HHP258 Endometriosis with Phee: Decisions When Science Has Gaps

11/15/2026

Contents

Proem

No Periods, No Pain, No Problem?

A Decade to a Diagnosis

Proem

I met Oceane Pittet at the 2026 Camden Coalition's National Center for Complex Health and Social Needs conference, Putting Care at the Center. She spoke about her endometriosis research. I texted Phee; should I invite her to be a guest? Of course! My interest was piqued on several levels. A researcher with lived experience, an early-career researcher, a person from another country, and the Photo Voice methodology for listening to research participants. Let's jump right in.

No Periods, No Pain, No Problem?

Health Hats: When did you first realize health was fragile?

Oceane Pittet: I have endometriosis. I think I realized quite early that it I had something that was wrong with my hea- with my health. And so I had very painful periods from a young age, and basically from the time I first started menstruating.

And I remember talking with my friends about it and realizing that they weren't experiencing the same thing. And yeah, when you're in so much pain that you are basically vomiting and, so you realize that this, that isn't hap- happening to the other people around you. You start to understand that maybe this isn't normal.

And so back in the days, I spoke with my mother about it, and yeah, she took it seriously. And I made an appointment with a gynecologist and, but at t- that point, endometriosis was never mentioned, and I was simply prescribed the contraceptive pill basically to stop my periods, and that was es- essentially it.

No periods, then no pain, and kind of problem solved. Or at least the problem was hidden. And it was only much later when I was, I think, around 18 years old that I first really heard about endometriosis, and I started reading about endometriosis looking at the symptoms. And I remember thinking like, "I tick every box."

And I think that was really a turning point for me. And so after that, I started researching specialized endometriosis centers. And so I went to one of these centers to see a speci- specialist in endometriosis. And even before thinking about treatment, simply having an explanation for what I ha- I had been experiencing and for all these years made a hu- a huge difference, and it helped me understand my own body.

And yeah, also realized that the pain I experienced from such a young age wasn't something I was ex- Simply supposed to accept as part of being a woman.

Health Hats: Wow. Thank you.

Phee Marcial: Thank you for sharing.

A Decade to a Diagnosis

Health Hats: Phee, do you wanna introduce yourself?

Phee Marcial: Yeah. It's great to meet you, Oceane. I'm Phee. I am a artist and illustrator. I met Danny through my mother who's in the, the health informatics space. He's like an uncle to me. I've heard him a lot on calls throughout yeah, my, my childhood and heard about him through my mom. But we came together for this project about endometriosis because I was officially diagnosed last year after a decade of trying to figure out what was going on with me. Almost beat for beat how it was for you getting put on birth control, like at, I think, 13. Yeah. And just, the, the lack of information that was available to, to me and my family made it really difficult to- Even start talking about endometriosis, let alone get a diagnosis and get the kind of treatment that I needed.

Grappling with Gaps

Health Hats: Do you wanna talk a little bit about your research?

Oceane Pittet: I have a background in psychology I worked a few years on a project to promote patient and public involvement in research and health projects. And last year I started a PhD on this project, so on the theme of endometriosis. More specifically this research it aims to develop and evaluate a care team interface, for health professionals and a patient decision aid to help patients, so compare different option for managing endometriosis symptoms and make informed but also value-based decisions together with their healthcare providers.

The goal is not to replace the healthcare provider. And we want to take into account both the medical and also the non-medical approaches, as well as fertility preferences, and goals. So maybe I can say a few more words on what is the patient decision aid.

Health Hats: Yeah.

Oceane Pittet: The patient decision aids, they are every evidence-based tools. And they are designed to help patient make specific and deliberate choices from among healthcare options. And as I said earlier, they are intended to supplement rather to replace clinicians counseling about options. They differ from usual health education materials because they state the dec-the decision to be made they provide detailed, specific, and personalized information on available option and their outcomes to support decision-makings.

Because endometriosis there is no cure and there are a lot of different treatments, but there is not a gold stand- gold standard treatment. That's why we thought it was important to have evidence-based information and a patient decision aid to help women with endometriosis make informed choices.

