**Name:** 4. Dealing with the unknown

**<Files\\E01\_Anne> - § 16 references coded [44.32% Coverage]**

**Reference 1 - 0.34% Coverage**

**Interviewer:** [00:00:16] Right. OK. So first question is, how did you become interested in PMS or premenstrual syndrome?

**Anne:** [00:00:28] [Redacted- personally identifiable data].

**Reference 2 - 1.28% Coverage**

**Interviewer:** [00:08:36] So was it in childhood? Was it when you were training?

**Anne:** [00:08:42] Yes, it was when I was training, so I can not remember... I have no memories of being aware of it during my teenage years, you know, having started my periods. Obviously, friends, teenage friends, I have no memory of it then. Erm, Or really during medical school, to be honest, I can't remember having any teaching about it. It was when I went to... was training as a GP and I can't remember a 'particular' patient who perhaps triggered my interest. It was more around the reading material, the things I was exposed to in terms of my training then, that... where I developed my interest. Yeah.

**Reference 3 - 3.56% Coverage**

**Interviewer:** [00:09:37] That's great. Thank you. And so you've touched on this previously, but how common is p.\_m.\_s roughly?

[00:09:50] [pause] Erm, I would put the prevalence of... Pre... if we're talking about premenstrual disorders. So, you know, it just very simply the cyclical mood, er the cyclical symptom change with impact on quality of life. I would put that around the 20 percent mark. And then the very severe end of the spectrum, about 5 percent. I do have a... a slight confusion or difficulty around the diagnosis of premenstrual dysphoric disorder because that is based on... (now. I'm just going to use a little bit [my notes]. So it is... that is based on the American Psychiatric Association's, the definition of where you need five out of eleven symptoms, one which must be from a list of the first four. And so that... that I think myself and the other trustees at NAPS come from a very clinical background where we do look at specific definitions. And I think that that definition, that diagnosis of premenstrual dysphoric disorder excludes some women that don't conform to those criteria, but still have very severe symptoms that impact on negative life and may make them feel suicidal. So I do have a slight issue. You know the... just the uncertainty around that. And I think that's why [names of colleagues] produced the comparison of a different definition definitions, which is on the website. I can't... Remember the original question now? Sorry.

**Interviewer:** [00:11:54] It was about prevalence...Well, with all prevalence, to be honest, it's a little bit with a pinch of salt, isn't it? It's a..

**Anne:** [00:12:02] It is, absolutely. Yeah. So to answer your question very simply. Twenty percent for p.\_m.\_s premenstrual disorders. Five percent for what we're saying is PMDD. But I think that five percent should also include the very severe end who don't conform to the criteria of the DSM 5.

**Reference 4 - 2.86% Coverage**

**Interviewer:** [00:12:34] So, er... again, this is your understanding, I just want to hear from you. What's your best understanding of why pre-menstrual symptoms occur?

**Anne:** [00:12:48] {pause] I think it's best to split that down into the... er the physiological and then the social and the psychological. So in a particular woman, there will be a complex interaction of those factors that then lead to how she experiences pre-menstrual symptoms. So we'll take those each in turn. Physiological: So lots of work has been done around whether it erm, you know, particular hormones or chemicals contribute. And my understanding at this present time is that there is likely to be a genetic component, which, you know, research is going on about that... that is not due to a particular deficiency of a hormone. But put simply, there are variations on this. But put simply, what happens is that there are cyclical changes in the normal menstrual cycle... when ovulation occurs. The hormone changes change again. And there are... there are sort of feedback pathways up to the brain...? And when those hormone changes happen in susceptible women and this possibly is where the genetic thing comes in [laugh] that affects neurotransmitters in the brain. So things like your serotonin, your GABA. And that it is those... Chemical changes, which can affect a woman's mental and physical health. I think it's more complex than that. I think the physical changes, those are linked in with er adrenal function. So it's there. That's where it becomes quite complex.

**Reference 5 - 2.96% Coverage**

they're looking at a drug that you inject in the Luteal part of the cycle. And that, I think affects GABA metabolism. So looking at. So that's an overview of the physiological. Erm social: This is where, you know, our social situation effects or psychological health, such as, you know how stable we are in terms of our home, our work, our family. Erm, What's going on at work? So any stress is going to lower the threshold for symptoms to be experienced and then psychological: So... if ... if somebody has... a woman has... er... perhaps a predisposition because of her personality... or some underlying psychological condition, then perhaps she's more likely to experience premenstrual symptoms. And, you know, that brings me on to the group of women who get the premenstrual exacerbation where they have an underlying psychological or physical problem, but then it does get definitely worse. And that, you know, that's... er... I'll bring it up now. But you're probably going to talk about it. That's why it's just so important in these women to track their symptoms. It can give you sooo much information about what is actually happening. And, erm, you know, I have had women who really come and they really feel that they've got PMDD or p.\_m.\_s. And if they track the symptoms over two... two months, there's just no correlation to the bleeding at all! And you just think that but that is actually quite... very useful because to actually see it... visually that that's not happening can actually be helpful for them. And also can guide your treatment about what would be the best management for them.

**Reference 6 - 7.25% Coverage**

**Interviewer:** [00:17:25] progestogens.Another tricky one. Again, this is in your understanding, in your opinion, what's the best way or ways to manage p.\_m.\_s?

**Anne:** [00:17:35] I don't think there is a clear cut one answer to that, so I'll just go through how I would approach a person who or the management of a woman coming along to me in my general practice. So I would... this is always difficult because you just have so little time in general practice, but you would often get people back to talk more, er, so just try and get an overview of what's happening. As I said, in the end of answering the last question, absolutely essential. Unless... unless I mean, the gold standard is to track symptoms. But if you get a woman who gives a very clear history of what's happening, then I don't think it's always essential. But... I... I think, you know, you have to be very clear otherwise. And the standard is to do two months, over two months prospectively. They've shown that retrospective collection of data isn't very accurate. And so I would then, you know, get it. Obviously, in general practice, you've got the medical history there. But I would explore, you know, just come up to date on get myself up to date on that. What medication shown? Is there anything what hormonal treatment she's on? Because as you know, exogenous hormones can sometimes exacerbate. Has there been a change, as you know, women... Some women are sensitive to progesterone and progesterone. So it can often. And the woman hasn't realized that it's actually... was related perhaps to starting the pill. So I'd look at all that and look at her lifestyle. And there is, you know, some evidence that if a woman maximizes the good life style in terms of diet, spacing her food, having the... more of the low glycemic index foods, exercise, some case control studies have shown that exercise is very good, er can alleviate symptoms. And then I would... as I've illustrated there's a lot to go through! {laugh] So I. And being a part of NAPS so I would direct them to the guidelines that [colleague name] has written. And because... I mean we are planning to update those, but they're still current and so start to introduce possible complementary therapies and then explore what the woman wants. And there are basically... errrr, two main groups of treatment. First of all, if... you know, based on what I've said about why it happens if you suppress the cycle, then... and the woman isn't sensitive to the hormone you're giving to do that. There's a good chance you're going to help her. So I've seen a lot of success erm, giving... This isn't licensed for this use. It is like... this treatment is licensed for HRT... in hormone replacement therapy, but not for p.\_m.\_s. So transdermal estrogen to a level where you actually suppress the cycle. But you can't. If a woman's got a womb, you can't just give oestrogen on its own. You have to give progesterone. And that can be where there can be a problem with PMS because a lot of women are sensitive to the So that's where they get the benefit of seeing a doctor or specialist nurse who's got expertise in this area is so important. So you know, you can find a regime that helps the woman and doesn't exacerbate symptoms. So that's the hormone... Sometimes the contraceptive pill can help because it suppresses the cycle. But as I've said, sometimes the woman is sensitive to those hormones. You're giving. the other route is the anti-depressants called the selective serotonin receptor inhibitors, SSRIs. [Laugh] And they, as the name suggests, affect the serotonin metabolism in the brain. So counteract the changes that I was talking about. And interestingly, they've been shown to be just as effective given in the second half of the menstrual cycle as given continuously. So they obviously work in a slightly different way to how they do in depression. And that can be a useful treatment option.

**Reference 7 - 2.61% Coverage**

**Interviewer:** [00:31:43] what is the difference between p.\_m.\_s. versus PMDD.

**Anne:** [00:31:49] The difference?

**Interviewer:** [00:31:50] Yeah.

**Anne:** [00:31:59] [long pause] So... {pause] so, I think I have gone into that, that PMDD is a premenstrual disorder that... And to be diagnosed as having that. It's a definition that was put together by the... the American Psychiatric Association as in the 'DSM', the 'Diagnostic and Statistical Manual of Mental Disorders' number five, and those five out of eleven symptoms need to be demonstrated. One out of the first four, which are all psychological symptoms and... [pause] The true definition of PMDD. Actually, it doesn't include exacerbation of another psychiatric disorder. So again, I think that excludes quite a number of women, whereas p.\_m.\_s premenstrual syndrome. Erm, That I mean, if we're looking at the actual definition, I know people refer to p.\_m.\_s in a lot of situations, but the pre-menstrual syndrome, that's the American Congress of Obstetrics and Gynecology. And that definition is one out of six mood symptoms and one out of four physical symptoms... does include exacerbation of another psychiatric disorder. Or... both do require significant impact on quality of life. So I think what I've described is the. Specific criteria for the definitions of PMDD and p.\_m.\_s. But I think we do use those terms much more loosely across the board.

**Reference 8 - 1.61% Coverage**

**Interviewer:** [00:35:31] Brilliant, thank you. this is...this is one that I like getting the answers to. In your opinion, what does the term bloating specifically refer to?

**Anne:** [00:35:47] Tummy. Your stomach. So... erm, A feeling of sort of tightness. Around the abdomen. I think, you know, if it is a pre-menstrual thing, it's sometimes related to fluid retention. I mean, there are lots of different reasons why women feel bloated premenstrually. So it can... can be associated with breast tenderness as well. But no, I would bloatedness. I would say is... more... if somebody said that, I'd be thinking that they're getting fullness around their tummy or stomach,.

**Interviewer:** [00:36:38] So Do you mean trapped gas, maybe?

**Anne:** [00:36:39] Well, that's another cause of it. Yes. Yes. Just as in irritable bowel, it's very common. Or after a big meal [laugh].

**Reference 9 - 2.61% Coverage**

So p.\_m.\_s is considered by some to be a controversial diagnosis. What is your understanding of why this might be?

**Anne:** [00:43:08] [long pause] I think I probably answered that in the question of when I was talking about The RHS Garden that I think every individual will have. A perception, a view of what p.\_m.\_s is. Which is based on the underlying knowledge, which is based on how interested they are, what experiences they've had, whether it's touched their lives. Erm, And so. I don't think you can generalize. You will get some people who are very understanding and I think it's just that really reflects why peer support groups can be so useful. We have one. I have a colleague who is very set up, a peer support group in Derby, which I go to. And it's just so helpful for people, actually. Women actually talking about their own experiences. But then it's a bit like the menopause. I think the more we can get it out in the open, the better. It's a lot around understanding. It's about. [pause] Some... you know, why do people view it negatively? A lot of that will be because they just don't understand. So it's a bit like what's happened with the menopause, a lot more teaching in the workplace, making colleagues aware of the problem. I think would be really helpful because I think there is still a lot of lack of information and knowledge out there. And I think that reflects in how people view it.

**Reference 10 - 1.39% Coverage**

Basically,are you aware of (.) anyone saying, "oh, it's not really real" or, you know, sort of dismissing it?

**Anne:** [00:46:39] Oh, yes, I've definitely come across people like that. Both friends or relatives of women or health professionals, to be honest. As I said, I think that just reflects a lack of understanding and you know many (.) people often make fun of things because they don't they don't want to face it themselves. They don't want to face or er even, you know, it's a lack of understanding. But for some people, they don't want to know what it is. They're not interested. So I think it's about it it's about empathy isn't it? it's about compassion for that person, you know, giving sympathy, but also understanding how they're feeling.

**Reference 11 - 3.46% Coverage**

**Interviewer:** [00:47:39] Ok, so the Montreal consensus that you've already mentioned.

**Anne:** [00:47:46] Yes.

**Interviewer:** [00:47:47] Decided to go for the. 'Any symptoms count' definition so long as they occur in the luteal phase, that they resolve shortly after menstruation and their severe enough to affect daily life. How do you feel about that particular definition?

**Anne:** [00:48:06] [pause] I think it was.[pause] Very good. Because there have been so many different definitions that it's been. Difficult when it comes to, say, in the research field, comparing studies because different criteria have been used. So the main aim of the Montreal consensus was to come to a consensus on a definition so that it could be applied consistently both in the clinical field and also research in the future. I mean, I know a few of the people who were on the group, and I know that it was very, very difficult because everybody was coming from different schools of thought about it. So it must have been very difficult to come to a consensus. I think the other thing that I like about the Montreal Consensus is that you've got the core premenstrual disorder and then the different variants as well, because it is very complex. But that... that I think they did [pause] group that very well to include premenstrual exacerbation, to include premenstrual disorder, even with an absence of menstruation, say somebody has got a hormone coil or they've had a hysterectomy. And so I thought it was very good in that respect as well. And. I think one of the problems around premenstrual disorders is you've got these two disciplines, you've got the psychiatrists who favor the psychiatric symptoms and you've got the gynecologists who will tend to focus more in on the menstrual symptoms, physical symptoms. And so I thought it was good in that it brought together both disciplines.

**Reference 12 - 3.17% Coverage**

**Interviewer:** [00:51:42] Yeah, and actually both of them are almost exactly based on the DSM 5...

**Anne:** [00:51:48] Right. Yes. Yeah. No, they are very weighted towards psychological symptoms, aren't they? So no, I agree. [pause] I think. That I must admit, in art, we based our menstrual calendar or diary, on the Moo's menstrual questionnaire as well, which is one that goes back a long way, and I can I think one of the...

**Interviewer:** [00:52:19] Was it the really long one? Because There's a full one and there's also the shorter one...

**Anne:** [00:52:26] It was based on the short one, because the eleven symptoms that I was talking about earlier on is what we extracted from that. And I think that's one of the things that we were looking at, how we could have done things better in our study that we emphasized the psychological symptoms too much. So, no, I think the ideal questionnaire would. Conform more to the Montreal consensus and have a range of physical and psychological symptoms. I don't think they've actually produced a questionnaire. Have they?

**Interviewer:** [00:53:04] No... and I know that there are other issues. It's about what's been clinically proven and what hasn't. And I think that's basically why these are the tools that are currently recommended. It's because they have met those clinical quality criteria. But it's just interesting that at the moment there's a little bit of a mismatch.

**Anne:** [00:53:24] Yes. Yes. But whether you could know whether a useful thing would be 'any other symptoms' or something where people can actually record what symptoms they have. But, you know, the question does need to be validated, doesn't it? So that in itself is a big thing to take on.

**Reference 13 - 2.54% Coverage**

**Interviewer:** [00:54:39] And also separate from p.\_m.\_s. How do you feel about that? Is that something that's useful?

**Anne:** [00:54:48] I as [pause] I said earlier, I [pause] I don't... Erm, I think a lot... Quite a proportion of women who I've seen who've been given the diagnosis, of PMDD have underlying. Psychological symptoms, although throughout the cycle and they just get an exacerbation and, you know, in the... Erm, The International Association for Premenstrual Disorders, which where there is very much an emphasis on PMDD, they talk a lot about PME as well, don't they?

**Interviewer:** [00:55:31] Yeah.

**Anne:** [00:55:32] So that doesn't that isn't part of the PMDD definition. So I think that's a little bit... I think there there are some women who I feel are severe enough to warrant that diagnosis but still get symptoms... Even though it's less severe, less symptoms or throughout their cycle so, but by definition, they can't have PMDD because that's what we wanted to emphasize in the statement on the NAPS Web site. Not only that, but also there are some women who are severely affected that don't conform to the DSM criteria, and yet they've still got very severe PMS.

**Interviewer:** [00:56:26] Yeah. I mean, this is why I'm asking these questions. Within even single definitions there are tensions sometimes.

**Anne:** [00:56:35] Yes. Yes, that's right.

**Reference 14 - 3.77% Coverage**

**Interviewer:** [00:56:40] So normally, particularly the most recent clinical guidelines haven't included information on the psycho-social. So like you're saying, the kind of nonbiological or external life experiences that can contribute to these disorders. How do you feel about that?

**Anne:** [00:57:07] [long pause] I suppose they might have... er... Felt that they've covered that when they talk about counseling and CBT as part of the treatment because, you know, within that you will be addressing those issues... I suppose where... you know I hadn't really picked that up. These are from the RCOG guidelines, are they?

**Interviewer:** [00:57:31] Yeah. I mean I think it's just that there's pressure to not write so many pages, you know...

**Anne:** [00:57:38] Yeah.

**Interviewer:** [00:57:38] If You want people to read them. But I think it's interesting that across a few of them recently it hasn't really been mentioned. But you're you're right. CBT is mentioned as a treatment.

**Anne:** [00:57:49] Yes... Which would cover those things. But you know, where I think it's a shame that that that's been missed out. Is for the GP really because. You know, just actually teaching them that it is important to look at the whole... I mean GPs do, that's what they do, they practice holistic medicine. But, you know, really important that actually the social situation, some... if somebody has a poor mental well-being, then the threshold for getting the PMS symptoms will be lower. Yeah. You know, that's a good point. If you don't mind, I'll take that on board when we're doing our guidelines?

**Interviewer:** [00:58:37] Yeah, Well, I'm more than happy to help with that. That's my kind of... that's my overall aim is that my thesis will eventually really help improve that kind of... I know it can never be 100 percent accurate, but to sort of get to somewhere that's as good as possible on..

**Anne:** [00:58:52] Right. I mean, do you mind if I take that to the trustee meetings?

# E22

**Interviewer:** [00:58:56] No, no. Absolutely. Fine. Thank you.

**Reference 15 - 2.29% Coverage**

I think what I'm getting at is that the moment the DSM definition is of a mental health disorder and yet it's including menstrual changes, you know, that are always.. you know, going to happen.

**Anne:** [00:59:48] Yes. I suppose they... They've... they've acknowledged that there are physical changes, but I very much regard the DSM diagnosis as more psychological psychiatric symptoms. Yes, I suppose they have just acknowledged it to... To exclude those completely I think would be wrong. But they've weighted it very much towards mental health, haven't they?

**Interviewer:** [01:00:22] Yeah.

**Anne:** [01:00:25] And I don't know whether you have to have a physical symptom in that?. No, you don't, do you?

**Interviewer:** [01:00:31] it doesn't differentiate them...You don't have to. And in fact, most of them are in one line in one of the eleven criteria. It's kind of...

**Anne:** [01:00:38] Yes,.

**Interviewer:** [01:00:39] Six or seven. are usually listed in one box,.

**Anne:** [01:00:43] Which isn't helpful particularly. Is it?

**Interviewer:** [01:00:45] No

**Anne:** [01:00:46] Like because.. it doesn't differentiate ...

**Interviewer:** [01:00:48] Yeah like between breast pain and gas, for example [laugh]

**Anne:** [01:00:53] Yeah.

**Reference 16 - 2.63% Coverage**

**Interviewer:** [01:01:07] Well I think you will have definitely of the one. Have you ever used or read about the use of diuretics like Spirolactone?,

**Anne:** [01:01:25] Yes [name of colleague] That was one of his first studies around PMS. He did lots of you know, he did lots of. And his team did lots of erm.. systematic reviews of the different treatments. But he did do a study in the 80s about Spironolactone... Well, [pause] Gosh you're testing my physiology now, but I think for... there's some evidence that for... [pause] Fluid retention. It has a positive effect, but I must admit it wouldn't be one of the first line choices. There are other drugs now that have an anti diuretic effect. You know, there is drosperinone in some of the combined oral contraceptives that have a similar... work in a similar way. And so I think most clinicians would favor giving that, you know, combined oral contraceptive with drospirinone and that out of this... Now, the story around combined hormonal contraception is. A complex one because the original studies didn't show benefit. But more recent ones have shown that giving long cycle therapy and using combined oral contraceptives with drospirinone in can have a positive effect on pre-menstrual symptoms, particularly with respect to fluid retention, which is what the spironolactone did and erm, anti- androgenic effect so like for acne. So good for that side of things. Yeah.

**<Files\\E02\_Babara\_email> - § 12 references coded [50.05% Coverage]**

**Reference 1 - 0.74% Coverage**

# E3

1. Do/ did you identify as someone who gets PMS?

NO

**Reference 2 - 1.35% Coverage**

1. How did you first come to know about PMS?

Working in gynecology in an academic medical center.

**Reference 3 - 4.22% Coverage**

1. What is your understanding of *why* premenstrual symptoms occur?

The etiology remains unclear. It is hypothesized that the biochemical changes of PMS involve central nervous system-mediated interactions of the reproductive steroids with neurotransmitters. Hormone levels alone are NOT the cause.

**Reference 4 - 5.93% Coverage**

1. Men can also experience nearly all of the same symptoms described as being associated with PMS, just without any cyclical pattern. Do the same symptoms therefore have different biological mechanisms, depending on the patient’s sex?

If there is no cycle pattern, it is not PMS. Most symptoms in this world are non-specific and must be explored in relation to the individual and his/her situation to understand a diagnosis.

**Reference 5 - 2.80% Coverage**

1. PMS is considered by some to be a controversial diagnosis- what is your understanding of why this might be?

It lacks a clear etiology. It has been widely misused for complaints that are not PMS/PMDD.

**Reference 6 - 6.46% Coverage**

The latest (ISPMD consensus-based) guidelines on PMS state that ‘any’ symptoms count, so long as they occur in the luteal phase, resolve shortly after menstruation begins, and are severe enough to affect daily life. How do you feel about this particular definition?

This seems to be the definition given to PMS as well. If the symptoms are carefully monitored to provide evidence of their pattern and occurrence, it will likely result in what is termed PMS.

**Reference 7 - 6.42% Coverage**

Such guidelines on PMS also promote the use of symptom tracking tools in order to assist formal diagnosis. However, the most popular tools are based on the specific symptoms associated with the DSM diagnostic criteria for PMDD. What do you think about this?

There are widely used tools for PMS also (Not PMDD). Any symptoms can be added to a daily symptom list. If it is an unusual symptom, it should be a signal to investigate other possible disorders.

**Reference 8 - 4.58% Coverage**

1. The guidelines categorize PMDD as a core premenstrual disorder alongside PMS rather than as a mental health disorder that is triggered or worsened at certain points in the menstrual cycle. What do you think about this?

PMDD is its own diagnosis. It is NOT another mental health disorder that is linked to the menstrual cycle.

**Reference 9 - 5.55% Coverage**

1. Clinical guidelines on PMS do not usually include information about the role of non-biological or external life experiences as contributing factors in menstrual cycle-related health e.g. ‘psycho-social’ factors. What do you think about that?

The diagnoses are symptom-based. That does not exclude the fact that symptoms may be due to life events. A good diagnostician will likely explore all.

**Reference 10 - 4.94% Coverage**

1. **[Optional]** What do you think about the use of diuretics (Spironolactone) in the treatment of PMS?

The primary sympotms of PMS/PMDD are mood symptoms. Spironolactone is not likely to greatly improve these symptoms. There is little scientific evidence to support its use for clearly defined PMS/PMDD, although , as always, some women may find benefit.

**Reference 11 - 2.38% Coverage**

1. **[Optional]** What do you think about surgical interventions in the treatment of PMS/ PMDD?

It is difficult to justify any non-reversible treatment for these disorders.

**Reference 12 - 4.69% Coverage**

1. I think it is possible to better integrate the various clinical, academic and patient discourses- to inform an evidence-based and standardized list of cyclical symptoms. How do you rate my chances?

It already exists in the literature if it is sorted out to examine well-designed, placebo-controlled studies where symptoms are charted.

**<Files\\E03\_Fran> - § 3 references coded [32.04% Coverage]**

**Reference 1 - 1.85% Coverage**

1. **Interviewer:** OK. Great. Do/ or did you identify as someone who gets PMS?

**FRAN:** Did I have PMS? Is that what you’re asking?

**Interviewer:** Yes.

**FRAN:** {inaudible]

**Interviewer:** Sorry, I didn’t get that…

**FRAN:** No, I personally never had PMS.

**Reference 2 - 4.03% Coverage**

1. Um, and again, in your understanding, roughly how many premenstrual symptoms are there?

**FRAN:** Um, I think there’s a large number… Um, I think there’s… There are several emotional symptoms which are largely captured by the DSM 5 criteria. There’s maybe ten… several physical symptoms and behavioural symptoms which are less emphasized in the DSM-5 diagnostic criteria. In the last 30 years of literature describing PMS, there have been 50-60 symptoms described, but most are not included in daily ratings used in studies.

**Reference 3 - 26.17% Coverage**

1. **Interviewer:** Great. Thank you. Um, so obviously men can also experience nearly all of these same symptoms but without any cyclical pattern because they don’t have a menstrual cycle. Does this mean that the same symptoms therefore have different biological mechanisms, depending on the patient’s sex?

**FRAN:** I would assume that in women it is due to the interaction between their neurotransmitters and hormonal fluctuations and in men, uh, they don’t have hormonal fluctuations in the same way [inaudible]

**Interviewer:** OK. Sorry but you broke up a bit then…

**FRAN:** I’m… I don’t… I think they’re different because in women the symptoms are because of a vulnerability to hormonal fluctuations.

1. **Interviewer:** Ok. Great. So, the following questions are mainly about the Montreal consensus process and why it had to happen and the definition we have ended up with. So, the first question is this… PMS is considered by some to be a controversial diagnosis- what is your understanding of why this might be?

**FRAN:** Er, what kind of a diagnosis is it?

**Interviewer:** Sorry. ‘Controversial’

**FRAN:** [Pause] You’re saying that PMDD is controversial?

**Interviewer:** Well, it can be. Erm, so, sort of thinking of people who might think that it is the medicalisation of women’s moods… Or, you know, there are lots of different academic and erm, different disciplinary perspectives on these experiences…

**FRAN:** Right. I don’t… I was on… participated in the ISPMD committee that met to review diagnosis and aetiology and the ISPMD consensus meeting on treatment for PMDD. I don’t think that there was a consideration that PMDD was a controversial diagnosis. What I do remember from the original meeting is that er, on purpose, they didn’t specifically define what premenstrual symptoms should be included in the diagnosis of PMDD. Clinicians in mental health in the group thought… felt that the emotional premenstrual symptoms are what is likely to make a woman seek diagnosis and treatment, while clinicians in gynaecology seemed to think that some women present with more problematic premenstrual physical symptoms such as cramps, or breast tenderness. The committee was not able to say that PMS comprised specific symptoms in their view. I think everyone on the committee was in agreement that what was important was the “on-offness” of the symptoms through the menstrual cycle and the interference in a woman’s life.

1. **Interviewer:** OK thanks. Sorry, you do keep breaking up a bit. But I’m getting probably about 80% of this. So, erm , relating to what you just said, the latest [ISPMD consensus-based] guidelines on PMS state that ‘any’ symptoms count, so long as they occur in the luteal phase, resolve shortly after menstruation begins, and are severe enough to affect daily life. How do you feel about that definition?

**Original FRAN:** I think we… there was a lot of discussion about that and as I was saying, I tend to… if you ask me what I think are the most frequent… Those are emotional symptoms but because a large number of gynaecologists on the committee feel that women present more to them with the physical symptoms [inaudible] it could be a bothersome symptom that [inaudible]. But those of us who do PMS research in the mental health field feel that [inaudible] and we may just try and support them to [inaudible]…

**Edited FRAN:** I agree with the definition as put forth by the ISPMD consensus meeting.

**<Files\\E04\_Andrew> - § 8 references coded [31.85% Coverage]**

**Reference 1 - 4.67% Coverage**

**Interviewer:** [00:04:30] OK. And how would you describe p.\_m.\_s to somebody who maybe has never heard of it before?

**Andrew:** [00:04:38] First, I would say that absolutely central to this concept is the timing of the symptoms that they should appear at some time in the pre-menstrual phase and they should disappear completely within a few days after the onset of menses. And that they should really. Disappear completely if you have remaining symptoms in the follicular phase. It could be that you have some kind of premenstrual aggravation of something else a depression, bipolar depression or generalized anxiety disorder or something like that, it should be this timing is absolutely crucial. And then I would say that the... as already indicated by your initial comments, that that the definition of p.\_m.\_s is poor and that er.. um... many gynecologists using the term p.\_m.\_s also referring to the ICD nomenclature of p.\_m.\_s, they regard any symptom as qualifying for this condition. And also they don't demand a certain severity degree, either. So if you have any of many different symptoms also to a mild extent, you by definition have p.\_m.\_s. I personally do not think that is a very suitable definition for the condition to study as a medical condition, because that would mean that the majority of women of a certain age have has a diagnosis. And since most of these regard these... these complaints as very trivial and do not require treatment, there is no need to have a diagnosis for that. So I have in that regard been skeptical about the the p.\_m.\_s definition in ICD. And I then personally prefer, though it's not perfect. I prefer the DSM definition of Premenstrual Dysphoric Syndrome. So that's how I would briefly discuss what this is all about.

**Reference 2 - 5.00% Coverage**

**Interviewer:** [00:08:56] Thank you. And what is your understanding of why pre-menstrual symptoms occur?

**Andrew:** [00:09:04] Firstly, I think there is a biological explanation, and that is, of course, also discussed this in terms of various socio demographic aspects, socio economic aspects and so on and so forth. I personally believe it mainly that it's a biological course that is related to the hormonal variation in the blood and supporting. This is, for example, first that if women... that they are unaware of the fact that a certain cycle has been an anovulatory which happens now and then, then they have no symptoms. That is in spite of the fact that they don't know that this will be anovulatory cycle. So that is one... one... one argument. Another argument is that if you take away the the sex steroids, with drugs or an other way, then the symptoms disappear. If you give back to these women the hormones, then you can elicit the symptoms. So so I I think, A, that the sex steroid fluctuations are the trigger for these symptoms. B, I don't think that women with p.\_m.\_s or P M.D.s differ or PMDD differ from from other women respect to levels of these hormones. But I think they have a somewhat enhanced sensitivity to these hormones. Finally, I don't think that this is a pathophysiological condition. I think it's a physiological condition that is probably normally distributed. I think it has some. The Rudiment here is probably the oestrus cyclicity that you see also in various other species in terms of sexual behaviour and other stuff that is a behaviour change associated with the estrus cycle. I think that this is a reminiscence of that in other species. I would guess I don't think it's then pathophysiological. I think you could have a normal distribution curve that most women have some mild symptoms, some are totally devoid of symptoms. Some have severe symptoms.

**Reference 3 - 4.65% Coverage**

**Interviewer:** [00:24:25] Great. So obviously, men can also experience nearly all of exactly the same symptoms, but not in a cyclical pattern because there is no menstrual cycle. So do the same symptoms therefore have different biological mechanisms depending on the patient's sex?

**Andrew:** [00:24:47] Yeah, I think and sometimes it's it's the. This is the claimed as an argument against the concept of Premenstrual syndromes. And I... I have never shared that view. For... for premenstrual symptoms the female sex steroids are clearly very important. For male aggression, which in many instances is of course is more a more common... Common societal problem than female aggression. Then I am convinced that testosterone also plays an important role. So so I think there is a corresponding hormone driven influence on mood in both sexes, and it's very well-established that that that that androgens in men both provoke aggression and also sexuality, of course, and so on. So so I think I think there are hormone driven, some to some extent similar erm behavioral influences in males and females, but they are also to a great extent different, which is not surprising since it's different hormones that are important for the two different conditions. In fact, we we for some years, many years ago believed that andro... testosterone could be involved in Premenstrual syndrome in women, but other groups have not confirmed our findings. So I don't know about that. But but but I I I I I don't think men display the typical constellation of symptoms characterizing Premenstrual dysphoria, but certainly some of the same. All of the symptoms could of course be apparent in men, and some of them are clearly hormone dependent in men such as irritability or anger.

**Reference 4 - 4.16% Coverage**

**Interviewer:** [00:30:10] Ok. Thank you very much. So as I think we mentioned already, the latest or at least the ISPMD Consensus or Montreal Consensus guidelines on p.\_m.\_s, they now state that any symptoms count so long as they occur Pre-menstrually and abate afterwards and are of a certain severity. What do you think about that kind of definition?

**Andrew:** [00:30:36] And that was the strong opinion from our Friends in gynecology. So if I had written those papers myself, that would not have been my my understanding of the situation. I'm more in the camp that want to divide these different syndromes. But what we said, I think was a typical consensus group compromise that each and every symptom may qualify for p.\_m.\_s, but that there are important sub categories of the condition. And so it's kind of a compromise that that it's still acknowledged that there are different subtypes that are quite distant from each other. And then it's merely a semantic question. If you want to have a common heading for all these subtypes or if you want to regard them as entirely different conditions. And I think we would never have reached consensus in any of these groups if we had not agreed to have some kind of umbrella term for all premenstrual conditions, because this is how they have traditionally been dealt with within gynaecology. And to some extent, gynecologists have owned this condition because it's usually... these are the doctors usually treating these patients who they have have. It's part of their repertoire of disorders. And that is how they regard it.

**Reference 5 - 2.86% Coverage**

**Interviewer:** [00:35:20] PMdd is listed kind of alongside p.\_m.\_s that they're both called core pre-menstrual disorders. Well, in a way that, for instance, pre-menstrual exacerbation of other conditions is a different thing.

**Andrew:** [00:35:36] Sure.

**Interviewer:** [00:35:37] So it's kind of implying that PMDD is related. but Separate from p.\_m.\_s.

**Andrew:** [00:35:45] Absolutely. Yeah, I think there are two two ways of defining this. First. You have to get rid of all the variants that are not really p.\_m.\_s that are not exclusive for the Luteal phase where you have aggravation or exacerbation, also where they are elicited by oral contraceptives and stuff like that. That is something else. And then you have a core p.\_m.\_s or p.\_m.d. \_s, and within that you have those two conditions as as reflecting the thinking of the gynaecological camp and the psychiatric camp where the gynaecological camp are more for the p.\_m.\_s definition and the psychiatrist more for the PMDD that those are... both belong to the core category because both are restricted to the luteal phase.

**Reference 6 - 4.47% Coverage**

**Interviewer:** [00:41:02] Yeah. Great.Here's another slight tension in the DSM 5 criteria for PMDD? One of the... one of the eleven criteria contains a whole lot of physical menstrual changes that for many people are just normal menstrual changes, things like bloating. So this can be seen as being in tension with it as being a mental health. You know, as the PMDD definition being more of the mental health symptoms? Why do they include these physical changes in that criteria?

**Andrew:** [00:41:46] Absolutely! And I think again, that is what I mentioned before, that I regard this as a kind of compromise. On the one hand, they did a strong emphasis on the mood symptoms. You need to have at least one of the four and the somatic symptoms are only given one of eleven items. So that is a way of downplaying somatic symptoms. But still they do include them not to annoy the gynaecologists too much, I assume. And I if I if I were king, I would I would have not regarded them as part of this at all. What I would say that there are two different conditions. One is... or maybe several conditions. I think. premenstrual headache is one, I think perhaps bloating and breast tenderness is one. I think mood symptoms is one, and I don't think there is today strong evidence to claim that they've belong together that a women that has got breast tenderness is more inclined to also have irritability or headache in the premenstrual phase. I don't think there's any strong evidence for that. And I think so. So so... er I I I believe that it's a... I think we should regard Item number eleven, in the DSM as a compromise. And it's perhaps not that er... there's no robust scientific basis for that.

**Reference 7 - 3.32% Coverage**

**Interviewer:** [00:44:21] Great. What do you think about surgical interventions in the treatment of p.\_m.\_s or PMDD?

**Andrew:** [00:44:32] I think that is a very harsh treatment for a condition that could be managed in a less dramatic way, so I would not encourage that. Also, if you remove the ovaries, that would be the option here, then you would have to give add back hormone treatment and that add-back hormone treatment might induce pre-menstrual symptoms. So I don't think surgery is an option here, really. I could also add that in fact, the effects of the SSRIs on the mood symptoms is very big. It's a good effect. It's a big effect. It's a large effect. We have we have, you know, normally one one regard point zero as a no effect size. Point five is the median effect size. Point eight as a good effect, size in in. If you look on the focus on irritability and look at the SSRI. We have an effect size. of about 1 or 1.4 or something very high effect size with a response rate of 95 percent. Well, all self-rated irritability, for example. So so I think if if the mood symptoms are the dominating ones, I think intermittent SSRI administration is in most cases very effective. So I really don't see any room for such a harsh treatment as a surgery.

**Reference 8 - 2.71% Coverage**

**Interviewer:** [00:49:23] I'm not testing anyone [laugh]. I really am interested in, for instance, how a gynecologist expert is going to answer these same questions. You know, I might get different. Well, there'll be similarities. You know, I find it interesting, the different discourses we draw on when we're talking about these experiences.

**Andrew:** [00:49:44] If you would like the extreme gynecologist position, I think you should ask the now, since long retired [colleague's name], he has been a strong advocate for the. He's not very. He doesn't like the DSM and he doesn't like the SSRIs. He's very much a guy who wants a hormonal approach. But then, of course, [colleague's name] has had a lot of impact on these consensus documents you refer to. He had a key role, of course, there. So he would be one to interview. Yeah. No, I think you will, by and large hear the similar story from from the different people. But I don't know.

**Interviewer:** [00:50:22] OK. Oh, thank you for your time, that's very, very helpful.

**<Files\\E05\_Debbie> - § 16 references coded [52.31% Coverage]**

**Reference 1 - 0.21% Coverage**

**Interviewer:** [00:00:41] So how did you come to be interested in premenstrual syndrome?

**Debbie:** [00:00:48]

**Reference 2 - 0.97% Coverage**

**Interviewer:** [00:06:48] Great. And do or have you ever identified as somebody who gets p.\_m.\_s?

**Debbie:** [00:06:58] [long pause] No. [pause] I identify as someone who... I've always identified, as somebody who has.[pause] Um, Menstrual depression. So more like my. Well, I would say it's like a worsening of a chronic depression, right?. So I would say it's like menstrual exacerbation [laugh]. But premenstrually I seem to be fine. So it's very different to what a lot of the patients describe.

**Reference 3 - 0.73% Coverage**

**Interviewer:** [00:07:29] Um, this is a difficult question because it kind of relies on memory, really. Can you remember how you first came to know about p.\_m.\_s?

**Debbie:** [00:07:40] I don't think I could say I do. I don't remember. It was young. You know, it was young... Surely as a child. Yeah, yeah. But I don't remember. It wasn't talked about a lot. But but I, you know.

**Reference 4 - 0.96% Coverage**

**Interviewer:** [00:08:54] OK. And what is your understanding of why premenstrual symptoms occur?

**Debbie:** [00:09:02] Oh, this is so loaded for me.[covers face] I think there's like 18 different pathways, you know, and we're trying to suss that out. And I think it's likely that it's not the same for everyone. I don't want to go into the weeds too much. I think so. Again, I know that we're going to talk about PMDD later, but... Yeah, that's kind of the only thing I can really talk about.

**Reference 5 - 7.66% Coverage**

**Debbie:** [00:09:28] I don't... It's not clear to me whether the mechanisms of these really mild symptoms are like the same, but just a matter of degree or if it's like totally different. But just assuming that it's sort of the same, but a matter of degree [laugh] or frequency or whatever. for PMDD. There's a variety of insights that we have from experiments. One is that in people with severe p.\_m.\_s, let's say that is impairing. We know... and that it has an emotional component. We know that the... Um, So the Gabba system in the brain is a system of neurotransmitters that's responsible for sort of slowing down brain activity and inhibition of things... it has a very calming effect. Usually when you activate it, alcohol works on this system, benzodiazepines work on this system, and it happens that the metabolites of progesterone also work on this system. And in and in most women, they have sort of the same effect as would, alcohol or benzodiazepines. They're calming. They they sort of make you a little bit sleepy [laugh] and slower, right? they're not activating. But in p\_m\_DD. The group of molecules that make up the GABA-A receptor where the metabolites fit... fit in [physical gesture to show physical fitting]. There's a differences in gene expression where the wrong... sort of the wrong subunits are. So it's like if they put together this receptor sort of in the wrong way with the wrong units, [laugh] and then because of that it's not acting in a calming way anymore. When those progesterone metabolites hit it, instead, it's agitation, irritability, um, mood swings [laugh]. You know, it's sort of really having this opposite effect where now it's decreasing the ability of that calming system to really work. So. So that is something that we understand to be the cause of this, something sort of more conceptual... thing we talk about and that we've found, which is that people with severe PMS/ PMDD, are abnormally sensitive to normal hormone changes. So we've tried in this literature over and over again in biomedical studies to... to identify hormone imbalances and with... we just don't see them and they seem to be normal. So then we've done studies where we just shut the whole system down and we've put a medical menopause in place with a GNRH agonist and then add back estrogen or progesterone or both. And for about a month, we see symptoms come back in women with p.\_m.\_s/ PMDD, but not in controls who don't have that. But then after about a month, if you keep the estrogen or progesterone or both stable, then the symptoms go away. So it seems to be really... er, and the sort of going back to that underlying GABA-A receptor system. It takes about a month, we think, for those sub units to sort of reset themselves after this acute change in hormones. So that's why you get this surge in hormones in the early luteal phase, you get increase in these sort of bad sub units of this receptor. You get these agitating bad effects for you, maybe, two weeks, three weeks, and then you know, and then it sort of wears off as the system breaks itself. I I think what we believe is that as a field at the moment is that normal Women have maybe a few of those changes in the early luteal phase, but their system corrects very quickly. And so they have more what we call GABA-A receptor plasticity, whereas women with p\_m\_ MDD for some reason don't. And it's just not it's very, very slow to adapt to the change. So I think that's sort of the best. Reason I can give, there's also implications of the serotonin system, which are somewhat related, but that's not my area of expertise [laugh]. So I think it's biological. We also know that stress worsens PMDD. I don't think that it causes it, but it certainly plays a role in making symptoms worse and harder, you know. Worse. You could take it from sort of moderate to severe, if you will. Erm, [pause] Yeah, sorry that was long. That's that's my understanding.

**Reference 6 - 3.58% Coverage**

**Interviewer:** [00:14:32] In your opinion, is there a best way to manage p.\_m.\_s or PMDD?

**Debbie:** [00:14:45] [long pause] As with any... [pause] Distressing or impairing syndrome [light laugh]? My perspective, which is not the only perspective, but my perspective, is that the most ethical thing is to start with treatments that have been vetted in clinical trials and ... beat placebo. The best. Right. So some things beat placebo, but only a little bit, right? It's like better than placebo, but only a little bit. You know, I think we should start with the things... I think it's most ethical because it's most likely to decrease the most amount of suffering [laugh] to start with. The thing that is vetted in the clinical trials and has the largest effect size. So that would be SSRIs. And then Yas. And then [cough] [laugh] combination of both and then GNRH agonists with stable add back. And then if there's some problem with suppressing ovulation that way or that can't be tolerated for some reason or there's co-morbid endometriosis, then we go to surgery. [intake of breath] But the beauty of the scientific perspective is that... the evidence based perspective is that there could be evidence that comes out tomorrow that completely [laugh] unsettles that. Right. This [SSRI name] treatment coming from [pharmaceutical company name] in Sweden. I hope that that goes to... pops to the top of the list. You know, so.. but I would. For me, the best way to treat anything is to look to the clinical trials and go down through [gestures movement down a list]. And then, of course, if somebody doesn't respond, you can experiment with other things. And that's great. And people should have access to try what they want to try. But I think from a.. as a... as a provider, I sort of think the most ethical thing is to start with the data.

**Reference 7 - 3.38% Coverage**

**Interviewer:** [00:18:20] In your understanding roughly how many pre-menstrual symptoms are there?

**Debbie:** [00:18:32] Oooph. I mean [laugh]... [pause] the correct answer to that question depends on the context. You know, for the purposes of public health and measurement, we wanted we wanted to design not me personally, but people who have been doing this work for, you know, 50 years... wanted to design a set of items that were most representative, but that wouldn't create like if we have to do daily ratings with people, we can't have 100 item list. Right. We have like reasonable... a reasonably small checklist of symptoms that basically cover it.[laugh] [pause] I don't.. I mean... So I think for the purposes of. Measurement.[pause] for.[pause] PMS/ PMDD. I don't think there's a right number of symptoms, but I would use no more than 30... that I'd think could sort of cover 90 percent of it. And then there I would have an understanding that, of course, there are idiosyncratic symptoms that we're not going to capture and just hope that. You would be able to sort of get the basic idea anyway? When it comes to a patient sitting in front of me. I think that's different. I think when I make the daily rating form with them, we go through and go through all the symptoms. We eliminate the ones that they never have. And then we add their own idiosyncratic symptoms. We add side effects if they're worried about having, you know.... [inhale pause] So. [exhale pause] Yeah. I dunno. [laugh] I don't have a good answer. The Correct number is the right... is the number that it takes to get the particular job done that you have sitting in front of you! [laughter] That should be set, and specialized and calibrated for the test.

**Reference 8 - 5.74% Coverage**

**Interviewer:** [00:28:19] OK and as you know, lots of chronic health conditions can get worse at certain times in the menstrual cycle. Do you count the expression of these as premenstrual symptoms?

**Debbie:** [00:28:43] Uuuum [pause] Is a question like, would I not diagnose somebody with P MDD or p.\_m.\_s severe p.\_m.\_s if they had chronic symptoms that got worse?

**Interviewer:** [00:28:57] Yeah, I think it's... it's this sort of. There's this tension in some definitions between premenstrual exacerbation for some things, but maybe not for other things. And so we'll have terms like menstrual migraines or cyclical asthma. And then within PMDD particularly, technically it shouldn't be a premenstrual exacerbation of a chronic thing. But in practice. Some people do include it and so this is just asking your... what you think.

**Debbie:** [00:29:33] There's a paper by Sally Hartledge. I think it's... I think it's 20oo and.... That's called a Method's Dilemma, where she talks about this and I really like her view on it. I... and her view (Uh, 2001!) [finds reference] differentiating... "differentiating PMDD from pre-menstrual exacerbations of other disorders and methods dilemma". So she talks about basically going symptom by symptom. And that is where the [diagnostic tool], which is the like algorithm that I made that makes the diagnosis. That's where that... was.... That's what inspired this idea of like there might be some symptoms of depression, for example, that are there all the time and get worse. But then others that yeah, technically they're symptoms of depression, but they're only there. Premenstrually. Like suicidal thoughts, Right? Like maybe somebody is depressed the whole month, but has a totally different quality of their depression [laugh] such that now they have mood swings and suicidal thoughts and want to eat a lot. Right? Whereas the rest of the month that's just like not part of their symptom profile at all. I would include those symptoms and those individual symptoms as PMDD. But if... but if there's a symptom, for example, low mood that is that is of the same quality. The whole month but just gets worse. I. My view is that's the sort of exacerbated underlying symptom. Now whether that has anything to do with biology or is useful, I don't know. But just from a sort of like trying to make definitions of these things that work for research, that's sort of where I've landed is with her approach there. so that somebody could have chronic depression with PME and also P MDD, where some of the symptoms are depressive symptoms, but they're just not ever there the rest of the month... It's not a great... I'm not... I'm not... it's not an area I feel particularly confident, about [laugh] I don't think we really we're not... we're not there yet with it, you know?

