| TPWKY |  | This is Exactly Right. |
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| Susie |  | Hi, my name is Susie. From a pretty young age I taught myself not to pay a lot of attention to my body. When I was younger I didn't really have any issues but after puberty I started to have pretty bad cramps. I had to go to the bathroom fairly often and I also found out that I was anemic and I would occasionally, if I was exercising too hard, start to black out. Nobody really had a good explanation for this and nobody really directed me to a doctor or anything. So I just ignored it and moved forward. Lots of other people in my high school had period cramps, plenty of people are going on birth control to try to control the cramps. And, you know, it was easy enough for me to get past it was a little bit of ibuprofen. |
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|  |  | I was also raised very religious and I'm still quite religious and unfortunately some American purity culture crept into my upbringing. And so I didn't spend a lot of time thinking about for, lack of a better word, my reproductive parts. I spent a lot of time ignoring them, spent a lot of time pretending nothing was really going on and generally being embarrassed about it. So I got good at disassociating from those parts of my body. |
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|  |  | After I got married I ended up having extremely painful sex and I assumed that it was related to purity culture and I assumed it was psychological. I talked to my PCP about it. I think I got a referral to pelvic floor therapy at one point but nobody was really concerned. And again I just decided that it wasn't a very big deal, it was just something that was in my head and I was able to move past it. In our first year of marriage, I got pregnant unexpectedly and had no problems with the pregnancy except that I was very nauseous through the entire thing. I was in a lot of pain and then when I had to have cervical checks I was in tremendous amount of pain. Again I told them that I thought this was due to growing up with a certain amount of purity culture and that it was psychological and nobody questioned it. |
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|  |  | So after I had my daughter eventually my period returned and I started having worse and worse cramps. But everybody tells you that after you have a baby your periods get worse. That's just what people tell you. And so once again I chose to disassociate from it and ignore it. Some of the painful sex symptoms subsided, others remained but mostly I was just proceeding with business as usual. Last year I started having cramps so bad that I would have bladder spasms which means that I would literally pee my pants with no control. It only happened a few times, thank goodness, but I also ended up starting to have to lie down when I had my cramps. And I was surprised that it wasn't great but I could generally manage it with like three to four ibuprofen and a heat pack. |
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|  |  | But by the fall things had escalated and the ibuprofen wasn't cutting it and the heat pack wasn't cutting it. But the killer was when I noticed that there was blood in my stool. I didn't really want to do anything about it but by January my sister told me that I had to do something about it. So I went into urgent care. They took some samples and told me that I needed a colonoscopy and that I should not have any ibuprofen until after I had the colonoscopy. Then on my 35th birthday, I spent the entire day in agony and the worst pain I've ever had because I was experiencing my cramps without any sort of pain blocker. I went in for a colonoscopy at the beginning of March and I didn't expect them to find much of anything because again I didn't really believe that I had any problems. And I thought to myself the only problem that I could really have is cancer because cancer runs rampant in my family, both my father and my brother died of fairly rare cancers. My father of uveal melanoma and my brother of cholangiocarcinoma. |
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|  |  | So I was a little anxious about the colonoscopy but not overly so. When I woke up from the colonoscopy the doctor went to get my husband and took me to his office and sat me down and told me that he had found something and it was very likely to be cancer. So this was incredibly traumatic for me because I was immediately convinced I was going to die. I also delivered the news to my family and told basically everyone I know because I decided that if I did indeed have cancer, I wanted everybody to start praying as quickly as possible. And I maintain that it worked because a week later the same doctor called me back and told me that the cell samples, to his great shock, had come back not as cancer but as endometriosis. I literally fell to my knees on the ground. I changed doctors. So I went in for a second opinion. I had not another colonoscopy but a flexible sigmoidoscopy. And the doctor told me he thought that I had endometriosis and maybe cancer. And I was referred to the gynecological oncology department. |
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|  |  | I went in and met with one of the directors of the gyn-onc department who told me that she thought yes there's a possibility of cancer but mostly it was horrible endometriosis. So she showed me the images that they had taken of my body in the MRI and everything. And we could see that there was something growing out of my left ovary into my colon. And we knew that it was probably in other places but there is no way to confirm endometriosis except by surgery so they could not confirm. And they thought there was a possibility that there was still cancer. So the other thing that the gyn-onc told me was that she thought I was going to have to have a complete hysterectomy and oophorectomy. I had been trying for a second child at this point for almost a year and this was devastating but because there was a chance of cancer, I was like, just take it all, I don't want it, get rid of it. |
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|  |  | So I had a period farewell party with my friends over Zoom, we drank cranberry juice, we toasted, I wrote a letter to Aunt Flo sending her out into the world and my surgery was scheduled for May 4th. My last period was one of the worst pains I've ever had in my life. The ibuprofen didn't ease it. The heat didn't ease it. I was just lying in bed for two days and was more or less silent screaming. It was horrific. I had surgery. They confirmed stage four endometriosis. I discussed with my surgeon that I wanted to try to keep my right ovary if possible because I didn't want to go into surgical menopause at 35. There are a lot of issues associated with going into menopause early and I wanted to avoid them if I could. Also I have struggled with my mental health, I have depression, anxiety, and I knew that the severe hormonal shift would be very difficult. |
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|  |  | Although there was less than a 5% chance that they could save my ovary, the surgeon was able to do it. There is still an insignificant amount of endometriosis on my right ovary, it's less than one centimeter. But they were able to remove 14.5 centimeters of colon which is about the size of a Sharpie, a 6 centimeter rectovaginal septum tumor which is about the size of an egg, and a 7 centimeter left ovarian tumor which is about the size of a peach, and the left ovary. I woke up to the very happy news that I still had an ovary which I did not expect. And about a week later I got the even happier news that there wasn't cancer. It was just endometriosis. So after the surgery, it took me about three months to feel normal again. The biggest shift since the surgery is that I've had to re-learn my body. I have to relearn what feels good and bad, what's painful and what's not because I just disassociated from it so much that I had no idea that I was in pain. |
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|  |  | The emotionally challenging part of this aside from thinking that I was going to die of cancer for a fairly significant amount of time was that there's almost no chance of me ever having another biological child and so I've had to give up on that particular dream because the hope was just too much. But we got a puppy and so that's my replacement baby. I have also learned to be a lot kinder to myself and to trust my body more. I accept now that I am living with a chronic illness, I try to take naps a lot. I try to listen to what feels good and what feels bad. |
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|  |  | But when I stop to really think about it the thing that really makes me angry is that I had no idea I had endometriosis before any of this started. It is absurd that no one thought of endometriosis, that I was never presented with any education about endometriosis, that no one in my friend circle ever talked about endometriosis, even though I found out more and more people have it. And I just feel like I know so little. In a post I wrote on Reddit, I wrote, "I've been a feminist for my entire life without understanding that I've been trapped in a patriarchal pain trap." So thank you for listening to my story. |
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| TPWKY |  | (This Podcast Will Kill You intro theme) |
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| Erin Welsh |  | Thank you so much, Susie, for taking the time and being willing to share your story. It was... Oh my gosh. |
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| Erin Allmann Updyke |  | Yeah, I can't. Wow. Thank you. |
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| Erin Welsh |  | Yeah. Hi, I'm Erin Welsh. |
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| Erin Allmann Updyke |  | And I'm Erin Allmann Updyke. |
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| Erin Welsh |  | And this is This Podcast Will Kill You. |
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| Erin Allmann Updyke |  | It's gonna be a big episode, Erin. |
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| Erin Welsh |  | This is certainly my longest notes by I think kind of a bit. So just, yeah, it got away from me. But I'm excited about it. |
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| Erin Allmann Updyke |  | I am too. I have a lot of feelings about it, so it's going to be a good one. |
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| Erin Welsh |  | Yeah. And what exactly is going to be a good one? |
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| Erin Allmann Updyke |  | Oh yeah, that's right. Today we're covering endometriosis. |
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| Erin Welsh |  | That's right. What even is endometriosis? At the end of this episode, will we have a satisfactory answer to that question? |
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| Erin Allmann Updyke |  | I think we'll have at least most of a satisfactory answer. We'll have a clinical definition. |
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| Erin Welsh |  | That's true. That's true. Where does that leave us? I guess we'll find out. Before we get into the nitty-gritty of all of that though, should we do quarantini? |
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| Erin Allmann Updyke |  | We really should. |
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| Erin Welsh |  | What are we drinking this week? |
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| Erin Allmann Updyke |  | We're drinking The Chocolate Cyst, of course. |
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| Erin Welsh |  | Oh boy. |
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| Erin Allmann Updyke |  | Honestly I think that's a grosser name than our diabetes one. |
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| Erin Welsh |  | Sweet Pee. Yeah. |
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| Erin Allmann Updyke |  | I think this is grosser. |
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| Erin Welsh |  | Is it grosser than our MRSA one? |
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| Erin Allmann Updyke |  | No, maybe. I don't know. |
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| Erin Welsh |  | You tell us, listeners. |
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| Erin Allmann Updyke |  | You tell us, listeners. |
|  |  |  |
| Erin Welsh |  | Yeah, what's the grossest one yet? So why are we calling it The Chocolate Cyst though? |
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| Erin Allmann Updyke |  | Yeah, okay. So a chocolate cyst is like one of the descriptors for an endometrioma which is when you get endometriosis on your ovary. We're going to get into all of it but basically sometimes you get these things that look like a little chocolate truffle, liquidy-er. |
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| Erin Welsh |  | Oh gosh. Okay. Well definitely garnish this with a chocolate truffle, if you can. |
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| Erin Allmann Updyke |  | Yeah. (laughs) So what's in the chocolate cyst? |
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| Erin Welsh |  | Chocolate liqueur, banana liqueur, coffee liqueur and cream. And then of course garnish, like I said, with a chocolate truffle. And also the placeborita is just probably going to be the most decadent, delicious chocolate milkshake you've ever had. Chocolate banana milkshake. Yeah. |
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| Erin Allmann Updyke |  | I can't wait. |
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| Erin Welsh |  | And you can find our recipe for our quarantini as well as our non-alcoholic placeborita on our website thispodcastwillkillyou.com and we'll also post it to all of our social media channels. |
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| Erin Allmann Updyke |  | On our website thispodcastwillkillyou.com you will find everything that you could want to find. We have merch, we have links to Bloodmobile who provides the music for this podcast, we have transcripts of all of our episodes now which is thrilling. We've got a bookshop.org affiliate account, we've got a Goodreads list, we have a link to our Patreon. It's all there, it's all there. |
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| Erin Welsh |  | It's all there and more. |
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| Erin Allmann Updyke |  | With that Erin, should we just get into the endo-meat-rium of this episode, Erin? (laughs) |
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| Erin Welsh |  | (laughs) Yes. Yes, please. Please. Let's take a quick break first. |
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| TPWKY |  | (transition theme) |
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| Erin Allmann Updyke |  | I can kind of sum up this whole episode with one of the more recent papers that I found. It's the title of a paper from 2021 and the title is simply 'The epidemiology of endometriosis is poorly known as the pathophysiology and diagnosis are unclear'. |
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| Erin Welsh |  | Wow, that's the title. |
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| Erin Allmann Updyke |  | I know. That's the title. Yeah. We're off to a really good start. Strong. |
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| Erin Welsh |  | Yep. Spoilers, I feel like. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | Were in that title. |
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| Erin Allmann Updyke |  | Okay so endometriosis. I know there's probably a good subset of our listenership who has never heard of this and I am going to get to the official definition really soon, I promise. But some little lead in, okay. Endometriosis is almost always described as a disease of women of childbearing age. That is how it is described. It's a problem straight off the bat because this description ignores number one, anyone who is trans or non-binary that has a uterus or has endometriosis; number two, it ignores the fact that endometriosis pain and endometriosis itself can persist or even sometimes arise after menopause aka after quote, "childbearing"; number three, it also ignores the fact that cases of endometriosis though very rare have occurred in people assigned male at birth which means that a uterus isn't necessarily a prerequisite for the disease. And finally, and I think most importantly, I don't know, they're all important, but by designating this disease to this particular group, quote, "women of childbearing age" and Erin, I know you're going to talk a lot more about this- |