Prevalence and Burden

Health Hats: We can't say that there's a ton of research out there about endometriosis. When you say evidence-based, it must be challenging because if you're going for the evidence and much of it isn't there how do you... what do you do with a decision aid when the science has gaps

Oceane Pittet: Yeah, that's a good question. So indeed at the research level, endometriosis as a whole remains really significantly under-researched especially relative to its prevalence and the burden it places on patients.

Health Hats: Yeah so prevalence and burden.

Oceane Pittet: We estimate 10% of women of reproductive age will have endometriosis, so that's huge. Huge. That's really huge. And also the, the impact on quality of life is also really huge. And so also it's a chronic disease, so you can have that your whole life, even after menopause.

We have more and more research on that because not long ago we thought that you could only have endometriosis from when you start your periods until menopause. But it's not totally real. And and also, as I said earlier, there is no cure and no gold standard treatment, so you have to find what works for you and also to find a treatment that that fits with your goals if it's to reduce pain, if it's to have a child. It really depends on what your goals are, and also it's really preference sensitive. If you do not want to take hormones, if you do not want to do a surgery. So it's really important to so to, to hear the patient and to hear what she wants to do. But yeah, the, the problem is that indeed, it's really under research.

So as of today, we have some guidelines, Still, we lack some information and some research. But the goal will be to take everything we have so far and to put everything in the patient decision aid. What I didn't say earlier is that it will be a chatbot and it will be a, a RAG chatbot, retrieval-augmented generation, I think is the acronym. And so we will basically feed the chatbot with information And then the chatbot will give this information back to the patient in a more understandable way. And the advantage is also that the chatbot can for example, speak in the language of the patient. It's always available, and the patient can say, "Oh, I don't know, I don't want to take the hormonal pill," or, "I'm afraid of these side effects," et cetera. And the chatbot can help the patient understand what kind of treatment could be the best option for her.

So it's difficult to find money to do research on endometriosis today, at least in Switzerland, and I think that in the United States it's maybe not a, a perfect time for this kind of research, I imagine. It's always astonished me that a lot of research are on the experience of the partner- Even though we still lack a lot of research on the patient, but there are a lot of research on yeah, how the partners experience the fact that their wife has endometriosis and has difficulties having sex or things like that.

It's crazy. And also regarding fertility. But more and more research focus also on the quality of life, on the pain of the patients, and it's encouraging. And also for example, in Switzerland, we have very strong association for endometriosis, and they really try to push also the government to do something about this disease. Because as we said earlier, it's it's crazy how prevalent it is. 10% of women, it's huge.

The Stars Aligned: Getting Funded

Health Hats: So maybe we should say here that you live in Switzerland. That might be- ... an important fact for people to know. So okay, so when you think about research, first there's a supportive place to do research. You had two presentations at panels, and there was somebody there who was clearly rooting for you. And I got the sense that this might be somebody that you were working with. How did you find a place to do this research that was supportive?

Oceane Pittet: Yeah, absolutely. I was already working with this person on this project to to improve the involvement of patients in research. Her name is Marianne Durand. She's a professor at u- the University of Lausanne in Switzerland, and also at Dartmouth College. She is really interested in all of the participatory methods and also in women's health. She's a very nice person too.

Health Hats: So- That really helps, doesn't it? To work with,

Oceane Pittet: absolutely. And that's why I decided to try to find funding for this project with her, because I knew that she will be supportive and I knew that it will be a subject that she will be interested in. And so we we submitted some proposals to different grants in Switzerland, and we had the chance to get the biggest one, so it's from the Swiss National Fund. , I was a bit astonished because we had this grant at the first try, and it's really not easy to have a funding from them. But it's also because all of the endometriosis association were pushing to have a project studying endometriosis. Because for the last few years, no project were funded regarding endometriosis, so it was quite crazy. And so I think it was also a bit easier for us to get this grant, to be honest. So we had some- ... yeah, some luck regarding this. Yeah,

Health Hats: yeah. The stars were in alignment.

Oceane Pittet: Absolutely.