**Interviewer:** [00:31:58] No, and we might never be there, [laughter] there's this kind of constant process and compromising, really, I think!

**Reference 9 - 10.53% Coverage**

**Interviewer:** [00:39:23] And do you have any feeling of any controversy between, for example, like gynecology, background versus psychiatry?

**Debbie:** [00:39:33] Only [pause]. well,[exhale] in different ways, in different parts of the world. Interestingly, so working with IM P M.D., it's like... I didn't realize like there are all these like local controversies, right? I feel like in the UK from what I've heard, there is a lot of like controversy, but the form of that controversy is um, gynecologists are the ones who are willing to treat it as a biological disorder. And psychiatrists are sort of less knowledgeable about it... and at least is what I'm hearing. And I suppose want to... you know. Perhaps they'll diagnose SSRI, but then they won't prescribe other things and they won't do hormone stabilization interventions like GNRH agonists or Yaz. And so, of course, you know, then people get shuffled into therapies that haven't been tested for.. you know psychiatric therapies, that haven't been tested for PMDD before They are given evidence based things. So from that perspective, you know, if that's the cult, the culture, I think it's very admirable and correct for gynecologists to.. to fight for a greater understanding and to fight for... the way I see that kind of going is like the gynecologists then say, well, this is our job. And she shouldn't be... you shouldn't be treating these people. We should be treating these people. But I think everyone who's an expert knows and agrees that it's a brain disorder.[pause] Like, I think the people who I've talked to who call it a gynecologic disorder, when we... when I drill down, I'm like, well, what do you mean by that? They understand that the pathologies in the brain that at least that our best evidence is that what goes wrong is in the brain. They just... what they're saying is we want gynecology to be in charge of this. So that's kind of interesting. And also, of course, women love it when you call it a gynecological disorder instead of a brain disorder, because people have all this mental health stigma and they think you're calling them crazy, it's not what we're doing. We're brain disorder experts. We're just as biological as everybody else. But they don't get that ownership. OK, so that's in the UK... in the States. There are a lot of similar um dynamic, some of the similar dynamics. But I would say that psychiatry is really the... are really the experts over here in PMDD. We created the diagnosis. You know, the DSM 5 is a psychiatric manual. Psychiatrists were the ones over here that did all the seminal experiments to show the unique hormone sensitivity. psychiatrists prescribe GNRH agonists. They prescribe Yaz. They do all of the same hormonal interventions that gynaecologists would do in the UK. And so and... so that... that differentiation between like, "oh, no, gynecologists need to do it because we need to flatten out the cycle"... Well, psychiatrists can flat up cycle too. That's no problem. Right? So I think that is a little bit less over here. I think over here. Gynecologists just don't want to touch it [pause] over here. Gynecologists are like, "yep. Psychiatrist, you got this. Go for it. We don't want"... they. The ACOG retracted their guidelines. The American College of you know, like your RCOG - they retracted their guidelines. And they also they refused to take any premenstrual dysphoric disorder um presentations at their conference.

**Interviewer:** [00:43:27] Oh, right!

**Debbie:** [00:43:29] Because I've tried to go because I think it's so important to educate gynecologists, but they are just very anti this. So I think the... I think there's a lot of different points of conflict. Who... who is willing to administer these Evidence-Based treatments all the way through? Who... which specialty is more stigmatizing for sufferers? You know, obviously, gynecology is less stigmatizing, but that doesn't mean that it's not a brain disorder. Right? So I think there's a lot of... I'm a clinical psychologist. I'm actually neither [laughter]. This puts me in a nice position. I mean, i'm in a psychiatry department. But, yeah, I think both need to work together, you know, because I've seen so many cases where there are complex endo[metriosis], you know, co-morbidities with like physical gynecological stuff. And, you know, then the psychiatrist will be like, "I don't know what to do!" [puts on high pitched voice]. You know, so I mean, you know, and then sometimes on the same hand, gynecologists trying to do the cycle flattening with the GNRH agonist will have somebody who becomes suicidal or struggles with that process. And then they're like, "argh!, we need support on this". Right? So I would love to have a... Team that sort of... everybody, you know, and we sort of have that, but it's hard to get the gynecologists to care, over here. So it's weird. It's very cultural. It's very. Yeah.

**Interviewer:** [00:45:05] It's interesting... it's similar even for postnatal depression and for pregnancy, depression or exacerbation of psychoses and things. And of course, are biological. And. You know, mental of physical symptoms will happen but then. Who owns it becomes a different problem.

**Debbie:** [00:45:30] Yeah. I mean, I would love to live in a world where everybody takes equal ownership and a woman could go anywhere and get good care [laughter]. I don't see any reason why not?

**Reference 10 - 0.96% Coverage**

**Debbie:** [00:46:28] I think it's the same as what I talked about because they said resolve after menstruation. So I think that what they I think they're talking about this. I mean, I think they're saying exactly what I said, which is that it doesn't matter if the symptom is a disorder... of another disorder, you have as long as you don't have it the whole month [laugh]. I think that's what I mean by that. As long as it resolves. Right. Because what they mean by resolve is like it goes away.

**Reference 11 - 2.32% Coverage**

**Interviewer:** [00:47:39] Great. So recent guidelines so I'm thinking of the Royal College guidelines and some more recent ones as well. So these are guidelines on p.\_m.\_s, not PMDD, and yet they promote the use of tracking tools that are basically based on the PMDD diagnostic criteria. What do you think about that?

**Debbie:** [00:48:07] [colleague's name], who is, you know, really looms large, he's wonderful a wonderful man. I really like him. I've met him multiple times. He's been sort of like the grandfather of p\_m\_DD and he really dislikes the word dysphoria. He thinks...

[00:48:28]

[00:48:34]

[00:48:41]

[00:49:06]

[00:49:10]

**Debbie:** [00:49:29] [Colleague's name] he doesn't like the word dysphoria. So he's fought really hard against this and just wants to make it all p.\_m.\_s. And I think it's just a it's just a matter of words. And I don't.[long pause] Yeah, I think that by p.\_m.\_s they mean the spectrum that I was talking about. That's how I. And so they would say "yes. So there's really, really mild PMS and there's really, really severe p.\_m.\_s". And, you know, they would just sort of not put the PMDD thing in there. You know, that's how I read it.

**Reference 12 - 2.47% Coverage**

**Interviewer:** [00:50:07] Hmm. So as a result of this consensus, there are these core premenstrual disorders and p.\_m.\_s is one and P MDD another. How do you think about the way that has come about?

**Debbie:** [00:50:29] I mean, I think everybody is doing their best to like integrate.[laughter] [Sigh] I mean, I would love to live in a world where we just, like, scrap all of it and come up with some kind of single dimension, because I do think p.\_m.\_s has weird connotations that probably we need to leave behind. And PMDD is maybe too restrictive. You know, I mean, maybe like 'premenstrual mood disorder', right? Spectrum. And then we can sort of rate it on severity and quality. But yeah, I do like that They include progestin-induced mood disorders in there as well. I have that [laughter]. Whatever that is? like. That's what I was talking about is that I can't take... um oral contraceptives because I don't have PMDD, but I have definitely triggered... um have those symptoms triggered by progestin. So yeah but I I think they're doing their best to sort of integrate it all. I think it's an imperfect way of talking about that spectrum and acknowledging that some people really have this much more severe thing that... you want to give another name to. Yeah.

**Reference 13 - 5.14% Coverage**

**Interviewer:** [00:51:49] Ok. And again, some of these recent guidelines that are based on the Montreal Consensus. Some of them don't have... don't include information about the role of. Social or psycho-social or external life experiences as contributing factors. They might not even include the fact that smoking can make symptoms worse. Which does have an evidence base behind it and instead kind of go straight to anti-depressants, or hormonal sort of pharmacological solutions. What's you thinking about that?

**Debbie:** [00:52:30] So my read on all the lifestyle factors smoking included is that they've got the causal direction wrong. And that actually I mean I... I don't I can't say this for sure, but I'm on a grant with [colleague's name], who just got a... We got a grant to look at smoking across the cycle. And the pilot data that we have are just so clear that people who have more irritability, pre-menstrually, really have massive increases in smoking when they're irritable and it's like the self-medication thing. So I... I'm not saying that smoking couldn't make it worse. It certainly could. I think that's very plausible. On the other hand, I think at the very least, it's bi directional where... You know, like probably smoking reduces your overall health, which doesn't do your mood any favors. [laughter] Then, you know, probably it's a way of coping with p.\_m.\_s P MDD too. But ... um I don't know. I mean, I think that it sort of regardless of where symptoms come from, I think there's this idea that your treatments always have to target the underlying cause. And sometimes that's true and and warranted. But sometimes it's it makes it unnecessarily difficult. Like sometimes you can take a pill that interferes, you know, at some later stage of the process and still sort of short circuits, the whole thing and the symptoms go away. And so it depends on how much somebody is suffering. Right? If it's like mild to moderate p.\_m.\_s where they're like, "I'm not I'm not feeling great some of those days, but like, I'm not it's not bothering me so much that I really feel I need treatment" then. Then absolutely. You know, the lifestyle changes. Great, you know. But for most people that I meet who identify as having p.\_m.\_s or PMDD, I would say like they're suffering enough that they really deserve something a little heavier hitting than that. And that often what I see is once they start SSRIs or Yaz or GRNH agonists or whatever it is that works for them, then they can stop drinking, smoking, fighting, [laugh] then they can start sleeping. Then they can start eating right. You know that... Just my my thought.

**Reference 14 - 4.13% Coverage**

**Interviewer:** [00:55:04] That's great. Thank you. And so in the DSM 5 criteria for PMDD, it includes I mean, most of them are in one box, but it includes several normal physical menstrual changes as part of that criteria. What do you think about that?

**Debbie:** [00:55:30] It's interesting.[pause] Because the idea is that overall the person needs to find. [pause] I think... my read of the DSM 5 is that the person needs to find the collection of symptoms that they experience distressing or impairing, right, but then it needs to be moderate or greater. But what's a moderate cramp for me might be a mild cramp for you? You know?, and maybe maybe the only thing that's really impairing about my cluster of symptoms, even though I have 10 of them, is my irritability. Right? You know, um... I don't know. I don't think I have a good answer to that. I think we do have some evidence that the number of symptoms that show this on/ off pattern is. Strongly predictive of whether or not the person will... will have impairment or not. So there does seem to be sort of a linear relationship and we did something called a ROC curve, which tries to identify the number of... the number of symptoms showing this sort of on /off pattern in the daily ratings before the person also showed the same pattern in impairment. Does that make sense? So how many symptoms turning on and off do you need to have to optimally predict having impairment that turns on and off and that was four.. And and so that is interesting because the DSM 5 uses 5. But a lot of people have argued like, "oh, just one is enough", you know? [shakes head] I don't know. It's really hard. I think.[pause] I think it's okay for them to be normal [slow speech]. But then I would also say I would challenge the idea that it's normal for somebody to have moderate premenstrual symptoms, even if they are things that are common, like I think it's normal for somebody to have mild cramps. But I don't think it's normal for somebody to have moderate to severe cramps every month. I don't think that's normal. So that, you know. Yeah. Sorry. That's rambly! [laughter].

**Reference 15 - 1.87% Coverage**

A way of defining p.\_m.\_s, particularly rather than PMDD. That is a little bit tighter. How do you rate my chances?

**Debbie:** [01:04:26] [laughter] Alone? Not very good. Networked into the world of, you know. I mean, this is for any of us, right? I think... I rate you... I would say I rate your chances of impacting this ...this conversation in a positive way. Ten out of ten, I would say. It's like what tends to happen is that... and this is what you're doing is so brilliant is like we all get into our little silo's and like have our own answers and whatever. But I think as long as we can sort of have some sort of basis for agreement, like the scientific method or at least some integration of the scientific method and rational discourse. But I I I think. Your chances of. Of making a strong case and and working with the, you know, community to improve things are very, very high.

**Interviewer:** [01:05:40] Thank you. Very diplomatic of you.[laughter]

**Reference 16 - 1.67% Coverage**

And do you have any questions or comments you'd like to add at this point?

**Debbie:** [01:05:53] Oh, great. I think it's great. I'm so impressed. You know, I'm so entertained and and um you know. It's been thought provoking to sort of pull at all the little edges. You know, I mean, I do this on my own anyway, but actually in a lot of different ways than what you did. And I think this is because I spent all my time thinking about different biologies and like ways in which within PMDD there are differences [laughter]. And so I think this has been good. Yeah, I think it's great. Well done. I'm very I'm really excited about. what you're doing wonderful. I can't wait to read it!

**Interviewer:** [01:06:42] I'm interested.... I still have no idea how it's going to end up because it's very dependent on what people tell me. And sure, it's quite variable.

**<Files\\E06\_Celia> - § 11 references coded [40.57% Coverage]**

**Reference 1 - 0.87% Coverage**

**Interviewer:** [00:08:17] And do you or did you identify as somebody who experiences PMS?

**Celia:** [00:08:24] Did I, do I have it or do I?

**Interviewer:** [00:08:27] Yeah.

**Celia:** [00:08:28] I personally don't have it. I never had it. No.

**Reference 2 - 1.45% Coverage**

**Interviewer:** [00:08:30] Um, this is a tricky question because it's about trying to remember when this happened. But can you remember when you first came to know about p.\_m.\_s as a thing?

**Celia:** [00:08:53] [silence- very long pause]

**Interviewer:** [00:08:54] Like maybe childhood, teenage years? Older?

**Celia:** [00:08:54] No, no, it was when I was a gynaecologist. I never heard of it before.

**Reference 3 - 5.17% Coverage**

**Interviewer:** [00:09:43] Thank you. What is your understanding of why Premenstrual symptoms occur?

**Celia:** [00:09:51] Ha! [laugh] Good question. [laughter] I think that we... what we... the general concept is that there's a triggering event somewhere based on the rise and fall of sex, steroids with mid-cycle. It could start with the pre ovulatory progesterone blip that occurs. It could be then with the onset of product... production of progesterone or other neuro steroids from the ovary and brain at mid cycle. Having said that, [pause] and then changes... as far as the research goes, changes in GABA receptor configuration and serotonin... serotonergic function. Having said that, there's always a conundrum with women who are taking oral contraceptive pills, for example, who have symptoms that look very much like p.\_m.\_s / PMDD in timing as well. But their hormones are not focussed... er not fluctuating and the symptoms don't wait to occur until you stop the active pill and are on that placebo week, they can even start during the active pill. Um, And then, of course, the the biochemical changes which are postulated from either models or animal models don't really... um we can't combine this with the brain imaging findings because isn't really a Rosetta Stone to translate. We may know that there are some changes in the medial lateral frontal cortex, but we don't know what that means for neurochemistry.

**Reference 4 - 3.22% Coverage**

**Interviewer:** [00:14:53] Ok. So we're going to talk a bit more about symptoms, um in your understanding. Roughly how many Premenstrual symptoms are there?

**Celia:** [00:15:06] Ha! [laugh] Well, I think my understanding is that it's not specifically the symptom, it's the timing. So that could mean that there are, you know, large numbers of symptoms, really. But, you know, when it comes down to it, it usually falls into a clustering of the more common ones. But I think theoretically it could be many different symptoms. And unfortunately, that would have to be parsed out from the fact that most underlying disorders are worse Premenstrually. So if someone has lupus and they have more joint pain premenstrually, it's... you know, it's hard to say if that's a p.\_m.\_s symptom or an exacerbation. And I think that's true with some of the confounding, let's say less typical symptoms.

**Reference 5 - 3.41% Coverage**

**Interviewer:** [00:17:00] That's great. That's more than 10, so Thank you! What is your understanding about the difference or differences between p.\_m.\_s and PMDD?

**Celia:** [00:17:16] {pause- audible intake of breath] Well, PMDD originally came about as a... as a psychiatric er addendum. So in that sense, an individual had to have a moderate to severe psychological or psychiatric symptom such as anxiety, depression, irritability, tension, that sort of thing. Whereas based on the umbrella of p.\_m.\_s, you could theoretically have two severe physical symptoms like fatigue and breast pain, for example, and not have any mood symptoms. And if as long as they're bothersome or intrusive, that could be considered p.\_m.\_s. So my impression is that the PMDD is a subset which... which includes at least one moderate to severe emotional symptom [pause] and has to include five symptoms as opposed to maybe three symptoms or two symptoms...

**Reference 6 - 2.88% Coverage**

**Interviewer:** [00:19:32] Yeah. Thank you. OK. So, again, in your opinion, what does the symptom 'bloating' specifically refer to?

**Celia:** [00:19:43] Abdominal distention, um in general.

**Interviewer:** [00:19:50] So in general, do you mean both gas and maybe water retention or would you differentiate?

**Celia:** [00:19:57] Patients tend to say they don't feel more gassy and they don't necessarily complain of diffused water retention. But when... I think when it was studied years ago, they did find that there is more fluid retention in the wall of the bowel and the abdominal wall. So I think it probably is a fluid retention phenomenon. But considering it may be in the bowel, well also that may be why it's more problematic than just, say, water retention in your ankles or fingers?

**Reference 7 - 6.49% Coverage**

Does this mean that the same symptoms can have different biological mechanisms...

**Celia:** [00:22:00] [interrupting] Yeah

**Interviewer:** [00:22:00] depending on the patient's sex?

**Celia:** [00:22:02] Yeah, definitely... Well, [audible inhale] depending on the sex or even the time of the month, I mean, you can have bloating. That may not be, you know, and you can have irritability. That may not be the same mechanism. So I think the symptoms are not really specific along those lines.

**Interviewer:** [00:22:24] Thanks. All right. And so PMS and PMDD are considered by some to be a controversial sort of diagnosis. What is your understanding of why that might be?

**Celia:** [00:22:41] Well, I think initially that there is a thought that there is some cognitive impairment associated with that time period, decision making, er judgment. Um, There was... we did some studies on cognitive functioning in the Premenstrual phase I think in the 80s and er we were hoping not to find anything. And I honestly don't remember the results. I don't think that we did find very much. I think and then some others did studies as well. And mostly what they found was a little bit of difference in fine motor coordination. So I think that's the main aspect: judgment, whether judgment would be impaired either by the emotions or by the um physiological state.

**Interviewer:** [00:23:28] So do you mean because... because most women have a menstrual cycle? Well, women of a certain age that it could have implications for gender equality... like it is not the kind of cause that you...

**Celia:** [00:23:42] Yeah, I mean, for... um as I said, aeroplane pilots, surgeons, anyone who has to be very precise has to make judgment, decisions that have implications. Life and death implications. Yeah.

**Reference 8 - 4.30% Coverage**

**Interviewer:** [00:23:59] Ok. And again, as you've already touched on the latest Montreal consensus based guidelines on p.\_m.\_s state that any symptoms count so they don't list any specific symptoms. They say that any count as p.\_m.\_s, so long as they occur in the luteal phase and resolve shortly after menstruation and the severe enough to cause some sort of debility or impact on daily life. And what are your thoughts on that definition?

**Celia:** [00:24:32] Yeah, I think that sounds reasonable. Again, I think you have to separate out in [medical] history what... what's underlying and what may not be, and sometimes that's very difficult, particularly for someone who has underlying depression or anxiety disorder, bipolar disorder or anything like that. But I think it's important because the treatments as you say may be different.[pause] I think if you're concerned about giving someone a label, then it may be an issue. If you're just saying you have one physical symptom and you now have p.\_m.\_s. But I'd like to see the pejorative nature of the label disappear. Now, I don't know whether that's possible and I haven't. As I said, I haven't heard much about it recently.

**Reference 9 - 3.38% Coverage**

**Interviewer:** [00:25:17] Um, there's another interesting thing that since this consensus on p.\_m.\_s, the various guidelines that I've seen that have come out, they promote the use of symptom tracking tools, which is great, but the ones that they promote tend to be the ones directly based on PMDD diagnosis. So the eleven boxes with all of the physical ones in one line. Do you have any thoughts on that?

**Celia:** [00:25:47] Well, I like to see validated questionnaires used, and so that's what's been validated so far, if other ones came up, I think it would be of interest to look. What I tend to do with my patients when I take the history is if I find that they... have one or two columns that are more or less blank, that they can put in a symptom that they have that they can track. Um So I either have them cross out one that they don't have and put in their symptom or add to those other columns so that you can track them.

**Reference 10 - 6.40% Coverage**

**Interviewer:** [00:30:49] And so thinking move the PMDD diagnostic criteria so it's categorized as a mental health disorder, and within the eleven criteria, one box has got several physical changes and in fact they're quite normal menstrual changes. So there's a bit of tension there. That this is a supposedly a mental health disorder. And yet some of the diagnostic criteria include things that are common , you know breast pain, abdominal pain, headache, symptoms that are common physiological processes. So the question is, what is... how do you think about that or do you have any thoughts?

**Celia:** [00:31:38] I think it's sort of an artificial dichotomy. If you ask... if you do look at studies or you ask patients who have depression, most of them have pain. In fact, it's very common to have pain when... physical pain. And so to say that it doesn't belong in a mental health diagnosis I think isn't true. And also the fact that the SSRI's can help those physical symptoms. Studies where they were, they always have categories for physical symptoms. So it's hard to say whether they have different aetiology. Presumably they might. But if you're looking at a syndrome and you have symptoms, that come into that based on frequency of women having them than I can see why they put it in there. I think it's not a bad idea for the PMDD that it's only one category. So in other words, you can't get five symptoms by having four physical symptoms. and One mood symptom. Um... I I think the. Um There just haven't been many more treatment trials since the time when the pharmaceutical companies were funding these studies. So we really don't know. Take a PMDD diagnosis and compare, say, an hormonal contraceptive with an SSRI. No one wants to pay for that.

**Reference 11 - 2.99% Coverage**

So I think it's possible to better integrate the various, particularly the clinical perspectives and discourses on PMS to sort of come up with a better or tighter definition of PMS, particularly. How do you rate my chances of helping to do that? Well, not particularly 'me', but do you think it's something that could happen?

**Celia:** [00:35:55] [pause] Yes, I think. I think it probably could. I think you probably need to study large numbers of women with prospective recording to see what we're dealing with out there now. And then come together with some sort of ADelphi group. Need not just include experts could include patients in separate meetings, you know, focus groups and that sort of thing. I don't know how these forums or these things are derived nowadays, but I think it's certainly an important process.

**<Files\\E07\_Sarah> - § 15 references coded [44.02% Coverage]**

**Reference 1 - 0.01% Coverage**

**Reference 2 - 0.73% Coverage**

**Interviewer:** [00:06:11] Brilliant. Thank you. Um, Did you ever identify as having p.\_m.\_s yourself?

**Sarah:** [00:06:21] Did I have PMS myself? No, I didn't actually. Which is pretty interesting. I also studied menstrual migraine and I didn't have that either, so...

**Reference 3 - 1.05% Coverage**

**Interviewer:** [00:06:35] Yeah. Um... This is a tricky question, but can you remember when you first heard the term p.\_m.\_s or pmt? Was it in childhood? Later on? Or was it when you were studying?

**Sarah:** [00:06:45] No... It would have been when I was researching the area. I don't think I'd really come across it as a medical student, so I would have been in um, around my mid 20s.

**Reference 4 - 3.80% Coverage**

**Interviewer:** [00:08:03] Thank you. What is your understanding of why Premenstrual symptoms occur?

**Sarah:** [00:08:12] Well, it's definitely linked to the cyclical changes of menstrual cycles. If we don't have a cycle. You won't get it. So all the women that we saw who identified as having significant symptoms. And some of them, you know, we were able to see who did or didn't because we had their daily rating chart of course. Um but when we asked some other questions like did it happen? What happened when you were pregnant? Symptoms didn't occur! They usually felt terrific over pregnancy. It didn't happen when they were breastfeeding because of menstrual, you know, the cycle is suppressed. It doesn't happen after menopause. It doesn't happen before menarche, it's linked to the menstrual cycle. So it's... it is related to the effect that the hormones of the menstrual cycle have on neurotransmitters. And some women are very sensitive to this. And that probably effects their genotype, and there are twin studies demonstrating you know that there is some You know, that's a crude way of demonstrating genetic links, but it does demonstrate that. And then there are, you know, there are other factors that also could make it worse. You know, stress makes it a lot worse so if you get anxious about it it's gonna get worse or some other stress in your life. Is gonna make it worse.

**Reference 5 - 6.31% Coverage**

**Interviewer:** [00:09:34] That's brilliant, thank you. And so in your opinion, what is the best way or the best ways of managing PMS?

**Sarah:** [00:09:45] Well, you know, again, you've first got to demonstrate that it is actually occurring because of the women who came to us, sometimes we found it was actually some other, more significant problem, present. So you know, you always have to have a complete health check and you know make sure that in fact there isn't some inter-current problem like alcoholism or something else that really needs to be dealt with. So that's the first thing is exclude other disorders. I mean, you really need to know what's going on in this woman's life. For example, if she said she's only had these symptoms for the last 18 months. Well What happened 18 months ago? You know, was it you know that her cycles changed after she gave birth to a baby, and finished breastfeeding? Sometimes that happens. But it might have been that there was some significant stress in her life and if it is stress-initiated then you would be looking at what you could do to reduce that.. Perhaps with referral for cognitive behaviour therapy and so on... to see if you could reduce those aspects because you might not have to do anything after that. You need to confirm that there is actually Premenstrual syndrome occurring before we start any treatment. And that means you've really got to send them away with the daily writing chart for a couple of months. But nowadays with the Internet, people often come with their daily ratings. You get the chart already filled out. So it's not quite like when we first set up a clinic. In fact, they come with those charts and you know you can work from there. So if you demonstrate that there is change linked to the cycle linked to menses etc. and there aren't current stressors that you can first deal it. Then you would be looking at each person as an individual and you would talk to them about the range of treatments that are available. Um, Some women would prefer to take a tablet and don't really want to do any work themselves to reduce their overall um background stress level. Other women prefer to do that. So if you really have to find what any individual... and Generally, a combination of treatments is often the best way to go about it.

**Reference 6 - 3.42% Coverage**

**Interviewer:** [00:11:53] Great. Thank you...

**Sarah:** [00:11:56] [Interrupting] Of course, there are more severe syndromes. You know, I mean... because I had as a psychiatrist had to deal with postpartum... with um menstrual psychoses, which is, you know, that can be quite severe. We had a woman in our ward, who um, I was asked to see, because she was self-immolating, she was you know, she was psychotic and um tried to set fire to herself at menses. And it was.. the problem was. She had um four young children. She was you know, a baby, six months old, or something. And her sister had successfully set fire to herself and died the year before, in our ward. So you know, the ward was very concerned about it. And we... I suppressed her cycle using very potent you know medications. We didn't have GNRH analogues then but something something similar, Danazole, and the whole thing stopped! And before that [laughing, shaking head] I'm telling you, it was still happening despite giving her the oral contraceptive pill to suppress the cycle. It wasn't suppressing the cycle and she was... and she was still doing it. So, you know, there are... in those situations. You know, this sort of treatment, you know, is stepped up to deal with the emergency.

**Reference 7 - 3.33% Coverage**

Um. So PMS is considered by some to be a slightly controversial diagnosis. What's your understanding of why that might be?

**Sarah:** [00:24:18] Well, I think it's like many things to question, for example, it means different things to different people. If you start talking about a major depressive disorder as defined by DSM Five, we're all talking about the same thing. So it does come back to the definition. So, for example, we ... I did some work with international colleagues to come up with definitions for Premenstrual disorders, because this term 'PMS' was just bandied around in the media and everywhere else and had different meanings for different people. I couldn't compare my research with somebody else's really until you know we started to get the DSM 5 crit... you know diagnosis that at least we were talking about the same thing, even if we are only talking about a small subset of people. So yeah I think I think that's a problem with the term 'premenstrual syndrome' as a cause of contention, I think lay terms that are used in various ways by various people. It doesn't doesn't really help, you know, a lot in terms of diagnosis. You are still trying to sort out well do they need a diagnosis?

**Reference 8 - 2.51% Coverage**

**Interviewer:** [00:26:23] Um, So at the moment, the guidelines on p.\_m.\_s rather than PMDD. Recently there's been some in the UK and I think that some even more recent ones have come out elsewhere in Europe. The tracking tools that they recommend. um GPs and other doctors use are actually based on the DSM criteria for PMDD. So, I was wondering, what do you think about that? So this is in p.\_m.\_s guidelines, but they're using the tracking tools that are based on PMDD criteria.

**Sarah:** [00:27:35] Well, I mean, you can adapt. You know, we used to adapt the rating charts we use. We would hand them a chart, it had 10 symptoms to... to rate each day. But we would say now if you don't really notice any of these. Would you like to cross a couple of these out? and put in the ones... any others of your own? I mean, you can adapt these things. It doesn't have to be so proscriptive. But you have to start somewhere.

**Reference 9 - 4.33% Coverage**

**Interviewer:** [00:29:19] So, again, these more recent guidelines that have happened after the consensus meetings they don't always include information about these kind of lifestyle changes or like you were saying, asking about stresses or social factors in people's lives and they're much more concentrated on pharmaceutical decision making and it's kind of either hormonal or SSRI treatment. Do you think there's a place for those kind of more lifestyle... erm, for that information to be in clinical guidelines?

**Sarah:** [00:29:58] Yeah, I think it's... Well, I think it's an important thing to know about. You know, if people have got a really dreadful diet. Or If there's been some major stress, some major change, it may still be ongoing that they're trying to deal with. Then I think you do need to do... take note of that in a holistic way of treating the whole person. So I don't see why that would be left out of good clinical care... would be to make those inquiries. I mean, interestingly, when we saw people at our Sessions Clinic um the majority of them had already been through all the things that were available in terms of um... um... Evening Primrose oil, you know, various herbs, you know, diuretics. You know, I mean, they listed for us everything they had already tried I mean they had already been through all of that. By the time they got to us, but what they may not have been considering is that's the role of these other stressors and the other problem I saw often was this sort of alcohol abuse. That is certainly imp... it's important that we've found.[pause]

**Reference 10 - 1.65% Coverage**

**Sarah:** [00:31:15] Because people are often abusing alcohol and drugs to self-medicate. So it comes back to what are they medicating against and where is the distress really coming from? You know, I've been spending most of my more recent years seeing the adult survivors of childhood sexual abuse. That wasn't something we asked specifically about Premenstrual tension clinic many years ago and realised how prevalent it was. It caused some... We also didn't realise in my country anyway, that this is also prevalent for boys as well as girls, those sorts of things. all in a very long clinical career...

**Reference 11 - 2.20% Coverage**

So, how do you feel about having those physical changes as part of the the definition of the mental health disorder?

**Sarah:** [00:32:49] I don't know if I've ever seen anyone who had... the mental changes without any physical changes. So, you know, I think they should be there. I think they could occur more frequently in the population then do the severe mental health symptoms. Um [pause] Look, you know, these these... the way in which consensus is reached for something like DSM is just, it's fraught. You know, it's really based on a lot on the literature, but also on who the panel is and how they drive it. You know, there was a lot of problems with that particular panel and other panels in the DSM 5. You probably know about that... This is not a religion and it's not an exact science.[pause]

**Reference 12 - 6.60% Coverage**

**Interviewer:** [00:35:08] Yeah, thank you. So the next couple of questions. They are just your opinion, and if you haven't used these options, then feel free to just say so. So the first one is what do you think about the use of diuretics, there's one called Spirinolactone...?

**Sarah:** [00:35:26] [interrupting] That's a relatively old treatment. Um, I can't remember. I mean, I may have used it back in about the early 1980s, I suppose. But before we had any other treatments really available, I mean, look, [laughter] the problem is that there's a very high placebo effect. So what do you think of any treatment? Well, you've got to get above a placebo effect for it to be effective. That's a problem. There's a very high placebo effect in this condition. I mean, way way way Back when we first had the clinic and before we had informed consent. I made up a... I talked to the pharmacy. And had them produce a sugar pill with a fancy name. And I can tell you a lot of people got better on it. I just wanted to see what effect a placebo had. So would it have been maintained if conducted it for a while, I don't know. I mean, equally? We ran a trial of Alprazolam for PMS, you know many years ago and we had to give the informed consent. So there was a whole string of side effects. Well, so many people got side effects from it in a single blind month... erm, beforehand. That I went to our hospital pharmacy and accused them of stuffing up the blindness of the trial.[laughter] Because we just couldn't have this number of effects occurring on what was the placebo month. And they were all placebo-induced from the informed consent form, so you Know, you know, it's very difficult. That's what has made treatment evaluation. Difficult in the end is the very high placebo effect. And what does that show? It shows that really you can modulate a lot yourself. And that's why, you know, the psychological treatments need to be considered as well as the pharmacological. Right? And but you've got to go with the woman herself... We offered our women... that they could take part in um cognitive behaviour program, which did have terrific effects. So, I mean, I think it was you know, certainly more effective than the various control groups that we had and helped a lot of people. But you have to be willing to commit yourself and put the time in. The majority don't want to do that, they just want a tablet, Thank you!

**Reference 13 - 2.71% Coverage**

**Sarah:** [00:38:36] Similarly, nobody ever complained about filling out those rating charts, except the control group didn't... who didn't have PMS. It was so hard for them to do it. But the people who had it were intensely interested in doing it, and also in the results because sometimes we could show that look here's your menstruation but you're getting these symptoms as regularly over here as you well as you are over here [indicating different places on a monthly chart] And I would often say to them, just put an arrow when something else major happens. You know, like, you know, some crisis at home or with your kids or whatever at work, just whenever there's a stress, put an arrow. Just show me what's happened. And after a while, they were often picking up that their symptoms were related to these other stressors. That would, you know, nicely get them to go to counselling and deal with learnt techniques to, you know, to deal with that. So I found that charts very therapeutic.

**Reference 14 - 4.47% Coverage**

So yeah, your work was very useful. Because it just... you started with a kind of an open mind and asked people what they're experiencing, whereas I think a lot of studies start with a list of symptoms and then they ask you to record them...

**Sarah:** [00:44:58] The same thing happened in menopause research... you know we had this list of symptoms come up for menopausal symptoms. And they were from a gynaecologist who said "right, well it's this, this and this" but no one had actually gone and asked women for a start what they thought the symptoms were. When you asked them you got a very different list... and they left out... they managed to leave out some important changes by not asking women, you know if you don't ask the right questions and they're not in your symptom list, well then you'll never see it. when we studied what happened to women when they went through the menopausal transition? So that's from active menstrual cycles to becoming very irregular. That symptom of breast tenderness was, you know, came up as so important, you know that because what happened, of course, was that you're getting high levels of oestrogen, as the ovaries sort of being... kicking in to try and respond to what's happening. And so it's it's varying and you're getting some high levels of oestrogen with unopposed progesterone because, you know they're not... And so that was actually quite an important symptom that was happening in the transition into menopause. That was left out of all these scales from the early researchers where they hadn't asked women? You know, what thought was important or it would have been included.

**Reference 15 - 0.90% Coverage**

**Sarah:** [00:46:56] Yes. But it all. I mean, it's part of the new you know, well not new now, but some years ago NIH decreed that rating scales had to be developed from the people up, rather than [laughter] from the experts down. But until then, that was a normal way to do it. It just wasn't a good way of doing it. basically.

**<Files\\E08\_Thomas\_edited> - § 14 references coded [41.23% Coverage]**

**Reference 1 - 0.23% Coverage**

So first of all, how did you come to be interested in Premenstrual syndrome?

**Thomas:** [00:02:49]

**Reference 2 - 1.74% Coverage**

How would you describe p.\_m.\_s to somebody who's not heard of it before?

**Thomas:** [00:08:34] Well... it's a... it's a number of symptoms which changes with the different phases of the menstrual cycle. Usually they are er at maximum during the five Premenstrual days, the days just before the onset of the menstrual bleeding and they disappear when the menstruation proper has started. Then it's usually gone within three to four days. and er, In a pure situation. The symptoms should be... away and not present during the rest of the menstrual cycle until the ovulatory period where there can be some symptoms and then they increase after the ovulationduring the fifteen days from the ovulation to the onset of the bleeding, that's my way of describing it.

**Reference 3 - 0.70% Coverage**

**Interviewer:** [00:12:32] Yeah. And can you remember, I mean, you've sort of just told me... Was that the first time you came to know about PMS?

**Thomas:** [00:12:42] Yes, yes, 1972.

**Interviewer:** [00:12:47] And you were a medical student or had you finished?

**Thomas:** [00:12:50] Yes. Medical student.

**Reference 4 - 3.61% Coverage**

**Interviewer:** [00:16:06] And what is your understanding of why Premenstrual symptoms occur?

**Thomas:** [00:16:12] Well, at least the mental symptoms are quite well defined as as being caused and Now I'm talking about the let's say the pure version, which is different from the one that is a aggravation or an exacerbation of other types of disorder. And in this situation, my my understanding of... that's that is a result of our research is that there is a compound that comes from the corpus luteum of the ovary, which is... it's active in the brain. It's a very important one with, er. It's more potent than benzodiazepines and more potent than barbiturates. And it can be used as anaesthetic. So that is actually disorders, where people who are falling into coma due to this and we are investigating a condition called hepatic encephalopathy which is a coma, coma-like disorder or a coma... it induces a coma. In fact. And now we know that in in certain individuals are actually reacting negatively on this compound, which is some having its effects similar to benzodiazepines. And also similar to alcohol, so they are they are working on the same receptor, which is the GABA-A receptor. And uh we know that in certain situations and especially in certain individuals, they react paradoxically**.** And this can also be seen in in anaesthesia, where you give small doses. If you give a small dose, benzodiazepine, to... to. For instance, children, which is a common situation, some of them actually go berserk. Totally become wild and... And that is the same type of reaction

**Reference 5 - 5.89% Coverage**

**Interviewer:** [00:23:45] Mmm. Could I just ask you to clarify, you just mentioned a compound from the Corpus Luteum. Could you give me the name of that?

**Thomas:** [00:23:53] Yes. It's called Allopregnanolone[check]. Now, I don't know if you know but... we have done studies where we looked at, you know, some of the menstrual cycles are actually spontaneously anovulatory.

**Interviewer:** [00:24:13] Mmmhmm

**Thomas:** [00:24:13] Er, About 10 percent, of the cycles and it becomes more**..** you older. woman in the in the premenopausal Period it could be even up to half the number of cycles are anovulatory. And we have followed women with PMDD with daily ratings. And in these cases, we had eight patients who had one cycle which was ovulatory and one cycle which was anovulatory and in the ovulatory cycle**.** They had these typical patterns. Of... of the negative mood changes during the premenstrual period while in the anovulatory cycles, these symptoms were flat. Nothing happened and the same occurs. If you induce anovulatory, anovulation with er, for instance, with a compound called GNRH Agonist. So that's... Several studies have been made by several groups, including ours Group, where we have given GNRH agonist in a placebo controlled study to patients with PMDD or or p.\_m.\_s, severe p.\_m.\_s. And um they... the symptoms disappeared in cycles, and that is a clear cut indication that something coming is coming from the corpus luteum or the ovary, which are provoking these kinds of symptoms. And er to see whether actually that was progesterone or a progesterone metabolite, which was the the provoking factor. We asked post-menopausal women. Who wanted the HRT to take Oestrogen plus a progesterone pessary or a progesterone oral, micronised progesterone. To see actually what happened with the symptoms and at the same time they did they did daily ratings and we could then induce a similar pattern as we see in in in the PMDD or p.\_m.\_s with menstrual cycle-linked mood changes.[pause] And that's i s the... That is the classical way that endocrine disorders has been being sort of diagnosed or or the parthenogenesis of these disorders has been evolved or discovered. It was the way, for instance, diabetes was was discovered. and Thyroids, thyroid disorders was discovered and so on. So we are quite confident to say that this is **a** condition. The cyclicity is a condition which is caused by something which is coming from the corpus luteum and. We are quite convinced now that this something is this GABA-A receptor active compound, which is very potent...

**Reference 6 - 1.56% Coverage**

**Interviewer:** [00:27:51] Uhuh. Great. So, again, in your understanding, what's the best way to manage p.\_m.\_s?

**Thomas:** [00:28:00] Well, it's dependent on whether actually you are going for the, let's say, chronic treatment or whether you are going for... [cough] Let's say a short, relief. But there are some treatments which have been clearly proven as effective. And that is this GNRH agonist treatment. Then there is also an SSRI aadepressant which has been used. And the interesting thing with the anti- the the depressives is that they interact with this GABA system. So it might actually come down to the same aetiology in the end. But it might also be a different aetiology.

**Reference 7 - 3.06% Coverage**

**Interviewer:** [00:29:03] Mm hmm.

**Thomas:** [00:29:04] And those are the two ones which are or let's say, used in practice usually. Oral contraceptives are not that good in that way, that they usually cause the same kinds of symptoms. And if there is a... it's severe p.\_m.\_s, then these patients usually don't stand the oral contraceptives. They develop the same kind of symptoms and they are not feeling well on them. So they they take it for one or two months and then they stop. [short pause] There is one which is less provoking than the other ones, and that one is called Yaz. What is it called?

**Interviewer:** [00:29:53] Don't worry, I used to be on it, so I know... I know which one.

**Thomas:** [00:29:56] Ok. OK. So it's a. It's a less provocative. So it's. But I have patients who also can't take that one, so. So it's it's not a... a let's say a complete relief. [pause] But I would say that less... less severe conditions. They could... They could manage with... with this one. Then there are are for the less severe cases there are also a different kinds of psychotherapies. Cognitive behaviour, sorry, cognitive therapy, and that is.. is very effective in situations where the... the condition is not so. severe... that's . But in the really severe cases, it's it's not enough. That's my experience at least. [pause]

**Reference 8 - 2.30% Coverage**

**Interviewer:** [00:38:56] So as you've already said, lots of chronic conditions can worsen at certain times in the menstrual cycle. So you consider those to be Premenstrual symptoms?

**Thomas:** [00:39:06] No, not really. We... we consider them to be Premenstrual aggravation of that condition. And it could also be treated by the original treatment of the condition, and not by treating the menstrual cycle, but on the other hand. Usually when they come to me, at least these patients, they usually have tried everything. Migraine, for instance, is a very very common disorder. Well They have tried everything and. It's not good enough... they still have this menstrual- related migraine. It's not premenstrual in that way. It's more menstrual [during the bleed]. So it has a similar pattern. as the... the uh Epilepsy. So it's it's more. There is a term actually catamenial epilepsy perhaps you've heard that one?

**Interviewer:** [00:40:07] Yeah.

**Thomas:** [00:40:08] And catamenial migraine... [pause]

**Reference 9 - 7.27% Coverage**

**Interviewer:** [00:40:14] And. Are there any positive menstrual changes?

**Thomas:** [00:40:19] Oh, yes. Oh, yes. And there are a number of individuals which actually are feeling better during the luteal phase than during the follicular phase. And I would say that... uh But they are less and they are not seeking help for... the the... they are not suffering from these symptoms. They are only happy with them. So. So we don't see them in the medical. But if you do population studies. Like have done in in Iceland, for instance, more or less the whole population of Iceland was participating in that study that we had about well, twenty percent of individuals that actually felt better during the premenstrual period and during the ovulation. Most people feel better. So it's also a... let's say, a variation in the wellbeing in relation to. To the ovulatory period and we made our scale... scale.. you know every scientist in this area more or less has made their own scale for daily ratings and we made a scale and in that scale. We had also positive symptoms and they showed very clear cyclicity. But in the opposite. Except for around the ovulatory period. Where were they showed this peak of well-being.

**Interviewer:** [00:42:00] Ok. So we sort of discussed this a little. Um obviously, men can also experience many of the... Many of the same symptoms, just that they don't have a menstrual cycle, so they don't get them... [overlapping].

**Thomas:** [00:42:11] We did actually a study on partners. And they they did daily ratings. And they showed similar pattern in their mood as their partners. Well, so... so they... Well, I don't know whether... how that should be interpreted, but we thought that perhaps it was, a, a a a related to the fact that they actually felt in the same way as their partners, they experienced what the partners had had...

**Interviewer:** [00:42:57] So my question really is, is, does this mean that the same symptoms can have different biological mechanisms depending on the person's sex?

**Thomas:** [00:43:10] Well, in that case, in in those men's I think it is psychological, it's not biological. On the other hand...[pause] On the other hand, there are are also, let's say, stress related conditions, which are, of course, also appearing in men, and these stress related conditions are, according to my mind, are also based on the same kind of, let's say, provoking compounds, but then coming from the adrenal instead... and they they are not showing this menstrual cycle pattern. They are showing different types of patterns. Diurnal patterns and seasonal patterns. So... we know also from from the many animal studies that are that testosterone on mammalian hormones are showing season... especially seasonal patterns. And these male hormones are also having metabolites which are active on the GABA receptor in the same way as as... progesterone and allopregnanolone. So. So it's it's not unreasonable to believe that that these kind of of patterns can occur. Also, in men and different than men. And hepatic encephalopathy, which we are now investigating, this is mainly occurring in men.

**Interviewer:** [00:44:48] Ooh, interesting!

**Reference 10 - 3.37% Coverage**

How do you feel about that kind of. 'Any symptoms' part of the definition?

**Thomas:** [00:51:01] Well, it's again, a question of severity. So if you have one symptom like you had nausea, if that nausea is so severe that it's actually hinders you to work 2, 3 days per month. [pause] Then it's worth treating. So it's... it's... it's all it's a question of severity all the time, and that question of severity has not been resolved completely. So. So that is a important issue for research to actually define. How severe should the condition be to be be treated? And in that case, I think that... one something... there's another issue which is also interesting in that regard, and that is if if you have these symptoms in 14 days every month. Is that worth.. Worse than if you have it in three days. But very intense. In three days?

**Interviewer:** [00:52:16] Yeah. Yeah.

**Thomas:** [00:52:17] In 14 days. But let's say a of a lower degree. If it is... Intense in in 14 days, of course, it's worse... We actually made a trial of this in the 80s. We made a score trying to elucidate the number of days with symptoms and without symptoms and the intensity in our ratings scale, how how intense they had rated their symptoms. So the mean rating of the or, the median rating of the intensity combined with the number of days they had symptoms. And that made the score which showed out to be normally distributed. [long pause]

**Interviewer:** [00:53:18] Yeah. Thanks for that.

**Reference 11 - 3.08% Coverage**

**Interviewer:** [00:57:06] So again, relating to that, the DSM criteria for PMDD puts nearly all of the physical symptoms into one box.

**Thomas:** [00:57:15] Yes.

**Interviewer:** [00:57:16] And that can be a little bit confusing for some people, mainly because it's a mental health disorder by definition...

**Thomas:** [00:57:27] Yes.

**Interviewer:** [00:57:28] And then some of these changes, as you're saying, are quite normal. For a lot of people...

**Thomas:** [00:57:32] Yes,.

**Interviewer:** [00:57:32] ...breast Tenderness or constipation, diarrhoea, that kind of thing. So what do you think about that? Their inclusion as PMDD diagnosis?

**Thomas:** [00:57:41] [Immediate response] I think it's wrong.

**Interviewer:** [00:57:43] Ok.

**Thomas:** [00:57:46] [Pause] Because there are conditions which are only having breast tenderness, only having bloatedness, only having urine problems or incontinence and only having diarrhoea, constipation and nausea and whatever. And those are are not to be categorized as p.\_m.\_s. I think they should be categorized as a Premenstrual aggravation or something else. Whatever. That's my view.