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| Erin Welsh |  | Oh yeah. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | Also I thought it's also been found in infants. |
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| Erin Allmann Updyke |  | Oh, that's a good point. Yeah, it can definitely be in before childbearing age as well. |
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| Erin Welsh |  | Everyone can get endometriosis. |
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| Erin Allmann Updyke |  | Everyone. But by designating it as a disease of women of childbearing age it makes it really, really easy in our society to dismiss it as a condition for 'Oh young women just have poor pain tolerance' or 'Oh this is a women's problem' or even worse as a 'normal part of young womanhood'. Spoiler alert, it is none of those things. |
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| Erin Welsh |  | I'm going to be talking so much about this aspect of it. |
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| Erin Allmann Updyke |  | I know, I can't wait. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | I'm gonna try and just hit us all with the little that we do know about the biology. So let's actually define the topic of today's episode, shall we? Okay. So the technical definition of endometriosis is simply the finding of endometrial glands and stroma which just means endometrial-like tissue outside of the uterus. So what does that mean? |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | To talk about that, I want to first talk about my personal favorite organ, the uterus. That's my favorite one. Do you have a favorite organ? |
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| Erin Welsh |  | I've never thought about it. |
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| Erin Allmann Updyke |  | I do. It's a uterus. |
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| Erin Welsh |  | No, I don't. I think I would need more time. |
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| Erin Allmann Updyke |  | Okay, that's fine. Okay so we talked, I think, a fair bit about the uterus in our birth control episode because we talked about the whole menstrual cycle. So I'm just going to briefly recap. The uterus is an organ that's made up of a muscular wall, the myometrium and an inner layer, the endometrium that's composed of glandular cells. So there are these cells that basically form into little glands, as well as stroma or like support cells is how you can think of them, that surround these glandular cells. And this endometrium, this inner lining of the uterus is constantly in flux. This lining is what responds to and changes with the influence of cyclical variation in our hormone levels, most specifically, estrogen and progesterone. This is the menstrual cycle that we went over in our birth control episode, which was now a couple of years ago. |
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|  |  | To recap it, under the influence of an increase in estrogen, oocytes in the ovaries begin to mature and the uterus lining the endometrium proliferates, it grows in number, these stromal cells and these glandular cells. And this is known as the follicular phase or the proliferative phase where this lining is growing. And the endometrial lining is becoming thicker in preparation for the potential implantation of a blastocyst. Then that peak of estrogen prompts a surge of another hormone that causes the release of an egg aka ovulation. |
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|  |  | And then as that surge of estrogen declines, progesterone, another hormone, begins to increase and the uterus, the endometrium, enters what's known as the secretory phase where these glands thicken and the arteries within there widen and proliferate in number. And the endometrium undergoes this process further preparing it for receiving a blastocyst. And then without anything that implants 14 days go by and progesterone levels, sharply decline. And this withdrawal leads to the separation of all these cells from their basal layer and they slough off, aka menstruation. All of that endometrial tissue then exits through the cervix which is the opening of the uterus through the vagina and that is menstruation. Right? |
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| Erin Welsh |  | Yep. |
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| Erin Allmann Updyke |  | Right. Okay. So if that all is the menstrual cycle and that's what's happening inside of a uterus during that menstrual cycle, then what is endometriosis? If it's the finding of these same type of cells that are found inside of a uterus, these endometrial, glandular and stromal cells, but now they are implanted in tissue outside of the uterus. So instead of being inside the lining of this muscular organ, it's outside on the wall of the organ or on the wall of your belly which is called the peritoneum, the inside wall of your abdomen. It could even be on your bladder or in your fallopian tubes or on your ovary or on your rectum. It could be anywhere literally in your body. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | So then the question is how does this become a disease or a problem? Why is it a problem to have this tissue outside of the uterus? Well this tissue is still active, it's hormonally sensitive endometrial cells that are undergoing the same proliferative and secretory and then degeneration that happens within the uterus and would end in menses leaving the body through the vagina but it's happening in an abnormal location and therefore leading to not only abnormal responses in our body and massive amounts of inflammation but it's also then not able to leave the body. So this inflammation stays contained within the body. That leads to tissue damage which can then lead to scarring and fibrosis which leads to the symptoms of endometriosis which are chiefly pain which doesn't begin to describe adequately the true symptoms. And also infertility or difficulty conceiving or sustaining a pregnancy. So that was a lot all in a very short amount of time. And that's all we know about endometriosis. Just kidding. We know a tiny bit more than that. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | So that explanation left a lot of open-ended questions. And I think the first one that I would like to be able to answer is how. How does this endometrial tissue end up in a place where endometrium shouldn't be? Tissue types in our body, like different cell types, are actually pretty tightly regulated. So the tissue that makes up our lining of our abdomen is different than the tissue that makes up the lining of your uterus which is different than the tissue that makes up your heart or your blood vessels, etc. Right? |
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| Erin Welsh |  | Right. And so then because it's so tightly regulated, shouldn't your body recognize that like hey, this isn't necessarily in the right spot? |
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| Erin Allmann Updyke |  | Yeah. And in the case of endometriosis, that's part of the problem is that your body does recognize it as something that's not in the right spot and therefore causes a lot of inflammation within it. Right? |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | And so then that leads to part of the problem. Or at least we think that maybe that's how it's happening and with a lot to do with endometriosis, it's hard to know who's the instigator, like which is the cause and which is the effect. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | Right? But yes, that can be part of the problem because our body does recognize when a tissue is not in the right place a lot of times. But again, this doesn't happen very often to have a tissue type in a location in the body where it doesn't belong because in general as we develop from a single cell all the way into our multi-cellular human selves, our cells undergo this process of differentiation into all of our specific tissue types in a very characteristic pattern during the process of embryogenesis and development. So all of our cells have very explicit sets of instructions that they follow and explicit influences that they're under in order to develop into these different tissue types in certain areas and not in others which is why we don't see heart tissue in our bones or brain tissue in our guts for the most part. So why on earth do we sometimes get endometrial tissue outside of the inside of the uterus? And the short answer is we don't know. |
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| Erin Welsh |  | We don't know. |
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| Erin Allmann Updyke |  | We do not know. Let me go through the quote "prevailing theories" and then maybe Erin, you and I can have some opinions. So what's obnoxiously still called the "prevailing theory" on how this happens, on how endometrial glands end up implanting and then replicating and proliferating outside our uterus, is something called retrograde menstruation. Or what do you call it, Erin? |
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| Erin Welsh |  | As I've been calling it, menstrual backwash. |
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| Erin Allmann Updyke |  | Menstrual backwash. |
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| Erin Welsh |  | Cause I could not for the life of me remember retrograde menstruation. |
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| Erin Allmann Updyke |  | It's a good visual, menstrual backwash. |
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| Erin Welsh |  | Yeah, yeah. |
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| Erin Allmann Updyke |  | Essentially. So if you've not recently looked at a picture of a uterus, let me paint you one. So the uterus is connected to fallopian tubes at the top. They look kind of like ears that come off or maybe little arms and these fallopian tubes are open at the end, they have these little fimbriae, little fingers at the end. And just outside of these fallopian tubes is where our ovaries sit. So during menstruation all of the endometrial lining and tissue comes out through the cervix which is the base of the uterus and also the top of the vaginal canal. That is the normal flow of menstrual products. But the top of the uterus, those fallopian tubes, are open at the ends. So in fact there is in many people who menstruate, menstrual product aka endometrial tissue that goes backwards. And it goes out through those fallopian tubes and enters our peritoneal cavity. That's it. |
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| Erin Welsh |  | Backwash. |
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| Erin Allmann Updyke |  | Backwash. And it was thought that this certainly must be the way that endometriosis happens. These endometrial tissues are entering our peritoneal cavity. Boom. There you go. |
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| Erin Welsh |  | I think there's a really interesting parallel between this like wandering endometrial tissue concept and the wandering uterus hysteria concept. |
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| Erin Allmann Updyke |  | The wandering uterus, yeah. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | It's the same. It totally is. |
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| Erin Welsh |  | It's very interesting to me. |
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| Erin Allmann Updyke |  | And there is some evidence in support of this because a sizable portion of endometrial implants occur in areas where this menstrual backwash, this retrofit menstruation, would end up. And in a lot of people where they have looked at does this person with endometriosis have retrograde menstruation? They have found yes, they do. And so there's a correlation there. But as it turns out this is very common and happens in at least if not more than about 40% of people with a uterus who menstruate pretty much every time they menstruate to varying degrees. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | So it doesn't explain why some people then go on to develop endometriosis and others don't. It also doesn't explain how endometriosis can happen in people without a uterus to begin with which again is incredibly rare but has happened. And it doesn't explain how endometrial cells can end up outside of the abdominal cavity entirely which it can. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | You can get endometriosis in the diaphragm, in the thorax, in the lungs. So this menstrual backwash theory, doesn't quite- |
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| Erin Welsh |  | Needs some work. |
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| Erin Allmann Updyke |  | It needs some work. |
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| Erin Welsh |  | Or it just needs to be discarded for a new one or integrated with another hypothesis. |
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| Erin Allmann Updyke |  | Yeah. And we'll get there actually cause there's an interesting integrative one. So then there is a theory of stem cells of which there are kind of two different schools of thought. So stem cells, I think that I might've touched on this in the HPV episode, I'm not positive, we've talked about them before but anyways- |
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| Erin Welsh |  | I don't know. |
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| Erin Allmann Updyke |  | A stem cell is a cell that has the ability to differentiate into other cell types. So like I was saying how when we develop from a single cell into a multicellular human our cells are differentiating, they're becoming like grown up, quote unquote "grown up" cells that have a specific job and function. Well stem cells are kind of like baby cells that have the ability to grow up and become any other type of cell or many other types of cells. So there's a theory that perhaps bone marrow stem cells which have the ability to differentiate into a number of cell types might somehow find their way into the peritoneum or the abdominal cavity. And then there, they would embed and under certain hormonal influences would differentiate into endometrial cells for some reason. Yeah. That's one theory. It's not a great one. |
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| Erin Welsh |  | Yeah. How does that explain timing of things or...? |
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| Erin Allmann Updyke |  | Honestly Erin, it doesn't. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | It's not my favorite of the theories. So another one that's I think at least a little bit more easy to understand is a theory that it's endometrial stem cells. Okay? |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | This is coming a little bit closer. And this theory can actually kind of tie into the menstrual backwash theory but adds onto it a little bit. So in this case, it's not the menstrual backwash per se. |
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| Erin Welsh |  | I love that we're calling it menstrual backwash now. (laughs) |
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| Erin Allmann Updyke |  | We're all in. Okay. So it's not the retrograde menstruation of just any old endometrial cells but of specifically endometrial stem cells like the basal cell layers that have the ability to differentiate into the different endometrial cell types. If those maybe are either backwashed or find their way into our bloodstream or our lymphatics, then perhaps those can embed and they already have the ability they're programmed to differentiate into endometrial cells. So it's logical then that they would be responsive to the same hormonal influences that they would if they were still inside of the uterus. Does that make sense? |
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| Erin Welsh |  | Yeah, that's interesting. And so are there any studies, animal studies or something showing support for this or even just like tissue culture studies showing support for this? |