Not Wanting Kids Got Me Care

Phee Marcial: Yeah, that's great. It's always wonderful to hear stories of research getting funded right now. I think everybody's in a place of just hoping as much as possible hoping for some luck. I know that at least, more anecdotally from my patient experience the research that my my gynecologists are doing themselves, like in addition to surgeries and patient care. It's hard to imagine how they have the time for it and where the money comes from. The gynecologist that did my surgery recently did a presentation at a conference that was about what you were saying about seeing the endometrial scar tissue after menopause and what her treatment plan has been that she's developed for these patients. And I thought it was really interesting that the, motivation there is primarily about pain and quality of life because a woman cannot have children after menopause.

And so there is obviously a complicated relationship between, for the individual, but yes, of course, across the board in research and in politics between trying to improve fertility and trying to improve women's quality of life.

I, myself am not interested in having children, and so that played a major part in my ability to get the kind of care that I needed. It's different for everybody, but I think if I had been struggling to get pregnant, for example, I maybe would have seen somebody sooner who had a better idea of what I had going on.

And instead, since I was dealing with a constellation of symptoms that were not specifically hallmarks of endometriosis, I was experiencing those, but I was also experiencing really severe GI problems and issues with mood. And so I was seeing psychiatrists and gastrointestinal doctors, right?

And those people did not know how to point me in the right direction. I don't think necessarily out of pure maliciousness or something , but they did not have the knowledge to get me going in the right way. That definitely is an interesting change that I've noticed in research and in, in treatment that there is at least among female doctors, all of my doctors are female, that they are interested in pain and in really trying to improve the long-term quality of life of an individual rather than specifically try to orient around fertility.

I think that change has in the past few years really made it possible for me and a bunch of other people to get care. I don't know that I would be where I am without that change.

Phee Marcial: And I imagine it also probably has to do somewhat with trying to suss out what the, difference is between I wish I had better technical terms for these. I'm sure you could help me with this, but like hidden prevalence versus increasing prevalence. Whether people are under-reporting endometriosis or whether there are more people who have it than before. And that's a very difficult thing to understand if we don't have those numbers from prior years, right?

Hidden or Increasing?

Oceane Pittet: We still don't really know why we have endometriosis, and so it's multifactorial. So genetics, but also the environment can have some impacts. Imagine if today it's 10% and in 50 years it's 20%. Why does this happen? Was endometriosis already a very prevalent disease 100 years ago? Is it the PFAS? Is it the, the, the thing we have in our environments that have an impact on this disease? So personally, this will be an interesting information to understand further why this disease exists,

Health Hats: I get it.

A Community Born of Crisis

Phee Marcial: I can say at least for the, the individuals that I've spoken with and, whether they're patients or clinicians I think spreading the word is not enough. Being able to treat patients is the end goal it's what I've found in this community, and it is really wonderful.

It is a type of community that arises from crisis situations, right? So it is a complicated dynamic, but I've never met clinicians who are willing to try like crazy shit to- ... get their patients the kind of care that they need. That, is a double-edged sword because you can- be trying crazy stuff that doesn't work, right? Yeah ... and at the same time, there are a lot of people in this community who need that kind of, like I was saying- ... creativity and who are really desperate to learn more about their condition so that they can- ... do more about it.

Health Hats: Yeah.

Phee Marcial: So I think it's really cool that the project that you're working on, Oceane, is about patient advocacy from the direction of education the idea is to empower the patient to have the agency to make their own decisions or at least to, make decisions together with a clinician rather than feel like they are at the hands of a system that doesn't know what to do with them.

Wearing Both Hats

Health Hats: Oceane, you're a researcher and a person with lived experience, and I imagine that it both helps you and creates challenges for you. And so can you speak about that dynamic of either merging those hats you wear or distinguishing between them from moment to moment?

Oceane Pittet: Yeah I think that studying endometriosis has definitely changed my relationship with the disease. So in some ways it has given me a greater sense of control over it, and the more I understand the disease, the less mysterious it feels. And I think that knowledge can be very empowering as you said earlier, Phee also especially when you're living with a chronic condition but also at the same time, the more I studied, the more I realized how much we still don't know about this disease, and how little has historically bes- been invested in endometriosis research compared with the number of people affected by it, and that can be quite discouraging.

