**Name:** 1. Normal v pathological

<Files\\E01\_Anne> - § 8 references coded [17.94% Coverage]

Reference 1 - 1.56% Coverage

**Interviewer:** [00:07:05] So you didn't feel yourself, that you've ever experienced it?

**Anne:** [00:07:10] I would say. I mean, I'm now post menopause. Erm, I would say that er , when I was having periods, I couldn't tell where I was in my cycle. Get a little bit more irritable with the partner/husband. But I don't feel it ever significantly impacted on my quality of life. So, no, I've been lucky. I haven't had a personal experience, I would say where it... it interfered with things. Also, I'm sure you're aware that there tends to be that sort of triad of hormonal conditions. Women with PMS tend to be more likely to suffer with perinatal depression and depression around the menopause again, all we think, hormonally related. And you know, luckily I'm just like a normal person. I have my ups and downs, but I wouldn't say that that hit me.

Reference 2 - 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 3 - 1.73% Coverage

I think it's very important to review women. in both treatments... You've got to really give them sort of three months. And I'd just like to qualify everything I've saaid.... Er, Going back to the original question, how would you manage these... a woman presenting if you have a woman who is threatening to commit suicide every month because of her premenstrual disorder, then you don't start with vitamins. You know, you... you go... you go straight in and treat much more actively. No, not 'active' that's not quite the right word, much more go for something that you... you know... that perhaps what we could call the more.Erm, The treatments that you... think are going to definitely likely to work. So, for example, you might... this is just an example, but you... you might start an SSRI at an earlier stage than somebody who's getting not too much of an impact of her symptoms, you might then look at lifestyle for three months.

Reference 4 - 2.29% Coverage

And I would say there were two distinct groups. And I think this describes the social structure very well. And I came away thinking that. So you get the... There were a number of women who were sufferers and really appreciated just chatting through, er, being given extra information and often shared with us the difficulties they've had in the workplace, erm, sometimes in relationships, actually trying to explain... Erm, one: I think there's a lot about... They don't feel that they can explain things or they feel that this is a 'normal' thing, so they shouldn't be complaining about it. Erm, So maybe that's what comes through in the workplace and in their home situation at times. So it's just very, very appreciative that people were actually taking it seriously. So I think that in a nutshell, that's one thing I think a lot of people don't take it seriously. And the other group of people ... either didn't know about it or almost...[pause] erm, {pause] used it as a as though it's 'women making an excuse to be irritable or angry'. You know, it's almost as though there's a little bit of stigma, and that may be why a lot of women find it very difficult to be open about things, about all the suffering... how it's affecting them.

Reference 5 - 2.59% Coverage

**Interviewer:** [00:37:52] Great. And are there any positive menstrual changes?

**Anne:** [00:38:01] Oh, no.... er, Yeees, I think you do occasionally come across women that... pre-menstrually do you mean?

**Interviewer:** [00:38:15] Yeah.

**Anne:** [00:38:16] Any anything at any time in the cycle?

**Interviewer:** [00:38:21] Yeah.

**Anne:** [00:38:23] Ooh, yes. No, definitely. Erm... It's quite a tricky one, really. I think it is balanced against the negative things we've talked about... Women can feel very good at certain times in the cycle. [pause] And I think looking at it another way, I've seen a lot of women who are going through the menopause who have noticed in a drama- often dramatic changes in their mental and physical well-being because of their declining levels of oestrogen. So turning that round in the menstrual cycle and the normal menstrual cycle, that's really important for the well-being of women. And the other example is testosterone, which is important for energy, for libido. The general well-being and you know, women who, for example, have an early removal of their ovaries and therefore removal of their testosterone, it's... it's so important to... to give them add back replacement... erm hormone replacement, both oestrogen and testosterone. So, you know, what I'm saying is in the day to day, all those hormones are really important for mental and physical well-being.

Reference 6 - 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 7 - 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 8 - 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.

<Files\\E02\_Babara\_email> - § 5 references coded [17.20% Coverage]

Reference 1 - 3.12% Coverage

# E7

1. In your opinion, what is the best way to manage PMS?

Mild-moderate symptoms can be managed with exercise, diet, relaxation techniques. If such approaches do not help, medications may reduce moderate/severe symptoms.

Reference 2 - 2.73% Coverage

1. Are you aware of any societal stereotype of someone with PMS? If so, can you describe it?

There are many jokes in circulation. They are not funny to someone who is truly distressed by symptoms.

Reference 3 - 3.98% Coverage

Many chronic health conditions get worse at certain times in the menstrual cycle. Would you count the expression of these as premenstrual symptoms? Why?

NO. See #1 above. Treatment is more likely effective treating the primary disorder, not the secondary premenstrual symptoms.

Reference 4 - 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 5 - 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.

<Files\\E03\_Fran> - § 3 references coded [20.45% Coverage]

Reference 1 - 4.34% Coverage

1. **Interviewer:** Great. OK, so what is your understanding about the difference(s) between PMS and PMDD?

**FRAN:** To me, PMDD is at the most severe end of the spectrum of premenstrual symptoms, again, as I was saying in my first answer, maybe 80% of women have some premenstrual symptoms, but 20% of women, they notice it, it lasts a couple of days, it’s not that severe that they can’t get out of bed or go to work but in 5% of women it does affect their functioning and quality of life for several days, and they often seek treatment for the symptoms, and that’s PMDD.

Reference 2 - 5.42% Coverage

**Interviewer:** Sorry. Um. In PMS guidelines, so those specifically on PMS and not PMDD, the tools that they recommend for diagnosis do tend to be based on the PMDD… Well, basically the DSM 5 diagnostic criteria for PMDD…

**FRAN:** And you’re asking what I think of that?

**Interviewer:** Yeah. It’s just that…You know, it’s just a bit confusing.

**FRAN:** Well there aren’t other criteria for PMS and most people feel that PMS is a less severe form than PMDD- maybe not quite five symptoms, maybe just lasting a couple of days, maybe less severe symptoms. We do not have a validated daily rating scale that differentiates PMS from PMDD. My view is that most of the symptoms of PMS are included in the PMDD criteria].

Reference 3 - 10.68% Coverage

1. **Interviewer**: Brilliant. Thank you. Um, the clinical guidelines on PMS do not usually include information about the role of non-biological or external life experiences (even though we know these are contributing factors) as contributing factors in menstrual cycle-related health e.g. ‘psycho-social’ factors. What do you think about that?

**FRAN:** Can you give me an example?

**Interviewer:** Well, some guidelines don’t include ‘smoking’ as a factor in worsening or triggering PMS, but even things like ‘external stressors’ in life, work stress or personal issues having an impact on those experiences.

**FRAN:** Erm, I’m not really sure which guidelines you are talking about? I myself have published on the effect of stress and it making symptoms more prominent. So, I don’t think stress is considered a direct risk factor.

**Interviewer:** So, the guidelines I am talking about are… in the UK the clinical guidelines for primary level doctors who would see a patient first. And it basically goes straight into pharmaceutical rather than covering in detail the role of lifestyle factors and changes that could be made to improve symptoms…

**FRANFRANFRAN:** Most review papers that I read or have been involved with is that dietary recommendations, exercise, relaxation, and CBT could deal with the external stressors, so I think all of these treatments are as accepted as pharmacological treatments.

<Files\\E04\_Andrew> - § 8 references coded [32.21% Coverage]

Reference 1 - 1.51% Coverage

**Interviewer:** [00:06:44] Thank you very much. And do any of your close family members identify as having p.\_m.\_s?

**Andrew:** [00:06:53] No, not the close. I wouldn't say that, but I, of course, know a lot of persons also personal contacts that have it... but, but not in the closest family no. Or... or that again, depends on the definition. If you have a very wide definition realizing that the menses are approaching, then I think the answer would be yes. But if you define it, that's a considerable... errr. [pause] considerable discomfort. Then the answer will be no.

Reference 2 - 2.85% Coverage

**Interviewer:** [00:07:30] Ok. So in your understanding, how common is p.\_m.\_s?

**Andrew:** [00:07:36] Well , there has been a lot of epidemiological studies on this, and I would say that a majority of all women have got... perhaps 80 percent have got a condition that so that they can feel in some way from somatic complaints or maybe mood symptoms that the menses are approaching. And that is a majority. And for most of them, these symptoms are entirely trivial and they would not dream to ask for help for them, etc. Then if you look at a condition that is so severe that it's regarded by the women themselves to be a considerable problem, I would say around 5 to 7 percent or so of women of fertile age. If you use the DSM criteria and ask women to rate their symptoms daily for two prospective cycles and then use a definition in that that they should have a cyclicity in at least 5 symptoms, then you would be down to 2 percent or so I think. But but that I think is fair to say that 5 to 7 percent have got symptoms that are sufficiently severe to be a major problem for them.

Reference 3 - 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 4 - 1.65% Coverage

**Interviewer:** [00:22:56] Fine, thanks. So lots of different chronic health conditions can get worse at Certain times in the menstrual cycle. Do you count those as premenstrual symptoms?

**Andrew:** [00:23:09] No. And I think that's important not to do because the treatment would be different. And I think there is a general agreement among researchers, both in the psychiatric camp and the gynaecology camp, that you should not include those you can call them, They are sometimes called premenstrual exacerbation, or premenstrual aggravation or premenstrual magnification. But I think that should be kept apart from true PMS.

Reference 5 - 6.62% Coverage

**Interviewer:** [00:26:46] Thank you. So, PMS is considered by some to be a controversial diagnosis. What is your understanding of why that might be?

**Andrew:** [00:26:56] It's a mix of two ideologies. One is that there is a a feminist approach claiming that this is to label women expressing a rightful annoyment of various examples, from lack of equality in society that this kind of that that the women expressing anger that they should express are are getting a diagnosis. And therefore, that's been been been argued from feminist camps that this is a negative thing. On the other hand, are other feminist groups that have said that p.\_m.\_s is a typical example, that female conditions are not it's not done research on female conditions as much as for male conditions. And the fact that there are not more treatments for p.\_m.\_s and so on is a also an example of lack of equality. So there are two different views on this from the feminist camp. That's definite that there is one important argument that that this should this is a labeling of a ... err er er...labelling healthy women with a diagnosis and the other ingredients in the in this mix of all of... this. Ideological stance is that a general skepticism, in respect to psychiatric disorders that is common in society and from different angles there is of, for example, a questioning of the ADHD concept. Many people believe that that this also should not be used at all. And they are skeptical to the entire DSM activities. And they say that DSM is just acting on behalf of the drug companies so that they should be able to sell their drugs and they are all all corrupt and bribed and so on. This is an entire fake altogether. So I think that, ah, this is a mix of these two tendencies in in the questioning of the of the p.\_m.\_s. Yes. And of course if you question p.\_m.\_s then you don't... that that is not the DSM concept of course. And that is not coming from say, psychiatry. So then it's more like a something coming from the Feminist stance. But if you particularly criticize the DSM concept, there is for example, I think her name is [colleague's name] and she has been an advocate for that view. When I know that she has, I think just been on previously been on a DSM committee and tried to stop PMDD from being included. So so and that I think it's a mix of of both tendencies because I think the same debate that I maybe I may be wrong, but I think the same debate has also been argued against, for example, ADHD. And so so a yeah.

Reference 6 - 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 7 - 7.97% Coverage

So at the moment, there's sort of erm... It goes straight to the pharmaceutical kind of options rather than these... less medical interventions. So what are your thoughts on that?

**Andrew:** [00:37:41] I haven't seen those recommendations first so I cannot comment on them. I think this is the same... partly the same problem, that you have in other psychiatric conditions that you have for mild conditions. There are certain recommendations that are likely to be positive but that.... [pause] But often the evidence base is not perfect because it's very different... Difficult to have a reasonable control group in those studies. You should have a control group to diet change and so on. How should that control treatment look like? And so and some of those writing recommendations, they don't take this with this evidence based aspect that seriously. So they feel free to include various recommendations of that kind, things that definitely could not harm and might be helpful, such as exercise, diet, things like that. Others may be very... feel restrained by being evidence based. And then it's difficult to claim that these interventions are really effective. So I think it's it's... this is not... this is not unique.. for for premenstrual syndrome. It's the same in various other psychiatric conditions that you you have this problem. But I haven't seen I haven't seen this information. We have some other factors in play here. One is that particularly in U.K., there have been some influential gynecologists that have been very much in favor of hormonal treatment. And that has been fairly unique for U.K. That's not been that that hyped. In other countries, but they have suggested various oestrogen treatments and other hormonal treatment. And that is one aspect that might have influenced particularly the English accommodations. I haven't seen them, but I guess that would not surprise me. And on the other hand, there... we have the fact that no SSRI is, in fact, approved in Europe and they are approved, officially approved as an indication in the United states and one of them in Sweden, in fact, but none in Europe. And that has a commercial background that the drug companies never really tried that because it was too late for them to... the patents were running out. So they didn't care about the European market for SSRIs. So it's I really don't know how the various English and English writers or recommendations deal with these various aspects, both the fact that SSRIs are usually regarded as first-line treatment but not officially available. And then the local influences for hormone treatments. So I haven't seen them, so I cannot comment on that. And I would say in most review papers and consensus documents, where I have been co-author or read, usually these these non-specific treatments that you mention diet and stuff like that and avoiding stress and so on are usually mentioned. So I don't think it's it's not controversial to to mention these possibilities for the mild conditions.

Reference 8 - 3.74% Coverage

**Interviewer:** [00:47:51] And how do you feel about this interview? Do you have any questions or comments that you'd like to add?

**Andrew:** [00:48:00] It was a pleasure. And I think the questions were all very relevant. Absolutely. I think one should not... should not underestimate first the controversy around this diagnosis that you mentioned briefly, that there really is such a controversy. And in some ways, it's quite understandable, a condition that pictures women are as angry and unpleasant. Of course, it should be controversial. On the other hand, if you have seen men and women with severe symptom, which I I could tell you also that that when he first approached me, this gynecologist that many decades ago, and said that should we do work together on p.\_m.\_s, I said p.\_m.\_s is that really something to do research on?. We were working with schizophrenia and severe depression. Bipolar. Is that really a real condition. I asked. But then in our clinical trials, I mean, I interviewed a lot of patients that I got a tremendous respect of the really serious consequences this may have. So but I think, you know, I think you you you at least briefly mentioned that aspect and you. Also, the questions to... have me expose the the the differences in opinion, I think. Yeah. I think it was a good interview. You used the right questions. I don't know if the answers were right, but the questions were right.

<Files\\E05\_Debbie> - § 12 references coded [38.42% Coverage]

Reference 1 - 1.22% Coverage

**Debbie:** [00:05:01] Erm, For me, PM.S. is... is..is very mild.[pause] Symptoms in the two weeks before menses that could be physical or psychological or behavioral, emotional, cognitive, you know, could be anything really. Doesn't have to be... like emotional, cognitive, behavioral, like we think about PMDD. Um, But I think the main criteria for me is it really can't interfere with your life at all. It's a... it's a it's a nuisance... only... nothing more than mild nuisance. Premenstrual symptoms. That don't affect your life. [pause] But that... and I would say that that is present for some percentage of the population.

Reference 2 - 0.88% Coverage

Yes so I would say it affects a small percentage of the population. But I guess it's hard for me to answer that question without talking about PMDD because I think of them as a sort of continuum. But I really conceptualize anything that is impairing or significantly distressing at all. As a PMDD symptom. Whereas p.\_m.\_s, I would say, is not disordered. It's just sort of little mild changes that are not of any consequence and don't really bother you.

Reference 3 - 1.43% Coverage

**Interviewer:** [00:08:03] Cool. And we've touched on this, but I'm going to ask you it again anyway. How common is p.\_m.\_s?

**Debbie:** [00:08:14] It depends entirely on how you... [pause] operationalize it. You know, how common is it for people to have mild changes that don't... like What I'm trying to think of is like, how common is it for people who have mild changes? that Don't interfere with your life. Probably like really common. Probably, you know, 80 percent or something like this. I wouldn't say all. I've known quite a few women who are like 'I've never had any symptom whatsoever'.[laugh].

**Interviewer:** [00:08:44] Yeah.

**Debbie:** [00:08:47] So it's like almost everybody, you know, at one time or another, you know?

Reference 4 - 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 5 - 6.05% Coverage

**Interviewer:** [00:22:15] And so what is your understanding about the difference or differences between p.\_m.\_s and PMDD?

**Debbie:** [00:22:24] [Intake of breath] Well, I'll preface this by saying I think some people say p.\_m.\_s and mean PMDD and some people mean mild... Some people say mild PMDD and they mean PMS. I don't think that they're... functionally different things. I think that. By the time somebody gets to a level of severity, you know, sort of this like bell curve, right? of you've got p.\_m.\_s somewhere down here and then it turns into PMDD. But what I would say about my... way of thinking and talking about it is that p.\_m.\_s is like a rather a small chunk [laughter] over here that is... truly not impairing. And the reason I say that is that a lot of people are like, "oh, well, you know, I don't really meet this like big criteria set, you know, whatever. But it's really interfering with my life". And I'm like, okay. Then you have PMDD... like that is good enough, right? Like if it's interfering with your life. You probably do have... maybe you're not using the same words that are in the... the thing. But if you... if it's interfering with your life, if we dug deep like you probably do have five or more symptoms that turn on and off, you know. Oh, so. So. Yeah. So I guess my... what I would say is that p.\_m.\_s is the like very mild left most tail of the bell curve that is PMDD biology and symptoms. And it's, you know, a large section of women that have some cramping and even mild irritability for an hour or something like that, you know. But then. But then the rest is sort of like anywhere from.. you know you start to move around the bell curve. And it's like, okay, now you have people who like every third month will have, you know, a more severe..., for whatever reason will have a more severe set of symptoms. And they're really having a lot of cramps and stronger irritability where they might have a fight with their partner. And but then it kind of goes away after a day, you know, and then you move over where there are like people basically have a fight and, you know, you have problems with productivity for three or four days, but they can still sort of get away with it. And then, you know, it really goes over to the like suicidal every month and like, really can't cope for two weeks. Right? So I see all of that as a continuum. And to make things nice and complicated, I don't think people necessarily stay in the same place on the continuum. Like, I think a lot of people say, like, "oh, after I had kids or as I age like... it got more severe before, it was like really mild and it never bothered me". Other people say like, "oh, you know". [pause] "You know, I used to have some of that, but it's gotten better". You know, I have heard that from people. So, yeah, that's how I would say I would say it's all just a continuum. But I'm... I don't disrespect or think that there's anything wrong with people who use p.\_m.\_s instead of PMDD to describe. It's just the it's just the way that my culture and community kind of talks about it. So it works better for me.

Reference 6 - 1.95% Coverage

**Interviewer:** [00:25:40] Ok, thank you. And do you consider period pain or. Well, I mean, really, is uterine Cramps as a premenstrual symptom?

**Debbie:** [00:25:51] If they're pre-menstrual![laugh]

**Interviewer:** [00:25:54] So, it's just the timing.

**Debbie:** [00:25:57] Yeah. And you know, from the perspective of the DSM 5 and I think also the ICD 11 now, too. The idea is that we sort of ignore what happens for the first four days of menses and anything that happens like... as a... when it comes to diagnosis. So if you have really severe premenstrual cramps that continue into menses, as long as they're sort of minimal to absent by day 5, then that's gonna be a PMDD symptom. But if somebody has like no symptoms until their period starts, then technically I think we would call that dysmenorrhea. But I don't know that we have any evidence that the biology is different. It may not be a real distinction. But from a like current diagnostic standards [laugh] like that, that's what we would say.

Reference 7 - 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 8 - 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 9 - 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 10 - 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 11 - 5.55% Coverage

**Interviewer:** [00:59:03] Right. And what do you think about surgical interventions for the treatment of p.\_m.\_s or PMDD?

**Debbie:** [00:59:14] I think they're absolutely necessary for a lot of people. I think that, you know, I've... I've referred a lot of people for that. And I have written a lot of letters [laugh] to argue that people need that.[pause] I think that somebody has to want it. First of all, you know, we would never. Sort of force somebody to do that. [long pause] In 2017, there was a paper that came out showing that when you do add back of estrogen and progesterone on top of the GNRH agonist. Right. So you put somebody with PMDD in the menopause. They're fine. Then you add back estrogen and progesterone. Their symptoms come back... because of that. We had thought for a long time that if somebody has PMDD, we use the GNRH agonist trial to find out if surgery will work. Right. So we use medical oophorectomy with the GNRH agonists to figure out if surgical oophorectomy will work. And then we immediately put them through to surgery because we can't give them estrogen and progesterone, which they need for heart and brain and bone health. So we just have to, you know, we just have to use it as a test to make sure the surgery is going to work. And then we put it, but we can't put them on this long term because they don't tolerate it. Their symptoms just stay there. But then in 2017, this paper comes out saying, "oh, no, it turns out that if you suffer through [laugh] the first month, of add back and you don't say, hey, doc, I can't stand this, I have to get off", which would be understandable. If you suffer through that. Then when you come out the other side, as long as you keep things stable, you can tolerate the add back long term. And why not... In that case, why make somebody go through major surgery if you can just keep them in a medical menopause and add back the hormones in a stable way on top? That seems more sensible. So that's what we're doing now in my clinic. That's what we recommend. And some people don't have adequate ovarian suppression with the gnrh agonist. And we see that they're still ovulating. [exhale sigh] Some people have co-morbid endometriosis or some other really painful physical condition that makes surgery more appealing. But I think that my thoughts on that have evolved a lot since that paper came out, because I. And so I I. The difficult thing about it is that month. And I have people come in to see me, you know, every week and sometimes more frequently just to like get them through it. Right. Like, you know. And everybody wants to come off. But then four and a half weeks in, they're like, "oh, I feel better". So that's kind of... it's kind of evolving. But I think it's a necessary tool to have. I'm hoping that it's necessary for fewer and fewer women as time goes on.

Reference 12 - 0.53% Coverage

**Debbie:** [01:03:20] You know, we wrote a position statement on that. You know, it's like for them, they just think of hot flashes. Right. They're like, "oh, it's just a few hot flashes". It's like, no, this like can make people suicidal. Like, this is a big deal, you know?

<Files\\E06\_Celia> - § 8 references coded [33.97% Coverage]

Reference 1 - 1.62% Coverage

**Interviewer:** [00:09:07] Um, in your opinion and understanding how common is p.\_m.\_s?

**Celia:** [00:09:13] Well, I think probably it depends on the definition you have if you're talking about disabling symptoms. Certainly that would be under 7 percent if you're talking about bothersome symptoms. It could be up to 20 percent depending on whether you require one symptom or more than one or whether you require more than one day. Premenstrually.

Reference 2 - 6.45% Coverage

**Interviewer:** [00:11:32] Thank you. Another tricky one. In your opinion, what's the best way to manage p.\_m.\_s?

**Celia:** [00:11:42] Well, what I like to do is to start with that two months of daily prospective ratings and during that time ask the individual to do a number of things. Do some, quote, holistic approaches such as um increasing calcium, vitamin D, increasing exercise, um trying to work on sort of self styled cognitive behavioural approaches, stress reduction, possibly meditation um... if they have pain, breast pain and whatever they can consider um the NSAID Premenstrually. And er anything that... that might be over the counter if they wanted to try. There is some small meta analysis with low dose with vitamin B 6. As long as they stay under 50 to 100 milligrams a day with magnesium. But I don't recommend that they start anything pharmacologic for the first two months. Then when they come back with their prospective rating, then we'll have a discussion about whether they're going to try a hormonal contraceptive such as the one that has FDA approval in the states um the drospirenone. 20mic pe or whether they're going to go with a luteal SSRI.[pause] Um I also, if the symptoms are only a week, for example, discuss the possibility of symptom onset SSRI, or SNRI, although there aren't many studies on that. If they want to stay with something that they might call, quote, more so... sort of homeopathic, there's the chaste berry tree. Studies predominantly in the British literature. I haven't really had anyone who's had a good response with it. But, you know, I think that... that's out there and um they can certainly go for more intensive emotional regulation therapy. You know, other sorts of things along those lines, acupuncture, etc..

Reference 3 - 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 4 - 1.79% 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.

Reference 5 - 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 6 - 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 7 - 9.05% Coverage

**Interviewer:** [00:26:21] Great. Thank you. So at the moment, the kind of consensus agreement was that PMDD sits kind of alongside PMS. They're both kind of parallel categories to each other. And so that obviously means, well it implies definitely that PMDD certainly isn't a mental health issue that gets worse premenstrually; that it's a stand alone Premenstrual disorder, but also that it's kind of. Slightly separate from PMS, like there might be a divide between mental health symptoms and physical health symptoms. Do you have any feeling on the way that that ended up being defined?

**Celia:** [00:27:17] [Long pause] No. I mean, the other issue is that... I haven't looked at it recently, but at one time a company came to me and asked if I wanted to do a study on a diuretic for the physical symptoms of p.\_m.\_s. And we literally could not find many patients at all who had severe physical symptoms without, say, endometriosis or some other being.. you know a pain problem, without having moderate to severe emotional symptom, at least one. I think it's pretty uncommon. And having said that, if they just have severe breast pain premenstrually. I wouldn't give someone a p.\_m.\_s diagnosis, although by definition they... they would fall in that category. But... Anyway, I forgot what your question was [laughter]

**Interviewer:** [00:28:04] It was sort of how it's ended up, I think having to come to a consensus that PMDD is sort of slightly separate. Now from p.\_m.\_s. And it leaves p.\_m.\_s without a clear like you're saying, there's no clear. Definition for PMS, whereas it is quite clear for PMdd. But it's a it's a DSM diagnosis. It's a mental health diagnosis.

**Celia:** [00:28:28] Well, I was hoping that the definition that the consensus conference came to, under and the paper that was published, I think in the Journal of Women's Mental Health, the paper with [colleague's name], I think and his group as the first authors, I'm sure you're aware of those papers...

**Interviewer:** [00:28:44] yeah

**Celia:** [00:28:46] That... that the concept of Premenstrual er disorders, that that could end up becoming the definition of p.\_m.\_s. I saw that ACOG withdrew their p.\_m.\_s practice bulletin and I don't know that another one ever replaced it. So I agree that I don't know that there is a medical p.\_m.\_s definition now, and I think that is a problem. [Pause] On the other hand, you know, maybe it should be left in the lay area and just call it Premenstrual disorders and...

