after reading these.

I try to work out I try to not eat like a lot of salt. I try I still do. I'm just trying to like overall take care of myself better. I've started going to therapy, drinking a lot of water.

Do you actively engage in these discussion boards?

I've never posted anything I just read it

Do you ever look up any like Facebook groups or did you ever join an organization or anything that?

I liked Reddit and blog posts because they were already there. And like very easy to access. And I could kind of just like scroll through and read without having to like, sign up for anything or, like take any action on my part. I feel like doing like joining a Facebook group for me is a little too personal because I'm more of like an observer type. And also, like, I just don't really join groups like that.

Do you prefer these, like, posts from actual individuals more? Or do you like the news article 30% more scientific information on both?

I think it depends on what I'm looking for. I like the news articles for like information. And I like to compare different news articles to get the most accurate information or like the most information possible. But then I also because I know that like facts and news articles are just like the average or like the predicted fact. I like reading on forums to see what people personally experienced. Because like anyone who has PCOS knows that like you don't experience what is expected because obviously you have this condition that makes you not experience what is normal. So then it's nice to read the facts and then to eat people's actual experiences so I like both for different reasons

So when you doing your research do you feel like the information that you find fulfills your needs and concerns?

No because I feel that you can read other people's experiences all day long. You can read all articles all day long. But at the end of the day for something like this, like, it's such a personal experience that I'm never going to read something that satisfies me, like my story exactly. But it does satisfy like, my loneliness in it. Like I feel less alone. And I feel more informed about it. Because, like on like, online provides more information than my doctor did. Huh. So that was that. Actually, yeah, that's a big factor. Because when my doctor like, I feel like because I knew of like a lot of information beforehand. I felt okay about it. But like what my doctor actually told me she didn't really explain anything to me. Like I found out most of the information through Google going through searching online.

So what do you wish was different about your experience meeting with a doctor and receiving your diagnosis?

I wish she told me talk to me more about it and like because when she diagnosed me, she was just like, oh, you just got on birth control, but I feel like she didn't really explain what it was or why it happens or what it can do in the future or like, anything like that, or like how I can treat it naturally. Or, you know, like, she didn't really do any of that. She's kind of said that like, what it is, is that you have cysts on your ovaries and like hormonal imbalance and you fix it by taking birth control, which I feel like this is not the doesn't paint the whole picture. So I wish like I feel like there's something like this, which is like really common balsam really misunderstood. We should have specialized doctors for it.

So when you're looking at information online, what makes you trust that information? Like how do you how do you know like that information is like what you're looking for.

So if I'm like, if I'm reading an article, I like to check the source so Web MD is good. Or like one of the one of the ones I always read that that I know of already, like the brand or like the website name. And then if I'm reading another article that is like from a lesser known website, but they're stating facts that I know are true already that I'll like half trust that website because I know that some of the factors they are true so there are other ones could be true as well. Or if it just makes sense my head

What do you think is the most useful source of information?

I like Web MD. But honestly, the forums are really useful because people go in detail about like their diagnosis and what their doctor tells them. And through those like posts, you can kind of get little facts that you wouldn't get on like just one article. You can like accumulate a lot of different facts that a lot of different doctors told their patients

So you mentioned that food and physical exercise, and therapy were some of the things that you do to take care of yourself? Can we talk a little bit more about each of those. So you might also talk about how you started doing all of this after or after your diagnosis.

For me it was just kind of an ongoing thing but after I was diagnosed, it gave me more motivation..I feel more compelled to do it now. Because I have my risk. I spend like three times a week exercising and then cooking and stuff like three hours a week.

And are you satisfied with outcomes?

I don't know. I feel like it's one of those things where it's like, you don't really see the short term effects. Yeah. I mean, even if I didn't have PCOS eating healthy and exercising is good.

For your exercise and cooking, do you find inspiration from other people or do you just follow like a general recipe?

I get inspiration from other young people who are trying to be healthy

What kind of recipes were you looking for?

Something that's tasty but also healthy. Somewhere in the middle. I don't like to be too healthy because then I just go crazy. Like it's on sustainable.

Is there a common like form or like a source where you find your recipes

I like all recipe, Food Network. A lot of times I just go on Google Images and look at the plate and decipher the recipe on my own. I like YouTube. I like following recipes of people that I follow already.

And do those people have PCOS? Or no?

No, but this girl that I love went through the whole weight loss journey, but the way she cooks is like healthy, but also tastes really good. So I like that.

So you like learning about what other people are doing?

Yeah, I like learning hacks for so like, for example, so the tuning sour cream with Greek yogurt, I think is a really good hack, because it still tastes really good, but it's a while here.

And those are kind of the kind of information you find from other people.