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| Erin Allmann Updyke |  | There are certainly studies that show that these stem cell types exist and can embed and then become endometrial-like tissue. |
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| Erin Welsh |  | Okay. And how then would those stem cells... So these would be like the deepest basest layer? |
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| Erin Allmann Updyke |  | Yes. That's my understanding. |
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| Erin Welsh |  | Okay. So then how do they escape the uterus? |
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| Erin Allmann Updyke |  | Yeah, that's the question that we don't have an answer to. |
|  |  |  |
| Erin Welsh |  | Interesting. |
|  |  |  |
| Erin Allmann Updyke |  | There's another theory. And this is the coelomic metaplasia theory which is your coelum is the inside of your abdomen. So in this theory regular old abdominal cells wherever in your abdomen just undergo metaplasia. Metaplasia means they develop mutations and then they change. And so instead of being a differentiated let's say abdominal wall cell, they de-differentiate and then re-differentiate into endometrial cells. So in this theory instead of a baby undifferentiated stem cell that has the potential to become any cell type, you're taking a fully formed adult cell and changing it into an endometrial cell. |
|  |  |  |
| Erin Welsh |  | Yeah. Okay, that seems a little complicated. So currently today, we're recording this in 2021, I know that the prevailing hypothesis is still this menstrual backwash thing. |
|  |  |  |
| Erin Allmann Updyke |  | Yep. |
|  |  |  |
| Erin Welsh |  | But what is the timeline for these other hypotheses? And are there any of them that are seeking to dethrone that one? |
|  |  |  |
| Erin Allmann Updyke |  | So the thing is not really. |
|  |  |  |
| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | Cause the thing is, and here's the problem, is that none of these theories in and of themselves fully or adequately address the question of how exactly endometriosis occurs. Right? |
|  |  |  |
| Erin Welsh |  | Right. |
|  |  |  |
| Erin Allmann Updyke |  | And they also don't answer the question of why do some people get endometriosis and other people don't. What are the risk factors? And so I think where there is more research being done is trying to understand the second part of that question. Why do some people get endometriosis and others don't? Maybe it is one of these theories that we already have. Maybe it really is menstrual backwash but it still doesn't answer the question of why 40% of people have menstrual backwash and not 40% of people have endometriosis. Right? |
|  |  |  |
| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | And part of the answer to that question at least seems to be genetic. So in a number of genome-wide association studies which is when you look at someone's entire genome and you try and figure out what's going on, there've been I think at least like 10 or 15 different gene loci, so different locations that have been shown to be associated with endometriosis. So we know that there's a strong genetic component but knowing that there's at least 10 or 15 different genes is also maybe not all that helpful because it's hard to know what that means. Right? It does seem like all of these gene regions are in some way related to hormonal regulation in some respect. |
|  |  |  |
|  |  | So a lot of this is a hormonally-driven disease and really an estrogen-dependent disease in a lot of ways. But really one of the prevailing thoughts is that it is this kind of genetic and epigenetic factors combined with these unknown environmental insults that leads to endometriosis. And endometriosis is associated with a number of other autoimmune disorders. And that's kind of the thinking with autoimmune disorders as well, right? It's these genetic predispositions and some kind of environmental influences that combine together to then lead to this disease. It's not satisfying. |
|  |  |  |
| Erin Welsh |  | But it does make sense in that if there's a high level of inflammatory response to this self tissue even in places it shouldn't be compared to people who may not have as high of a strong inflammatory response and so might not have as strong symptoms or might not have the development of endometrial lesions or whatever. |
|  |  |  |
| Erin Allmann Updyke |  | Exactly, exactly. |
|  |  |  |
| Erin Welsh |  | Then that kind of goes along with it. |
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| Erin Allmann Updyke |  | Yeah. Especially because while this is, if you look at endometriosis tissue histologically under a microscope, it looks just like endometrial tissue. Histologically it is endometrial tissue. And in some ways it does behave in the same way as endometrial tissue inside your uterus, right. It proliferates with estrogen, it degrades, etc. But what's different is that outside of the uterus, this endometrial tissue is associated with hugely increased amounts of inflammation. And this we do know. So we know that local inflammation and immune dysregulation is a really big part of the pathogenicity of endometriosis. And this inflammation itself is what then leads to the fibrosis which leads to these adhesions which can lead to such significant pain and symptoms. |
|  |  |  |
|  |  | So one way to think of it is that it's all related to the bleeding because endometrial proliferation and then degeneration leads to so much bleeding, the bleeding itself, blood itself is very, very inflammatory. So the fact that it's trapped somewhere inside your body rather than traveling through the vaginal canal leads to a lot of inflammation which leads to immune cell infiltration which etc, etc, all the way down the line. But it's also not clear that that's the order in which things go. It could be that do you have underlying inflammatory changes, differences in the way that your inflammatory markers react that then leads to the increased inflammation? Does that make sense? |
|  |  |  |
| Erin Welsh |  | Yeah. So it's like a chicken and the egg but it's like the chocolate cyst and the inflammation. |
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| Erin Allmann Updyke |  | That's exactly right, Erin. Yeah. So that is what we know about the kind of pathogenicity of endometriosis. |
|  |  |  |
| Erin Welsh |  | I'm still confused. |
|  |  |  |
| Erin Allmann Updyke |  | Same, same. |
|  |  |  |
| Erin Welsh |  | Okay, questions. |
|  |  |  |
| Erin Allmann Updyke |  | Okay. |
|  |  |  |
| Erin Welsh |  | Or rather question. What do these lesions look like? How big do they get? What are the variations in them? |
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| Erin Allmann Updyke |  | Good question. |
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| Erin Welsh |  | How do you know when you have one, etc, etc? |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. So typically endometriosis is classified into kind of three main subtypes. So there's superficial peritoneal legions which means these little endometrial implants that are primarily within the abdominal cavity, either on like the serosa which is the outside lining of other organs or on the walls of your abdominal cavity may be tucked behind your uterus or up on the front, anywhere really. But they don't extend deeply into the tissues, these superficial lesions. And they're generally small, I don't have an exact size for you. But they don't extend very deeply. That's the first type. |
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|  |  | Then there are ovarian endometriomas which is where we got the name for our drink. And this basically just means that the endometriosis has implanted on or within the ovary. It's actually thought that it might be like where the eggs pop out. If endometrial implants find their way in there they then become enclosed. And then they can form these really rather large cysts. And because they are enclosed within kind of ovarian tissue and scar tissue around them, they undergo the same cycles of proliferation and degeneration. And within time that blood is contained inside this cyst and over time that becomes a very dark chocolate color which is how they got the name chocolate cysts. |
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| Erin Welsh |  | It also sounds horribly painful. |
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| Erin Allmann Updyke |  | Yes. And they can get very quite large. And then the third subtype is deeply infiltrating endometriosis. Literally acronymed as DIE, like who came up with that? |
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| Erin Welsh |  | Yeah. It's not great. |
|  |  |  |
| Erin Allmann Updyke |  | Yup. And this deeply infiltrating form by definition invades into deeper structures which means instead of just being on the surface of say your abdominal wall or on the surface of your bladder, it's invading deeper into the muscles of your bladder, into the walls of your rectum through your urethra or your ureter for example. |
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| Erin Welsh |  | Oh my god. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah, it can be horrific. And so especially deeply infiltrating endometriosis can cause not only incredible pain but also can then cause damage to and blockage of really important structures like your colon or your bladder or your ureters. |
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| Erin Welsh |  | So what is the association with these different stages and pain intensity? Or is there any association or with infertility or subfertility? |
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| Erin Allmann Updyke |  | Yeah, it's a really good question. There's not a solid answer to that. In general, deeply infiltrating lesions are kind of the worst as well as endometriomas, especially the ovarian endometriomas are also associated with infertility. But the problem is that just by looking at somebody's endometriosis, like during a surgery for example, you can't tell how bad their symptoms are going to be. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | So what it looks like doesn't correspond very well with actual symptom severity. |
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| Erin Welsh |  | Which can be problematic. |
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| Erin Allmann Updyke |  | Very problematic. But of course the deeply infiltrating endometriosis has the most potential to cause problems in other organs for example but in terms of pain which is kind of the biggest symptom of endometriosis, any of the types can cause pain or any of the types might not be associated with pain. So in that respect, it's difficult in terms of pain. Erin. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | So pain is classically like the hallmark symptom I guess of endometriosis and most classically it's dysmenorrhea which is painful periods which sounds like, 'Oh, doesn't everyone have painful periods?' So period pain, typical period pain should not be so bad that you are missing school, that you are missing work, that you are laid out in your bed for an entire week because you can't function as a human being. And that's the kind of pain that is often associated with endometriosis. You're not able to function because of how much pain is associated with it. But it's not just with menstruation, especially as these endometrial implants sort of just persist over time. It can also be dyspareunia which is pain with penetrative sex which can be hugely impactful on somebody's life, pain with defecation, dyschezia, painful urination. Just pain, pain with everything, pain all the time chronically. So but here's the thing about pain. I'm probably not going to do this justice but I want to just briefly talk about the neurobiology of pain if we have time, okay. |
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| Erin Welsh |  | Let's do it. |
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| Erin Allmann Updyke |  | In this long episode. |
|  |  |  |
| Erin Welsh |  | This is gonna be a long episode but take a break if you need to come back to it, whatever. |
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| Erin Allmann Updyke |  | Have a Chocolate Cyst, etc. |
|  |  |  |
| Erin Welsh |  | Yeah, yeah. |
|  |  |  |
| Erin Allmann Updyke |  | So pain at its core, like the definition of pain I guess is when specific receptors, nociceptors are activated and send signals to our brain which are then interpreted by the brain, processed in certain areas of the brain and then transmitted and we then experience pain. Like that's a really general description of it. But there's a few things about endometriosis pain and about chronic pain in general that I think are really important to kind of understand. First, studies have found that endometriotic implants, this endometriosis in your abdomen often has higher densities of nerve fibers. So they're more densely innervated than the surrounding tissue. They're also more highly sensitized. So they actually respond at a lower threshold of stimuli which both of those things combined lead to an increase in pain signal transmission to the brain. |
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| Erin Welsh |  | Yeah. It's like efficiency in signals traveling. |
|  |  |  |
| Erin Allmann Updyke |  | Right. |
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| Erin Welsh |  | They're like, 'Oh, I've gone down this route before. Oh, I know how to get there. Oh, boom.' |
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| Erin Allmann Updyke |  | Exactly. Boom, boom, boom, boom. |
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| Erin Welsh |  | It's this way, it's easy. |
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| Erin Allmann Updyke |  | But also there are literally brain architecture changes that happen with chronic pain. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | And this is something that we do not fully understand and people are finally just now doing a lot of research on. |
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| Erin Welsh |  | Finally just now acknowledging that it might be real. |
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| Erin Allmann Updyke |  | Right, that it's not just psychosomatic which is what it was thought to be for the longest time. But there are now a lot of really good studies on this, that the brain changes in relation to experiencing chronic pain. And while there aren't as many studies on this in relation to endometriosis-related pain specifically or to pelvic pain specifically, there are a few and the ones that do exist that have looked at people for example with dysmenorrhea or very painful periods, people who have chronic pelvic pain have a lower peripheral input at which they experience pain and a higher activity, higher activation of their central nervous system in response to that pain. They are literally primed by experiencing chronic pain to then experience more pain. |
|  |  |  |
| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | And I want to be clear that this is not the same thing as saying like, 'Oh, you have a low pain tolerance.' |
|  |  |  |
| Erin Welsh |  | Right, right. |
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| Erin Allmann Updyke |  | That's not what this means. This means that in response to pain your body reacts and changes and experiences a greater amount of pain from the same stimuli as someone else because of these changes to your brain. |
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| Erin Welsh |  | It makes complete sense and it's so frustrating that it's not widely known about or understood or taught or researched. |
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| Erin Allmann Updyke |  | So frustrating. Right. Yep. And it's also not saying, like I said, that this pain is psychological in origin because it's not. However it's also really important to point out just how comorbid chronic pain conditions like endometriosis and mood disorders like depression and anxiety are because this comorbidity, having these two things together leads to further exacerbation of the experience of pain because of disruptions that depression or anxiety have on your brain function. |
|  |  |  |