**Interviewer:** [00:58:24] Yeah. Great.

**Thomas:** [00:58:26] But I'm not saying by that they don't need treatment or help.

**Interviewer:** [00:58:32] No. Just a different categorization.

**Thomas:** [00:58:35] Yes.

**Reference 12 - 2.60% Coverage**

**Interviewer:** [01:00:00] And then the other one is, what do you think about surgical interventions for PMS or PMDD?

**Thomas:** [01:00:06] Yeah. I've seen that in the literature. In a situation when you have a condition which is life threatening. [pause] Which acute intermittent porphyria is... So we had a patient who actually died in in in her acute intermittent porphyria in the luteal phase. And and in those situations, I could think of of a oophorectomy, but in other situations I think it's... it's a bit too much. On the other hand, if it if now it turns out that nothing else is helping and they are suffering a lot. And especially if they also have pain, which is not an uncommon that they have have endometriosis, for instance, that also can happen. Then one could. Think about it. I have never done a oophorectomy or hysterectomy on the... on the indication p.\_m.\_s or P. MDD. But I have used GNRH agonists, which are, let's say, a medical oophorectomy. And that has been very successful. It medicates...

**Interviewer:** [01:01:48] And then do you use add-back oestrogen?

**Thomas:** [01:01:50] Of course! of course. always.

**Reference 13 - 2.91% Coverage**

**Interviewer:** [01:01:58] So that's ... we're very near the end. I'm quite interested in some of the physiological changes that have perhaps been under researched, things like blood pressure changes, the role of maybe anaemia, pain, as you were saying, that kind of as a co factor in some cases. Do you think there's any kind of benefit in trying to look further into those physiological changes as well?

**Thomas:** [01:02:32] Well, I mean as a medic or as a..a..let's say health care giver... Of course, everything which causes problem for the patient should be investigated and treated and and helped. So whatever it is I mean, I think that's that's the... my view. On the other hand, I mean, one has to prioritize because the amount of money available is limited and that perhaps one could say yes, well. I'm surprised that you have got grants to be able to do this research?! [laughter]

**Interviewer:** [01:03:20] Well, it's maybe back in? We're in a new era. It's fashionable again. Periods are...

**Thomas:** [01:03:25] Yeah, OK. That's nice. Anyhow, anyhow, that's that's something which is so. So I think that first. First thing first and then the second thing. And what... Whatever. I mean the most common things I think would be good to be able to treat it properly.

**Reference 14 - 2.92% Coverage**

**Thomas:** [01:03:52] I can also say that we are not or, I am not completely unbiased... in that way that I am. I have discovered that there are possibilities to actually antagonize this provocateur, as I believe allopregnanolone provocateur with a medication, with a compound that we are developing as a medication. And we have in fact made a preliminary first study where it was very positive and in in patients with PMDD. And we are now doing a major study. And I'm sure you have talked to [colleague's name]. I Suppose...

**Interviewer:** [01:04:46] I hope to. I'm finding him difficult to contact because he's retired from his clinical... from his university position. Yeah. I hope, too. I know people who know him very well. so I'm hoping to be able to contact him...

**Thomas:** [01:04:59] Yeah, he was a he was the chairman of this group.

**Interviewer:** [01:05:04] Yeah. yeah.

**Thomas:** [01:05:09] There is also a person, [colleague's name], do you know her?

**Interviewer:** [01:05:14] Yeah.

**Thomas:** [01:05:19] She's now one of the most active persons in in these studies, which we are doing.[pause] So... and this this study is published. It's a gynaecologist, [colleague's name], who is the first author? I'm sure you have seen that paper. It's a quite recent one.

**<Files\\E09\_Susan> - § 16 references coded [53.03% Coverage]**

**Reference 1 - 3.16% Coverage**

**Interviewer:** [00:04:04] That's great. How would you... or how do you describe p.\_m.\_s to somebody who's never heard of it before?

**Susan:** [00:04:17] Well, what I would say is that many women experience change over the menstrual cycle. So I often talk about Premenstrual change or Premenstrual distress rather than p.\_m.\_s. It depends who I was talking to. If it was, somebody who said to me, what is p.\_m.\_s? If that's the question. Um, I say... what I would say is Well, women expect change over the menstrual cycle. That's quite normal. Um and that we don't understand why. And that we know that there are a small proportion... a smaller proportion of women who experience distress as part of that change and distress that might have a significant impact on their lives. And that that is often referred to as p.\_m.\_s. Premenstrual syndrome. But p.\_m.\_s that... that's a label... social label that's put on to that experience. But what that distress is caused by, why women get that distress is to do with a complex interaction of factors which might include factors within the body, which might be hormonal changes, or changes in the neurotransmitters. And we don't understand fully what's happening there because not all women get that... or not or not all women get the distress interacting with what's happening in a woman's life. So if she's under pressure if she's under stress, er what she's doing in terms of diet and exercise and then what she thinks about those changes. So what meaning she makes of those changes in terms of her own psychology. And that is taking place in a particular cultural context. So if you live in a context where... and this is probably not something I'd say to a woman in the street 'cos it ends up getting a bit academic here. But if you live in a context where we have a concept of PMS, which we do in the West then, you might call those changes, 'p.\_m.\_s'. But if you live in a context where there isn't a cultural label for those changes, then you may not even take note of them and you certainly wouldn't call them PMS. So that's a bit of a long winded explanation.

**Reference 2 - 1.84% Coverage**

Did you identify as somebody who got p.\_m.\_s?

**Susan:** [00:06:38] Did I? Yes. I... I have... I mean, I don't menstruate anymore, thankfully. From about a year ago. And that's a great relief in terms of not having those monthly changes. And so I have always had changes premenstrually and sometimes quite dramatically, um... [pause] mainly psychological changes in terms of feeling quite irritable and angry. And sometimes feeling down, so feeling bad about myself. Um... But, yeah, I mean, I've never been suicidal around PMS. But I do... Yes, I have had them, and I think they had.. definitely having an impact on relationships. I didn't... I wasn't aware of it when I was younger and I actually was one of my friends that I lived with... I lived in a shared house at Uni. And it was one of my women friends who actually said it to me then. That she thought I had PMS. So I had no awareness of it at the time. But it's yes, I think I would identify as having had quite... you know... moderate to severe Premenstrual change and something that felt wasn't a good thing. But I mostly learned how to cope with it in terms of psychological strategies. I've never taken anything medical... biomedical for it; pharmaceuticals for it.

**Reference 3 - 3.08% Coverage**

**Interviewer:** [00:08:06] So you've just touched on this. So the question is, how did you first come to know about PMS? So it sounds like when somebody else thought you might have it, so what kind of age were you at that point?

**Susan:** [00:08:20] Oh, I probably would be...Twenty? So I would have been in my second year at uni so I would have been twen... nineteen twenty? Um, I don't know whether I had... I don't know if I had heard of it before... But I think when... it was my friend who actually said it. And I obviously had a knowledge of what... I must have had some notion of what PMS was, because I didn't say "what is that PMS you're telling me I've got?" so I must had awareness of it. It was something that was talked about. But it wasn't something I was Particularly tuned in to. But she said it. And then I think, I though "yes, I have got it". But it wasn't something that I was then obsessed about or thought too... thought about. So it didn't become a kind of defining narrative in my life. It wasn't something that... but it was just. Then I had that moment when I read that paper that I thought, "oh, my God, yes! Someone said to me, I've got this, and yes, I do think I do have those changes. And yes, this is something I could study". So then I suppose it became more of a defining narrative in my life as an academic. And I think in my early writing. I didn't identify as a PMS sufferer... I didn't, you know 'out myself' as a PMS sufferer or take a particularly reflective stance around it, and certainly the p\_h\_d\_ I did was very experimental. So there was no space for reflexivity in that. I didn't know what reflexivity was, so there even though I went on to study it. It wasn't. "I'm studying this and I experience this". That was... it was like they were completely separated because I was being a good, positive psychologist where all of that was outside of the framework. And um... I was really you know I was doing it because I was interested in it. But then I found a way of studying it, which completely objectified it.

**Reference 4 - 11.84% Coverage**

**Interviewer:** [00:15:08] So what is your understanding of why Premenstrual symptoms occur?

**Susan:** [00:15:16] I would take... what some might call a biopsychosocial approach, or I call a material, discursive intrapsychic approach. And I would say that there is [pause] something happening in the body. We know that there are hormonal changes across the menstrual cycle. We know there are potentially... there are changes in autonomic arousal. That's one of the things I did in my own PhD. I looked at um changes in autonomic arousal across the cycle and there may also be changes in neurotransmitters. [pause] Um, We don't know exactly. That [pause]. Those hormonal changes can lead to, or can be associated with, changes in how a woman experiences her body. So feelings of... um, Breast tenderness, or swelling, of tightness of um in terms of emotional reactivity, feeling more reactive, feeling more vulnerable. A sense of change in terms of how you feel within yourself, which is often described as mood. Now, that might seem like a really reductionist... you know, answer to you. But I would also say that how we then experience those changes is influenced by the cultural context in which we live. As I've already said... so in the West we have an expectation of stable mood, particularly for women and being in control of our bodies and our moods all of the time, particularly for women. And so if I am a woman who is experiencing you know, a slight change in how I am this week, as opposed to how I was last week, that can lead to me feeling out of control of myself, which is how women report p.\_m.\_s. You know, that... in a sense what PMS is, because I shouldn't be like that, because I've got this sense of a stable me. That's always nice and perfect and kind and good and always in control of myself... and feeling happy. So that can then lead to me feeling bad about myself. It can lead to me um, looking for a biomedical explanation because that's what's given to me in our culture as why I'm feeling like this... it's to do with my hormones, which are bad, you know, that are causing a problem for me. Um, And that can then lead to me to feel completely distressed. And to have PMS. Whereas you could take a different explanation, you could say, um for example, if you take a more Buddhist explanation or more Eastern explanation of change, you could say change is accepted. Change is part of life. We're not going to feel the same. Every day, every month, every year, every moment. And in fact, if you take a mindfulness practice and you're actually looking at change, you can actually see there are change... changes happening to you over seconds [emphasis]! Never mind. Over minutes, over hours, over days. And so the notion that change is part of life. And so actually having a change over the menstrual cycle, which you can predict that you might feel slightly differently, could be seen as a really positive thing, because, you can know, when you've going to feel a bit ratty with your partner or not feel great in your body, say you're not going to want to go and do a, I dunno, a movie show, or stand on the beach in a bikini or if you're that kind of person, go to the gym. You know, it's a time when you need to be doing a little bit of self care and not going and giving a conference paper! [interviewer laughs] Change is normal and accepted is not a pathology. It's just something that happens. It's part of being a woman in the same way, I'm not having one at the moment. But if you menopausal, you get a flush, it's like, what's the big deal? I've got so many really nice fans [interviewer laugh] everywhere in my house and on my desk and whatever hand bag like it's not a big deal. So I think it's it's... why it happens. Yes, there is definitely something happening in the body. And as someone who is no longer menstruating, I don't get that regular pattern of change. And that's really interesting as a menstrual cycle researcher. But it doesn't mean I'm never ratty or irritable because I am still, but I can't predict when it's going to happen. It's happening at the moment because I'm completely devastated by [names a nearby natural disaster]! I feel quite traumatised by that. Erm, so I feel really emotionally labile at the moment in a way which is quite similar to when I was Premenstrual. But I'm not premenstrual. So other things can give you... other things can... [pause] um,[pause] Elicit those changes, those emotional challenges and even physical changes, like if I went out and ate masses, I'd probably feel bloated in a way that you can when you feel premenstrual. So it's not... those feelings and not unique to PMS. And I think that's why one of the um areas of research that really excited me, before I did, my PhD and I actually wanted to do in my PhD, but I couldn't for various reasons. Was, um, [Randy Ceski- check] work on attribution theory of PMS and the idea that women attribute moods to the menstrual cycle when they're in the Premenstrual phase of the cycle, but they attribute them to other things. When they're intermenstrual, when they're... And I think that that's a really important piece of research that I think is still really valid today. And she did it in nineteen eighty three to earlier than that... It must be earlier, because I started my PhD in '83.. So I think it's '81 she published that... because those moods we get around PMS, those changes we get around PMS can happen at other times and not be associated with hormonal changes across the menstrual cycle. That's why there's that um... [sigh] Arg, I can't remember the name of the paper, there's a ... 'cos I've got a terrible memory for names.. I'll probably remember it afterwards, you probably know it? It's a paper that came out in 2012...

**Interviewer:** [00:21:06] Oh! Romans... Romans et al?

**Susan:** [00:21:10] Yeah. When they looked at the you know, changes across the cycle and there is not a predictable pattern. So in answer to the question, what is PMS? I give you the answer that I gave. But what I would also say is that those mood changes can happen at other times. They cannot be explained by a simple hormonal pattern. And that's why the simple hormonal explanation for PMS is not sufficient in my view. So I think for some women, there are clear hormonal changes. The other thing that I think is important, is It's not the same every month. And that women will... you know, as someone who's done lots of PMS studies where we've recruited women who do the three month daily diaries before they come into the study, and I've done that a number of times in both [two different country contexts]. You'll get women who come in and say, I have you know really bad PMS. And they fill in the retrospective survey and it shows real bad PMS. And then they do over three months. And then they... many of them quite high proportions don't show those patterns. So and there's lots of explanations for that. One of them is the attribution explanation that women are attributing this to Premenstrual to PMS, premenstrual phase, When actually... there's many other you know other stages of the cycle, they might get those moods but attribute them to elsewhere. But the other thing is it's not consistent. And even if I... if I look at myself as somebody who had it, it was worse some months than others. And that was usually to do with what was happening in my life, to be honest. And women... I often say... my classic question, I would say to everyone I interviewed, with this "how's your p.\_m.\_s when you're on holidays". And most women would say, "oh, actually, it's not that bad". So there's always an interaction going on between what's happening in the body, what's happening in your life, what's happening in terms of putting meaning to it and what sense you make of it, what you think about it, yourself. And we can't separate those different factors out.

**Reference 5 - 5.57% Coverage**

**Interviewer:** [00:23:04] That's brilliant. Thank you. Again, we're going to touch on some of these things again. So when we do feel free to just sort of.. um.. answer 'As I said before! or something. So in your opinion, what is the best way to manage p.\_m.\_s?

**Susan:** [00:23:24] Um. Ok. Awareness. [pause] So having awareness and tracking your cycle, as a first step. I actually did a podcast, with [a period tracking app] recently, um which went a bit viral in terms of the media, and I actually said that, and I think they were so delighted that didn't prompt me to say that. [interviewer laugh]. But I do think... I think that must've been so happy with me. And they didn't, you know, they just asked me to talk about PMS. But I think awareness, it's so important for us to be aware. So I would say tracking... tracking your cycle and making a note, of what the common changes are for you. But also, what's going on in your life, why you might be feeling bad, because that will help to keep track of... if you are having mood changes... um, are they to do with... Is there a pattern across the menstrual cycle and many women, as you probably know doing the tracking is Actually, it's one of the best ways of intervening in PMS, which is a dreadful thing for PMS researchers because you get women into your studies and they fill out the daily diaries and then they're cured! And in fact, in studies where we've done RCTs with PMS interventions and I've done a number of those, the um, control group that's keeping the daily diaries actually do show a positive effect. You know, those women do find a reduction in symptoms. And so, yes, awareness is really important. Um, self-care. So actually making sure at those times, if you do have a pattern of mood change and you find it has a consistent time when you know that you are feeling...And I would find it as 'more vulnerable', 'more reactive', um... needing to self nurture or be nurtured, not all women want to be nurtured, at that time. To actually engage in self-care. And that would be... that would include things like taking time out. So it might be just taking some small amount of time for yourself, going easy on yourself, not putting the pressure on yourself that you might put on yourself at Other times, not having the expectation of high performance, whether that's at work or with your family or with friends, that you might have at other times; actually going easy on yourself. Um, and then engaging in positive strategies around physical self-care. So making sure you're eating properly, making sure you're sleeping. Doing exercise has an amazing impact on health at all times of the menstrual cycle or the life cycle. And I'm not a... I'm not a big exerciser, I'm not a gym bunny. I basically walk and do pilates a couple of times a week. But it makes a massive difference. Um, as many women are not eating they're dieting. So trying to be thin. And if you're not eating and you've got really low blood sugar and you'll feeling more reactive, then you are going to be more irritable and you're going to feel more depressed. Um, I think also. If you find that your... [pause] PMS is about being angry and irritable, which it is for a lot of women, and that's often why women self-diagnose, um actually thinking about what it is you're angry about or irritable about when you're Premenstrual. So is it things that actually need to be addressed at other times in the cycle? That are not... that you're not addressing. You're not... you're not discussing because you're self-silencing. So, if you;'re angry at your partner, or really angry with the children, which a lot of women are... addressing...[interrupted by interviewer having coughing fit]

**Reference 6 - 1.88% Coverage**

**Interviewer:** [00:28:34] Thank you. Right we're on to the second section. So in your understanding, roughly how many Premenstrual symptoms are there?

**Susan:** [00:28:50] Well, the list of symptoms that are on symptom profiles.There are multiple symptoms. I mean, there are... it's not like there's a standard where we can say 'there are only thirty six' there may be hundreds? Um, but there are core Symptoms which are commonly reported; psychological symptoms which tend to be anxiety, depression, irritability and then there's symptoms which are potentially more psychosomatic like sleeplessness or dizziness. There's classic physical symptoms would be breast tenderness, feelings of swelling, bloatedness. But one of the arguments as to why PMS is not an not a 'syndrome' in the way of how syndromes are defined. Is it doesn't have a core set of symptoms that all women report... there are many, there are multiple symptoms. And if you talk to different women who report Premenstrual distress, there are, you know, multiple... whole ranges of different symptoms that women report. So, you know, as I've argued many times in writing, PMS doesn't meet the core definition of the syndrome because it doesn't have a core set of symptoms that everybody has.

**Reference 7 - 2.37% Coverage**

**Interviewer:** [00:32:29] That's brilliant. Thank you. Would you consider period pain or more specifically, uterine cramps as a Premenstrual symptom?

**Susan:** [00:32:41] [inhale] Well, Period pain, no. It's dysmenorrhea Because that's happening during menstruation. But many women do experience changes that go from the Premenstrual phase through to the menstrual phase. But technically, any... p.\_m.\_s stops when menstruation starts. But I think in terms of understanding women's experiences of their bodies I wouldn't make that distinction. So some of the work I'm doing at the moment and working with p\_h\_d\_ student [name] where we're using body mapping to look at PMS and women's experiences with their bodies, how they see their bodies... pain is something women talk about a lot. And so I would from that point of view, I wouldn't say, [puts on stern voice] "no, no, you can't include that because that happens when you menstruating. So we're going to draw a really big red line here and say, you're not allowed to include that as part of your experience". But of course, it's part of women's experiences. If they're feeling emotional changes and feeling bloating, then they start bleeding and they have pain, then it's... they... they're not drawing a great red line through that experience. That's all part of it for women. And I think anticipation of dysmenorrhea, for many women, could be a cause of anxiety, particularly if they have severe dysmenorrhea or they have endometriosis. And we're getting more and more aware of the number of women who do have endometriosis.

**Reference 8 - 1.90% Coverage**

**Interviewer:** [00:35:16] Brilliant, thank you. So many chronic health conditions can get worse at various times in the menstrual cycle. Do you... would you consider those to be Premenstrual symptoms?

**Susan:** [00:35:35] [long pause] Er... I suppose for the individual woman, if you've got asthma or headaches, you know migraines, which I know are two... that are chronic conditions, which have been shown to get worse? Well, so I'm doing some work at the moment, Actually, about bipolar disorder. And we're particularly looking at menopause. But there is some evidence that bipolar symptoms can get worse premenstrually. Um, for those women, Yes, they are symptoms, but they are not standard symptoms of this thing. p.\_m.\_s. But I think that I would say as part of the Premenstrual experience, there does seem to be some evidence that if women have other conditions, that those experiences can be exacerbated. Premenstrually. There's not a huge amount of research on this, which I think is interesting. And I suppose what I would say is if this was happening to men, there would be masses of research, and masses of funding on this, because if you have a chronic condition and it gets it gets... it it it.. gets worse once a month. That's a really pretty bad thing.

**Reference 9 - 3.37% Coverage**

**Interviewer:** [00:38:34] Thank you. So men can obviously experience pretty much all of the same symptoms that are counted as Premenstrual symptoms. Only that they don't have them in any kind of cyclical pattern. With the exception of perhaps uterine pain and maybe breast pain. So are we talking about the same symptoms, having quite different biological mechanisms? Basically, depending on the person's sex? Is that something... Well, what do you think about that?

**Susan:** [00:39:10] Well, I've kind of already answered it in terms of saying that the moods that women get and changes, that women report premenstrually can also be reported at other times. So they're not... there isn't a single... There isn't a linear causal relationship between the female reproductive organs or the fe... female reproductive cycle and Premenstrual change. It's it's not a single linear relationship so, The fact that men can express all of those changes doesn't mean p.\_m.\_s doesn't... that you know, there isn't such a thing as Premenstrual change. I think that because... what... So I don't... I think it's a bit of a non argument. Really. Um, when I.. um one of my p\_h\_d students supervisors [name]. He did a lot of... He did a lot. He's a psychologist in the UK. He went into private practice. Or, consultancy, but he... That was kind of one of his arguments was that men get cyc... Well, he argued that men get cycles, but they're not menstrual cycles, and that looking at cycles for men is much more about days of the week and things like that. And so I think you can look at cycles that people have. And I think that's a whole other area of research, you know looking at cycles across, you know, how people feel going back to work after having had a break. Like it's pretty hard getting back to work. So you could have a cycle in terms of work and there's cycles... We know that people feel much better on a Friday than they do on a Monday. So there are other cycles. But the fact that men get those... that many of the... what are seen as symptoms of PMS, are also experienced by men, it's the same that many of those experiences... symptoms are experienced by menopausal women. But it's just not in a regular cyclical pattern for Post-menopausal women.

**Reference 10 - 4.43% Coverage**

**Susan:** [00:48:10] So, I think go back to your question. You need to actually use the symptoms of the woman. And the level of distress associated with them.

**Interviewer:** [00:48:20] So, this isn't a question, but just responding to what you just said. So let's say somebody is really body conscious about how fat they are and feeling bloated, premenstrually then becomes quite traumatic. I suppose that would, in an ideal world, that would have implications for the treatment. To take that into account and maybe to reassure that person that they weren't getting super fat... But that could be a sort of... It could happen that if it was a blank form or, you just went for whatever most distressed somebody, that it might be reproducing some of these gendered um,gender norms. Like thinking that being out of control is the worst thing. Or being bloated is a terrible thing. So these sorts of ideas, so we can't solve it now, but it was just something I was thinking about. Something I keep finding in the literature is whatever symptoms you put, people will start noticing them. So, it's a good idea therefore to just start with what people are already seeking help for. But then you have to make sure that the treatment is well-informed about the whole biopsychosocial context isn't just Immediately gonna say "Oh so you feel very distressed because your mood changes... OK SSRI" ... Anyway...

**Susan:** [00:50:01] Yeah and I think I think what my understanding is, if you use the method of getting women to report the symptoms that would... that are more important for them in terms of the daily tracking. You probably start with a list of what the common... You'd either do it by what women are reporting themselves because they're coming forward. You know, it's not like someone's going out in a community and grabbing women off the street, telling them "oh, come and see if you've got PMS", although, you could say that's what the pharmaceutical companies are doing in their advertising. But it's... a common way of doing it would be to either say to women, what are your key changes that are distressing for you? And then you track those. And/ or you might give them a list of the common Premenstrual changes in this massive list, as you know. And they would pick the key ones for them out of that. And then you track those. And it means they're not then having to fill in 30 items every day, because that's one of the difficult things is getting women to fill in daily diaries. Is really difficult. If you've got to fill in like fifty six items, which is what most of them have.

**Interviewer:** [00:51:08] Yeah.

**Susan:** [00:51:08] You know, some have thirty five but you know, fifty six. That's pretty hard filling in Fifty six items every day. But if you know that you're you've got a core five or a core ten... and mostly it's you know, four or five that women will have. You can actually pick those out of that and get women to check those.

**Reference 11 - 4.20% Coverage**

**Interviewer:** [00:51:25] Yeah. Thanks. So, again, as a result of this consensus building process, we now have Premenstrual disorders as the umbrella term. And then underneath that really there are two of those Premenstrual disorders. One is PMS and the other is PMDD. So again, I think this creates a bit of a... Tension at the very least in that they're seen as kind of separate conditions, and obviously the implication is that p.\_m.\_s is somehow the physical one. And PMDD is the psychological one, or at least I think that could be an implication of that separation. Do you have any thoughts of that kind of new way of positioning them?

**Susan:** [00:52:15] I do. But I need to just go to the loo. So, can I just take a break?

**Interviewer:** [00:52:51] Sure, sure, yeah. [2 min break]

**Susan:** [00:54:19] Ok. So I think the first thing I'll say is I think there's a problem in reifying um psychiatric diagnoses as if they are a thing is if we're measuring a thing within the woman, in a way you might measure a cancer cell or whether someone has influenza or not or whether someone has cardiac... cardiac problems. but PMS and PMDD, as I said earlier, are discursive constructions that are given to a set of experiences that women report. And so the idea of there being this thing, PMDD and this thing, PMS, and that they're very different to me is nonsensical. But what I would say is that we have... and I've said it many times, so I won't labour it here is that there is a contin... that many women experience Premenstrual change. For the majority of women, it's not problematic and that there is a continuum of distress which is dependent on the interaction of physical, psychological and socio-cultural factors which might determine whether a woman is at the extreme distress end of the continuum. And if it's helpful to label that as PMDD to identify that particular group of p... women that are needing support, professional support, whether it's psychological or medical, and if having that label helps them through getting insurance through legitimation of their distress, then I think it's not necessarily a bad thing. But from a feminist point of view, the idea of using PMDD as a label that you might apply to all Premenstrual change, which then implicitly and indeed explicitly pathologizes all women of reproductive age, who have any rep... premenstrual change, I think is incredibly problematic. And I think that there is clear evidence. I mean, it was contested that big pharma and in terms of the drug companies well, specifically ELi Lilly, actually were advertising SSRIs and using a very broad definition of PMDD as if it... as if it included all levels of Premenstrual change. So that has been happening. And I think in that sense, the diagnosis of PMDD is really problematic.

**Reference 12 - 2.78% Coverage**

**Interviewer:** [00:56:49] Thank you. So, again, these more recent guidelines, particularly the U.K. ones. They don't include so much about what you were saying before, external factors- so, external stressors or even things like smoking or dietary issues. They touch on a few nutritional supplements that have been sort of to clinical trial, but they don't really talk about diet and lifestyle changes or external stressors as having an impact on people's experiences. Do you have any thoughts on that?

**Susan:** [00:57:29] Well, it's not surprising because they're being developed from a very biomedical perspective. So the focus is very narrowly, um... very narrow and reductionist and focussed on the body. And so it's conceptualising p.\_m.\_s as a bodily disorder, that originates within the body. And therefore, that you treat the body. And I think that's a very narrow biomedical view. So if those guidelines, I haven't seen those particular ones that you're talking about... the consensus statements do actually acknowledge that's cognitive behaviour therapy can help. They don't say a lot about it, but they do acknowledge it. And they do acknowledge that, um you know, giving women some sort of support or counselling as you know, an early form of intervention is a positive thing. But if you've got [new] guidelines, I'd be interested to see them. I haven't actually seen them... They're coming at it, kind of obst & gynae fields are taking that perspective. Then I think it's very unfortunate and very narrow...

**Interviewer:** [00:58:32] They do mention CBT, but it is very much like a kind of an offhand mention that some women can find it very helpful to have CBT or there is limited evidence that shows that it's helpful or something like that. And then it really goes into either Hormonal or the SSRI approaches.

**Susan:** [00:58:57] Yeah.

**Reference 13 - 1.11% Coverage**

**Interviewer:** [01:00:42] So the next two questions, it's up to you, whether you want to answer them because you might not have any experience working with these approaches. The first one is what do you think about the use of diuretics in the treatment of PMS or PMDD?

**Susan:** [01:00:54] Um, I haven't used them, so I don't... I think. I don't know. I don't know how. they're used... I think if women. If If if I don't know, I don't. I haven't used them or been involved in using them. I know that feelings of bloating are a problem for a lot of women. And if diuretic's help women. I don't know if it's any evidence that there's more water retention at that time, but I'm not a medical practitioner, so I probably shouldn't comment on that.

**Reference 14 - 2.35% Coverage**

**Interviewer:** [01:01:29] OK. And what do you think about surgical interventions in the treatment of PMS or PMDD?

**Susan:** [01:01:40] [Long pause] I've certainly heard people talk and probably some of the people that you're going to interview about hysterectomy, as you know, the ultimate cure for PMS. I know there's some research... Well, you'd have to take out the ovaries as well if you... if you're going to take a really biomedical position on it. And I seem to remember although, I haven't seen it for a while that there is some research showing that women still might position themselves as having PMS even when they have had their ovaries removed. And certainly women... um certainly position themselves as having p.\_m.\_s when they're on hormonal interventions, such as oral contraceptives. When you'd think they wouldn't be getting those changes as monthly cycles? So I think that what... it's really the extreme end of positioning Premenstrual distress as if it's an entirely embodied um experience, I would hope that most clinicians wouldn't do a hysterectomy on a woman lightly for any disorder. I suppose, that would be my comment on that. I think just going back to your diuretic question, though. Um, I think if women are experiencing so much distress around bloating and p.\_m.\_s that it's also important to look at the meaning of that bloating for women. As I've already talked about previously, not just the bloating itself, but if a simple diuretic could help and it's not having any other adverse effects on women, then it's probably not problematic.

**Reference 15 - 0.53% Coverage**

**Susan:** [01:09:43] I think if you do that from a GP perspective... Having a standard question that GPs might ask women if they're coming along with a chronic condition. Saying, "does that vary across the menstrual cycle?" And women might not be aware, of it themselves, but just getting women to track it. And I think that would be a really positive thing.

**Reference 16 - 2.60% Coverage**

**Susan:** [01:14:18] No.. I don't... I don't think so. I think the only thing I'd say is... I suppose my view of PMS has changed over my own life. Partly to do with my experience of my body and Premenstrual change. And also my own academic journey in terms of different ways of thinking. And I think academically, I moved from a you know, very positivist, you know, experimental view point to a social constructionist let's dismiss it, let's deny it. You know a much more political position to where I am now which I've talked to you about, so I won't repeat that. Where, I do acknowledge the embodied aspects of it and the hormonal aspects of it. I mean, I don't if it's hormonal. I'm not a biomedical person. And I think in terms of my own experience, not menstruating anymore, it's actually really interesting. And I haven't you know, I've been so busy in the last year when I haven't been menstruating. That I haven't had time to... to really sit and think about it and think about what that means in terms of how I would be... how I am as a menstrual cycle researcher. [change in tone] But I'm really amazed by the difference in not having those cyclical changes. You know, it's it's... and it really... I wouldn't have ever denied hormones anyway. I think earlier on in my career I would have done, like I really did. I went through a phase in my 20s and 30s when I really was you know 'anything hormonal is terrible' kind of thing, of people who took hormonal positions. It's really interesting from a personal perspective, even that like academically I am... I always acknowledged them any way. But it's really interesting personally to stop menstruating and actually see that those cyclical changes are not happening. So yeah...

**<Files\\E10\_Marta> - § 16 references coded [59.31% Coverage]**

**Reference 1 - 0.45% Coverage**

Um, so first of all, how did you come to be interested in Premenstrual Syndrome?

**Marta:** [00:00:40] [Redacted- personally identifiable data]

**Reference 2 - 1.39% Coverage**

**Interviewer:** [00:02:19] OK. And this is a bit tricky, but can you remember when you first came to know about PMS?

**Marta:** [00:02:32] Ahhh... It must have been during my... my... when I was a med student in the OBGYN course, I think... [pause] I don't think that it was.[pause] Maybe I had read about it in the media before going into med school, but um it wasn't something that was really discussed that much, at least not in... in the media.

**Reference 3 - 7.72% Coverage**

**Interviewer:** [00:03:02] And again, in your understanding, how common is PMS?

**Marta:** [00:03:09] [audible exhale] Well, that's a good question. And if you're asking about my understanding, I would say I don't really know.[laugh] I think the general estimates that are typically given... I mean, what I write myself when I when I write a paper, er... I would say it's it's found in three to five percent of women. I would definitely lean more towards 3 percent than the 5 percent. And... but... In all honesty, I think that even the 3 percent prevalence is probably a bit overrated.[pause] I'm saying this because I'm currently working on a project on an endocrine disorder called Polycystic Ovary Syndrome, which is also common in [Sweden] and in women. And the typical prevalence rate reported in the literature is... if you take the low range around 6 percent. But when we look at the number of women who've been diagnosed in the Swedish registers, because in Sweden we have registers for everything. Every diagnosis made by a doctor. We can only see that about 1.5 percent of all women actually have been diagnosed with PCOS. And of course, you can suspect that some women go undiagnosed, but not... not seventy five percent that seems unlikely. And I think the same thing is going on with p.\_m.\_s. That it is common. I mean, anything that's above 1 percent is common in women, but maybe not as common as 3 percent.

**Interviewer:** [00:04:56] Do you have any theories about where that... for want of a better word exageration or where that idea that maybe more women are affected than are?

**Marta:** [00:05:09] Can you repeat the question? I have problems...

**Interviewer:** [00:05:14] Do you have any theories or ideas about why the prevalence might be slightly exaggerated?

**Marta:** [00:05:23] I think that there's... I mean, the studies that have been done on on the issue. I think the best study whatsoever is, is a prevalence study that was made in Reykjavik, where they actually asked women to perform daily symptom ratings for a number of months and they used very strict criteria to diagnose PMDD. Whereas I think that some of the higher estimates derive from... also population based studies, but more interview studies... er, where so that that probably means that... um we know that from from just women reporting they have p.\_m.\_s. If you're actually try to verify prospectively quite a... almost 50 percent or something, actually don't have PMDD.

**Reference 4 - 2.98% Coverage**

**Interviewer:** [00:06:20] Thank you. Again in your opinion and understanding why it is Premenstrual symptoms occur?

**Marta:** [00:06:32] In my... according to my understanding, and I'm pretty sure about this. I think this is due to progesterone. [inhale] I don't know exactly how it's... how it's due to progesterone because I mean, the the arguments people put forward is that the symptoms only occur during the luteal phase and um what characterizes the luteal phase is that you have progesterone levels at that time point. But then again, it's also quite apparent that the most intense symptoms happen after the progesterone levels have declined. But somehow I still think it's connected to progesterone. And I'm currently analysing a randomised controlled clinical trial that we have done in women with PMDD. Where, we've given them a selective progesterone receptor antagonist and it's really good. It really helps. So. progesterone, definitely.

**Reference 5 - 4.02% Coverage**

**Interviewer:** [00:07:40] That's great. Thank you. And again, in your opinion, what is the best way to manage PMS?

**Marta:** [00:07:52] Er, I think that the best ways to manage it by using antidepressant drugs er.. and using the cyclical treatment or symptom onset treatment. I think that's... that's been proven by a number of studies to be highly effective and it's a safe treatment. I think that... which is not yet published, but we hope to publish it this spring. I think that the treatment we are now proposing using progesterone receptor antagonists would be really, really, really promising. But they are... that would be off-label use because the progesterone receptor antagonists are used to treat uterine fibroids and they're only used to treat... um for pre-operative treatments. I think they're only... you're only allowed to use them for three months. So my study is a proof of concept, but I know that there are new progesterone receptor antagonists coming into the market and and that the development program aims to...to have treatment.. long term treatments for... for fibroids. So I think that could be a treatment in the future. [cough- pause] But our findings have to be validated of course, and It has to be safe. But as of now, definitely the antidepressants.

**Reference 6 - 1.74% Coverage**

**Interviewer:** [00:09:20] So can I just clarify something? The progesterone antagonist you are talking about about. Is that the same as GNRH?

**Marta:** [00:09:28] No!

**Interviewer:** [00:09:30] It's a different thing...

**Marta:** [00:09:32] It's a different thing. And the beauty. I mean, they... they more or less have the same effect. They induce anovulation. But the beauty with the progesterone receptor antagonist is that they don't have the same side effects as the GNRH Agonists. So um it would be much more um... useful for the women. Absolutely.

**Reference 7 - 6.53% Coverage**

Again in your understanding. Roughly how many Premenstrual symptoms are there?

**Marta:** [00:10:34] Are you asking them about the eleven symptoms that that make up the list in DSM 5? Or are you asking me to choose between these eleven or can I add extra symptoms if I want?

**Interviewer:** [00:10:46] You can add extra symptoms.. This is up to you. Some people have... This has really varied according to the person. So maybe a little bit beyond the PMDD... Well, maybe not beyond. But for instance, in the PMDD criteria, there's number eleven, which has all the physical ones all in together. Some people would separate those out...

**Marta:** [00:11:16] So, I mean, I think that that one thing that hasn't really been stressed in the diagnosis is that... I mean, in my understanding and when I see patients, I really see that the two... the two dominant symptoms are depression and... and irritability. And... and that strikes me as quite a... that's quite an odd combination of symptoms that doesn't really happen in... in any other parts of psychiatry. I mean, irritability is a symptom of anxiety, but irritability does not belong in the depression diagnosis, for instance. So though those two... I think they're not emphasized sufficiently, but they... I think more or less all my patients have kind of a mixture in-between these two. I once tried to see if we could separate, separate, different subtypes of PMDD... looking at how many have the depressive-genic PMDD and how many have the irritability- PMDD. But it turned out that almost everyone had had combinations of these two. As far as symptoms that are outside of the diagnostic criteria. I don't really have any opinion now because I haven't really systematically asked women about their symptoms over the past 15 years. I've just used the scales that are available, so that has never been any of my research concerns. And it's... I don't... if I think back to the women I'm meeting what kind of symptoms they describe on on open questions, they usually fall within what is described in the... in the current criteria.

**Reference 8 - 2.00% Coverage**

**Interviewer:** [00:16:11] So would you consider, period pain or uterine cramping as a premenstrual symptom?

**Marta:** [00:16:17] No, I wouldn't because I'm a gynaecologist. I would say that's dysmenorrhea or potentially endometriosis.

**Interviewer:** [00:16:25] Uhuh...

**Marta:** [00:16:26] I think it's it's a big misunderstanding to include Cramps in the PMDD diagnosis, first of all, the cramps, don't... they usually happen... once the menses start. And I think it would be unwise to incorporate it in the PMDD diagnosis because that would mean potentially we would miss... er the opportunity of an endometriosis diagnosis instead.

**Reference 9 - 1.16% Coverage**

**Interviewer:** [00:18:44] So for you, something like perhaps a possible bipolar or depressive condition. You would just rule it out from the daily rating process?

**Marta:** [00:18:58] Er, Yes! [emphatic] that's... that's... I think that's one of the most important tools... reasons why we use the daily ratings is actually to rule out underlying mental conditions. Yes.

**Reference 10 - 4.16% Coverage**

**Interviewer:** [00:23:47] Ok. The latest guidelines, that are mainly based on the ISPMD consensus process, erm, state that any symptoms count so long as they fit the timing... and resolve shortly after menstruation begins? How do you feel about that definition?

**Marta:** [00:24:12] I think it's... I think it's OK. I mean, we have to acknowledge that that women are different [from each other] and that we don't know everything. And I mean, if I would ever meet someone who came to me with a symptom that I hadn't previously heard about, I would, of course, still count it as a symptom. Although I would say in real life practice, given the way I'm using open questions when I see my patients, I don't see that many patients who come in with symptoms out... outside the typical ones. [Pause] One symptom that I think is not sufficiently captured in any of the questionnaires that are typically used in PMDD is suicidal ideation, which I think is far more common than... than people think about. And I think I would absolutely vote for an item like that to be incorporated in the diagnosis because I think... looking in my own data now, I think it's... it's almost around 50 percent, 45, 50 percent [cough] of the women we include in this progesterone receptor trial, who acknowledge they have suicidal thoughts, er at base line.

**Reference 11 - 1.63% Coverage**

**Marta:** [00:26:46] Uhhh. Potentially. But I don't think it's a major problem. I don't think that er, I'm missing patients... because they have a symptom that's not on the list. I mean, from a clinical point of view, I rarely count... to see if they have five symptoms. I just assume if they come to see me in the clinic, they have really severe symptoms. And then if they just say it's irritability, and depression, I'm fine with that. So I have a very... I mean, you have to be pragmatic when you're working with women.

**Reference 12 - 3.14% Coverage**

**Interviewer:** [00:27:19] Yeah. Again, there's this slight... slightly strange thing now with the ISPMD definition of PMDD as being kind of parallel to p.\_m.\_s under this umbrella term of 'Premenstrual disorders', so there's this kind of... the idea that there are two core premenstrual disorders so one is PMS, and one is PMDD. Do you have any thoughts on the way that's categorized?

**Marta:** [00:27:56] Er... No, I think... I think it was. I mean... I.... I think I was.... I wasn't part of that.... I was part of one of the errr.... Conferences. They had... but I think I was part of... on the... on the one on the treatment, but not on the one on diagnostic criteria. So I... I don't know exactly how the discussions went. But er I think that these two disorders, they were. Both put in under the umbrella to sort of accommodate for the fact that some of the people in the group were gynecologist's and other people were psychiatrists, and I don't think they're really founded in in real science.

**Reference 13 - 4.16% Coverage**

**Interviewer:** [00:30:07] Erm, quite often now the guidelines on PMS and PMDD tend to go straight to pharmaceutical treatment options and they haven't got as much on these kind of lifestyle changes. So, yeah, kind of non-medication based interventions that people could try. Do you have any thoughts on that?

**Marta:** [00:30:33] Oh, no, well it's not surprising. I mean, this is from a scientific perspective. This is a very, very underdeveloped area of research. So I think it has to do with the fact that simply too few people are interested in PMDD and that's why we haven't seen any of the other interventions. I mean, there's been studies done on physical activity or yoga. What have you, but usually not really well executed. And um... so I think it's just... not it's... not that many people in the business. So I'm happy for... happy that you take on this challenge! [referring to website?] [laugh]

**Interviewer:** [00:31:16] Yeah! I'm having second thoughts, I must say... [laugh] So for you, it's about this kind of evidence based medicine the fact that we might know that some lifestyle changes could have an effect. But there isn't that body of evidence there yet to formally recommend it?

**Marta:** [00:31:37] Mmm Mmmmmm. But I'm... I'm sure that at least physical activity would be really, really good. And. Yeah.

**Reference 14 - 4.24% Coverage**

**Interviewer:** [00:33:10] So the next two questions... You may not have experience of these treatment options. So just let me know if you don't want to answer. The first one is what do you think about the use of diuretics as treatment for PMS?

**Marta:** [00:33:29] Oh, I have experience from that... of that! [laugh] So I'm I'm... quite old. [laugh] And when I started as a gynaecologist in the... in 1991, I think spirinolactone was probably the only treatment available for... for PMDD. At that time. So that was what we prescribed and it was really crappy.

**Interviewer:** [00:33:57] [laugh] So particularly on the mood symptoms or just it didn't work?

**Marta:** [00:34:02] Um, I think particularly around the mood symptoms, I think that er for some of the physical symptoms, potentially also the swelling, they were maybe good, but er not for the mood symptoms. And also I use nowadays, I use spirinolactone to treat hirsutism. In women with Polycystic Ovary syndrome. And then I use four times higher doses than I did for for PMDD in the 1990s. And it's also a very crappy drug [laugh] for for hirsutism. And I've never had any patient coming back saying that... they 'Oh you know, as a side effect, I've noticed that my my PMDD also disappeared'. So. So they tend to have side effects from Spirinolactone but I've never heard about mood improvement.

**Reference 15 - 5.18% Coverage**

**Interviewer:** [00:35:00] And then what do you think about surgical interventions for PMS?

**Marta:** [00:35:09] Er.. [laugh] Er, Yeah. I'm not really fond of it.[laugh] And I've never... Um, I've never.... um [long pause] what's... erm, I've never used it for any of my patients.... I've... I've used it once for a patient who had Premenstrual epileptic seizures and I cured her [smile and laugh], which was really, really rewarding both for me. And, of course, for the patient. But that, I think, is the only time I've ever had... made an oophorectomy.

**Interviewer:** [00:35:57] Um, That sounds like an interesting case. Did you do um hormonal add-back after the surgery and that still didn't affect the epilepsy?

**Marta:** [00:36:06] No, I didn't do anything. It was a really tragic case. This was a woman who... she was born normal, but I think she had an incident like this when she was at the age of one, two, three, very young. And that also meant that she was not... she also... she was also slightly mentally retarded? And she was having petit mal seizures and sometimes also generalized seizures from those. And she was really, really suffering. And she came to me in the clinic three times and two times before the surgery and once after the surgery. And she had several seizures just waiting for me in the waiting room. And the staff were really upset. And we discussed the possibility. But for her, it was just too troublesome to start taking any more drugs than the ones she was already taking for epilepsy. So we we thought it best not to provoke seizures again with any hormonal treatments because she was so happy that she was improved.

**Reference 16 - 8.81% Coverage**

**Interviewer:** [00:37:20] Yeah. Um, That's about it. So the last bit is just How do you feel about this interview? And do you have any questions or comments you'd like to add?

**Marta:** [00:37:34] No, I think I've said pretty much everything I wanted to say. And one of the things I really wanted to point out was... was about suicidal ideation, which I think hasn't really been... been that well known. And it also seems... to me is... is one of the reasons I say that this is actually a relatively severe mood disorder and not just a mood disorder. I think it's severe for many women. And I think it should be emphasized for the sake of the women so that people can understand that this is far more.... More severe than most people think about. I also think what we have... I also dislike the way that people are using p.\_m.\_s to categorize a number of symptoms. That seems to be more like menstrual symptoms. You were talking about dysmenorrhea... I think that's also important that we shouldn't mix... mix these these symptoms up for many reasons. So those were really the two major points I wanted to make today. And one... And you asked about it! But I mean, I like the interview. I like. I like what you're doing. And I think that there's not really sufficient research ongoing at the moment. And I can certainly say from the... from the interest we've had in the study we did that there are many women out there. And they really want to be... They really want us to do more research about this and provide them with more treatment options. Because even though I say that anti-depressants are really, really good. Doesn't mean that the women think that it's really, really good, and that they want to continue taking them. It's absolutely clear from.. from the trial that we've done there's an interest in participating that women want alternatives. So I think what you're saying about lifestyle interventions and other alternative treatments, that that area should also be developed.

**Interviewer:** [00:39:46] Yeah and just... Um just out of interest. Are you finding more patients are using apps to track their cycles anyway?

**Marta:** [00:39:59] er... Not yet, but I think maybe it has to do with the... I mean, most women who come to me in the clinic, they're... they're 30 to 40 years of age. I think when... when the next generation is coming into the PMDD age, they will probably be more used to using apps to monitor their health than... than the women I've been seeing over the past 20 years. Er... Occasionally it happens. And if I get questions from patients on my e-mail, for instance, that's usually what I tell them. Find an app that you really like and... and monitor the symptoms and bring the app and then and the output from the app to your doctor. occasionally I've had patients with apps.