But as a researcher, I also find it incredibly motivating, and it makes me feel that there is so much work worth doing and so many questions that still needs answered. Meeting and speaking with so many people with endometriosis through my research has also, I would say, changed my perspective. It has made me reali- realize just how many of us there are, and there are experiences that feel incredibly familiar, moments where I hear someone describing something, and I just think, "I know exactly what you mean." But at the same time, every person's experience of the disease is different, and their symptoms, their journey, or their diagnosis, their priorities and the impact endometriosis has on their life can vary enormously.

Navigating that as both a researcher and someone with endometriosis can sometimes be difficult. Example, there are moments during interviews when I relate very strongly to what someone is telling me, and it can be quite emotional. And you have to remain a researcher, but you're also a person sitting across from someone whose experience may really resonate deeply with your own experience.

Health Hats: Yeah.

Wow.

Oceane Pittet: That has given me a s- very strong sense of responsibility. Because these women, they are trusting me with very personal parts of their lives and their stories, and I feel a responsibility to do justice to what they share with me. In a way, I also feel indebted to them, and it makes me want to make sure that the research we produce genuinely contributes something meaningful.

A Camera in Their Hands

Health Hats: Wow. I have to think about that. I'm really interested in the, the state of methodology for research. Endometriosis produces many methodology challenges because we don't necessarily have the methodology that is really good at the, the incredible variation.

Oceane Pittet: Because endometriosis really is highly heterogeneous and You can have very different symptoms. You can have pelvic pain, dysmenorrhea, dyspareunia fatigue, infertility. 95% of women with endometriosis, they have one or more comorbid disorder. It's crazy. So they have endometriosis, but most of them also have another condition. It is also a goal to have women with different kinds of symptoms and different kind of experiences, and that's what's interest us- Yeah ... to have this different kind of experience. And so we use participatory method because it really it gives the opportunity to participants to speak about their experience to say what is important to them.

So that's why we used this photovoice method. Maybe I can say a bit more about this method

Health Hats: sure. Please.

Oceane Pittet: Okay. Maybe one thing that is important, because Phee you spoke about the fact that we do art, and I think it's important to clarify it that we didn't initially choose art simply as an alternative way of communicating scientific findings.

Art, or more s- more specifically for PhotoVoice photography was actually part of the research method itself. Essentially you put a camera in the hands of participants. And so we invited women with endometriosis to take a photograph representing aspect of their experience, and then to provide commentary on those images. And then this photograph, they become starting points for discussion and reflection. And then this discussion they become part of the data we analyze for our study.

Health Hats: Wow, that's cool.

Staying the Researcher

Phee Marcial: Yeah, I was also going to say that's, I imagine, a really good way to start a conversation about something that is extremely personal. I'm sure that's probably one of the major reasons that you wanted to do it, because it's very hard to start a conversation about endometriosis with somebody. Even, when I've had individual conversations with somebody, one-on-one where I'm speaking to somebody who I know has the condition, and she knows I have the condition, and we're, like, on the same page, it takes a little while to start talking about it more seriously, because it's still very stigmatized. In a lot of cases, I've spoken to somebody who's told me that she's never told anybody else before what I'm hearing. I imagine in interviews, when you're acting as a researcher, to have somebody say that to you is very impactful. I see that you have a very strong sense of responsibility, Is it, was it too much? Did it get to be, like, really overwhelming at times? It would be overwhelming for me.

Oceane Pittet: Yeah. I totally agree with you, and that's what's very powerful about photo voice- it can really express experiences that are very difficult to put into words. For example- Yeah ... pain is very difficult. Yeah it was not easy to do that. We did focus groups, ... with the patients. So I was always with a patient partner- ... and also with my supervisor. So if I needed help, I they were there to help me. Sometimes it was not easy, especially when I really related with someone's experience. I wanted to answer and not as a researcher. I wanted to answer- Yeah ... as a woman with endometriosis and say- ... "Oh, yeah, I totally feel you," or, "Yeah, I had the same experience," but you cannot. And it was a bit frustrating, to be honest. But I was teached to do that. How to manage a focus group, how to ask questions, and how you're supposed to act, as a moderator in a focus group. It isn't easy for everyone, even my supervisor, she was a bit shocked because she didn't know much about this disease. And she wasn't aware of how- impactful it was on this woman's life. And when she heard their stories, she was shocked, a, a bit emotional because she was like I didn't know it was that bad."