Reference 8 - 4.50% Coverage

**Interviewer:** [00:29:21] Yeah. Well, I think there's lots of different opinions on that, but Yeah. Um So in fact, you mentioned quite a few non-pharmaceutical treatment options when you were saying how you might treat patients. A lot of these recent clinical guidelines, don't include that information, at least in the UK. They go straight to SSRI or hormonal medications. I'm just wondering about your thoughts on these lifestyle changes. You know, all the ones you listed, you obviously think they're worth trying.

**Celia:** [00:30:02] Well, I think during the two months of doing the prospective recording, patients, I think benefit from the recording because it gives a sense of control to patient and family and whatever. But I don't like to give anything prescription based before I have a diagnosis. So I think because there is some evidence in the literature; not always frequent randomised control, but some evidence. And because they're I feel fairly harmless. I think it's reasonable for patients to do that. And some of them find it to be very effective and really don't need to have anything further. Generally not the ones with the more severe symptoms. But, you know, I think they... I think they're reasonable to to try.

<Files\\E07\_Sarah> - § 10 references coded [31.70% Coverage]

Reference 1 - 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 2 - 2.39% Coverage

**Interviewer:** [00:07:02] Thank you. OK. In your understanding how common is p.\_m.\_s?

**Sarah:** [00:07:11] Well, it depends if you're talking about. I mean, most women notice a little bit of a change in something... it might be a little bit of breast soreness. So they know from that that they're about to get a period. That's a good thing. they know when their Period's due. They could be prepared. That is not a disorder. So if you're talking about a disorder that really it is debilitating. It's I think it's a small percentage of women it would probably be about 5% of menstruating women. If you're talking about how many women notice a change that causes them a little bit of distress, uh you know a little bit more than that... being a severe disorder? You know, it could be up to about 30 percent of women. But It's, you know, the intensity of symptoms vary a great deal.

Reference 3 - 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 4 - 2.57% Coverage

**Interviewer:** [00:18:37] Great. So many chronic health conditions can be worsened at specific points in the menstrual cycle. Do you count the expression of those as Premenstrual symptoms?

**Sarah:** [00:18:53] Um. No. but I think it's... it's fair to say that a number of disorders are... can be worsened by the menstrual cycle and you need to be aware of that... I don't think they are specific Premenstrual Syndromes, though. But they... it's just an important aspect to know about.[long pause].

**Interviewer:** [00:19:15] Right ...

**Sarah:** [00:19:15] [Interrupting] So, you know, you could get worsening of um blood pressure in pregnancy, prior to delivery or gestational diabetes, or whatever... So it's, you know, it's something you need to know about.

**Interviewer:** [00:19:33] Yeah...

**Sarah:** [00:19:34] [interrupting] But you might be... what you might end up doing is modifying the cycle... so that those symptoms aren't worsened.

Reference 5 - 6.86% Coverage

**Interviewer:** [00:21:17] Yeah. So slightly linking to what you just said. Men, obviously can experience nearly all of the same symptoms apart from breast pain and uterine pain, but obviously without a cyclical pattern because they don't have a menstrual cycle. So does that mean that the same symptoms can have different biological mechanisms, basically depending on the patient's sex?

**Sarah:** [00:21:42] Well, they don't have a cyc... I mean, all the symptoms we've talked about, it can happen in women at other times, too. It's the cyclical, nature of it... Now, men can induce cyclical changes. I don't know if you're aware but in New Guinnea there was a cult, an island of menstruating men. So men in this tribal situation. um feared Women menstruating... and so couldn't shake hands with a woman 'cos she might be menstruating and have her evil curse put on them. And they sort of figured that women had some sort of power so they were cutting themselves, ritualistically on the genitals to produce menstruation. Of course it was not real menstruation... So [laughter] you can you can fabricate things too, if you wanted to. It's just ridiculous to even suggest that men have similar... [fades out]

**Interviewer:** [00:22:36] Yeah. Well, but like say if they get irritable. Um that the mechanism behind that is different than the irritability that we would get before menstruating.

**Sarah:** [00:22:51] Well, I mean, if you want to do a PET scan, you'd probably find that it's a similar part of the brain gets activated when any one gets irritable... you know in certain sorts of behaviours. Um, So what we're talking about is not the end result. But we're talking about. Why a constellation of things changes with the menstrual cycle. It's a different thing. We're not talking about specific symptoms as originating from the menstrual cycle. Even menstrual migraine, you know people get migraine at other times, it's not necessarily linked with menstruation, which becomes important for aetiology. The mechanism of migraine is the same. And you could still treat that Migraine with the same triptan or whatever you'd use to treat a migraine at another time? But if it's only occurring in association with menstruation, well then you may want to look at evening out the cycles. So they don't get that triggering... Do you understand?

**Interviewer:** [00:23:53] Yeah, yeah. It's just um people have very different ways of describing this so... you know, That's what I'm trying to gauge, how you would put it.

Reference 6 - 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 7 - 1.51% Coverage

**Interviewer:** [00:28:23] So after the Montreal Consensus, we have this kind of Premenstrual disorders umbrella term and then kind of beneath that you have p.\_m.\_s and PMDD and separate disorders. How do you feel about that, this kind of slight separation of those terms or those experiences?

**Sarah:** [00:28:50] Well, I think that's fair enough and just given that the PMDD is just a small subset. And you know, they are gonna be those that have the more severe mood symptoms that you may need medication to help. So I think it's a reasonable thing.

Reference 8 - 3.70% Coverage

**Sarah:** [00:33:44] [interrupting] But all the symptoms can occur. I mean, you've got I mean normal people who aren't suffering a depression, a depressive disorder, can feel depressed at times. Right? So it's... it's every single thing can happen at times to normal people as part of normal life experiences. It's only when it is actually causing distress and interfering with the way in which you can conduct your life. So that is With your relationships or your ability to work or study whatever is important to you in your life that it becomes a disorder. So you might have some breast soreness. You know, I did have a little bit of breast soreness. I'd never think of that as being a disorder. I thought it was a helpful hint. Thank you very much. Right? But if it was so bad that I couldn't bear anyone to touch me, and I had to get special bras for it and I had to keep my husband away at that time of the month. You know, I couldn't have a cuddle or anything. or I'd be screaming in pain. Then I reckon that's a disorder, right? So that's the way you really have to look at these symptoms. Not you know a little bit of water... But is it... is it significant? And I think that's. What DSM says all the way through, it's, you know, that these symptoms should be enough to be really causing interpersonal distress or affecting the person's functioning.

Reference 9 - 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 10 - 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.

<Files\\E08\_Thomas\_edited> - § 8 references coded [26.23% Coverage]

Reference 1 - 4.47% Coverage

**Interviewer:** [00:12:53] OK. So in your understanding, how common is p.\_m.\_s?

**Thomas:** [00:12:58] Well, it's very common, it's er.... I can only refer to... I was part of a television program. And in the city of of where I live, it's about 150K inhabitants. And and during the two days after this program, the department had about 50 calls from patients who wanted to come and see us. So it was a very common common way. But I mean, the severity varies a lot. And as a... as I would say that more... or more or less well over 50 percent perhaps, or up to 70 to 80 percent it has been recorded feel some changes in relation to the menstrual cycle. So it's... it's more uncommon not to feel changes than feel changes, although I mean, these are not to be considered to be pathological, I mean, to be considered as um 'disorders'. But these... these figures about three to five percent of the female population, in fertile ages... that have have this a more severe condition. That's that's also something which which would need treatment and help in any way. And in in... I would say that it's it's more more than the ones that actually fulfil the criteria of PMDD that need help. I would say about ten to fifteen percent or perhaps even more but, but at least in, in, in that range I would say. And the rest of course, I mean I think that they can manage themself by by knowing what it's... what is happening. And also by. By changing their lifestyles, sometimes... many patients which I have met, they say that they keep a diary in advance so that they know the days when they are going to feel bad. And that helps them to, to at least feel.... I mean, you're able to cope with the situation. But er, Of course, I mean, 80 percent of the female population in fertile ages, are not being... have not a disorder. That's something which I have to say... Some lay press, it seems, has everyone more or less as having this disorder.... and That's not true.

Reference 2 - 2.09% Coverage

**Interviewer:** [00:36:25] Great. Thank you.[cough] So what's your understanding about the difference or differences between p.\_m.\_s and PMDD?

**Thomas:** [00:36:37] I think it's. Well, that's my opinion, there might be different opinions, of course, but my opinion is that it's a question of severity. It's actually the same condition. I would say. And it's only that certain persons are more, let's say, sensitive to these hormonal changes than others. And we have actually shown that there are... that patients with PMDD are more sensitive or differently sensitive than the controls which have with the Contrast group, which are those without any symptoms, Any cyclicity in symptoms. So, so and those of course, exist as well. And whether... and it seemed to be a genetically... a genetic factor, because if you ask the patients, it's very often that there are PMD... p.\_m.\_s in their relatives, mothers, sisters.

Reference 3 - 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 4 - 2.49% Coverage

**Interviewer:** [00:45:03] Oh brilliant, thank you. So PMS is considered by some to be a kind of controversial diagnosis. What is your understanding of why that might be?

**Thomas:** [00:45:17] Well, it's it's because er... it's it's a sort of.... It's [pause] it's a less severe condition. In many cases and in those cases, of course, one should... should. Consider it as being.., a part of life... being part of normality. And if... if one then is saying that this is a disorder. Of course. I mean, then then you are in trouble because then it will actually cause some confusion. Among the population, confusion in relation to...[pause] What is a cond.. What is a disorder and what is not a disorder? So I would say that the main benefit you could do in this one is to actually define when. Is actually this cyclical mood changes related to the menstrual cycle. To be con... is considered as a condition. And when are they actually. To be, when should they be considered as normal?

**Interviewer:** [00:46:52] Yeah.yeah.

**Thomas:** [00:46:53] And that is not being clearly pointed out.

Reference 5 - 5.02% Coverage

**Thomas:** [00:46:58] In in the clinic where we have the the saying, at least in Sweden, we say it. And I think we are. I am quite... I can talk for the most of the doctors that are... are treating these patients that if there's this... if the symptoms are so bad that the patient actually seeks help for that. Then we consider it worth helping and treating... so so that becomes some some kind, of line or a border where you consider it to be something which is needing help. Whether one should call it a disorder or not, it's something else. PMDD a disorder so severe that that... that has to be considered as one. But that's three to five percent. And then... then the other ones, the p.\_m.\_s. It's a question of ... who should be treated and who should not be treated and then and who should be given advice about [pause] living and and so on. As a doctor.

**Interviewer:** [00:48:22] Yes.

**Thomas:** [00:48:22] Or or when one should we consider that. And if you... if I say and actually that's the reason why I wanted to talk to you. Because I actually think that is a quite important issue. And also also to be considered where [tut slight frustration] and and I think we should we should define it differently. I think that the word p.\_m.\_s is is too established to be.., to be taken away. So it's more to add on a prefix like severe p.\_m.\_s and severe p.\_m.\_s. Then perhaps it's... it's something that should be. Given help for. and then, of course, one can define it depending on what kind of condition is the basis. If there is something else. One should have the... That's that's. My my advice that I. I teach my my students or the. The doctors in training that the first-line treatment in those conditions is actually to treat the underlying condition. Because if you can't treat the underlying condition. I Mean if it's actually goes away, usually the menstrual cycle linked symptoms are all so minute. And you're also all usually also goes away, or at least so small that perhaps they don't need treatment.[pause] And my my general view is that one should not treat anything that is not needing treatment. Of course, [laughter] that sounds like it's obvious, but it's not obvious.

Reference 6 - 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 7 - 3.42% Coverage

**Thomas:** [00:54:27] Well, as my experience is that the difference between PMS and the.**..** and perhaps I may repeat myself. Now it's mainly due to the severity. And if if it is the same condition and the same symptoms are the main ones, which which is my experience with a lot of exceptions, of course. But like, let's say, the core core symptoms are... are more or less the same. So... so my experience is that... that is... that is. I agree with the consensus in that way that that the core symptoms are or more or less the same. But some people have it very seriously and others don't. They have it less severe oh And then in... in addition to this, there are a number of all symptoms which are related to other disorders or other... other factors or other organ systems like increased urine production, for instance, which is the reason for the... for the increased incontinence. And and so on. They... it's something which... which of course, is... is related to the basic problem and not so much related to the menstrual cycle. Per se. Not only caused by the menstrual cycle and and by that I mean we do the category session of pure PMDD or or core p.m.DD or what we now or would like to call it. Or core p.\_m.\_s and core and an Premenstrual aggravation, of whatever condition or Premenstrual exacerbation or whatever the original system or or condition and. I think those are the cate... cate.. categories. Not whether actually PMDD and p.\_m.\_s is different. That's that's my my view of it.

Reference 8 - 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.

<Files\\E09\_Susan> - § 18 references coded [60.12% 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 - 1.04% Coverage

**Susan:** [00:10:02] But I've certainly talked about it and written about it since. Um, and often when I have given talks around PMS and talk about my journey as a PMS researcher, which started in a very positivist way and has moved away from that. I then will use that as an example. And one of the reasons why [emphasis] I moved away from that was partly because women,[pause] um when I'd give a kind of critical session, constructionist analysis of p.\_m.\_s, women would say, "well, you're completely dismissing my experience" and I was also dismissing potentially my own experience. So, that's partly how i've kind of come to bring my own experience into it. So I'm happy to talk about that.

Reference 4 - 3.91% Coverage

**Interviewer:** [00:12:20] Yeah. Thanks for that.[laugh] Um... so in your understanding, how common is PMS?

**Susan:** [00:12:33] Well, I would say that... Well, what the research shows us.. it's not... That simple. So, there's a lot of studies that show that the majority of women say... so some studies say like 95 percent of women get some sort of Premenstrual change, but that can be quite minor. It might not be noticeable. Women can cope with it and it certainly doesn't have any effect on women's daily lives. What, the research suggests is that between five and eighty...[correction] eight percent of women, depending on whatever study you're looking at, experience moderate to severe Premenstrual changes which cause distress. Um, and there's some studies that say about 30 percent of women get moderate changes and then This 5 to 8 percent get severe changes. It depends on where you draw the line. In terms of what PMS is. So I would. That's why I kind of talk about it much more in terms of Premenstrual distress and impact on lives, because you can have a change. Um, I don't know, I'll give you an example in terms of the menopause, which is I'm kind of in at the moment. So I get hot flushes and I'll probably have to get out my fan, actually (Oh, it's here in front of me!) so I'll probably get one while I'm talking to you. But that doesn't cause me distress... because I normalize my menopausal changes. The main change I have is hot flushes, which makes me feel hot. And then I'm getting a bit like that now. And I just get my fan out... and I'm not distressed by that. But there are many women who have that change that I'm having, and they're extremely distressed by it. And the idea of in the workplace or in an interaction with another person, someone knowing they were having a hot flush, causes them a lot of distress. And then they go and take drugs for it. So I suppose my... I would make a similar argument around Premenstrual change in that many women experience Premenstrual changes. And for some they're quite minor and they might know they're a bit more clumsy or they're a bit more irritable. Physical changes are an issue and I'm increasingly interested in issues around the body and embodiment And how women feel about their body's premenstrually which you know, I'm happy to talk about separately, if you want to talk about that? But we react to those changes differently as women. And so this thing about how many women get it is a hard number... I think lots of women get the changes, but it's how they then respond to it. And... that that is whether they've actually got pms.

Reference 5 - 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 6 - 2.51% Coverage

**Interviewer:** [00:30:26] Yeah, that's fine. Um, what's your understanding about the difference or differences between p.\_m.\_s and p.m.MDD?

**Susan:** [00:30:31] Severity. But I can say more if you want? But if we're speeding then, 'severity'. I can give you... if you want one word answers, you can have them.

**Interviewer:** [00:30:46] Well, if you're happy just saying 'severity' then that's fine.

**Susan:** [00:30:57] Well, on the one hand, i'd say severity, but I would say briefly the difference between PMS and PMDD is that PMDD is in the DSM and PMS isn't. Um, PMDD is used as a justification for positioning women within the psychiatric discourse much more formally. Um, it's used as a justification for giving women psychotropic medications. So SSRIs and officially women, particularly in the U.S. where the DSM operates primarily. But it also is used in [home country]. I don't know how much it's used in the UK. PMDD is a formal psychiatric diagnosis, so that's the difference between p.\_m.\_s and PMDD. But in terms of what it... how menstrual cycle researchers tend to use it is they'll say women with severe symptoms have PMDD, as if it's a thing and women with moderate symptoms have PMS as if it's a thing. But they're both social constructs, they are both diagnostic labels that are created by clinicians and yeah know we know the diagnostic history, you don't need me to go through it. From going back to Frank and Karen Horney in 1931 to try to Dalton to a LLPD to PMS and PMDD. We've got a whole history of psychiatric nosology here, which actually is giving a label to women's distress. So how it's framed is that PMDD is the extreme end of the continuum.

Reference 7 - 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 8 - 2.44% Coverage

**Interviewer:** [00:36:51] Are there any positive menstrual changes? And if so, what are they?

**Susan:** [00:36:57] Yes, there are and they're often overlooked, as I'm sure you know. And [colleague's name] and colleagues have done some really good work around this. Where, they've shown... And we... we've done some work around it as well. Um [colleague's name], who was a p\_h\_d student working with me, did some really interesting work around this. So some women feeling increased... increased, sexual arousal, um sexual response, increased energy, creativity. Some women athletes talk about feeling better in terms of sporting prowess. And we found in a study, this study that I did with [colleague's name], that there were Changes Women report... one of the changes women reported was around increased tidiness, which seemed to me a kind of strange positive symptom, but that's something women talked about. And because some women feel that their breasts get larger premenstrually and that's distressing for some women, but other women like it. So, yes, there are, and I think... that's something I always talk about when I talk to the media about p.\_m.\_s and premenstrual change. And I know myself it was something I... that energy that you can get Premenstrually, which can be anger, can also be channelled quite positively. And we've interviewed a lot of women who've talked about it... I don't know whether it's a kind of self-righteousness, but that sense of... that anger that that's like a kind of real female energy, like a primal energy, which can be a rage, but is also something that can be channelled positively.

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 - 2.32% Coverage

**Interviewer:** [00:41:05] Ok, so run to the last section. So PMS is considered by some to be a controversial diagnosis. What is your understanding of why that is?

**Susan:** [00:41:18] Because it pathologizes normal changes that happen for some women across the menstrual cycle because it positions it within a psychiatric discourse and implicitly in many accounts, positions it as a bodily disorder that needs to be treated through... By by my by... (sorry) by BioMedical practitioners and often through pharmacological means and big pharma have played a huge role in pushing that. And you know, there's really good critical work and I've written about it and [colleague's name] has written about it um, the way that Big Pharma actually started to market SSRIs with PMDD and marketed them through pink packaging and basically telling women with Premenstrual change, they needed to go on Prozac on SSRIs. And so psychiatric diagnoses of Premenstrual change I think is a very dangerous road to go down. At the same time, we need to acknowledge that some women do experience very severe distress at that time of the month. And having that diagnosis can help them to get... help through therapy or through psychiatry or through pharmacology if it can help them. So I think it's a real double edged sword for women. I think we do need to acknowledge the severe distress that many women do experience and I work with many of those women clinically, and I've interviewed many of them as part of research. And I'm not in any way dismissing their experiences.

Reference 11 - 2.89% Coverage

How do you feel about that particular definition? That is kind of a timing based definition rather than a symptom-based definition for PMS?

**Susan:** [00:43:50] I think it's a good one. I think it's taking women seriously and not trying to fit women into... Um, you know, One of the things that's really difficult about PMS research is that so many women are positioned as false positives. If they say "I've got p.\_m.\_s" and then they're given a standardized symptom checklist and they don't have, you know, X number of criteria on the checklist that they're expected to have and then we dismiss all of those women and say, "oh, you don't have PMS, you're not coming into the study" and if that's happening clinically. For women who feel that they have PMS severe enough to need help, then I think that's appalling. So I think what we do need to do is actually acknowledge... but it moves us away from the notion of a syndrome because a syndrome has to have a set number of core symptoms. So it really... but I think if we actually say that women have Premenstrual change and it's on a continuum and some women need support and actually let's talk to them about what's happening and their pattern and whatever their symptoms are, we take seriously then I think that's a good thing. But I think if it's used to then... pathologize all women. Then it's dangerous. But you've got... my understanding of those consensus guidelines. And of those definitions of p.\_m.\_s is you'd need to do that tracking and that daily diary... those daily diaries to see what my symptoms are? And if somebody was saying, you know, I felt I had an itchy foot for.... I'm just trying to think of something ludicrous.... That my foot was itchy, you were nearly driven out of your mind? Well, that's not PMS. Like, you might have a change that happens. Or, you might be feeling more sexy or more energetic. Well, that's not PM... that's not a pathology.

Reference 12 - 2.65% Coverage

And yet the tools that they're recommending are essentially the criteria for PMDD. So what are your thoughts on that?

**Susan:** [00:46:29] I think that's problematic. And, certainly I think that the ideal would be to... um have to talk to each woman herself and ask what her key symptoms were, or her key changes are. And to use the tracking of those, and use the tracking of those and the level of distress associated with them. So not just the changes, because it's about how problematic are they. Like I might experience changes, but it's not a big deal... like there's days of the week where I'm more energetic than others. But it's not a really big problem. I don't get in a state about it. Whereas for some people I know, it is. You know, other people close to me who are really... some of whom have experienced, chronic fatigue syndrome. And who are were very tightly into monitoring their levels of energy and how much exercise they could do, and things like that. And it's a real big issue for them if they wake up feeling tired or can't go for a walk or can't go for a walk. Whereas if I wake up one day and, don't feel like going for a walk 'cos I feel tired, well it's not a big deal, I can do it tomorrow. So I think you've got to always bring that psychological element into it. You've always got to bring in. What does it mean to the person? So, if I feel bloatedness. Personally, it was never a big issue for me. I just wore looser clothes. But some of the women that we interview, it's a really massive issue for them! But they... it's catastrophized. And that's because of what the meaning is of being fat. One of the reasons it's about. The meaning of being fat and how they feel they're being seen and how they feel in themselves and their bodies.

Reference 13 - 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 14 - 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 15 - 2.12% Coverage

**Interviewer:** [00:58:57] So the next couple of.. oh no, sorry, I've missed one. So within I think you've kind of covered this, but within the DSM definition for PMDD, they put a whole lot of physical changes and I would say most of them are quite normal physical changes all into one box as one of the eleven symptoms that they use. Do you have any thoughts about that?

**Susan:** [00:59:30] [pause] I don't know if I can say any more than I've already said, to be honest. I think that, you know, different women have different physical changes that... most women seem to... the common physical changes women, report are breast tenderness, bloating, problems with sleeplessness. Some women report dizziness, some women report um changes in terms of diarrhoea... Um, they are commonly reported so I don't know what... what you want me to say about them. I think that there may be some hormonal connection to. I don't know.

**Interviewer:** [01:00:02] I suppose for me it is, if this is a mental health disorder, the DSM definition of PMDD, I think it's a bit problematic to have normal menstrual changes listed as one of the crit... the diagnostic criteria or... or even just slightly illogical, because these are commonly experienced changes.

**Susan:** [01:00:30] Yeah. No, I agree with you, and I think that. I think that's. I mean, I. I can't. I mean, I don't think I can say any more than what I've already said...

Reference 16 - 5.20% Coverage

**Interviewer:** [01:03:15] OK. Just a couple of kind of evaluation points. Um, so at one point I was quite optimistic that I know whether I'm still as optimistic that it might be possible to kind of... come to a better definition or at least clearer guidelines for (I'm particularly thinking about UK g.\_p.\_s.) So the first line people who tend to have to respond to people seeking support for cyclical symptoms to get some sort of... um, More accurate, if not perfect definition of cyclical symptoms and how to differentiate pathology or at least severe distress from normal menstrual changes. And so the question really is just do you think that's something that's even possible?

**Susan:** [01:04:13] No. Because I think... well, what's implicit in your question is the notion of, you know, pathology and normal as if there's a dividing line... and pathology is something which is a construction. Um if you look across the history of psychiatry and if you're doing your p.\_h.\_d within medical sociology, there's great writers within that discipline. If you look across the history of psychiatry and what we pathologize, it changes across culture. It changes across history. And PMS is a construction of 20th and 21st century Western biomedical and arguably psychological thought and practice. So the idea of... your question implies some sort of realist... Um, conceptualisation of p.\_m.\_s and PMDD as if it is a thing and you can find this absolute criteria that if you tick these magic boxes, then you have got it and someone else hasn't got it. So I think you're chasing a kind of ... I dunno what the proper metaphor is... a red herring, really? Maybe I can think of a better one when I come off the call... But it's... it's... it's... it's I don't think that's the thing to be chasing. I think it's... what I would say and I think your intention is really good about getting awareness of cyclical changes. So I think what you're trying to do in your question is what you need is, in a sense, your answer. I think what we need is greater awareness of women's cyclical changes if they're causing distress. And I think that's one of the posi.... One of the onl... one of a few positive things about the DSM across the board in terms of diagnostic categories is, It's about symptomatology. But if that symptomatology is causing distress [only], so that's you know. So I do a lot of work in the area of sexuality as you probably know and you can have changes in terms of sexual functioning, but if it's not causing distress, it's not a pathology. If you've got no libido or if you're a man and you've got no erectile functioning, it's not causing... If it's not problematic, to you, then it's not a pathology. And so I think that's what we need to be doing about PMS, is having greater awareness that many women or some... some women... some women experience cyclical changes that cause distress. So it's important for GPs to be aware of those and how they impact on women. And as you said in a previous question, if that's interacting with other underlying conditions or chronic conditions to have awareness of that and not be looking for some magic formula, that's... so a GP can say, "ha ha!, you've actually got it!" 'cos it's about that individual woman and her symptomatology and the level of distress and then understanding why it's causing distress, what's actually going on. That's what I'd say as a psychologist, it's not simply giving a pill to get rid of it.