**<Files\\E12\_John> - § 11 references coded [60.03% Coverage]**

**Reference 1 - 2.45% Coverage**

**Interviewer:** [00:04:15] And what is your understanding of why Premenstrual symptoms occur?

**John:** [00:04:22] Um... [exhale] I believe that there's probably a number of different conditions that fall under the umbrella of what we call Premenstrual Syndrome. And I believe that it's likely to be a different reason in different subgroups that we haven't really fractionated out yet. There is probably a genetic predisposition and then there is a sensitivity to hormonal changes.But I think that sensitivity is likely to differ from one person to the next. So I think some people may be more sensitive to the progestogen increase that occurs at the time of ovulation premenstrually. I think for some people it might be the drop in oestrogen that occurs. I think for other people it's potentially something else. Er... indirectly related to one or other of those things.

**Reference 2 - 6.04% Coverage**

**Interviewer:** [00:05:18] Thank you. In your opinion, what is the best way or best ways to manage p.\_m.\_s?

**John:** [00:05:26] I think any medical condition is usually best managed within a bio psycho social model. And er... in essence, what that means is starting off with conservative treatments like looking at people's diets and you know drugs that they may or may not be taking, exercise um... and then moving from that. If that doesn't ameliorate things, I mean, for many women, they can actually have a very profound impact on their symptoms by altering their diet, exercising, etc.. Um... So that's the starting point. Um... Environmental factors, I think many women that come into this clinic will.[pause] Describe how their symptoms got worse in the context of something else happening in their life and then feeling stressed or upset about something and the p.\_m.\_s occurs in the context of that so trying to address those environmental things and or the way somebody thinks about them. That's more psychology. [pause] Um.. And if people can get it- CBT and evidence based psychological treatments are certainly top of the list, um there are some non pharmacological er... treatments with some evidence base to support them. Usually before people have come to this clinic, they've tried most of these things, but I'm sure you're aware of things like Agnus Castus and things that have some evidence base. The thing about p.\_m.\_s, though, that we're also aware of is that there's a very significant placebo effect for many of the treatments out there, which in a way is a good thing, because it means that many things can help it. But I guess it also leaves some people a bit more open to.... Non-evidence based, charlatan type things, which.[pause] May... may or may not be problematic [inhale, almost laugh]. And then there's the medical treatments, which er... could be loosely or clumsily described as being psychiatric and gynaecologic um.. or hormonal or non hormonal. And right at the end of that, algorhythm as you probably know are Surgical options, which. um, are sometimes recommended, but not that often in this clinic.

**Reference 3 - 7.15% Coverage**

**Interviewer:** [00:12:46] So obviously, many chronic health conditions can get worse or be exacerbated or triggered by the menstrual cycle. Do you count the expression of those as Premenstrual symptoms?

**John:** [00:12:59] Do I count those as Premenstrual symptoms? Er... Yes. And it becomes very difficult actually to decide whether somebody has p\_m\_ D.D. as strictly defined by DSM 5 or whether they do actually have an exacerbation of something. And even if somebody doesn't think they have an exacerbation of something, there's always a question mark as to whether or not it's just below the level of their errrr... conscious or unconscious um recognition. But I would say that many of the people that I see... when you drill down, even though they might not complain of those symptoms during the first half of the cycle, will acknowledge that they're there to some degree. Um, And the way that I describe it to many people is it's a bit like you've got a fire burning and then premenstrually what you're doing is chucking petrol on it. So you've got two choices. You either put the fire out or you stop the petrol and. For some women, the fire is not significant enough to want to put out. They can put.. just stop the petrol, that's enough. For other women they would acknowledge if you could put the fire out. That would be very helpful because it ain't great all the time, even though it's a lot worse. Premenstrually. Erm I dunno if that answers your question?

**Interviewer:** [00:14:30] Yeah, just to clarify... So, for you, PMDD you know, the most severe symptoms are quite similar to perhaps in terms of categorizing to maybe things like epilepsy or asthma.That are significantly worse or could just be cyclically experienced. Or do you think there is this... because there's a kind of divide in the literature between whether PMDD is a completely separate and hormonal, you know, sex-hormone, I suppose, dependent Mental health disorder or as you are sort of implying there that it could be possibly other mental health disorders and then this trigger?

**John:** [00:15:20] Yeah. And as I say. I think there's a bunch of different conditions that we all give the same name

**Interviewer:** [00:15:25] Yeah.

**John:** [00:15:27] And I think there probably is a pure form of PMDD. But I also think there's probably a lot of people that have. Something else that's bubbling away that's exacerbated premenstrually. And some people where it's not bubbling away, they've got another condition and it's exacerbated premenstrually.

**Reference 4 - 3.00% Coverage**

**Interviewer:** [00:15:50] Thanks, um are there any positive menstrual changes?

**John:** [00:15:56] Menstrual or premenstrual?

**Interviewer:** [00:15:57] Er.. premenstrual, I suppose!

**John:** [00:16:26] [very long pause- approx 25 seconds] I mean, I'm thinking about that. The reason why people come to a clinic like this is because they've got a problem. Not because they've got something that's helpful. Um, but if you speak to people with bipolar disorder, they will quite often tell you that the manic bit of their condition is something. If they could just have that, up to a certain point, they they would value it and rather not have that treated. And I have had people who premenstrually have been on the manic side- that they would not say is a problem, but they would say that what then happens is problematic. And so I don't know whether that answers that?

**Interviewer:** [00:17:06] Yeah.

**John:** [00:17:06] But they wouldn't be coming here telling me that... that's. "They were here just to say how wonderful things are premenstrually" [quiet laugh].

**Reference 5 - 7.10% Coverage**

**Interviewer:** [00:17:19] So obviously, men can experience nearly all of the same symptoms, just not in any kind of cyclical pattern because they don't have a menstrual cycle. So does this mean that exactly the same symptoms can have very different biological mechanisms depending on a patient's sex?

**John:** [00:17:45] Um... [pause] I'm just trying to think of how to answer... just say that question again.

**Interviewer:** [00:17:47] It is a tricky question. It's, you know, obviously, apart from really period pain and maybe breast tenderness. Nearly all of the symptoms and changes that people get premenstrually men or in fact, menopausal women, children can also experience. So it's thinking through.Does this mean that there's a specific biological mechanism for these Premenstrual ones that is different somehow very different to the mechanisms underlying these symptoms experienced either by other people or by people after they finish menstruating?

**John:** [00:18:21] Well, I suppose men can experience these symptoms in a couple of situations. So men, if they have prostate surgery, get their hormones switched off and they would experience some of these symptoms. As you probably know, they did try to invent contraception for men, which was effectively a progestogen (Depo) shot. And that led to... Well, the reason that those trials were stopped was because quite a few men became suicidal. So it would seem that those mechanisms are in place in men, but they don't have that being triggered in the same way perhaps that women do. And as far as depressive symptoms go, which make up many of the PMS symptoms, those can get triggered by other things if they're not hormonal and are probably pretty similar... I mean if you're feeling low in mood, Hopeless, and wanting to kill yourself is a symptom. You can have premenstrually, but it's certainly symptom of... or symptoms that you can have for other reasons. So...

**Interviewer:** [00:19:25] I mean, there isn't a definite answer to these questions it is just sort of trying to hear how you would describe it...

**John:** [00:19:34] Yeah, well as you probably know, there's another group of physicians out there who treat men who have the andropause, and many men who have the andropause will describe... Similar symptoms in terms of low mood, low energy, but perhaps at a lower level..

**Interviewer:** [00:19:50] Yeah, and they ascribe that to testosterone, don't they, generally...

**John:** [00:19:52] And they go get testosterone supplements, yeah

**Reference 6 - 3.03% Coverage**

**Interviewer:** [00:24:44] So and again, after the consensus er... process, there's a kind of umbrella term 'Premenstrual disorders' and then sort of sitting underneath that is PMDD and p.\_m.\_s, as kind of parallel, but different diagnoses. Do you think that's a sort of useful way of framing these categories?

**John:** [00:25:20] Um [pause] Well, I think anything that sort of is more inclusive is better. Just because of the reasons... mentioned in terms of not. Preventing people that need treatment, getting treatment. I mean, I... I know that there is quite a lot of talk about the semantics of these different definitions, but. I'm not sure if people really are getting that hot and bothered about it? Clinicians don't seem to- someone comes to you and they've got the symptoms, you treat it. Um [pause] I think that maybe it's more of a academic debate that perhaps... maps less well on to what happens in clinical practice in reality. That doesn't mean that I don't think that there should be some attempt to categorize these things, but... [pause] [quiet laugh] yeah.

**Reference 7 - 8.69% Coverage**

**Interviewer:** [00:26:22] So I've noticed in clinical guidelines on p.\_m.\_s, there's relatively little attention paid to these kind of lifestyle or the psychosocial treatment options that that might be able to help some people. And there's more of a focus on the kind of medical... medication. um Treatment pathways. Do you think there's a role for including slightly more information about these non-medication approaches?

**John:** [00:27:01] There would be if there was more studies. But the fact is, the studies that have been done are pretty poor... underpowered. And therefore, there isn't an awful lot to say about them specifically with regards to PMS. I think if you look at those sorts of studies, as they've been applied to other mental health conditions. There's more of a literature. So again, I think it's... um, [pause] It's common sense to apply literature that's out there on the benefits of lifestyle things as it relates to mental health more widely, to p.\_m.\_s. But if you want to go and find studies that have been specifically done on p.\_m.\_s and these lifestyle factors, you're not going to find many RCTs that have been done.

**Interviewer:** [00:27:50] Yeah.

**John:** [00:27:50] So I don't think people can talk about those more because there's less to talk about. There have been more studies done on pharmacological interventions. I mean, in part probably because they're easy to do. You've got something that is going to be the same. that you can basically replicate in part because you've got a system that's set up whereby you've got doctors and clinicians and people that are using those things and they're actively involved in research. The lifestyle stuff is slightly outside of that domain, isn't it?

**Interviewer:** [00:28:30] Yeah, but there is this tension that I think a lot of clinicians do actually, depending on the severity, I think, of the patient... Do actually suggest some of these lifestyle changes or at least take them into account in the history of the patient?

**John:** [00:28:44] Yeah.

**Interviewer:** [00:28:47] And I suppose what it is, is when I've spoken to GPs if they're just reading the NICE guidelines or the Royal college guidelines, they may not be aware of this kind of... things that they could try?

**John:** [00:28:59] I think most GPs are pretty aware of the fact that diet, exercise, help mental health. And if somebody is coming with anything, that's got that. er, Aspect to it then it would be reasonable to to look at that. I don't I don't think they are gonna really pick up the guidelines. and say "well, It's not in there. Therefore, I'm not going to be recommending that, you know, stop eating 88 chocolate bars a day, and you know, sit on your sofa and don't do any exercise and expect any medication is going to help". But they would say that. So, again, I don't... I don't I mean, I could be wrong, but I don't think clinicians are that. um. caught up with Guidelines for making that sort of suggestion. As I always, say to people anyway, that they're guidelines they're not kind of... written in stone.

**Reference 8 - 1.53% Coverage**

And so the next two questions, you may not have had experience of using these as treatments. So feel free to just say, I don't know. or 'I don't have that experience'. What do you think about the use of diuretics? So particularly spinolactone in the treatment of PMS?

**John:** [00:32:41] I don't use it.

**Interviewer:** [00:32:43] And you never have, or?

**John:** [00:32:45] I never have.

**Interviewer:** [00:32:45] And is that because you don't think it's going to be effective or?

**John:** [00:32:52] It's not an evidence based treatment.

**Reference 9 - 0.64% Coverage**

**Interviewer:** [00:32:59] Thanks. And what do you... what do you think about surgical interventions in the treatment of PMS and PMDD?

**John:** [00:33:08] I think for some people it's appropriate, but it's at the end of the line.

**Reference 10 - 1.74% Coverage**

**John:** [00:33:35] [pause] Er.... I don't think so. I suppose I'm just listening to the way that the questions have been developed, which is very much one of. um... A heightened concern about how DSM 5 has described PMDD. At least that's my reading of it. That's kind of. It has that kind of feeling about it. And. um... I don't think any diagnostic classification of a condition is gonna be perfect, and I think it's probably helpful to have something to sort of work around... that. Provides a framework. I don't think most clinicians are that literal in terms of how they use these things. Whatever the condition is.

**Reference 11 - 18.66% Coverage**

**John:** [00:36:24] I think I mean, as far as the p.\_m.\_s and PMDD area goes, I think one of the more controversial things which I've strayed away from that I think is of some interest is the appropriateness at the moment of that falling far more in the gynaecology than the psychiatry camp. [pause] And I think there's a couple of good reasons for that. One is psychiatry is completely overwhelmed with mental health problems that it can't manage already. It certainly does not want to have another condition in there to have people coming, to. And the other one is that people with p.\_m.\_s symptoms will sometimes fear that if it's categorized within mental health, the stigma associated is one that will not lead them to searching for treatment. But in fact, I think that gynecologist's. Certainly in.. for a lot of things that I see, are gonna be out of their depth and... are Probably misdiagnosing people. Now there's a gynaecologist out there. Who you, I'm sure have read who suggests that that's what psychiatrists do. That we're, misdiagnosing people with PMSS with bipolar disorder. And I'm sure that there are cases of that. And as much as the ment... The mind is it's complicated and as a psychiatrist. You always have a differential diagnosis, which you don't seem to have quite so much in gynaecology. It's much more black and white. So we're kind of used to existing in a world where we're not sure we've got a bunch of differential things that we're thinking about. I'm going for one and testing it, and thinking about the other options. At least that's how we're trained. And I think, you know, for a gynaecologist to work out, for example, what a personality disorder looks like and feels like when it walks into the room. And how that might be impacting on some of these things, I just don't think it's going to be something that is going to be done well. Um, And I think teasing out what's bipolar and what's borderline and what's ADHD and what's... is very, very hard. I think psychiatrists find it hard and I think a lot... if I look at the people that come into this clinic. They're complicated in terms of the pathology. And it's a case of having to tease those things out. And I personally think that it's something in an ideal world you'd have... You'd have psychiatrists more trained up in, as opposed to gynaecologists more trained up in...

**Interviewer:** [00:39:08] yeah

**John:** [00:39:13] But um... I don't think I'd get many of my psychiatry colleagues sort of cheering that on because they're there. fire-fighting. Suicidal, psychotic patients with a resource that's limited. They don't want to have 5 percent of the female population who have got the severe condition that they're not currently having to treat. I don't think they want them.

[00:39:35] Yeah.

[00:39:37] And then if it's bigger than 5 percent because we're actually going to treat everyone that doesn't fulfil the strict criteria. That's a big burden for a speciality to take. And at the moment, it falls onto g.\_p.\_s predominantly.And I think they probably are well-placed for the kind of lower level patients. But anyway, that's something that you know... If I were doing what you were doing, I would also be interested to tease apart in terms of, you know, who is it, That's managing it? And is it the right speciality?

**Interviewer:** [00:40:17] Yeah.

**John:** [00:40:18] And if it's not, why isn't it?

**Interviewer:** [00:40:21] And if I could just ask you, do you think psychiatrists would be happy to prescribe hormonal...

**John:** [00:40:28] I think with a bit of training... I mean, at the end of the day there's a bit of stuff to learn. But we've all had our medical training and errrr... it's it's not a biggie.

**Interviewer:** [00:40:40] And then vice versa. I suppose gynaecologists aren't allowed to prescribe or...?

**John:** [00:40:43] Well, I think that, as you say, we've gynaecol... It's not just the prescribing, it's the diagnosing and working out what's going on and managing that risk. And gynaecologists would need a huge amount of training to be able to do that. Whereas psychiatrists would need a relatively small amount. [pause] so... I believe in the states because it's a commercial system. There's also a I mean, it's been suggested by this particular person who thinks that the psychiatrists get it wrong, that the reason why it exist within the mental health system in the states is financially driven. Er... Which I think is a pretty cynical... Observation. I mean I'm sure there are financial... Ramifications, but I also think that...

**Interviewer:** [00:41:38] Well one pharmaceutical company in particular did behave slightly cynically, but as to whether or not that's why psychiatry in general got behind the PMDD diagnosis... it's probably for different reasons...

**John:** [00:41:54] Yeah, I don't know which drug company, which drug this is?

**Interviewer:** [00:41:57] Eli Lily. So they rebranded Prozac, as Serafem, specifically for PMDD. To extend the patent. So, the patent was coming to an end for Prozac..

**John:** [00:42:12] right.

**Interviewer:** [00:42:12] And so it was rebranded. Which means you can extand... basically you can have a new patent. So it is the same chemical compound made pink. For women, and called Serafem to make it clear that it was for women and they were er.. held.. they were sue..sued, or I don't know. The FDA had to get involved because they also then included a self-diagnosis tool, which was essentially menstrual changes, fairly er, you know normal menstrual changes. And then they did talk about mood but they were kind of pathologizing low level mood changes like all people experience for whatever reason. So they did have a kind of. financial reason. But then also in the States, you couldn't get any treatment covered for what we call PMDD or severe p.\_m.\_s because it wasn't listed as a. Diagnosis under insurance policies. And so getting PMDD in the DSM was important for those patients who needed treatment and up until that point kind of fell through the gaps. If they didn't meet the criteria for bi-polar or...

**John:** [00:43:27] Yeah

**Interviewer:** [00:43:27] So it's complicated,.

**John:** [00:43:30] But then that's a, that's a pragmatic reason isn't it?

**Interviewer:** [00:43:33] Yeah.

**John:** [00:43:33] erm...

**Interviewer:** [00:43:33] Sorry I've used up plenty of your time.

**John:** [00:43:40] That's all right. I've found it quite interesting.

**Interviewer:** [00:43:43] Yeah. I mean, I find it fascinating.

**John:** [00:43:45] Yeah. I suppose yeah, I don't really get asked these things very often.

**<Files\\E13\_Laura> - § 5 references coded [27.65% Coverage]**

**Reference 1 - 3.01% Coverage**

**Interviewer:** [00:03:49] Thanks. Again, in your understanding, why do Premenstrual symptoms occur?

**Laura:** [00:03:55] I think it's... I think it's a hormonal withdrawal effect that. Er, Leads to some changes in neurotransmitter signal... signalling.

**Interviewer:** [00:04:09] Any specific hormone or all of the ones involved in the menstrual cycle?

**Laura:** [00:04:14] Er, I don't think we know. Um, It's more likely, I think, to be progesterone and progesterone metabolites.

**Reference 2 - 3.68% Coverage**

**Interviewer:** [00:05:25] Again, in your understanding, roughly how many Premenstrual symptoms are there?

**Laura:** [00:05:34] [intake of breath] That's a little bit of a dicey question because, you know, people have identified dozens of symptoms. And just because it has occurred during the Premenstrual phase, they say it's a potential Premenstrual symptom. Um, I don't think that's really the case. So I think in terms of candidate symptoms that really reproducibly, are found in women during the Premenstrual phase and lead to some degree of impairment, it's probably within 15 to 20.

**Reference 3 - 6.15% Coverage**

**Interviewer:** [00:08:36] So obviously, lots of chronic health conditions can get worse. at times in the menstrual cycle. Do you consider the expression of those symptoms to be Premenstrual symptoms?

**Laura:** [00:08:49] I think [exhale] that... [Long pause] We don't know if a number of conditions actually... Worsen during the Premenstrual phase, or whether people experience some Premenstrual distress and that makes the other condition worse? So I think that's pretty complex. Um, You know, there is a literature on Premenstrual magnification of depressive disorders. I've... I've published a paper with [colleague's name] to see if bipolar disorder worsens premenstrually. And we were unable to show that. So I think it's... it's inaccurate to say that all conditions worsen during the Premenstrual phase because I don't think that's the case. I think there probably are some conditions that do and some that, you know, at any random period of time, it's going to be worse.

**Reference 4 - 3.64% Coverage**

**Interviewer:** [00:12:58] So I'm going to talk a bit about the ISPMD... the consensus building process and the definition that's come out of that. So as a result, the definition states that any symptoms count so long as they occur in the luteal phase and they result shortly after menstruation begins and are severe enough to affect daily life. How do you feel about that definition?

**Laura:** [00:13:25] Well, that's their definition. It's not a definition of PMDD. It's a definition of p.\_m.\_s. I rarely see anybody. Who... Has functional impairment because of physical symptoms.

**Reference 5 - 11.17% Coverage**

**Interviewer:** [00:16:55] Yeah, that's great. So some clinical guidelines don't include information about sort of lifestyle changes or environmental changes that could particularly for moderate symptoms rather than the very severe end of the spectrum. Those sort of lifestyle changes aren't typically included in clinical guidelines, at least the ones in the UK. Do you have any feeling...

**Laura:** [00:17:25] [overlapping speech] I think that... I think there... they are in those guidelines. I think for mild p.\_m.\_s they do recommend exercise and dietary changes. As I recall, I mean I haven't looked at them in a couple of years, but...

**Interviewer:** [00:17:39] I think clinicians do recommend them but some of the guidelines aren't including them anymore, and I think it might just be that... That's presumed as um 'already known'.

**Laura:** [00:17:55] Well, I think it's also fair enough to say that. There are no... the data on exercise, actually ameliorating the symptoms is weak... are weak. The data are weak. So now there are some dietary. Treatments such as what the Wurtmans [famous carbohydrate and serotonin theorists] looked at. This p.\_m.\_s diet, which boosts serotonin and that actually work quite well. So there are. There is a basis to some of the dietary instructions, although the dietary instructions are the opposite of what one would assume that they should do, like we assume that eating healthy means that you eat a lot of greens and, you know, protein and you don't have a lot of carbohydrates... and their diet. That empirically validated diet is a complex carbohydrate diet, which is not what people would probably think of if they had to change their diet. So there are... there's evidence for that. So that should be articulated in guidelines.

**<Files\\E14\_Zoe> - § 9 references coded [37.52% Coverage]**

**Reference 1 - 0.38% Coverage**

And so the first question is, how did you come to be interested in Premenstrual syndrome?

**Zoe:** [00:00:32] [Redacted- personally identifiable data]

**Reference 2 - 1.12% Coverage**

**Interviewer:** [00:02:30] Yeah, and do or did you identify as somebody who experiences p.\_m.\_s?

**Zoe:** [00:02:38] Er, No. No. I know lots of people who... who do and my partner experiences um quite severe p.\_m.\_s for me. I get clumsy and... but I'm clumsy. Most of the time anyway. So. [laugh] But generally, no. I I I was quite fortunate not to experience um p.\_m.\_s. I experienced a lot of menstrual pain and menstrual distress, but not PMS, no.

**Reference 3 - 4.17% Coverage**

**Interviewer:** [00:03:05] Can you remember how you first ever heard of p.\_m.\_s?

**Zoe:** [00:03:10] Oh.[exhale] [pause] I'm not sure I had too much of a... It wasn't part of the vernacular um... and part of the discussions we had as adolescents. Um, So when there was still... there was and still is. But for my cohort or for my my experience, um menstruation and just bleeding more generally were... were quite shameful and people didn't speak about it. Apart from the sort of [interference noise] The technical clinical description. (I'm getting reverb are you getting reaverb?

**Interviewer:** [00:03:51] No, it's fine at my end.

**Zoe:** [00:03:54] Ok. It's just... it's stopped now. It started and then it stopped.) Apart from the very clinical technical definitions you sort of got in you know, school sex education classes. Um and... and from my mother, there was not discussion of it. So it was not something that was widely discussed um within my peer group, within my family. Um not... not because of an overt shame. It just wasn't discussed. And so it was more of a silence than a, than a stigma or a shame? So I suppose. Um, I probably just became aware of it through popular culture, I can't remember when I became aware of it, but I do remember that in my um late um... in my late teens, my early 20s, when I was coming towards the end of my honours degree, I was already interested in women's reproductive health as a... as a topic area. So I was reading about it and... and coming across it both in terms of academic literature and popular culture at that time. But it was not something that was actually discussed amongst any of my peers or with my peers.

**Reference 4 - 2.91% Coverage**

**Interviewer:** [00:05:48] And again, and your understanding, why do Premenstrual symptoms occur?

**Zoe:** [00:05:54] Well, I think it's a combination of... it's a combination of factors. There's clearly something cyclical and physiological occurring. And um I don't need to, you know, don't need to go into the exact operation of, you know, what, hormones are in flux at what time. But there's clearly something that's physiological that... that's actually occurring. And um that then in a sense,[exhale] I don't want to say 'causes' because I don't think it's as simple as that. It's not that linear but that is occurring at the same time um that other things might be... that a woman might be experiencing other things. And so as a result, she just has less resources, less cognitive, emotional and sometimes physical resources to actually deal with that increased stress just because of the increased activity that's... that's occurring. So there's definitely something physiological that's occurring, but it's that interaction with what's actually happening in the woman's experience in the woman's life. And emotionally, that that makes the difference, I think.

**Reference 5 - 3.21% Coverage**

**Interviewer:** [00:19:01] So we know that many chronic health conditions can worsen or be triggered at certain times in the menstrual cycle. Do you count those? Do you count the expression of those as Premenstrual symptoms?

**Zoe:** [00:19:14] No. Would you like to give? It depends. Are you talking about ones that are related to to women's reproductive function or...?

**Interviewer:** [00:19:24] So it could be epilepsy or asthma or migraines or it could be a mood? You know, maybe a more chronic mood disorder that is significantly worsened.

**Zoe:** [00:19:34] Yeah. Um, generally no. The exception in that list, I would probably say would be Premenstrual migraine. I think that does seem.. there seems to be evidence that Premenstrual migraine is a standalone condition because there are people who don't experience migraine at other times, but only experience it. Premenstrually. Um,if someone also experienced it at other times, I probably would see it as something that is exacerbated during this period of instability and an increased sensitivity. But I would not see them as Premenstrual symptoms. I would just see this as the the Premenstrual that during the Premenstrual stage that they say these things may be exacerbated. But I would not view them as Premenstrual symptoms.

**Reference 6 - 12.69% Coverage**

**Interviewer:** [00:29:26] Um so the recent.. Royal College of Obst & Gynae in the UK. They did some guidelines on p.\_m.\_s. Um, they promoted the use of symptom tracking tools, which is considered good practice. But the tools that they promoted, the symptoms are directly based on the DSM criteria for PMDD. What's your feeling about that?

**Zoe:** [00:30:00] Um [exhale] I think [exhale] you would need to... OK. I think it's interesting to know when you're talking about tracking like for what purpose tracking is used? I think in research purposes it's useful. Um, Tracking can be useful and it can be useful... to help us identify or help us classify participants depending upon the nature and the focus of the study. So I think there are times when we do want to track and there are times when we want to classify. I'm not sure they're necessarily useful for all women all the time to be just used as a as a routine social app or as a routine lifestyle app. I'm not sure they're necessarily useful in all circumstances. So I've got my own views on the utility or not of tracking. So you began by saying that tracking tools were useful. Like, I don't necessarily accept that they are useful. I think they are useful in some circumstances, but may, depending on the tool, can can potentially not be useful in others, especially if the tool doesn't actually provide, if it's not accurate, if it's not providing good information, if it's not actually saying what to do once you've tracked something. I think they're... just tracking something is not necessarily good in the... in the first instance. So. So I wouldn't accept that first part of what you said, that they are good. That being said, you're referring to a particular tool that's using a very limited criteria pool. Again, it depends on what they are wanting to do with that? If it if that's about trying to help women, engaging in awareness of their cycle and awareness of their own body, well, then that's obviously not going to be useful because it's not an extensive enough list of what women's experiences are. If it's being used in a very discreet and very isolated in a very restricted form for a research study or for legal identification or medical identification, then that's a different issue altogether. So I don't think I can answer that because it depends on what the tool's being used for... um..

**Interviewer:** [00:32:04] Well, I think in these particular guidelines, it's supposed to help you diagnose p.\_m.\_s. And for me, the thing that was quite striking was they were obviously making a case for p.\_m.\_s as opposed to PMDD then because probably because of the only tools that have been tried and tested recently ar PMDD related. They then have to use the tools that are basically associated with a slightly different diagnosis.

**Zoe:** [00:32:35] Who or why? Well, I think to me it comes down to who or y is doing the diagnosis and for what purpose? Like if this is for a woman to... as part of her own self awareness, that's a different issue altogether. Diagnosis isn't an issue at all. It's just about being aware of her own changes. But if you're saying they need to be diagnosed, I'm I suppose I'm asking what's the imperative? What's the diagnosis? What's the imperative for the diagnosis?

**Interviewer:** [00:33:07] So this would usually be for general practitioners to use. Who didn't know so much about what what counts and what doesn't count as p.\_m.\_s. And it's providing them with the tools that they should use. And then it also provides information about different evidence based treatment options.

**Zoe:** [00:33:26] OK. So if it is if it's being used in in a more therapeutic context, in a medical context, I probably would be safer with it actually being a more a more constrained and restricted list, because whilst I do like the... as as I do agree with there being a much broader range of experiences, if you were talking about diagnosis, we need to ask for what purpose of diagnosis. And if it is in a medical context, for potential intervention, then I would always caution on... I would always be more cautious. I'd probably go on a more more restricted. I would probably um lean towards a more restricted, restricted sort of list rather than medicalizing a broader range of what our natural common experience. I would find that actually more dangerous in that context. But on other as I said, that there are so many of these tools, you know, menstrual trackers I think they are about the third or fourth highest frequency app that is out here. So there are lots of these menstrual Trackers and various different forms of of those sorts of things. Yeah, a broader list is is useful in those contexts. Not for women to diagnose as such, but just for women to be aware of what's happening in their body, their changes. I think that's fine. But for diagnosis of... if you're talking about it potentially being used by general practitioners in that sort of a context, I would I would actually er on the side of a more cautious one to avoid other medicalizing common experiences.

**Reference 7 - 8.40% Coverage**

**Interviewer:** [00:35:04] Right, so I'm going to skip ahead to a related question in that case.

**Zoe:** [00:35:08] OK.

**Interviewer:** [00:35:09] So this is about the DSM 5 criteria for PMDD. So this is the more restricted diagnosis criteria. And so obviously it's categorized as a mental health disorder by virtue of being in the DSM. And one of the 11 boxes is basically for most of the physical... physiological changes and physical changes. And actually a lot of them are quite normal changes that you would commonly expect women to experience on a regular basis. Do you have any thoughts about that, this inclusion of. And so it would only be one of the five, so it wouldn't unnecessarily weight the diagnosis more than just one, but they are there.

**Zoe:** [00:35:59] So I'm not I'm not following the question...?

**Interviewer:** [00:36:07] Sorry. You know, for PMDD you have to have I think it's five of eleven criteria. One of those crit... one of the eleven is actually this box with all of the physiological changes that has breast tenderness, bloating and headache. I think so, physical changes. But what it means is this mental health disorder has included physical physiological changes, which some people argue are quite normal changes that in fact they are very common experiences. And so why why are they there? And just do you have any thoughts on that?

**Zoe:** [00:36:48] Well, I have I have thoughts on the whole. As I said, pathologizing of of menstrual distress as a... as a whole. Yes. I have lots of concerns as to how the diagnosis or how the labelling, of PMDD occurs and the classifying of women then as a result with a mental health issue or mental health concern. So I do have real concerns with that in terms of what that means socially and culturally and in terms of women's lived experiences and daily lived experiences. But there's also another side that I appreciate that. We don't set the rules on how health authorities and how medical authorities and insurance companies um determine access to services. And sometimes, you know, you need to do what you need to do in order to access a service or need to access a treatment or a regime. And, you know, for many, many women with limited access and limited resources, this may be the only way in which they could actually receive support. And services so so I get that there's a bind. I get that there's a reason why sometimes we need to be able to classify, I say 'classify' rather than than 'diagnose'. I get that there's a reason for that. But I'm very uncomfortable with those two situations. I don't like that... In no way do I believe that this means that a woman has a mental health issue or a mental health concern. But if that's the only way she's going to get services or get support, then you take the label. So I take an... an expedient approach, i'm quite, yeah. I'll be Machiavellian in in in my approach to this, because I think sometimes it's the only way that women can actually get access to services. And that may not be so. And in that, they they're receiving the care and support for a whole range of experiences that might be using PMS as as the inroad or PMDD in this instance as the inroad for getting a range of access to services and support. And I would not I would... I would never say women shouldn't have access to that. If that's her only way in.

**Reference 8 - 3.49% Coverage**

**Interviewer:** [00:40:06] Some clinical guidelines don't include what is known as lifestyle changes, so typically around diet, but also relaxation or exercise and other interventions. Um, largely because of kind of the perceived lack of evidence base for those interventions. Do you have any thoughts about that?

**Zoe:** [00:40:34] We have actually just in our own research, but also in the research we know of colleagues and others. I actually think that there is a strong evidence base actually for the efficacy of some of these what you're calling lifestyle interventions. So, yeah, I would definitely... um, I think they need to be available and they should be made available in the end and provided as part of the toolkit that you... that a woman can access. Women's experiences are so broad. And it is my firm belief is that we need to actually rather than classifying and clumping. And that's the problem. Once you clump people or classify or diagnose people, it implies that their experiences are all the same and their experiences are not the same; two women who might meet criteria for p.\_m.\_s are still going to have very different experiences. And I think that's where you need to make a range of things available to them and our experiences that these lifestyle changes and lifestyle interventions can be and are very effective for some women. Um, So yes, I'd support their inclusion.

**Reference 9 - 1.17% Coverage**

**Interviewer:** [00:42:07] That's fine. What do you think about surgical interventions for p.\_m.\_s or PMDD?

**Zoe:** [00:42:14] [pause] I could see no need for a surgical intervention for PMS or PMDD. Now, that's not to say that a woman may not need a surgical intervention for another condition and she may also be having PMS. And PMDD, and there may be a resulting improvement or exacerbation. But for PMS and PMDD, no there can be no reason for a surgical intervention.

**<Files\\E15\_Geraldine> - § 12 references coded [46.98% Coverage]**

**Reference 1 - 0.43% Coverage**

**Interviewer:** [00:02:13] Okay. So, first of all, how did you come to be interested in Premenstrual syndrome?

**Geraldine:** [00:02:21]

**Reference 2 - 3.73% Coverage**

**Interviewer:** [00:03:16] Yup. So how do you describe p.\_m.\_s to somebody if they've never heard of it before?

**Geraldine:** [00:03:23] Actually, I've had to do that. Let's see... this is just an anecdote, which probably is useless, but er... in 1988 I went to a conference in Singapore and I put in a proposal to talk about p.\_m.\_s and a bunch of Asian women came to the session because they had never heard of it and they wanted to find out what it was. So that was about 10 years after I discovered it. Um, you know, they didn't know either. So usually people think of p.\_m.\_s as a cluster of symptoms that appear before menstruation and er disappear after the menses begins. So that's probably the closest definition, you know, that people would agree on. But even that is contested because you know what does 'before the menses' mean? Some people say it's like 3 to 5 or maybe 7 days before the menses. But you can read other sources that say any symptom after ovulation. But before the end of menstruation is PMS. So that's giving you like three weeks out of every four, which is crazy... uh for a definition. But that's what some sources do say.

**Reference 3 - 5.03% Coverage**

**Interviewer:** [00:07:16] What is your understanding of why Premenstrual symptoms occur?

**Geraldine:** [00:07:22] Well, um... some of them are clearly tied to circulating hormones such as... Uh, water retention is connected to progesterone levels, for example. I think some other symptoms um are probably more connected to attitudes, beliefs and expectations. Now, I tend to be a social psychologist, so what people are expecting to see is what they notice. And I would also mention that stress is very common. Stress symptoms overlap a great deal with PMS symptoms. So if people are under stress and they experience something, they often attribute it to the menstrual cycle, whether it belongs there or not. And then you mentioned sleep before. If you don't sleep, you don't feel well. There are a couple of studies that seem to show that poor quality of sleep is connected to PMS symptoms. But whether that has to do with circadian rhythm or lack of dream time or just fatigue, which is a p.\_m.\_s symptom, or it's stressful not to sleep. You know, I mean, there are so many explanations. It's hard to know, but some symptoms, a few symptoms clearly have a hormonal connection. But the rest of them, I think, are contested. [Pause] It's not clear and how many symptoms? That's one other thing. Some sources say there are more than one hundred and thirty symptoms of p.\_m.\_s. So, you know, this is getting up to a category of ridiculousness. You know, if we have... give people a list of a hundred and thirty symptoms, everybody's going to have something.

**Reference 4 - 1.81% Coverage**

**Interviewer:** [00:12:50] What is your understanding about the difference of differences between p.\_m.\_s and PMDD?

**Geraldine:** [00:12:59] Well,[exhale] the psychiatrists say that PPDD is more serious. But, you know, a smart alecky comment about it would just be "Who are you going to to get some help?" So, if you're going to a psychiatrist. You're going to get a PMDD diagnosis. If you talk to your general practitioner or your OBGYN, you... you're going to get the p.\_m.\_s definition or diagnosis. They overlap so much.I mean... [exhale with slight laugh]

**Reference 5 - 2.93% Coverage**

**Interviewer:** [00:14:42] And again, in your opinion, what does the Premenstrual symptom bloating specifically refer to?

**Geraldine:** [00:14:50] I think it refers to water retention. Yeah. You know, feeling your belt is a little tight. Your bra is a little tight, maybe? Your ankles are a little swollen, so I think probably when people say bloating, they're probably talking mostly about abdominal. But again, you know, you hear that phrase and it's not well-defined. Kind of like. Another thing that women talk about a lot, at least according to popular sources, is feeling out of control. And when I asked women out of control of what, they can't really answer the question. So presumably it's emotional control, but they just say "out of control! You know, out of control!" [puts on emphatic voice/ tone] [laugh] So, yeah, it's one of those things we hear and we don't really think about what it is.

**Reference 6 - 4.12% Coverage**

**Interviewer:** [00:15:43] So it is known that lots and lots of chronic health conditions can get worse at certain times during the menstrual cycle...

**Geraldine:** [00:15:49] Yes. Right.

**Interviewer:** [00:15:51] Would you count the expression of those as Premenstrual symptoms?

**Geraldine:** [00:15:56] Well, I would... I would not. I mean, so, [exhale] Nancy Woods - you probably are familiar with her term PMM. She says Premenstrual magnification of existing symptoms. So, you know, an example of a disease or a disorder that is affected by menstrual cycle phase is multiple sclerosis. So symptoms are more likely to flare up during certain points of the cycle than at other points in the cycle. But that is how you sometimes see these lists of one hundred thirty symptoms- will sometimes have things on there, like strokes or migraines or other things that are really related to problems that women have in general but are affected by changing biochemistry. Even depression. You know, that's one of the arguments that a lot of feminists made about putting PMDD into the psychiatric nomenclature, is that these women may be depressed, you know, need a diagnosis of depression not PMDD, but their depression might be worse or more salient at certain points of the cycle.

**Reference 7 - 4.50% Coverage**

**Interviewer:** [00:17:20] Um, Are there any positive menstrual changes?

**Geraldine:** [00:17:25] [laugh] Well, since we so rarely ask women about them, we don't really know. Also, we are so trained to look for negativity. You know that phrase from social psychology, the 'illusory correlation'. You know, if you're expecting to see something like when the moon is full, you expect to see bad drivers on the road. So you notice them. But if the moon is not full, maybe you don't notice them even. So, that's how we categorize a lot of the Premenstrual symptoms. I think we expect to experience them. And so if we experience one, we say, "Aha! no, I'm getting my period in a few days", but we don't say, "well, i'm really joyful today or I'm full of energy or I'm feeling really sexy". But there are some studies where women, you know, keep filling out forms every day across several cycles. And you do notice certain things like feeling more interested in sex right before menstruation. Some women report greater creativity, before menstruation or during menstruation. So there are some... there are some things, but we don't ask about them. So we don't really have a good handle on that. There's only a very few studies about positive aspects. And one thing that researchers tend to report is that the participants are so surprised to be asked that they don't really know what to say [laugh]

**Reference 8 - 1.02% Coverage**

**Geraldine:** [00:23:50] And then, I should also mention that because we don't know how to treat it, that's part of the controversy. Women have been treated with hormones that have lots of side effects. Women have been treated with hysterectomy, which causes lots of other problems for them. I mean... [exhale] right?

**Reference 9 - 5.82% Coverage**

**Interviewer:** [00:25:22] So, how do you feel about that type of definition?

**Geraldine:** [00:25:26] Well, I think that the timing for the symptoms to start is wide. That's... that's the main problem that I have with it. I also think. You know, they don't... The definition doesn't say that it has to happen regularly. So if it happens once, do you have p.\_m.\_s? Or does it have to be something that routinely you experience in the time before menstruation? One other thought about that. In the US, the National Institute of Mental Health had a very similar definition. And I do like the phrase 'severe enough to impact a woman's daily life'. But when I talk to my students about that. You know, they... they think that just experiencing it is impacting their daily lives. You know, I have to point out to them that they get up to go to class and they go to their sports team practices. They do... they study and they do everything. And if you can do everything, it hasn't impacted your daily life. But one time I had a student yelling at me. That she gets headaches. Premenstrually, and she has to take an aspirin. I said, "so take an aspirin". But she said, "well, that impacts my daily life. I don't take an aspirin every day", I mean, so You know, people interpret these definitions in so many different ways. It's really hard, I think, to come up with something that is clear and precise.

**Interviewer:** [00:26:57] Yeah, and I and even mild experiences of some symptoms are debilitating. I used to get nausea a lot and that was quite debilitating because I didn't want to vomit in public.

**Geraldine:** [00:27:09] yeah! No, Of course it makes you anxious and you want to stay in? Yeah. You don't want to go out. Go too far away. Sure. I would agree that that impacts your daily life.[laugh]

**Reference 10 - 5.15% Coverage**

**Interviewer:** [00:29:10] The other thing I've noticed is that clinical guidelines, particularly more recent ones, don't tend to include information about the role of lifestyle changes or...

**Geraldine:** [00:29:20] Uhuh

**Interviewer:** [00:29:20] Non medication based things that people can try...

**Geraldine:** [00:29:25] Right

**Interviewer:** [00:29:25] In order to improve their menstrual health. They do... they do tend to list CBT actually as a potential support. I think specifically in regard to mood symptoms, but other than that they don't mention smoking cessation even.

**Geraldine:** [00:29:44] Uhuh

**Interviewer:** [00:29:44] Or diet or sleep. [overlapping]

**Geraldine:** [00:29:48] Better sleep...

**Interviewer:** [00:29:48] Do you have any thoughts about that?

**Geraldine:** [00:29:52] Well, a lot of women do feel better if they get more sleep, if they learn stress management techniques so they can take some downtime like get away on their own from the family. The stress of family life. Go out to a movie by themselves or talk to a friend about how they're feeling. So, yeah, I think it's a it's a problem that that's not mentioned, especially since, you know, we don't know the cause of most of these symptoms. And so many of them are probably related to stress in women's lives. And then there was also that study showing that women who had experienced trauma early in life are more likely to complain of p.\_m.\_s. So, you know, that's kind of important as well?! [laugh] What people need treatment for. You know, It's not necessarily an antidepressant, that they need.

**Reference 11 - 9.06% Coverage**

**Interviewer:** [00:33:19] I'm actually going to ask you an extra question because of your experience and knowledge. So I've spoken to some patients that exper... experience, very severe mood changes. Premenstrually, including sort of suicidal thinking and really very debilitating mood change and as far as they're concerned and they have tracked it, It is a Premenstrual related experience. Sometimes they've expressed that... Um, so quite often they've mentioned feminist speakers or things on YouTube. So not necessarily. Entirely evidence based opinions, but...

**Geraldine:** [00:34:01] Right.

**Interviewer:** [00:34:02] but people sort of saying that p.\_m.\_s isn't real or that PMDD isn't really a mental health disorder or isn't kind of. Yes, I suppose a real illness and they feel that it undermines their. Experiences and that this is kind of another way in which they are disbelieved... quite often they have been disbelieved by their family and partners and everyone else. And I find this personally, so I believe that it is possible that you can experience a mental health... Um, 'experience' is for want of a better word than 'illness' and that it could be triggered just like epilepsy can be triggered or asthma can be triggered. I mean, it is difficult then to... It's like you're damned if you do, and you're damned if you don't! Either. All women are mad, or those that are feeling very mentally unwell, are told that "no, nothing is happening" to them?

**Geraldine:** [00:35:08] Right. Well, I would never tell a woman that nothing is happening to her. [exhale] First of all, how would I know I'm not her right? My interest has been in... I'm a social psychologist and not a clinical psychologist. So my interest has been in. This stereotype notion that 'all women' have the same experience, that 'all women' go crazy right before their period, which is not true. But that's not to say that no women suffer. Because we've all talked to women who have suffered to various degrees. And so, you know, when I was talking to you before, I said most women have mild to moderate symptoms that they can cope with and manage. But some women have more severe symptoms. Now, you know, it's possible that those women might have experience of trauma early in life that could relate to this. It's possible that they have a form of depression that waxes and wanes and is affected by biochemical changes associated with the menstrual cycle. So they may feel suicidal at certain times of the month, but maybe generally depressed overall. I mean, there's a lot of possibilities. And so treatment really has to be related to individual patients. There's never going to be, as far as I can tell, after studying this from the 1970s. It's never going to be one thing that is going to work for everyone.

**Reference 12 - 3.39% Coverage**

**Interviewer:** [00:36:47] So my original goal with all of this was to somehow come up with a much better definition, [laughter] perhaps one that could bring supposedly oppositional perspectives a little bit closer together, or at least to better differentiate what is healthy and what is in it, perhaps requiring some sort of intervention, be it medical or lifestyle. Do you have any thoughts about whether that's even possible?

**Geraldine:** [00:37:18] [laugh] Yeah, I was going to say, how are you doing with that? [laughter] Well, I think that. I don't know, I wouldn't say it's impossible, but. It would have to be embedded in something that says that changes in physical and psychological and cognitive experiences are normal. And if a change is severe or impacts a person's daily life, then they should seek some kind of help. You know, it would have to have those elements in it, I think. So that it's not so broad as to say that everybody experiences it. But not so narrow that women can't make their own evaluation of what's normal for them

**<Files\\E16\_Chris> - § 21 references coded [76.52% Coverage]**

**Reference 1 - 0.22% Coverage**

**Interviewer:** [00:00:05] Right. How did you come to be interested in Premenstrual Syndrome, originally?

**Chris:** [00:00:11]

**Reference 2 - 2.53% Coverage**

**Interviewer:** [00:01:42] Ok. How do you describe p.\_m.\_s to somebody who maybe has never heard of it before?

**Chris:** [00:01:50] Ok. You mean in very scientific terms or in... er?

**Interviewer:** [00:01:53] No, I think in clear terms...

**Chris:** [00:01:55] Like I was just doing with that person there. 'Cos I told them you what you coming here to do. And so I went through it with her.

**Interviewer:** [00:02:00] Oh OK, Yeah.

**Chris:** [00:02:00] Okay. It's a mood disorder which occurs only premenstrually. And the key thing is that the symptoms resolve after the period. And to be pure p.\_m.\_s, they have to be completely absent. The underlying cause of this is uncertain. It may be due to the direct effects of progesterone on receptors in the brain somewhere like the amygdala or somewhere else. And it affects the... possibly the GABA receptor. The other thing that may be stimulating that is a metabolite... Oh, no. Sorry. I won't tell you all this... This is the 'lay' version! [laugh] So so progesterone affects the er, the receptor. It's like a key on a lock. And it goes in there, progesterone stimulates the receptor and causes symptoms. And the symptoms can be a wide range and they can be so bad as to promote suicidal ideation or attempt....

**Interviewer:** [00:02:55] Right...

**Chris:** [00:02:55] And of course, it also causes, lesser effects, such as effects on the family job, spouse, relationships and so forth.