| Erin Welsh |  | Right. And I know that there has been a lot of, 'Oh, well your depression or anxiety is probably causing your chronic pain,' instead of maybe considering that it might be that persistent, never ending, excruciating, inescapable pain might lead to, I don't know, say a bit of depression or anxiety. Couldn't that be the case? |
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| Erin Allmann Updyke |  | Yeah, yeah. And then both of those things change your brain architecture to make them both worse like a self-fulfilling prophecy. Yeah. It's not great. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | It's really not great. The other biggest sequelae of endometriosis is infertility or difficulty conceiving. And again here we don't know why. |
|  |  |  |
| Erin Welsh |  | Really? |
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| Erin Allmann Updyke |  | Yeah. We don't know if it's because of scar tissue that can form, especially if it's from endometriomas on the ovary, like scarring the ovary or disrupting the number of ovarian follicles that you have left or if it can cause scarring in the fallopian tubes. O there's some thought that it's just from how much inflammation exists in the pelvis because of endometriosis. Because again it's an open cavity between your ovary and your fallopian tubes, so small space but it's all bathed in the same fluid. And so if that fluid is full of inflammation, then how is that egg supposed to make it safely into the uterus? |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | Right? So we don't really know the mechanisms but endometriosis is strongly associated with difficulty either getting pregnant or carrying a pregnancy to term but especially in getting pregnant. And let's talk about something that can have a huge impact on your mental and emotional wellbeing, especially in a society that often ties a uterus holder's worth to their ability to conceive. Like that's not small potatoes, that's a big deal. |
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| Erin Welsh |  | Right, right. Yep, it is. |
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| Erin Allmann Updyke |  | Yeah. What else do you want to know about endometriosis, Erin? Cause that was a lot. |
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| Erin Welsh |  | I mean, I would ask about treatment but... |
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| Erin Allmann Updyke |  | You want me to answer that? I'll answer it. |
|  |  |  |
| Erin Welsh |  | Yeah, okay. |
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| Erin Allmann Updyke |  | Treatment is a mixed bag. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | So some people with endometriosis respond very well to hormonal birth control, either combined contraceptives or something like an implant or an IUD and that can be hugely beneficial. It can lighten periods, it can make them stop altogether, it can substantially reduce pelvic pain. But for anywhere from a quarter to a third of people that doesn't work at all or they can't even try it because of other comorbidities or risk factors they might have or maybe they want to become pregnant. |
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| Erin Welsh |  | Or maybe hormonal birth control pills have messed with other parts of their day to day life. |
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| Erin Allmann Updyke |  | Right. There's a lot of risk factors associated with birth control as well. So for some then the next kind of step can be what are called GnRH gonadotropin-releasing hormone agonists, which essentially put you into early menopause. That's what they do. They block all of the hormones associated with the menstrual cycle much more completely than combined contraceptives alone.But again, they have their very long list of side effects like hot flashes, skin changes, acne, mood changes. These can also affect your bone mineralization and bone density. So they put you at risk for osteoporosis and even these don't always work. So then there's surgery. And surgery sometimes is still cited as the kind of gold standard or the only quote "real way" whatever to diagnose endometriosis. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | The trend is moving away from that, thankfully. |
|  |  |  |
| Erin Welsh |  | Okay. |
|  |  |  |
| Erin Allmann Updyke |  | Okay. |
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| Erin Welsh |  | And how much does that vary country by country? |
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| Erin Allmann Updyke |  | It's a good question that I don't know the answer to. |
|  |  |  |
| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | Yeah. But in general the consensus in the medical literature is moving away from surgery as a necessary diagnostic step because it used to be that you had to have histological proof of endometrial tissue outside of the uterus to call it endometriosis. And the only way you could get that was from surgery. But now we have other methods of being able to identify it, not only just with clinical history but also with imaging modalities like MRI and ultrasound which can help to identify some kinds of endometriosis. But surgery is often also seen as a treatment option. So ablation or excision of the endometrial lesions can help improve pain for a lot of people but it can also in some cases create more inflammation and more adhesions which can then exacerbate symptoms or possibly even lead to more endometriosis lesions if we think that it's inflammation that's the driver rather than vice versa. |
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| Erin Welsh |  | That makes sense, yeah. |
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| Erin Allmann Updyke |  | Right? And hysterectomy or removal of the uterus with or without removal of the ovaries along with it used to be seen as curative, used to be done all the time, still is done a lot. It is not curative but it is still done sometimes for people. So yeah, that's the treatment for endometriosis. It's not great. We don't have a lot. And especially when it comes to the pain, medicine today in 2021 is bad at treating pain, especially chronic pain. We don't have a lot of good options for it. So that part of endometriosis is very difficult if these other therapies aren't effective. So it's a bummer, Erin. |
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| Erin Welsh |  | I mean it's infuriating is what it is. |
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| Erin Allmann Updyke |  | It is, yeah. And that was the longest biology section I've ever done. Wow. |
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| Erin Welsh |  | There's a lot to unpack despite the fact that we are still left with so many questions. |
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| Erin Allmann Updyke |  | Yeah. Right. We don't know anything and yet I talked for an hour. So Erin, tell me all about it. How did we get here and why, why? |
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| Erin Welsh |  | Why? Yeah, I will start on the longest history section right after this break. |
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| TPWKY |  | (transition theme) |
|  |  |  |
| Erin Welsh |  | Before reading about endometriosis, I figured that it would be one of those episodes that followed like a relatively straightforward formula. What evolutionary significance does it have? When was it first written about or first identified as a medical condition? Who discovered it? How has our knowledge about the pathophysiology changed over the last hundred years and how have we gotten better at treating it? Yeah. And it's true, I did come across a lot of information while researching that would answer those questions and fit into that formula. But as I read more, I felt like that wasn't what I wanted to talk about. What I found more compelling and in my opinion more important was how the entire story of endometriosis kind of perfectly encapsulates many aspects of misogyny and gender inequality in medicine and the implicit and explicit biases that often keep women from getting the healthcare they need and deserve. So that's what I'm going to talk a lot about today. |
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| Erin Allmann Updyke |  | Good. |
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| Erin Welsh |  | And before I dive in, I want to briefly discuss the language I'll be using. The story of endometriosis involves aspects of both sex, aka common biological differences between males and females, as well as gender, aka the socially constructed roles that vary between gender and that people identify with. And as you mentioned Erin, endometriosis can affect people who don't identify as women. It can affect people assigned female, male, or intersex at birth and its label as a female only or women's disease can be very damaging and can delay diagnosis even further for those that don't fit the description of a typical endo patient, whatever that means. But much of what I'll be talking about today is a gendered issue. It has to do with the way that women are perceived in medicine and how that impacts their treatment. |
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|  |  | The fact that endometriosis primarily occurs in people assigned female at birth has given rise to many of the social issues and medical disparities surrounding endometriosis. Many of these issues such as how people experiencing pain are perceived by medical providers are discussed in the literature and in scientific studies using the terms men and women without saying whether they mean sex or gender but generally speaking refer to cisgender people. This is definitely a huge limitation of these studies and of this discussion as well, especially since there are many ways that trans or gender non-binary people are treated differently than cis people in medicine, often in ways that negatively impact their health. And I'm going to try my best to be inclusive and not to ignore the experiences of those people or exclude them from this history but studies examining those aspects are scarcer. |
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| Erin Allmann Updyke |  | Yeah. Like her horrifically scarcer as in almost non-existent. |
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| Erin Welsh |  | Basically yeah, almost non-existent. Okay, so let's dive in. Like I said, I want to talk broadly about medical bias against women and what that means for endometriosis. But in order to do that I should first tell you a bit about the history of endometriosis. |
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| Erin Allmann Updyke |  | Yeah, tell me a little. |
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| Erin Welsh |  | All right. Evolution first. Why does endometriosis exist? |
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| Erin Allmann Updyke |  | Oh, Erin. |
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| Erin Welsh |  | I mean I have no idea. |
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| Erin Allmann Updyke |  | No one does. |
|  |  |  |
| Erin Welsh |  | Let's be clear. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | But I have some food for thought maybe. So as you said Erin, endometriosis is often associated with infertility or subfertility and while we don't have a complete grasp on what causes endometriosis, like you said Erin, heredity does seem to play a part. And many diseases are caused by a mixture of genetic predisposition and environmental factors and it seems like in the case of endometriosis, I've read that it's about 50% genes and 50% environmental factors. |
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| Erin Allmann Updyke |  | Yeah, that's what I read as well. |
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| Erin Welsh |  | Yeah. So it seems like it should be selected against at least a little bit just by virtue of the fact that people with endometriosis tend to be less likely to pass on those alleles or the predisposition for endo but that's not what the numbers seem to show. And as I'm sure you'll talk more about, endometriosis is incredibly common. I've seen estimates from 10-15% and those frankly seem like they could be conservative estimates are underestimates because I'm sure many people with endometriosis never get a diagnosis for any number of reasons, such as whether they can afford to see a doctor to take time off work and find reliable transport to a doctor. Or even if they can see a doctor, maybe they're just dismissed or called dramatic or maybe they just don't know that debilitating periods aren't normal because periods are a taboo discussion topic. |
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| Erin Allmann Updyke |  | I feel like that's such an important one because it's still so common today that people have no idea that they don't have to exist or they shouldn't have to exist in that much pain. Like that shouldn't be normal. |
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| Erin Welsh |  | Yeah. I mean even periods themselves. Do we need to have periods? |
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| Erin Allmann Updyke |  | No. |
|  |  |  |
| Erin Welsh |  | No, we don't. |
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| Erin Allmann Updyke |  | No. |
|  |  |  |
| Erin Welsh |  | It's very interesting. Anyway, so yeah. And then of course on top of all of those factors there are these racial and economic disparities in obtaining a diagnosis that are very frustrating. Doesn't really begin to cover it, but yeah. But whether it's 10-15% or likely much higher endometriosis is extremely prevalent. And again, more than it seems like it should be maybe for something that can affect fertility. But remember that it's not just your genes determining whether or not you get endometriosis, it's also environmental factors. And it turns out that endometriosis might not deserve the reputation it has for causing infertility. So it seems like in a lot of the literature an estimate around 30% is often reported but more recent studies put it actually lower at about 10-13%. |
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| Erin Allmann Updyke |  | Like of people with endometriosis that will have infertility? Got it. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | I think most of the numbers that I saw cited was like of people with infertility, how many of them have endometriosis? Which is a very interesting way to look at the statistics. |
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| Erin Welsh |  | Right. It is, yeah. But yeah, so it seems like this reputation that endometriosis has for basically being a one-to-one infertility is not necessarily the case. |
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| Erin Allmann Updyke |  | Yeah, yeah. |
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| Erin Welsh |  | And I also read a couple of papers that proposed an evolutionary explanation for endometriosis. So I will admit I feel a little bit out of my depth here but I'm going to just attempt to do my best. Essentially in these papers which were from 2021, the author suggested that endometriosis and polycystic ovarian syndrome are opposites. Did you read this paper? |
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| Erin Allmann Updyke |  | I saw that paper and I was like, 'ooh, what's this?' Interesting, Erin. Interesting. |
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| Erin Welsh |  | Mm-hmm. And so endo and PCOS are at these like two extremes of a spectrum, this is what the author suggested, that is determined by levels of prenatal testosterone exposure with high prenatal levels equaling PCOS and low prenatal levels equaling endometriosis. So during development if a fetus is exposed to levels of testosterone that are outside the quote "normal range", certain traits associated with fertility or fecundity are brought to their extremes. And the way that I started thinking about this was like too much of a good thing. So individually these traits might be helpful for fertility but when you have too many of those traits or they are expressed too highly, it can be hurtful. So something like uterine contractions, it's great for when you have a fetus with a big head in there but horrible for when you have menstrual cramps that lay you flat. Or like inflammation, right? Inflammation is good, it's what keeps us healthy. |
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| Erin Allmann Updyke |  | Right. |