Reference 17 - 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 18 - 3.76% Coverage

**Interviewer:** [01:16:16] I have... like loads of weird things have happened to me. Like I started experiencing some symptoms that I never used to get and I started experiencing the exact things that some interviewees had told me about. And I don't know if it's psychosomat... You know, I don't know if it's that i've been primed or it's coincidence. It could be either. It could just be a... kind of that I'm noticing things that I didn't notice before. Things, I always had, but it's been quite weird and there's no kind of um... It would be impossible to tell anyway, because I'm just one person. And this is my experience and I have quite variable experiences. It's weird when it happens to you, and you think "Ah! Okaaay..." [laugh]

**Susan:** [01:17:04] Yeah. Well there is that a positivist symptom complex that exists in any culture and that we express our feelings of distress through that symptom complex. And I think, PMS is one of those for women today. And it's... it's a... it's a way that we give meaning to our experiences of distress and we can articulate our experiences of distress. So it's not surprising that you are becoming aware of more symptoms from talking to people that you might then tune into them in yourself, and you might have had them before but not noticed them. So it might be... so that's another argument, you know, with increased awareness. You could say "Oh my god, you're going to get everyone to self-diagnose" but most women having awareness and then actually... awareness that you can cope with them and change. I mean, I suppose that's the other thing I'd say and you probably know this, hopefully you know it, anyway? Is that in the research that I've done both with [colleague's name] and the research that we've done here in [country] is that psychological approaches to ... to Premenstrual distress can actually really work. And they are as effective as Prozac, as SSRIs, and that they don't get rid of the symptoms, but they alleviate them and they help women feel that they can cope with them and they reduce the level of distress massively.

**Interviewer:** [01:18:23] Yeah,.

**Susan:** [01:18:23] So, I suppose that's really important to acknowledge, but it's not getting rid of the change. Women still get changes, but they don't feel distressed by them. And that to me is also you've got to really look at that physical, psychological and then the sociocultural and the meaning-making. And I'm going to have to go because I've got a meeting in five minutes...

<Files\\E10\_Marta> - § 8 references coded [22.43% Coverage]

Reference 1 - 2.64% Coverage

**Interviewer:** [00:13:14] So this question sort of kind of repeats this a bit. Could you list a top five or top ten, of the most common Premenstrual symptoms?

**Marta:** [00:13:29] Not with any scientific certainty. I mean, depression, irritability, definitely mood swings... Also very common.. anxiety. Very common. But for the rest of the symptoms I'm on. I'm not really sure. I would say that. Appetite is very common. Or I mean, appetite disturbances is a very common symptom. I would also say that fatigue or lethar... lethargy? I don't know how to pronounce it. I think that's a common symptom. But that's a common symptom in all women. So, I'm not sure whether it's... it's really PMDD specific or not. I think that the physical symptoms are also quite common, but that's usually not what's... what's er the greatest problem for the women.

Reference 2 - 3.50% Coverage

**Interviewer:** [00:14:40] So in your understanding, what are the difference between PMS and PMDD?

**Marta:** [00:14:50] In my understanding, I mean, I see p.\_m.\_s as a milder condition. And I think of it. I mean, from my clinical practice, I think of it this way, that women who take... who bother to come and see me, I... I simply just assume they have PMDD because otherwise I mean, you have to wait long time to see a gynaecologist for your problems. And I would expect then that women who specifically seek medical... medical care for... for [indicates air quotes] what they call p.\_m.\_s, they really have PMDD and I... I'm also guessing that the great majority of women with p.\_m.\_s I never see in the clinic because they find ways to cope with it or they can probably handle it by use of contraceptives or... or over-the-counter drugs or physical exercise or other sort of lifestyle interventions. That's that's just the way I see it from. From a clinical perspective. I mean then of course we have the different criteria for 'scientific' purposes. But if you ask me how I see it, I think it's a matter of severity.

Reference 3 - 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 4 - 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 5 - 4.15% Coverage

**Interviewer:** [00:21:57] Um, so PMS is considered by some to be a controversial diagnosis. What's your understanding of why that might be?

**Marta:** [00:22:05] So controversial by... by ... Who are you talking about now? By doctors. By psychiatrists or by people in general?

**Interviewer:** [00:22:19] Erm, So, again, people have spoken from different angles. But it could be the public perception or the media perception about this labelling 'all women'...

**Marta:** [00:22:33] Uhuh, uhuh OK...

**Interviewer:** [00:22:33] ...in a certain way or even just between psychiatry and gynaecology, perhaps?

**Marta:** [00:22:42] I don't see much of that. To be honest. I think that er there used to be a professor who... who was very critical to the concept of PMDD or PMS, er... but I think she probably retired by now because I haven't heard anything from her er in recent years. And I mean, she was claiming that this was something invented by the pharmaceutical industry to sell drugs to women.[Pause] And I think it's easy to have that kind of opinion when you don't meet the women. So I don't see it. [pause] I never meet with psychiatrists who... who don't believe in it or think that it's phony or. And I certainly don't meet gynaecologists or women or journalists or so... very little of controversy. Actually, I would say.

Reference 6 - 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 7 - 2.17% Coverage

**Interviewer:** [00:28:42] Yeah, it's definitely a tension at the moment. It doesn't. um, Yeah, like you say, it doesn't really help.. because Are you talking about level of severity on like a normal curve or...

**Marta:** [00:28:55] Aha.

**Interviewer:** [00:28:56] Or are you talking about different types of you know, both have a similar mechanism, but different types of things or diagnoses...

**Marta:** [00:29:05] Yeah, that seems that... that really seems unlikely. And I think that er I mean, in a sense, we... I mean, for a range of physical conditions, we just use arbitrary cut-offs like diabetes, hypertension. So why wouldn't the same case happen for for PMDD or depression or anxiety?

Reference 8 - 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.

<Files\\E12\_John> - § 8 references coded [28.34% Coverage]

Reference 1 - 1.70% Coverage

**Interviewer:** [00:01:40] Hmmm. So how do you describe PMS to somebody who's never heard it before?

**John:** [00:01:47] I would say that it's a mixture of predominantly psychological but also physical symptoms that many women get premenstrually. But for some women, they're particularly extreme and those are the type of people that we are typically referring to when we say PMS, as you probably know, about 80 percent of women have some symptoms. It would be inappropriate to pathologize every woman in that group of 80 percent. But there are clearly some where that's disabling and in need of some help.

Reference 2 - 0.70% Coverage

**John:** [00:03:56] Well, it depends on the definition that's used. But Premenstrual syndrome as defined, er... which is basically any [emphasis] symptom, physical or psychological, premenstrually that can be attributed to that... about 80% of women.

Reference 3 - 2.65% Coverage

**Interviewer:** [00:10:22] That's great. Thank you. And again, what is your understanding about the difference or differences between p.\_m.\_s and PMDD?

**John:** [00:10:33] Well, I think PMDD is an attempt to er... [pause] Fractionate out the subgroup of women that have got the worst [emphasis] symptoms, but also a group of women where it's not an exacerbation of something else. Premenstrually but something that is. Uniquely separated from it and... um What's the question?

**Interviewer:** [00:10:59] If there are any differences or how you see p.\_m.\_s and PMDD as different things?

**John:** [00:11:05] Yes. So I think that the key differences are the severity. In as much as one needs to have... Er... Several different symptoms, um three of which need to be from er... a specific group. Um, In addition to... it not being exacerbation of something else. But that's what differs it from... that differentiates it from other diagnoses.

Reference 4 - 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 5 - 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 6 - 5.78% Coverage

**Interviewer:** [00:21:15] Thank you. So the latest guidelines I'm talking about the ones post the ISPMD consensus building process. Now state that any symptoms count so long as they occur in the luteal phase and resolve shortly after menstruation begins and are severe enough to affect daily life. How do you feel about that way of defining PMS?

**John:** [00:21:46] I think it's unfair to [pause] restrict treatment to people who... fulfil a group of criteria that one bunch of people have decided is correct and not to another group of people who are suffering. So within reason, I would say that if somebody is suffering and wants treatment, that it's appropriate for people who can deliver that to deliver it and not get too caught up with definitions and classifications.

**Interviewer:** [00:22:24] Yeah, I mean, pretty much all the clinicians I've spoken to have said they don't really stick to the PMDD criteria. So if somebody has very severe... one symptom or two symptoms and they got to the point of seeing them, they count that as PMDD...

**John:** [00:22:41] Yeah. And the people that come here, I would say that... the crit... They usually end up ticking, actually. Most of them. But er... the area that they would fall down on with regards to the PMDD criteria would be the 'not an exacerbation of another condition'. Or at least that would be one where I would say it's unclear to what degree it's an exacerbation of something else.

**Interviewer:** [00:23:09] And that would affect treatment options?

**John:** [00:23:11] No. Well...

**Interviewer:** [00:23:12] [overlapping speech] So it's just in terms of the diagnosis?

**John:** [00:23:14] I said it wouldn't effect treatment options. If somebody came here and for example, they had bipolar disorder that was exacerbated premenstrually, I would try and treat the bipolar disorder more effectively before going for the hormonal Approach. Or if they were psychotic and that got worse. Premenstrually, you'd want to treat with psychotic symptoms first. So it does influence it in that way.

Reference 7 - 1.68% Coverage

So at the moment, the guidelines on p.\_m.\_s rather than PMDD specifically promote the use of symptom tracking tools as good practice. At the moment. The ones that are promoted are based directly on the DSM criteria for PMDD. So there's a little bit of a tension between the kind of wider, more inclusive p.\_m.\_s definition and the actual tools that people are using. Do you have any thoughts on that?

**John:** [00:24:23] Not particularly, I mean, I think that the.[pause] I think that the symptoms that are described in the DSM 5 criteria are pretty inclusive. It's just how you then use them.

Reference 8 - 5.70% Coverage

**Interviewer:** [00:29:55] Yeah. OK, so... I'm now talking about the PMDD criteria in the DSM. As you're saying, one of these criteria is basically all the physical symptoms lumped in together. And some of those are kind of quite normal menstrual experiences or Premenstrual experiences. And so I think some people are concerned that some very normal and common menstrual experiences have become part of the criteria for a mental health disorder. Do you have any thoughts on that?

**John:** [00:30:33] Well, some people would say it's not a mental health disorder. Full stop. Wouldn't they?

**Interviewer:** [00:30:36] Yeah.

**John:** [00:30:38] Maybe you need to have some physical things in there to... um, reflect that? But I think that if you said... if you picked any of those things like. um, [pause] Sleeping more, or sleeping less. Er... You could say, well, isn't it inappropriate that sleeping more, that could mean, you know, half an hour more you're going to call... or half an hour or less and that, you know, you're going to suddenly pathologize that? Well, again, you're kind of becoming a bit concrete in how that's meant. So if people are complaining of breast tenderness and they're really complaining of breast tenderness and bloating and those are problematic, those would be things that certainly I would consider to be relevant. But if somebody is just saying those things just happen to have them and they're Not a problem or happening to a degree, that's not that significant. I Probably wouldn't count it. So I think it's all about whether it's a symptom... or a problem. Or something of a degree that somebody is complaining about rather than... Something more trivial?

**Interviewer:** [00:31:51] Yeah, I think also it's the kind of slightly arbitrary 'five symptoms' that if you've got all the physical ones in one, I can see why, because it's the criteria for a mental health disorder. But most people will be able to tick that, you know, without any pathology because.

**John:** [00:32:12] Yeah.

<Files\\E13\_Laura> - § 9 references coded [32.57% Coverage]

Reference 1 - 1.12% Coverage

**Interviewer:** [00:00:00] OK that's fine. Right. So then how did you come to be interested in Premenstrual Syndrome?

**Laura:** [00:00:11] [Redacted- personally identifiable data]

Reference 2 - 2.51% Coverage

**Interviewer:** [00:01:56] And do you or did you identify as somebody who got PMS, yourself?

**Laura:** [00:02:01] I think when I was younger, I... I definitely... I certainly had bloating. And then I realized I was eating a lot of potato chips and salt when it was Premenstrual. But I think I also... I think I would... I would get annoyed very easily. So I think I had a little bit of the irritability.

Reference 3 - 3.17% Coverage

So in your understanding, how common is p.\_m.\_s?

**Laura:** [00:03:03] So p.\_m.\_s is about... p.\_m.\_s symptoms occur, but we don't have a good definition of p.\_m.\_s ACOG really hasn't... Well, I guess the International Society for the Study of Premenstrual Disorders has a reasonable one. Um But [pause]. About.[pause] 20 percent of women probably experience at least an annoying set... set of symptoms, which would constitute a syndrome. Um, PMDD occurs in about 3 percent of women... at tops 5 percent.

Reference 4 - 4.64% Coverage

**Interviewer:** [00:07:04] Thank you. So what is your understanding about the differences between p.\_m.\_s and PMDD?

**Laura:** [00:07:14] So there are two cardinal features that differentiate them. One of them is the obligatory emotional symptoms that occur in PMDD and they're not obligatory in p.\_m.\_s. And the second is the degree of functional impairment. So impairment is much greater with PMDD than p.\_m.\_s, but p.\_m.\_s is kind of... or PMDD is a subset, if you will... of P MDD [correction] of p.\_m.\_s. So there's this larger group with p.\_m.\_s and then there's this subset of people who have emotional symptoms and it's really impairing, you know. And then there's nuances like you have to have 5 symptoms out of whatever. But. Yeah.

Reference 5 - 3.49% Coverage

**Interviewer:** [00:09:59] Are there any positive menstrual changes?

**Laura:** [00:10:02] They certainly are reported in the literature. I mean, we don't tend to... as as a physician and somebody who takes care of and treats patients. I wouldn't see... Nobody would come in and see me and say I'm having problems because I feel so much better when I'm Premenstrual. But the literature certainly endorses that.Um, In terms of research, I wouldn't even see it in research because we actually ask for people who have distress, not people who are feeling better.

Reference 6 - 4.47% Coverage

**Interviewer:** [00:11:45] Thank you. So PMS is considered by some to be a controversial diagnosis. What is your understanding of why that might be?

**Laura:** [00:11:56] I know that there is a concern that it stigmatizes women. And I would just say that. Most people who I have heard... Make that claim are not clinicians who treat patients who are suffering.

**Interviewer:** [00:12:19] And what about within medicine? Do you think it's controversial?

**Laura:** [00:12:31] I think having treatments for it and having it in DSM 5 has actually normalized it. I think there was a history in medicine, to, to denigrate people who complained of p.\_m.\_s and say they were just character disordered or crazy or whatever.

Reference 7 - 3.67% Coverage

**Interviewer:** [00:13:54] So for you, PMS is... it isn't debilitating or just... Because you said before that PMDD was a sort of subset of p.\_m.\_s. And that is obviously more severe and mood related. So I'm kind of interested in what is left for p.\_m.\_s.?

**Laura:** [00:14:17] I'm just saying, I rarely see anybody who is functionally impaired by just physical symptoms, and I know that this was years ago, there was an attempt to try and... study treatments for women who had primarily physical p.\_m.\_s and they were... It couldn't complete the study because it couldn't find people.

Reference 8 - 4.33% Coverage

**Interviewer:** [00:16:05] Again, as a result of this consensus process, there's a kind of umbrella term, which is Premenstrual disorders. And then underneath that it's PMDD and p.\_m.\_s kind of in parallel. Do you have any feelings about that way of describing them?

**Laura:** [00:16:24] People have talked about Premenstrual disorders for... well before... This group.

**Interviewer:** [00:16:31] Uhuh

**Laura:** [00:16:34] But my view is... so I think what the attempt was, was to segregate out PMDD. And then the rest of the Premenstrual disorders. I see... I still see PMDD as a subset of p.\_m.\_s. because Anybody that meets criteria for PMDD is going to meet criteria for p.\_m.\_s. Right?

Reference 9 - 5.18% Coverage

**Interviewer:** [00:19:15] Um, and this one's a bit more about the DSM 5 criteria for PMDD. So obviously it's categorized as a mental health disorder by being in the DSM and within the 11 or so criteria. There's one box that has a lot of the sort of physical menstrual changes. Um, so some people feel that that's a little bit out of place in that these changes are very common and are kind of happening. Regardless, really of whether you have the mental health disorder or not, but others are keen to keep them in, so I was wondering about your opinion on that?

**Laura:** [00:19:56] Well, I worked on the DSM 5 and I chaired the subgroup on this, so I guess that tells you something!

**Interviewer:** [00:20:02] [Laugh] So, you think they are of value within the DSM?

**Laura:** [00:20:07] Well, they are part of the syndrome.

<Files\\E14\_Zoe> - § 10 references coded [51.13% Coverage]

Reference 1 - 1.60% Coverage

**Interviewer:** [00:04:56] Thanks Um, so in your understanding how common is p.\_m.\_s?

**Zoe:** [00:05:04] Um... I would say p.\_m.\_s is fairly common, like um if... if... it's impossible to put... It's not uncommon. I don't want to put percentages on it, but it's not an uncommon experience. Um, I think what is uncommon is um women who may have quite extreme experiences, but I think most women or many women um have a period of time before their Period. And it may not be every cycle, but it can be um with... with many cycles where they experience an increased sense of just sensitivity and vulnerability to... to... to managing stressors.

Reference 2 - 4.41% Coverage

**Interviewer:** [00:06:58] And again, in your opinion, what is the best way or ways to manage PMS?

**Zoe:** [00:07:05] Um, I think it comes down to um what if, you know, if the woman experiences interference. I don't think you need to manage anything. If it doesn't, if it's not actually causing a problem. Um, people have lots of... have.... or manage... or manage is sort of the wrong word there. People have lots of things that they experience. Not all things need to be managed. Some things just need to be experienced. Um, and so um if a woman um does find that it is interfering with her, functioning with her, sleeping with her, with elements of her physiology, she may want to manage that through things that actually target and respond to those physiological changes. So she might want to do something that's more active, something that's around sleep, something um that's around exercise, something that's actually addressing that in extreme situations. If it's interfering quite significantly, she may need to have a look at some sort of hormonal intervention um just to correct or or not to correct but to bring back into balance what might be... what might be happening there. If the interference is happening at an interpersonal level, well, then she needs to have a look at what's actually happening at that interpersonal face. But sometimes that might mean managing the physiology first in order to have some clear space. So some clear air to do that. So I think it's... it's really down to a woman assessing what's the level of interference or what's the level of distress and then um doing what's appropriate. And that's... that can be physiological. Psychological; it can be personal. Er, could be walking the dog. It can be a whole range of issues.

Reference 3 - 6.67% Coverage

**Interviewer:** [00:14:04] Thank you. That's very good. What is your understanding about the difference or differences between p.\_m.\_s and PMDD?

**Zoe:** [00:14:16] [pause] [cough] I'm sorry for that cough. Well, clinically, there's I I I think legally and medically there are differences um that come down to um classification and status. So so so one set of differences are around um the need in some jurisdictions and under some insurance schemes to actually receive a diagnosis in order to have access to services and access to care. So that's one difference between them. Um, simply the difference could be seen as one of severity, but then that suggests that they're on a continuum. And I don't necessarily think they are on a continuum, but I think people would assume they're on some sort of continuum. Well, many people assume they're on a continuum. Hence, um PMDD is just the extreme end of p.\_m.\_s, I don't necessarily think that's the case. No, I don't think there's the evidence for that. It's a difference.... [sigh] I don't know they... they are blurring because especially again, in some cultures. In some. [skype delay] some women believe... some women who may have something that is much more like Premenstrual distress or just Premenstrual symptoms may choose to identify and classify and adopt. Labels like PMDD because they're looking for um... there can be comfort in a diagnosis, whereas there's not necessarily a comfort um in just a set of experiences. It's natural that they're finding them distressing. [pause] um... What was the question again? What's the difference between or what do I see as the differences?

**Interviewer:** [00:15:57] Yeah

**Zoe:** [00:16:00] Um, I think there are real differences in in terms of how... what it means for women who are either positioned this way or take up that positioning. And we can have a really long... you know, that's a long one there. As I said, some people find comfort in a diagnosis and some people don't. Some people... and some people are labelled and can be stigmatized with the diagnosis and but others may not necessarily have that experience. Um, I think they are different conditions. I don't actually.. the evidence that I have come across and in the research that we've done ourselves. Women with PMDD present differently to women with just severe p.\_m.\_s. I don't think that. They're at the end of... um.. It's just a more extreme form of PMS. I think they're actually something very different.

**Interviewer:** [00:17:00] Um, you're breaking up a little bit but I do...

**Zoe:** [00:17:01] Those with PMDD do also have other emotional conditions and experiences.... Uh I've lost sound!

Reference 4 - 4.18% Coverage

**Interviewer:** [00:22:20] So men and menopausal women can obviously experience pretty much all of these same symptoms, possibly with the exception of breast tenderness and period pain. Does this mean that the same symptoms have very different biological mechanisms, depending on whether it's cyclical or not?

**Zoe:** [00:22:43] Um... I don't. I don't. I wouldn't agree that men can experience the same symptoms or biological men would experience the same symptoms. I think menopausal women can. But I don't think men can um because whilst I think there is definitely something physiological going on. So I absolutely believe it's something physiological going on. But what is occurring physiologically for a woman, whether she's, you know, pre-menopausal or menopausal or, you know, during the menopausal transition is very different to what's happening for a man. I don't think that men have the same cyclical changes. They do have hormonal shifts and changes, but they don't have the same cyclical changes that are producing the changes in women. The fact that they may experience irritability or anger is not what makes it a Premenstrual symptom. What makes it a Premenstrual symptom is the fact that it is cyclical and it's occurred in that cyclical fashion, not just experiencing anger. Doesn't make it a Premenstrual symptom. So I would I would challenge that men actually experience it. But if the essence of your question is, is there an underlying physiology to what's going on here? Yes, of course there is an underlying physiology to what's going on here. And I think it is uniquely related to the female reproductive cycle and of the female reproductive pattern.

Reference 5 - 1.11% Coverage

**Interviewer:** [00:24:13] Can I just clarify then? So I'm trying to think of a good symptom, so let's say men feel bloating, a feeling of bloating. That is not going to be cyclical or, you know, I'm talking about cis male people here..

**Zoe:** [00:24:33] Yeah

**Interviewer:** [00:24:33] and. So the mechanism behind that bloating is going to be quite different then, to the bloating as experienced cyclically?

**Zoe:** [00:24:46] Yeah, yeah..

Reference 6 - 6.60% Coverage

**Interviewer:** [00:24:53] Right. So p.\_m.\_s is considered by some to be a controversial diagnosis. What is your understanding of why that might be?

**Zoe:** [00:25:06] Again, it's. It can be controversial for lots of reasons. Personally, I find it a controversial diagnosis because of how it labels and positions women. Um, I do think it is um [pause] an experience... Women do experience... Some women can experience Premenstrual distress. We don't need to pathologize that in order to.. to work with women or to assist women or to lead women to their own to their own devices.[slight laugh] You know, experiencing distress is is you know, is something that occurs in this instance it's occurring around Premenstrual change... it's occurring around the Premenstrual period. But distress is... is... is a part of life. I don't... I don't think that's something we need to necessarily pathologize. And then in terms of what the social and the legal and the economic ramifications are of that for women. And I also don't think we need to do it to medicalize it either. I think there's a whole set of medical interventions that come into play once we make something 'a diagnosis'. So I don't think we need to do that for PMS. And um.. yeah... yeah. Have I lost... Have I lost your question? I can't remember.

**Interviewer:** [00:26:22] No.. Well it's considered by some to be controversial. So you know what? What's your understanding of why it's controversial?

**Zoe:** [00:26:30] It's also controversial because some... some people challenge or contest, whether there are... they those whether there are those changes? And they can they contest those changes. Some contest them within a culture, some contest them across cultures. So it can... So it's a contested condition. If nothing else. So. So some people... yeah take it from that perspective. I think yes, there are.... My experience in research would indicate that there are definitely changes. Some women report distress. And but whether we have to actually classify that and position that as a treatable illness or an illness that needs to be treated or untreated is a different matter altogether.

**Interviewer:** [00:27:24] And again, just to clarify, is that including that small percentage of people with quite significant experiences?

**Zoe:** [00:27:33] Um, I think... as going back to a previous answer, I think PMDD is different. I think PMDD is a different set of experiences to just severe p.\_m.\_s. That's not to say that some women who experience severe PMS may not want to do things to manage that interference. But I do think it's actually something very different to PMDD.

Reference 7 - 2.77% Coverage

**Interviewer:** [00:27:56] Ok. thank you. So in the ISPMD or the International Society for Premenstrual Disorders consensus building process. Um, as a result, the guidelines now state that any symptoms count as p.\_m.\_s so long as they occur in the luteal phase and resolve shortly before or during menstruation and are of severe enough disruption to somebody's daily life. And how do you feel about that type of definition?

**Zoe:** [00:28:40] Um, I think that's that's fine. It's more the definition is fine because I do think it is very much around.... There's a range of experiences and I think that's capturing the idea that there are a range of experiences. My concern is more in how definitions are used or what the purpose of such labels or definitions are. But as a definition, I think yes it's it's it's fine because it does capture a range of experiences or allows for a range of experiences. It also allows for you not to adopt the label if you don't want to or adopt the classification if you don't want to. So, yeah, I think it's fine as far as labels go. We do need them in certain circumstances.

Reference 8 - 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 9 - 9.95% 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.

**Interviewer:** [00:39:08] Thanks for that. Right. So in these new kind of the consensus approved guidelines, we now have an umbrella term, which is Premenstrual disorders. And under that is PMS and PMDD as kind of parallel categories. Um do you have any thoughts on that? Just bearing in mind that, you know, you have slightly answered this in previous answers?

**Zoe:** [00:39:43] Yes, at least they're different... as I said, I don't see them as a... on a continuum, which many people do. I do actually think they're different conditions. So yeah, I don't know if I can add too much more to what I've already said... yeah.

Reference 10 - 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> - § 14 references coded [50.60% 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 - 1.19% Coverage

**Interviewer:** [00:04:46] Do you or did you identify somebody who gets p.\_m.\_s?

**Geraldine:** [00:04:51] Er, No [laugh]. No, no. Of course, you know, that's not to say that I never had breast sensitivity. Or acne or something like that before my period. But I never had anything that I would categorize as p.\_m.\_s based on any definition or measure that I've ever seen.

Reference 3 - 2.29% Coverage

**Interviewer:** [00:05:16] Yep. And you touched on this already, but can you remember how you very first came to know about PMS?

**Geraldine:** [00:05:23] Just from reading about it.

**Interviewer:** [00:05:26] So what kind of age were you then? That was at university?

**Geraldine:** [00:05:31] Yeah, Graduate school. So, you know, in my 20s. [Pause] So now, you know, my mother did say when I was a child, occasionally my mother would be in a bad mood and she would say, "I got up on the wrong side of the bed today". And so, you know, decades later I thought, "Oh, I wonder if she was Premenstrual when she would tell me that I got up on the wrong side of the bed". That was her explanation for being in bed.