**Reference 3 - 0.56% Coverage**

**Interviewer:** [00:03:39] Can you remember how you first came to know about PMS?

**Chris:** [00:03:44] Hmmm I think... I think the resear... Oh no, it was probably slightly in the undergraduate curriculum, but it wasn't very prominent. And then it was in the curriculum for the Royal College exams, but very low key...

**Reference 4 - 1.32% Coverage**

**Interviewer:** [00:04:00] So you would have been sort of young adult?

**Chris:** [00:04:04] Young adults. Yeah. Yeah. It was always said to be in women of...You know, in the... in the... in the... in the... in the journals and so forth, to be in women who were heading for 40. But of course it can.... And then when... So when it presented in adolescence and they got diagnosed as bipolar and other behavioural problems and borderline personality disorder and the like.

**Interviewer:** [00:04:27] Oh right. So there used to be a kind of age differential?

**Chris:** [00:04:30] Yeah, it was... There was a tendency to think that way, that it occurred after 30, after 35, 40, which was not fact. But that's what... I suspect that was in the textbooks.

**Reference 5 - 0.95% Coverage**

**Interviewer:** [00:05:27] So what is your understanding of why Premenstrual symptoms occur?

**Chris:** [00:05:33] OK. It... more scientifically than I said just now? So this is unknown. It is either progesterone occuring, sorry, stimulating somewhere in the brain... because of the close relationship with progesterone production following ovulation. Um, or it may be a metabolic byproduct/ breakdown product of progesterones such as allopregnanolone and allopregnanolone... um, If this is true, affects the GABA receptor. Um, And that's it!

**Reference 6 - 10.52% Coverage**

**Interviewer:** [00:06:15] So again, in your opinion, what is the best way to manage PMS?

**Chris:** [00:06:19] Oh, You can't answer that question [amused tone]. First of all, you make... you make a specific diagnosis by um... and don't treat until you've made a diagnosis because retrospective diagnosis by the patient herself is not accurate. OK? And so you must do a prospective evaluation and even a lot of people say that and then don't do it. But I've always done a prospective evaluation looking at two cycles and seeing if it occurs. So if you don't make a prospective diagnosis, it's gonna start to be in trouble in terms of treating it. So the treatment starts with the diagnosis. Then it... it is so varied. You can't say how would you treat it, um unless you cover the whole lot. So, you know, I wrote with others the Royal College guideline. So basically you start simple, which is a pill. And I'll come back to the pill, in a sec or an SSRI. Yeah. And so they're good starting points... or maybe even greater, simpler starting point is that... to, to counsel a patient. Maybe. Maybe get a.... [pause] um CBT or something like that, but it's very difficult to get that through general practice. And so. So it's just simple things First. If you're going to use um, if you're gonna use an SSRI, it doesn't matter which one; you can use it continuously or luteal phase only. If you're going to use the pill, then some pills because they've got progesterone in them. They suppress ovulation, but you're still giving them a cycle of progesterone. That progesterone could go to the receptors and cause a problem. So maybe pills such as Eloine or what used to be called Yaz has... does not to the same extent affect the receptor, I've got a lot... I've got a fair bit of... got more experience than most people with that and there are patients who will still get p.\_m.\_s with it. Um... So that's... that's the um milder patients. If they don't respond to that, of course then they're severe. They're severe but didn't respond. So you can stop the hormonal cycle, um you can stop hormone cycle with the pill. But there's progesterone in it, you can stop the cycle with Danozol, but that's an unpopular drug now because it causes male side effects (like hair and baldness and so forth). But it was very effective. It also... you can also suppress the cycle with oestrogen Only. If you give oestrogen only, it's... if... it um down regulates the hypothalamus, pituitary, ovarian axis and the symptoms go away. But if you give oestrogen only long term, that also stimulates the lining of the womb the endometrium and you then run the risk of endometrial cancer. You can prevent that by giving progesterone, but of course the progesterone brings the symptoms back. So you are going round in circles. One way of getting out of that is to put the progesterone in the uterus in a Mirena coil or levogestral containing IUS and that'll protect the endometrium. And the progesterone will suppress ovulation and treat the symptoms... so I've treated many patients like that... slight difficulty, some patients absorb the levogestral. It goes to the brain and stimulates p.\_m.\_s. And then it's continuous p.\_m.\_s like symptoms. So for a large number of patients that I was treating, suppress the hormone cycle with oestrogen, protect the endometrium with the Mirena; pretty good. If that doesn't work. You can give a GNRH agonist analogue. They have the disadvantages of stimulating in the first part of the cycle and then they suppress it. And I almost think if you still have symptoms after suppression with GNRH, then you must question the diagnosis... Uh, as a long term therapy. It's got disadvantages because it creates a pseudo menopause, gives them hot flushes and all the side effects insomnia and long, long term the risk of osteoporosis. You can give add back, but of course when you're giving add back you're in the cycle again of oestrogen and then needing progesterone. There's a drug called Tibalone, which works in quite a lot of patients, and may not re stimulate. the cycle... So you're always in this business of having an endometrium. So if the endometrium is there and you give oestrogen, everything's fine, but you can't give them... um you can't give them progesterone because of bringing about symptoms. But if you're not giving them progesterone they get cancer of the lining of the womb. So you've got this cycle. So I would sit in my PMS and menopause clinic and half of the time I'd be um causing p.\_m.\_s and the other half the time i'd be causing menopause symptoms! The only way... there's only one cure, well there's two cures. One is a natural cure. That's the menopause. And the other cure is take out the uterus, ovaries and cervix. Why uterus ovaries and cervix? Well, if you just take out the uterus, you won't have a period, but you still have the hormone cycles, so you'll still have the p.\_m.\_s, but you won't get diagnosed with p.\_m.\_s because the GP will say you can't have p.\_m.\_s, you haven't got any Periods. So um. So those cycles still continue. If you just take out the uterus... No! that's if you just take out the uterus... If you just take out the ovaries, then you've created a menopause. So you've got to give oestrogen and you're back into that problem of giving... needing to give progesterone and and... er bring the symptoms back. So that's a disservice. You could do the patient, if you take out the uterus and the ovaries, you can give oestrogen and you don't need to give progesterone because there's no endometrium. If you do it down a lateroscope: um keyhole surgery, you... there's always a temptation for the surgeon to leave the cervix in. But the cervix contains sometimes a little bit of endometrium. So you're back with 'can't give oestrogen'. So taking out the lot and giving oestrogen is the only cure. But of course that's in a very, very small percentage of patients. Yeah, am I going too fast?

**Reference 7 - 4.90% Coverage**

**Interviewer:** [00:12:33] No, thats' interesting. So, I've heard much of that before.

**Chris:** [00:12:36] Yeah.

**Interviewer:** [00:12:38] But I hadn't heard about the cervix...

**Chris:** [00:12:38] Ah Yeah. Well Okay. Well there's... You see if you're a laproscopic surgeon, the easiest thing to do is take out the ovaries. Quick, quick, easy operation. But you've still got the uterus so you're in trouble. If you're not... If you're gonna take out the uterus and you say well we'll leave the cervix. Because it's good for sex, (which it's not). But there was a few papers saying that. But if you leave the endometrium in and then you're in trouble because you've got to give progesterone. And then I got a patient. The last, one of the last few patients I had, she she was on my waiting list for the full works. She went off to another hospital because of the waiting list initiative, they had... took out just her ovaries, she had severe complications. Um... She got a ooph...No, she had her uterus out - left the cervix. No, it's... can't remember now!

**Interviewer:** [00:13:29] They left something...

**Chris:** [00:13:30] They left something in and there was a very very... No I think they left just the cervix in. And she was still bleeding. I think that was it. So I will always emphasize that there is no logic in leaving in the uterus or the cervix. And in the guideline, I had endless arguments with the chairman of the guideline committee at the college because he likes to just do the... er... There's no evidence either way on any of this. I wouldn't take out the uterus and ovaries except very last resort and I wouldn't take it out without a GNRH test which tells you what's going to happen. The GNRH test has never been scientifically validated, but if you've still got symptoms after that, then um... then the trouble is some patients have... um... have menopause symptoms and they don't know whether they got p.\_m.\_s symptoms or menopause. So I'll give them GNRH, wipe out the cycle, give them oestrogen because that'll get rid of the menopause symptoms and then you don't need to give them progesterone... Well you do because if they tolerate the progesterone, you can treat them with oestrogen. GNRH and progesterone, there's not many like that. Um So it's just it's a good way of finding out what will happen. I say, well, this is a test of taking everything out. Not saying you should have it out, but it's a good test for it.

**Interviewer:** [00:14:48] Can you give me any rough numbers? As to like, I'm guessing that the surgical is for really very few cases...

**Chris:** [00:14:57] Yes. Twelve a year? I would... But but then I would be. No, not 12 a year. I think maybe twelve in five years. And I would be seeing the worst of the country. Yeah?

**Reference 8 - 1.94% Coverage**

So again in your understanding roughly how many Premenstrual symptoms are there?

**Chris:** [00:17:23] Oh, the strict definition by the ISPMD. is that there's no.... Now there are specific symptoms for PMDD. Okay. And I can never remember what they are... You'd have to go through the thing.

**Interviewer:** [00:17:38] Yeah.

**Chris:** [00:17:38] Yeah.. There's this 1 -5 and all that business. Um PM... in the... in the... one/ two... Second I think or the third consensus of the ISPMD we did a delfi thing and we... we decided that... Um... er.. Oh no, no it's actually in the first one! So any symptom. Physical. Or psychological. And so it could be infinity. OK? So whereas... whereas PMDD is very specific and they have eleven symptoms and subcategories and all that... with... with... p.\_m.\_s in the ISPMD thing, it was any symptom of sufficient severity to cause stress, distress and... Have an effect on relationships, effect on work, effect on normal functioning and hobbies and so forth. So. So that's a... that's a group of symptoms. Meaning that the symptoms have to have that effect.

**Reference 9 - 1.33% Coverage**

**Interviewer:** [00:18:48] We'll cover some of these again, for sure. So bearing that in mind, do you have any idea or could you share what you think are the most common premenstrual symptoms?

**Chris:** [00:18:58] Oh, yeah. OK. So, yeah, maybe.... I may not get this right now, but er they are the ones on the top in the PMDD, of course. So they're depression, anxiety, mood swings, anger, aggressiveness... Er... anymore? [Laugh]

**Interviewer:** [00:19:14] Um that's five.... SO you're alright with a top five.

**Chris:** [00:19:15] That's five. Yeah? [Pause] And so. So this of course there is also the question of how common they are and how important they are, 'cause suicidal ideation is obviously less common, but more important than anxiety. Perhaps?

**Reference 10 - 2.95% Coverage**

So in your opinion, what does the Premenstrual symptom bloating specifically refer to?

**Chris:** [00:21:46] Ok. It's abdominal distention. It may or may not be associated with weight increase. Patients feel like they've got a weight increase. I did some research in both London and Nottingham where we looked at weight, abdominal dist... abdominal dimensions, breast size through the cycle. And we didn't show much change. So it was a symptom rather than major physical changes. And we also looked at the... total body water and the sodium and everything like that. When we, when I was in London and we showed no changes there. What I actually think bloatedness is due to is- this is a thought rather than a fact- could be to do with redis.. redistribution of fluid. But we didn't show that in the London study.... It could be the effect on the bowel? And so if women get very distended abdominally and they... and they're not putting on weight, then progesterone acts on the receptors in the gut and relaxes it. And so you can get a build-up of gas and faeces... And it gets distended and then many women when their period comes they get diarrhoea as well. And a lot of gas, and that's what I think is happening. But I couldn't tell you that was factually shown.

**Interviewer:** [00:23:06] That's kind of why I'm asking that question. Partly that it's ill defined. I think some people think it's water retention and others think gas...

**Chris:** [00:23:13] Yeah, well, it may be all three. But yeah, but if you if you're retaining the water, then you should be putting on weight. And some women get leg oedema. Premenstrually.

**Interviewer:** [00:23:24] Yeah, I do!

**Reference 11 - 6.06% Coverage**

**Chris:** [00:23:32] Is that what... OK. Is that what stimulated you to look at this?

**Interviewer:** [00:23:36] So. So for me, I had nausea and vomiting.

**Chris:** [00:23:40] Yeah,.

**Interviewer:** [00:23:40] And it was unexplained physiologically. And very early on. The GP said, is this a monthly issue? I'm, you know, highly educated and I knew what they meant. But I'd wrongly assumed, and perhaps my GP also did, that if something was hormonal it would just be once a month, you know, that it would just be premenstrually; those few days. And actually, I was having symptoms around ovulation, premenstrually, a few days and during menstruation. And it wasn't until I had an Excel spreadsheet of all my symptoms. (I was expecting a dietary issue) that I saw there was a cyclical....

**Chris:** [00:24:20] But you ahad a symptom free week didn't you?

**Interviewer:** [00:24:22] Well, no I don't...

**Chris:** [00:24:22] Oh! [disappointed]

**Interviewer:** [00:24:22] ... because I have a short cycle, 21 days... up to 24 days. And that's where this overlap wasn't clear to me because I was ignorant. And I thought Premenstrual symptoms were maybe one or two days before menstruation only. And so through that lack of knowledge and communication. I had Two years of being quite ill, debilitated, being sick in public and things. And then I sort of realized there was this bit of a gap, particularly around nausea, actually. So it's a reasonably common symptom But there's a .... there's a bit of a gap in that it doesn't always get listed in... in like the NHS website.

**Chris:** [00:25:03] Yeah, yeah.

**Interviewer:** [00:25:04] Or in diagnostic criteria. So that's ultimately my... um My motivation, but then I've been doing this research since 2013, on my own. I was already a professional researcher and since then I've been noticing each cycle more... You know, I've treated my own cycle as a bit of a testing process....

**Chris:** [00:25:26] Yeah, yeah. Well, I'm not surprised! [laugh].

**Interviewer:** [00:25:28] So I have noticed... Yeah, swelling.. particularly in the summer where I'm drinking more fluid?

**Chris:** [00:25:32] Yeah.

**Interviewer:** [00:25:33] That there will be a visible change in my legs.

**Chris:** [00:25:37] Yeah but do you measure your weight?

**Interviewer:** [00:25:37] No, I wasn't doing that.

**Chris:** [00:25:37] Oh [disappointed].

**Interviewer:** [00:25:38] But this was.... Um I went on a triathlon holiday and it was very hot and because we were training I was having to drink a lot of those isotonic drinks...

**Chris:** [00:25:49] Yep.

**Interviewer:** [00:25:51] And it seemed to literally go straight...

**Chris:** [00:25:52] Go straight there.[overlapping] Yeah yeah.

**Interviewer:** [00:25:55] Yeah. It was quite obvious.

**Chris:** [00:25:56] Um, have you? Ehhm, just another aside. Have you seen my app?

**Interviewer:** [00:26:00] No I haven't seen it, but I've heard about it!

**Chris:** [00:26:01] Yeah. Well see that gives you... that gives you a load of symptoms. But it also gives you the opportunity of putting your specific symptoms in there as well. And it also measures the response to treatment. If you give things like GNRH. So...

**Interviewer:** [00:26:19] No, I mean, my life is a testing bed at the moment so I kind of... I know how to treat my symptoms, but at the same time I'm always testing new Things sometimes trying dietary things...

**Chris:** [00:26:29] Yeah.

**Reference 12 - 0.87% Coverage**

**Interviewer:** [00:26:29] Right. So many chronic health conditions can get worse at certain times in the menstrual cycle. Do you count the expression of those as Premenstrual symptoms?

**Chris:** [00:26:42] If you could assume that... then again, if you have symptoms that are unique to the Premenstrual phase, then that'll be a Premenstrual symptom. If they're symptoms that you've got all month but get worse Premenstrually, then that's Premenstrual exacerbation. Of an underlying condition.

**Reference 13 - 0.69% Coverage**

**Interviewer:** [00:27:05] Uhuh. Are there any positive menstrual changes?

**Chris:** [00:27:11] Ohhh... Yeah, I think so... But people don't come to doctors with positive changes, and that's rare.... But I think some... some women get more drive and become more efficient and more drive. But I think that's a... that's I don't know of as an expert because people don't complain of good things.

**Reference 14 - 1.85% Coverage**

**Interviewer:** [00:27:35] So obviously, people who don't have a menstrual cycle can experience nearly all of the same symptoms that...

**Chris:** [00:27:44] You mean men can?

**Interviewer:** [00:27:44] Men, menopausal women, and girls...

**Chris:** [00:27:45] Yep!

**Interviewer:** [00:27:45] ...but there wouldn't be a cyclical pattern because it's not something that is menstrual cycle-related. So do the same symptoms therefore have different biological mechanisms depending on the patient's sex or their time of life?

**Chris:** [00:28:04] [pause] Hmmmm. Yeah, I would have thought they'd be lots of different mechanisms for anxiety, and so... I think the answer to that is yes. [pause] Of course. When I see patients. They may say they've got p.\_m.\_s and then more likely... as time goes on. To say they've got PMDD because then people'll take more seriously. And... [pause] And so that... that's the biggest difficulty, really- separating out women who've got symptoms, for other reasons, like you say, as opposed to due to their progesterone.

**Reference 15 - 2.06% Coverage**

**Interviewer:** [00:30:54] Yeah. And so the latest guidelines are generally based on the ISPMD consensus...

**Chris:** [00:31:00] Yep [overlapping]

**Interviewer:** [00:31:00] ... process that has happened over 10 years. So the current definition is that any symptoms count so long as they occur in the luteal phase...

**Chris:** [00:31:11] And you ca... well, it was... the best time in the world to diagnose p.\_m.\_s is in the follicular phase because the symptoms are now absent.

**Interviewer:** [00:31:20] Unless you have a short cycle!

**Chris:** [00:31:20] Unless you have a short.... Yeah. Yeah.

**Interviewer:** [00:31:22] I don't really have a... you know, I'm either menstruating or...

**Chris:** [00:31:27] Do you know if you ovulate? Do you ovulate?

**Interviewer:** [00:31:30] I'm sure I do. But er, no. I don't have any pain.

**Chris:** [00:31:34] No?

**Interviewer:** [00:31:34] I suppose there's you know, there's cervical discharge changes. That I could spot it if I was bothered... but it's very... um particularly if it's 21 days,.

**Chris:** [00:31:45] 21 days is regular...?

**Interviewer:** [00:31:46] Yeah. And I always have been.

**Chris:** [00:31:52] Yeah

**Reference 16 - 7.56% Coverage**

**Interviewer:** [00:36:34] Yeah. Um, so the Royal college guidelines and I think probably other guidelines as well, now have PMDD and p.\_m.\_s as almost parallel...

**Chris:** [00:36:44] Erm, Severe p.\_m.\_s and PMDD..

**Interviewer:** [00:36:46] Sorry Yeah..

**Chris:** [00:36:46] I would say severe p.\_m.\_s.

**Interviewer:** [00:36:47] They are both PMDs, though...

**Chris:** [00:36:49] Yeah. Correct. Yeah. Yeah.

**Interviewer:** [00:36:52] So how do you feel about that, this kind of idea that they're aligned... as separate categories...

**Chris:** [00:36:57] That's fine.

**Interviewer:** [00:36:57] But of the same kind...

**Chris:** [00:36:57] That's fine. Yeah. Because it's a subcategory and I suppose I made the mistake in... if you think about it, of introducing on top of PMS & PMDD - 'p\_m\_ D'! [laugh]. So that's um... that's almost negative except over.... So they're all PMDs. Yeah.

**Interviewer:** [00:37:17] So. So it could be PMS at the top?.

**Chris:** [00:37:24] You can have p.\_m.\_s. It doesn't make... you have more patients with p.\_m.\_s, I think. But you'll have exact... severe p.\_m.\_s. And yeah, let's just go over that definition again. So this is the third consensus paper and it's also my opinion that PMDs can be divided into patients with severe psychological symptoms which are also PMDD, severe psychological symptoms and physical symptoms which can be PMDD only.... [pause] Erm. I'm not answering your question.

**Interviewer:** [00:38:03] Well, it's a tricky question.

**Chris:** [00:38:06] I think severe PMS and PMDD are synonymous. [long pause] And PMDD, ... yeah so virtually synonymous. Yes, you're right.

**Interviewer:** [00:38:22] I mean, what might help is... Some people have said that they think of it as a normal curve.. And that PMDD is the most extreme end of that?

**Chris:** [00:38:32] Yeah, yeah, yeah. I mean, that's what we always... you're right? That's what we say...

**Interviewer:** [00:38:35] Rather than it being um... You know, that would be different to Premenstrual exacerbation, because that's just something else.

**Chris:** [00:38:44] Yeah, that's a different category.

**Interviewer:** [00:38:45] It is, yeah. So that would make PMS, not as severe. that would therefore make PMS not as severe as PMDD...

**Chris:** [00:38:54] Well that's the same as saying severe PMS is PMDD. Se, PMDD has a couple of problems with it. It excludes patients with a small number of symptoms. Let's imagine... it's hypothetical. You have a patient who only feels suicidal from day twenty five to twenty eight and never feels suicidal... um after the period she wouldn't fit the Category for PMDD. So she wouldn't... in America be able to claim it from psychiatrists because that's why it was. I think that's why... partly why it was developed so they could say it was psychiatric. And you come to us with it. Um, So they would be excluded... if they only had one symptom. Then they'd be excluded as a diagnosis with PMDD But they wouldn't for p.\_m.\_s. So that's another... that's another element, yeah?

**Interviewer:** [00:39:44] I'm interested in.. there are these tensions between practice and these guidelines and obviously guidelines are just guidelines, they are not the law, for example

**Chris:** [00:39:52] Yep

**Interviewer:** [00:39:52] Um, and several physicians I spoke to said they don't do that '5 symptoms'. You know, if someone says I have severe anxiety, irritability, and suicidal thinking...

**Chris:** [00:40:06] And it gets better after the Periods.

**Interviewer:** [00:40:07] Yeah, [overlapping]. They are not going to exclude them...

**Chris:** [00:40:08] Yeah. Well to me they've got severe p.\_m.\_s, OK? I don't care if They've got PMDD or not. It's irrelevant. Patients tend to come and say "I've got PMDD" because they think it's the severe end and They'll get taken notice of... That's the reality.

**Interviewer:** [00:40:28] So you think that... basically severe PMS and PMDD are the same things ; PMDD, is literally the DSM...

**Chris:** [00:40:36] 5. Yeah.

**Interviewer:** [00:40:38] You know, version.

**Chris:** [00:40:39] Okay, let's just... let's just say what you said. I'll say [pause] Severe p.\_m.\_s and PMDD are almost certainly identical, except patients with severe PMS and only physical symptoms aren't PMDD. Yeah?

**Reference 17 - 2.85% Coverage**

**Interviewer:** [00:40:56] Yeah. Great. Thank you. So mos... most recently guidelines on p.\_m.\_s haven't included a lot of information on the role of non biological or external life experiences as contributing factors in PMDs, so, psychosocial factors. What do you think about this? Do they need.... Does that information need to be in these guidelines?

**Chris:** [00:41:26] Well, the RCOG guideline does say that these women could have CBT, which will which will... at a tim... really should have it before going on to hormonal treatment (well, if available?). And therefore, in CBT, the whole spectrum of symptoms would be addressed. So therefore, if they're... if they've got an underlying issue that'll be addressed. And of course, probably a woman who has severe p.\_m.\_s. Doesn't like her husband, has a terrible mortgage rate, has seven children who are behaving badly. Might be more affected by her p.\_m.\_s than somebody who is um, on a yacht going around the world with her new boyfriend! Yeah? So the... so those... those sort of... the underlying... I think... I suspect that not many women who are refugees will notice their moderate p.\_m.\_s while they're coming across the channel in their boats. Do you know what I mean? So other things must [emphasis] play a part in it. I don't think they're really in the guidelines, as you say. Except that in terms of treatment, then that maybe well... be covered by the CBT but nothing else. And of course, if you treat someone with... who's got depression and [emphasis] p.\_m.\_s and you treat them with an SSRI, then that's addressed in that situation as well.

**Reference 18 - 4.73% Coverage**

**Interviewer:** [00:42:53] Yeah. So the PMDD criteria - the DSM criteria. Obviously, it's categorized as a mental health disorder because...

**Chris:** [00:43:03] Yep [overlapping]

**Interviewer:** [00:43:03] ... it's in the DSM.

**Chris:** [00:43:05] Yep [overlapping]

**Interviewer:** [00:43:05] And it includes a lot, well nearly all of the physical changes.

**Chris:** [00:43:09] Yep [overlapping]

**Interviewer:** [00:43:09] Are in one box. Within that box, there are actually quite normal physical menstrual changes, things like... breast swelling, or breast pain

**Chris:** [00:43:19] Premenstrual, not menstrual!

**Interviewer:** [00:43:21] Premenstrual... And so do you have any feelings about this? So I suppose I'm asking this question because it seems slightly odd to see healthy changes included in the diagnostic criteria.

**Chris:** [00:43:38] Oh, well,.

**Interviewer:** [00:43:40] Some of them are not. [pause] It's are they relevant or not for that PMDD diagnosis? So if it says breast swelling, abdominal pain...

**Chris:** [00:43:56] Well, I think. Let's take the breast one because that really feels more hormonal, doesn't it? That can be a very important symptom for some patients. It's a matter of degree. So let's try this one. You go down the motorway and you know, there's not going to be a service station for a while. You're desperate for a pee and it gets more and more painful as time goes on. You'll get bladder pain. That's normal. But if it's intolerable, then there's probably something wrong and therefore maybe a condition. That's the best I can do.

**Interviewer:** [00:44:36] Yeah. See, for me, I can see why it would be in the p.\_m.\_s. Anything goes in PMS. But in relation to PMDD, I feel it's a little bit...

**Chris:** [00:44:45] Oh I see what you mean! It doesn't need to be in the PMDD. Well that's a... that'll be pragmatism on the side of... The psychiatrists said "oh we'd better pay a bit of attention to the uh, gynaecologists here". And they unged it in! [smile in voice]. That's my real view.

**Interviewer:** [00:44:59] Somebody did say it's more... What's it called when you make a pact with somebody?

**Chris:** [00:45:09] Yeah, I know what you're trying to say, well, that's the same as I said....

**Interviewer:** [00:45:13] It is consensus, but it's kind of. To bring people in...

**Chris:** [00:45:18] Yeah. Yes, it's it's it's. Yeah, it's not exclude them in a way. Whatever that phrase that neither of us can think of. OK.

**Interviewer:** [00:45:35] Compromise? It's a little bit more like compromise.

**Chris:** [00:45:38] Yes, OK. There's a better word than that isn't there? But I cannot think of it. So we both know what we mean.

**Reference 19 - 3.97% Coverage**

**Interviewer:** [00:45:47] Yeah. Ok. So you're going to be the most qualified person to answer this one. What do you think about the use of diuretics, perhaps spirinolactone in the treatment of p.\_m.\_s?

**Chris:** [00:46:01] Yes. OK. [pause] Um... Depends on the symptom... Well, OK, my study, which I published in 1979. And there was some studies later... showed that it was. It showed that there were no differences in any of the hormones. No difference in aldosterone. No differences in progesterone, really. But therefore, the logic for giving it weren't there. But it did seem to resolve symptoms, both psychological and particularly physical. So... so 100mg given in the luteal phase of the cycle seemed to improve it. There's been studies since and I think the general consensus is choose it for physical symptoms. But it may work for psychological? I've not used it often since doing my study, but I have used it and it can be effective. There is something that's come out since which long term therapy of spirinolactone might have a carcinogenic effect somewhere... but You'd have to look that up becaus eI can't remember it.

**Interviewer:** [00:47:15] And some of the.. Like Yaz and Eloine, they sort of act like a diuretic...

**Chris:** [00:47:17] Yes. OK. So the drospironone in that is derived from spirinolactone. And this is the.... And it has retained its anti-androgenic and anti-aldosterone effect. So therefore, it's licenced in the states for p.\_m.\_s in patients, for p.\_m.\_s, sorry, for contraception in patients with p.\_m.\_s and as contraception patients with what you call it? Hair? Hursuitism! And um... there is no licence independently for it. And it's not licenced in this country. In fact, virtually nothing is licenced in this country for p.\_m.\_s. And if anything works, it is unlicensed. If the... the only thing is progesterone is licenced, which causes it... so.. And so there's nothing licenced. So anything that's..

**Interviewer:** [00:48:09] And is that just the UK or an EU thing?

**Chris:** [00:48:10] No, it's not an EU thing. Not an EU thing. I think it's a bit more accepted in the EU. I think Eloine is licenced in the same way as America in, say, Ireland and some European countries, but I'm not absolutely sure.

**Reference 20 - 13.82% Coverage**

**Interviewer:** [00:52:40] And Somebody else mentioned. Um, when they were discussing "Gynaecology versus psychiatry" and that sort of 'ownership' or not really 'who deals with these women'. It was quite a pragmatic response, saying, well, psychiatrists, are well suited in a way to perhaps differentiate um... differentiate bipolar from PMDD. But do they really want 5 percent of women of reproductive age when they're dealing with, you know, basically the lack of resources in both gynaecology, that they implied that there might even be a rather than a fight for ownership... a kind of ?

**Chris:** [00:53:27] Well, you see you've got to distinguish. No, I don't. Yeah, in the States. If it's private, they're fighting for ownership- in the UK. They're hoping that somebody else will take you away. You know, unless they're interested in the subject. So that's the reality. Gynaecologists are in.. tend to do surgery earlier, Oh, well psychiatrists aren't going to do surgery. But there more... and you know, more... you're going to more likely get [emphasis] surgery. With a psychiatrist, you are more likely to get labelled as non hormonal bipolar disorder, which in... that's the reality. That's my experience.

**Interviewer:** [00:54:11] I'm quite interested in this because I came from... I used to evaluate social projects in interbnational development which are very complex, that's very difficult to know who did what. When I came into medical research, I thought it would be really scientific.

**Chris:** [00:54:26] Oh, [laugh] well, it is. Well, well, well, anything you read about me is very scientific. There's nothing wishy washy in there at all. But to say... to do it scientifically, work out whether they should go to a psychiatrist or gynaecologist is not a scientific question. That's the trouble.

**Interviewer:** [00:54:43] But I suppose I thought medicine was a bit more um...

**Chris:** [00:54:50] No, well it's not!

**Interviewer:** [00:54:52] You know, Scientific is the best word I can come up with. Sort of.. or at least..

**Chris:** [00:54:59] A Bit more organized. Even?

**Interviewer:** [00:55:01] Or just get... you'd get guaranteed. You know, that people would follow the guidelines and you would do this... But it isn't. It seems to be very (well not quite haphazard), but it really depends who you get referred to.

**Chris:** [00:55:12] Yeah.

**Interviewer:** [00:55:12] As to what treatment you'll receive.

**Chris:** [00:55:12] Yeah,Yeah. I mean, maybe there should be... I mean I would say that... gynecologists should.... I have said this somewhere- possibly better if a gynaecologist sees patients when the GP hasn't got anywhere and the Psychiatrist hasn't got anywhere. Then they should be seen by a gynaecologist. That's almost what I really think. But... um that said, if tyou're trying to do research on it, you want them to come, in private practice, you want them to come. So it's not quite as straightforward as that. And the GPs don't want see them at all. Because they don't know how to manage it. Because it's really complicated... because I haven't told them how to do it well enough. Maybe?

**Interviewer:** [00:55:54] Yeah, well, there's also this pressure on GPs. They have ten minutes.

**Chris:** [00:55:57] [overlapping] Yeah. You can't... you can't... diagnose PMS in ten minutes!

**Interviewer:** [00:56:03] You can't expect people to monitor... It's getting easier with apps and lots of smartphones and whatever

**Chris:** [00:56:04] Yeah

**Interviewer:** [00:56:08] But still I think patients don't take time off work lightly in order to see their GP and would almost prefer... There's definitely a feeling that people want treatment. Right now.

**Chris:** [00:56:21] Yeah.

**Interviewer:** [00:56:22] Rather than taking 2 months. But I don't think that's a good enough excuse for GPs to not... um... Because they.. I don't actually have anything against GPs because they they do deal with this quite often. They're the front line, they have to rule out anything that could be serious. You know, first particaulrly for gynaecological things, but...

**Chris:** [00:56:44] And particularly for.... particularly for suicidal.

**Interviewer:** [00:56:48] Yeah. And if somebody's suicidal. They have to follow certain guidelines on that of course. And then they may not see that person again. You know, it is.

**Chris:** [00:56:59] I don't think... I don't think it can be dealt with in general practice, to be quite honest. I think that's my real view. And then it should only be seen by psychiatrists who understand.... Have you spoken to the guy in [named university]?

**Interviewer:** [00:57:20] [Name of colleague]? Yeah.

**Chris:** [00:57:21] Yeah, yeah, yeah. Well, someone like... well he's done gynaecology and psychiatry, hasn't he?

**Interviewer:** [00:57:29] Yeah. That's why I was keen to speak to him...

**Chris:** [00:57:30] ...And he's on our guideline. Yeah?

**Interviewer:** [00:57:33] Yeah. I thought that'd be interesting because in one person he's got both of these...

**Chris:** [00:57:38] In theory! [laugh]

**Interviewer:** [00:57:40] But he... I think he comes... I think he came down slightly on the 'psychiatry side' (if there's a psychiatry side?).

**Chris:** [00:57:46] Yeah.

**Interviewer:** [00:57:48] But, you know, part of my thesis is really looking at how your discipline, how your resourcing of that discipline does make some of these decisions regardless of....

**Chris:** [00:58:02] Oh, absolutely. Yeah. Yeah.

**Interviewer:** [00:58:04] Well, if he runs a clinic in, you know, his situation- then like your situation is different. So. This is what I find very interesting...

**Chris:** [00:58:15] Well, let's let's see... in my situation I will treat with SSRIs. I'll... I won't treat with lithium. I'll treat with hormones and I'll treat with surgery- in his situation. He is not likely to use hormones. He's only likely to use SSRIs. And in fact, if you look at anything written by the psychiatrists in the states. Where PMDD exists, they really... everything is designed around SSRIs, if SSRIs don't work. I don't know what they do because they object to anything surgical? They object to hormones... Not object, but they're very, very unhappy with them. So I think you need someone. I think you need to be able to do everything, including the surgery. You can refer for the surgery, of course, yeah..

**Interviewer:** [00:59:11] I'm also interested just... earlier you said some gynaecologists want to avoid it.

**Chris:** [00:59:17] [overlapping] Yeah, because they don't understand it, either!

**Interviewer:** [00:59:18] Because it's not their interest or, you know, they're not comfortable with it? Or is it that they prefer to do surgery?

**Chris:** [00:59:26] They prefer... they prefer not to deal with it because it's a very difficult subject. You know, if you're a gynaecologist without interest in p.\_m.\_s./ PMDD Um... You. Try to avoid this topic coming up... You know, if you've got a quarter of an hour. For a follow up appointment. You really don't want to. It's you.... you want to avoid it, if you can.

**Interviewer:** [00:59:55] Great. Last question is how do you feel about this interview? Do you have any questions or comments you'd like to add?

**Chris:** [01:00:01] You're obviously, I don't know how you were with your first few interviews because you've obviously got a lot of the knowledge, now. And I don't think you can get the knowledge just from all... because of all the different views or just from reading the papers. But you obviously got it... I think you've got a fairly narrow personal experience because you don't fit all that well for the... for the generality. And... And uh... But you've obviously got a great knowledge now. So, yes. It's an easy interview. That's all I know about that, I've forgotten everything else.

**Reference 21 - 4.85% Coverage**

**Chris:** [01:03:40] So... [pause] remember, I said it might be due to a breakdown product called allopregnanolone. So let's assume for the rest of this conversat... this bit of the conversation that allopregnanolone goes into the GABA receptor in the brain and causes p.\_m.\_s. So the study is related to a Swedish company...

**Interviewer:** [01:04:03] OK, is this [colleague's name]?

**Chris:** [01:04:03] [Colleague's name] Yep. And the. Oh, you've interviewed [them] have you?

**Interviewer:** [01:04:10] Yeah.

**Chris:** [01:04:10] ... and [they've] not told you about this?

**Interviewer:** [01:04:13] No, [they have] told me.

**Chris:** [01:04:14] Okay. So basically you got allopregnanolone going into the receptor causing PMS. We're injecting iso-allopregnanolone, which is also naturally occurring so it's a funny shaped molecule goes in. It doesn't stimulate but blocks, so it's competitive. And so that study since recruitment....

**Interviewer:** [01:04:37] Yeah, so I'm interested in this 'cos isn't allopregnanolone from the corpus luteum... So it would only be if you were ovulating, not generally?

**Chris:** [01:04:47] Yeah. Well if you wouldn't have PMDD if you weren't...

**Interviewer:** [01:04:49] But then wouldn't the pill just work, if it prevents ovulation?

**Chris:** [01:04:52] No, because the pill has got progesterone in it. So the pill suppresses ovulation but it gives you a new progesterone cycle and that progesterone cycle goes to the receptor and turns on the PMS.

**Interviewer:** [01:05:06] So allopregnanolone is, is there whether you ovulate or not? Because this is kind of is it the causal factor, or is it just one of the...?

**Chris:** [01:05:16] I think allopregnanolone is... it is hypothetically the causal factor. And allopregnanolone... So that's allopregnanolone, iso-allopregnanolone competes with it and stops it going into the receptor and blocks it. It's not known if that's exactly happening, but that's the theory.

**Interviewer:** [01:05:35] This is the thing, I think... Like allopregnanolone could be key and this could work. But I don't see how it can only be on ovulatory cycles because then just the normal pill should work.If it's just ovulation that's causing...

**Chris:** [01:05:53] No, no, no. Okay. So so hang on. So you ovulate and you produce progesterone and you produce allopregnanolone. Well, maybe very low levels of iso-allopregnanolone, naturally. So the progesterone or and/or, the allopregnanolone go into the receptor. So if you go on the pill you've got no... um... Well I don't know what happens to allopregnanolone on the pill!

**Interviewer:** [01:06:21] Yeah, neither do I...

**Chris:** [01:06:22] I've never asked that question.

**Interviewer:** [01:06:24] OK, thank you very much.

**<Files\\E17\_Jo> - § 13 references coded [38.71% Coverage]**

**Reference 1 - 0.32% Coverage**

So how did you come to first be interested in Premenstrual syndrome?

**Jo:** [00:00:31]

**Reference 2 - 5.16% Coverage**

**Interviewer:** [00:01:46] Do you or did you identify as somebody who gets p.\_m.\_s?

**Jo:** [00:01:51] Did i identify as someone? No.

**Interviewer:** [00:01:57] Or any members of your close family or friends? Was it something you had some experience with?

**Jo:** [00:02:03] Not at all. And I think in a way that sometimes um, has a negative influence on how you would accept that diagnosis. D'you know what I mean? I think sometimes people are very much like "because I don't have it and I'm a woman and I've got a cycle, then it doesn't exist". But... I think that this study, was really.... What has been really influential, because the patient population that we saw, were just... You know, they were incredible, really. And... Um, we've probably seen the whole range of... Probably severe end of the spectrum, but [inhale] not so much me but the study nurse spoke to. I think she spoke to a thousand women and she's spoken to every every type of woman with p.\_m.\_s. And I think following on from that study, I have um had lots of contact with women. So, you know, again, I can see how catastrophic that can be on somebody's function. And it affects affects family function as well, then.

**Jo:** [00:04:05] I did wonder whether [name of colleague] who was our research nurse had had it... Because she was so amazing. I mean, well be... Beyond anything you'd have expected. but, I didn't ask her [laugh]. I just didn't.

**Reference 3 - 2.23% Coverage**

**Interviewer:** [00:04:23] Can you remember how you very first came to know anything about PMS?

**Jo:** [00:04:28] Yeah. So I first got to know about p.\_m.\_s. Well, I might have known something about it before? But I went to a meeting I think was 2009 in Berlin, that [pharmaceutical company name] supported and [colleague's name] spoke at that. They had other speakers there. But everyone just, you know, it's obviously quite high level endocrinology and to be honest, at that stage in my career, I was a bit like, "wow, too much for me" kind of thing. But they were looking at potential treatments, which was good.

**Reference 4 - 3.57% Coverage**

**Jo:** [00:06:00] And they're obviously coming because they're quite desperate. So I think it's good that there are um.. [pause] Groups that women in touch with other women because otherwise they'd be incredibly isolated, wouldn't they? But I mean, a lot of the patients that I'm dealing with are coming from far away. So a lot of it's being done by Skype or, you know, some sort of video conferencing; they might be in London. They could be in Hull or [inhale] wherever. But actually, for this particular problem, that doesn't matter as long as you can find somebody to co-manage them. So, you know, I have women in North Wales and I've just ended up finding out who the gynaecologists are who will be sympathetic to the problem. And a lot of... A lot of the colleagues I've got are through British Menopause Society. And it's obviously it's not... It's not to do with menopause, is it? But I think it's that interest in hormones that means that they might have a co-interest in PMS?

**Reference 5 - 1.31% Coverage**

So again, in your opinion, what's your understanding of why Premenstrual symptoms occur?

**Jo:** [00:07:38] So it seems to be to do with sensitivity to... Either, you know, hormones or neurotransmitters. [inhale] And it's not like there's any. Measurable difference between women who are affected or unaffected, but it is to do with that individual's response.

**Reference 6 - 3.33% Coverage**

**Interviewer:** [00:08:03] And your opinion, what's the best way or ways to manage PMS?

**Jo:** [00:08:08] I think that's... That's the problem, isn't it? So you could have a sort of natural solution, which would be menopause or a medical solution and that'll involve the available options; um, removing the ovaries and the uterus, cervix, the whole thing. It is going to work in women who've got clear cut or core PMS. But at the moment, drug... Drug options are limited. You know, you see things like "70 percent of women will respond to an SSRI". It's worth trying. But the ones that finally filter through, I think, are the patients where SSRI's haven't worked or using contraception to inhibit ovulation. That's fraught with its own difficulties with how affected women will respond to the hormones that you're then giving them. So, yeah, so I think basically there is... There is a real lack of a good treatment.

**Reference 7 - 1.86% Coverage**

Pause] Righto. What's your understanding about the differences or difference between p.\_m.\_s and PMDD?

**Jo:** [00:15:21] I think that's just um, [pause] UK/ states thing. I don't think thay're any different. I think it's just um how it's been identified in different countries. And I think, now, actually, women are becoming quite drawn to the whole PMDD as a diagnosis, maybe because it's new and maybe because it would be given more credi... Credibility, but they're [laugh] in my opinion, the same thing.

**Reference 8 - 3.00% Coverage**

**Interviewer:** [00:16:09] And again, in your opinion, what does the symptom bloating or Premenstrual bloating specifically refer to?

**Jo:** [00:16:18] Abdominal distention, discomfort. That's not bowel-related. Difficult to tell sometimes.

**Interviewer:** [00:16:27] So so, you would be more along.... Some people sort of say 'gas'. Other people say more like 'water retention' in the... in the cells.

**Jo:** [00:16:36] Yeah, I suppose it could be either actually. Possibly to do with smooth muscle relaxation due to progesterone? I think that there are a lot of things that we just really don't know about PMS [laugh]. I mean, you ask me what cause and I'm thinking, "Oh, could be alloprgnanolone. It could be anything to do with GABA receptors or serotonin receptors. But, you know, I don't think we really we know for sure.

**Reference 9 - 1.90% Coverage**

[pause] So lots of chronic health conditions can get worse at certain times in the cycle, particularly Premenstrually, would you count the expression of those sorts of things as Premenstrual symptoms?

**Jo:** [00:17:47] So what d'you mean like asthma getting worse and things?

**Interviewer:** [00:17:50] Yeah.. or mood changes if it's you know, more chronic?

**Jo:** [00:17:54] I think it's all possible. And I think if it happens recurrently, that's what's important. You know, it's that that cyclical nature to things.

**Reference 10 - 2.90% Coverage**

**Interviewer:** [00:18:41] So this is kind of a tricky one. Men or male people or menopausal women or young girls can obviously experience a lot of the same symptoms, but they wouldn't be in a cyclical pattern because there isn't a menstrual cycle. So does this mean that the same symptoms can have different biological mechanisms dependent on that patient's sex or the time of reproductive and reproductive age?

**Jo:** [00:19:13] I think so. But again, I I just think we really don't know enough about it to you know, there are all kinds of theories I've seen of jigsaws with five pieces and different causality for p.\_m.\_s, which you... It doesn't mean that men or women without a cycle can't experience exactly the same symptoms and maybe they do have a similar causality. It's just not cyclical.

**Reference 11 - 7.46% Coverage**

**Interviewer:** [00:23:00] So the latest kind of consensus based guidelines on PMS. So this is PMS and not PMDD state that any symptoms count so long as they occur in the luteal phase and they resolve shortly after menstruation begins and they are severe enough to affect daily life. How do you feel about that as a definition?

**Jo:** [00:23:28] [pause] So that there's just any symptom that's worse in the Premenstrual phase and that's...?

**Interviewer:** [00:23:35] Yeah... So what happened at the... The consensus meeting process, which was over the past decade was this sort of separation of PMDD and PMS. PMDD having the DSM 5 criteria and whether clinicians actually stick to that exactly or not, is something else, but it has a clear definition. But then it's left PMS with this very broad definition, which is now any symptoms. So long as they're a problem and they are cyclical.

**Jo:** [00:24:12] I think that's a bit woolly and I you know, I think there is no difference between... In my opinion, no difference between PMS and PMDD and the ICD Eleven definition probably is the better one in this country, I think, because the problem of accepting a diagnosis of PMDD is that is a psychiatric diagnosis. And we don't know that this is necessarily a psychiatric illness. It causes symptoms which could be classed as psychiatric symptoms, but it... They go away completely. So these are not women who've got, you know, continual mental health problems. And that in itself, it could be quite stigmatized. But, I think there's a big issue with the classification than the diagnosis and acceptability. But at the end of the day, this is just a name, isn't it? It doesn't matter what it's called. This understanding, if we can, as time goes on, try to understand more about it. I think virtually all women, I mean, me included, will have had some sort of Premenstrual issues, whether it's sort of irritability. But it's not catastrophic, it's not impacting on day to day living. I don't think it's reasonable to include that in a diagnostic category.

**Reference 12 - 3.44% Coverage**

**Interviewer:** [00:30:17] Ok. And this one is about the PMDD criteria. One of the criteria, one of the kind of eleven possible symptoms you can have. There's basically a box with a lot of physical symptoms in. It's got the breast tenderness, bloating, and lower back pain. Obviously, quite a few of those changes could be described as just normal menstrual changes that happen to really a lot of people. Um do you have any thoughts about their inclusion in the PMDD diagnosis?

**Jo:** [00:30:52] Um [exhale] [pause] I think... I think that's a very fair point. Is it absolutely necessary to include those? Possibly, not? I don't.. Out of all the patients I've seen. It's not the physical symptoms that are causing the distress, it the psychological. So, no, it's probably... It's probably something that needs to be discussed and decided on. I'm not I'm not sure it's it's absolutely crucial. Whereas the other the other things I think are important.

**Reference 13 - 2.24% Coverage**

**Interviewer:** [00:32:25] And then the last main question is, so what do you think about surgical intervention? You briefly touched on this before, but as a treatment for PMS or PMDD?