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| Erin Welsh |  | Too high levels of inflammation can be really, really bad. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | So taking all that together, I feel like we can start to see why endometriosis exists and why we see it in fairly prevalent numbers today. So my next question is do we have more endo today than we've had in the past? How long has endometriosis been around? Endometriosis often gets called a modern disease or a modern epidemic. Did you come across papers describing it that way? |
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| Erin Allmann Updyke |  | No, but I'm not surprised. |
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| Erin Welsh |  | Okay. I don't like this for a number of reasons. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | First, I don't love the term 'modern epidemic' to describe endometriosis because I'm not convinced that we have enough data about historical rates to say whether there's an actual increase or if it's just that we're more aware of it, so it's diagnosed more often. Second is that calling it a modern disease implies that it has emerged only recently which is untrue. Humans have probably been experiencing endometriosis for millennia as I'll get into. And some people who defend the use of the term 'modern' to describe endometriosis say that it's because it was only defined as a clinical entity within the past 100 to 150 years and that definitive diagnosis by examining tissue under a microscope was only possible in the last hundred years. So despite the existence of ancient medical texts describing abnormal bleeding associated with pelvic pain and infertility, those descriptions apparently aren't specific enough to be called endometriosis which I'll grant is fair. Retrospective diagnosis is always a problem. |
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| Erin Allmann Updyke |  | Yeah, and there's a lot of things that can cause pelvic pain and abnormal bleeding. |
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| Erin Welsh |  | Absolutely. But I still think it's misleading to call endometriosis modern. |
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| Erin Allmann Updyke |  | Yes, I agree. |
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| Erin Welsh |  | Because I feel like by that definition, there are a whole lot of diseases that have likely been with humans for millennia but quote "discovered" only recently. Does a disease exist only when it's been given a name and a clinical description? |
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| Erin Allmann Updyke |  | No. |
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| Erin Welsh |  | No, of course not. |
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| Erin Allmann Updyke |  | No. (laughs) |
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| Erin Welsh |  | All that said, it is possible that endometriosis is on the rise and we should look to see if it is and if it is the case, we should obviously try to find out why. But endometriosis is an ancient disease. There are descriptions of painful menstruation which could be endo dating back to 1855 BCE from Ancient Egypt. And then again in ancient Greece in the Hippocratic texts from the 5th and 4th centuries BCE describing menstrual dysfunction as a cause of disease with pain and infertility resulting if left untreated and pregnancy as a possible cure which despite not being true, not being a cure, is often still recommended today. In fact, I read in one book for this episode that somebody commented on a Facebook page for a group called EndoActive about this. Quote: "My doctor told me having a baby would help my pain. I'm only 11." |
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| Erin Allmann Updyke |  | What? |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | Oh no. |
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| Erin Welsh |  | Mm-hmm. |
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| Erin Allmann Updyke |  | Oh no, Erin. |
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| Erin Welsh |  | Yeah I've been mad for the entire time I've been researching this. |
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| Erin Allmann Updyke |  | I'm not going to get over that one. |
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| Erin Welsh |  | I know, I know. Yeah. So in these Hippocratic texts are also the descriptions of the groups most susceptible to these gynecological disorders. Women who remained childless, young widows, and virgins who had already menstruated but remained unmarried. Some of which sounds disturbingly familiar to the nickname that was given to endometriosis in the 1960s to the 1980s or so, the quote "career woman's disease". |
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| Erin Allmann Updyke |  | Oh my God, I saw that in one paper and I barfed in my mouth. |
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| Erin Welsh |  | I know. Basically it's like, 'Well you put off your childbearing duties and rejected your social and gender roles so this is what you get.' |
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| Erin Allmann Updyke |  | It's the natural consequence. |
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| Erin Welsh |  | Obviously the Hippocratic texts didn't refer to these symptoms as endometriosis or as even one specific disease but rather they were part of what was called 'hysteria' after the Greek word for the uterus. And I'll talk more about the history of hysteria and its wandering definitions in a bit. But first I want to wrap up the history of endometriosis, even though they are tied together, so many people who were diagnosed with hysteria probably had endo. Anyway, from those ancient texts describing pain during menstruation and abnormal periods, there doesn't really seem to be a ton of other mentions of what could be endometriosis. Not because people weren't experiencing it, but likely because there was and still is a huge taboo surrounding menstruation. From Leviticus in the old Testament, quote: "If a woman has a discharge and the discharge from her body is blood, she shall be set apart seven days and whoever touches her shall be unclean until evening." Fast-forward to the first time that the word 'period' was said on television, you know, like menstrual period, 1985. |
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| Erin Allmann Updyke |  | No way. |
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| Erin Welsh |  | By Courtney Cox in a tampon commercial. |
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| Erin Allmann Updyke |  | Wow. So I'm sorry, before that they had tampon commercials without saying the word period? |
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| Erin Welsh |  | Or did they have tampon commercials? |
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| Erin Allmann Updyke |  | Maybe they didn't have tampons. Wow. |
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| Erin Welsh |  | (laughs) The history of the tampon would be a fascinating one to research. |
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| Erin Allmann Updyke |  | Wait, we haven't even done just like regular menstruation. |
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| Erin Welsh |  | I know, I know. |
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| Erin Allmann Updyke |  | Anyways. |
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| Erin Welsh |  | Anyways. But we have been conditioned to think of periods, these absolutely normal things as gross and shameful when they are neither. And that stigma surrounding periods can lead to this damaging silence where because we are shamed from talking about periods because it's not polite conversation, we don't know whether our own periods are normal because we don't hear the experiences of others. |
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| Erin Allmann Updyke |  | Right. |
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| Erin Welsh |  | The persistent labeling of menstrual periods as a distasteful and shameful subject has profound implications for public health and it creates enormous inequities for people who menstruate. In most states tampons for example are subject to sales tax. And also in most states prisons charge inmates for menstrual products. I know, there's just so much, there's so much. |
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| Erin Allmann Updyke |  | There's so much. |
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| Erin Welsh |  | But circling back to the history part of this, maybe the reason that endometriosis doesn't show up very much until basically the 1800s is because the people writing medical texts were primarily men, most of whom would have considered it deeply improper and probably gross to ask a woman about her periods. It's absolutely possible and likely that women discussed periods amongst themselves and there was probably a great deal of knowledge held by women healers which was mostly lost as medical licensing laws came into effect which both prohibited them from practicing - reasonable, licenses are good - and even applying to medical school. If you weren't a white wealthy man, you weren't getting. But with the increasing popularity of autopsies in the 19th century, people begin linking more and more signs and symptoms of disease with pathological changes in the body. Carl von Rokitansky whose name you may remember from our puerperal fever episode- |
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| Erin Allmann Updyke |  | There it is. |
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| Erin Welsh |  | He was friends with and worked at the same hospital as Semmelweiss. And he was like the king of autopsies, he performed an incredible number of autopsies. Rokitansky is usually credited with being the first person to describe endometrial lesions. In the 1860s he published a paper where he wrote that quote, "some fibrous tumors of the uterus contained gland-like structures that resemble endometrial glands" end quote. |
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| Erin Allmann Updyke |  | End quote. |
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| Erin Welsh |  | And there was a series of autopsy studies done by other physicians from England, Germany, Holland, and Scotland also in the 1800s that went further than Rokitansky to characterize the disease. But it wasn't until 1921 that it was given the name endometriosis by John Sampson, who was an American gynecologist who also did the first systematic study of the disease and proposed a hypothesis that is still the most popular today, the menstrual backwash hypothesis. The papers published by Sampson marked a turning point in the history of endometriosis. They turned it from a medical curiosity into a clinical entity and now that it had a name, it meant that information could be compiled and shared under that name. Receiving a diagnosis itself didn't do much good, similar to today in many cases and often did harm because like you said Erin, usually a complete removal of the uterus was suggested as the only effective treatment. |
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|  |  | A couple of decades after Sampson's papers, endometriosis of the lungs, large bowel, colon, rectum, bladder, lymph node, cervix, round ligaments, and so on had been reported. And physicians began to realize that it was a lot more prevalent than Sampson had thought, who described it as a rare disease. Laparoscopic surgery began to be more regularly used for the removal of lesions starting in around the late 1970s, early 1980s. But frankly, as you went over, not a whole lot of progress seems to have been made since. Yes, we know more about endometriosis now than we did 100 years ago but we're still limited in treatment and a hugely lacking in awareness among both medical professionals as well as the general public which has led in part to the ridiculous delay in endometriosis diagnosis. I mean, I've seen estimates of 6-12 years. |
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| Erin Allmann Updyke |  | Yeah, I've seen even higher sometimes like 10-15 years lag between symptoms and diagnosis. |
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| Erin Welsh |  | Right. And this delay is of course not equal across racial and economic groups with people of color and those in lower economic classes experiencing a much longer delay. So what I wanted to take time to explore in more depth was why this damaging diagnostic delay exists. Why is it 6-12 years or 10-15 years? Why do we still not seem to know very much about endometriosis? What causes it, how to treat it? Why do some people get and others don't? And exploring those questions kind of led me into reading more generally about the pervasive mistreatment and undertreatment of women by the medical system. Right off the bat I want to mention the books that I read for this because I'll probably be quoting from them a lot, one in particular, and they are phenomenal and I learned so much and got so angry along the way. |
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|  |  | Doing Harm' by Maya Dusenberry and 'Pain and Prejudice' by Gabrielle Jackson are both nonfiction books about the systemic issues in medicine and how women are treated. 'Ask Me About My Uterus' by Abby Norman and 'Giving Up The Ghost' by Hilary Mantel are memoirs about endometriosis. Hilary Mantel's book includes a section on her experience with endometriosis, it's not entirely about endo. I loved them all and you should read them all. Okay. So the way that I wanted to structure this discussion is taken directly from Maya Dusenbery's 'Doing Harm'. In this incredible book she lays out what she calls the knowledge gap and the trust gap. The knowledge gap is basically that there isn't as much scientific and medical knowledge about women's bodies and health issues than there is about men's and this goes all the way from the very basic biomedical research only including male animals and studies all the way to women being underrepresented in clinical trials and diseases specific to women receiving less funding. The trust gap is simply that quote, "women's accounts of their symptoms are too often not believed." |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | The trust gap and the knowledge gap don't operate independently. They reinforce each other to perpetuate the mistreatment and undertreatment of women by the medical system. Quote from Dusenberry: "Women's symptoms are not taken seriously because medicine doesn't know as much about their bodies and health problems. And medicine doesn't know as much about their bodies and health problems because it doesn't take their symptoms seriously." End quote. Dusenbery points out that these issues aren't about a few bad apples in the medical system mistreating women but rather the unconscious bias that is structurally embedded in medicine. So let's explore these two facets in a bit more depth, starting with the knowledge gap. As with any structurally embedded issue we discuss on the podcast, the knowledge gap has deep roots stemming from the hundreds of years during which women were seen as biologically inferior to men and whose bodies were either not worthy of study or improper to examine. |
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|  |  | And if they were studied, for instance, by the so-called father of gynecology Marion Sims who built the profession on the backs of enslaved women, they were essentially tortured, given no anesthesia or pain relief, seen to be subhuman. The ideal baseline that defined what was medically quote "normal" or "human" was a white adult male. And let's be honest, a wealthy one. This is pretty clear when we look at how menstrual periods were described in medical texts throughout the 1800s as times of ill health. Anytime a woman was either pregnant, menstruating, or in menopause she was considered unwell and her thoughts scattered and disturbed which was used in arguments against women being allowed to attend universities and higher education anyway was thought to atrophy the uterus. |
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| Erin Allmann Updyke |  | Atrophy the uterus! Can't have that. |
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| Erin Welsh |  | Absolutely not. |
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| Erin Allmann Updyke |  | With all that brain thinking. |