Reference 4 - 1.73% Coverage

So obviously this is a slightly tricky question. How common is p.\_m.\_s?

**Geraldine:** [00:06:29] Ha ha! [laugh] Well, [exhale] you know, the psychiatrist say that PMDD is about 2 to 3 percent of people in epidemiological studies. I don't know of any good estimates of how common p.\_m.\_s is... Uh, Premenstrual symptoms. If you don't call it a 'syndrome', that's very common. Um... Maybe 90 percent of women experience something? So it's a very slippery definition. But as I said before. Most women, anyway, seem to think they have it.

Reference 5 - 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 6 - 3.04% Coverage

**Interviewer:** [00:10:44] So the next question was, in your understanding roughly how many Premenstrual symptoms are there?

**Geraldine:** [00:10:52] Well... I don't know. In my understanding, I can't give you a number, but it's a lot fewer than 130. I can tell you that. [laugh] some of them are just you know, things that people made up. For example, I once read I was reading um in the late 1980s, I read all of the popular media articles about p.\_m.\_s and one of them said, "your perfume smells different". [laughter] Yeah. So I just imagined a bunch of women sitting around in a magazine editors office just talking about their own experience with their menstrual cycle. And somebody said, you know, [puts on high pitched voice] "my perfume smells kinda different when I'm Premenstrual" and they wrote that down and put it in the article. And now women think that that's a symptom. [laughter] So there's a lot of nutty things like that.

Reference 7 - 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 8 - 7.64% Coverage

**Interviewer:** [00:19:02] Yep. Um this is a slightly weird question, so obviously menopausal women or men or people with male reproductive anatomy...

**Geraldine:** [00:19:15] aha

**Interviewer:** [00:19:15] Can also experience pretty much nearly all of the same symptoms just not in any kind of cyclical pattern. So does this mean that the same symptoms have different biological mechanisms depending on the patient's reproductive status or sex?

**Geraldine:** [00:19:38] Well, I suppose there are some that might be. But in general, I would say no. So, you know, as I mentioned before, there's a big overlap between the symptoms of stress or signs of stress and other so-called signs or symptoms of p.\_m.\_s. So, you know, I would often tell my students that, you know, a man and a woman wake up in the morning and experience some symptom. And she thinks it's related to her menstrual cycle and he thinks he has a hangover or is getting a cold or, you know, he's worried about his biology test in the afternoon. You know, it's... a lot of it is about attribution of the symptoms. Like what? What they mean to you, what you think they are.

**Interviewer:** [00:20:24] Yeah. This is a side... This is a side note not on my question list, but I looked into clumsiness because a lot of people report having a kind of clumsy day, usually one day a kind of 18 hour window and it's attributed to the menstrual cycle. But then when I talk to men and they quite often have clumsy days too,.

**Geraldine:** [00:20:47] Sure they do!

**Interviewer:** [00:20:48] And they attribute it to hangover or just tiredness. And I think that really makes it... but it was interesting because myself, I had. Taken that on as a menstrual thing myself. You know, I'm not clumsy normally and occasionally I would be and I'd think it "Oh it must be my hormones" because I'd heard of that.

**Geraldine:** [00:21:08] Yeah, that's interesting. We don't hear that too much on this side of the pond! [laugh]

**Interviewer:** [00:21:12] Well, I've never heard about bad driving at Full Moon! That's really interesting.

**Geraldine:** [00:21:16] Oh, you haven't! Oh my!

**Interviewer:** [00:21:17] No, we have the whole like 'lunatics' like there's more fights and there's more... I mean, it's not true but people think that people go mad...

**Geraldine:** [00:21:26] Right... People think. Yeah, yeah.

Reference 9 - 5.57% Coverage

**Interviewer:** [00:21:31] So, P.\_m.\_s is considered by some to be a controversial diagnosis. What is your understanding of why that might be?

**Geraldine:** [00:21:40] Well, of course, there's the question of whether it's a culture bound syndrome. You know, as I mentioned, in 1988 when I talked about it in Singapore, none of the Asian women had ever heard of it? And they were having trouble understanding what it what it is. So, you know, a lot has to do with our beliefs about menstruation, our beliefs about women's nature. So that's one element of controversy. Another element, I think, is how it contributes to stereotypes about women. And these can harm women's ability to attain leadership positions in society. For example, when Hillary Clinton was running for president, in 2008, I Googled just for the fun of it. p.\_m.\_s and Hillary Clinton and I found thousands of hits and she was, of course, post-menopausal. There was no way she could have been Premenstrual or had PM.S. But you know, this is just the kind of thing that people believe and so it's controversial because it can be a problem for women, who are diagnosed. But if you talk to the women who suffer, you know, and experience symptoms that they believe are related to their cycle, they often feel that they're being somehow punished if it's not recognized. So that's another controversy. You know, getting a diagnosis is helpful to some women, but it's not helpful to others. And, you know, this belief that's become so common that 'all women' have this is harmful to all women because most women have mild to moderate symptoms. Premenstrually and some women have none. And so it doesn't affect everybody. But yet the assumption is that it does.

Reference 10 - 3.14% Coverage

**Interviewer:** [00:24:09] OK. So I don't know if you know, but there was this consensus building process held by a group called the International Society for Premenstrual Disorders?

**Geraldine:** [00:24:23] Oh, really? I've never heard of them! How interesting...

**Interviewer:** [00:24:26] It was a group of American... largely American psychiatrists and UK gynaecologists. And then some others... [overlapping].

**Geraldine:** [00:24:34] Uh![overlapping]

**Interviewer:** [00:24:34] Like pharmacologists and endocrinologists. And they had I think four or five meetings over a decade between 2006 and 2016 to try and come up with a consensus definition on p.\_m.\_s.

**Geraldine:** [00:24:50] Ah! And did they?

**Interviewer:** [00:24:52] Well, so [laughter] at the moment they state that any symptoms count so long as they bring in the luteal phase of the two weeks before menstruation...

**Geraldine:** [00:25:04] Yeah, Two weeks. So half the month, women are ill! [smiling]

Reference 11 - 2.12% Coverage

**Interviewer:** [00:27:21] Yeah, but it's this thing... it's what's. It's not only the severity level. A couple of people have said it's actually it's the. other boundary between what's normal and what you know, it's the lower level. Plus this kind of severity level that needs to be better defined. But it's incredibly difficult to do so...

**Geraldine:** [00:27:44] Right! Because we don't feel the same way every day. And, you know, men don't feel the same way every day. Pre-menarchial girls don't feel the same way every day. Post-Menopausal women don't... I mean. So it's not just feeling differently. You know, it has to be something more than that.

Reference 12 - 1.85% Coverage

**Interviewer:** [00:30:58] So. PMDD is categorized as a mental health disorder by virtue of being a DSM category.

**Geraldine:** [00:31:07] Right.

**Interviewer:** [00:31:07] But within its diagnostic criteria. There are several normal physical menstrual changes...

**Geraldine:** [00:31:14] Right

**Interviewer:** [00:31:14] Which sometimes can be symptoms if they're very severe. Do you have any thoughts about their inclusion in a mental health disorder?

**Geraldine:** [00:31:23] Yeah. They don't belong there. [laugh]Yeah. I mean, that is where they overlap with p.\_m.\_s.

Reference 13 - 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 14 - 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> - § 10 references coded [25.02% Coverage]

Reference 1 - 0.81% Coverage

**Interviewer:** [00:03:10] So do did any of your close family members or friends identify as people who got PMS?

**Chris:** [00:03:17] I bet you my mother did. Except that we didn't know what p.\_m.\_s was. And maybe my daughter, don't know?

**Interviewer:** [00:03:26] So is that just sort of with hindsight..?

**Chris:** [00:03:29] With hindsight, with my mother, yes. 'cos She varied in her...[pause] mood and I'd be extremely surprised if it wasn't p.\_m.\_s.

Reference 2 - 1.04% Coverage

**Interviewer:** [00:04:43] So in your understanding how common is PMS?

**Chris:** [00:04:47] So we're talking PMS... [Pause] Because it's difficult until you define it, so it probably occurs... Premenstrual symptoms are almost certainly physiological and they probably occur in over 50 percent of the population. Severe p.\_m.\_s. Depends how you're defining it. Because I sort of think severe p.\_m.\_s and PMDD are more or less the same thing. And so. So then you say it's 5 to 8 percent of the population, but of course you will find 25 percent of the population say as having severe symptoms.

Reference 3 - 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 4 - 1.19% Coverage

**Interviewer:** [00:20:55] So do you consider period pain as a Premenstrual symptom?

**Chris:** [00:20:59] Technically, it can be if it's Premenstrual. Except that it's not typical um... p.\_m.\_s. It's pre... Premenstrual Period pain i.e. before the period. More typically associated with endometriosis. The definition does allow that... Of p.\_m.\_s - it doesn't allow it for PMDD. [pause] So it's not... it's not uncommon for women to have both severe PMS and Premenstrual pelvic pain.

**Interviewer:** [00:21:32] Aha, yeah, no... some of the patients, that I've spoken to have had severe pain as well as...

**Chris:** [00:21:38] Yeah

**Interviewer:** [00:21:38] ... mood changes.

Reference 5 - 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 6 - 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 7 - 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 8 - 1.91% Coverage

**Interviewer:** [00:31:52] So, where was I? Oh yeah, so the current definition is that any symptoms as long as they occur in the luteal phase and resolve. Shortly after menstruation begins...

**Chris:** [00:31:59] Yep.

**Interviewer:** [00:31:59] ... and are severe enough to affect daily life...

**Chris:** [00:32:01] Yep.

**Interviewer:** [00:32:02] ...How do you feel about that definition?

**Chris:** [00:32:04] Oh, I think that's the definition I would go with, yeah.

**Interviewer:** [00:32:07] So you're happy with that?

**Chris:** [00:32:08] Yeah, that's the definition. For WHO, the ICD Eleven. It's the same as the RCOG guideline. It's just that I think it's pretty much the same PMDD APA guideline? So I think that's perfect. Yeah, but... but... but also you've got to think of the subcategories or the atypic... the atypical variance.

**Interviewer:** [00:32:36] So it's almost standardised then, across these formal... [overlapping] publications

**Chris:** [00:32:40] I think it's pretty standard. Not... Not till relatively recently. But it's it's pretty standardized. I think.

Reference 9 - 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 10 - 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.

<Files\\E17\_Jo> - § 9 references coded [30.42% Coverage]

Reference 1 - 1.61% Coverage

**Interviewer:** [00:01:11] And how do you tend to describe PMS to somebody if they don't know much about it at all?

**Jo:** [00:01:17] So I would make the point that it's a cyclical problem. It's not there all the time. And that's really important. And also... Lots of women will have um... symptoms related to their menstrual cycle. But if it's not resulting in impairment, then that's not an issue. So impairment is a big part of the diagnosis.

Reference 2 - 3.01% Coverage

**Interviewer:** [00:05:02] So in your opinion, roughly how common is p.\_m.\_s?

**Jo:** [00:05:08] It's a lot more common than I think we we had previously thought. I mean, it might be 25 percent of women will have some element of PMS. I think it's... As time's gone on as well, because I have now [pause] As a result of this study attracted lots of women, who who either are self-diagnosed or they've been diagnosed or or they've struggled to be diagnosed. I think it's one of these things that's very difficult because the number of women with core PMDD is probably relatively small, but there are lots of women who've got other mental health issues or co-morbidities or whatever you like to call them. And so it's... It's a... I think some you know, lots of the women that I'm speaking to, now, are really very difficult to manage?

Reference 3 - 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 4 - 2.94% Coverage

**Jo:** [00:11:10] And I think the other thing is that I think sometimes when women will make um several appointments. So they'll make an appointment when they feel horrendous and then they feel better, and then they think "Actually I don't need to go". And they know... They know that there is a recurring cycle going on. But it's like when you feel, well, you just want to be well, don't you? And you don't want to think there's something. Well, that's what I think, anyway. That they don't want to think that there's something wrong.

**Interviewer:** [00:11:33] Yeah. I've done some research on endometriosis and heavy menstrual bleeding and the optimism with which people (or denial), whatever it is, is this kind of once it's over, it's like, "OK, well, I'm fine now for a bit" And they don't seek treatment.

Reference 5 - 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 6 - 5.00% Coverage

**Interviewer:** [00:19:45] Ok. One to the last section. And so p.\_m.\_s is considered by some to be a controversial diagnosis. What's your understanding of why that might be?

**Jo:** [00:19:58] And I think in some situations it's not properly diagnosed. So that would be very controversial then. I think it's really, really important that women have a proper prospective diagnosis. And it is quite an uncomfortable place to be as a clinician when you've got some day in front of you who's saying "every month, I feel horrific". And you're asking them then to go and record... Their record, their symptoms and bring them back to you. But I think for those women who may be going to have surgery, it's absolutely crucial. I had a patient in very recently who was told by a gynaecologist that she had p.\_m.\_s. She had had no children. She had a hysterectomy noth ovaries removed. And then they changed the diagnosis to rapid cycling, was it rapid cycling, bipolar, bipolar disorder? And so, you know, she's well, she's going through a litigation process but had that gynaecologist shown that they had gone through all the steps to make a clear diagnosis. I think there would have been less of a case to answer to. I Think it's a big step to take somebody's uterus out, and ovaries, when you haven't got anything to prove your diagnosis. Apart from that, you thought they had p.\_m.\_s.

Reference 7 - 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 8 - 1.54% Coverage

This is not PMDD. And then the tools that they recommend to use for tracking are basically the DSM type eleven or tweleve criteria. So do you have any thoughts on that?

**Jo:** [00:26:27] Um. I think that. Is going to make it difficult for the women who are severely affected. I think they become lost then in the bigger group of what really are nor... Normal women with a spectrum of how they feel on a day to day basis.

Reference 9 - 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.

<Files\\P01\_Alice> - § 10 references coded [20.12% Coverage]

Reference 1 - 1.18% Coverage

But if I'm having one of those one in every three and it's very erm.. it's completely immobilizing, so I will... You know, I've been out in public when this has happened, so I will vomit. er, I can pass out. I'll be on. I'll have I'll have everything at Both ends. So it's very grim. So I'll have complete... the vomit will be pain relief because I'll be er 10 out of 10 more pain. I mean, over-the-counter medication doesn't touch it. I'm not somebody that would want to take loads of that anyway. But it doesn't touch it. So I will vomit in relief because the pain and then my stomach will just go to shit, literally. And I will just sometimes need a bath and the toilet because it's so awful.

Reference 2 - 0.52% Coverage

Well, I might have as well as I'll pass some real thick blood. And so like some clots. But not you know, I've spoken to medical professionals about this and they'll describe it as a massive clot, it isn't it's just clots, you know, like we all get clots and sometimes just a lot of blood that comes out.

Reference 3 - 1.98% Coverage

Although, to be fair, I no longer speak to any health professionals about it because my experience has been 'It's normal. Get on with it'. So I just deal with it myself. Um, I have tried, as was saying, to to try and. You know, because I'm a health professional myself, so I know about medication, so I try and look at the symptoms. Am I gonna have one of those explosive days. So I try and take the medication to sort of get in there before it happens. So that's one thing that I might try and do, but that depends on context and circumstances. Often I get these in the middle of the night or sometimes when I'm... er... one time. It happened when I was cycling and I thought I was going to blackout and pass out and it was happening. I was in the road and luckily I was in the local area. So I just cycled straight to my parents' house, managed to ring the doorbell and then passed out on the doorstep. My dad had to carry me in and put me on the toilet and then put me in the bath. He has experienced that and my partner has experienced it. And I think for other people, it's really quite frightening to see you in that state. They think 'this can't be right'.

Reference 4 - 1.25% Coverage

Alice: [00:20:50] I do not let it overrule my life. You know, I will rarely… I mean, if I've had like a horrible one of those one in three periods and it's happened in the middle of the night and I've been up all night, then I might be late for work for three or four hours and I'll have to call in. And I won't tell the truth. You know, I'll say I've had… I'll just say 'I’ve had vomiting' and often then they'll be like 'don’t come in, if it’s something infectious or whatever'. So I don't… I do not let it ruin my life. I just get over it. Do I worry about each month? No… [00:21:32] I have people around me said, you know, you really need to do something about it. Yes, but to be honest, I've got to the point of, just ignore it.

Reference 5 - 2.03% Coverage

Interviewer: [00:21:42] So this is a similar question. How would you react if someone could wave a magic wand and you would never menstruate again?

Alice: Erm…

Interviewer: [00:21:52] I mean, as a choice, not forced upon you! [laugh]

Alice: Well, I wouldn't want that necessarily because that would mean I can’t have children. [00:22:01] I'm… actually I think releasing an egg and go through that process is something that a lot of people say, 'oh, God, I never want that to happen again'. But for me, it's more of a necessity for new life. And I think if you speak to women who go through the menopause, which is maybe another study you could do [laugh]. There's a real lack of evidence and research and that and a lot of people would say, 'I would give anything to go back to feeling the way that I felt when I did menstruate, even if I had terrible menstruation'. So, no, I wouldn't want that for the reasons that I said. And, you know, I am a bit more fearful as well of what happens to your body just physically and emotionally when you do go through the menopause. But if I could have a magic wand to take away my one in three only for those four hours, that would be great.

Reference 6 - 4.84% Coverage

So, How many types of symptoms do you think that can be or that there might be? So 10, 20, 50, a hundred more? What's your sort of feeling about premenstrual symptoms?

Alice: [00:44:46] I think it's there's probably not… there's not probably a defined number, I think. Again, like I said before, I think it's very individual. I think you could give an umbrella category of symptoms. You may experience. I don't think it's black or white. You know, it's a bit like if you Google something that you think you might have… [00:45:10] They'll say, you know, you may get this, this, this, or this? I think it’s similar. And you might you might get a temperature change. You might get hot and clammy and sweaty. You might put on some weight. You might feel lethargic. You may experience abdominal discomfort. You might get constipation. You might get diarrhea. You know, it's a bit like that. [00:45:33] You… you may feel flat. You might feel emotional. You may get sleep problems… [00:45:43] Erm, You might feel less engaged to communicate with people, you might feel socially isolated. I think there isn’t a defined number… [00:45:53] I think, you know, there are certain probably symptoms that are more common, like I definitely get diarrhea. Whereas other women don't. And that's apparently to do the amount of hormones that are in your body… I said apparently… [00:46:12] But that's but that's not because... [pause] I think this is an area that hasn't been explored. [00:46:17] So, yes, there are like any. Like any. The only thing I would say that I think is important here is it's not a disease or an illness. So like having a period is a natural process. [00:46:34] And actually, I think maybe we need to change the language that we use within health and society. [00:46:41] And I'm not surprised that you've just said that there's another disorder. That I don't know about. [00:46:46] Well, isn't that convenient? [laughter]

Interviewer: Yes…

Alice: I think we we just need to look at that… Women release an egg because they are... they have the anatomy. That means that you can bring life into this world, which is quite remarkable. But in that it's such a highly complex, amazing, physical and physiological process that goes on and emotionally. [00:47:13] There are so many factors that interplay here and our world in the West is even more complex because of the food we eat, the way that we produce food, the plastics in our society, the air that we breathe and the stress that we have, the location that we might live in. You know, all of these factors are likely to impact the way that our symptoms may present. And I don't think it's a disease or an illness. It's just a physical process. And you may get some of those symptoms or you may get more of those symptoms dependent on what's going on in your life at that point.

Reference 7 - 3.75% Coverage

If you wanted to talk more about the pain,[sigh] the pain. So I suppose for me, the pain is immense. And that time and the pain can vary from if I'm having a normal period or just be. It'll be painful, but I never feel I really need to take any drugs. But that could be because I know what it's like for it to be extremely painful that I just manage that type of pain and that’ll be cramping, throbbing. Like a few sort of fireworks down in the sort of lower abdomen area. [00:51:06] I suppose you could describe it like that and it will come in waves. So it will happen and then it will get a bit of relief and then happen again. And get a bit of relief and that’s happening on day one or day, two. And then I won’t have pain for the rest of the week. But If it's like one of those terrible experiences. The pain is like more than 10 out of 10 pain and it will start gradually and then it will build and then that build will happen for a good couple of hours. And I've not ever had a baby yet, but I imagine it's a bit like having contractions.

Interviewer: So like you have waves again?

Alice: Yeah, So it's all waves and then I'll get maybe 30 seconds of off. I can relax and then it’ll come again and then it builds and builds and builds and then I'll vomit. Oh, And the other thing that happens is I like when, you know when you're gonna pass out for whatever reason, you've got an illness. I get incredible... I know it's happening because I get so clammy and sweaty and hot. And I think I'm going to… I can’t stand up, I have to lay on the floor and I will get that layer of like…. I will get drenched. I will be absolutely pouring sweat. And then I will just projectile vomit and vomit and vomit, but I need the toilet at the same time. And I know when I reach that point, which is just horrible, I've reached like [laughter] a finale and then I'll be like, phew. It's over. But getting to that point is absolutely horrible. And then I'll be exhausted. So for hours, because it is just this bit of the process. And then I'll be fine.

Interviewer: [00:52:47] It sounds horrible. [laughter] Very well articulated.

Alice: [00:52:52] Thanks, yeah. And then I'll go to work! [laugh]

Reference 8 - 1.01% Coverage

Personally, the pain I experience…[00:56:35] You know, if someone said to me it doesn't exist. I would say, well, when I'm having one of those horrendous experiences, just come and see what it's like, I guess… [00:56:44] I think the physical associations of that pain that occurs to me… So, you know, the vomiting isn't painful and diarrhea isn’t painful, but that for me is the consequence of the pain I'm experiencing. If somebody said that I was making that up and causing that myself… [00:57:10] I think that would really upset me. Erm, but I'm sure that somebody might say it [laugh].

Reference 9 - 1.13% Coverage

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,

Reference 10 - 2.43% Coverage

Yeah, yeah. Well you’re the first person who has… well obviously I have spoken to my friends and family and they've witnessed it first hand. And I've got the pressure from them to go and do something about it, which must mean that I am to them… that this is not normal. There's a problem… but I feel much more relaxed about my physical symptoms than they do. But I think they see it as alarming. But I think you're the first person who's wanted to listen to the actual my thoughts and knowledge and understanding and the journey of the symptoms that I've experienced. What I mean by that is when you do go and see a health professional, you don't expect necessarily an outcome. But, I mean if they had just said to me, this is normal,

…that's fine, but no one tells you anything. They look at you like you are an absolute nutcase because. This… or, you're making it up because they have never witnessed this.[01:07:53] And actually, when I did have the worst one ever, which was when I was having a miscarriage, which is different than the bloke told my mom on the phone, she was panicking so much that he needed that she needed to call an ambulance…[01:08:06] And now I said, 'no, this will pass'. I know myself more than anybody. [01:08:13] But actually people don’t have time to listen to these stories and they don't want to know. [01:08:19] And I think talking about it can make you feel more normal than alien [laugh].

<Files\\P02\_Beth> - § 10 references coded [22.64% Coverage]

Reference 1 - 1.87% Coverage

**Beth:** [00:09:18] Because I'm trying really hard to self-manage it at the moment and not pick. I'm down to my sort of last self inflicted scab that had almost healed but because I'm premenstrual right now. My period's due imminently... last night I had a bit of a relapse. I've just had a bit of a pick, at this almost healed scab on My neck and I know I'm going to pick more... erm, until my period starts... erm, because that tends to be how it goes and how it's been over the last several years, really. So I've covered up the area so I don't pick it further. So, yeah, I guess from the point from... The point of view of that particular condition. I am more aware before my period that I'm more likely to pick because recently I've started to make a real effort to manage it. I... I am more aware that I need to make a bigger effort before my period to try and stop picking.

Reference 2 - 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 3 - 1.95% Coverage

**Beth:** [00:20:22] [long pause] Erm, Personally. It's just something I've accepted really... but I think I've been pretty lucky, though, because... Over the whole course of... Erm, My life since I started menstruating, I haven't had any major problems with them. I'd imagine for a woman who'd had really, really painful periods ever since she started or really heavy periods or other sort of major health problems associated with them. It would be a real drag and quite debilitating for her to look ahead and think, 'oh, god, I'm gonna have periods until I'm like in my mid-forties, mid-fifties'... But for me, it's just a thing, you know. It doesn't bother me that much. It's only been over the last, I guess, five years. That premenstrual symptoms have become more of a drag. And I sort of don't look forward to that every month. But. Apart from that, the thought of having periods for many years doesn't bother me.

Reference 4 - 1.78% Coverage

**Beth:** [00:27:55] [long pause] I'd say some girls and women find that... They can feel different and sometimes a bit unwell before they start their periods or over the first couple of days of their period. This is called p.\_m.\_s and it varies a lot from person to person and not everyone gets the same symptoms. It involves lots of symptoms like really common ones might be; Feeling just tired or a bit down and you don't know why and you're more likely to cry at things, but it it can also mean that you get a bit of an upset tummy or.... Well, you find it a bit hard to go for a poo. And, you know, there's a lot of variation between the symptoms and Not everyone gets it. Some people don't get any p.\_m.\_s at all, but it's quite usual and common to get it as well. Although I don't think that's explaining it well, at all! [laugh].

Reference 5 - 1.60% Coverage

**Interviewer:** [00:34:18] Yeah, that's great. That's a really good answer. How do you manage your symptoms?

**Beth:** [00:34:38] It's kind of a work in progress, and I don't know if I actually do manage all of them. I think most of them I just put up with and wait till they go away [laugh], I think just by being aware of them as being down to the menstrual cycle and knowing that they're not going to last forever and knowing why they're happening. Or at least you know, when they're going to happen. It's helpful because it means that... You know, I can think 'Oh, this is only going to go on for a few days and then I'll feel better'. I think just that awareness is helpful cause to be honest, there's not a huge amount else I feel I could do about it.

Reference 6 - 1.59% Coverage

I must say there's probably more I could do in terms of getting exercise. Another significant premenstrual symptom, I guess, is, is constipation actually, and I know. That...There's stuff I should do to help with that, but I don't. Erm. Because I know I don't drink enough fluids and if I did increase my fluid intake. In the week before my period, it'd probably help. I know that in my head. But I just don't. I don't do it because... I like... some some people naturally get thirsty and drink a lot. And I... I just. I can go through the day without having a drink [laugh] and that's really bad for you. So, yeah, there's stuff I could do to help that I don't because I'm lazy. and forgetful [laugh] Yeah, so I'm definitely not helping myself.