**Jo:** [00:32:37] I think for women who've had an accurate diagnosis and who are at the severe end of the spectrum and who have been provided with GNRH analogue so that they know exactly what happens when you remove any cyclical influence, then there is a place for surgery. But it's for a very small number of women. And I think the problem is that for severely affected women, actually at the moment, there are no other treatments.

**<Files\\P01\_Alice> - § 13 references coded [31.10% Coverage]**

**Reference 1 - 1.37% Coverage**

And I would say, 'oh, mom, what's going on?' And she... and that's what she started the education. And actually, I asked her when I was probably older, not old, but, you know, 17, 18. What what her experience was.

Interviewer: [00:01:53] Hmm

Alice: [00:01:53] And she said, well, right from the off, she wanted to make us aware of what to expect. And it was more actually not necessarily about the symptoms at all. It was more that expectedly once a month. And this is how you manage it. Yeah, that was it, really. But that was because she had a very shocking experience where she suddenly bled as quite a young girl. So you'd say she...I think she was maybe twelve or thirteen and no one had told her anything.

Interviewer: [00:02:22] Yeah

Alice: [00:02:22] So she didn't want that to happen.

**Reference 2 - 0.78% Coverage**

Interviewer: [00:02:53] What was your first period like?

Alice: [00:02:56] Well, actually, it was erm, something that I kind of thought wasn't ever going to happen because I was quite old, as in when I say old, all my peers it had happened to. Whereas I didn't get mine until I was 16. So I just thought. 'Oh, it will appear at some point'. And it appeared when I was on holiday with a friend in Scotland. And unfortunately, I didn't expect it to appear.

**Reference 3 - 1.01% Coverage**

You know, maybe it's my experience in speaking to some professionals that they sort of see this as very scientific and that they often have said things like we'll do a scan and then we might have to do something invasive and you might have all these physical issues and actually I’ve had multiple scans and they’ve not found anything wrong at all… [00:18:39] So no religious. No spiritual, no. But I think as I said to my mum, 'I felt a few things, which is I think the whole fertilization is much more spiritual'. And, you know, maybe spiritual isn't the right word, but it's more magical.

**Reference 4 - 0.62% Coverage**

I'm just a woman who releases an egg every 28 days though I didn't even… I didn't even know it was every 28 days until we started trying for a baby. Another gap in my knowledge, people don't even talk about looking at that or tracking any of that, what any of that means or what secretions are… they don't know because they're only taught one thing, two things.

**Reference 5 - 2.35% Coverage**

Interviewer: [00:27:23] So a bit like how you described periods to a child… would you be able to describe PMS, … like how would you do that?

Alice: [00:27:39] I don’t really know about PMS, but I could describe like (.) what it's like before and during and after, because I think PMS is associated with (.) I think it's used maybe differently medically or with a layperson. I don't think people realize what it is? So I don't think I could describe that because I think people don't really know what it is. I could describe before, during and after (.) But that's what you want me to describe?

Interviewer: No, I mean, you've kind of said (.) you’ve answered the question well enough (.)

Alice: [interrupting] I mean, all I can say in society, you might people might say you experiencing PMS or you're about to have your period or you just have your period or on your period (.) and people will have a certain (.) preconception about it or experience themselves, and depending on who you're speaking to, one woman might not experience anything. One man might have a wife who experiences it and knows what it's like. So my partner didn't have a clue that a woman could go through it until he met me, in the way that I do (.) So I think you can describe it, but the problem is the association is so different for so many people that it's kind of got lost in translation.

**Reference 6 - 0.85% Coverage**

Alice: [00:30:16] I mean, I think my experience when I know I'm about to get my period because I get some pre symptoms and pre-menstrual symptoms, but actually I think most people think p.\_m.\_s is the bleeding. Yeah. You know, people think PMS is right now - bleeding – whereas it is actually, you know, the abbreviation PMS is the before, but no one even ever talks about the after really, it’s sort of an umbrella term is if anything is used as an umbrella term for the whole pre during and past.

**Reference 7 - 5.52% Coverage**

So it happened once when I was in [an East Asian country] and I was with my sister, my older sister and my dad… [00:34:43] And I said to them, 'I really don't feel good'- we were in the big shopping mall. And they say, I said, 'leave me on this bench'. And so they went downstairs for a different floor... [00:34:56] And when they came back up, I kind of knew it was about to happen, but I couldn't go anywhere. I had vomited and had diarrhea all over the place and I passed out in the middle of a shopping mall. And about fifteen [East Asian] women were openly fanning me and one had run to the chemist and got tissues. And my dad and sister arrived to find me in this heap. It was hard and really embarrassing, and I think that they were quite shocked at what had happened. So they rushed me to see a Singaporean GP who was in the shopping mall somewhere and the health services are completely different there. And he just took my blood pressure. And did all the normal observations. And, you know, I said, 'I'm on my period and I get this. Sometimes it's stress. I was in the wrong place and I wasn't at home'. And he just said, oh, I said, 'yeah, you're fine now. Everything's fine. Go home and rest. I think you passed an ovarian cyst'. And I was like, 'Oka::y, right. OK.' But I knew that I didn't have any cysts. You know, maybe I did. I'm a bit sarcastic about it, to be honest, because I just sort of think that we get fobbed off. So anyway, I went home and after a bit of pressure from family members, I think I had actually already maybe… I can't really remember the details, but I'd previously gone and like asked… just had a bit of a consultation and they just said this was normal… [00:36:44] But then I went back and eventually asked to be seen. So I went to a GP, who referred me to a gynecologist and he was a man. Which is fine… [00:36:56] But they took they had an internal transvaginal scan where they look to see if they could find anything. And they couldn't find anything at all. They couldn't find any cysts… And he said it was unlikely that you'd passed a cyst. And he said. And he offered me. He said two things. He said, 'there aren’t any signs of endometriosis but It sounds like endometriosis'… [00:37:22] So I thought, okay. He said, 'so we can't determine whether you have endometriosis. The only other option is to have an invasive…' I can’t remember what it is called…

Interviewer: a laparoscopy?

Alice: yeah… [00:37:39] And he then said, 'obviously, this is an infection risk. [00:37:42] And if you have that and we find that you do, we can, you know. What's it called like surgically? Try and tidy it all up by sort of cutting it, etc..' But to be honest, for me that isn't a solution. I don't want to go and have an invasive surgery. And if I do have it, why don’t I have this traumatic experience every month? I only have it like once every four, once every three, or once every six months. And I don't have any of the other signs of endometriosis. So the jury is still out there. So after that, I just thought. Well, that’s less than useless for me. So I didn't go back. I continue to get pressure from family members to go back. But I have to say.[sigh] [00:38:41] I think it's a waste of my time.

**Reference 8 - 4.46% Coverage**

Interviewer: [00:38:46] So there’s a sort of sense of not knowing. And managing anyway. Or, does it make you a bit anxious that you haven't had like a definitive…

Alice: [00:38:59] Not really. I think it’s more anxious for other people. I think I just. I just have learned to live with that and deal with it. And certain strategies work, and I don't live in fear… Thinking, is this month going to be one of those months? I just hope that it isn't going to be, and get on with my life. I think other people who have witnessed it find it pretty traumatic to watch… [00:39:26] So I've had that… when I'm in public, it’s so much worse… when I'm at home, it's fine. So once in the [overseas] shopping mall in public, it's bloody awful. And then once on the doorstep of my parents’ house. But luckily my dad was in. I’ve had it at home lots of times. When I’m on my own, I find them quite scary because I always know I will pass out for a little while and just hope that I wake up. So when I had one of my miscarriages, I did pass out. And my parents found me on the floor. So I think it can be much scarier for other people than it is for me because I have just learned to deal with it. [00:40:08] So then they push you to say that must be something that can be done. But I actually just found that I think this is just a period for some women, full stop. And yes, you can get people who have endometriosis. Yep, and you can get women that have polycystic ovary syndrome. Yep. I think it's just menstruation, slightly different physical makeup's, hormonal imbalances. I mean, I haven't looked into any of this apart from my own research and reading… certain things can trigger and induce it and make it worse. So I know how to cope with certain things and… then exercise works for a lot of women. And I think it's like probably having a period or PMS or whatever the certain categories that women may experience these symptoms or no symptoms. [00:41:04] And I don't think we've done enough research to look into why there are the variations of… of physical and emotive symptoms…[00:41:15] I think we just it's easier sometimes to say let's do an invasive test… to fix it or… it's normal – get on with it… [00:41:27] But I do think it shouldn't be that… you should… you shouldn’t have to be like that. I mean, when I say that I've I think I’ve learned to cope with it, but I don't think you should have to cope with the traumatic ones. I don't think you should ignore that… I think there should be something that can be done. But my experience has been that there isn't anything that can be done. So I just get on with it.

**Reference 9 - 2.64% Coverage**

Interviewer: So there's another thing that happens that some pre-existing conditions or more chronic conditions like migraines, asthma, epilepsy and even mental health conditions can be sort of worsened, or also perhaps even triggered by the menstrual cycle.

Alice: Yeah.

Interviewer: So, again, do you think that's the same thing as a premenstrual symptom again? [00:53:20] How would you categorize these things, things that can be worsened?

Alice: Yeah, I don't know. Because for me, I don't have any of those.[00:53:28] You know, I don't have epilepsy or I've never smoked. What were the other ones?

Interviewer: Asthma's one, migraines…

Alice: Never had migraines with it at all. Although some women, I think, just get migraines. I haven't mentioned that as one of the common symptoms, but that's because my experience is not of headaches. So, no, I don't… I can't comment on that because I haven't got any predisposed conditions. I think my mental health, although, [laugh] you know, Who are you to judge your own mental health, you have to ask everyone else [laugh]? [00:53:59] I think, um, I think my mental health fluctuates when I’m about to have my periods. And people around me would say, you know, you get a bit emotional, you know. [00:54:11] But I only accept that from people that know me very, very well. And I don't… think that's like preconceived. I think that's just me having… having that change in hormones, if that is what it is. But I can’t really comment, because I don't have any of those other conditions.

**Reference 10 - 7.75% Coverage**

Interviewer: [00:57:19] I think I mean, we've kind of covered this as well. But you're saying that you wouldn't ever describe yourself as having ‘PMS’ and that there is a reason for that…

Alice: Yeah,

Interviewer: …that it's got this Connotation. So that's kind of what I'm asking you about… how..

Alice: [00:57:35] [interrupts] I think… I think it's dependent on who treats you. [00:57:41] And that's been my experience…. Well, two things. Which is that on one side, I think women, who experience periods and period symptoms. I think that on the one side, women would… would appreciate it if healthcare practice and research, or if more research was done, first of all, but if there was a better understanding of what pre-period or period, or post-period presentations are just full stop and that there’s variability amongst women. And I haven't even touched on the fact that there’s probably variability amongst different ethnic women… So I think that that's an area of health and medicine that hasn't really been explored yet sufficiently to develop and create understanding of, you know, of even just terminology, because I think you have used the word, ‘Diagnosis’ and stuff like that, to me, ‘diagnosis’ is again associated with something that's wrong with you. Having periods are normal, you know, and there's nothing wrong with you and you will have a straight line where you're lucky that you just have a simple bleed and you get back to normal life in its last three days and that's every 28 days that you tick the box at complete regularity. Great. Brilliant. Now, I wish I was that woman, but we know that they can happen between 20 and 21 days and 32 days. So you might be a woman that has them every two or three weeks. You might be a woman that has them every four or five or six weeks. I of that scale you… you may present slightly differently whether you've got pre morbidities like they say or preconditions or a previous journey or previous complication. All you're just having a period, you know, and you will be placed slightly differently. I am one of three sisters. My experience is different from the other two sisters. Why am I any different? I don't know. So it is not about I think it's about a real gap and lack of insight into that process. For women… [00:59:59] And again, I would say that that happens for the menopause as well. I think there's more research has been done on the menopause, but I think they’re massively connected. And I wouldn't be surprised that if you've experienced having periods in a certain way that you then experience having a menopause in a certain way. Who knows? I mean, they may be completely different. But the… but the research also comes from money. And we know that when you hit menopause there’s the HRT drug, which drives research, which creates money, which drives the economy. So why wouldn't we research that? There isn't any money for [research into] women having periods apart from contraception and the pill so that our lives are researched on that- one solution is to go on the pill because it apparently can ease symptoms better – I in the past did not believe in that because you then induce even more drugs into your system. So I think it's like it's the words that we use and the language that we use to describe the releasing of the egg and what happens to a woman's body during that time. And it's, uh, it's still a very male dominated field. In medicine, I think I think that's changing. [01:01:14] And I think the that the… [01:01:20] Emphasis and the time that is required to... It is ironic. Cos’ We've been going through this for thousands of years, you know.[laugh] But I don't think it's seen as a priority area of health. Actually, you could suggest that it is because I think some associated symptoms that some people experience to the extreme, which does cost the healthcare system huge amounts of money. And actually, if they if they did research this more, they might find that if they got this understanding better… [01:01:56] So I don't mean like diagnosis because it's not a diagnosis, just a process, a physical process. If they understood that better. Other associated things that do happen to some women may mean that they they don't go down that line of healthcare. Say, for example, like complex pain or mental health or whatever it might be. [01:02:21] And actually those associations are dealt with in the forefront to give women better, more understanding and self-management and empowerment to take care of themselves better down the line.

**Reference 11 - 1.21% Coverage**

Alice: [01:02:53] The one thing that I would say is, you know, I'm a health professional myself. But I do not think we have. Health care. [01:03:01] Full stop in the UK which is open to me as a woman going to see my GP, which is where everything starts… To be able to say ‘This is what happens. What can you do?’ Because having done that. Twice or three times my experience has been it's a shut door… [01:03:23] And actually the only and I don't want a diagnosis, ah, I mean, maybe I do have endometriosis, but, you know, I don't think I do because I. I've looked that up. I just think that. Maybe the fact that we even go to the doctor to say what's wrong with me tells you a lot about how society views periods.

**Reference 12 - 1.08% Coverage**

Interviewer: [01:03:49] That’s brilliant, and it leads very nicely on to this one… Have you ever experienced a positive menstrual changes? Again. We’re talking about the whole cycle.

Alice: [01:03:57] Well, getting pregnant [laugh} [01:04:03] And I have to say, I've sort of. I've sort of already talked about this a little bit, but because of because we've gone through a quite traumatic journey in the last year trying to have a baby and again, like I've had three pregnancies. But if I did have endometriosis, you struggle to conceive. But we haven’t had that. It's just you know, I think it's just unfortunate what's happened.

**Reference 13 - 1.46% Coverage**

It’s only after I've done my own research and I've really kind of understood my own body and that's for me. It's been. Kind of a breakthrough in its own right, and I don't think we educate people.

Interviewer: [01:05:54] So do you think that knowing more has actually improved yourhealth? Like=

Alice: [interrupts] definitely!

Interviewer: = like physically and….

Alice: Yeah, yeah, definitely. [01:06:04] I'm not a big drinker or big coffee drinker anyway before, obviously. Now I'm not at all [due to pregnancy]! [01:06:09] But I think all of the stimulus that can happen in your diet and your environment. You know, it's become a bit trendy to talk about all of that stuff. You wouldn’t have talked about all that a hundred years ago… But I think knowledge gives you empowerment. And if you've got that, then you can self-manage anything.

**<Files\\P02\_Beth> - § 11 references coded [27.57% Coverage]**

**Reference 1 - 0.90% Coverage**

**Beth:** [00:07:40] [Pause] Definitely over the last several years since erm, my mid 30s, I've really noticed that a lot more... probably when I was younger, I... whether it didn't happen that I didn't get the symptoms or I was just less aware of it. I don't know. But yeah, over recent years I have noticed definite premenstrual symptoms and symptoms around the time of ovulation as well. Yeah, there's a definite pattern.

**Reference 2 - 0.96% Coverage**

**Interviewer:** [00:12:41] OK. Thank you. And how would you describe periods to a child, or someone who, you know... who didn't know?

**Beth:** [00:12:51] Oh, gosh. I'm trying to remember now how I talked about it... With my daughter. Erm... [Long pause]

**Beth:** [00:13:03] It's a really hard question, actually, because at the time I think I just sort of went with what I felt was right and try to make it sound normal and not scary and not embarrassing.

**Reference 3 - 4.63% Coverage**

Erm, I guess I'd describe it as a normal thing that starts to happen to girls. And... It can be... Erm, when you were as young as 8, so sometimes girls in primary school start getting it, or it might not be until you're... you're 15, 16, but. Erm, But both... Both can be normal. So. Erm , Yeah. And it's part of growing up and... Usually a few changes happen to your body before you get periods, so erm, it's it's all part of that process of erm, changing from a child into an adult. Erm, If you were to describe what happens when you get a period. I guess you have to tie it in with making the child aware of sex and where babies come from. So you've... you've got to explain that, you know, women have have a womb and that's where babies grow. And every month the body prepares the womb to get ready for a baby growing there. You know, obviously, most of the time that doesn't happen. So. So then the womb gets rid of... all the lining that's built up to prepare for the baby and that comes away and it comes out of your vagina as bleeding and that can go on for a few days... There's actually. A lot to explain! And it's a lot of information for a kid to take in.

**Interviewer:** [00:16:04] Yeah

**Beth:** [00:16:04] Yeaah, and it doesn't sound normal at all really, to, you know, potentially... you're explaining it to a sort of 8 year old who potentially could be starting their period quite soon. Erm, Yeah. There's there's loads of information that sounds quite weird for a kid to take in. Erm, It's a bit of a challenge to explain it in a way that they're going to understand and not... Be sort of scared of, I guess, because, yeah, it is... it is quite hard to explain to a kid that, you know. Every month, blood's going to come out of you, but 'that's normal'! And, It's because your body is preparing to have a baby and then you don't have a baby. But of course, you're not gonna have a baby, you're 8!! [laugh]. So, yeah, it is quite, quite a challenging thing to explain, I suppose. I don't know what the right way to do it is, I do remember having a conversation with my daughter about it. That was very matter of fact. And she just went. 'OK, cool'. [laugh]

**Reference 4 - 3.79% Coverage**

And. You know, it's. Enabled me to... the fact that I have periods is an indication of, you know, fertility, it's allowed me to have a child. Theoretically, it still gives me the option to have another child, although I think that's quite unlikely given personal circumstances. Erm, So I think, you know, that's the positive side of having periods for many years... is the sort of fertility side of things for women who actually want to carry on having children.

# P10

**Interviewer:** [00:22:10] Aha. And again, relating to that one. If you could wave a magic wand. I don't know why it has to be a wand. But imagine that. And get rid of your periods, would you?

**Beth:** [00:22:31] [Long pause] Ohhh! Probably not, because... Although I really don't like. Some of the premenstrual symptoms I get. Erm, I don't know how I'm going to feel... I think it's a case of better the devil you know, from, you know, from a personal perspective. In that if my periods just stopped... I'd effectively be menopausal. So would I feel even worse if I wasn't having any periods at all [laugh]? I don't know if you mean is this just a magic thing where you could just stop your periods and there'd be no sort of menopause consequences of that? I think I'd rather be having periods than go into the uncertainty of an early menopause right now. And also it would also take away the option of having a child ever again. Even... which is silly, because rationally, I know that I'm, you know, ninety nine point nine nine nine percent sure I'm not going to have another kid, but just the fact of completely taking that option away, I'm thinking 'not sure I'm quite ready to like say definitely no 100 percent not just... Stop my periods and that's it'. You know, it's not rational, but that's how I feel.

**Reference 5 - 2.77% Coverage**

**Beth:** [00:32:09] I. [pause] I always will, not always, but you know. With my sort of medical training. I... I thought, oh, PMS is due to... The fluctuations in hormone levels, and that's what causes these symptoms, but I think... Obviously. Well, I don't know if it's obvious, but I think that's a big part of it. But. I was thinking recently about why is it that... not just for me, but anecdotally, I've heard a lot of women say, oh, my PMS has got worse... in my late thirties, in the years leading up to the menopause... is that just cause the way the levels of oestrogen and progesterone fluctuate throughout the menstrual cycle, change as you get older? Is it that or is it because. er, other factors that aren't anything to do with your sort of hormonal physiology. And I was thinking, you know, a lot of women. Who have children... around that age.. their kids are getting older. They might become a bit more challenging to parent. They might be having marital breakdowns. They might be having to juggle working with parenting. So stress from sort of social issues might be more of a factor as you get to that age or that might be contributing to sort of increasing p.\_m.\_s symptoms? Erm, I don't know. I mean, I don't think it's just the hormones. I think it's other... other factors as well.

**Reference 6 - 2.01% Coverage**

**Beth:** [00:37:43] There's other things I do. I take a vitamin B complex. Actually, because I did read somewhere there was a particular B vitamin that could help with p.\_m.\_s and another B vitamin. A different one that could help with the skin picking behaviors. So... so though there's not a huge evidence base for that. I take it anyway. Yeah, to be honest, I'm not sure if it makes a big difference or not, but I feel generally a bit healthier when I type vitamin B complex and vitamin C supplements, so. So who knows? What else do I do? Oh, I take a lysine supplement as well, because I did go through a very long phase a couple of years back, of getting a break out of cold sores before every period, which was just horrible cause it meant. I couldn't really put anything on my face. It was really painful. They wept all the time. So I had to put dressings on them. I got really fed up with it. So, yeah. I still take lysine... Erm, Yeah.

**Reference 7 - 3.63% Coverage**

**Interviewer:** [00:41:18] Yeah. Do you think that doctors like family doctors, GPs, have enough knowledge or training on menstrual cycle related symptoms?

**Beth:** [00:41:30] No.

**Interviewer:** [00:41:33] [laugh]

**Beth:** [00:41:33] [laugh] Well, that was the brief answer. I don't think we do. I think we... we do get... our training. That's relevant to periods and menstruation is very focused on the menstruation part of it. And problems associated with that. So if women have very heavy periods, what treatments we can prescribe to try and reduce the blood flow and then what investigations we can refer for it, if that doesn't help. Or if they have very painful periods, then likewise what medications can be prescribed and then when we should refer to see if there's an underlying cause of very painful periods. And then if women are getting irregular cycles or, you know, bleeding in between periods, could that be a problem with the cervix? Could it be fibroids? Could it, you know, be polycystic ovarian syndrome?

**Beth:** [00:42:35] There's training for dealing with those conditions. But I think p.\_m.\_s is sort of given a bit of a...'oh, by the way. Some women get p.\_m.\_s.' What can you do type thing... It's probably a bit better than it used to be in that... you know, that there's a bit of it in GP training. There's a bit of a mention of, oh, sometimes the, you know, hormonal combined contraceptive pill can help with p.\_m.\_s symptoms or sometimes a low dose SSRI antidepressant can help. But.That's about it, really. Erm, there's... there's not much other mention of p.\_m.\_s in in GP training, apart from that, I don't think it's seen as a massively important thing to know how to manage.

**Reference 8 - 3.41% Coverage**

So do you personally track your menstrual cycle related symptoms? Do you record them in any way?

**Beth:** [00:50:54] Not at the moment. I have done. Erm. Over. Probably not long enough, actually, because you should do it over three months, shouldn't you, to get a proper pattern of data? But I probably did it for two months at most. I think that. Was... I don't a moment. But, Yeah, I did... But it was more with the purpose of tracking a specific set of symptoms to see if my menstrual cycle had any influence. Not to try to track my PMS symptoms. So I'll try and explain briefly, because I know I'm rambling on a bit... I've got possibly a condition that's being investigated at the moment called postural tachycardia. So I was tracking my pulse and blood pressure over the course of a couple of months and also tracking that alongside when my periods would occur... to see if it got any worse before a period or not, because I suspected it might. Alongside that because I was getting some random fevers, as well... I tracked my temperature, which didn't seem to tie in with my menstrual cycle? But I wasn't tracking all my p.\_m.\_s symptoms because I had already noticed that the anxiety and the bowels and everything got worse. at certain points. So I didn't feel the need to formally track those because it was so obvious to me when they were happening. But I think. Tracking is definitely a useful thing to do if you get lots of symptoms. Well, if you got lots of them or if you get just one or two symptoms and you're not sure whether that's due to the menstrual cycle or something else, yeah.

**Reference 9 - 2.01% Coverage**

**Interviewer:** [00:52:56] Ok, thank you. In your understanding, again, not a test. Roughly how many premenstrual symptoms are there? Like we're talking 10, 20, 50, 100 or hundreds? Where where would be your feeling?

**Beth:** [00:53:17] Are we talking self-reported? Or are we talking? What? There's evidence for what the guidelines say. So far.

**Interviewer:** [00:53:24] What's your feeling about. The experiences of people?

**Beth:** [00:53:33] Well the experience of people, gosh, it's probably loads! I think several tens. So 50 to 100, I'd guess, if you're talking about every woman's experience combined. But whether all those symptoms are definitely p.\_m.\_s or. Something else, I dunno. I guess we don't have enough evidence at the moment because there's not enough research to say that for sure.

**Interviewer:** [00:54:08] that's great.

**Beth:** [00:54:08] but I think There are probably lots! - Not very scientific is it? 'Lots'! [laugh]

**Reference 10 - 1.55% Coverage**

**Interviewer:** [01:01:26] And again, you've mentioned this before, but have your typical symptoms changed over time, like, you know, as you've got older?

**Beth:** [01:01:33] Yeah, definitely. Probably I mean, I'm 39 now, and I would say since my mid 30s, the PMS symptoms have become a lot more pronounced. Although the bad ones have probably always been an issue, why... I think I've just become more self-aware of the pattern of these things happening. Whereas I probably was paying less attention to the timing of the symptoms when I was younger. So it's difficult to say whether I've only had the symptoms since my mid thirties or whether I've only become aware that it's p.\_m.\_s since then because I've been tracking it all.

**Reference 11 - 1.93% Coverage**

**Interviewer:** [01:05:45] Ok. And then this is the last question. How do you feel about having had this conversation? Has it made you feel or think any differently than you did before? And don't feel obliged to say anything but just some reflections on as you've been speaking?

**Beth:** [01:06:05] Yeah. Definitely. I think it's. It's made me think about. How how p.\_m.\_s and periods are discussed a lot more. I don't... I don't think we think about it enough. When you asked me about how I'd explain periods to a child that was so challenging. You know, it's really highlighted to me that, you know, we probably don't explain menstruation. Well, enough to children in a way that they would understand. You know, me as a parent and a doctor really struggled to do that, then I guess a lot of other people would struggle. To have that discussion as well. So it's really useful to have that flagged up. Yeah.

**<Files\\P03\_Dani> - § 11 references coded [31.58% Coverage]**

**Reference 1 - 0.83% Coverage**

I was aware of like tampons around in my mom's bathroom. So that wasn't like it wasn't like a hidden thing. I remember seeing them quite a lot. Not quite understanding what they were, but. But yeah, definitely wasn't hidden.

**Reference 2 - 2.57% Coverage**

**Interviewer:** [00:06:44] Okay, then what's your understanding of why periods occur? Obviously, it might be related to what you've just said.

**Dani:** [00:06:54] Yeah, basically the above. Erm, Yeah. To get your womb ready for a baby and then it doesn't come and So the lining basically sheds and gets ready for the next month.

**Interviewer:** [00:07:09] Right.

**Dani:** [00:07:11] Is that Right?

**Interviewer:** [00:07:13] So what I'm doing is... it's kind of the words and way that people describe this is what I'm comparing so there aren't any like right or wrong answers... so... I'm not testing...

**Dani:** [00:07:23] I know but still I feel that I should get it right.[laughter] Okay, cool

**Reference 3 - 4.84% Coverage**

**Dani:** [00:09:50] I mean, before I started working in periods, I just don't think I really cared. Like I just was like, it's just you can either be on the pill and it not be your period. And you could do that or you could have the coil and not have periods at all. Or you could just crack on which I was, but like I just didn't because they don't really affect me or they didn't... I didn't notice that they did because I wasn't tracking. I didn't really care. And I still don't actually quite... not enjoy. But I appreciate having my period now because it probably because of the work I do like because I kind of have to... but I think that it's always just been to me, it's just part of life. It's not like it's not a bad thing. It's not a good thing. It's... it's... it's just your body. It's just your body works basically by having a period. [pause] Yeah. I mean, obviously, like I'm furious about all of the inequalities surrounding periods because, you know, we're made to feel like we're dirty, we're made to feel like we're like less capable, you know, all of this. But.[pause intake] I just... I don't see it as being true.. I think there's a lot of education to be done. But yeah, I think it just doesn't really feel... it often feels quite neutral to me having a period. That's just what it is.

**Reference 4 - 4.56% Coverage**

**Interviewer:** [00:13:03] Erm, This is this is hard just because it's hard to remember. But do you remember how you first came to know about p.\_m.\_s as a thing?

**Dani:** [00:13:21] God, it must have been from a magazine or something. Got a lot of my like sexual and reproductive education from girls magazines like shout and bliss and stuff. I'm sure they used to print all this kind of stuff. It must have been through there,.

**Interviewer:** [00:13:41] So probably as a child?

**Dani:** [00:13:44] Yeah. I would have been like 10. I think I probably knew what it was, but just didn't really. In fact, the first memory I have of it is when I was in Florida on holiday and I remember being in a... in a big sort of pharmacy and there was a whole aisle that said p.\_m.\_s. [laugh] And I remember saying to my mom, "what is that?" But I don't know, but I. But then I have like a mixed memory. Of whether, she said, "oh, no, it's just the American version of PMT" or something like that? So I might have known, but I hadn't started my period then, so. Yeah, but I really can't remember. It's just I think it's always just been something that is just, you know, I've known about since I've known about periods maybe. I'm not sure. Sorry.

**Reference 5 - 3.09% Coverage**

**Interviewer:** [00:14:39] That's alright! So similar to telling a child about periods, how would you describe p.\_m.\_s to somebody who hadn't heard of it before?

**Dani:** [00:14:52] Erm, [pause] I would just tell them that... [pause] Your hormones affect you in different ways, you have different... [audible woooah]... you have different hormones acting at different times of the month, and that at one point... they can just make you feel... either a bit more irritable or a bit more in pain. I actually don't know why we get p.\_m.\_s! But yeah, I think that's how I would describe it, and it just at some point you just gonna feel a bit worse, but it always passes and it passes usually when you get your period or just after. But erm, yeah, it's just a sort change of mood and maybe change of... physical. how you feel physically.

**Reference 6 - 2.75% Coverage**

**Interviewer:** [00:15:40] Ok. Again, I'm not testing your knowledge. in your... in your understanding or just in your experience. How common do you think PMS is?.

**Dani:** [00:15:56] Erm, [pause] I don't know, actually, I'd say it's pretty common like. [pause] I'd say that like probably quite a few... people who menstruate and women sort of experience it from time to time, but maybe it's not always recognized as that. Maybe it's sort of. It is sort of recognized as being in a bad mood or something or vice versa with your knowl... with your education [referring to interviewer]. I don't know. Erm, Yeah, I'd say it's probably like [pause] relatively common, but I don't think everybody who menstruates experiences it or suffers from it.

**Reference 7 - 2.30% Coverage**

**Interviewer:** [00:16:38] Ok. So we touched on this. You just sort of mentioned this before, but. What's your understanding of why pre-menstrual symptoms or changes happen?

**Dani:** [00:16:54] I don't actually know. I think it has... something to do with spiking of hormones?, but I could have just completely made that up. I don't know!

**Interviewer:** [00:17:07] That's fine.

**Dani:** [00:17:08] Embarrassingly![laugh] well, at least I'm not a doctor. [laugh] but Yeah,.

**Interviewer:** [00:17:14] [laugh] Honestly, I'm not testing you...

**Dani:** [00:17:14] No! I know you're not. But I'm... I'm like testing myself.

**Reference 8 - 2.71% Coverage**

**Interviewer:** [00:22:53] Have you ever heard of PMDD which stands for premenstrual dysphoric disorder? And if so, what's your understanding about any differences between p.\_m.\_s and PMDD?

**Dani:** [00:23:05] Yeah, I've definitely heard of it. I think that it is a much more extreme version where like the person suffering from it can actually feel suicidal and [pause] incredibly unstable and unhappy at certain times. So right before their period. But... I have a couple of acquaintances who've suffered from it. And it's basically sort of, not ruined but basically upended their careers because they were unable to be in the workplace because of it. But yeah, very unda under known about. That's not a word! Erm, problem I think.

**Reference 9 - 3.33% Coverage**

**Interviewer:** [00:23:52] Ok. We're on to the last section, which is about your experiences and what you do. So do you track your menstrual cycle related changes and symptoms?

**Dani:** [00:24:08] I don't track as much as I did because I pretty much know now... for a good year and a half. I tracked everything and that's where I started to notice patterns. Like "Oh, That's why I'm really tired at this point". And, you know, that was blah blah blah... But I still put in just because I've ... now I've got this implant.. I'm trying to work out what's actually going on with my cycle with it. I just... just track the bleeding days. But I don't really tend to track everything else. but I did. I used to track everything like from energy to sex drive to like what I was eating. And I did find that really useful. But I just don't tend to need to as much anymore. But yeah, i still track the bleeding.

**Reference 10 - 1.80% Coverage**

**Interviewer:** [00:30:24] Yeah. And if you ever met someone who didn't believe it, you or someone else was really experiencing these symptoms.

**Dani:** [00:30:38] Erm... Have I? Good question. [pause] I don't think so. [pause] I'm sure I've met people who don't understand what the pain feels like because it's not just like having the stomach ache, it's like. It's almost like you can feel your womb working. Sometimes I think people don't quite understand, that if they don't have it.

**Reference 11 - 2.80% Coverage**

**Interviewer:** [00:31:03] Yeah. Are you aware that p.\_m.\_s is considered a controversial diagnosis by some people?.

**Dani:** [00:31:16] I don't know if I knew that, but it doesn't surprise me.

**Interviewer:** [00:31:22] Why would you think it might be controversial? Again, I'm not testing you.[laughter]

**Dani:** [00:31:27] Well, I think because it's so variable. It probably is the kind of thing that maybe like the scientists don't like because it's not like... But, you know, it's.. it's harder to test as well, probably. But yeah, because it can be so variable and it can change from month to month. I guess it could be to do with other things as well. But yeah, I'm not I'm not surprised that it's considered that. But it doesn't make any less real.

**<Files\\P04\_Emma> - § 12 references coded [29.23% Coverage]**

**Reference 1 - 1.13% Coverage**

I remember having a book as well that that my mom bought for me. I think I must've been maybe nine or ten. And it was all about puberty and the bodily changes that happen. And I remember just... I think that was the kind of... way in to the conversation about periods and puberty and what happens and all of the lovely fun and shenanigans [laugh] and changes that occur. Yeah. So that's... that's what I remember about family and conversations.

**Reference 2 - 0.87% Coverage**

And then after usually around day four of my cycle, day 4/5, I feel the benefits of oestrogen increase in oestrogen and I usually feel a turn around in my mood and an uplift in my energy. But again, this month I'm on day nine today and I'm still waiting for that to happen. It hasn't quite happened this month. so I feel a bit shortchanged.

**Reference 3 - 3.00% Coverage**

Do you do anything special or maybe refrain from doing anything around your period?

**Emma:** [00:10:34] I... try to plan ahead. So I have a calendar, a desktop calendar, which is color coded around my cycle. So I use that as well as an app on my phone to... [inhale] to consciously try and schedule things to fit around either my good days or my my bad days. And I will try and keep day one at least day one and day two of my cycle completely free if I can. It doesn't always... In fact, most of the time it's not possible to do that. Or I work from home to avoid travelin'. But certainly anything that requires a lot of energy that I know I'd really struggle with, I try where possible to avoid that durin' my period. Maybe because I know that I won't be able to give it my best. And I just won't be in... physically. I won't have the energy or even the mental capacity to engage with anything that... Requires much thought or energy or positivity. Erm, Yes, so I'm much, much more aware of planning and scheduling and avoiding travel and meeting people and socializing and anything that's going to need me to be with other humans. Really? Yeah, that's that's kind of what I do.

**Reference 4 - 2.85% Coverage**

**Interviewer:** [00:12:35] Can I ask you a bit about that? Because obviously menstrual cycle changes in length a little bit for most people each time. So do you have to kind of plan quite a few days like, you know, roughly when it ought to be, or do you just kind of wait until, you know, do you note ovulation and then you've got more of a clear idea? How do you do that?

**Emma:** [00:12:55] That's a really great question. So my... I'm really lucky in that my cycle is relatively predictable. Give or take one or two days. So, yes, I'll give perhaps three days where I'll put black stickers on... they are my 'flow' stickers [laugh]. And then I've got red stickers, which are my PMDD symptoms. So they are bad days where I know, um, I'm probably gonna struggle. Erm, But ovulation... Yeah. I'm also also very conscious of when I'm ovulating again, I'm really lucky because some people don't really know when it's happening, but my body does get lots of signals. And yes, I use that because I know that my period will arrive about, oh, God, I can't do the math. Twelve days after that, because I have relatively short cycles.

**Reference 5 - 1.04% Coverage**

**Interviewer:** [00:21:31] And again, I'm not testing your knowledge in these questions. I'm more interested in how different people respond to them. So then what's your understanding of why periods occur?

**Emma:** [00:21:51] [long pause] We need the menstrual cycle or the ovulatory cycle to have children, so biologically it it allows us to.[pause] To... Procreate. Er, Yeah, in a very basic simple form! [laugh]

**Reference 6 - 1.67% Coverage**

**Interviewer:** [00:30:20] And what is your understanding of why pre-menstrual symptoms occur?

**Emma:** [00:30:27] From what I understand, it's linked to the hormonal changes and fluctuations. In the case of PMDD. It's almost like an allergic reaction whereby the body can't process those fluctuations. So it's not an imbalance. It's just a difficult and... [pause] Yeah. In the process involved, those peaks and troughs of the menstrual cycle... some people, are sensitive to progesterone. So when progesterone is dominant in the luteal phase, that can trigger symptoms for a lot of women. And that's why... that's why we see p.\_m.\_s in that part of the cycle.

**Reference 7 - 5.80% Coverage**

**Interviewer:** [00:31:30] Ok. Now, you've touched on this a bit, but I've got to ask again. How do you manage your symptoms?

**Emma:** [00:31:43] So. [long pause] For mood related symptoms, I take citalopram I'm on a low dose of citalopram every day, and that just helps to erm, stabilize my mood. So before I was taking that, I would have full blown depression for about four days. I don't get... I don't get that Now that takes citalopram. I definitely still have low mood. But it's not nothing compared to what it was. I take ibuprofen around ovulation and in the days leading up to my period, because with PMDD one of the... one of the views is that the body has an inflammatory response around ovulation and premenstrually to these fluctuations. So I take ibuprofen to try and manage that erm, and anti-histamines as well, which help particularly with erm premenstrual headaches. But I get... I try and lead a fairly healthy lifestyle, so I try and cut out gluten. Where I can because I do, I can get IBS symptoms around ovulation and pre-menstrually. God it's all fun and games isn't it! [laugh] and I try to eat a lot of vegetables and fish and cut out processed refined sugar and... Stuff like that, which is just going to make things a whole lot worse. I take oil of evening Primrose. B vitamins, iron supplements, vitamin D. Agnes cactus, ahh Agnes Casta.. Argh, I never get it right.

[00:34:12] Agnus Castus?

[00:34:13] Vitex root, yeah? What else do I do? Yeah, and I think more recently just... we talked about it earlier, but just conscious scheduling. So making sure that. When I'm pre-menstrual or the days after ovulation, I've got some free time, some downtime where I can just have a nap. Some things so, self-care. Actually planning and scheduling in some time for self-care. Usually for me, that is literally just going to bed... or watching Netflix or it's just staying out of my inbox. [laugh] And yeah. Well, yeah, and tracking tracking the symptoms as well. And that's really helped me. And so I mentioned I'm going to the doctor's next week and that's because every day I'm really thinking about, OK, how do I feel, how is my mood, has my energy erm and doing that allows me to see any kind of changes or anomalies. And then I can go in and speak to my GP.

**Reference 8 - 1.72% Coverage**

**Interviewer:** [00:38:33] And just to clarify something, when you say that the contraceptives made it worse, do you mean the mood symptoms were worse?

**Emma:** [00:38:41] Yeah, Mood symptoms? And also, I just I've always found this with contraceptive... The contraceptive pill, just this sense of being numb. Almost like a 'not in my body' type of feeling.

**Interviewer:** [00:38:56] Mm hmm.

**Emma:** [00:38:56] Which. Yeah. I've tried lots of different kinds and have never. Never felt right. Never felt like me. But again, for some people, it's a lifesaver. So it's just I think just for me, it hasn't either haven't found the right one or it it's just not the right treatment.

**Reference 9 - 2.62% Coverage**

**Interviewer:** [00:39:29] Thanks. And do you think doctors have enough knowledge and training about menstrual cycle related symptoms?

**Emma:** [00:39:38] No, I don't. And. I think this extends beyond menstrual cycle symptoms to to menopause and all female reproductive health, really if we bring endometriosis and polycystic ovary syndrome. And all of those things in the conversation. And it unfortunately, it's not just g.p.'s, but it's it's all health care practitioners. So psychiatrists and psychologists who are.. who are seeing patients and don't ask the question, are you tracking your Menstrual cycle and I dread to think how many women are... are in counselling and therapy. And it's linked to... to their menstrual cycle and nobody has asked them to track the cycle or. Yeah. So I think to come back to your question, I think, you know, there's not enough awareness and there's not enough training and that for me would be a really positive step to to improving things in terms of female reproductive health and well-being.

**Reference 10 - 4.49% Coverage**

**Interviewer:** [00:54:23] Have your typical symptoms changed over time? So when you were younger, was it any different?

**Emma:** [00:54:30] That's a great question. So when I was younger, I I don't remember happened. The psychological symptoms, actually, no, that's...[long pause] I'm gonna... a recent realization was that... I didn't remember having any psychological symptoms. But, I used to have panic attacks, and on those days I would find it really difficult to go in assemblies... And because I felt really claustrophobic and it didn't happen all the time. It only happened sometimes. And now... now that I know what I know about PMDD and what I experience now as an adult, I'm almost convinced that that was happening in pre-menstrually. And I didn't realize because I didn't know about it and I didn't track my cycle. So the other differences were that I used to have incredibly painful periods to the point where I would almost faint and I missed school, had to be picked up from school because I was just crippled in pain. And that.. that seemed to ease with age until fairly recently where the pain has come back. And the length... the actual length of my cycle has changed. Again, that's been quite a recent thing, so I've noticed a change. I think more significantly from my. Mid 20s to now, so I'm 33 now, nearly 34, and I've got a much shorter cycle. I've got a much shorter. [pause] Bleed. But less pain and more mood related symptoms? Erm, So I don't know it.... Sorry for the complicated answer. in answer to your question, I... I don't know if The mood related symptoms have been there all the time. and It's just that I haven't been aware and haven't been tracking and haven't been conscious of them or whether they have come on from my late 20's?

**Reference 11 - 2.34% Coverage**

So how do you feel about the diagnosis of PMDD and how you sort of have to have... certain types of symptoms from the list? How do you feel? Do you think it's a good definition, a good way of diagnosing?

**Emma:** [01:04:57] I think it's helpful to have those lists, that list of symptoms. But I think we still don't know enough about PMDD to be that prescriptive so there may be other symptoms. For instance, a lot of women report impulse, high impulsivity, so impulsive behavior and irrational behavior. And I don't think that is listed as a symptom? We have people who have [pause] tinnitus issues. And issues with... what is it?? Misanphonia?. So high noise sensitivity. And again, I don't think that is on the diagnostic list, but it seems to be prevalent among the PMDD community. So I think it's a good starting point. But we need we need to understand more about that, about the aetiology and about the symptoms.

**Reference 12 - 1.70% Coverage**

**Interviewer:** [01:06:14] Thanks. So last one. How do you feel about this conversation? Has it made you feel or think any differently than you did before?

**Emma:** [01:06:23] I've really enjoyed it. So thank you. You've asked some really thought provoking questions, and I'm surprised that. I've struggled quite a lot to articulate what I thought I knew, which is really weird considering, um, presenting on this... So, yeah, it was challenging to actually think about opinions and what I think about things. So that's a lot of food for thought. And I'm super curious to read your paper and see what the themes are that. Come out.

[01:07:10] You and me both! [laugh]

**<Files\\P05\_P06\_Faith\_Gemma> - § 20 references coded [18.82% Coverage]**

**Reference 1 - 0.46% Coverage**

So first of all, growing up. How did your family talk about Periods.

**Faith:** [00:00:30] When I first came on, my mom said. (Actually, this looks horrifying that she said) "that this means that if you have sex, you'll get pregnant". And that's the only conversation we ever had [laugh].

**Interviewer:** [00:00:37] Oof! [laugh]

**Faith:** [00:00:42] Everything else. I think I learnt from school and through conversations with my friends.

**Reference 2 - 0.18% Coverage**

But then after a while, they were like "this is happening every month. Are you sure you're not on your period?" And I'm like "I don't know, I don't think so" [child's voice].

**Reference 3 - 0.40% Coverage**

**Gemma:** [00:03:58] And for me. Yeah. The first period was fine. Didn't even know... I was shocked a little because 'Oh my god, there's blood'. And I don't think I was aware. I don't think I knew about periods before I had one. I heard other people speak about it so I knew it Happened... but it still came as a shock. but I had no pain and the first one it was a complete surprise.

**Reference 4 - 0.20% Coverage**

But that's the cycle and I know it. So I'm kind of. It's really weird. I kind of look forward to it because I know, OK, this is gonna happen. This is gonna happen. And then you're gonna be okay.

**Reference 5 - 0.46% Coverage**

**Interviewer:** [00:09:44] Yeah. So you wouldn't get more drunk or anything. It was just the hangover?

**Faith:** [00:09:47] Yeah. And I guess I thought it was that and I used to tell everyone 'Oh it's the oxygen!' [laughter]. I was tryin' to figure out like, what was it? [laugh] But then I realized that my period would always come next. Straight after... So, it was that.

**Interviewer:** [00:10:01] That's quite common.

**Faith:** [00:10:02] Really?

**Reference 6 - 1.32% Coverage**

**Interviewer:** [00:12:42] [Turns to Faith] And just because you told me before this interview that you work three days a week, do you think that's partly because of your period pain, that it's like you... prefer part time?

**Faith:** [00:12:52] Um I would definitely say, I feel a lot more um... What's the word? It's not really active but I feel a lot more... Um, like I'm living... like I'm able to like manage life a lot better now.

**Gemma:** [00:13:05] That's good...

**Faith:** [00:13:06] So it's not the reason why I stopped. Well, why I cut down, but it is um... just because I know how my body works and I haven't quite... I'm allergic to like different things that now i'm Better able to try and um balance life. A lot better.

**Gemma:** [00:13:22] That's good...

**Faith:** [00:13:22] But funny enough, since I went to three days [at work], I haven't had my Periods, so...

**Interviewer:** [00:13:27] You don't know yet?

**Faith:** [00:13:28] Yeah. So I had an injection. I don't really know the name for it...

**Interviewer:** [00:13:33] The Depo Provera?

**Faith:** [00:13:34] Yeah! I had that in July. And my period was supposed to come back in October . so it is something I'm a bit worried about... but It hasn't come back yet. So since July I haven't had a period.

**Reference 7 - 0.48% Coverage**

But how would you describe Periods to a child, or to somebody who just didn't know about them?