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| Erin Welsh |  | (laughs) And this perception of periods of course didn't just disappear suddenly in 1900. There's even a textbook from the 1970s that describes dysmenorrhea as a symptom of a personality disorder. |
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| Erin Allmann Updyke |  | I don't have any words. I'm just going to keep fish mousing over here. |
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| Erin Welsh |  | So that just made me think that there are probably some physicians still practicing today that may have been trained on that information, right? |
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| Erin Allmann Updyke |  | Oh definitely. |
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| Erin Welsh |  | Yeah. Up until at least the 1990s, although you could argue probably successfully that it's still the case today, it wasn't that science knew nothing about women's bodies and health, it was just that they knew a lot less than they did about men's. And let's look at why this is. As I mentioned earlier, the medical licensing laws enacted in the 1800s in effect excluded women and people of color from practicing medicine and contributing to the field. Those that remained were white wealthy men and so a white male as the baseline for comparison and the health ideal became entrenched in medical training and medical knowledge well into the 20th century. The 1960s and 1970s saw a great deal of change in terms of medical ethics as things like Tuskegee and thalidomide revealed the enormous failings of informed consent and protections for vulnerable individuals. Many of these developments in drug safety studies were overwhelmingly positive in terms of preventing people from being coerced into unsafe studies and being harmed. But one unintended consequence was when protection turned paternalistic, essentially preventing women from being included in drug trials simply because they were women or more specifically in the 1977 FDA policy, excluding women of quote "childbearing potential" from early phase drug studies. This meant anyone who potentially could get pregnant. |
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| Erin Allmann Updyke |  | Right. Anyone with a uterus that was presumed to be working. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | Just any of them. |
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| Erin Welsh |  | Any of them. It doesn't matter. This is a complicated subject of course because ensuring that no coercion occurs with informed consent is still tricky and there are potential risks associated with participating in clinical trials. But also without the inclusion of women of quote "childbearing potential" in these studies, how would we know if that drug is safe or effective for them? This is especially problematic and tricky in terms of pregnant people where it's kind of like a rock and a hard place situation, basically forcing a choice between including pregnant people in clinical trials which could put the fetus and the person at risk or in effect testing it out on them later in an uncontrolled fashion, hoping that the studies showing it's safe in people who are not pregnant will mean that it's safe for pregnant people. It's complicated and I'm not going to go into it here cause I just don't have the background knowledge to do so. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | But one thing that does seem to be clear is that there is under-representation of women and pregnant people in clinical trials. |
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| Erin Allmann Updyke |  | Yeah. That's why all drugs during pregnancy just have these like wacky like, 'Well, we don't know if it's safe but we don't know if it's harmful so it's probably fine.' |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | Like the scales that you use to define whether or not something is safe in pregnancy are not the same as when you're not pregnant. Yeah. |
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| Erin Welsh |  | It's far from a perfect system and it needs a lot of work. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | But the lack of inclusion of women in medical studies can't all be chalked up to this protective policy. Women were also explicitly excluded simply because they were women. Explanations ranged from, 'Well men and women are so similar that results from an all men study can be extrapolated to women,' to 'Women's menstrual cycles and hormonal shifts could confuse the study results.' |
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| Erin Allmann Updyke |  | (laughs) You can't have it both ways. |
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| Erin Welsh |  | Exactly. A) if results from men-only studies could be extrapolated to women, then why weren't there any all-women studies that were extrapolated to men? B) if there were no meaningful differences between men and women, why not include them both in the clinical trial? C) if menstruation could significantly affect the result of a drug trial, why on earth is it not a reason then to include women rather than to exclude them? And the answer to all of these... Here's another quote and I should say that unless I say differently these quotes are from 'Doing Harm' by Maya Dusenberry. Quote: "In short, studying only one sex was cheaper and easier and men were the chosen ones because women's bodies were thought to be too complicated." |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | Yeah. And there's also the matter that the medical community which since its infancy had been comprised primarily of men, either consciously or subconsciously felt that to know the health effects on men was enough. Right? Like, 'Well, we know it on men so that's good.' Right? |
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| Erin Allmann Updyke |  | Yep. That's all we need. |
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| Erin Welsh |  | And maybe it wasn't this malicious thing, maybe it just wasn't even thought about, women didn't even enter into the consideration which feels malicious even though I'm saying it wasn't malicious. I don't know. (laughs) But it wasn't until the late 1980s that enough women were involved in the medical community to bring these enormous gender disparities in medical research to light. At this time a group of scientists who were women formed what is now known as the Society for the Advancement of Women's Health Research and they demanded an audit by the government accounting office, the GAO, of the NIH's research efforts to see how well they had stuck to the 1985 policy for the inclusion of women in research. |
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| Erin Allmann Updyke |  | Ooh. |
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| Erin Welsh |  | This GAO report which was published in 1990 was staggering. They had done next to nothing. |
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| Erin Allmann Updyke |  | Wow. |
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| Erin Welsh |  | In most of the studies at the NIH funded, they couldn't say whether women were included or if they were, how many. So far I've talked about this more generally, right, in more descriptive abstract women are excluded from studies. So let's get into some more solid examples that illustrate the knowledge gap. For example there's a famous study called the Baltimore Longitudinal Study of Aging that was started in 1958 and aimed to study quote "normal human aging". This was the one that found that a baby aspirin a day could be protective against heart disease. You know that like now that's conventional wisdom or whatever. Yeah. That study didn't include women, included thousands of men, it didn't include women for 20 years. Another large scale study started in 1982 whose aim was to study the effects of dietary change and exercise on heart disease included 13,000 men and zero women despite the fact that heart disease is and was then one of the leading causes of death in women. And then there's this. I think it takes the cake. Quoted directly again from 'Doing Harm' by Maya Dusenbery. There's a quote and then a quote within a quote. The inception of quotes. Quote: "An NIH supported pilot study from Rockefeller University that looked at how obesity affected breast and uterine cancer didn't enroll a single woman." |
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| Erin Allmann Updyke |  | I'm sorry, breast and uterine cancer? |
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| Erin Welsh |  | Mm-hmm. It is true that people assigned male at birth do develop breast cancer. |
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| Erin Allmann Updyke |  | Uh huh. And uterine cancer, Erin? |
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| Erin Welsh |  | I don't think so. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | No. |
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| Erin Allmann Updyke |  | You need a uterus for that. Yeah. |
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| Erin Welsh |  | Continuing the quote: "As representative Snow noted dryly at the congressional hearings, quote, 'Somehow I find it hard to believe that the male-dominated medical community would tolerate a study of prostate cancer that used only women as research subjects.'" End all the quotes. |
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| Erin Allmann Updyke |  | (laughs) |
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| Erin Welsh |  | That one just echoed in my head for days. Nearly anywhere they looked there was a striking lack of inclusion of women and enormous consequences because of that. Biological differences between people assigned male at birth and people assigned female at birth have historically been used to claim inferiority or superiority while failing to examine the potential health impact of that difference such as in the way drugs are metabolized which is impacted by fat distribution and hormones among other factors. So when women aren't included in drug trials, should we be surprised by the finding that women are quote "50-75% more likely than men to have an adverse drug reaction"? That's not a surprising finding. It's horrible. |
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| Erin Allmann Updyke |  | Well and I also just wonder how many of those adverse drug reactions are often just passed off as being not real, discounted, not considered. |
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| Erin Welsh |  | I'm sure many. Yeah. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | The dosing of too many drugs has been determined by how it affects men's bodies and also overall like people within a certain BMI range. Or take chronic pain for example which women are known to be disproportionately affected by and studies indicate that women experience pain differently than men. And again, these studies didn't make the distinction between whether they were talking about sex or gender or whatever. Despite these pain differences there was a study from 2005 that found that almost 80% of animal pain studies used male animals only. And while the lack of sex analysis in animal studies of all kinds is hugely problematic, it really only captures one aspect of the knowledge gap. These studies don't take into account the gender bias and social factors that influence health and are hugely important to examine. |
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|  |  | The 1990 GAO report did change some things for the better but we're still not even close to equitable and many studies simply failed to report any sex or gender analysis of results. There have been suggestions to require the inclusion of such analysis for publication in peer reviewed journals but that has been met with some resistance for vague 'scientific' reasons. Whatever that means. But still even a things are getting better there's a huge lag time in between when those studies are conducted to when the results are analyzed and published to when it becomes presented to the interested field to then the wider community to then when it becomes included in textbooks to then when it trickles out to the rest of the public. |
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| Erin Allmann Updyke |  | Right. |
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| Erin Welsh |  | Let's illustrate. Picture someone having a heart attack. |
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| Erin Allmann Updyke |  | Okay. |
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| Erin Welsh |  | What do they look like? What are they doing? What are the signs and symptoms they seem to be feeling? |
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| Erin Allmann Updyke |  | This is a really good example, Erin. |
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| Erin Welsh |  | I love this example. Is it an older man? Probably an older white man clutching at his left arm and his chest. |
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| Erin Allmann Updyke |  | Little salt and pepper hair. |
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| Erin Welsh |  | Mm-hmm, salt and pepper hair. Maybe he's got a short sleeve button up shirt on. |
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| Erin Allmann Updyke |  | Definitely. |
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| Erin Welsh |  | Sweating a lot. |
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| Erin Allmann Updyke |  | Sweaty, super sweaty. Hee describes a pressure in the center of his chest which radiates to his left arm and maybe up into his jaw, he clutches at his chest, he might be gasping for breath. |
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| Erin Welsh |  | And then collapses. Yeah. How many of you pictured a woman with maybe some uncomfortable back pain or flu-like symptoms? Did anyone? |
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| Erin Allmann Updyke |  | Anybody? |
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| Erin Welsh |  | Maybe. I bet there are some out there for sure. Because much of the early research on heart attacks was focused on men, that's the search image we have and it can be deadly. Like when a study from 2000 found that quote, "young women" and I think by this was meant under the age of 50, "are seven times more likely to be sent home from the hospital in the middle of having a heart attack." Seven times! Those have fatal consequences. |
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| Erin Allmann Updyke |  | Oh god Erin, there's so many good examples of this. Do you know about the testicular torsion one? Testicular torsion, it's when your testicle twists on itself and it can cut off the blood flow. It's an absolute emergency. It causes excruciating pain, okay, in the testicles. And they say time is tissue, you have six hours to like diagnose and treat testicular torsion. And people are really good at it. There's a lot of studies in hospitals, like the time from into the emergency room to treatment and into the OR, it's super short. Ovarian torsion- |
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| Erin Welsh |  | (laughs) I knew you were going to say that. |
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| Erin Allmann Updyke |  | Same exact thing, okay. Your ovary twists around itself. The time from diagnosis to OR is I think at least twice as long if not missed entirely. It is staggering. |
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| Erin Welsh |  | Oh yeah. Yeah. There are honestly just grab bags full of examples about the diagnostic delay for anything, the treatment delay, what kind of treatment that's received. In general, men are seen as sick while women are seen as stressed. And all of these examples that you and I just sort of went through, these are tied to both the knowledge gap and the trust gap. Medical doctors only know what heart attacks look like in men and they are disinclined to believe that women's symptoms are real. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | So now let's get into the trust gap. If you thought the knowledge gap had deep roots, wait till you hear about the trust gap. In order to explain these roots I'm going to take us through a brief history of hysteria which was first described in Ancient Egypt and got its name from Ancient Greece, like I said, from the Greek word for uterus 'hystera'. What is hysteria? It's basically the idea that a woman's health and mental status is tied directly to her uterus and that all disease in a woman came from the uterus wandering around the body, like literally wandering. |