Reference 7 - 2.78% Coverage

**Beth:** [00:39:25] Probably... Erm, I don't know. It could be because, I mean, probably the most significant premenstrual symptom I get is the anxiety, but... But I have generalized anxiety. Anyway, I don't think it's caused totally by my menstrual cycle. It's not... It gets... I've got pre-existing anxiety that's aggravated by changes in my menstrual cycle. but the menstrual cycle isn't the cause of the anxiety, you see what, I mean, so, yeah, I've consulted a doctor several times about my anxiety... But I haven't really brought up with my doctor that it gets worse. As a p.\_m.\_s thing, because to be honest, I don't really know what they're gonna do about it. I'm already on medication for anxiety... I have past experience of not getting on very well with hormonal contraceptives, which I guess a doctor might offer as a potential treatment for p.\_m.\_s. So I've kind of assumed that there's no point in me personally. Raising my p.\_m.\_s symptoms with a doctor cause. I have kind of... I've found a way that's good enough for me to self manage it and I dunno What they're going to add to that, That might be a bit pessimistic? And I wouldn't... I don't. I wouldn't want that to put other people off, you know, seeing their doctors about p.\_m.\_s symptoms. But for me, I don't think it... would help?

Reference 8 - 1.94% Coverage

So the mood disturbance was enough to cause problems in day-To-Day life and functioning. That's what I understand.

**Interviewer:** [00:49:28] So how is that different to p.\_m.\_s or what's the relationship then?

**Beth:** [00:49:38] [long pause] Well, you can get a bit irritable and tearful. Before a period. PMS. but not to the extent that it. Might be classed as a clinical depression. Whereas PMDD would be a more significant mood disturbance, but the timing of the symptoms would be the same for it to be classed as premenstrual. If that makes sense?

**Interviewer:** [00:50:09] Yeah. Brilliant. Thank you.

**Beth:** [00:50:14] PMDD is actually classed as a psychiatric disorder, I think, whereas p.\_m.\_s, isn't...? Am I right with that? I don't know...

**Interviewer:** [00:50:22] You are, yes! This isn't a test, this is this kind of because.

**Beth:** [00:50:27] Oh no, I just like to know these things! [laugh]

Reference 9 - 3.12% Coverage

**Interviewer:** [00:58:00] Yeah. You've touched on this before, but this is one of the questions. Do you have any other health conditions that get worse at certain times in the menstrual cycle? And if you do. Do you count these as premenstrual symptoms?

**Beth:** [00:58:19] [pause] I do. Yes. I mean, I've got generalized anxiety disorder. And that's what I find it difficult to know whether to call the anxiety... the increased anxiety I get around ovulation or a period p.\_m.\_s or whether it's a pre-menstrual exacerbation of my pre-existing anxiety. But that's personally for me. I know that anxiety can Be a premenstrual symptom and I know anxiety can be part of p.\_m.\_s in women who don't otherwise have generalized anxiety. If you see what I mean?

**Interviewer:** [00:59:01] Yeah.

**Beth:** [00:59:01] So, I think for me it's not simply p.\_m.\_s but that it can be a p.\_m.\_s symptom for other women.

**Interviewer:** [00:59:10] Yeah, That's great.

**Beth:** [00:59:11] And likewise, with the skin picking thing I know that's not p.\_m.\_s, it's a separate condition I have, but it gets worse before my period.

**Interviewer:** [00:59:23] So you wouldn't count that as a premenstrual symptom?

**Beth:** [00:59:29] No, no, it's a condition I have that is aggravated by premenstrual changes, but it's not simply caused by PMS. Well, none of it's simple. But I mean, I wouldn't say it's p.\_m.\_s. No, because it's an issue at Other times... it just gets worse around my period.

Reference 10 - 1.39% Coverage

Are you aware or have you been made aware at any point that PMS is some sort of controversial diagnosis?

**Beth:** [01:03:57] [Very long pause] No, I don't... I don't think so. I mean, it's not... I'm thinking about conversations with other medical professionals. I don't think it's really discussed much at all among medical professionals, as a diagnosis. And. I mean, I can imagine that some women might feel dismissed if they were told they had PMS as being told they had something insignificant or that couldn't be treated. But that's just me theorizing. Really, I haven't been in a situation where I've been told it's a controversial diagnosis. No.

<Files\\P03\_Dani> - § 6 references coded [16.98% Coverage]

Reference 1 - 1.61% Coverage

**Interviewer:** [00:03:00] Ha.[laugh] Do you feel any different before, during or after your period?

**Dani:** [00:03:09] Yeah, I feel really tired before my period and like just a bit. I get quite grumpy and my boobs hurt. It's not the same every month. But it is pretty much or they're a bit sensitive. Yeah, pretty much. I just feel a bit low. I think I would say not like and it is... not depressed of any sort. But just a bit low.

Reference 2 - 1.65% Coverage

**Interviewer:** [00:03:45] OK. Do you do anything special or maybe refrain from doing anything around your period?

**Dani:** [00:03:52] I don't like refrain from exercise, but I would if I feel too tired to go to the gym, I wouldn't make myself go... basically but like I wouldn't be like, "oh, I won't go to the gym because I'm on my period". But I would I would possibly just be like. "Oh, I'm not. I'm not really up for it. Yeah, that's fine".

Reference 3 - 4.49% Coverage

**Interviewer:** [00:04:17] Okay. Does your period affect you at home or at work or socially?

**Dani:** [00:04:24] It... it depends. and Now, I've got... for the past couple of months I've had the implant, so it's not... you know in the arm. So I don't think... it's not like a proper period anymore. Is that Right? I don't really know.

**Interviewer:** [00:04:40] It depends. I think it stops ovulation in most people...

**Dani:** [00:04:44] Yeah. But for some reason I still got the withdrawal bleedin', which is nice. But what was the question? Does it.?

[00:04:52] Does it affect you at work, or just like socially?

[00:04:53] Yeah. like not really socially, but at work, I sort of find it a bit harder to concentrate. Just because I feel a bit tired. But it's not... some like... occasional months. It really affects me. but in general. It's like I just get on with it. But it's. Yeah. I haven't had pain in a while. But you know, when I get that then sometimes you just need to go home or just sort of lie down. But aside from that, like it doesn't affect me too much. It's more that post period.I do feel much more energetic So I sort of use that, you know, I mean, rather than worry about the bit before.

Reference 4 - 3.16% 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]

Reference 5 - 3.26% Coverage

**Interviewer:** [00:17:22] Erm, How do you manage your changes or symptoms?

**Dani:** [00:17:31] Usually just some painkillers and just being a bit like kinder to myself normally, just like if I'm just feeling exhausted, I just let myself sleep a bit longer. Yeah. It doesn't take very much, but it is just yeah, it's usually just painkillers or... [pause] sometimes I know you're not supposed to, but I just need some extra sugar so I just have like biscuits or something that that kind of thing. And sometimes I really crave meat around that time. So, I'll have that. But yeah, I don't really need to do much to manage my p.\_m.\_s as it were. Like it just sort of. It just is. And I just sort of accept it and let it be. And that's sort of enough for a lot of the time just to realize that's just because of where I am in the cycle rather than trying to cheer myself up or anything.

Reference 6 - 2.81% Coverage

**Interviewer:** [00:18:32] Yeah. Have you ever consulted a doctor about your experiences?

**Dani:** [00:18:41] Only in terms of when I've gone on the pill. So I went on the pill when I was 17 because my periods were so irregular, which is I'm really annoyed about that now because I'd only been menstruating for like four years. Of course it was irregular! So that's really the only time that I've been to the doctors about anything to do with periods. So not to do with PMS or anything. It's just never been... it's never been repeatedly that bad. So I've had like a couple of months here in there where the pains the cramps have been quite bad or I've felt really shit, but it's never been repetitive. So I've never really needed to sort of get it checked out.

<Files\\P04\_Emma> - § 13 references coded [35.92% Coverage]

Reference 1 - 2.28% Coverage

**Interviewer:** [00:02:23] OK. thank you very much. And what was your first period like?

**Emma:** [00:02:26] I have absolutely no idea. I can't remember it. I've asked my mom because I couldn't even remember how old I was. I was eleven. She said that I'd been complaining of cramp and then... told her that I thought my period had arrived and that was it! But I literally can't remember it. So it yeah, it wasn't, ironically, for all of the problems it's caused, that first one was obviously insignificant. I don't know where I was. I don't remember how I felt. Nothing. Sorry. It's not very helpful.

**Interviewer:** [00:03:15] No, It's good. It might be because. Eleven is quite young, so...

**Emma:** [00:03:24] I think maybe I was expecting it as well because I'd been talking about it and because I had my book [laugh] and it was ... it was more expected and just normal, like a normal occurrence.

Reference 2 - 7.54% Coverage

**Emma:** [00:05:05] Before my period I feel absolutely horrendous. I have erm severe premenstrual syndrome, premenstrual dysphoric disorder. Erm, So I have some really awful symptoms that are debilitating. So I really struggle with fatigue... and low mood... and erm, negative thoughts that can be intrusive. And I get very down about things and question everything and over analyze. Er, I find it difficult to be organized, and to be productive. So work becomes very difficult. I don't want to talk to anyone. I tend to become completely introverted. and I just want to shut myself away. I become very irritated erm by random things, from noise to just people and movement. And so going, somewhere like Central London, when I'm premenstrual is a nightmare. And it's really anxiety inducing. It just it yeah, it's just really hard. But being around people in particular and having to talk to people, that's really difficult. I also have a lot of self-loathing and... Just a real drop in confidence. and Feelin' gross. Feelin' absolutely gross and rotten on the inside and that lasts... So that starts after ovulation. So about three two/ three days after i've ovulated. And then I get a few days respite where I'm okay. Then the week leading up to my period, that's when things become really difficult. So I have to take anti-depressants to try and stabilize my mood. And that has really helped... But I've actually got an appointment next week because I've noticed a drop recently and a change... So I'm gonna go and get that checked out. when my period arrives. I am usually a write off for two days because I get really painful period cramp. I usually have very heavy periods. Again, the... the fatigue really hits me and I just have no energy. So even getting up out of bed some months can be really, really difficult if I can. I tend to be at home with a hot water bowl bowl? Hot water bowl? [laugh]

**Interviewer:** [00:08:30] A hot water bottle? [laugh].

[00:08:30] And just I literally can't do anything. I'm just useless for day one and day two of my cycle. That being said, last month I went and presented and pushed through it... like we do. and I'm not quite sure how I got through that, but I did. 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. And that's the cycle that I tend to go through every month with my cycle. I'm not on any kind of birth control either, because I've had really awful experiences with different contraceptive pills. And so I try and manage as best I can with erm, a very low dose of anti depressants and painkillers and trying to lead a healthy lifestyle. So exercise and diet help. But it's very hard to stick to that when PMDD kicks in.

Reference 3 - 1.80% Coverage

**Interviewer:** [00:20:06] And how would you describe periods to a child, to someone who just doesn't know about them?

**Emma:** [00:20:17] That's a really good question.

**Interviewer:** [00:20:20] I don't... This isn't a test, by the way. It's not like I'm looking for technical information. It's just how how would you go about explaining to a child?

**Emma:** [00:20:28] That's a natural part of being female? And it is something that we experience. [pause] Every month.Erm. And it gives us the opportunity to have children if we want.[pause] It can be. It shouldn't be, er, painful or debilitating an experience.[pause] Yeah, that's a ... 've never thought about how I would explain. That's really interesting!

Reference 4 - 0.75% Coverage

**Interviewer:** [00:26:28] Ok. So this could be a very simple answer. [laugh] If you could wave a magic wand and get rid of your periods, would you?

**Emma:** [00:26:35] Yes. [laugh] Yes! [laugh] If I had a genie with a lamp and three wishes, that would be one. Yeah, I would definitely. Definitely.

Reference 5 - 1.87% Coverage

**Interviewer:** [00:26:51] right. Thanks. OK. Thanks for that. That was really great. And we're moving on to the p.\_m.\_s section. So do you identify as someone who gets p.\_m.\_s?

**Emma:** [00:27:03] Yes.

**Interviewer:** [00:27:08] [pause] And in your case. Well, we'll come to this later. But do you say to people 'you get PMS' or do you go straight for PMDD?. How do you describe it when you're talking like people?

**Emma:** [00:27:23] So exactly as as I brought it in earlier. Severe p.\_m.\_s slash p.m.dd and I usually have to... or I usually feel like I have to follow what PMDD is. Or 'Have you heard of that before?' or you know what, that is?. Yeah, but. But that can lead to a conversation of what it is and how it differs to p.\_m.\_s.

Reference 6 - 1.35% Coverage

**Interviewer:** [00:27:59] OK. Erm, This is a tricky question because it is about memory, really. Do you remember how you first came to know anything about PMS?

**Emma:** [00:28:12] I think.... I can't be certain, but I think probably through through my mam, through conversations with her because she... she suffered with PMS. I don't think she ever had PMDD, but definitely she had p.\_m.\_s. And so I think she probably talked to me about it.

**Interviewer:** [00:28:46] So when you were a child, you think?

**Emma:** [00:28:49] Er...Yeah.

Reference 7 - 1.87% Coverage

**Interviewer:** [00:28:54] Cool. So again, how would you describe PMS to someone who's never heard of it?

**Emma:** [00:29:05] [long pause] So, PM... I would probably say p.\_m.\_s. Relates to symptoms that people can get before their period. As a result of the change in hormones. For most women, symptoms are manageable, erm but for a few women they can be severe to the point where they're debilitating.

**Interviewer:** [00:29:40] Right. And this is... again, this isn't a test. But how common do you think PMS is in the population?

**Emma:** [00:29:51] I think around.[exhale] 80 percent of... People probably experience p.\_m.\_s symptoms and out of those I would say around 10 percent, 8 to 10 percent have. PMDD, so very severe symptoms.

Reference 8 - 3.93% Coverage

**Interviewer:** [00:35:49] Well, that leads nicely onto the next question, which is Have you ever consulted a doctor about your experiences? And if so, how did that go?

**Emma:** [00:35:59] I was fortunate to be seen by a lovely GP when a was struggling with... Well, I didn't know it was PMDD at the time, but I'd noticed these cyclical mood changes and realized it was linked to my periods and when and spoke to. Yeah. My my GP. Who was a female doctor. Probably around a similar age as well. And she she listened and said well it sounds like severe p.\_m.\_s. She didn't use the term Pmdd she said 'severe p.\_m.\_s' and. Presented a couple of options which was birth control, contraceptive pills, and anti-depressants. At the time, I guess I didn't really understand. Why I was being prescribed anti-depressants because I wasn't... Depressed. but, that was she was supportive and I certainly wasn't dismissed or not taken seriously, which I know is the case for a lot of people in that position. And she wanted to see me again for a follow up appointment, if I remember Right. I did go back two or three times because I think we did try a few contraceptive pills and they just didn't help? In fact, it made things worse. Yeah. And then I moved away. So obviously, when you move away, you lose. that that support and that relationship that you got with with the GP. But then I had done my own research and looked into managing symptoms and then treatment and things like that. So, yeah, I think the citalopram. Worked enough so that I could self-manage.

Reference 9 - 2.64% Coverage

**Interviewer:** [00:41:03] Mmm. Great. Is there's a stereotype of a person with p.\_m.\_s.?

**Emma:** [00:41:08] [inhale] I think. I think there is... in that. We tend to think of it or this. This is my perception. We tend to think of PMS in its extremity of... a woman being out of control or completely full of rage or bawling her eyes out or an emotional wreck or... And it's a spectrum. It's a spectrum of severity. And I think sometimes it is... Perceived very negatively. But it is.. it is common and... [pause] I haven't articulated that very well, but I know what I'm trying to say.[laugh] We tend to picture a woman who is like a monster with p.\_m.\_s and there are lots of these memes on the Internet. I'm just thinking of one that I saw. 'I've got PMS and a GPS. That means I'm a psycho and I'll find you!'. [laughter] It stuff like that, which I think has really stigmatised not just p.\_m.\_s but people who do have p.\_m.\_s. and yeah. I think sometimes it is pooh-poohed because of that. When it is serious and. That's that's really sad.

Reference 10 - 2.81% Coverage

**Interviewer:** [00:43:07] Okay. So this question is. Have you ever heard of PMDD, premenstrual dysphoric disorder? And if so, what's your understanding about the difference between p.\_m.\_s and PMDD?

**Emma:** [00:43:22] Yes. I have heard of PMDD. And the way I see the difference. I'm not sure if this is clinically accurate, er but it's the it's the severity of symptoms and it's the impact of symptoms. So PMS usually can be self managed and it usually doesn't cause that much of an impact in everyday life. But PMDD has. Some severe psychological symptoms that that are debilitating and that do impact everyday life. It is disabling. It affects relationships. It affects. Jobs, careers, friendship, family, life, work. It just impacts every part of life. It's very difficult to self-manage. But I think that's what the difference is and also the fact that it only affects a small number of the population. Whereas PMS is. Fairly well, it is common and I guess experienced by the majority of women PMDD is only really experienced well we think. Only experienced by around 8 percent of the population. So...

Reference 11 - 1.56% Coverage

**Interviewer:** [00:51:47] So some people do get this, for instance asthma or epilepsy. Some people get it with mood, or you know anxiety disorders that they have more chronically. If people get that, would you count those as pre-menstrual symptoms?

**Emma:** [00:52:06] Yeah. So I would class that as pre-menstrual exacerbation. Where the menstrual cycle's actually makin' that health condition worse in some way. Um. But yes, I would... I would class that as... [pause] As part of the pre-menstrual symptoms I can't think of the word...

**Interviewer:** [00:52:36] grouping?

**Emma:** [00:52:38] Yeah. Category. Yeah.

Reference 12 - 3.36% Coverage

**Interviewer:** [00:57:15] Ok. Erm, have you ever met anyone who didn't really believe that you were really experiencing these changes and symptoms?

**Emma:** [00:57:32] Yes. So when I think back to when I was at school, I played a lot of netball. And did dance classes and things like that. I remember one of my friend's moms. I couldn't play in a netball match or go to practice or something like that. And I remember she was just incredibly dismissive about it and was like, oh, it's just just a bit of cramp. You can you can get over it or something like that. And. I guess that that's stuck with me because I remember it, so it must've hurt at the time. Yeah. And then. More recently, in fact, very recently, I was at an event and Had a discussion with someone after talking about PMDD and had presented. erm, Some some brain scans to show the difference between p.\_m.\_s patients. and er Women in the general population and I had a discussion with this person who who.[pause] Was questioning whether or not we have been socialized into believing that PMS is a... is a cult... is a socially constructed thing, and it's not a biological thing. And that was really difficult to hear. Yeah. So, yeah, I've come across people who don't believe in it or don't believe it's a thing and don't understand how it can affect people.

Reference 13 - 4.15% Coverage

**Interviewer:** [00:59:40] So linked to that. Are you aware of PMS being a controversial diagnosis?

**Emma:** [00:59:53] In what sense? If it's okay to ask,.

**Interviewer:** [00:59:59] It can be in any sense a little bit like you're just saying that that person thought that it's a social construct only, that there's no biological basis to p.\_m.\_s...

**Emma:** [01:00:11] And I think so. The same person was also [long pause] concerned about about portraying women to be weaker because of the menstrual cycle. Talking about PMS in that capacity, she thought that somehow we were almost... I was almost victimizing women. And so I think it can be controversial from from that perspective.[pause] And I don't think it's. Necessarily seen as a. [pause] As a medical diagnosis. [pause] Either. so I think that aspect of it is controversial, and maybe that's why there are so many people who go for years on undiagnosed livin' with PMDD.

**Interviewer:** [01:01:26] Do you mean that it's seen as like p.\_m.\_s is just a natural.

**Emma:** [01:01:36] Yeah,.

**Interviewer:** [01:01:37] Part of the menstrual cycle... so that it can't be severe enough to actually count... Is that what you mean?

**Emma:** [01:01:45] Yeah, that's exactly what I'm getting at. and. [pause] This goes back to yes, with the majority of people. It is... it is a normal thing and it doesn't have much of an impact and it goes unnoticed. But for others, it it really does have an impact and it. [audible tapping on table] It is disabling in some cases and. We don't... we don't often consider it through that lens.

**Interviewer:** [01:02:25] Thank you very much. That's great.

<Files\\P05\_P06\_Faith\_Gemma> - § 24 references coded [34.08% Coverage]

Reference 1 - 1.48% Coverage

**Faith:** [00:00:48] Erm, my period pains started in year five, which is interesting, but I think my period came.. Year seven?. I would say. so, for two years. I kept having pains every month. And it got to the point when the school thought I was lyin'.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]. And then to be fair, it was just before secondary fso it was maybe during that summer break when secondary school started? So the symptoms came before the actual Periods.

**Interviewer:** [00:01:21] So you didn't know it was anything to do with Periods?

**Faith:** [00:01:23] [Overlapping] No, I had no idea

**Interviewer:** [00:01:23] You just had a sore tummy?

**Faith:** [00:01:23] Yeah.. I'd like vomit all the time, and like really bad like debilitating pains. I had very regularly and just didn't know why.[voice breaking- sadness]

**Interviewer:** [00:01:36] Ahhh. [sympathetic sound]. And you told your family and you told the teachers?

**Faith:** [00:01:39] Yeah. So like in the beginning. Well, my family was always sympathetic, but with the school in the beginning, they were sympathetic. But, you know, if you're always going there every month and " Aw, my belly hurts", then eventually they were like "Oh, she's just trying to get out of let's say PE , or something..." that sort of approach...

Reference 2 - 1.42% Coverage

**Interviewer:** [00:01:51] And, Gemma How did your family talk about Periods?

**Gemma:** [00:01:58] My mom was away. She was a police officer so she was training at the time. I can remember it because my Aunty Mary was was at my house and she was really good about it. She'd like she sat me down and she was like, you know, "this just means that you are transitioning into a woman". So they related to like my womanhood kind of thing. So I had a good experience in that way. But when... my mom was always really... my mum's quite 'tough love', but on my Periods, I can remember her being very caring like I would get really.. do you remember [to Faith].... like I got really bad cramps in the beginning, but she would really baby me like get me a hot water bottle and she kind of really took care of me when she knew I was in pain because of my period. So I knew that like it was... I I knew that it was okay. Like I said, I knew that it was something that we go through. And I had the support. So yeah, I had a bit of a different experience. And we're cousins, so that's a bit weird... [laughter]

**Faith:** [00:02:47] I think my mum was just petrified.

**Gemma:** [00:02:47] Yeah

**Faith:** [00:02:51] So, I think this just goes to show her train of thinking like 'sex'[laugh]

**Interviewer:** [00:02:56] Yeah, and yeah 'don't get pregnant' {yeah and laughter] that's the fear.

Reference 3 - 1.37% Coverage

I swear to you, this is gonna sound so crazy cos' I've never been pregnant. But I think I get contractions. Like, I literally go [breathing noise] through the pain. And then this is a bit explicit. but I need to go number two. Very strange. And then it closes again. And then I'm like. I breathe through it like [breath out] and I get hot. I take all my clothes off. Yep. And then I go on the toilet. Then it happens again. And it's a cycle. It actually happened three... I was in [European city] for work and I had to go upstairs for like an hour because I had to just do it. And after it's done, my body is very exhausted. so, I have to lay down for about 10 minutes. Then I'm fine. I'm. I'm absolutely fine. After.. It's like one day of that for about an hour and a half or an hour or two hours. Then my period is absolutely fine. No pains. It happens very early in the cycle so it's like day, two.

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

**Gemma:** [00:07:41] Then the other three days I have, short periods as well. They're like 4-5 days max. So not the next few days are a breeze. No problems. I'm very light. Everything's fine. 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 4 - 1.30% Coverage

**Faith:** [00:08:00] Yeah. Cause... why... why I was asking if you know, and that it's okay.

**Gemma:** [00:08:04] Yeah, I do!

**Faith:** [00:08:04] Is 'cos sometimes I don't! Which is weird like it happens every month but sometimes I don't... you're in that hole so you kind of.. you can't...I don't really tell myself 'oh this could be because of my period' I'm just like...

**Gemma:** [00:08:12] You still feel it though, isn't it?

**Faith:** [00:08:16] And Afterwards, it's like 'Oh that was why!'

**Gemma:** [00:08:17] Oh, okay. That was why. I think I... I've got the tracker. So I... it's the moment I start feeling off. I look at it and I'm like, okay, this is okay. If it... if it isn't like sometimes you might be having a bad day. And if it isn't, then I'm like 'Gemma, please... get it together' [Laughter]. But if it is because of my period. Then I'm like, it's okay to feel this way because you always feel this way and this is your cycle. So, Yeah. But I swear I have contractions. I literally go [birthing breathing]. It's really strange. Yeah. And I naturally do it. It's not something that I told myself to do. I literally... no one told me... I go. [birth breathing] I breathe in. Breathe out. breathe in breathe out. So strange. very strange.

Reference 5 - 1.60% Coverage

**Gemma:** [00:10:06] Do I do anything... Or do I stop myself from doing anything? Not really, no, no. I tried to make sure because I tried to make sure I'm in a hou... It's weird your body, because somehow I always... It's like when that day comes, with the contractions. I'm always at home. I'm never really at work when it happens. Only because I was in [European city] that time [for work]. But it's always that late at night or whatever where It's like I can manage it. I never get that thing. Rarely have I ever... I can count how many times in my life I've got it at work and I've had to go... I've never had to go home. But I've got it at work and I can kind of hold it. But it's always like towards end of the day. It's weird how my body kind of knows this is when you're gonna go crazy now. So I've never had to stop myself from doing anything. Erm, with drink I feel like I get more... more drunk definitely if I'm on my period and I'm drinking. It hits me much quicker. Um, That's about it. I don't really stop myself. I don't really swim anyway. So... and yeah... I wouldn't. I'd actually gym more. Which is weird. I actually feel more inclined to get out and do something when I'm on my period. [To Faith] Do you get that?

**Faith:** [00:11:08] Yeah. I second that, actually. I'm a lot more um...

**Gemma:** [00:11:08] Active!

**Faith:** [00:11:08] Yeah.

**Gemma:** [00:11:08] Which is weird, right? Cos your body is supposed to be in all this pain? but I actually want to be more active when I'm actually... During that time of the month.