**Faith:** [00:15:42] {Pause] Ok. I'm tryin' to think... What would I start with? I think I'll start with... [long pause] Ok. Yeah, I think I'll start with puberty. So, I'd say men and women or boys and girls go through puberty when they're becoming men and women and for girls. We begin to... Ach, how do I explain ovulation, 'cos that's a strange kind of concept...?

**Reference 8 - 0.32% Coverage**

So you may experience pain. You may not experience pain, but whichever... whatever way you experience it, it's okay, because I think a lot of that... as a child, you're scared. So it would be more so around re-assurance, because to be honest, I don't really understand Periods myself, which... and I'm 28.

**Reference 9 - 0.66% Coverage**

What's your understanding of why Periods occur?

**Faith:** [00:21:29] Um. Theeeee preparation for childbirth. So the egg fertilised or whatever or expecting to be fertilised and then it's not... [pause] and released? [laugh]

**Interviewer:** [00:21:39] And Gemma?

**Gemma:** [00:21:39] Preparation for childbirth is the only thing I was told, the only thing I know. Still don't understand, Fully. Honestly, it's really weird but I just don't. But yeah, your body is preparing to have a baby and it's not having a baby. so you bleed. And that's why when you're on... when you're pregnant. For the most part, you don't get your period... so.

**Reference 10 - 0.79% Coverage**

**Interviewer:** [00:30:44] That's actually extremely common!

**Gemma:** [00:30:45] Is it really common?

**Interviewer:** [00:30:48] Yeah, No. So, constipation before then. Diarrhoea when you start...

**Gemma:** [00:30:52] Yeahhh

**Interviewer:** [00:30:52] bleeding... very very common,

**Gemma:** [00:30:52] Really?

**Interviewer:** [00:30:52] maybe the most common

**Gemma:** [00:30:52] Gosh!

**Interviewer:** [00:30:52] experience.... Maybe the most common.

**Gemma:** [00:30:55] It makes me feel better that it's common! {laugh] Yeah. So. Yeah.

**Interviewer:** [00:31:01] And please just say, anything, I don't have any like. 'low bar' for topics [laugh].

**Gemma:** [00:31:03] OK. OK. Good, good, good good. Yeah. It's A lot of that. A lot of diarrhoea [laugh]

**Reference 11 - 0.69% Coverage**

can you remember when you first knew about p.\_m.\_s as a thing?

**Faith:** [00:31:23] [Pause] It definitely wouldn't have been when I got my period first. I think it would have been down the line. I don't think we ever spoke about symptoms when we were... like in secondary school?

**Gemma:** [00:31:30] No, definitely not.

**Faith:** [00:31:33] So, I can't remember when but i know it was significantly after my Period.

**Interviewer:** [00:31:38] So like maybe when you were a teenager..?

**Faith:** [00:31:40] Yeah, I don't even know where... I guess it was... I think it would have even been something informal like through conversation? how did I find out about it?

**Reference 12 - 0.98% Coverage**

**Interviewer:** [00:33:36] Okay. So a bit like we talked about Periods. How would you describe p.\_m.\_s to someone who had never heard of it?

**Faith:** [00:33:45] Um, d'you know... for me... I would highlight mental health. Cause mine is really bad. During... Like... so. I think I'd start lightly like things like your emotions may be.... Your emotions may be um a lot more um apparent than usual. Than you're used to... you might be a lot more reactive, but you might go through depression and anxiety and just feel really Low. And not be able to put a finger on why. And even when you can get a finger on why, you can't get yourself out of that. And when you find it's happening regularly, it could be part of the symptoms... and then the more physical things like cravings and... Dehydration and so on and so forth. And as for why I wouldn't know how to explain why [whispering] I've never actually been told why our bodies go through that...

**Reference 13 - 2.82% Coverage**

How common do you think PMS is?

**Faith:** [00:35:30] Ooh. I'd assumed... now that you're askin'... [laugh].

**Interviewer:** [00:35:31] It's not a trick! I just want to hear you to respond...

**Faith:** [00:35:34] Yeah. I assumed it was everyone, but now I'm thinkin' maybe it's not?

**Gemma:** [00:35:38] I actually don't think it's for everyone. Yeah, I think it's I think maybe it is for everyone. Yeah, but different... Because I think for me personally. My brother 'cos he lives with me. He knew I was on my period. My friends don't like. I've never heard it in my life. I think that... It doesn't affect... I can kind of control it. Like I cry a lot more. But again, those are moments when I'm by myself watchin' telly. Those are very alone moments, I think... And in the moments my friends have said it to me... like they pass a comment, I haven't been on my period, I've just been snappy that day.[laugh] So I feel like with me. Unless you live with me, unless you're very, very close to me, you probably wouldn't know. Whereas with other people because they're less able... because they experience it more, you would know? So maybe not everyone feels it. Or maybe people feel it. Maybe everyone experiences it but at different levels? What do you think?

**Faith:** [00:36:29] In terms of like. Does everyone get it?

**Gemma:** [00:36:36] [Audible sigh- exhalation] That's a tricky one. I don't know. I was thinking like maybe everyone does. But then at varied... like it ranges. So maybe you... maybe everyone gets it, but it's like so... {interrupted] like such a small thing.

**Faith:** [00:36:46] Someone might just be craving ice cream or something, whereas someone might be going through emotional... [quietly interrupting]

**Gemma:** [00:36:46] But I think everyone... I think. I don't know. I would assume that most people do. Is there an answer to that question? Cos I'm actually intrigued?

**Faith:** [00:36:57] Yeah.

**Interviewer:** [00:36:59] Well, interestingly, it's a very difficult one to measure.

**Gemma:** [00:37:03] Yes.

**Interviewer:** [00:37:05] Because it's not always the same time in the cycle for different people and it's different things. And also it's how you define pms and that's like, is it just the severe things? Or is it like the normal things? So actually it's kind of an impossible question.

**Gemma:** [00:37:19] Yeah

**Interviewer:** [00:37:20] But what's interesting is how different people will say very different... Things. like. Some people think everyone. Some people think very few. Some people are more specific like, well. Nearly everyone gets it, but it's nothing.

**Gemma:** [00:37:35] Yeah

**Interviewer:** [00:37:35] So, yeah, it's just to compare what people think..

**Reference 14 - 0.28% Coverage**

Um what is your understanding of why Premenstrual symptoms occur?

**Faith:** [00:38:02] Yeaah... I generally. I assume it's related to hormones, but. I don't know why. Those hormones react in that way or... Do certain things for some people, and not for other people.

**Reference 15 - 0.54% Coverage**

**Gemma:** [00:42:49] And I think it's nice now because we understand it so that when we have younger cousins and stuff and they come to us, we're like "Oh, my gosh, poor baby" Like We understand. Um because we... we don't have this whole... Even though we were treated that way, we don't have the approach of " get on with it!"... {overlapping]

**Faith:** [00:43:03] We don't...

**Gemma:** [00:43:03] Especially because of Faith, like because of her experiences of her sharing them so openly with me. I take it much more serious.

**Reference 16 - 3.75% Coverage**

So then I had that... um keyhole surgery and that's when they found fibroids. But they hadn't made me aware... so like. Two years later, I'm having the same sort of pains. So I go back to the doctor and then you go through the whole referral process again. You know, it's like you wait months. for just. The blood tests and then another few months for the scan. so eventually it came back that I had fibroids, but because... I can't remember how old I was, but I was early 20s. So he was olike "you've already had surgery around that area. So it's too much trauma before childbirth to remove the... Fibroids, because you've already had the keyhole surgery", so he recommended that I don't do... anything about them and just stay with the fibroids, but now they've ended up growing. So in September, I had... So. this year they've been like really bad so I guess that's because they were growing. So this year I've had like a lot of hospital and doctors appointments. And in September, a gynae... he literally just stuck two fingers up me. and he was like, "You have to have to get them removed, you have to have myomectomy because like, the size that they are at now... um, fertility will be.... Um, near impossible, sort of thing." Because there's... the one inside my womb is six centimeters or on top is like nine centimetres. So he was like "the size that they are at like you can't even..."

**Interviewer:** [00:53:23] It's a risk...

**Faith:** [00:53:23] If I lie down then my belly is like that [indicates pregnancy-like bump], like they are very prominent now, and I can't lie... it's like literally like having a pregnancy because I can't lie on my stomach, and I can't lie on my back because then it. It's like the way it goes onto whatever's underneath it sort of thing... So then it makes me feel gassy and I can't breathe. So just through all of that I've now had the myomectomy um scheduled..

**Gemma:** [00:53:43] Do you know when it is?

**Faith:** [00:53:48] It was meant to be around April, but. I I wasn't... I don't know if you guys remember from the forum [a speaking event at which Interviewer had spoken about fibroids] when I was sayin' that i want to get a second opinion. So I asked for referral to Professor X [London fibroids expert surgeon] who is like the fibroid specialist. And that's going to be in January.

**Gemma:** [00:54:01] Amazing!

**Faith:** [00:54:03] But then it ended up being like there was no point because... after the forum, everyone was pretty much like "You're gonna end up having them out... anyway ['anyway' said in unison with Gemma]". So I'm just delaying the inevitable. But I still want to see him...

**Gemma:** [00:54:13] Yeah still see him and see what he says - he is the specialist.

**Interviewer:** [00:54:17] Can I just ask you. Um when you switched from Yasmin to depo, was that because of the fibroids? Did somebody say that would be a good idea?

**Faith:** [00:54:23] No, actually, that was because I was er having sex. I haven't really had like. Consistent sex. So that's when I started having consistent sex. And then we had um Not used a condom once, and I got really panicky so I literally took the Yasmin... like this is really bad, but I took the Yasmin pill. I took the morning after pill and I was like I'm going to take... I want something more like concrete because what if I forget to take the pill or something so Let me get um... I actually went to get the implant.but she was like "You've got fibroids, right? Why don't you try this?" Because apparently it could have an effect on kind of reducing the size...

**Interviewer:** [00:54:57] Yeah

**Reference 17 - 1.54% Coverage**

**Interviewer:** [00:59:41] No, It's not good... Um, Do you think doctors have enough knowledge or training [laughter] menstrual cycle related... [interruption] symptoms?

**Gemma:** [00:59:49] Nope! [laughter]

**Faith:** [00:59:50] Funnily enough, there's been a couple of times when I've been to my doctor and she's like.. and not even just her, like a couple of doctors like, just like, they'll just like Google something. Or be like "Oh yeah. Must be that" Or Look up, they have this doctor's book. and she'll be like ok let me look for this or I'll say um, I went to this clinic, or this place, and they said to check out this and ensure that... And she'll look it up like she's never heard of what it is....

**Gemma:** [01:00:11] What?! [whispered]

**Faith:** [01:00:12] So she'll just go to the book and go "OK. The textbook does this... says this so this should be our approach" Like you said, I empathize because they have to know about everything. But um it would be nice to... Have at least like. Just one person. Per practice [laugh] who knows. OK. This is the person in our practice who will know about fibroids or will know about all of these um chronic hidden illnesses or that sort of thing, because like you just mentioned before, I feel like now the situation, that I'm in, possibly could have been avoidable. So, yeah, it's unfortunate...[whispered last words]

**Gemma:** [01:00:48] No.

**Interviewer:** [01:00:48] Anything to add to that? [laugh]

**Gemma:** [01:00:48] Just no.

**Reference 18 - 0.95% Coverage**

**Interviewer:** [01:02:59] Ok, so i'll start with you then, Faith. Do you track your menstrual cycle related symptoms?

**Faith:** [01:03:05] No, I should. But I had um... I had found that sometimes my periods will come every two weeks, every four weeks, every three weeks. So it wasn't until you kind of told us at your forum [fibroids talk], I thought there's no point tracking it if it's all... It's always gonna come when it pleases sort of thing. but Then at the forum I learned that it's normal for it to have different... [pause] Schedules,[laugh] I guess, but yeah. So because of that, I hadn't and since the forum, I still have been on the injection so... [not bleeding].

**Interviewer:** [01:03:36] Yeah. And Gemma, do you track your symptoms?

**Gemma:** [01:03:42] Yes, on that... Period tracker.

**Interviewer:** [01:03:48] Do you find that useful?

**Interviewer:** [01:03:49] Very useful, very, very useful.

**Reference 19 - 1.11% Coverage**

So in your understanding, roughly how many Premenstrual symptoms might there be?

**Faith:** [01:04:09] Well. Um. [pause] So i'd say... emotional, mental, physical... [pause] Can I do it like that?

**Interviewer:** [01:04:21] Yeah yeah

**Faith:** [01:04:21] So, I'd say emotional, mental, physical. Yeah. So physical is like the cravings and stuff and dehydration. emotional. Just being emotional. and then mental, when you're feeling low and sort of subtle things...

**Gemma:** [01:04:40] I was actually going to just say three. Yeah. And I'd say emotional, mental and food like that's all I'd say.

**Interviewer:** [01:04:49] That's great. Thanks.

**Gemma:** [01:04:49] Also emotional. Physical and food. That's probably what I would say.

**Faith:** [01:04:57] How many are there [whisper] [laughter]

**Interviewer:** [01:04:57] So some people say like 200...

**Gemma:** [01:05:00] Really? [loud]

**Interviewer:** [01:05:02] But it's really interesting for me to see who says what.

**Gemma:** [01:05:04] OK.

**Interviewer:** [01:05:05] so I really liked your response! [gentle laugh]

**Reference 20 - 0.90% Coverage**

Like Sometimes like getting period pains before like getting like some sort of like pain or feeling like "Oh, am I on my period yet?" and not even just the pain like sometimes I feel like I'm... let me go and check my pants because I feel like my period might have started... But I don't know, maybe that might be common. Like having the physical pain and I don't know if it's moisture... or I don't know what to call it? Before the...

**Interviewer:** [01:06:40] Yeah the sensation of the discharge or the flow. but there's nothing there

**Both F&G:** [01:06:44] Yeah!

**Gemma:** [01:06:44] I definitely get that

**Interviewer:** [01:06:44] Phantom discharge!

**Faith:** [01:06:48] That's it! [laughter]

**Interviewer:** [01:06:50] That's what it should be called...

**Faith:** [01:06:50] It's got a real ring to it! [laughter]

**Gemma:** [01:06:50] That makes sense.

**<Files\\P07\_Helen> - § 22 references coded [28.30% Coverage]**

**Reference 1 - 0.48% Coverage**

**Interviewer:** [00:01:02] Right. So growing up, how did your family talk about Periods?

**Helen:** [00:01:09] I will be honest. I don't think they did.[laughter] I don't think we did. I don't think it was really explained to me until the day I got it. Maybe? I feel like my education was based on what I learned in school. Not... not in the home.

**Reference 2 - 1.17% Coverage**

And can you remember what your first period was like?

**Helen:** [00:02:45] Um.... Yeees, I remember being at my aunt's house. This is so gross. It's So much information. But I remember I think I had a yeast infection right before that. So It was like a double whammy of like "what is happening" [put on high pitched confused voice], you know, "to my body!" [gentle laugh]. But I remember being in my aunt's house using the bath... I remember the bathroom. I was there. I remember all of it, like just that [emphasised] moment. But it was very like, you know, I told my mom and my Aunt and they were, like, "oh, you got your Period". Like, I don't remember it being like a big... like it was celebrated in a small way. I think I got a box of candy or something? [laughter] But again, it's like thirty years ago, I can't remember! [laugh].

**Reference 3 - 1.18% Coverage**

**Interviewer:** [00:05:53] Thanks. And did you do anything special or have to refrain from doing anything around your period?

**Helen:** [00:06:02] Like as an adolescent?

**Interviewer:** [00:06:04] Yeah... so some people wouldn't swim or they wouldn't drink alcohol or people, have had quite a range of things that they don't do.

**Helen:** [00:06:16] Well, gosh, let's see. I'm about... I'm gonna say no. I don't think I really did... not until I realized like we... got a formal diagnosis of PMDD and really understood what it was. Did I try kind of controlling the situation... But growing up, you know, as an adolescent through my 20s. not knowing that I had PMDD. I don't... Nothing was really done to... other than trying birth control and anti-depressants. As far as treatment. But I didn't change any lifestyle behaviours to minimize it.

**Reference 4 - 0.77% Coverage**

**Interviewer:** [00:09:18] How would you describe Periods to a child or to someone who didn't know what they were?

**Helen:** [00:09:26] Oh, God.[still wiping eyes and laughter] That's a really good question. Since I have an eight year old daughter [laughter] I think about this all the time. I'm like "when do I start talking about this?" Um... So. How do I describe a period? Your body gets ready to... I don't know, this one is really uncomfortable. [laugh] I don't know! [laugh] My god! I'm failing at my job. [still wiping eyes but smiling]

**Reference 5 - 1.53% Coverage**

**Helen:** [00:10:46] [Laughing] but who gets to read this report?! "Activists don't know how to explain Periods to their own children" [Laughter].

**Interviewer:** [00:10:55] Yeah. Like if I was a tabloid writer. Yeah, That would be right... But don't worry about it. And I have er several nieces. And so far, I haven't been allowed to give them the talk. even though I'm like bursting, to. But I think I would get very technical. I think that would be my issue is I would go straight to like the science. And really, they don't need all of that.

**Helen:** [00:11:21] I think that's what it would be... I think because it crosses the line of, you know, being a parent, you do it on the fly. Most of the time, you know, we're just learning as we go and then talking to a... someone else in the field or someone else that's a peer. Like talking to a peer is highly different than like how do I explain this to a child that's age appropriate, you know, when it was never one explained to me. Age appropriately. There is a need for a class for moms to explain this to their daughter! [laughter]

**Reference 6 - 0.47% Coverage**

So a place for the egg to go. So at the time when you release the egg if it's not fertilized, then your body says, "well, I don't need this lining" and it sheds it out into a menstrual period and if it is fertilized, the egg, will, ideally attach to the uterus lining and stay there for nine to 10 months until it's ready to come out.

**Reference 7 - 1.09% Coverage**

**Interviewer:** [00:21:10] How did you manage your symptoms?

**Helen:** [00:21:12] Poorly! [Laughter] it started on and off over you know, 20 years, 21. Let's say I'm 40 now. I had them out when I was thirty five minus twelve, so... wow Twenty three years of Periods. You know, we did everything from birth con... um oral contraceptives, IUD, anti-depressants, anxiety medication, hypnosis. Acupuncture, dietary changes... [pause] What else? And then, I never did get to do Luperon, but I had an oophorectomy and hysterectomy... [Long pause] Oh, I was even put on... So, also um mood stabilizers I tried, as well. And those... those... nothing worked- it either made me worse or did not work long term. [pause] I enjoyed the acupuncture, though, very much. That I will say...

**Reference 8 - 0.44% Coverage**

[00:22:39] Seriously. As somebody who is like, I tend to run a little high anxiety... when I go for acupuncture, she puts that needle in and I'm like, you just feel everything like melt away. And I use it for back pain, for insomnia, for anxiety. Like, it's wonderful. Go, go! The first chance you get [laugh].

**Reference 9 - 1.83% Coverage**

**Interviewer:** [00:25:22] Um, So this question... obviously you have. So have you ever consulted a doctor about your experiences? Really this is about how did you feel? How seriously do you feel you were taken from when you first started seeing doctors about this?

**Helen:** [00:25:40] Ergh [shaking head] Just the answer, transverses many peaks and valleys.[Laugh] Just, you know, some did and some... most didn't. Most. I mean, I was told 'this is all in your head you've got...' I was told I had cystic ovaries... like just I mean, I was never given like a consistent, straight thing outside of "Go home, take a midol. Go shopping. You'll feel better", you know, until. I met a gynaecologist who actually diagnosed me with PMDD. And I had never heard of it. You know, I just was like, I feel terrible before my period. I feel so depressed. And she's like, have you ever heard of PMDD? I'm like, "Oh no...", I feel like that started it. But even after that diagnosis, even after finally being believed, I still had doctors being like, oh, like throughout the diagnosis, " Oh no no, you know, you're you're bipolar" or, you know, like just I got painted with every brush by varied Professionals. It just stinks [shakes head]. And I know that's true for so many. Like my experience is very similar to a lot.

**Reference 10 - 0.87% Coverage**

**Interviewer:** [00:26:50] And did any of them before your PMDD diagnosis. Ask you to track your symptoms to actually see whether it was cyclical or not?

**Helen:** [00:26:59] Never. never once, not even after I was diagnosed. Was I ever asked to track my cycle. That was something I took upon myself after connecting with others with the disorder and... and learning more on my own independently. yeah.

**Interviewer:** [00:27:19] OK. So do you think doctors have enough knowledge or training on menstrual cycle related symptoms?

**Helen:** [00:27:28] I believe progress has been made for sure, but there's a long way to go.

**Reference 11 - 0.55% Coverage**

Unfortunately, you know, while research has some good leads. We don't know why there is a difference in those with PMDD. We generally see everyone has the same level of hormones with and without PMDD. There's, you know, everyone pretty much has the same level of hormones. But there is something in the brain that is responding in a very different way to those hormones in those with PMDD.

**Reference 12 - 0.89% Coverage**

**Interviewer:** [00:31:15] This question was originally. Do do... did you track your menstrual cycle related symptoms?

**Helen:** [00:31:23] Yes. Once I became aware of PMDD and that I was... most likely had it. I started tracking all the time.

**Interviewer:** [00:31:32] And so you could see a clear Premenstrual pattern to your symptoms?

**Helen:** [00:31:35] Absolutely. I could see it on paper. I could feel it in my body. I remember like two to three days after my Periods started and I'd be singing in the car. I just felt like this huge weight had lifted from inside of me. And then it was right there as well on my my tracking.

**Reference 13 - 0.67% Coverage**

**Helen:** [00:32:16] OK. Yes. So p.\_m.\_s. Oh gosh, I think there are 100, 200 some recorded. But you know, being that anything can be premenstrually exacerbated. It's so... you know and I think this leads back to what you were saying about there's not a good definition of p.\_m.\_s unfortunately. You can't like... P MDD. We have a very clear diagnostic criteria that must be met to define it whereas PMS. It's like everything's p.\_m.\_s and everything is not p.\_m.\_s, you know?

**Reference 14 - 1.71% Coverage**

**Helen:** [00:35:47] Yeah, no, I wouldn't say I got any of those things. I mean, every now and then I get a migraine or something. But I wouldn't say it was like a consistent enough thing to call it PMS thing like a p.\_m.\_s symptom in itself. It would be like just an occurrence. You know, the things that were consistent were the more emotional socio you know, the psychological, emotional symptoms I was experiencing and the cramping and the bloating. Those were my constant. So it's hard, but it is hard to say. It's like what is being... what is a Premenstrual exacerbation? See it's like I would file PME under p.\_m.\_s almost, you know? Because you can't really say, oh, sorry. I'm not. I was just going...

**Interviewer:** [00:36:27] [overlapping] This is just what I am trying to get at... these slight kind of tensions, for want of a better word. It's like what's in and what's out?

**Helen:** [00:36:38] Yeah, I think if something exists in the absence of a period like if we stopped your menstrual cycle and the condition is still present, even if symptoms aren't as severe, it is not a Premenstrual symptom. It's not a Premenstrual p.\_m.\_s. It couldn't qualify, but the exacerbation of it. Yes. Would qualify.

**Reference 15 - 0.82% Coverage**

**Interviewer:** [00:37:40] Can I ask about the cramps, obviously were they severe the whole time? You know, from adolescence?

**Helen:** [00:37:49] No, I feel like it definitely got worse. They were I mean, they were bad like I remember as a bartender and I lost my job because. I couldn't leave the walk in cooler. I was just absolutely debilitated and doubled over in pain. And it's like, how do you explain that? But I don't. I can't remember. If it was like ovulation straight through. I think it was just a day here and there that it would happen. But I mean, it's difficult to...

**Reference 16 - 0.82% Coverage**

**Interviewer:** [00:39:16] You can't always tell if you've got fibroids from like, heavy bleeding and severe pain. So I think that's something I'd quite like to look into after this

**Helen:** [00:39:25] Oh, my gosh... Please do! That's interesting to hear. Again, it's like even even six, seven years doing the work. I do, I'm like, I don't even hear this because you're just hearing pieces of people's experiences. You don't get to always sit down and have a conversation like this. Tell me about your pain. Tell me about where and when and how and the result. Yeah. So interesting.

**Reference 17 - 4.64% Coverage**

**Interviewer:** [00:44:10] She's... She's really just being very precise in her language. all she's really saying is not that people don't experience severe cyclical symptoms, but that it's not a Premenstrual syndrome because really right from the start it should never. have been called a syndrome.

**Helen:** [00:44:26] Yeah.

**Interviewer:** [00:44:26] Because it implies something that it isn't. And then there's a lot of confusion now because PMDD is a you know, it's in the DSM. It's a mental health sorry, mental health disorder. And so that's controversial because obviously there's a biological it's just a physiological process involved in certain symptoms. So I think what she's really saying is that the term P.M.S is not a good term. And actually, it just isn't. But it's kind of the one that... it's very well known.

**Helen:** [00:45:05] Yeah,.

**Interviewer:** [00:45:07] And it's not as bad as Premenstrual tension, which is the original one, because that was really only talking about the tension bit.

**Helen:** [00:45:15] Right.

**Interviewer:** [00:45:16] Which is just a part of it.

**Helen:** [00:45:20] I know, I think it's hard like people get so caught up on on the... and i'm sure it does matter. I'm really sure it matters. But like you know, people are upset that PMDD is in the DSM, that it's under, you know, a mental as a mental disorder when it's clearly both gynaecologic. I think it's just... it just speaks to the whole separation of the brain from the rest of the body. You know, when it's it's defined as one or the other. But I feel bad. When I see people getting really upset, they're like, I don't have a mental illness. And it's like, don't... you don't have to be ashamed about it. I mean, and I say this as somebody who has like vulnerability hangovers still. And I work, you know, and I do the work I do, but I don't want anyone.. It breaks my heart, my when even when I do it, that people get caught up in labelling themselves. You know what I mean in the label in the label in general. But I get why it's from a clinical standpoint.

**Interviewer:** [00:46:29] Yeah, I know say the stigma all over the place because there's a mental health stigma. So nobody wants to be mad or whatever. And yet it actually doesn't help if you say it's a biological thing or a genetic thing. It's been proven that that's also stigmatized even it's known that let's say you're severe... Severe anxiety or something might be genetic or have a genetic component. It doesn't actually alleviate the stigma.

**Helen:** [00:46:58] I know.

**Interviewer:** [00:47:01] And there's the stigma attached to the menstrual cycle. You're not supposed to talk about it. And all these stereotypes about women being somehow inferior. So you're left with you know, I think it does contribute to this. Damned if you do, damned if you don't.

**Helen:** [00:47:20] Exactly. Yeah.

**Interviewer:** [00:47:22] Because know you're either... So I think that woman who you were talking about who did the TED talk. Well, it's partly because she went with that line as a click bait...

**Helen:** [00:47:34] Right! [laugh] This is the wrong thing to lead on...

**Interviewer:** [00:47:39] That isn't really what she's saying.

**Helen:** [00:47:42] Yeah, I think it came across as invalidating.

**Interviewer:** [00:47:46] Yeah

**Reference 18 - 1.83% Coverage**

**Interviewer:** [00:51:38] So I think we'd got to this question which was did any of your typical symptoms change as you got older, did you notice any changes in what was normal for you?

**Helen:** [00:51:48] Yeah, the severity, the severity and regularity, I would think. And that might have been... the regularity might have been a result of... I was expecting it at that point in my life. But Definitely the symptoms became more and more severe.

**Interviewer:** [00:52:09] So you, you got more regular or less regular?

**Helen:** [00:52:11] I felt more regular. I was able to track it very clearly. The only time in my life I wasn't able to track it was I had a miscarriage between my two children. And then I just I was so off and I just... I was even hospitalized at that time um because, I mean, it was just like a double whammy and I could not track for quite some time after that.[pause] Actually, I take that back. It was only a few months I couldn't track because I got pregnant that December. So I miscarried like in August, September. And then I got pregnant again in December. And I did that [conceived] with tracking. So it was just a few months there. Sorry, total side note, but yeah...

**Interviewer:** [00:52:58] Don't worry, it's hard to remember these things.

**Helen:** [00:53:02] Yeah.

**Reference 19 - 2.42% Coverage**

But after someone's passed away, you diagnose them...

**Interviewer:** [00:55:22] Postmortem?

**Helen:** [00:55:23] Yeah? To try to go and say, oh, "maybe they had PMDD and I see that. And it almost. It's a little scary because, you know, I think the community is looking for... I think has happened with Gia Allemand [US actress who committed suicide in 2013] when she passed away as our organization, it was happening for a while. You know, we worked with them for a while [The Gia Allemand Foundation became IAPMD]. I think there is, you know, almost a... not celebratory, but there's almost this like hope of, oh, we'll get somebody that... "we'll get somebody". Gosh, that's... I'm doing air quotes I dunno if you can see me? I don't know how to explain it. I think there is. I think what I'm getting at is out of desperation of the patients. I think there is a real risk of in order to validate their own diagnosis. And I think even with doctors, because even gynaecologists have the ability to prescribe, you know, anti-anxiety and antidepressant medication, I think there is an absolute you know danger of In addition to mis[diagnosis] and missed diagnosis. You just gotta. There needs to be... one day. We just need a definitive test that isn't based on symptom.... reporting symptoms. Does that make sense? Like we need a blood test. We need a DNA test. We need some type of test that definitively can diagnose p.m.dd. I don't know what it is... based... You know, obviously. But it's so needed because if we just go trying to diagnose everybody based on their retrospective, you know, symptom reporting, we're gonna have a lot of... lot of problems as we've had throughout the history [laugh] of this disorder.

**Reference 20 - 1.50% Coverage**

**Interviewer:** [01:02:30] And just because.... this is an extra question for you, because you had the oophorectomy and hysterectomy. How did you find it immediately after that? And then have you found that now in regards to your mood and how that's been?

**Helen:** [01:02:47] Yeah. You know, immediately after surgery, I think I just felt this huge sense of relief. I was so nervous that it was going to not work, that it was going to be painful... like everything that you're scared about surgery. But I was scared the most. It wouldn't work. And I was doing this huge decision. So when... I remember waking up and for like two weeks, I just felt amazing and I felt so clear headed, like all the incessant chatter in my brain had stopped. It was just all this space. Um, But then after two weeks, I was on no HRT. And I absolutely crash... I don't know if it would've been the same if I was on HRT, but I just crashed. I crashed so hard. It was awful. I felt like everyone was looking at me, expecting me to be normal, like every day, ever since and That wasn't the case.

**Reference 21 - 1.17% Coverage**

**Interviewer:** [01:06:04] And so for you, it did also vary with the concentration of oestrogen?

**Helen:** [01:06:10] Yeah.

**Interviewer:** [01:06:13] Or the way in which you were receiving oestrogen that they had to get that right afterwards...

**Helen:** [01:06:18] Yeah. Yeah. You distilled that very well. So I had no HRT after surgery, which honestly I wouldn't recommend to someone else. I feel like my doctor... as most gynaecologists are like I don't really know what I'm working with here, but I'm gonna believe you. You seem like you know what you're talking about. You know, I've done my research as a gynaecologist. So she gave me the surgery. But even. Post-surgery She was like, "I don't know". You know, she's just like, I don't know. We're just kind of... like I was almost a case study. You know, for her in a way.

**Reference 22 - 1.48% Coverage**

**Helen:** [01:06:49] So I felt really good for a while. And when I stopped feeling good, I would go to her in a panic. And she really had no answers. So then I started kind of a new process of bouncing from doctor to doctor, trying to figure out what to try. And I think that... and this is why I M.P.M.D is working on a surgical menopause program, because, you know, it's the last line treatment option for PMDD. And then we're now put in the bucket of 'all women' who have had oophorectomies, no matter the cause. And then we're all also, again, being treated the same way. So there, you know, I was put on one milligram. I don't know what that translates to in the UK, but it was one milligram of oestrogen gel. And I was like I went from hating myself to hating everyone else. And I wanted to, like, flip a car. I couldn't walk out my front door. It was awful. So I went off of it. But that's what they prescribe 'Most women' post surgery. They give them start them at 1 milligram. Well, as for me, Who is hormone sensitive. That was extremely too high.

**<Files\\P08\_Kathleen> - § 17 references coded [30.21% Coverage]**

**Reference 1 - 1.42% Coverage**

**Interviewer:** [00:00:19] A bit about PMS and then more specifically about your symptoms and how you feel about them. Okay. So growing up, how did your family talk about periods?

**Kathleen:** [00:00:45] My family didn't really talk about periods... Um, from what I can remember... um, certainly not when I was little. I think that... probably um [pause] as I... I think it was probably around even primary school or just around starting secondary school, that um... my mom may have talked to... to me about what might happen or what would happen... at some point. But definitely not until kind of, around nine or ten. I don't remember conversations about periods.

**Reference 2 - 0.52% Coverage**

**Interviewer:** [00:01:28] And what about at school, did you get anything at primary school?

**Kathleen:** [00:01:36] Um... [long pause] I mean, there must be a session, but I don't remember it, to be honest. Um... Yeah. There must have been. Yeah

**Reference 3 - 1.02% Coverage**

**Interviewer:** [00:01:45] Can you remember what your first period was like?

**Kathleen:** [00:01:54] Er... I don't remember what it was like in terms of the look and feel, but I do remember... Er, I did physical... physically feel but I do remember feeling a little bit anxious, you know, er... I didn't quite know what to expect. I think my mom had talked to me. So I knew what to do. So that was fine. Um.. But it was yeah. I think I was feeling a little bit anxious about it.

**Reference 4 - 0.73% Coverage**

**Kathleen:** [00:02:56] [long pause] Um... [pause] So before my Periods, no. But saying that I do tend to get... I don't know how. But I do have a knowing that I'm just about to come on without always seeing any blood. I don't... I don't know what that is, but I just know. And then I'll just put a pad on, and the next morning, it'll be there.

**Reference 5 - 2.62% Coverage**

**Interviewer:** [00:08:40] Just thinking about your experiences there. Did you ever tell anyone at work about this kind of fear of leaking... and...

**Kathleen:** [00:08:48] No... no.

**Interviewer:** [00:08:48] It was just your private anxiety?

**Kathleen:** [00:08:54] Yes, it was... it was terrible, actually. And also, the thing is... like when I knew I had it was fine but for quite a lot of that period, I didn't actually know what was going on. Um... but I was leading quite a very, very busy life at the time. And I just did not take the time to investigate it. So, I was managing it for a while. So no I didn't tell anyone. Um, I had some incidents actually where, you know, you've got those blue chairs at work ? And so one day you know, I bled, and I.. you know I leaked onto the chair. And so I used to... I used to pretty much work very long hours. And so I think when I got up and realized I don't know if there was anyone else in the office, but they weren't on my side. And so I had to kind of discreetly try and find a way to clean the chair... then I had to change, you know, change and er... Yeah. It was really quite... [pause] I think that happened more than once, I think that happened a couple of times.

**Reference 6 - 0.59% Coverage**

And I'm sure there'd be follow-on questions after that! "But what do you mean? Why do you have eggs?" [in child-like voice] [laughter].

**Interviewer:** [00:13:17] Yeah, you might have to talk about sex, but...

**Kathleen:** [00:13:24] Exactly! but yeah, something like that.

**Reference 7 - 0.45% Coverage**

**Interviewer:** [00:13:26] That's very good. Thank you. Um, what's your understanding of why Periods occur?

**Kathleen:** [00:13:42] [pause] Um... [long pause] Periods occur... I should know this better but.. um...

**Reference 8 - 1.58% Coverage**

**Interviewer:** [00:19:30] Great. So in your understanding, how common do you think PMS is?

**Kathleen:** [00:19:48] Er... [long pause] I don't know. I mean, I haven't heard PMS talked about for a while. Um, and I have a lot of very good female friends. We don't talk about it. I can't say that I've ever been around my friends. Definitely not for a very long time where I thought, "oh, you're in a bit of a mood, I wonder if your per.." Ach! It just doesn't enter my mind. It's not something we refer to so I don't know if that's because they're not experiencing it or just that they've learnt to manage it in a way. I'm just kind of... yeah I'm blind, but it's definitely not something that comes up in my conversations sort of thing...

**Reference 9 - 3.01% Coverage**

**Interviewer:** [00:29:51] Yeah. Do you think doctors have enough knowledge and training on menstrual cycle related symptoms?

**Kathleen:** [00:30:02] No, I'm afraid [laugh]. Just my own experience and also from obviously, the group that i run [fibroids support group]. I hear it from women all the time. They're not listened to, or um.. the doctors just don't take the time for them to explain symptoms... and I think I told you about um someone I know who went to the doctor. A female doctor, actually. And was explaining what was happening with her body and thought it might be fibroids and she explained that... And she was having a slightly heavier periods, than she was used to as well. Um, She explained that her mom had had fibroids, both her sisters had fibroids, and it was a bit of a fight just to do... to get the tests. So I'm sure maybe it's fine for some women, but um [pause] Generally, I think there could be a lot more education on that. Um, my doctor, I think for me, my personal experience, my doctor was probably... she was a lot more sensitive because of the test result, because it was, teamed with the anaemia. I don't... I think if I'd just been for Periods, I'm not quite sure what the response would have been.

**Interviewer:** [00:31:18] Yeah, I think that's probably right. I think that's the beauty of being able to do a test for something...

**Kathleen:** [00:31:24] Yeah,.

**Reference 10 - 0.73% Coverage**

**Interviewer:** [00:32:26] Um, have you ever heard of Pmdd, which is Premenstrual dysphoric disorder?

**Kathleen:** [00:32:34] [long pause] I wanna say no. I feel like I probably heard it at one of the workshops at the women's health things [govt task group of which the interviewer and interviewee are both members], but I don't... I don't know.

**Reference 11 - 2.83% Coverage**

**Interviewer:** [00:32:59] OK. So on to the last section. Do you track your menstrual cycle changes?

**Kathleen:** [00:33:08] I do note when I start my period um but that's it, really.

**Interviewer:** [00:33:12] And did you ever track them or it wasn't something you did?

**Kathleen:** [00:33:19] In terms of like the mood changes and that kind of thing?

**Interviewer:** [00:33:27] Yeah, or anything.

**Kathleen:** [00:33:27] [pause] No. I mean, I've always... I've always tracked when I'm on my period, but that's about it. Not... not kind of 'heaviness' although, looking back, I suppose I should have done that more. Yeah.

**Interviewer:** [00:33:45] Would you try and predict when you were maybe due or you just sort of reacted at that... each time?

**Kathleen:** [00:33:53] Yeah, no, I used to, I used to try to predict. I think sometimes. Yeah. Like I said, I used to just be very, very busy and I used to travel quite a bit as well. So I used to try to just to figure out would I be on, when I went away, or that kind of thing. Now not so much. I just I think I just continue to track out of habit, I think it's just good practice. for me to know. But it doesn't mean as much now when I come on, it's just 'I'm on'. And I'm not trying to prepare for anything I don't feel like... yeah. I need to know as much as before.

**Reference 12 - 0.45% Coverage**

**Interviewer:** [00:34:37] So again, just in your understanding, could you have a guess at how many Premenstrual symptoms you think there are? Just roughly?

**Kathleen:** [00:34:53] [long pause] 50? [unsure voice]

**Reference 13 - 1.30% Coverage**

**Interviewer:** [00:37:00] What does the term bloating specifically mean to you?

**Kathleen:** [00:37:03] Um, it's when my stomach just gets much bigger in size and [long pause] Yeah, and that's... There's just a feeling of general heaviness... Yeah, I think I think that... I'm just trying to think if it feels in any other way?

**Interviewer:** [00:37:34] Do you feel like gassy? Or is it more like water retention?

**Kathleen:** [00:37:38] [Pause] Eh.. Mine doesn't feel gassy. but I dunno! It also doesn't feel like water, either. It just feels like there's stuff inside.[laugh] It just feels really heavy.

**Reference 14 - 2.95% Coverage**

**Interviewer:** [00:42:02] Um, are you aware at all of PMS being a kind of controversial diagnosis?

**Kathleen:** [00:42:09] I would... So It's not that I've read anything in particular, but I would think it would be. Er... I get the sense that, you know, it's probably not investigated, researched as much as just other conditions. And because there is you know, and I I.. these stereotypes of women and, you know, going on their period and "Oh don't talk to her, when she's on her period" or you know, actually I have... I have had... Sorry I should have said this before. I have had men ask me, actually, when maybe I've had a disagreement with them and I have had someone say, "Oh, well, you... are you on your Period?" [laughter].

**Interviewer:** [00:43:01] And what did you say?

**Kathleen:** [00:43:04] I said, I'm not answering that question and I can't believe you just said that.

**Interviewer:** [00:43:10] And was this in the workplace?

**Kathleen:** [00:43:12] No, this is personal.

**Interviewer:** [00:43:14] Oh! personal. Oh, god! A brave person, indeed! [laugh] [pause] A few people have said this and there's this stereotype of PMS and sometimes in the workplace. people go "Oh, you know it's her time of the month" And quite often they mean menstruation. So, they don't mean Premenstrual at all, they mean the bleeding.

**Kathleen:** [00:43:41] That's right.

**Reference 15 - 1.58% Coverage**

**Interviewer:** [00:46:03] So slightly relating to that. Would you consider PMS to be an illness?

**Kathleen:** [00:46:15] Nooo. Um, I dunno actually. Let me think about that.[Very long pause- 19 s] Um I think it just depends on. How it is presenting itself in women, I think. Does that make sense? Like... Yeah, I think if someone's experiencing very extreme symptoms. As a result of their Period. Then there's definitely some... you know, it's a condition. I don't know what the term would be? Um and then maybe it wouldn't be called an illness but I'd want it to be recognized properly. Um, I wouldn't want to say it's not an illness just because I don't suffer it in the same way [laugh]. So um yeah, I dunno if that's a yes or a no.

**Reference 16 - 1.79% Coverage**

**Kathleen:** [00:48:46] [long pause] Yeah, I mean, I think it's been good to talk about what's happening in my own body 'cos I haven't really talked about it, I've just processed it in my own mind. You know, I think about my own symptoms. Um, what was really helpful actually... because you... after your talk [interviewer's presentation at fibroids support group] I've thought a lot about how I view Periods and the shame aspect of it. You know? Yeah. You know what... I've been thinking about what if someone sees the blood then why is it such a big deal? When it is a natural part of... So, I'm still thinking through that. And just talking today as well.. Has made me um Think about just owning the experience or feeling ok in our bodies and kind of naturally owning that a bit more but I don;t know what that would look like? For me.

**Reference 17 - 6.63% Coverage**

So I saw the doctor a little, two weeks ago. And I talked to him about it. And he was very... [pause] He didn't really understand my worries. He was very professional. And what was good was that he knew a lot about fibroids, which is very rare. So I was quite happy about that. But he was he was very, very kind of like "Oh, don't worry!" [paternal tone]. you know "Now now!", you know,.

**Interviewer:** [00:55:05] Yeah, like it's an inconsequential thing to be worrying about. But it isn't...

**Kathleen:** [00:55:10] He was trying to be sympathetic yeah. But he. Yes. I think he's trying to be sympathetic, but he er.. I don't know if he understood just how worried I was... And I've seen another doctor previously, a lady doctor, and she's the one who sent me for the tests. And she's very sympathetic. I don't know if that's because she's a woman or because she's experienced it herself. I don't know. But it was... I just... I just loved it because I went in and I just explained what was happening. I explained my previous history. And before I knew it, she got out her pen and said, "OK. I'll send you for this, I'll send you for that". It was all very straightforward. There weren't any questions, you know, or... she just believed what I said. and it was really good. So it was interesting. And again i dunno if it's a gender thing because there's so many things at play, isn't it? This male doctor knew lots about fibroids, he's drawing pictures and doing lots of explanations to me but um he was... he was a little bit about kind of "Don't worry. Oh, you'll be fine. It will be okay". And, you know, and I realized the other day that he sent me for a scan, but he put it as a normal scan. But in my mind, I was like "that should have been urgent because I need to know as soon as possible!". You know, so it's that kind of thing. And so obviously, it takes a lot longer to get the non-urgent scan. So, yeah, that was an interesting experience. But I didn't I'm not... to be honest, the only I would have been very critical of him had he not, because I went there prepared because of all the knowledge I have about fibroids. I'm just not going to take any nonsense. So in one sense I was happy that he knew all the lingo and understood it from a medical point of view, but on the other hand. [smiling] He's trying to encourage me, I think. but I don't know he quite grasped how I was feeling about it, especially because I lived through it before so um.. that... I think that would be I don't know what training doctors get on these kind of things, but I think it's just sensitivity to why someone might be more. Anxious about something when they've been through the journey, might help them. I'm not... I might even be being overanxious? Everything might be fine?

**Interviewer:** [00:57:48] No. Well, I mean, I think you should get it checked out just because I think every bleeding shouldn't be... It's not... it's nothing to be sniffed at... Like you don't want to get anaemic again. It's just such a hard road getting the iron levels back up.

**Kathleen:** [00:57:57] Yeah,.

**<Files\\P09\_Aisha> - § 16 references coded [35.71% Coverage]**

**Reference 1 - 1.68% Coverage**

So the first question is growing up, how did your family talk about Periods?

**Aisha:** [00:00:33] We never spoke about it at all. [emphatic] Literally, I started and that's when we spoke about it.Like you have to do this. End of story. Like erm, Yeah. You have to put your pad on. You have to change it every hour or whatever and. Yeah. And you have to have a bath and shower after you've finished. And. Yeah. And because it is the... obviously, I'm Muslim and when you're on your period you're not allowed to pray. So it was explained you can't pray and et cetera. And that was it. To be fair.

**Reference 2 - 2.29% Coverage**

**Interviewer:** [00:01:03] So you didn't know about them before you started?

**Aisha:** [00:01:05] No, but my mom knew that. It's kind of taught to us in school. So she let them do it.

**Interviewer:** [00:01:13] Uhuh. Yeah, I mean, that's pretty much what everyone's said. Um, can you remember what your first Period was like?

**Aisha:** [00:01:19] Erm, I think like... oh, my gosh, it was.[pause] I think it was a shock, like I was probably havin' symptoms before I started and... you know like as in... er... I don't know. I knew I was gonna.... I didn't know I was gonna start but erm, my first period. It just came. If that makes sense? I hadn't er, can't really remember it, Can I? I just remember I was crying when it... when I started. And that was about it. And it was really heavy. I remember. It usually is.

**Reference 3 - 1.62% Coverage**

**Interviewer:** [00:02:02] And so at school can you remember when you had the lesson, did you have anything at primary?

**Aisha:** [00:02:06] Not in primary... it's more secondary school.

**Interviewer:** [00:02:08] Secondary school. And that was just like a lesson about puberty?

**Aisha:** [00:02:12] Oh sorry... primary school was the lesson, but it was about more about sex education and I don't remember being fully taught about Periods, if that makes sense? We knew it was coming because other people were gettin it, but we wasn't taught a lot about it, if that makes sense?

**Reference 4 - 5.90% Coverage**

And so does your Period affect you at home or at work or socially?

**Aisha:** [00:04:47] Definitely, like my relationships... erm, with my mom and my sisters. Obviously, I go to the extent... my anger goes crazy, so I'm constantly arguing. At work. My manager's actually picked it up like... he'll be like, "Oh, you're so good at your job". Like they love me and they love what I do, too. But that week I go downhill and he's still trying to figure it out and that week I'll have arguments with him for no reason as well. So it's like he's saying "you're amazing. You're amazing". But... suddenly I become a different person, he says.