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| Erin Allmann Updyke |  | Just wandering around. |
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| Erin Welsh |  | But just like these restless uteri, the definition of hysteria has also wandered substantially throughout history. In Ancient Greece, in Hippocratic texts from around the 5th BCE it seemed to be thought of as an organic biological process, one which was likely to happen if marriage was put off for too long or if a woman didn't get pregnant early enough after puberty. In Europe and the centuries after throughout the medieval period, the meaning changed and became more spiritually based. And it was thought that the uterus could be inhabited by a demon or evil spirits or possessed via witchcraft. And the uterus became the scapegoat for any disease or complaint that a woman had in hysteria, the catch all diagnosis. |
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| Erin Allmann Updyke |  | The poor uterus, it's so maligned, Erin. |
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| Erin Welsh |  | It is, it is, yeah. It hasn't gotten that much better but it's gotten somewhat. |
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| Erin Allmann Updyke |  | No, it hasn't. |
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| Erin Welsh |  | Yeah. And this quality of hysteria as a disease of exclusion, it was useful to physicians especially as the field of medicine itself evolved. I've talked before on this podcast about how medicine changed substantially when measuring tools began to be introduced and measurements began to be compiled for certain diseases. Like blood pressure, what's a normal range, what's not. Heart rate, red blood cell count, body temperature, etc, all of these things. I think in our sickle cell episode I talked about how these tools, in addition to medical specialization, led to medicine shifting to be less about the person and more about the body or a part of the body. |
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| Erin Allmann Updyke |  | Yep, yep, yep. |
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| Erin Welsh |  | It also led to this important distinction between signs and symptoms, signs being something that someone who is not the patient can measure or see or feel, symptoms are the things that only the patient can feel and describe. Signs are objective, symptoms subjective. As the ability to detect disease signs became more refined, diagnosis increasingly relied on signs rather than symptoms and a physician could listen less or not at all to their patient and still end up successfully treating them, offering a not so great precedent. But it also meant that if there were no signs or the signs didn't tell them anything, they could and often did disregard the symptoms as hysterical. In the 1800s Jean-Martin Charcot tried to reclassify hysteria as a neurological disorder rather than a personality flaw, believing that the ovaries rather than the uterus diverted energy from the brain during menstruation, pregnancy, lactation, menopause, ovulation, etc and that the brain drained of all this energy could barely function and left women weak. |
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| Erin Allmann Updyke |  | Ugh, poor things, just all the time. |
|  |  |  |
| Erin Welsh |  | Plaques and lesions that Charcot found around the ovaries and uterus during autopsies confirmed his hypothesis to him and led to an increase in gynecological surgeries such as the removal of the ovaries, the uterus, or the clitoris. Surgeries which were permanently damaging if not fatal which around 50-70% were in the mid 1800s. I'm not going to get into Charcot's ovary presser but suffice to say that he carried out extensive medicalized torture on women in asylums to try to confirm his ideas about hysteria. From a wandering uterus to demonic possession to a neurological disease, hysteria had one more major transformation to undergo and it was this final one that left such an enduring mark on how women are perceived in medicine today. Enter - ugh - Freud. |
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| Erin Allmann Updyke |  | One of the worst of all time. |
|  |  |  |
| Erin Welsh |  | One of the worst, I'm going to try not to talk about him too much simply because- |
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| Erin Allmann Updyke |  | Ugh, let's not give him any more air time. |
|  |  |  |
| Erin Welsh |  | Well I think he's important to talk about because of the damage that he's done. |
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| Erin Allmann Updyke |  | I know, I know. |
|  |  |  |
| Erin Welsh |  | But I also want to get past him cause there's not enough time in the world to do all of this. So Freud initially jumped on the Charcot train of hysteria as a neurological disorder but then changed his mind, turning it into a disease that was entirely psychological, often attributed to the under-development of libido or sexuality or the rejection of feminine values or feminine traits, cured through talk therapy. What this did was turn real things that women were experiencing, pain, fatigue, heavy or irregular periods, infertility even, into something that she was doing with her mind. It's all in your head. This probably sounds familiar to many people listening today who have maybe been told something similar by a doctor they thought they could trust to listen. Because despite how this story is sometimes told, hysteria didn't disappear after Freud. It may have fallen out of fashion and lost credibility as a medical diagnosis a bit but number one, it wasn't actually removed from the DSM, the Diagnostic and Statistical Manual of mental disorders, until 1980. |
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|  |  | And number two, it never really went away but was rather repackaged. Out of this umbrella term hysteria came endometriosis, MS, chronic pelvic pain, many autoimmune diseases, somatization, psychogenic illness, medically unexplained symptoms, so many things. Freud's transformation of hysteria into a psychological disorder turned women into unreliable sources on their own body. Essentially a woman is thought to be lying about her symptoms unless there is observable proof to the contrary or her symptoms are real but psychogenic unless you can prove otherwise. A gynecology textbook from 1971 said that quote, "Many women wittingly or unwittingly exaggerate the severity of their complaints to gratify neurotic desires" end quote. And in the same textbook that morning sickness quote, "may indicate resentment, ambivalence and inadequacy in women ill prepared for motherhood." As if you needed more things to get angry about, right? I know. |
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| Erin Allmann Updyke |  | I can't rage in front of the microphone. |
|  |  |  |
| Erin Welsh |  | It all explains so much about today and how women are treated. Women began being seen as mentally ill rather than physically sick. And throughout the 20th century, the rate of psychogenic illness diagnoses increased enormously. If you were experiencing pain and complained too little, you weren't taken seriously because you weren't experiencing enough pain. But if you complain too much, you were labeled as an exaggerator, as dramatic, as crazy. One proponent of psychogenic diagnosis says that quote, "the vehemence with which many patients insist their illness is medical rather than psychiatric has become one of the hallmarks of the conditions." So the more you say no, this is a real pain, the more likely you are to be diagnosed with a psychogenic illness? |
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| Erin Allmann Updyke |  | Yeah, yeah, yeah. |
|  |  |  |
| Erin Welsh |  | What? There are scientific studies backing up these implicit gender biases in medicine. And it's not just male doctors that are mistreating women. Women on average are more likely to report pain and less likely to receive pain treatment. And this is not just a gendered issue of course but a racial one as well with people of color incredibly undertreated for pain. One study showed that after undergoing a coronary artery bypass graft- |
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| Erin Allmann Updyke |  | Oh my gosh. I hate this study. |
|  |  |  |
| Erin Welsh |  | Men were more likely to receive painkillers while women were more likely to receive sedatives. A study from 2006 by Chiaramonte et al found that when med students and residents were presented with a description of a patient experiencing symptoms, they initially diagnosed these patients similarly regardless if the patient was described as male or female. But if a stressful life event was added to the description quote, "only 15% of medical students or residents diagnosed heart disease in the woman compared to 56% for the man and only 30% referred the woman to a cardiologist compared to 62% for the man." That quote's from 'Pain and Prejudice'. The explanation given for the woman's symptoms turned from biological to psychological. And there was no difference in the results based on the gender of the doctors. It seems that too often when physicians meet with a patient, they see the diagnosis in the identity of the patient based on implicit biases built into the medical training system. |
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|  |  | If you're a woman it's in your head or your uterus, if you're a black person you're drug seeking. If you're trans and you're on hormone therapy it's because of the hormones. If you're fat it's because you need to lose weight. If you've ever been diagnosed with anxiety or depression, clearly that's what's causing your pelvic pain or your chronic fatigue. It's rarely that endometriosis could be a source of anxiety or depression, right? Instead it's depression causing your pelvic pain. Take this anecdote paraphrased from 'Doing Harm'. There was an 11 year old girl who had severe abdominal pain and nausea. She went to the ER, the doctor told her it was menstrual cramps despite the fact that she had not yet gotten her period ever. The pain didn't go away so the next day in agony she had to be rushed back to the ER. And at this point her mom who was a physician demanded an ultrasound and they found the largest unruptured appendix that the surgeon had ever removed. Would that have happened if it had been an 11 year old boy instead of an 11 year old girl? |
|  |  |  |
| Erin Allmann Updyke |  | Probably not. |
|  |  |  |
| Erin Welsh |  | Did the doctor even ask have you ever had your period before? Does this feel like period cramps? Are period cramps so bad that you should go to the ER? No. |
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| Erin Allmann Updyke |  | They shouldn't be. |
|  |  |  |
| Erin Welsh |  | Right. If they are that bad and you're in the ER, you're there for a good reason. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah, exactly. |
|  |  |  |
| Erin Welsh |  | Oh well, you know, deal with it. Take some ibuprofen and go home. And that's with an observable, detectable condition, right? |
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| Erin Allmann Updyke |  | Right. |
|  |  |  |
| Erin Welsh |  | You could look to find the unruptured appendix. Women who seek medical care for a condition that's not objectively observable or measurable or easily measurable and as you went into Erin, boy we are inadequate at describing and measuring pain. I mean, absolutely inadequate. These women, these mystery women are often a source of frustration for physicians and their dismissively called malingerers, neverwells, etc. Concern turns to resentment as nothing seems to work and the answer to the problem seems forever out of reach. I can't see anything wrong with you. So there must not be anything wrong with you. A physician's sense of self-worth shouldn't be tied up in having an answer or the right answer. There's an incredible power and empathy and saying, 'I don't know, but let's find out.' So where does that all leave us with endometriosis? We have come a long way since the early days of hysteria and endometriosis and the people who have made the biggest strides in raising awareness of endometriosis are patient advocacy groups. People who have had to become experts in a disease that their own physicians often failed to communicate with them about. |
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|  |  | But we haven't come nearly far enough. Stereotypes about endometriosis have persisted long after being disproven, such as endometriosis is rare in women of color or only happens to women who put off marriage and childbearing. These stereotypes combined with the outrageous lack of knowledge about how endometriosis actually works and the tendency for physicians to dismiss or downplay the pain experienced by women, these all contribute to the long, often excruciating years people have to wait for a diagnosis. And still endometriosis is too often made to be about a woman's social or gender role. Endometriosis can absolutely impact a person's fertility and for someone who wants or thinks they might want to have children, that's hugely important. But often fertility is preserved as a default without asking the patient whether or not subfertility or infertility would be acceptable if it meant reducing the pain. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | And a 2003 study found that women who sought out doctors because of infertility received a diagnosis of endometriosis in half the time that women complaining of menstrual pain did. |
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| Erin Allmann Updyke |  | It's not surprising and infuriating. |
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| Erin Welsh |  | Exactly. |
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| Erin Allmann Updyke |  | Like infertility matters but it shouldn't have to cause infertility to matter. |
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| Erin Welsh |  | Yes, that's exactly right. |
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| Erin Allmann Updyke |  | It's so frustrating. |
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| Erin Welsh |  | Yeah. And I think a large part of this is due to the fact that menstrual pain is so normalized, it's so accepted, and it's reinforced intergenerationally. |
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| Erin Allmann Updyke |  | Yep. Totally. |
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| Erin Welsh |  | It's not viewed as interesting or worthy of research despite being described for over 100 years and affecting approximately the same number of women as diabetes. Endometriosis gets about 5% of the research funds that diabetes gets. |
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| Erin Allmann Updyke |  | I almost used diabetes as my example, Erin. |
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| Erin Welsh |  | What did you use? |
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| Erin Allmann Updyke |  | I'm going with breast cancer. |
|  |  |  |
| Erin Welsh |  | Oh, okay. |
|  |  |  |
| Erin Allmann Updyke |  | It's not too far. |
|  |  |  |
| Erin Welsh |  | I'm curious, yeah. But periods aren't fit for polite conversation. They're simply the price of being a woman, right? No, not true periods. Periods shouldn't be painful, people don't even need to have periods. And if there is pain, it should be believed and understood. Let's talk more about periods. |
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| Erin Allmann Updyke |  | Let's! |
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| Erin Welsh |  | Let's talk about consistency, let's talk about the number of times you have to empty your diva cup or change your pad or change your tampon. What brands do you like the best? Are there any things that you do that help your period and make you feel better? Like all of these things, so important. Okay. |
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| Erin Allmann Updyke |  | Yeah. Say it, Erin. |