We have to be also conscious as a researcher on the fact that we are human, that we have also, especially in qualitative research, emotions and that we can be impacted by some things by some stories. We have to take this into account when we, also when we then interpret the, the data and when we write the articles. It's really important to have this self-reflection. Yeah.

The Lake and the Chaos

Phee Marcial: Yeah. I'm so curious about what kinds of photographs you were seeing. Yeah, and if there were common threads.

Oceane Pittet: So we had very different kind of photos, and some were very similar, so it was really interesting to see. But I have some extract because we have the photos and then each woman they read a s- a small text to explain why they took each photo. So maybe I can read you an extract from two photos that really had an impact on me.

Phee Marcial: Yeah.

Oceane Pittet: So for the first photo, so if I can describe a bit the photo, so it was a photo of a woman with a buoy, an inflatable buoy. She was facing a lake. And so the text, it's only an extract. It's a bit longer- So the text says, "Like a lake, endometriosis is invisible, mysterious, opaque, murky, and sometimes distressing. Sometimes it even repels me. Standing before the surface of Lake Geneva, I am confronted with everything I cannot see, with everything that lacks clarity. I need a buoy to keep me from sinking. That buoy is made up of my family, my friends, my lovely flatmates, my job and my colleagues, my psychiatrist, my contraceptive pill, my anti-inflammatory diets, the possibility of giving birth. Everything that allows me to feel a certain degree of control over my body, a control that rarely allows me to let go."

Health Hats: Wow.

Oceane Pittet: And then there, there was an- another photo with this buoy, but all shrinked in a kind of in a ball. And the title of this second photo was Chaos. "The feeling of being broken inside, feeling as though I'm poorly made. The flare-ups returned with the return of my period. After a year and a half on pill, I wanted to get my cycle back do- without the tablets, function without artificial aids. And then there it was. In the middle of the night, on the eve of a special and important day at work, when I felt I was indis- indispensable, the endometriosis reared its head. The pain was sharp and sudden. She holds me still. I'm crying on all fours on my bed. My stomach was knotted with anger. My hope was dashed."

So yeah, every time I read this text- ... I find it's incredibly moving. And what strikes me is how clearly it shows the enormous impact endometriosis can have on someone's life beyond the symptoms of pain itself. And yeah, in the first text you can see all the things this woman has put in place to keep herself afloat, and there is this whole ecosystem of support and strategies that allows her to maintain some sense of control and live something close to a normal life.

And then, chaos shows how fragile th- that balance can be. And despite everything she has put in place, the disease can suddenly reappear and take that control away from her and there's the physical pain, of course, but also the anger, the disappointment, the feeling of being also betrayed by your own body. And I think that's something some scientific paper can describe, but perhaps not make you feel in quite the same way as this text and these photos. Because in scientific papers we can measure, measure like pain score, quality of life, work impairment, treatment use. But of course, these mea- measurements are important, but this piece, it shows the invisible work behind those numbers and how much effort can go into simply keeping your life together and how quickly endometriosis can disrupt it.

And for me, that's really the power of these photograph and testimonies. They really allows, allow us to really understand from, yeah, what these women experience in their daily lives in a very deep way

Not About Me

Health Hats: Wow. What's the bottom line here that you want people to take away from this experience that you're having as a person with lived experience and a researcher?

Oceane Pittet: It's not really my experience. I think my experience counts, yeah, but I really want to show what women experience, like other women, and all of the different experience we can have and how much this disease can impact their life. And I really want to provide a window into what happens within this experience. So I think it's interesting to also have the disease, but I think I'm not that important. I- It's more the, the work that I do that is important for the women with this disease and to really, show other people, not only the scientific, but also policymaker, the clinicians, the all of the different key persons what is really this disease and the fact that we should do more because we aren't doing enough, I think.

Health Hats: Thank you.

Phee Marcial: Thank you so much ...

Reflection