**Interviewer:** [00:05:19] Uhuh. And have you spoken to him about that it might be to do with your periods...

**Aisha:** [00:05:22] Well, I did tell him "oh I'm PMSing", but he just nods his head like he thinks he knows what PMS is. But I really don't think...

**Interviewer:** [00:05:29] like it's not a serious thing>?

**Aisha:** [00:05:30] Yeah yeah yeah... [pause] He doesn't understand what PMS is, I think.

**Interviewer:** [00:05:39] But at least he's kind of...

**Aisha:** [00:05:40] Or he's got it wrong... [overlapping speech]

**Interviewer:** [00:05:40] ... talking to you and has noticed it... you know, like...

**Aisha:** [00:05:44] But that's because of a long whole crazy.... It had to come to that point, like. [laugh] Because my mental health can be really low and obviously I've had to have a lot of time off and then they were not understanding and constantly telling me off, constantly picking on me. And then I had to go to occupational health... explained it to occupational health. "This is the situation. Blah, blah, blah. He just doesn't understand because they feel it's not a mental health condition". So then from then, my doct... that doctor had to get him in who was just being really nasty and then explain to him that it will go under the Equality Act and he does come under the Equality Act and um etc. And ever since then he's really... trying to understand. So it...

**Interviewer:** [00:06:26] Oh good!

**Aisha:** [00:06:28] Finally.

**Reference 5 - 1.64% Coverage**

So how would you describe Periods to a child or to somebody who, like, doesn't know anything about Periods?

**Aisha:** [00:06:42] Oh my God. I'll like... I'll make them understand that it is something... it is a major [emphasis] thing of your life and it does affect you and definitely to be always tracking your moods, regardless, every single day. And um, also, like, understand, like it's OK. It happens to... like. It won't necessarily... you won't have pain or whatnot. But you know, the mood side of things. I'll explain that to them because we was not explained that at all.

**Reference 6 - 0.78% Coverage**

**Interviewer:** [00:07:15] Uhuh. And what is your understanding of why we get Periods?

**Aisha:** [00:07:17] [pause] I guess it's for.... [pause] um, It's just the way our body kind of... I don't know? [pause] It's like... It's preparing us for birth type of thing, more. I think.

**Reference 7 - 2.54% Coverage**

**Interviewer:** [00:09:28] Thanks. Ok. So we're on to the p.\_m.\_s section. So do you identify as somebody who gets p.\_m.\_s?

**Aisha:** [00:09:33] Definitely, yeah.[long pause]

**Interviewer:** [00:09:40] And can you remember how you first came to know about PMS?

**Aisha:** [00:09:48] Um [exhale] I think it is because I must of tracked.... I don't know. It was a Google search. Definitely. And. "Why do I feel anxiety? Why do I feel this, that" and p.\_m.\_s came to a... It was because I kept... my mood. I kept arguing with my mom and I get so angry suddenly and I was just googling it. And then I went to my doctor and I'd kind of calculated. Yeah, I do have PMS. At first it was like a week before I noticed it. But then when it came... a consequence of when it was 14 days before, and then I realized you can PMS for 14 days beforehand as well. That's... with me. As soon as it's 14 days, I start PMSing.

**Reference 8 - 1.56% Coverage**

**Interviewer:** [00:11:22] OK. Again, this is just your understanding. What's your understanding of why these symptoms occur?

**Aisha:** [00:11:35] I do feel it's hormone imbalance... and why it occurs... erm. [pause] I feel as if maybe, I dunno... people... People say to me, it's food, but I don't believe it's that. Because even when... when I eat healthy, I believe I p.\_m.\_s more. So not necessarily that. Yeah, I just feel as if it's a hormone imbalance. That's it. Yeah. [long pause] Something's happening in the body that we don't know, basically.

**Reference 9 - 3.85% Coverage**

**Interviewer:** [00:12:48] So the 'staying out of people's faces'. So while you are PMSing, you know that you are?

**Aisha:** [00:12:54] Yes.

**Interviewer:** [00:12:54] So you are able to like step away a little bit?

**Aisha:** [00:12:57] I never used to be able to. It's taken a lot of years to come... to do that. For example, to certain people... like my household people, I won't be able to stand them, so I'll go out with my friends.

**Interviewer:** [00:13:07] Yeah

**Aisha:** [00:13:07] So you pick and choose certain people at that time, and you just know.

**Interviewer:** [00:13:16] Yeah. So have you ever talked to a doctor about your p.\_m.\_s?

**Aisha:** [00:13:19] Yeah. I have. But they don't suggest anything for it. I've never got anything for it.... Because I have PCOS as well. If anything, they just suggest the pill, but they don't... That's not necessarily for the p.\_m.\_s.

**Interviewer:** [00:13:40] So you feel like they do think you've got PMS...

**Aisha:** [00:13:41] Yeah...

**Interviewer:** [00:13:42] But they're not offering you any specific treatment.

**Aisha:** [00:13:44] No, no...

**Interviewer:** [00:13:47] And how about for the PCOS? Is that... do you feel like they're...

**Aisha:** [00:13:49] No. There's no treatment for it.

**Interviewer:** [00:13:52] So other than the pill. You haven't been given any other options.

**Aisha:** [00:13:56] No.

**Reference 10 - 0.59% Coverage**

**Interviewer:** [00:13:58] May I ask why you don't want to try the pill?

**Aisha:** [00:14:01] It's because I... I wouldn't.... I'm trying hard to lose weight and I feel as if that will make me increase the weight.

**Reference 11 - 0.96% Coverage**

**Interviewer:** [00:18:02] Right. So do you think doctors have got enough knowledge or training on menstrual cycle symptoms?

**Aisha:** [00:18:10] No [very quietly][laugh] Is that really bad? Sometimes I feel like I'm teaching them and then they call me an 'expert patient' or whatever they call it. I think it's just seen too much as a norm.

**Reference 12 - 1.36% Coverage**

[pause] But then people say apparently getting pregnant really helps with the p.\_m.\_s a lot... a lot... of my friends, that've been pregnant. Apparently that's just balanced it all out.

**Interviewer:** [00:20:14] Yeah. So it can do. So some people don't have PMS and then after they've had kids, they get it. So it can kind of go either way.

**Aisha:** [00:20:22] Oh right.

**Interviewer:** [00:20:23] Yah. It's one of the things that can just.... It's difficult to know why. [pause]

**Reference 13 - 2.90% Coverage**

**Interviewer:** [00:21:24] And have you ever talked to your doctor about maybe having that?

**Aisha:** [00:21:28] Erm I think I mentioned it but again he's just been...[Pause] I've not been diagnosed with that. I've been more diagnosed with borderline personality disorder instead...

**Interviewer:** [00:21:41] Uhuh. And so did you see a psychiatrist for that?

**Aisha:** [00:21:45] Yeah

**Interviewer:** [00:21:45] And did they ask you about p.\_m.\_s?

**Aisha:** [00:21:47] No, no. not at all.

**Interviewer:** [00:21:49] And they didn't ask you to track your symptoms?

**Aisha:** [00:21:50] Not at all.

**Interviewer:** [00:21:51] So that was just based on what you were saying...

**Aisha:** [00:21:53] Yeah

**Interviewer:** [00:21:54] Without thinking about your cycle...

**Aisha:** [00:21:58] So it annoys me to be fair.

**Interviewer:** [00:22:01] Yeah. So are you on any medications for that or is it just you get the diagnosis and that's it?

**Aisha:** [00:22:05] No treatment, nothing.

**Interviewer:** [00:22:06] Hmmm. that's not very good

**Reference 14 - 3.28% Coverage**

**Interviewer:** [00:25:14] Right. So do you track your...

**Aisha:** [00:25:16] Yeah.

**Interviewer:** [00:25:17] Menstrual cycle and symptoms?

**Aisha:** [00:25:18] I do have lazy times when I don't...

**Interviewer:** [00:25:22] Yeah yeah. And how do you do the tracking?

**Aisha:** [00:25:23] On their app.. on the app.

**Interviewer:** [00:25:23] Which app do you use?

**Aisha:** [00:25:27] Um, P-dot tracker something like that. from Apple Store. What about yourself, what do you use?

**Interviewer:** [00:25:34] I don't track anymore. So I did, that's how I worked out that I had cyclical symptoms. I did it on excel! [laugh].

**Aisha:** [00:25:45] Wow. Fancy! Fancy!

**Interviewer:** [00:25:46] Yeah, I'm a geek. Actually, it was before any period apps. This was... er, eleven years ago. But I've downloaded various apps and I've looked at them. But I just find it a bit boring. And I kind of know. I know now.

**Aisha:** [00:25:59] OK. That's good.

**Interviewer:** [00:26:04] But more and more people are using them. And it's very useful for doctors. So like if you have that, you can show ... when you go for your referral, you can say, look, I'm much worse at this time.

**Reference 15 - 4.13% Coverage**

**Interviewer:** [00:29:17] So do you have any other health conditions that get worse at certain times in your menstrual cycle?

**Aisha:** [00:29:23] Do you know, it's not a.... You know what? I forgot I had, you know, my thighs that stretching feeling that you need to constantly stretch i?

**Interviewer:** [00:29:30] Like they're Restless.

**Aisha:** [00:29:34] Yeah. Oh, my God. I forgot to add that! What symptoms get worse? None. Other than the mental health... wellbeing.

**Interviewer:** [00:29:49] Um, just for that restless leg. Magnesium, so.

**Aisha:** [00:29:53] So what can I have with magnesium in it?

**Interviewer:** [00:29:53] So it can be that you're a bit low in magnesium. So I always take magnesium supplements, but I guess it's in foods as well.

**Aisha:** [00:30:02] What foods are high in that?

**Interviewer:** [00:30:03] I dunno, if you Google I think it's nuts... And I think it's like basically healthy foods...

**Aisha:** [00:30:06] But. Oh my God. It's really bad at the moment, I'm just constantly stretching and I'm not starting [bleeding] and it's...

**Interviewer:** [00:30:12] Yeah and when you're trying to go to sleep sometimes it can be worse.

**Aisha:** [00:30:16] Yeah!

**Interviewer:** [00:30:16] So, that's usually a magnesium deficiency. That you can fix...

**Aisha:** [00:30:19] In the blood tests. It's all fine.

**Interviewer:** [00:30:22] Yeah. I don't know whether they test for magnesium, though.

**Aisha:** [00:30:25] I see. I see.

**Reference 16 - 0.66% Coverage**

**Interviewer:** [00:31:21] So have your typical symptoms, have they changed as you've got older or have they been sort of the same? [overlapping]

**Aisha:** [00:31:30] No... it's just that... sort of the same. but I manage it better now.

**<Files\\P10\_Mala> - § 11 references coded [41.81% Coverage]**

**Reference 1 - 2.53% Coverage**

Ok. So first question is growing up, how did your family talk about Periods?

**Mala:** [00:00:14] I think because I'm from an ethnic minority, it wasn't really um... [pause] we didn't really speak about it openly. Well, the male in our family didn't anyway. But the people that I went to, were my aunts and my... my mom, actually, is really good at explaining things. But I initially went to my aunt and then told my mom and my mom sent me to my aunt again. [laugh] So they told me what I needed to do, but I kind of knew what to do because of my educational background. Like when I learnt it in school.

**Reference 2 - 4.35% Coverage**

**Interviewer:** [00:01:03] Um, and what was your first period like? Can you remember?

**Mala:** [00:01:07] Um, my first period was a bit bizarre because... um most of my year group... So, I started in year eight. So I was fort... 13, 14, and most of the girls in my year group had already started. So I felt like I was a bit of a late bloomer. And I was wondering "when I'm going to start?" And when I did start, it wasn't really how I expected it to be because it wasn't like a lot... How you... Like they taught you lots of blood flow... It was more like, should I describe it?

**Interviewer:** [00:01:37] Yeah

**Mala:** [00:01:37] Brown, and it was dry and then nothing happened for the next three months. So I questioned was it even my period or not? And then after three months, then it started comin' regularly.

**Interviewer:** [00:01:47] Aha, mine was the same. It's called spotting, but nobody told me about that...

**Mala:** [00:01:51] Yeah, I never understood. I just thought it was going to be blood and blood and blood that's all...

**Reference 3 - 4.79% Coverage**

**Interviewer:** [00:07:46] So you know it as you're feeling it or do you only know it once you get your period and you're like "Ahhh! that's why I was like that before"?

**Mala:** [00:07:52] Before when... before... before I understood what PMS was. And I looked into it, I just thought, Oh, I'm going to be starting my Period soon. That's probably why I'm acting like that. And then I was curious as to why I was acting like that, because it wasn't normal for me to be just really angry. And next minute I'm happy. And I'm trying to make myself.... make myself understand. I shouldn't be acting like that. It like a continuous battle in my brain. Um, and then when I did look into it, I realized that, OK, that's my p.\_m.\_s. And now henceforth, when I'm when... I am when it's one week before and I'm feeling hungry all the time or cravings, or emotional I know I'm PMSing. So I think is a good way... it's good only because when I do... when I do feel it and I know that I'm PMSing I know how to regulate... I'm trying to regulate my emotions.. Like "Mala, you're PMSing?" So you need to calm down. It's a good way of me regulating my emotions.

**Reference 4 - 1.93% Coverage**

**Interviewer:** [00:09:41] Cool. Again. So how would you describe p.\_m.\_s to somebody who's never heard of it before?

**Mala:** [00:09:46] I would do it how my friend did it. So I would say this is the symptoms that you normally get. Do you ...do you get them? It's a feeling or um... sometimes it's a physical thing that you might get prior to your period or some times you get after your period as well? So, it depends on the person, what they're going through.

**Reference 5 - 3.69% Coverage**

**Interviewer:** [00:10:18] So how common do you think PMS is?

**Mala:** [00:10:22] In.. um amongst women?

**Interviewer:** [00:10:23] Mmm

**Mala:** [00:10:24] I think it's a lot it's very common. It's just I don't feel that people know about it um because... for example, my mom.. um I, she is from the elder generation. She would not know what p.\_m.\_s is, but I can see the symptoms when she's on... just before she's going to start her period. Like she's a bit like me. Like she will just go crazy on the littlest things.Um, so...

**Interviewer:** [00:10:51] So would you say like more than half? Most women?

**Mala:** [00:10:54] Most women, most women.I would think. They just don't... They just don't know, that they are. [pause] And they... just how I used to just feel it. Just get on with life. That's probably how they... 'cos they don't think it's... They think it's just normal.

**Reference 6 - 4.75% Coverage**

**Interviewer:** [00:12:12] So would you stop yourself from saying something? So you're kind of feeling angry and you just know why...

**Mala:** [00:12:18] Sometimes, my brain will be like, okay. Don't say it. Or sometimes I won't even... it's like I don't have control over my body [laugh] and I just say it. And then I'd get the reper... repercussions after. Yeah, but I just feel like maybe people don't understand that you are going through something, so they don't understand... They won't understand. If I was to have a lash out at somebody. They won't understand where I'm coming from because I'm p\_m\_sing. And I'll have to... It's like I have to make an excuse as to why I'm talking like this.

**Interviewer:** [00:12:50] So you wouldn't say to your family....

**Mala:** [00:12:52] So like they would not understand me...

**Interviewer:** [00:12:54] Like leave me alone or...?

**Mala:** [00:12:55] They would not... my family would not understand that... I've got to stop being silly. Get on. Move out my way. Or 'Fix yourself up!'.

**Interviewer:** [00:13:03] OK so you just sort of manage it on your own?

**Mala:** [00:13:04] Yeah.

**Reference 7 - 3.20% Coverage**

**Interviewer:** [00:13:08] Have you ever been to a doctor about your experiences?

**Mala:** [00:13:12] I haven't. No.

**Interviewer:** [00:13:15] Um, so you might not know this one, but do you think doctors have enough knowledge or training on this sort of thing?

**Mala:** [00:13:24] From other people that I've spoken to that have even severe PMS than me... I don't feel like they do. I think they dismiss it as just something got to do with hormones? It is got to do with... or partly because of it. But then what can we... What else can we do? Because some people... some people go through really, really bad stages of p.\_m.\_s where they can't... they can't control themselves at all. So what can they do about it? And there's no really an explanation or help for it?

**Reference 8 - 5.76% Coverage**

**Interviewer:** [00:15:12] OK, that's fine. So do you track your menstrual cycle?

**Mala:** [00:15:19] I do.

**Interviewer:** [00:15:20] Do you track all the different changes you go through or Just sort of when you get the bleeding?

**Mala:** [00:15:24] I just... when...Whenever I get my bleeding.

**Interviewer:** [00:15:27] And how do you track it?

**Mala:** [00:15:28] I've got a period tracker.

**Interviewer:** [00:15:32] Can I ask which one?

**Mala:** [00:15:28] I think it's called period tracker. It's on Samsung, Android... It's the P tracker.

**Interviewer:** [00:15:46] And why do you track that?

[00:15:48] Um, I initially first tracked it because it was a religious thing. Where, I was going to perform um... a pilgrimage. And so I needed to know when... Because when we are on our period we're not allowed to pray um and it... doesn't hinder the whole pilgrimage but certain parts of it. Um, so I wanted to know when I was going to be on my Period so I can... um take precaution beforehand so I can either take the pill to sort my period for that month or maybe book another ticket around my period... Yeah.

**Interviewer:** [00:16:20] And then you've just carried on?

**Mala:** [00:16:22] And then I just carried it on 'cos it's quite good... um, during Ramadan... em, when I know when I'm gonna be on my Period so I can plan my Ramadan properly... yeah, around it.

**Reference 9 - 5.02% Coverage**

**Interviewer:** [00:18:25] Um, so you said before you get bloating. Can you describe specifically what you mean? What does it feel like?

**Mala:** [00:18:37] So my stomach is... So um... what's that word? [long pause] I find it really hard to go to the toilet...

**Interviewer:** [00:18:46] Consitipated? [overlapping slightly]

**Mala:** [00:18:46] Constipated! I'm constipated. My stomach goes really hard and big... and it's just really uncomfortable because... first of all. I feel like it's because I'm not going to the toilet. But then it's like empty air in my stomach because I'm not eating much... yeah, my food intake isn't very high. Prior to it. I mean, during... after my period, when my period starts, my food intake isn't high- it is prior. So I'm eating a lot, but I'm not... unable to go to the toilet. And my stomach is bloated. So, I'm just like, "what is going on?" I need this period to start now [emphasis].

**Interviewer:** [00:19:20] And then, do you get... when your Period starts do you get a little bit of maybe diarrhoea? Like that it kind of releases that as well?.

**Mala:** [00:19:25] Yeah. Yeah,yeah yeah. I do get that as well. But that's only sometimes, not all the time.

**Reference 10 - 3.13% Coverage**

**Interviewer:** [00:21:17] Um, are you aware of p.\_m.\_s being a slightly controversial diagnosis?

**Mala:** [00:21:22] Yeah, well, in terms of what? Controversial?

**Interviewer:** [00:21:26] Well, things like, is it real or not? Or like is it really an illness?

**Mala:** [00:21:29] Yeah, I think in my community... I think it's because we come from... Um, I come from a Asian community. We do dismiss a lot of things, um especially if it's not measured or put down on paper. You can't really say there's an actual diagnosis. So it's seen as an excuse to get out of things.

**Interviewer:** [00:21:49] Right, like a sort of... Yeah. An excuse not to work or to go to school or...?

**Mala:** [00:21:54] Yeah or.... just excuse for the way you're acting.

**Reference 11 - 2.66% Coverage**

**Mala:** [00:22:39] I actually enjoyed this conversation... Um, maybe some of the things I.... like, maybe I can speak to my family more about it. So they are more aware of what p.\_m.\_s actually is. And also, maybe the way I'm feeling like when I'm very irritated it's not really... I can go to the doctors, and actually see what they can say about it because I've never actually been... to see if I could actually get help because it can get really... Hard on yourself at times. Um, yeah.

**Interviewer:** [00:23:16] That's brilliant. Thank you so much.

**Mala:** [00:23:18] No problem! You know, I have never actually spoken about it....

**<Files\\P11\_Noor> - § 12 references coded [43.07% Coverage]**

**Reference 1 - 4.48% Coverage**

**Interviewer:** [00:00:10] Right. Ok. So growing up, how did your family talk about Periods?

**Noor:** [00:00:17] We didn't.

**Interviewer:** [00:00:18] OK and do you sort of know why or...?

**Noor:** [00:00:24] [pause] No idea. It just never came up, if that makes sense? And then it's only in school when you... when your friends actually start.

**Interviewer:** [00:00:32] Yeah.

**Noor:** [00:00:33] The topic came up.

**Interviewer:** [00:00:35] So was it a lesson in school or was it literally your friend [overlapping speech] started?

**Noor:** [00:00:38] No, one of my friends started.

**Interviewer:** [00:00:41] And was that at primary school?

**Noor:** [00:00:43] Primary school yeah?

**Interviewer:** [00:00:58] So one of your friends started and did she know what it was?

**Noor:** [00:01:02] She did, roughly. So she was a bit nervous. And then obviously she told us, and we told the teacher and obviously, I came home

**Reference 2 - 3.57% Coverage**

**Interviewer:** [00:01:13] Yeah. So what was your first Period like?

**Noor:** [00:01:18] So I actually started in year 9, so everyone started and then I was later. So I was aware of it, if that makes sense?

**Interviewer:** [00:01:27] Yeah. And how did you feel? Sort of did you want it to happen at that point?

**Noor:** [00:01:33] I didn't realize like, d'you know, it's one of those things because you don't talk about it, you just know of it, but you don't want it. Does that make sense? So when I started I was like "Oh, okay". And then I show... came home and told my mom. It was... I think it was at home, actually. And I told my mom. And then she just gave me a pad and she was like "whenever you start wear this". That was it.

**Reference 3 - 6.68% Coverage**

**Interviewer:** [00:02:24] So do you do anything special or like not do something around your period just to sort of manage it?

**Noor:** [00:02:32] Do you know what? My body tells me like d'you know obviously you try and do healthy eating etc. But when I... Because I've got the calendar when I know it's three days. If I wanna eat, I just eat whatever and I just do my own thing.

**Interviewer:** [00:02:47] So you use the calendar. Is this like an app on your phone?

**Noor:** [00:02:50] Yeah.

**Interviewer:** [00:02:51] To...

**Noor:** [00:02:52] Monitor.

**Interviewer:** [00:02:54] So like, is it that you get the food craving and then you look at the calendar?

**Noor:** [00:02:58] Yeah...

**Interviewer:** [00:02:59] like 'Ah... [overlapping speech] that makes sense

**Noor:** [00:02:59] That makes sense.

**Interviewer:** [00:03:01] Or do you like think, "oh. In two days time I might..."

**Noor:** [00:03:06] I suddenly feel a bit like I want to eat everything. And then I'm like, oh, I do get bloatedness as well. And then... because some of the outfits I wear, I'd feel fat. And then I look at my calendar and then I know. Okay.

**Interviewer:** [00:03:19] So when you say you feel fat, is that literally cause the clothing doesn't fit the same way [overlapping speech] or you just feel it?

**Noor:** [00:03:25] Literally... It literally sticks out, if that makes sense?

**Reference 4 - 3.43% Coverage**

OK. So how would you describe Periods either to a child or to somebody who just has not heard of them?

**Noor:** [00:04:00] Oh, that's a difficult one! [laugh]

**Interviewer:** [00:04:01] Yeah it's a tricky one...

**Noor:** [00:04:01] Um.. [pause] Periods. I'd say it's something that every woman... has. I actually don't know! I'd probably do my research and then find the scientific stuff about it.

**Interviewer:** [00:04:19] So this isn't a a test. This is more like...

**Noor:** [00:04:24] Just what you would say.

**Interviewer:** [00:04:25] Yeah. What is it that you... Think I suppose, within yourself, even about periods?.

**Noor:** [00:04:30] Yeah,it's... Just that women that bleeds every month.

**Reference 5 - 3.37% Coverage**

**Interviewer:** [00:04:45] Cool. And again, not testing you but what's your understanding of why we get Periods?

**Noor:** [00:04:53] Er... I understand it, but to explain it, I don't think I'll be so great? [laugh]

**Interviewer:** [00:05:02] [pause] So to do with... Er, like having children or?

**Noor:** [00:05:09] Yes, so I know, it's the body um... What's that word? Every month.

**Interviewer:** [00:05:15] Yeah so just kind of cycling?

**Noor:** [00:05:15] Yeah. That's it.

**Interviewer:** [00:05:18] It's kind of like rejuvenating.

**Noor:** [00:05:20] That's the word yeah- rejuvenating every month, just to make sure that your body is normal, and it can have babies and stuff like that.

**Reference 6 - 2.79% Coverage**

**Interviewer:** [00:07:57] So this is tricky, just because it's difficult to remember. Can you remember when you first came to know about p.\_m.\_s?

**Noor:** [00:08:05] It's only the... probably the last. Four... I'd say five years. Only because of my little sister.

**Interviewer:** [00:08:18] So through her experiences?

**Noor:** [00:08:20] Yeah,.

**Interviewer:** [00:08:20] She'd been telling you about...

**Noor:** [00:08:22] P.\_m.\_s. Uhuh.

**Interviewer:** [00:08:25] So you never heard it at school or like anyone teasing anyone about PMS?

**Noor:** [00:08:30] Nowhere.

**Reference 7 - 2.22% Coverage**

**Interviewer:** [00:09:16] This is a tricky one again. So what's your understanding of why these symptoms occur?

**Noor:** [00:09:22] I think it's because of the change in your body.

**Interviewer:** [00:09:29] Any particular changes or?

**Noor:** [00:09:33] [Pause] I think your body's releasing something, so... Because of that, your body's trying to adapt to it.

**Interviewer:** [00:09:46] So you see it as quite a physical thing?

**Noor:** [00:09:48] Yeah.

**Reference 8 - 5.59% Coverage**

**Interviewer:** [00:10:33] So this is, again, just in your understanding. Do you think that doctors get enough training or do they have enough knowledge about menstrual cycle related symptoms?

**Noor:** [00:10:45] Um, I actually don't know because I've never been to them, but through my sister, like I feel like when they... when... you have to mention it for them to say it... so it wouldn't come up. Generally, like if you go to the surgery and say, "Ah, I'm being moody dah dah dah" They wouldn't think PMS straight away, they'd think oh probably she's got a depression. de de de de dah. All of those options will come first before the p.\_m.\_s.

**Interviewer:** [00:11:10] That's really great. That's really... that's basically what my...

**Noor:** [00:11:12] Yeah.

**Interviewer:** [00:11:13] A lot of my work is about that.. because of the silence about talking about menstruation.

**Noor:** [00:11:17] Yeah.

**Interviewer:** [00:11:18] That even doctors don't... It's not like the first thing...

**Noor:** [00:11:20] First thing...

**Interviewer:** [00:11:20] ...that they have. So, Well done for saying something that I want to write about [laugh].

**Reference 9 - 2.19% Coverage**

**Interviewer:** [00:13:04] So have you ever heard of PMDD which is Premenstrual dysphoric disorder?

**Noor:** [00:13:12] I have, but not like in depth just of that. The PMDD.

**Interviewer:** [00:13:18] So what is your understanding of it then? Or, like basically, what's the difference between just p.\_m.\_s and P MDD?

**Noor:** [00:13:27] I don't know, but I think that one is more of the intense one. So. People that have the PMDD find it much harder?

**Reference 10 - 2.82% Coverage**

**Interviewer:** [00:16:39] Do you have any other health conditions that get worse at certain times in your menstrual cycle?

**Noor:** [00:16:44] So I've got in an... anaemia so... When I was younger, that's why I used to be more painful and my bones really used to hurt where I used to get the um... Do you know Restless Leg Syndrome?

**Interviewer:** [00:16:57] Yeah

**Noor:** [00:16:57] So, I couldn't sleep because my legs were in pain, but I didn't realize it was because I was going to start my period. But now, because I'm taking my vitamins and stuff [laugh], it's much better.

**Reference 11 - 1.58% Coverage**

**Interviewer:** [00:19:35] Are you aware of p.\_m.\_s and actually PMDD as well, being a controversial diagnosis? So one that people might say it's not really an illness or...?

**Noor:** [00:19:48] Yeah.

**Interviewer:** [00:19:51] Where have you heard that?

**Noor:** [00:19:54] I think people are just not aware of those terms.

**Reference 12 - 4.34% Coverage**

**Interviewer:** [00:20:44] That's it. So how do you feel about this conversation? Has it made you feel or think any differently than you did before?

**Noor:** [00:20:53] I think I need to do more research on it![laugh]

**Interviewer:** [00:21:02] So this has been very interesting for me because... also because having spoken to your sister, it's really interesting to compare,.

**Noor:** [00:21:09] Uhuh.

**Interviewer:** [00:21:11] So obviously because of her experiences, she's got much more into like technical.

**Noor:** [00:21:15] Yeah,.

**Interviewer:** [00:21:17] Like the clinical side of defining it and things. So it's really great to get this comparison because, you know, you have the same family, same parent... But different...

**Noor:** [00:21:27] Different yeah

**Interviewer:** [00:21:27] But different experiences and different point of view. So it's been really great for me.

**<Files\\P12\_Ria> - § 6 references coded [28.37% Coverage]**

**Reference 1 - 4.72% Coverage**

Um, are... the way that I describe it to people is usually through the Four Seasons, though all like usually people can know what a period is. And I can talk about that. And then I say, OK, imagine that as winter. And then we go through. And then when I talk about p.\_m.\_s, I talk about how it's the autumn season. So it's a time to let things compost just like the trees are shedding their leaves. It's a time for us to let go of habits and things and people maybe that aren't working for us and we're ready to just like let fall away in our lives. It's a time to get ready for winter. So spending more time by ourselves, maybe doing a bit of reflection, snacking,[laughter] saving up our stores for the winter. I always like to talk about how my food cravings are Like. here [indicates high up above head] [laugh]. In PMS, in terms of charting. So just making sure people are getting the nourishment that they need. Affirming the fact that it's total... Like "go fo the nachos, go for the cake! Do what you need to do to get through it" And then just being also like self aware of the fact that we are going through a lot of changes because of the way our progesterone levels are changing, the way that um... in the modern world we... our food systems are so different. So we don't necessarily get the nutrients and all of the building blocks. Our body needs to have high progesterone levels. So I tend to start with like a metaphor and then I go into some of the emotional mental changes, some suggestions for rituals and ceremonies that people can do at that time. And then if they want to nerd out about like the physical, more like scientific Latin knowledge around like progesterone and hormones and um what the cervix is doing and all that stuff, then i'll... and then I'll go into it. Yeah.

**Reference 2 - 5.61% Coverage**

**Interviewer:** [00:09:44] Just a quick clarification point. This is... Is this in connection with the 'Red School' Way of thinking? [Reasonably well established alternative approach to menstrual education- which focusses on the '4 seasons'] Is that what this is from?

**Ria:** [00:09:53] Good question. I'm not familiar with Red School, but I'll definitely just make a note to look it up. The way... the way that I have come up with this idea of the Four Seasons is certainly not new at all. It's based on um ancestral knowledge from people all over the world, especially menstruators... And so I learned about the Four Seasons... Erm, Yeah, through mostly like indigenous. Coast Salish and Turtle Island writing so on North America, there are some great books. [One that I'm thinking of is called Life Stages of Native Women by a Kim Anderson. There's the Sacred Hoop by Paula Gunn Allen. And so those are indigenous women. And then Veronica Brezowski, who runs a organization called Cyclic Wisdom. She's from what's now Mexico, the bordered state of Mexico]. And yeah. So it's mostly through like women of colour ancestral organizing that I learned about this. And then I've also been learning more about my primary partner, who's a cis man, and his ancestry and his ancestors are euro indigenous. I've been reading about Wicca traditions and how even in like in indigenous traditions literally all over the world to talk about these four seasons, sometimes they're often talked about in terms of the lunar cycle. So that I've learned that back in the day when electricity doesn't exist, a lot of people based on the moon would menstruate, experience p.\_m.\_s, ovulate, experience, preovulation like pretty close together because like the way that the tides and the moon was working and then now in the modern world we're like... our menstrual cycles are they're so different. They're very... they're more varied. There's a lot more diversity in how people experiencing... experience it in terms of the length, the timing, etc.. All of that. So, yeah, those are that's sort of my lineage of how I came to learn about p.\_m.\_s being of them.

**Reference 3 - 6.91% Coverage**

**Interviewer:** [00:15:11] Yeah. I mean I've been in this... researching this subject for many years and I find that usually that weepiness, Premenstrual weepiness is quite often just empathy, I mean that should really be celebrated because I think that's a lovely human trait.

**Ria:** [00:15:30] Yeah!

**Interviewer:** [00:15:30] It's not quite the same as 'sad' tears, You're not kind of necessarily in pain, emotional pain.

**Ria:** [00:15:37] Yeah.

**Interviewer:** [00:15:38] It's more that something very moving has happened.

**Ria:** [00:15:40] Yeah,.

**Interviewer:** [00:15:40] So it might be a bit sad, but it might also be very beautiful.

**Ria:** [00:15:44] Yeah. That's so true. It's so true. And I love that. And also I feel like trauma is processed through laughter and tears. And so, you know, we can... It's great to laugh. I think that's important. And then also, just like how you're saying, like, not all crying. Is because you're like sad or upset. It's because, you know, you're feeling! [laughter] You're feeling for the world, you're feeling for humanity. We're in. We've always been in hard times but these are particularly hard times. From what I gather... around the world and what I gather from elders who are like, what did y'all do!? [laugh] Like, What's going on here? This is not good. So, yeah, and maybe even like as we cycle into the new decade. And think about reorganizing our societies in a way that is in right relation with each other and with the earth that. Can you imagine what it would be like if we used the Four Seasons as a way to like organize government or organize school? A lot of people talk about people missing school on their period and also during the p.\_m.\_s season. Like, what if we were just like, "that's OK. Like, take the time, go chill in your bed, take a nap, have your snacks" rather than being saying like, oh, this person didn't show up for work or school or isn't being a productive part of our society and therefore leading to pathologize it and turn it into a disease and something that we can fix. And you can tell just how I am. Like I'm just being very open. I don't usually. I have to be careful about who I obviously say stuff to because I think it's a really sensitive topic still and we're still maybe in the shifting phases, we're cycling into a new era of menstrual health activism and discourse. So, yeah. Not push it like not pushing people too far, but starting those conversations. So in our everyday life, how can we support p.\_m.\_s and see us... see it as this season? Then how could we even think about it for the long term and how we organize ourselves?

**Reference 4 - 3.09% Coverage**

**Interviewer:** [00:20:45] Sorry, yeah. What's your understanding of why they occur, these changes occur?

**Ria:** [00:20:48] Why they occur? OK. So again, I view health as including the four components; physical, mental, emotional, spiritual. So physically, why they occur based on my knowledge and work with a doctor who's an amazing endocrinologist... [name of doctor] and her work and school of Research that she's been doing for... Like 30 plus years and is very detail oriented and I think like very accurate, verifiable, trustworthy knowledge and science is that after ovulation occurs, our oestrogen levels as menstruators go down and our progesterone levels start to rise. And so physically, I understand it to be the rise in progesterone and then when things are like really, really hard on our bodies. So, for example, we might experience like p.\_m.\_s pain or just like a lot of tiredness in terms of body experience. It might be because we're not making enough progesterone? However, again, I don't want to like pathologize bodies. So I think it's just like a natural thing that occurs when our... that shift from oestrogen to progesterone happens. So that's physically.

**Reference 5 - 1.93% Coverage**

advice to people, it would be to physically take vitamin D magnesium and zinc. These are all and... Again, I can say a lot about the pharmaceutical industry and like how vitamins are made and all that stuff. So you can either take it as a supplement or eat foods that really boost those levels of vitamins and our... and vitamin D is considered a hormone as well in our bodies because just the way like ancestral food systems or modern food systems work is that our food and nourishment that we get today is very different, even if it's the same exact like food or carrot or wheat, for example, that our ancestors a 100 years ago. It just like it's very different. And so we don't get as much of the... they're not as nutrient dense.

**Reference 6 - 6.10% Coverage**

**Interviewer:** [00:39:16] And often people describe a symptom as bloating. In your opinion, what does that specifically refer to?

**Ria:** [00:39:27] Ahhh yes, bloating. So bloating for me is... for the most part, it's the expansion of like the uterus is taking up more space. Which is great because that's what the uterus does and it's taking up space just, you know, in doing what it's doing, menstruating and getting ready for a period is a pretty intensive body process. And then when it gets to the point where it's like uncomfortable or painful for people, I think it's a combination of that just expansion of the uterus, plus things that had been going on during period and pre-ovulation. For example, one medicine that a lot of people use to cope with trauma, etc. is various forms of alcohol. So depending on how much alcohol you drank in pre-ovulation or in the ovulation season. And your body type and all that stuff, very individual to the person. However, in general, I find that alcohol does tend to create a little bit more inflammation during the p.m.s and autumn phase. And so it's that inflammation that's like, ah, you know, the standard inflammation process, which also includes an expansion and pain. And so I think that bloating feeling that people get is is the expansion of the uterus, plus the effects of detox. The natural effects of detox that are body is doing. {pause] And the snacks! [laughter] you know, we're all snacking on some stuff. And as I mentioned earlier, our food systems now are different, to like our ancestors probably used to snack on, you know, fresh fruit that's in their.... My ancestors, at least in their village or like whatever, maybe they had access to sugar cane that people would chew on and that sort of stuff. And now we're like, my go to snack is nachos. So I get like corn chips then then cheese. And then salsa. And then, you know, every once in a while I'll make my own salsa. My partner is working on making homemade cheddar right now, but for the most part, I get those from like the big store and the quality and nutritional value of them are questionable. So it's also... it's great and I'm happy to eat it. But then it's also like bloating as a form of detoxing from the stuff that's just in all of our food. Basically, unless we grow it or make it ourselves.

**<Files\\P12\_Ria2> - § 6 references coded [35.04% Coverage]**

**Reference 1 - 3.27% Coverage**

**Interviewer:** [00:00:07] And so do you track your menstrual cycle changes?

**Ria:** [00:00:12] Yes, I do.

**Interviewer:** [00:00:15] And is that in like a phone app, or... How do you do that?

**Ria:** [00:00:19] I have a bit of a hybrid method where I note down my um... first day of my period and maybe like the next two days and then when I have like very high quality cervical mucus. So my peak day on a piece of paper, that's a little clipboard that's attached next to my toilet. So I don't forget to track. And then I... if I'm feeling like very, very nerdy that cycle, I'll use Kindara [Fertility awareness app] and take my temperature. However, yeah, I mostly just always know when those two days are? And then the rest of it, I'm learning how to be able to tell based on my body as opposed to the app. Um, however, when I first started charting two years ago yeah, I was like obsessively taking my temperature: didn't want to get pregnant. Every time that I got close to the end of my cycle, I was like, "Oh my god! Am I pregnant?!" Sort of freaking out[laughter]. So yes, now I'm a little bit more relaxed.[laugh].

**Reference 2 - 3.03% Coverage**

**Interviewer:** [00:02:29] Have your typical changes changed over time? Like sometimes with age people notice differences?

**Ria:** [00:02:37] Well, as I mentioned last time, I was on hormonal birth control for seven years. So during that time, I can't really comment because it just felt like a total shit show. And that corresponded obvious... And it also corresponded with like my typical point in human development at 18 where people leave their homes and all their childhood traumas and then go elsewhere or just evolve from that and are figuring out who they are as humans. And so, yeah, I wouldn't say that I was really paying attention then. However, in the last three years now since I've come off the pill, I would say that. In terms of changes, I think that I've just with more cycles and more knowledge of the cycles, I can now more predictably see the patterns. Whereas before I didn't, I think it was that I didn't understand what my patterns for emotional mental health were. I kind of only it understood the physical part of it.

**Reference 3 - 7.99% Coverage**

**Interviewer:** [00:07:12] So this is kind of related. Have you ever heard of PMDD premenstrual dysphoric disorder? And if so, what is your understanding about the difference betweenPMS and PMDD?

**Ria:** [00:07:27] So I have heard of p\_m\_ DD and the first time that I heard about it was going... joining a couple Facebook groups on... or looking up menstruation basically on Facebook and seeing what Facebook groups there were. And I noticed that there were a few p.m. D-D support type Facebook groups. And so I asked to join them because I was curious about what people were talking about. And from my understanding, I mean, mind you, Facebook is already biased and just has like spiritually, there's just a lot of anger and frustration and et cetera in that space. It was... it was honestly heartbreaking because I think it's people who... what I imagine is something is up with their progesterone, maybe their progesterone levels are really, really low or whatever. I can't... as I'm not like a clinical researcher, so I can't comment on that. I don't test their hormones or anything. I'm just basing this off... on my own observations. But yeah, I noticed that they were very, very angry, very sad, very depressed, really like low, low vibrational emotions. And so I guess I can say that the difference between p.\_m.\_s and PMDD, according to my understanding, is that p.\_m.\_s is commonly used phrase that people understand and associate with the autumn cycle of a average menstrual cycle. And then PM DD is a word for the autumn phase for people who not only experience an average menstrual cycle like the physical aspects of it, emotional, mental. However, I think that it's um... because of what's going on with their body, mind and spirit. They're experiencing an extreme case, an extreme feeling and sentiment of that shift and drop that happens when oestrogen comes down. and Progesterone hopefully goes up and helps bring up some of those serotonin and the neurotransmitters and all that stuff as well. So that's the physical piece. And then I would have to talk to them individually, probably to figure out where the spiritual and emotional piece of it is, because it could be, you know, like maybe they've experienced an intense amount of trauma in their life, sexual trauma. And so that's manifesting in this way. And then they go presumably go to see a doctor because they're like, "I feel fucking crazy". And the doctors, like you have this thing called PMDD because it seems to line up with the autumn phase. So that's my short, I guess, understanding of what it could be. And then there are few folks in my network who feel like they strongly identify with that. And it gives them... that it like helps them cope basically with it.

**Reference 4 - 11.98% Coverage**

**Interviewer:** [00:10:51] Thank you. That's really great. Do you think doctors have enough knowledge or training on menstrual cycle?

**Ria:** [00:10:58] Hard No![laughter] We're talking about like medical doctors who are trained in that system? Yeah. hard no. hard. No, I. Yeah. I could go on and on. You know, my dissertation project is studying medical schools. And I worked in them and know what their syllabus is like and all of that? And so. Yeah. Hard no, from my end. And then I speculate that for many different reasons. Right now, part of it, I think, is just the sheer amount of information that they literally try to cram into four years of medical school. And then even beyond that, the way it works is the first two years of medical school to become an M.D. are lecture based. And then you have two years of clinical and then you go on to do a residency, which is a clinical placement with practicing doctors. And so in those first two years is where people get introduced to like a lot of new theoretical concepts, hopefully new depending on the age of the instructor and their research interests and all of that. So, It's very subjective and a lot of it is focussed on the biomedicine. So I imagine that's what they do. See... I'll certainly share that information when I get there. so, I can't comment on what's included, but that's my understanding is that it's very crowded, the curriculum. It's very hard to make space. And then once they get into the clinical sites, they're basically just learning from people who have been in the health care system for a very, very long time, particularly doctors. And so already like that just limits what they're learning. So a mentor of mine who's an endocrinologist [name], I don't know if you've heard of her work, but [she is] a doctor and she's like the only endocrinologist who studies menstruation and runs a group called the Centre for Menstrual Cycle and Population Research. And she is one of these people that is able to... has just been so amazing at the quantitative piece. Getting people to literally keep men... these intense menstrual diary logs for a very long time. She writes a lot about menopause and oestrogen as it goes on in the life and what she... Her analysis of why it's not included is that the... is that the obstetrics and gynaecology department. So she's in endocrinology, obstetrics and gynaecology itself. She says that they're still using information and research from the nineteen eighties to teach. Ob's gynae, and you know, that's like 50 years ago now. And again, preview... my previous comment about how a lot of menstruators were not included in research back then. And so they're basing this knowledge just off of like maybe 10 people and then just building this whole curriculum off of it. And they really have not innovated since then. So that's troubling. It's very, very troubling. And I've been like on the caretaking side of many friends who have had experiences with OBGYNs, especially recently as a lot of people are getting pregnant and having babies. And it's like... totally confirms everything that she has been saying because it's honestly horrifying. So there's that piece. However, the exciting new movement is that we now have something, a new title called 'Nurse Practitioners', and it's a master's program and nurses. Ninety eight percent of whom are menstruators compared to I dunno What the stats are on OBGYNs. But I think it's still pretty high that it's disproportionately people who identify as male. But yeah, so the nurse practitioners, they can now they have now the same scope of practice as a family doctor or GP, and that's a new program as of like three or four years ago. And so they get paid on a salary. They have 30 minute appointments as opposed to 10 minutes. And so all this to say that in their new curriculum, I think that they emphasize a lot more on. The menstrual cycle, however, again, based on my frontline experience working with m.p.'s, a lot of them still do tend to prescribe the pill for anything! [laughter] Related to menstrual cycles... So, yeah, sorry. Long answer.

**Reference 5 - 3.28% Coverage**

**Interviewer:** [00:30:49] Yeah. So... Do you identify as somebody who gets PMS?

**Ria:** [00:30:55] Yes, I think I mentioned this before, which is that everybody with a menstrual cycle [laugh] experiences the autumn season p.\_m.\_s. It's just a fact of the menstrual cycle. And I would say even I'd be curious to see that in people who don't identify as menstruators, because we seem to have this idea of sex being binary, like you either have a menstrual cycle or you don't. And I actually think that we're actually all like on a normal distribution. So there might even be people who identify as male because males also have oestrogen and progesterone, just like quote unquote, 'females' have testosterone, that they might experience it in relation to the lunar cycle. So during the... waning moon phase. So after full moon going into New Moon, I'd be curious to know if if, you know, I magically got a bunch of funding to do a project to do a project about p.\_m.\_s. in people who identify as male and see if they also experience similar accounts of what we as menstruators talk about when we say p.\_m.\_s and the autumn season.

**Reference 6 - 5.49% Coverage**

**Interviewer:** [00:32:43] And then there was a slight difference between when women would experience certain things like headaches or I think mood changes as well. But also physical changes would be in this kind of what you'd say was the autumn phase. Well, actually, from ovulation to... to menstruation, so men would also get the same symptoms, well obviously not period pain but Otherwise - just more spread out. But in one study in the 70s found that men actually had more severe symptoms. So, there's some really interesting stuff when you male people as a control group or as a comparison. And it's a lot less formulaic, both for female people. But also there are these. I wouldn't say there's a pattern. Like I don't think I've seen anything where they've established any kind of pattern, other than day of the week, which is a social reason. You know, that's just feeling crap about going to work. But yeah, I really like that when they compare because we have this idea that we're categorically different. When we're not- just different types of humans and there's lots of ways we're different.

**Ria:** [00:34:00] Exactly. Yeah. And even, you know, maybe not even even if it's one person. I think that's why I identify so strongly with being a qualitative researcher, because I'm like literally every human is different! These generalizations about each other. But we are actually spiritually on a soul level, unique. And then when we think physically nin..., like biologists have shown that ninety nine point seven percent of our DNA is the exact same except for that point 3 percent. And even there's new emerging research coming out about, you know, the X and Y chromosomes and these... debunking previous understandings of it that people had. So, yeah, here's to more research showing that we're actually very unique and then also more similar than we think we are! [laugh]