Yeah, because it's like stuff I wouldn't think of

Do you encouter any problems when you're looking for new recipes

Yeah, it's hard to find good recipes because I think it's hard with food because you never know how something's going to taste. But it's also hard because there are so many recipes online and a lot of them are kind of similar. So that that's hard to like sift through and like, find the ones that I like for my personal taste. I like not a lot of meat. So if I had protein as my main course I would hate it because I don't really like meat that much. But then also like eating a lot of carbs really bad for you. So then like finding that sweet spot of like carb plus vegetable plus a little bit of meat is ideal.

What about your workouts?

I like workouts online. Yeah. Actually, for me, my workouts are pretty important. I just like to go jog, but if I'm like if I want to do more like strength training or like building on muscles, I like to look up workouts on YouTube.

Are they more going to the gym or follow along work out videos at home?

Usually they're like workout videos without any equipment that can just do in my room or at home, or like in a studio without any, like extra stuff. But actually, I looked up water exercises because it's better for your knees. So then I looked at it. I looked up YouTube tutorials for those two.

Is there anything you're looking for specifically when you're looking at workouts like is your main goal to find exercise? Is it just like doing your room without any additional equipment?

Yeah, my main goal is to find exercises I can do without any additional equipment, and also cardio exercises for us.

How well do you think you're accomplishing your fitness and healthy eating goals?

Not great. But getting better.

What do you think can help you achieve your goals better?

I think therapy is really helping me because it's really all a mental thing. I noticed that I eat really badly when I'm depressed, and I don't exercise on are depressed. So I feel like going to therapy and working through like why I turn to those things when I'm feeling down and realizing they're kind of just like a void, makes me more compelled to act against it or act against those impulses. Filling the void would help you act against those impulses. But realizing that I'm fit, like, realizing that I'm eating more because I'm depressed or like realizing that I don't want to exercise because I'm depressed. Like having that realization in my head makes me want to go workout even though I don't want to. Because, like mentally I know I'm going to feel better. If I exercise I know I'm going to feel better if I eat better. It doesn't work all the time, obviously, because like it's always a battle. But I feel like just having that awareness helps you break out of it.

What are some of the problems that you face when you're treating your PCOS?

So it's a mental block, right? Yeah. So like to make your PCs better, you have to have a healthier lifestyle, but at the same time, because I have PCOS like I go through depression and anxiety, they don’t help each other.

What are the some of the difficulties in terms of finding the resources for people at peace

There isn't a lot of conclusive evidence online important studies for PCOS as it's like still relatively a mystery to doctors. So when I'm looking for information online, I usually have to like piece together the puzzle and like figure things out from multiple different sources rather than having one comprehensive source, which is kind of frustrating because it feels like I'm like grasping for straws. And also just like the personal nature of it, like I can never find something that truly satisfies like me. I don’t know answers to specific question unless I go to my doctor.

If there was like a PCOS specialist that you could meet with and talk about your experience with, like symptoms, would that be something you're interested in?

Yeah

Are you aware of any resources that you think that's a valuable resource? Do you think it should be more accessible and available to people?

Yeah, especially since it's so common, and I read that a lot of people have PCOS but they don't even know it. And a lot of people don't still understand it. So I think it should be like funded more.

What else do you think should be done to raise more awareness piece?

Maybe there should be like a special birth control aid for people with these guys. For people who are taking it to treat their symptoms rather than like, you know, like a special one made for PCOS. It is so overwhelming to choose. Yeah, there's like too many options. I wish there was this one that was explained specifically for my syndrome rather than going to the other one and having different side effects.

What are some of the biggest takeaways that you learned since your diagnosis?

I've learned it's a lot more common than I thought. Because after I was diagnosed I realized that the people in my life had it. Another big thing was that you have risk of getting diabetes, heart disease and infertility. Another one was that you take birth control to Elise symptoms, but it's not curable.

Actually, the biggest thing that I learned was that it's diagnosis is very broad. You only have to have 2 of the symptoms for them to diagnose it. So like the four symptoms are cysts on your ovaries, missing period, like androgyny. And then there's a fourth one I don't remember. So it's interesting resistance. Yeah. So that I think it's like interesting how like diagnosis is so broad. So then, like, all these different people have very different symptoms, but they are diagnosed with the same thing.

Well, you mentioned that like there's no cure for PCOS. There's no definite scientific evidence for that. So what has been the most effective way to cope with religion?

Definitely making myself feel better about it. I like reading about how people with PCOS are still able to live normal lives. It really helps. Especially like, because my biggest concern is like having kids. And I've read a lot of stories of people still being able to get pregnant. So that makes me feel a lot better.

And then just wrapping up this whole session with a fun little question. But if you could create a service or a tool to target any aspect of your experience with PCOS, what would it be? How would it work and what areas would cover?

Yeah, I guess like PCOS would be really cool.