Reference 6 - 0.73% Coverage

**Interviewer:** [00:11:18] Yeah. Yeah. That's great. Um. So you've just touched on this. Does your Period affect you at home, work or socially?

**Faith:** [00:11:33] Um... all of the above! [nervous laugh] So just because like... like Those first like one to three days I'm not able to move, I'll just be kind of wallowing and just lying in bed. like if I'm at home that I'll be in bed. If I'm at work, then I'll find a couch somewhere. And I'll literally spend my whole work day on that couch. Um, I wouldn't really be out... Luckily I haven't... Yeah, I think my periods come at a time when I have to be out... One time it came when I was on a plane, which was awful [laughter] Wehn we went to America...

Reference 7 - 0.55% Coverage

**Gemma:** [00:12:14] Again, with me second day, it's like the first day's fine... pain, Yeah, but it's manage... it's very manageable. Second day is awful again, it tends to be the end of the day. So it tends to be... it yeah it tends to be the end of the day; really late at night. Or like I'll be woken up because I'm in so much pain. and I need to do that thing [referring to defecation] or when I've just come back from work. So it hasn't really stopped me socially in doing anything Like I would say it doesn't really affect me.

Reference 8 - 0.92% Coverage

Er, when they're not fertilised Then you'll begin to bleed or blood will come through... and that will be your period and. You... manage that by using tampons or using pads. And for some of us, there'll be a lot of pain. So you might have additional needs such as medication or the needs of contraception and... For that I would Definitely. Like try to put in like stuff about the sort of complications that they might have... So things like Polycystic um ovaries and fibroids and that sort of thing. But that's more technical, so yeah just for the basic Period, I'd say pads, tampons and you can expect to go through some emotional... um changes. A week or two before you see the blood, and that could include cravings, that could include feeling a bit low. That could include being short with people. And that's all fine because it's your body that's adapting to what's about to come

Reference 9 - 2.04% Coverage

**Gemma:** [00:18:15] That's much better than mine! {laughter] I would say you have... your body goes through a cycle and most of us experience that through the form of a period. And what will happen is that your vagina will bleed and erm, that's... that's OK. I' would definitely reaffirm to them. That is very normal. It's okay. And that we all experience Periods very differently. 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. So I think the way you explained it, because you've had to go through more of an understanding of what this is and what this means... for me is it's like I know that we're bleedin' because we're releasing the um eggs that didn't fertilize. So, I would say that. But even that I just feel like my vagina is bleeding for three days, three to four days. And for me, I think it's a cleansing. Very strange. I just feel like my body's cleansing itself because honestly. Because the way that I experience it, because I do the number two a lot [laugh] during that time, I honestly feel like my body's bein' washed out. And it's just after... because I honestly feel after i've come off of it [Phew- sigh] like a release. So I would explain it that your body is just cleansing itself out, not that you're not pure because you're having your period, but it's just like getting rid of like... um the things that didn't fertilise and you're just bleeding that through. And I'd also say to them that... this is a very powerful thing. I'd say to them that your period is very powerful. The fact that you're going to live with that and you manage it is very powerful and it's very unique. And I'd make them feel like... it's special. Even if it doesn't always feel like that [quiet laugh].

Reference 10 - 0.36% Coverage

**Faith:** [00:19:46] For me. I'd especially want it to be explained to boys and girls together.

**Gemma:** [00:19:53] Yes!.

**Faith:** [00:19:55] Because up till now, I feel kind of taboo when I tell a guy I'm on my period...

**Gemma:** [00:20:00] Yeaaah!

**Faith:** [00:20:00] But why should I?

**Gemma:** [00:20:00] Yeah.

**Faith:** [00:20:00] It's normal.

Reference 11 - 1.30% Coverage

**Gemma:** [00:23:00] For me, Spiritual. Yeah. Which is really weird. Just because I really do associate it with the cleansing because I think it's... I found my period very liberating. So I actually like the fact that I feel more. I think. I just think it's a beautiful thing. Like, I like the fact that I cry. I think it's so strange, like. And I think it's amazing as well. Like how our bodies are like, why am I crying and why is it uncontrollable? And I have no control over that. But I know it's going to happen and I can't stop it. So I just think I find it very liberating and very like spiritual, because I think, like, you don't have any control over this issue, your hormones, your body is kind of acting alone. and Just allow it. But again, my... I think I think that way. because I don't go through as much pain as a lot of women go through, touch wood [idiom]. So because of that, I'm able to see... but like if I was not able to walk for three days, I'm not going to find it beautiful, you know? Yeah.[laughter]

**Faith:** [00:23:54] No way! [laughter]

**Gemma:** [00:23:54] Because I get one day of like, you know, my contractions. Then it's not as bad for me. So I think that's why I'm able to see the more positive.

**Faith:** [00:24:02] Yeah.

Reference 12 - 0.77% Coverage

Oh my gosh! It's such a hard thing to navigate when your family are African. [laugh] I mean, "this is the way of life, You must... This is normal... Like, what's your problem. We've all done it before..."

**Faith:** [00:40:45] [interjection] "Get up and get on with it!"

**Gemma:** [00:40:46] [repeats] "Get up and get on with it". Like, that's the attitude. "What makes you so special? Every woman has gone through it... and they were fine" my mom used to say to me, "you think that people haven't had Periods before [laugh], are you crazy?" [laugh] Like when I say I want to be... I want to take a day of from work. She says "Are you mad? Do you think your Grandma's Grandma's Grandma's Grandma didn't have a period?" So it's very normalized.

Reference 13 - 2.35% Coverage

**Faith:** [00:41:08] That reminds me of school... um again because my periods were so debilitating there were times when you have to do PE [Gahhhh from Gemma] Imagine that sort of pain and you have to run around and [interruption] stuff.

**Gemma:** [00:41:16] And they just don't understand!

**Faith:** [00:41:17] And I'd tell her, like the PE teacher...

**Gemma:** [00:41:18] Yeah,.

**Faith:** [00:41:20] "I physically can't!" [emphasis] and she was like "So am I supposed to let every girl off every month?" sort of thing. And it's like...[Interrupted]

**Gemma:** [00:41:28] They're horrible!

**Faith:** [00:41:28] And it's like YOU feel guilty for even asking, sort of thing.

**Gemma:** [00:41:28] Yeah!

**Faith:** [00:41:31] And it's because everyone goes through diff... [overlapping speech] like we've touched on, everyone goes through different, um, levels of pain.

**Gemma:** [00:41:34] [overlapping] Yeah... And they think you're playin' up!. And it's horrible when you're young, especially where we're from. So like, school's already... [pause] 'resource scarce' so the teachers are tryin' their best, but then they don't have the resources and things are tight for them, so everything is an issue. Where was... we're not. We're not. We weren't brought up in the way that was privileged enough that these teachers could have more of a kinder... [laugh] a kinder approach to it, like " It's OK" ... because I could... I spoke to kids who went to school in [richer neighbourhood] for example, if they said this... it's "no, it's ok, sit down, it is fine, oh my gosh! I'll get you a hot water bottle" [laugh in background]. Us! Are you crazy? Better get up! You could be bleeding running at 13 and they don't care. So. [Pause] That's sad though, because it.. it makes... it internalizes the way that you feel about your own Periods [overlap] and you see it as negative and...

**Faith:** [00:42:23] Yeah, and then you... yeah. It was the internalisation that made me like 'OK let me stop complainin'"

**Gemma:** [00:42:23] Yeaah! And I'm dyin here... [Overlapping]

**Faith:** [00:42:24] [Overlapping] They thought I was exaggeratin'... yeah

**Gemma:** [00:42:24] But let me... maybe it's okay?

**Faith:** [00:42:29] Yeah.

**Gemma:** [00:42:30] And let me not ask for help.

Reference 14 - 0.72% Coverage

**Gemma:** [00:42:44] I was a child! It was all pain!

**Faith:** [00:42:48] And you're literally getting told off! [whisper][nervous laugh]

**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. Maybe I wouldn't have...

Reference 15 - 1.50% Coverage

**Faith:** [00:43:22] Erm... Tranexamic acid, co-codamol, hot water bottles... and I just drug myself up... like as soon as I feel an inkling of anything, I go straight to co-codamol which is really bad because I... really wanted to... Um... Like just through learning through um time, like you just learn about like the effects of medicine like relying on medicine and stuff. But my mom is like "your body is not like everyone else's. you can't like... Other people can survive. But you can't , you actually need it. It's awful like to think you reliant... but at the same time. I just can't not...

**Interviewer:** [00:43:56] So. It does help you?

**Faith:** [00:43:58] Yeah. Co-codamol, definitely. Tranexamic acid makes me vomit. And there's a new one that I had to try recently...

**Interviewer:** [00:44:07] So you don't do that anymore. You tried it and it was just too...

**Faith:** [00:44:10] Yeah, It got too much. There's another one. It starts with 'n' we spoke about it at the forum..

**Interviewer:** [00:44:14] Oh, Naproxen?

**Faith:** [00:44:14] Yeah. Naproxen. so, that's the most recent one I had to start using... but it's not...

**Interviewer:** [00:44:16] Is it not nice?

**Faith:** [00:44:22] Yeah. I remember being on the train and feelin' like... this is how I'm gonna go out.. I'm gonna die on the... die on the tube! [laugh] Like It's just so... it makes me really weak. It's really strong, but then it's the one that does the job.

Reference 16 - 2.09% Coverage

**Interviewer:** [00:45:14] And you? [To Gemma]

**Gemma:** [00:45:21] Oh, I just ride it out. I don't take medicine. I don't take medicine ever, though. I've got this whole negative... I studied anthropology... [laughter]

**Faith:** [00:45:28] Yeah, it's because of you and like... a few other people... cos a lot of friends I have and family members, like they all have your approach that medicine is... [overlapping] bad.

**Gemma:** [00:45:37] [Overlapping] Yeah, but again, pain it's like I I I don't take medicine by rule but If I'm... if I have a very bad period, I'll take it... I'll take it if I really need it. Again, like... generally they're okay. But there's months where they are bad and I will run to the medicine. So I completely, it's Because I don't need to. Do you know what I mean? the pain is manageable. It's hard. but it's manageable. But again, I have a day of pain out of my four days it's only one day so I can manage it. And I need to go to the toilet. And that happens. It is excruciating, though. I literally take off all my clothes. I'm sweating. I'm like "I'm givin' birth, I'm givin' birth!". [nervous laugh] And I need to just get out. But I... because I know it's going to end. I don't need to go to the medicine and often for me, as well. When I take... I used to take medicine because I used to think that is something you should just do... before the pain, even happens, my mum takes medicine to prevent the pain happening. With me. what I'd find is that when I took the medicine, it would only hold it for like two to three hours. Then the gap that comes when it's worn off was excruciating,.. [overlapping speech]

**Faith:** [00:46:34] Yeah, it's crashin' [overlapping]

**Gemma:** [00:46:36] Was excruciating. And then I had to jump to the medicine again. And then it would hold it again, but it would come anyway. It just came like lesser and I'd still need to go to the toilet so I thought like, do you know what? I just ride it out now, I'll just ride it out, I don't take medicine.

Reference 17 - 0.26% Coverage

**Interviewer:** [00:47:21] So, it's easy to forget. But I do think there's something about that we naturalize... Particularly period pain.

**Gemma:** [00:47:24] Yes.

**Interviewer:** [00:47:27] As just being like... it's just part of life... [nervous laugh]

Reference 18 - 1.09% Coverage

**Gemma:** [00:47:29] My mom thinks it's absolutely ridiculous. She thinks it's ridiculous. She takes medicine the day that she... She doesn't have her periods anymore, but the day She knows that it's coming...[pause] [indicates that she would take a pill]

**Interviewer:** [00:47:37] Hmmm

**Gemma:** [00:47:39] She never had period pains like that because she said that even in the gaps, it's because your body's just getting used to it. She said the more you do it, the more your body will just be accustomed to... It'll be lower because you're in the cycle of the suppressing, of like the pain. But she was just like. " You're crazy". She... she says, "take medicine". She forces me even when I've got a cold. "Take medicine. Buy medicine". So... I think you're right. It is just naturalizing, pain like it's a cool thing. Like "Oh, I've got through without the medicine" It's silly.

**Interviewer:** [00:48:06] Well, no. I mean, I don't think that's what I'm doing. But at the same time, I can't tell you why [laughter]... I don't do what I know would help.

Reference 19 - 1.27% Coverage

**Gemma:** [00:48:13] No, I do it because of that. Which is silly, I do it because I'm just like, "I want to get through this by myself".

**Interviewer:** [00:48:19] So it's self... [overlapping] Extreme self-reliance

**Gemma:** [00:48:20] Yeah! [Overlapping], yeah, yeah.

**Faith:** [00:48:22] I think it's also the anthropology aspect, though. Because you've studied the effects of relying on medicine. That must've had an... [interrupted]

**Gemma:** [00:48:26] Yeah. I did anthropology combined with medicine, like natural medicine. Um, And I saw like the effects of kind of using natural remedies, hot water bottles um... going through the motions of feeling pain and going out the other side. All this stuff... I think is like in my brain. But again, every... it is easy to say that. But again, education has the approach of everything is the same way for everybody. And that can be quite negative. They don't look at the individual experiences. So when you look at all these medicine and all these practices, they kind of assume... They will work on you based off of a level how you should experience pain. And that's wrong because we all experience pain differently and that we're all unique. So it's not one size fits all.

Reference 20 - 3.05% Coverage

**Faith:** [00:49:30] Yeah. OK. So with Periods, again as a thing where when I was younger it was like " Oh, she's exaggerating, let's give her ibuprofen". And then as time went on and I'd always vomit and I was nauseous. And it was quite debilitating. And so then they put me on to trans...

**Interviewer:** [00:49:47] Tranexamic acid..

**Faith:** [00:49:48] Yeah.[nervous laugh] And my body wasn't responding well to that either. So then they talking about contraception and then I was like, "I can't have contraception, I'm not having sex, so..." I always thought contraception meant sex, sort of thing.. but that's only recent that I've needed it for that use. So I thought that for a long time and then I gave in. But then they had to do trials and see which contraception worked well with my body... So a lot of them were not working well with my body. Eventually, I found the Yasmin pill and stuck to that before going on to the Depo Provera injection. Then with the cyst, that was the first issue that I knew I had. And the first... I was in Uni at the time in Birmingham, and the first time I went to the hospital um, they said it was food poisoning.[nervous laugh] without even examining me, they were just like "Oh yeah it's Food poisoning. Have a paracetamol and go home". Next time...

**Interviewer:** [00:50:40] Yikes!

**Faith:** [00:50:41] [laugh] Yeah. Next time, again, without examining me, he told me it was a UTI and then he said that if I come back and it's with the same pain. Then it's the... there's a possibility... that it could be something else. I can't remember what he said, but it was like this life-threatening disease.

**Gemma:** [00:50:56] Oh my god! [whispered]

**Faith:** And I was like, "Examine me or something before you say all of these things!" Then this was the time when I said that every time that I had high-stress then I would like vomit until I'm vomiting black. So... there was a day when I was supposed to go back to London, and I literally collapsed at the train station and I couldn't like move or anything. So my friend took me to the hospital and then called my mom from London to come and get me. And that was when I think we were like "I'm gonna get you some serious help" So I went to [London] hospital and um, you know how fibroids and those issues are quite common for black women?

**Interviewer:** [00:51:33] Uhuh.

**Faith:** [00:51:33] So luckily i had a black woman doctor and she was like "OK, I'm going to do this examination because I think that this is what you have." And she was like "You need to have an emergency keyhole surgery" And at the time, my dissertation was due, so I was like "can I have it after my dissertation?" and she said "Do you want to be alive?" [laugh] So, I always tell people she saved my life. [laugh] "if you wait for that dissertation, you might be coming back sort of thing". So then I had that... um keyhole surgery and that's when they found fibroids.

Reference 21 - 2.84% Coverage

**Interviewer:** [01:09:02] OK. So do you have any other health conditions that get worse at certain times in your cycle?

**Faith:** [01:09:10] Uum. My skin used to but it's not... I can still get maybe a couple of like raised spots on my forehead. Yeah. Maybe just skin conditions but other illnesses. I think... Yeah, because I didn't have any illness before I had the fibroids... And that's definitely heightened my sense is that it has heightened yeah, I think those are the main two things...

**Interviewer:** [01:09:34] Do you ever get anaemia?

**Faith:** [01:09:37] Oh, yeah, yeah, yeah.

**Gemma:** [01:09:38] Yeah you do

**Interviewer:** [01:09:38] It's kind of associated with fibroids and also with periods..

**Faith:** [01:09:41] Yeah. There was a point earlier this year when a doctor said... I can't remember what he said the safe level is, but he said "you are significantly [laugh] below the safe level. The iron blood levels" Yeah.

**Gemma:** [01:09:54] I'm anaemic, um, diagnosed by the doctor. So like you were saying. I'm just. I'm just much more tired. Like I'm so tired during my period... but not for the whole cycle. First two days. Exhausted and the the whole second day of pain really takes it out of Me... I'm knocked out. I need a nap. So, yeah.

**Interviewer:** [01:10:16] And do you take iron for that?

**Gemma:** [01:10:17] Yes, at times I do like the iron tablets from Holland & Barrett, but sometimes I think it is a psychological thing 'cos it's like "Did it even work?" Like I don't know if it's actually working or if it's in my brain because there's times when I don't and I'm... There's times when I don't take it I still have to go. I can go through the day, but I can't. You'd be like this [head in hands on desk] at work, like nodding off, even at work.

**Faith:** [01:10:38] Yeah, well I assume it's something like iron? Like that's what your body

**Gemma:** [01:10:40] Needs, yeah

**Faith:** [01:10:40] When you're anaemic. Like they are sayin' you've got low...

**Both F&G:** [01:10:44] iron levels [in unison]...

**Both F&G:** [01:10:44]

**Faith:** [01:10:48] [Whispered] So I would recommended that you do!

**Gemma:** [01:10:49] Yeah, I'll take it more often.

**Faith:** [01:10:51] Yeah, that's the one thing I'm on- that Ferris...? For my...

**Interviewer:** [01:11:01] Feroglobin is one brand. But anything with 'fero' in it is iron. So, I get it just with my Periods. And I don't always take the iron supplement, so I have them. They do... They definitely work. I know people like you. If you're really low, and you take it...

**Gemma:** [01:11:18] Yes.

**Interviewer:** [01:11:18] It makes quite a big difference. But for me, I just. No, I do know it makes a difference, but I still don't use it [laughter].

Reference 22 - 1.25% Coverage

Have you ever met someone who didn't believe you were really experiencing these symptoms?

**Gemma:** [01:13:52] Yeah. Doctors.

**Faith:** [01:13:56] [Nervous laugh] Yeah, so um yeah. Doctors and also working with men. [laughter]

**Gemma:** [01:14:01] Yeah

**Faith:** [01:14:01] So there's been times where I've been in like... Let's say for example at [employer]. I would have to go in with a hot water bottle, and I'd literally just sit there and be like "I'm dying" and it would be the whole sort of "Imagine if men said that!" and just that whole. "Girls, or All you women exaggerate. It's just a belly ache". But that's understandable because again, they haven't really been exposed to like the realities of having like a period...[laugh].

**Gemma:** [01:14:30] But is it understandable? [laugh]

**Interviewer:** [01:14:30] Yeah, I dunno. I mean if a male colleague needed a hot water bottle, I wouldn't put him down.

**Gemma:** [01:14:38] Yeah.

**Faith:** [01:14:41] Yeah. And doctors just not... and the extent, too...

**Gemma:** [01:14:44] Yeah. I think just me. Doctors, definitely doctors.

**Faith:** [01:14:50] And the school,.

**Gemma:** [01:14:52] Yeah, schools in general. Yeah, they don't get it.

Reference 23 - 1.22% Coverage

**Interviewer:** [01:14:57] Are you aware of PMS being a controversial kind of diagnosis?

**Faith:** [01:15:03] No! I thought it was just something that everyone knew about.. I guess [whispered].

**Gemma:** [01:15:05] In what... in what context? Like, if you was to say, I'm not going to work because I'm experiencing PMS?

**Interviewer:** [01:15:14] Well, some people think that because the menstrual cycle is a natural and a healthy thing for people with female reproductive bodies to have, that, it's not like an illness. That it is just that some people get more severe experiences. So that's one controversy. Is like should it really be a medical? Thing with medical treatments or not so much medical, but should it be this kind of idea that all women kind of get emotional, whatever, if it doesn't affect everybody in the same way?

**Faith:** [01:15:47] You know, That's interesting. I never thought of it as an illness..

**Gemma:** [01:15:50] Yeah neither have I, ever!

**Faith:** [01:15:51] I think I thought of it as an experience.

**Gemma:** [01:15:53] Yeah

**Faith:** [01:15:55] So, not the same as an illness.

**Gemma:** [01:15:55] Yeah. I never thought about the illness at all.

Reference 24 - 2.58% Coverage

**Gemma:** [01:17:13] It was a really good conversation. I think it's maybe like opened my eyes to make me feel normal [laugh]. I didn't know people dealt with the constipation and diarrhoea thing, so that's made me... and the contractions. Cause I know that. I know that. I know that when I have a baby and I'm in labour, that is going to be what it feels like. I just know because my belly goes in... the breathing is very.. it comes natural. It's so crazy. So I'm just glad that other women have the same experience. And I'm not weird.

**Faith:** [01:17:40] And I feel like... I feel like suing my doctor [laughter] but... So I'm a bit annoyed about that but Also, there were points that I felt quite emotional... and like there were certain things that made me feel quite emotional. And I can't say exactly why.

**Gemma:** [01:17:58] Yeah.

**Faith:** [01:17:59] Maybe it's just to do with my experiences over the past few years?

**Gemma:** [01:18:01] When you were talking, I was getting emotional when you talked about the whole um, your experience with doctors because I feel like a lot of it could have been prevented. So, yeah, Not the fibroids, of course, but the way it was managed.

**Interviewer:** [01:18:13] Yeah, me too. To be honest. I am feeling a bit emotional at the moment anyway. But it's just this sort of.. um... You know, it's 2020 and this isn't rocket science... like I've taught myself. All of this. It's very easy to understand. And um just this is very frustrating. And I think particularly for fibroids, cos they're really common, particularly common in young black women. And yet Those are the very people that don't get the help that they need.

**Faith:** [01:18:48] And I think that links as well. So to the "get on with it culture" that we spoke about, with our older black elders. So, like our aunts and our grandmothers. Our mums and stuff...

**Gemma:** [01:18:58] Yeah

**Faith:** [01:18:58] they had the issues. Cos, a lot of women in my family, have fibroids. But they just dealt with it.

**Gemma:** [01:19:03] Yes.

**Faith:** [01:19:04] So I feel like maybe it's new that people are voicing their pains and issues. And also the variety and the extent of what people experience with... changes and changes, I guess, along with that. I think maybe there wasn't enough pressure. in like. learning about it!

**Interviewer:** [01:19:24] It's like another thing that you might... It is the same with sexism as well. It's like a weakness...

**Both F&G:** [01:19:29] Yeah..

<Files\\P07\_Helen> - § 21 references coded [33.81% Coverage]

Reference 1 - 0.91% Coverage

**Interviewer:** [00:04:13] And so when you were menstruating, Did you feel different before, during or after your Periods?

**Helen:** [00:04:20] Um... Yes. So all through my adolescence, I was always regarded as hyper emotional before my period to the point where my mom took me to the gynaecologist and they put me on birth control even before I was sexually active to try to help with those emotional swings. And I don't know that my sister or friends had that same experience. It was just... I think I thought that was normal. But I look... you know, looking back, that wasn't normal. I think that was for me, early indication of the road to come.

Reference 2 - 0.85% Coverage

**Helen:** [00:05:11] Oh low mood! Yeah. Low mood for sure. I would be very, you know, defensive and weepy and I'd feel very um... Ah what's the word I'm looking for? Probably insecure. There's another word I'm looking for and I can't think of it right now. But just, you know, kind of... what's that word when you feel like threatened in a way you feel...

**Interviewer:** [00:05:31] Paranoid?

**Helen:** [00:05:34] Yeah. Paranoid! Thank you. I felt very paranoid, like about my friendships, my family. I felt very like, you know, I remember feeling like, oh, everyone's mad at me. You know, no one likes me.

Reference 3 - 1.38% Coverage

**Interviewer:** [00:12:55] Um, do or did your periods have any religious, spiritual or any other kind of symbolic significance for you?

**Helen:** [00:13:07] Noooo... But I kind of wish it did.

**Interviewer:** [00:13:09] Mmmm

**Helen:** [00:13:11] Yeah, I think it would have been less like 'this is just a thing you live with' and more of how... why this matters to you.[pause] I think it would have made a difference. You know, like as far as... because there's that you know, "Oh everyone has a period", you know, "you're just not... you're being mentally weak". "You're not... you know, everyone has a period and people don't act like you act, you know, before your period or during your period". So I think um ascribing a more, more or less what's the word, existential or more meaning to it, you know, as far as like ... you know anything like applying anything less biological meaning to it, I think would have been helpful. But it wasn't my family experience... so [laughter]

Reference 4 - 1.71% Coverage

**Helen:** [00:16:05] So hindsight, I have the benefit of hindsight, and the fact, that I don't have ovaries anymore so I am now living that life. It's much better obviously! [laughter] if I had a magic wand, I would have had an alternative. I would still I would have. I actually miss having a period. I miss the opportunity to be a normal woman with a period. Does that. Make sense? Like. I mean.[Pause] I don't know. Like, I guess there's some deep sadness about. This was... like if I had cancer, I guess I would feel the same way. Maybe if I had to have an oophorectomy for ovarian cancer. I still have that. You know, we didn't plan on more kids, but had I got accidentally pregnant it Would've been great to have another baby, you know, or it would've been great just not to be. You know, and pardon my this isn't P.C., but not to be a lunatic. [laugh] on my Period. If that was my wand, that would have been my my magic not to have to have surgery, to just have the normal p.\_m.\_s. Yeah. Or no PMS! [sudden realisation]. you know what, why am I shorting myself? If I had a magic wand. I'd have no PMS. I just have wonderful, beautiful always pad version commercial, you know, commercial version periods! [laughing].

Reference 5 - 0.53% Coverage

**Interviewer:** [00:17:32] Yeah, I mean, occasionally I meet people who don't get any. They don't get any symptoms. And their biggest complaint is that they don't know when they're gonna start. And it's like, well, that's not a bad thing, you know compared to what you can get...