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| Erin Welsh |  | I want to end finally after this very long history with a quote from of course again, Maya Dusenbery from her book 'Doing Harm'. Quote: "There is always a gap between when a symptom begins and when it is medically explained. It is unreasonable to expect that doctors who are fallible human beings doing a difficult job can close this gap instantaneously. And given that medical knowledge is and probably always will be incomplete, they may at times not be able to close it at all. But it shouldn't be unreasonable to expect that during this period of uncertainty the benefit of the doubt be given to the patient, the default assumption be that their symptoms are real, their description of what they're feeling in their own bodies be believed. And if it is medically unexplained, the burden be on medicine to explain it. Such basic trust has been denied to women for far too long." End quote. So Erin, I have a feeling I might just get angrier but can you tell me where we stand with endometriosis today? |
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| Erin Allmann Updyke |  | I can try, Erin. |
|  |  |  |
| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | Maybe we should take a break first. |
|  |  |  |
| Erin Welsh |  | One last break. |
|  |  |  |
| Erin Allmann Updyke |  | One break. |
|  |  |  |
| TPWKY |  | (transition theme) |
|  |  |  |
| Erin Allmann Updyke |  | Almost every single paper that I read, and I read a lot of papers, universally cited this statistic that 10% of women of childbearing age have endometriosis. And that's it. That's the number that I have, Erin. |
|  |  |  |
| Erin Welsh |  | Okay. And these numbers, when are these papers from? And so would those diagnoses have been based on surgical identification of tissue or..? |
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| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | I basically only looked at papers from 2010 and sooner, so within the last 10 years. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | And universally that is what they all said. I have found no papers that tried to dig deeper and really get a sense of are these numbers changing? Are we seeing it more, etc? And what's really frustrating is that none of the papers dug down into what does that actually mean? Because people who are not childbearing age can have endometriosis, lots of people with a uterus that aren't women of childbearing age can have endometriosis. And so does that 10% actually mean like 10% of people with a uterus have endometriosis? Or is that number higher because people with a uterus maybe had endometriosis when they were younger and now they're older, the symptoms have gone away? But those people still count, right. So I don't have an answer for you. |
|  |  |  |
| Erin Welsh |  | Right. Or what about people who have endometrial lesions and might not have symptoms that have led them to go seek a diagnosis? |
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| Erin Allmann Updyke |  | Right. And that's what's so infuriating is that this 10% number assumes that it includes those people. Yeah. And so it says that 30-50% of those 10% will then have pain from this endometriosis. |
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| Erin Welsh |  | I doubt. No, no. |
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| Erin Allmann Updyke |  | Give me strength. But statistics also cite that upwards of 60% of women, by which I assume what they mean is 60% of people with a uterus, that suffer from chronic pelvic pain have endometriosis as the likely cause of this pain. And those statistics, both of them, no matter how flawed they are, are incredibly high. |
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| Erin Welsh |  | I mean, staggering. |
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| Erin Allmann Updyke |  | 10%. Even if we assume that 10% of people with a uterus is the real number, 10% of people with a uterus. Okay, let's compare that. Erin, you mentioned diabetes. Almost used that but let's talk about breast cancer, shall we? |
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| Erin Welsh |  | Let's, let's. |
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| Erin Allmann Updyke |  | 13% of women in the US will develop breast cancer. 13%. That's really close to 10%. We have a whole month dedicated to breast cancer. Don't we? |
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| Erin Welsh |  | We have one for endometriosis too. |
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| Erin Allmann Updyke |  | Oh really? But no one's heard of it! |
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| Erin Welsh |  | (laughs) Yeah, that's fair. |
|  |  |  |
| Erin Allmann Updyke |  | But everybody knows about breast cancer. Everybody knows how important breast cancer is. Everybody knows somebody who has survived breast cancer or everyone has lost someone from breast cancer. Right? And so many people have no idea what endometriosis is let alone care enough to, I don't know, encourage funding of research for it. And I think - this is now my soap box - this is for a lot of reasons that Erin, you really kind of focused on so many of them and if we really drill down to it, it comes back to the patriarchy as it always does. But at its core it also is because, I think, endometriosis is classified in all of the literature as a quote "benign condition". |
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| Erin Welsh |  | What? |
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| Erin Allmann Updyke |  | So endometriosis is classified as a quote "benign condition". |
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| Erin Welsh |  | And so this means it doesn't kill you? |
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| Erin Allmann Updyke |  | So what this is in contrast to is a malignant condition such as cancer. And what that means is yes, in general a benign condition is not going to kill you if left untreated, at least not directly. Cancers which are malignant invade and metastasize, that is they spread in a way that if left untreated is often fatal. Now I can see your face, Erin. Endometriosis is really, really interesting because it in fact does metastasize. It can metastasize in a way, right? It can be found well outside the peritoneal cavity and by definition it is tissue found outside where it's supposed to be. And in the case of deeply infiltrating endometriosis, it does invade deeper tissues in the same way that cancer can but endometriosis causes pain, causes suffering, causes in fertility, and that my friends is seen as benign. It can invade your bowels and cause obstruction but it usually doesn't, that's uncommon. It can invade your bladder or your ureters and cause obstruction. It can cause destruction of your ureters but it doesn't often. And because it's a histologically recognizable tissue type and because it "generally" quote unquote doesn't invade to the extent that a cancer would and because it generally subsides after menopause, after the withdrawal of those hormones, it is quote "benign". It's clearly nothing of the sort. |
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| Erin Welsh |  | Obviously. So in non medical language, benign is like not harmful, not bad. So is there a different interpretation? I'm just trying to give that a little bit of the benefit of the doubt because this is so staggeringly appalling. |
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| Erin Allmann Updyke |  | Yes. It is, it does mean in the medical sense in that it is not a malignant condition. |
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| Erin Welsh |  | But I mean does the use of the word benign in medicine then influence people who are practicing medicine to view a condition as benign as in the popular interpretation of the term? |
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| Erin Allmann Updyke |  | In my opinion, how can it not? |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | When we're talking about pain and we've talked so much about how difficult pain is to understand, to explain and to sympathize with and to empathize with if your pain perception is different than someone else's pain perception or pain sensitization. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | Right? I also do want to point out that the risk of eventual ovarian cancer diagnosis, so cancer, the malignant condition in people with long standing endometriosis is two to threefold higher than in people without endometriosis. So even though endometriosis itself is not a cancerous condition, it's not without its risks. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | Right. So far as that goes. Isn't that just fascinating though? So I found that to be very sort of problematic, what I think is likely a big contributor to why endometriosis kind of has maybe the rap that it has, right. Just this classification of it. And medically, I actually found one paper that was kind of like, is it correct to call it a benign or is it not in terms of the medical definition of the term benign? |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | Because it does behave in ways that benign tissue doesn't and yet it doesn't behave the way that a cancer does. And it doesn't fit the definition of a cancer. There have been a number of new mutations identified in endometrial tissue that are associated with cancer but never enough of them, like only one mutation instead of three mutations, that would then cause it to be a cancer. So it is not a cancer and it does not metastasize the way that a cancer does but it's not normal tissue either. So it's an interesting disease in that respect and we have a long way to go to understanding it. I was thinking this and feeling this and then I went for a walk today and I was listening to an episode of Vox's podcast Unexplainable and they have an episode on endometriosis. It's really great, it has stories from 14 people who have been living with endometriosis. I recommend the listen. |
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|  |  | But they also had an interview with someone who researches endometriosis. It's Dr. Lisa Griffith, she is at MIT and runs the Center for Gynepathology Research. Her research is super fascinating, it focuses on tissue engineering, like growing endometrial tissue on chips. And they're trying to develop better diagnostic markers that can be used to not only diagnose but then also classify endometriosis into different subtypes which could then theoretically lead to more personalized or targeted treatment options which is amazing. But she also brought up this exact same thing that the language that we use surrounding endometriosis is so important. And she was saying that her collaborators kept calling it a benign condition, benign condition. And she was like, I live with this. She has endometriosis. She's like, there's nothing benign about it. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | Right? But it's that difference between quote "medical language" and colloquial language. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | But it matters, right. |
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| Erin Welsh |  | It matters. |
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| Erin Allmann Updyke |  | And it influences, we are all humans even in the medical community, it influences the way that we perceive it and then the way that we treat people who are living with it. There are a lot of people doing research on endometriosis from so many different angles because there's so much that we don't know. So I already mentioned some fascinating research by the Center for Gynepathology Research. There's also other groups like Citizen Endo which is led by Dr. Noémie Elhadad at Columbia University and their team, super fascinating, are using citizen's science-based tools to try and better characterize the symptoms of endometriosis to try and bridge the gaps between what clinicians know or think they know or think about endometriosis and how people who are living with it actually experience endometriosis which I love so much. |
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| Erin Welsh |  | I know, I love that project so much. It's so cool. |
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| Erin Allmann Updyke |  | Yeah. I think honestly in so many ways we're still in the phase, I think we've talked about this in a number of different episodes Erin, but we're at the phase in endometriosis right now where we still are trying to just like garner awareness about this condition. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | So I have a feeling after this episode maybe a lot of our listeners are going to be going to their doctor's offices like, 'So, can I ask you about endometriosis?' |
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| Erin Welsh |  | So I shouldn't be laying in bed all day, not able to go to work because of my period? |
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| Erin Allmann Updyke |  | Yeah. I didn't even get into like the statistics on the number of missed school days, the number of missed work days. |
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| Erin Welsh |  | The economic burden! Yeah. |
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| Erin Allmann Updyke |  | The economic and financial burden is in the billions of dollars every year. |
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| Erin Welsh |  | Yeah, yeah. |
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| Erin Allmann Updyke |  | So that is endometriosis. |
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| Erin Welsh |  | There it is. Sources? |
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| Erin Allmann Updyke |  | Sources. |
|  |  |  |
| Erin Welsh |  | I have some papers but I mentioned the four books that I read, all great, love them. And if you do want to know more about the medical history of endometriosis, who found it, who made this development and that development, sort of the argument over who was the first one to describe it, there is a very extensive, I'm talking like over 50 pages paper by Nezhat et al from 2012 that goes into all of that, found that very interesting. And in terms of the evolutionary biology, those papers that I mentioned are both by Dinsdale et al from 2021. |
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| Erin Allmann Updyke |  | I had a number of papers. I already said the title of one, 'The epidemiology of endometriosis is poorly known as the pathophysiology and diagnosis are unclear.' That was from Best Practice and Research Clinical Obstetrics and Gynecology from 2021. There was a number of other really interesting papers that dig deeper into what we know about the mechanisms of endometriosis. I think my favorite one was from Nature Reviews Endocrinology in 2019 as well as another one in the Annual Review of Pathology: Mechanisms of Disease from 2020. We'll post all of these sources from this episode and every one of our now 88 episodes. Wow. |
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| Erin Welsh |  | 88 normal season episodes. |
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| Erin Allmann Updyke |  | Right, not including COVID, on our website thispodcastwillkillyou.com. |
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| Erin Welsh |  | We will. |
|  |  |  |
| Erin Allmann Updyke |  | Yep. |
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| Erin Welsh |  | Thank you again so much, Susie, for sharing your story with us. I loved chatting with you and yeah, we just really appreciate it. |
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| Erin Allmann Updyke |  | Yeah, thank you. Thank you also to Bloodmobile for providing the music for this episode and all of our 100 plus episodes. |
|  |  |  |
| Erin Welsh |  | Thank you to Exactly Right media, we are so proud to be a part of this network. |
|  |  |  |
| Erin Allmann Updyke |  | And thank you to you, listeners. We make this podcast for you. |
|  |  |  |
| Erin Welsh |  | We do. |
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| Erin Allmann Updyke |  | And thanks for sticking through this really long episode. I hope you learned something new. |
|  |  |  |
| Erin Welsh |  | I hope so too. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | And a special thank you also to our wonderful, incredible, beautiful patrons on Patreon. |
|  |  |  |
| Erin Allmann Updyke |  | On Patreon, love you so much. |
|  |  |  |
| Erin Welsh |  | Well until next time, wash your hands. |
|  |  |  |
| Erin Allmann Updyke |  | You filthy animals. |