**Helen:** [00:17:46] Yeah [laugh] You could track that! mark it on a calendar! You're Good.[laughter]

Reference 6 - 1.17% Coverage

**Interviewer:** [00:17:54] Okay. So moving into the kind of middle section now. Did you identify as somebody who got p.\_m.\_s?

**Helen:** [00:18:05] Oh, yes, very much so. Because there wasn't like a diagnosis or term for PMDD. It was just 'you had PMS' Yeah.

**Interviewer:** [00:18:17] And...

**Helen:** [00:18:17] [overlapping] I feel like I'm at a therapy session right now! [laugh].

**Interviewer:** [00:18:18] Yeah it is a bit... But you know it's all confidential, people won't know it's you who is saying this!

**Helen:** [00:18:21] Great.

**Interviewer:** [00:18:33] So can you remember when you first came to know about p.\_m.\_s?

**Helen:** [00:18:39] Probably as an adolescent, you know, having my mom take me to the gynaecologist being like, she's so emotional, like p.\_m.\_s pretty much was, you know, a mainstay from the start.

Reference 7 - 0.40% Coverage

**Interviewer:** [00:19:38] That's great. And how common is p.\_m.\_s?

**Helen:** [00:19:45] From my understanding, PMS effects 70 percent or more of individuals with a period. I should say menstruating and not all of us have a Period, I guess! [Laugh]. Those who are producing eggs. Yeah.

Reference 8 - 2.79% Coverage

**Interviewer:** [00:23:14] Really? So. So what your doctors were advising, Your insurance didn't cover?

**Helen:** [00:23:19] Exactly. So it's quite a travesty, in the United States to have such a system. So my options were to pay out of pocket. And I don't quite... I remember, again, you know, just feeling completely like this is the end. Like I have no other option. The injections run, you know, upwards to twelve hundred dollars or more each time. So I was like, well, this isn't going to happen. Yeah. The cost is insane. And our insurance doesn't recognize it. I don't believe there's any. Um, Maybe one insurance company recognizes it as an effective treatment and so therefore will cover it. But somehow my doctor still got it approved and my insurance covered it- the surgery I mean. So the requirement was you had to do the GNRH trial before you could have surgery. But somehow she got it pushed through. And I remember it was very important to me that the reason was PMDD.[Pause] It just meant like... I didn't... she. So we had to say the reason for... they wouldn't cover my uterus for PMDD. We also couldn't leave it in, knowing what I know.[implying womb cancer risk]

**Interviewer:** [00:24:30] Yes.

**Helen:** [00:24:30] So we had... I I quote unquote "luckily had fibroids".[laughter] So she was able to use fibroids as the reason for my uterus removal for the hysterectomy and PMDD for the. oophorectomy.

**Interviewer:** [00:24:46] So the insurance were happy to cover... the oophorectomy on its own, for PMDD.

**Helen:** [00:24:50] Yeah

**Interviewer:** [00:24:52] God, it's so bad! [shaking head and laughing]

**Helen:** [00:24:54] Oh it's terrible, you've got to like market your body parts...,.

**Interviewer:** [00:24:59] It's very interesting...

**Helen:** [00:24:59] Yeah. I mean. It's insane. [laughter] It is absolutely insane. The loops You have to twist yourself and to to fit through in the United States for health care is beyond anything.[shakes head] Man...

Reference 9 - 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 10 - 1.67% Coverage

**Helen:** [00:29:38] Yes. So as I said before, you know, my understanding of p.\_m.\_s is it's a collection of symptoms that may or may not impede with your quality of life, depending how severe they are. But when we start crossing into PMDD is when you're having a severe emotional reaction or psychological reaction to... to the rise and fall, of your reproductive cycle. So some big red flags are going to be interpersonal uh relationship... you know, trouble with interpersonal relationships. So big problems with other significant others, with work, your you know co-workers and family members, your friends. You know, in the most severe cases, we're going to see, you know, depression, suicidal thoughts and behaviours. And that's when we know we're probably dealing more with something like p\_mDD. 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 11 - 0.90% Coverage

**Interviewer:** [00:34:38] Did you have any other health conditions that got worse At certain times in the menstrual cycle?

**Helen:** [00:34:44] Um, physically, I would say the fibroids, even though I wasn't aware, of that's pretty much what it was at the time. Let's see what else I would get. I mean, really, the rest would be psychological. You know, I had some underlying trauma issues. I was dealing with an anxiety that would definitely be exacerbated premenstrually. And, you know, even to this day, it's hard to untangle, which was what? But it's easier. It's easier to deal with the stuff that's not PMDD. Once you're out of it. [pause].

Reference 12 - 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 13 - 0.50% Coverage

**Helen:** [00:43:34] Funny as we're talking and I won't take too long [laugh] I know you have to go for a run today! I'm sure you've seen it. There is a gal I think she is a psychologist. She did a TED talk about how p.\_m.\_s is a myth. And I'm like, that's the one that always just burns me up at 2:00 a.m.. I just think about it. I'm like, oh, that lady!

Reference 14 - 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 15 - 0.73% Coverage

**Helen:** [00:47:48] You know, and I think it's also where you are individually when you're watching it, because when I was watching it, I was in PMDD and I or just battling it and it's like, great, another person, even a woman invalidating my experience, you know. So I think that's where it was problematic as a. As a tool to like what she was trying to convey, you know, there's a lot of barriers there.

**Interviewer:** [00:48:16] Yeah,.

**Helen:** [00:48:17] Yeah, but the way you say it, it makes sense! [laughter]

Reference 16 - 1.59% Coverage

**Interviewer:** [00:53:05] So this does touch on what we were just talking about. Have you ever met somebody who didn't believe you were really experiencing these symptoms?

**Helen:** [00:53:15] Yes. Many, [laughter] many, many people.

**Interviewer:** [00:53:23] And, was that like friends or family or doctors?

**Helen:** [00:53:24] So I would say friends and fam... Not so much friends. It was more family and my partner. I mean, I hate to say that. I don't mean to throw him under the bus. We're still married. But he had I mean, he'll even admit he's become a huge advocate as well. But before, because he had never experienced anything like this outside of me, like he even admits he's like, "there was just a time. I was like", he thought I was just being weak minded. Like he absolutely subscribed to the general view of all things premenstrually or mental health-related. Is "You can think your way out of this. You can't be as bad as you say. You're just being irrational. You're being overemotional". I think that was to this day, the hardest one to swallow.[pause] Is the lack of believing from my own partner.[serious tone]

Reference 17 - 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 18 - 0.90% Coverage

I think, you know,... I think [pause] [sigh] it's like I don't know, like any average person, any average person with PMDD doesn't feel believable, but they're like, "oh, if this famous person has it, they can be believed. And therefore, I can be believed because I can point to them and say, oh, this person has it And you all admire this person... you may not admire me, but you admire this person. And I have what they have". But I agree with you. Even then, someone's gonna look at them like, "oh, yeah yeah, you're just jumpin' on the bandwagon". You know, it is... it just sucks, being a woman sucks sometimes, doesn't it? [laughter]

Reference 19 - 4.87% Coverage

**Interviewer:** [01:10:11] There's just these differences depending on where you live.

**Helen:** [01:10:14] Oh totally. And they don't do testosterone here at all. I can't get it. Like I'd have to go to a compounding pharmacy like off label by myself out of pocket. I mean, I have no testosterone inside. That's one thing I will say sucks. Like I... I really... Oestrogen helps a little bit with libido. But I mean, I just did a lab probably six months ago. And now in the US we have... I know. And I think this is different in The UK, like we have access to everything. Like all of our medical records. Lab results. Do you guys have that?

**Interviewer:** [01:10:50] In theory, we can yeah

**Helen:** [01:10:51] In theory.

**Interviewer:** [01:10:51] [overlapping] In reality we quite often never see it...

**Helen:** [01:10:51] What's that?

**Interviewer:** [01:10:56] Sometimes... So you can ask. I've asked and I've still not seen it... So... um but in theory, we should be able to access it. But I think they lose a lot of our nights. It's a wonderful system, but it's also a bit rubbish in terms of admin.

**Helen:** [01:11:11] Yeah. It's not an exact science yeah. But like we have an app on our phone throughh our provider... My my my provider does and I can go see all my lab results all my different appointments and stuff. It would've been great when I was younger, but it's like a new thing. But I went in there and I was like, oh, there's my testosterone [laugh]. It's like at the very bottom of the scale. Yeah. The U.S. is just. Well.

**Interviewer:** [01:11:40] You know what I think? I think people are prescribing it here, but I think it's off prescription.

**Helen:** [01:11:45] Oh, is that it?

**Interviewer:** [01:11:46] Yeah. I don't think in the EU They have... I haven't seen a trial of the correct size to be able... for doctors to formally prescribe it. So I think it's something that people do... particularly if you talk about libido. I mean, I must admit my libido is terrible. And I... I still have a menstrual cycle and I only feel randy during menstruation, which is great because I don't want to get... I don't wanna get pregnant! [laugh]. But, you know, I don't fit this idea that you get randy around ovulation. I never have.

**Helen:** [01:12:26] I did before I had a kid now I'm just tired.[laughter]

**Interviewer:** [01:12:29] Yeah And I think... I think the tiredness is actually... and I think men are similar, their libido goes right down, even at our age and their testosterone hasn't gone. So, I think life has quite a big... part to play.. in some of these symptoms...

**Helen:** [01:12:44] Yeah, I think you're so right! I know. I tell people I'm.... They ask, "how are you doing post-surgery? Do you have a libido?" And I'm like, "honestly, no. But I also have two kids, a full time job, a partner, you know, a twelve year marriage... like my father passed away last year". I'm like there's... just 'life happens'. Like, you know, you forget to... you live so long. You know, with your diagnosis defining you. It's like you forget to drop a diagnosis. And also remember, we're human and life still happens with and without ovaries, with and without PMDD. And um yeah, so I tell people, "like, did the surgery work for me? Absolutely. And I'm glad I did it. Yes. Because they had no other options. But also to have realistic expectations because life will still happen. You know, you're cutting out your ovaries, not your heart". [laughter]

Reference 20 - 0.62% Coverage

**Interviewer:** [01:13:38] Yeah. I think that's true. I mean, I think for a lot of things, particularly mental health illnesses, we really really want a cure... that is actually a bit more than a cure and it's a bit more like MDMA or something where you just feel great [laughter] all the time. That would be wonderful, but that's not what human's lives are like...[laughter].

**Helen:** [01:13:55] Everyone would want that treatment! [laugh]

Reference 21 - 3.56% Coverage

**Interviewer:** [01:15:27] So,the very last thing is how do you feel about this conversation. Has it made you feel or think any differently than you did before?

**Helen:** [01:15:39] Honestly, I appreciate this conversation very much. I mentioned earlier about vulnerability hangovers. And er just. Just to get this off my chest. 'Giving Tuesday' [US social activism day after Thanksgiving holiday], there was you know, I've shared my story so many times over the years in media news articles online, in my my community. You know, and I had shared for Giving Tuesday my story and I had just moved to a new area, met new people. New people are friends with me on Facebook. And I posted it and I regretted it. And I just... like was angry almost and embarrassed. And I never had that feeling before. And I realized I'm like, I moved to a new place. I think I was finally ready to give it up. And then I felt a bit like... I went back to square one where I had become so confident and, you know, empowered by being able to share my story. I felt like I was being a stigma basher all these years. And then I went right back to square one. And I just. So I appreciate this conversation because it reminds me of why I share my story, why this matters, to talk to other people that are like, "oh, I get it. I've been there. This is my field". So I appreciate this interview today. Quite honestly. Yeah. I don't know if that all made sense?

**Interviewer:** [01:16:56] Well, I'm just going to ask if it's okay.

**Helen:** [01:17:00] Yeah.

**Interviewer:** [01:17:00] To clarify something about that. So you felt angry at yourself. For going back to this kind of earlier identity or what?

**Helen:** [01:17:10] Right. yeah. Yeah.

**Interviewer:** [01:17:13] So it's more like you want to move on and leave it behind?

**Helen:** [01:17:17] Yeah. Like, I just... I think it has defined me for so much... I think, you know, like earlier I shared a story and I became weepy. It's like... it's defined me for soooo looong, you know, like I don't want to ignore that it ever happened because, you know, we have this organization now because of this experience I went through. And all these people are big advocates all over the world. And people... like I think, you know, the collective experience, my experience, all this really matters. And people are being helped and a lot of progress has been made. But also as a hu... an individual, you know, I think I'm, you know, feeling like, OK, now that that was this first half of my life, what's the second half?

<Files\\P08\_Kathleen> - § 16 references coded [31.87% Coverage]

Reference 1 - 2.71% Coverage

**Kathleen:** [00:03:33] Yeah. So. So just if we talk about now. So yeah I just tend to know now. During my period. You know, I went for many, many years just not experiencing any particular change in mood or... um or just kind of carried on functioning really. But more recently I would say within the last year, I don't know if it's got to do with age or if it's got to do with, my fibroids journey, I'm not quite sure? But I definitely notice a change in my moods now. Um, It... I tend to feel. Just a little bit more down than I would normally or I just feel, maybe a little bit more on edge. But it's not in a major way but I notice it now, but I went for decades without really experiencing that at all. Um, the reason I remember that is because my friends always used to talk about how they felt. And so we had conversations about it. And I just knew that I just generally what... what was was okay. But more recently, I tend to notice a change in my moods a bit more. And I try to... not.. um I try to just carry on as normal as much as possible, Really. Um, and then, after my Periods... [pause] The other thing that happens as well during my period is maybe a bit of bloating. Yeah, and then afterwards that goes down. And then I'm fine. Back to normal.

Reference 2 - 0.84% Coverage

**Kathleen:** [00:14:02] Yeah, I know. but... um... I think Periods occur as part of a natural cycle. to um, yeah, a natural way to allow our eggs to leave the body.Um, because if they stayed in there they would... probably cause harm [laugh]. And, obviously it's part of um... Yeah, we have our eggs so that at some point we can have children, but I um... yeah, that's probably what I'd say.

Reference 3 - 0.51% Coverage

**Interviewer:** [00:17:19] You. Like would you say that you get PMS?

**Kathleen:** [00:17:27] Um [long pause] Until quite recently, I would've said no. But as said, the last few years...basically, I feel like um my mood changes slightly. Yeah.

Reference 4 - 2.62% Coverage

**Kathleen:** [00:24:50] She was she was just surprised I was... She said [puts on doctor's voice] "how are you? are you feeling OK?" You know, I was at my friend's house actually babysitting. [laugh] and I said, "I'm fine". She said "Are you sure?" And this was a Saturday night! Saturday night she called me. She said "are you sure because I've just seen your blood test results. Are you okay? Are you sure?" She said "you need to go to Á&E now!" And so I literally I went to hospital and they took more tests and they wanted to keep me in... And then it kind of got really extreme. But it was a miracle that I was kind of... To them [emphasis] that I was functioning as I was, they just couldn't understand by looking at the numbers. They did a few tests. They expected me.. You know, they wanted to put me on a drip, they wanted to give me iron in an injection. I kind of refused because I didn't really want to take them But, um. Yeah. So, yeah, I didn't... I think I was yeah... It was a miracle, that I just didn't kind of faint or.. they were kind of expecting me to kind of drop down, but I was functioning as normal. In a way- obviously, I was very fatigued. But um, yeah I was still just getting on with life.

Reference 5 - 2.65% Coverage

Just to ask you, why did you... why didn't you want the iron injections. Can you describe that?

**Kathleen:** [00:26:27] I...[long pause] I'm one of these people that I kind of al... my default position is always the most natural solution. I know that's not possible, clearly I've had surgery so, er.... But I just thought, I know my iron levels are very low. Um, so I kind of begged them to let me leave, taking I dunno, 6 iron tablets a day and promising that I'd eat lots of you know, iron-rich vegetable foods. And that's what I did, right... intensely for months and months. I think I had kale every day. Um... and these six iron tablets so that it slowly built up, so they were saying... they were encouraged every time they saw me that it was going up and up. Yeah, I just I mean, if it was you know, really really bad. I probably would have said yes to the injections, but I just didn't want to start off with that. I just wanted to try another alternative... um because I felt like if I had a set of injections then, then they probably would've said "oh come back again", then I'd come back again. And I just. Nat... just my natural default position is what can I do myself before... before there's the medical intervention?

Reference 6 - 2.89% Coverage

I don't have any strong feeling about taking painkillers, and I think I probably should, but [shrugs] I don't bother? Anyway..

**Kathleen:** [00:28:30] Maybe we're too hard on ourselves?

**Interviewer:** [00:28:30] And I think it's interesting... It's interesting because I think there is something about gender there. I think there's something about the naturalization of pain and the naturalisation of suffering and that... that we have to just do it for some reason.

**Kathleen:** [00:28:55] I think to me as well. I just... I'm not.[pause] Generally, I try to do the most natural thing, if that makes sense as well? I think it's... it's... it's.. that's what I believed it was. And I'm just... I'm quite conscious of what I put into my body. I'm not saying that, you know, I don't watch... you know, I'm not a kind of... Yeah, I'm not like, you know, a lot of people who pay a lot of attention to what... to their food. I'm not like that, but I do. I am one of those people that I just prefer to cook. I like to cook my food and, you know, and just have more natural things. And that might've just been the way we were brought up. But um... so that's why I'm a bit like you. I don't. I will take painkillers if I absolutely need to. But it's more that I don't want to put something... chemicals into my body as opposed to... Does that make sense?

Reference 7 - 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 8 - 0.63% Coverage

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 9 - 0.98% Coverage

**Interviewer:** [00:36:11] That's fine thanks. Do you consider Period pain or uterine cramps as a Premenstrual symptom?

**Kathleen:** [00:36:32] [long pause] Um... [long pause] I suppose it could be, yeah! I dunno, I wouldn't associate it very much with... Yeah, when periods like in the middle of the period. Or Yeah. I suppose so, yeah.

**Interviewer:** [00:36:50] So in your experience, it tends to be with the flow, not before?

**Kathleen:** [00:36:55] Yes.

Reference 10 - 1.17% Coverage

**Interviewer:** [00:38:21] So in your mind, would those count as Premenstrual symptoms?

**Kathleen:** [00:38:30] No. Particularly if they suffer from them at other times... I dunno, that would be generally asthmatic. Oh, right, I see what you mean. If they get worse at that time? [long pause] Yeah. Actually, I'll say yes, sorry. If they're... if they're just changing at that particular time of the month and actually at other times it's very different, then Yeah. Something's happening in the body around that time that's probably triggering it.

Reference 11 - 1.63% Coverage

**Interviewer:** [00:40:58] So this might not be relevant to you, but have you ever met anyone who didn't believe that you were really experiencing these symptoms? I mean, it might be relevant to your fibroids?

**Kathleen:** [00:41:09] Um... No, no. I mean, I haven't really... I don't really talk about it to be honest with people, not not my Period. I'm just trying to think because me and my sister are quite close. But we've never, it's never been that bad that I felt like "Oh I need to..." You know mention it . Obviously with the fibroids, it's a little bit different. But um, yeah.. and even now. I mean, I think I've told you about the change in my moods. But I haven't told anybody else. It's not that dramatic. It's just that I've noticed it. Um, yeah.

Reference 12 - 0.36% Coverage

**Interviewer:** [00:41:51] And again, with your fibroids, you had the anaemia... That was your very believable beginning.

**Kathleen:** [00:41:58] Exactly. Exactly, yeah.

Reference 13 - 3.20% Coverage

do you experience any positive menstrual changes?

**Kathleen:** [00:44:12] Hmmm [Very long pause- 15 s] That's a good question. Erm, I don't tend... I don't know if I do. And that's me thinking that you know, my period is a good thing. Yeah, It's just I think definitely at the moment, because it makes me just feel a bit more... a little bit uncomfortable with the bloating. A bit more tired, maybe. I'm not associating it as a positive thing. But, on the other hand, I'm not kind of wishing the symptoms away, but you know what? You know, I just see it as a natural part of, you know, of who we are. So, yeah, I mean, maybe some days if I'm like that it means that I stay at home and rest. So that's a positive thing.[laughter] The outcomes are positive! Um, but... Yeah. I don't know. No, I. Yeah. I haven't got um... euphoric feelings before. I know that after my Period there's definitely some kind of hormonal, pick up afterwards, I dunno, maybe that's another study maybe? And I've always noticed that. so my hormones do something very different just after I , you know, stop.

**Interviewer:** [00:45:42] So. So you mean like a good mood...

**Kathleen:** [00:45:46] Yeah.[overlapping]

**Interviewer:** [00:45:48] ...Or energy?

**Kathleen:** [00:45:48] Yeah. It's kinda even a better mood than I am normally. If that makes sense? It's almost like it's... bit like the mood is down here, then it goes up! [uses hand to illustrate fluctuating hormones] I dunno. That's what it feels like.

Reference 14 - 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 15 - 1.20% Coverage

**Kathleen:** [00:47:41] Yeah, my natural instinct is to call it a condition. i don't know the technical definition of 'illness' But clearly something is happening. Um in some women more than others.So, yeah I dunno! I suppose it's a bit like fibroids in a way, isn't it? Because 80% of women have fibroids, but most of them go on with their lives and they'll be absolutely fine. So it is still a condition or an illness when it goes to a more extreme level. It needs, it needs proper attention paid to it... So yeah, it probably falls into the same category.

Reference 16 - 5.90% Coverage

Um the only thing that I'm not so sure about. Is because I do have the heavier Periods and I don't know if that's... it's so difficult 'cos once you get to know your body to such a.. for a long time. You're fine. and then if there is a change um, you know, you don't know whether to worry or not? Once again, I don't know whether that's to do with my surgery. So that is something I am going to be looking at looking into more properly after. Yeah, and it's a long way of saying that It's been a good conversation!

**Interviewer:** [00:51:47] Just thinking about the heavy bleeding again. So are you slightly afraid that you might have fibroids?

**Kathleen:** [00:51:54] Yeah,.

**Interviewer:** [00:51:56] So, you sort of, you don't really want to know?

**Kathleen:** [00:52:00] Yeah, but I think just. I mean, the reason why I will get checked out. Because I I know the danger the last time of waiting and waiting. So. Yeah. So I mean I've been to the doctors and stuff I'm just trust in the process of doing that. Yeah. Then again, that's the thing, like, as women, well I suppose men do as well in a way. But definitely for women Given the... When you have fibroids and I'm sure other conditions as well. People with endometriosis, for example, a lot of these things just never go away. They just manage it. So I think for me, I had a good few years when i was fine and the bleeding was fine and then It got a bit heavier and then started thinking, "oh, I'm going to have to go down that path again", you know? But I'm hoping and praying that it's not there. But if it is, I would definitely report them earlier than the first time when I went for ages before I even sought help. At least now I'm thinking actually, yeah, It could be that my body's changing. But actually it could also be that... um, there are some fibroids there and that's what's making the bleed a bit heavier.

**Interviewer:** [00:53:22] Yeah. This is the thing is... it's the link with fertility. And obviously, then the fear and I've spoken to people even who've had children, and they know they don't... They're not planning to have any more. They still... it's such a big part of our identity. And In some cases, your future plans. That it's not like you don't want to know, it's that you're hoping it will resolve.[laugh]

**Kathleen:** [00:53:57] Yeaah!

**Interviewer:** [00:54:00] And Things do change, so!

**Kathleen:** [00:54:02] Yeahh. No, I think... I think you're right. It is attached to so much. [long pause] Yeah, it is a touch to say... if you haven't had children, like myself and er you do want to have children. It's not just about a check-up, you know.[short laugh] It's about... It is your kind of dreams that are Linked to these hospital check ups, you know.

<Files\\P09\_Aisha> - § 17 references coded [38.65% Coverage]

Reference 1 - 3.53% Coverage

**Interviewer:** [00:02:32] Yeah. So do you feel any different before, during or after your period?

**Aisha:** [00:02:36] Oh, yeah, definitely. So before my period and after my period. Definitely during my period. I'm a lot better.

**Interviewer:** [00:02:44] Yeah, so how how exactly do you feel before?

**Aisha:** [00:02:48] Before, I am constantly craving for food. My mood is like, you know, I've got patience for anything. But when I'm p.\_m.\_s, like, I believe I have PMS erm, I'm constantly just being a cow and snappy, snappy. And also my anxiety flares up. Um, definitely I have an increase of anxiety and feeling low and I either go through a crazy cleaning spree or I can't be bothered to do anything.

**Interviewer:** [00:03:20] And then what about afterwards, then what's happened afterwards?

**Aisha:** [00:03:23] Afterwards, I tend to feel very low and I don't like to socialize. Very low, definitely, and erm, it's more plays on my mood, my low mood side of things.

**Interviewer:** [00:03:36] And during what's that?

**Aisha:** [00:03:37] [noticable change in tone- to happier] During I'm uplifted, I'm me. Um, I don't really get pains or anything, but I'm a lot more energetic. That's when I get my goals done. I'm a lot more productive. Definitely.

Reference 2 - 0.94% Coverage

**Aisha:** [00:03:58] So obviously, like I don't pray durin my Periods... um neither. If I was to fast, I wouldn't fast. But before my period, what I do is... um is a long bath. so, I definitely increase that because it really helps, um anything special? Oh, and I just let myself loose. If I want to go crazy eating out, I'll eat out.

Reference 3 - 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 4 - 1.56% Coverage

**Interviewer:** [00:08:17] So overall, how do you feel about getting Periods and the fact that we're getting like 40 years?

**Aisha:** [00:08:22] Like um I've accepted, it. And I believe, yes. It is the right thing because when I don't get my Periods when I'm late. It really affects me as well. Like I'm really late at the moment and I'm not myself and I get a bit confused. Oh, my God. I meant to be PMSing. But I'm getting a late period and I like... I appreciate that.. it does come every you know, for 40 years. It feels normal. If that makes sense?.

Reference 5 - 0.44% Coverage

**Aisha:** [00:09:14] If you wave your wand about the p.\_m.\_s.. then definitely! yeah, but you know, when I'm on, I'm happy I'm normaal and. Yeah, I'm balanced.

Reference 6 - 2.27% Coverage

**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 7 - 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 8 - 1.21% Coverage

[pause] So is there a stereotype of a person with p.\_m.\_s?

**Aisha:** [00:20:36] No. [quietly] I think, everyone just says, "oh, there's no such thing". Everyone's ignorant to the fact... about PMS. It's so... taken so lightly.

**Interviewer:** [00:20:49] So you think it's just sort of seen as a normal... It's basically just the menstrual cycle, and people see it as a normal...?

**Aisha:** [00:21:03] [ends sentence] thing.. Yeah

Reference 9 - 1.35% Coverage

**Interviewer:** [00:21:03] So have you ever heard of PMDD, Premenstrual Dysphoric Disorder?

**Aisha:** [00:21:04] Yeah.

**Interviewer:** [00:21:06] So what do you know about that?

**Aisha:** [00:21:07] I know that it's a lot more intense. You feel more like high emotions, like suicidal, which sometimes I feel I have... 'cos I've felt really suicidal. It's lower mood. Stronger feelings. Is that correct?

**Interviewer:** [00:21:21] Uhuh, yeah

**Aisha:** [00:21:21] That's what I feel.

Reference 10 - 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 11 - 5.88% Coverage

**Aisha:** [00:22:13] I know. And I went through the whole 'getting assessed'. And then they're like, oh, they feel as if obviously I do have a borderline personality disorder. But treatment at this time would not be suitable. And I was really, really angry. But then I asked questions like "how many people a year get to get this treatment?" And it was about 15 a year. So I'm just thinking maybe that's possibly why...?

**Interviewer:** [00:22:39] It's like the lack of resources...

**Aisha:** [00:22:41] So, it's resources and stuff. And then now I'm gettin'... because it's been six months since I've been diagnosed with that. So I'm getting referred to that again, so I have to go through the whole assessment again. And hopefully...

**Interviewer:** [00:22:51] Um, definitely bring up that it gets much worse...

**Aisha:** [00:22:52] During my Periods...

**Interviewer:** [00:22:55] And the suicidal thing. Definitely mention that because for PMDD now, that's one of the key kind of things... they look for...

**Aisha:** [00:23:04] Yeah. So it's like [sigh] so annoying.

**Interviewer:** [00:23:07] No, it's not... I mean, it's really not good to get given a kind of label. A diagnosis and then for nothing else to happen...

**Aisha:** [00:23:15] Yeah... No I've... all my life. Because I feel as if in the past they've also done Cyclothymia... So my moods will change every three, four months. Again, I think that's a lot to do with p.\_m.\_s. Do you see what I mean? The older I'm getting the more exposure I'm getting to this stuff.... book... more books. I'm reading about Periods. I'm realising... I've been misdiagnosed. And you know, when you have it... if that makes sense?.

**Interviewer:** [00:23:42] Yeah. I mean, there is... So it's very difficult to know whether someone is pure PMDD or whether the menstrual cycle is like triggering...

**Aisha:** [00:23:52] Yeah yeah yeah

**Interviewer:** [00:23:52] A mental health issue, because in some people it could be that, and in some people it might be the other. But at least if you know that there are different options for treatments...

Reference 12 - 4.24% Coverage

**Aisha:** [00:24:02] Because then again, the borderline personality disorder, it does make sense because obviously, I've been raised. by my mom, single parent. So then that... abandonment has always affected me. So... then I think matching up the whole history. They're probably thinking, oh, right. So I don't know.

**Interviewer:** [00:24:20] Yeah, they're already putting you in a particular...

**Aisha:** [00:24:23] I don't know. I really don't. But then again, my sisters haven't been affected at all. And recently, I know my sister has p.\_m.\_s [laugh] If that makes sense?

**Interviewer:** [00:24:32] Yeah yeah

**Aisha:** [00:24:32] Because the more I'm telling my symptoms, I'm really close to my sister. She's realizing 'Oh my god' she's been tracking it and she's p.\_m.\_sing, too. And um, yeah, my older sister's is totally in denial about it. so, yeah. I dunno.

**Interviewer:** [00:24:45] It's hard to know, I'm the same... my mom bought us up alone. And whenever you mention that to a psychiatrist, you sort of see them...

**Aisha:** [00:24:54] Mental health...

**Interviewer:** [00:24:55] Think, oh, 'trauma' you know, you were traumatised as a child... When really, where I grew up. Everyone only had one parent.

**Aisha:** [00:25:02] Oh...

**Interviewer:** [00:25:03] So It was very normal.

**Aisha:** [00:25:04] Yeah.

**Interviewer:** [00:25:06] And sometimes, yeah, I think maybe they stop listening after they have decided.[laugh]

**Aisha:** [00:25:09] This is interesting... it really is interesting.

Reference 13 - 1.49% Coverage

So which symptoms do you experience nearly every cycle, every single time?

**Aisha:** [00:30:39] The food cravings. [long pause] But it's... that's the food cravings really creep up.

**Interviewer:** [00:30:50] And that's like sugary food?

**Aisha:** [00:30:53] Meat, sugary foods, spicy food. bubble tea. [laugh] Sugary foods, yeah.

**Interviewer:** [00:31:05] So basically, you're hungrier?

**Aisha:** [00:31:07] Yeah. Yeah and I can, eat... even if it's healthy, even if it's not... I can eat like... constant and never get full.

Reference 14 - 1.80% Coverage

**Interviewer:** [00:31:37] So have you ever met anyone who didn't believe that you were really experiencing these symptoms?

**Aisha:** [00:31:44] All the time!

**Interviewer:** [00:31:44] So who are these people?

**Aisha:** [00:31:45] My manager [laugh] Um... My big sister. Um. Yeah, close people, close relatives like my uncles and stuff. Men. (Some men get it! [laugh]). And a lot of older women like my aunt, for example. They... they find that's so normal.

**Interviewer:** [00:32:15] So they think because they didn't get it.

**Aisha:** [00:32:17] Yeah.

**Interviewer:** [00:32:18] That you're making it up?

**Aisha:** [00:32:18] Yeah exactly.

Reference 15 - 1.61% Coverage

**Interviewer:** [00:32:27] So are you aware of p.\_m.\_s being a slightly controversial diagnosis?

**Aisha:** [00:32:33] Yeah

**Interviewer:** [00:32:33] Could you tell me why you think it might be a bit controversial?

**Aisha:** [00:32:36] Some people feel it's normal. Some people feel it's got nothing to do with your Periods, your mood. It's a mental health condition, it's your environment, it's what you eat etc. So that comes before that diagnosis. Um. Some people don't even see it as it should be a diagnosis. They think it's a part of your symptoms and. Yeah, that's it.

Reference 16 - 1.18% Coverage

**Interviewer:** [00:33:00] Mm hmm. Yeah. Have you ever experienced any positive menstrual changes?

**Aisha:** [00:33:11] Yeah, like sometimes I feel more productive. Sometimes I feel like, oh my God, I can do everything I can meet Everybody. Did I... and I feel so happy you know? I have like a list of .... I have a bucket list anyways, and just to get them done [excited tone] and start planning things or I want to cook.

Reference 17 - 1.41% Coverage

**Interviewer:** [00:33:37] Mmmhmmm. And that's it! So how do you feel about this conversation? Has it made you feel or think any differently than you did before?

**Aisha:** [00:33:45] It's made me feel more that I need to... Um when I'm having that PMS to be able to manage it a bit more, to be able to go to the doctor and talk to them about it a bit more. And it has made me feel better talking about the period because I hardly speak about it. [laugh] It's usually a conversation with me and my brain.

<Files\\P10\_Mala> - § 9 references coded [25.14% Coverage]

Reference 1 - 1.12% Coverage

**Interviewer:** [00:03:09] Or just before? Sometimes people change their diet...

**Mala:** [00:03:12] No, I don't do anything. I just. Let me let myself feel. Or, I just... If I've got the craving? I eat. that's the only thing and I do get cravings for spicy food as well.

Reference 2 - 2.31% Coverage

So do you identify as somebody who gets PMS?

**Mala:** [00:07:17] I do.

**Interviewer:** [00:07:18] And why is that?

**Mala:** [00:07:19] Because my mood... I'm normal throughout the week and one week before, my period is meant to start. My... I am a totally different person. Like I feel like everybody needs to walk on eggshells around me and I feel it... I feel it, too. And that's how I know that I'm going to start my Period because my... my hormones are playing up. And when I do start my period, I'm normal again. So I know that I PMS prior to it.

Reference 3 - 3.17% Coverage

**Interviewer:** [00:08:56] And can you remember how you first came to know about p.\_m.\_s as a thing?

**Mala:** [00:09:02] It wasn't... not so long ago. Actually it was probably... I can give you months... probably like six months ago? Yeah.

**Interviewer:** [00:09:11] OK and How did you find out?

**Mala:** [00:09:12] A friend told me that you are definitely PMSing [laughter]it's becoming a thing. You are acting so strange and that's not you normally. And then I was like, why am I acting like this? And she's like "when are you going to start your period?" and then I checked my Period calendar and it was in a week's time. So she was like "you are definitely PMSing". And then I went through the symptoms. That's me. That's me. That's me. That's me.[laugh]

Reference 4 - 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 5 - 1.49% Coverage

**Interviewer:** [00:11:12] And what is your understanding of why we get these changes or these symptoms, why they happen?

**Mala:** [00:11:19] I think it's a hormonal thing. Your hormones... um are being regulated and you're going to get a release soon. That's how I think of it. So it's all clogged up. And then once you start your period, it's that release.

Reference 6 - 5.02% Coverage

**Interviewer:** [00:13:59] Um, are you aware of a stereotype like a typical type of person who would have PMS?

**Mala:** [00:14:06] No, I'm not.

**Interviewer:** [00:14:09] So, you haven't heard any...

**Mala:** [00:14:09] [overlapping] emotional?

**Interviewer:** [00:14:10] ...Jokes or anything like... nobody's sort of... or any cartoons or anything like that?

**Mala:** [00:14:16] No, I haven't. I mean we... We make jokes! [laugh] Me and my friends. Oh, you're defini... We say like you're definitely... Are you PMSing now? Do we need to leave you alone?

**Interviewer:** [00:14:31] And what's that sort of saying? That you were being a bit irritable or?

**Mala:** [00:14:36] When in their view... it's probably they're being irritable. And we're just trying to make... normal, normalise it... So they don't feel like... because when you are PMSing, you're very emotional and everything gets to you and you have to gauge how you act. But if you know, like if one of my friends are PMSing and she's OK, then make a joke out of it so she doesn't feel too bad about it. So, it's normalized like it's something... You're not... you're not abnormal for going through it. It's okay for you to go through this.

Reference 7 - 2.54% Coverage

**Interviewer:** [00:20:45] And have you ever met anyone who didn't believe that you're really experiencing these symptoms?

**Mala:** [00:20:49] [Immediately, almost overlapping whispered speech] My mum. [Short pause followed by laughter]

**Interviewer:** [00:20:52] So what does she say?

**Mala:** [00:20:53] So if I say I'm PMSing, that's why I'm actin' like this, she says "You're just overreacting".

**Interviewer:** [00:21:01] So, she doesn't like count it at all?

**Mala:** [00:21:01] [Overlapping] She dismisses it! [laugh] Yeah. 'Cos you're trying to make an excuse for your actions. SO I just ignore her...

Reference 8 - 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 9 - 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> - § 8 references coded [33.70% Coverage]

Reference 1 - 2.24% Coverage

**Interviewer:** [00:01:53] And do you feel different? Before or during or even after your period?

**Noor:** [00:01:59] Yeah. So I'd say about three or four days before I start. I want to eat everything in the world.[laugh] I feel a bit moody, not myself. I just want to be left alone if that makes sense?

**Interviewer:** [00:02:14] And then during or after- any differences?

**Noor:** [00:02:16] Mmmm, I'm back to normal. As soon as I start, I'm back to normal.

Reference 2 - 4.41% Coverage

**Interviewer:** [00:06:08] So how do you feel about the fact that we get Periods and that we'll them for like... Usually it's about 40 years?

**Noor:** [00:06:18] A couple of years ago, I'd be like "Eurgh", because I used to get so much pains, but now I'm used to it and I don't mind. It's just one of those things that happens.

**Interviewer:** [00:06:29] So has the pain got better?

**Noor:** [00:06:31] Yeah. Yeah. Much better.

**Interviewer:** [00:06:38] So if I could wave a magic wand and get rid of your Periods would you let me do it?

**Noor:** [00:06:44] Yeah, [laugh] definitely.

**Interviewer:** [00:06:48] Why is that?

**Noor:** [00:06:49] It's the bloatedness. [pause] The mood swings sometimes.

**Interviewer:** [00:06:58] So it's that you'd prefer... Because they're uncomfortable,

**Noor:** [00:07:01] Yeah,.

**Interviewer:** [00:07:02] You'd rather not have them?

**Noor:** [00:07:03] Definitely.

Reference 3 - 3.00% Coverage

Do you identify as somebody who gets p.\_m.\_s?

**Noor:** [00:07:15] I do.

**Interviewer:** [00:07:17] Why is that?

**Noor:** [00:07:21] I think it's... So that because of the mood swings. I would put that under PMS, but I don't know if it actually is.

**Interviewer:** [00:07:31] I mean, this is the whole point of my research, is that it's not really clear what is and what isn't...

**Noor:** [00:07:38] I think when you are not your normal self and it's just before your period and you know it's related to your period then. Personally, for me, that's PMS because that's something that's not in your usual behaviour.

Reference 4 - 0.98% Coverage

**Interviewer:** [00:08:34] Ok. So how would you describe p.\_m.\_s to somebody who hadn't heard about it?

**Noor:** [00:08:40] I'd say it is just before you start your period and you're not your normal self.

Reference 5 - 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 6 - 10.64% Coverage

Is there a kind of stereotype of somebody with p.\_m.\_s? Are you aware of one?

**Noor:** [00:11:36] Yes. So... [pause] People would just think your abnormal, if that makes sense, but... like, for example, if someone's acting really out of line they'll be like "Oh, what's wrong with her, something wrong with her mentally, etc". but really it's just p.\_m.\_s and I think... People forget, obviously, there's different stages where people change their moods. But that's generally me seeing it, seeing it... if that makes sense?

**Interviewer:** [00:12:06] So you think like the sort of stereotype like that would maybe be in the newspaper. Would be.... Um...

**Noor:** [00:12:17] I think, like if you see a female celeb just suddenly pigging out they'll be like "Oh she must be going through something mentally or depression", they wouldn't think, oh, she's p.\_m.\_s ing.

**Interviewer:** [00:12:25] Mm hmm. So definitely with the food that's not...

**Noor:** [00:12:28] Yeah...

**Interviewer:** [00:12:28] ... associated with PMS. What about mood changes? Do you think people are a bit more... aware?

**Noor:** [00:12:37] Well, I think they are aware, but they take the mick, if that makes sense? Like if you've... like for example, at work. If a female's moody, they'll be like "Oh, I think she's on" do you know what I'm sayin'? And you're just thinking. "OK. You just pissed me off now". So, I think things like that. I don't know how you would explain that...

**Interviewer:** [00:12:56] Yeah. And that's quite a common one particularly at work that you might be angry for a work reason.

**Noor:** [00:13:01] Yeah.

**Interviewer:** [00:13:01] And then other people might be going...

**Noor:** [00:13:03] "She's on, just leave her alone"

**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 7 - 2.24% Coverage

And so some people get things like asthma attacks or even epilepsy or migraines at certain times in their cycle. It triggers them. Would you count those as Premenstrual symptoms?

**Noor:** [00:17:34] Uh, yeah.

**Interviewer:** [00:17:39] And why is that?

**Noor:** [00:17:43] It's because... They're getting those symptoms just before they start. So it's triggering it off...

**Interviewer:** [00:17:50] So it's to do with the timing?

**Noor:** [00:17:50] Yeah.

Reference 8 - 4.59% Coverage

**Interviewer:** [00:18:51] Have you ever met someone who didn't believe you were really experiencing these kind of things?

**Noor:** [00:18:57] Yeah, it's more my female colleagues rather than the male ones.

**Interviewer:** [00:19:03] So because they don't get it.

**Noor:** [00:19:04] Yes.

**Interviewer:** [00:19:05] SO they don't believe you?

**Noor:** [00:19:06] Yeah.

**Interviewer:** [00:19:09] And how do they... how does that happen like. Do they say that to you or?

**Noor:** [00:19:14] So once what happened, I was like "I'm not feeling really well. I think it's because of been my period". And then she's like, "2oh, you'll be fine. You'll be fine. Just get on with it". But my colleagues could tell I was struggling. And then she was like "you'll be fine". And in the end, she left. So the other lady that took over said " It's, OK, go home".

**Interviewer:** [00:19:31] Mm hmm. So they kind of minimized it...

**Noor:** [00:19:33] Yeah.

<Files\\P12\_Ria> - § 7 references coded [34.74% Coverage]

Reference 1 - 1.77% Coverage

And there's like, you know, even just p.\_m.\_s probably... Is it in the DSM?

**Interviewer:** [00:07:02] 'PMS' isn't, but Premenstrual dysphoric disorder is.. so that's the most severe... That's when you're getting suicidal ideation...

**Ria:** [00:07:11] Got it!

**Interviewer:** [00:07:11] So, it's like 1 to 2 percent of people.

**Ria:** [00:07:15] OK. Yeah. And like, bless those people. I hope that they can get the help that they need and then in gen... But like looking at the normal curve and distribution, a lot of p.\_m.\_s quote unquote 'symptoms' or just things [laugh] that happen to us during that time, which are like beautiful and magical and also a huge struggle.

Reference 2 - 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 3 - 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 4 - 3.00% Coverage

Maybe toxic friendships or relationships, things that have been on our to do list that we keep putting off and keep putting off... Um, any sort of stresses in our life is a time when our brain is like really, really thinking about those things as a form of processing and bringing it to our awareness. So that then when we get to the winter and we get to the actual composting and period and... and like physical release of blood, then we can shed that alongside. And so I think irritability is also something that tends to happen a lot during that time. Those that's one of 'the symptoms' in quotations. So just being like annoyed at every human around [laughter]. And I think, yeah, that's just again, a response, a natural response that our selves are going through as like a calibration just to be like, "OK, this is my life. Let's take a little snapshot here. We have 14 days to just get a picture of what is going on and what are... what's not working for us". And so that's mental, emotional. So we can do a lot of crying, um laughing, just like processing some of those thoughts and traumas and things that have built up over the cycle.

Reference 5 - 9.53% Coverage

**Interviewer:** [00:25:48] Yeah, that was very full. Thank you. Um, so again, in your opinion, what's the best way to manage PMS?

**Ria:** [00:25:56] Um, so physically. I highly recommend. And I don't do one on one client work for... Several reasons. But if I were to do that sort of thing and give that kind of one on one personal 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. So if possible, supplement your eating plan or just food and build it into your menu to get vitamin D, magnesium, zinc. Um and then spiritually and emotionally, how to manage it? do things that make you that bring you just a lot of joy and do them by yourself. So I like to prescribe a good dance party to people. So just like put on your favourite song, dance it out, release it and let yourself just have a night in bed where you eat your favourite food, you watch maybe a movie or you read a book or whatever it is that you can just like get into and that you enjoy. These are things that I like. So I encourage people to do things that they really like. Maybe they like crafting, maybe they like baking, maybe they like. Dot, dot, dot. So mean different things. So for mental and emotional, do things that you really like and do it by yourself and let yourself sometimes, especially if you're going to cry like just let it out. And then I... some... like in my class, I teach at a university as well. I teach a process called regulating that I've learned from a friend of mine who's an energy healing practitioner. And basically, it's a body movement and a practice where you like, you go breathe in, breathe out, breathe in, breathe out, breathe in, breathe out. And you can move your hand, pedal your hands in whatever way or you can pedal your feet. And it's a way to bring your body, mind and spirit from being really activated, let's say, and like overwhelmed in the sympathetic nervous system and bring it to be more parasympathetic dominant and like a little bit more relaxed and grounded. And so, like, for example, when I was on the pill, there would be times where I was just like I would cry for like an hour. And it was just I was so upset over a certain thing. And in those moments, you know, there's a line between crying as release of trauma and crying as a coping mechanism to deal with some sort of underlying mental, emotional, spiritual, physical pain. So both releasing and self-regulating release, self-regulate and then spiritually, I encourage people to do whatever ceremony they're called to do, whether that's drawing tarot cards, whether that's going outside by yourself for a walk and just breathing and taking notice of like the beauty of the earth and more than human beings. Reading scriptures, if that's something that you do in your practice, just any kind of spiritual ceremony. And if they're not into the term spiritual, then we can come up with different ways to talk about what that means. A lot of reflection, that sort of thing.

Reference 6 - 3.96% Coverage

**Interviewer:** [00:35:14] And so relating to that in your understanding, what are the most common Premenstrual symptoms or changes? Could you maybe list the top five or top 10?

**Ria:** [00:35:25] Mm hmm. So the drop in sex drive![laughter] I'll put that as number one! because I feel like I notice it. I personally notice it the most and then in just talking. I like to always ask people about their menstrual cycle. So that's what I hear a lot as well. So drop in sex drive, um... greater... um, like more fluctuation in experiences of emotion. So like. Yeah, greater... Like greater changes and fluctuation as opposed to. Yeah. Maybe just having like a few waves up and down from like high vibe to low vibe in p.\_m.\_s. It seems to be like the changes are quite drastic. Three; increased food cravings, which is great and important because for the most part what I hear from people who are fertility awareness educators and do a lot of client work, especially with people who are trying to conceive, is that they're like, where's the food? Well, you're not eating enough [laugh], which is so contradictory to.... um, Yeah. What I see is a lot of focus on meaking..., things like making people feel shitty about their bodies and body image. And so increased food cravings and then decrease in energy. So just feeling a bit more tired, feeling like you might need a bit more sleep, which again, totally OK, very natural. And then the fifth one. I would say would be just like a general slowness, a slowing down.

Reference 7 - 6.47% Coverage

**Interviewer:** [00:42:12] Great. So, it's known that many chronic health conditions are worsened or sometimes I just triggered at different times of the menstrual cycle. Would you count those as Premenstrual symptoms?

**Ria:** [00:42:29] Like a Co-...? I guess the word might be like co morbidity of...

**Interviewer:** [00:42:37] Not quite co-morbidity. It will be... So there's cyclical epilepsy, cyclical asthma, irritable bowel syndrome tends to get much worse. In fact, there's like a lot of things get worse, just premenstrually and menstrually typically.

**Ria:** [00:42:57] Got you!

**Interviewer:** [00:42:57] Sometimes at ovulation as well, actually. But. Most often it's premenstrually. And then, yes, some things are actually just triggered, so menstrual migraine is a very common experience. People just get it in the luteal phase...

**Ria:** [00:43:15] Yes, OK. So then definitely I think there's the shift that happens during p.\_m.\_s; physical, emotional, spiritual shift, especially the physical piece of like basically progesterone taking over, as our... the main hormone that our ovaries are producing and working with. I think that does like trigger a big shift physically and then. Yeah, it's it's definitely, I would imagine, interrelated. You would know more than me and people who do a lot of client work where they really know a person's experience and and what they're going through in terms of their own. Well-Being. They would be able to tell like, "OK, this is like this is definitely a pattern that we're seeing with this particular thing". And then in terms of I'm trying to think of what people have talked to me about. Yeah, I don't think I can comment too much about it other than speculate and based on the research that I've done, that that's probably the case. And so it's a time then where we can, rather than stigmatizing it and pathologizing people more. Maybe we can emphasize greater self and collective care as a whole during that time. If we do have this information and even backed up by you know the idea of scientific research that things are more heightened during that season. So then how do we like build in more support and care for people during that time? So if they're not just experiencing standard p.\_m.\_s symptoms like bloating or low sex drive or etc., they're experiencing more... um more challenges to their wellness, then how do we support that rather than making them feel shitty or like ashamed about it? Yeah.

<Files\\P12\_Ria2> - § 4 references coded [20.33% Coverage]

Reference 1 - 1.96% Coverage

**Interviewer:** [00:01:30] Do you have changes that you experience nearly every cycle, like things that you can rely on?

**Ria:** [00:01:36] Yes. So I'll just list four for the Four Seasons. So period, I can always rely on flaking on the plans that I've made because I should learn to not make plans when I have my period. Like social plans... usually I want to stay in at home. Spring time I can usually count on my sex drive being a lot higher. Summertime. Around ovulation. I can count on... um really like huge, large creative ideas. And then p.\_m.\_s. I can usually count on preparing... having a well stocked snack pantry [laugh] so that I can snack to my heart's desires.

Reference 2 - 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 3 - 7.09% Coverage

**Interviewer:** [00:17:12] So one of them is, what is your understanding of why we have Periods?

**Ria:** [00:17:18] Like why we as menstruators... bleed?

**Interviewer:** [00:17:21] Yeah.

**Ria:** [00:17:25] Hmmmm.... So spiritually, I think that it's the way that the Cosmos has literally given us... a time to take breaks to care for ourselves [laugh], because it seems like in this humanity that we live in, that menstruators are time and time again the primary caretakers of the world.. of humanity [laugh]. And as a biologist, I can say the same in pretty much every mammal. Um, it's been well documented that the ones who bleed are the caretakers. And so it's like this cosmic balance between masculine and feminine. And, you know, all the things that femininity embodies and all of that. And then physically, I think a lot of people would probably say it's to bear children and like continue on and all of that stuff. So that would be one thing. But for me, physically, it's a way... it's a detox process. So the period is a form of our body detoxing. So in the other seasons, you know, we're exposed to all these toxins, toxic people, toxic chemicals, toxic, et cetera, et cetera, in the modern world. And then we ovulate. And ovulation has been shown to not only promote really good bone health for... in the long term, but, you know, like it's so good for our bodies. Our bodies love ovulating. So, yes. And then the period comes and it's a way of detoxing, everything we've been exposed to. And then mentally, I think the period again is a time of quietude in a world where our minds are just constantly stimulated and we spend a lot of time like up here in our 'feels' (?), not as much grounding to the ground. So the Period is again a reminder to just allow yourself to quiet the mind in whatever form people do that. And then emotionally it's also a form of release and detox because that autumn season p.\_m.\_s, as people call it, is so intense, like 'leaves are literally being like pulled from the body'. It's very... there's a lot of compost and movement and huge drops in um the temperature change, for example, even going up. And so the period is a way for that emotional release to also happen. I know there are days when I have a bit longer cycles where I'm just like, " Gah! period, like come already!" I'm literally like vibrating. I need... I need that release to come and happen. And then the physicality of it all.

Reference 4 - 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.