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Women's experiences of living with premenstrual dysphoric disorder (PMDD)

Portfolio submitted in fulfilment of the Professional Doctorate in Counselling Psychology (DPsych)

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September 2026

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Table 1: Participant demographics

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Declaration of powers of discretion

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Preface

Introduction

This portfolio is made up of three sections: a doctoral thesis, a publishable journal article and a combined case study and process report. Whilst they are three independent pieces of work, they are connected by a common theme of women's distress as a response to the pressures of social norms and expectations. The women in this portfolio share a belief that they should be able to cope on their own. An overview of each part is presented below, followed by reflections on my own experiences of becoming a counselling psychologist in relation to this theme.

Part A: Doctoral thesis

In this section I introduce my doctoral thesis which is the write up of a research study exploring women's experiences of living with premenstrual dysphoric disorder (PMDD). PMDD affects 1.6% of women (Reilly et al., 2024) and is a neglected topic in research leading to common misunderstandings and misdiagnosis in personal and professional contexts (Osborn et al., 2020b). Premenstrual disorders are often dismissed as part of the normal female experience resulting in women's distress not being taken seriously. The lack of research on women's health problems is reflected in the field of PMDD, and more empirical research is needed to further the understanding of the condition and the impact it has on women's lives.

My interest in this topic came from my personal experiences of being a woman with my own struggles with my menstrual cycle. I found the idea of PMDD as a diagnosis difficult to comprehend at first, however, as I familiarised myself with the topic, I became more open to the idea that this diagnosis could be helpful to women not detrimental. In the research I found that there was a focus on how to define PMDD, whether it exists and tracking symptoms. The priority was a search for the "truth" and getting the right answer rather than gaining insight into the subjective experience. I reflected on my own way of thinking about it following my own strong reaction to its inclusion in the DSM-5 (American Psychiatric Association, 2013) as a distinct diagnosis and noticed that I was following the same path. My attention was focused on figuring out whether it was correct

to diagnose women with PMDD and not considering how the women suffering from it understood their own experience. As I familiarised myself with the research literature and the online community of PMDD sufferers, I discovered that most women living with undiagnosed and diagnosed PMDD shared that a narrative of categorisation was helpful. I wanted to find out more about they were going through before jumping to conclusions about a right or wrong way to make sense of someone's distress.

The aims of this study were to address this gap in the research literature by exploring the subjective experience of living with PMDD and improve our understanding of how to provide support. Seven participants with a diagnosis of PMDD were interviewed by me and completed diaries in their own time, recording their day-to-day thoughts and feelings about living with PMDD. Data were analysed using interpretative phenomenological analysis (IPA) (Smith et al., 2022) and four group experiential themes (GETs) emerged. These themes reflect the struggles that the participants faced in their interpersonal relationships; challenges in accessing and receiving support and the social expectations and judgments of those around them. They also describe the internal battles that these women dealt with, for example self-blame, loss of control and feelings of failure. The women's self-blame stood out for me as significant and highlighted how the distress they described appeared to be linked to internalised beliefs that the women had about acceptable ways to think, feel and behave as women. The clinical implications of these findings are discussed as well as suggestions for future research.

Part B: Publishable journal article

In the second part of this portfolio, I present an article prepared to be submitted for publication. The article is based on the doctoral research presented in Part A and focuses on one of the group experiential themes that stood out for me: 'Making sense of their PMDD: a journey of discovery'. This theme captures the experience of seeking and receiving a diagnosis and the struggles that women faced afterwards. The main significant finding that I chose to highlight in this article is that receiving a diagnosis of PMDD alone is not enough. It felt important to make this the focus of the article to

support the argument for further research into treatment options for people with PMDD as this study shows the lack of support available. This article also demonstrates the women's isolation and self-blame which link the article to the common theme of this portfolio. The clinical implications for counselling psychologists and other clinicians who may work with women with PMDD are discussed

I chose to submit this journal article to the *Psychology of Women Quarterly,* and it has therefore been formatted according to their submission guidelines which are presented in Part B. This article fits with the journal's aims to publish empirical research that focuses on a range of topics related to women including physical and mental wellbeing, therapeutic interventions and feminist approaches. As far as I am aware this is the first study exploring PMDD using IPA and therefore contributes a new perspective to the experience of this phenomenon. I also chose this journal because it is well established and has a global audience. My hope is that my research will be read by a wide audience across different disciplines as I believe that these findings are significant for anyone working with women with a suspected or confirmed diagnosis of PMDD.

Part C: Combined case study and process report

The final part of this portfolio is the combined case study and process report. This describes a piece of clinical work that I carried out with a client in my final year of counselling psychology training when I was working in a secondary care mood, anxiety and personality service. The client, who I refer to using a pseudonym (Alexandra) to protect her anonymity, presented with low mood and anxiety and we worked together using a psychodynamic model of therapy based on attachment theory. Alexandra struggled with self-criticism and self-blame and made her own links between the distress she was experiencing and the impact of social norms and external pressures. This became one area of focus in the work we did together and is reflected in how Alexandra responded to the ending of therapy. In distancing herself from me and the therapy, Alexandra's experience seems to reflect the common theme of this portfolio, in which women feel a pressure to cope on their own when in distress. In this clinical piece, I reflect on the therapeutic relationship and consider how psychodynamic theory

informed the interventions used. I chose to present this case as I found it challenging and I felt that it represented my personal journey as a therapist.

Reflections

The process of carrying out this research and completing this portfolio has been challenging and has forced me to change in fundamental ways. I have always been a perfectionist and the realities of life as a trainee counselling psychologist and a new mother forced me to respond differently to the pressures and expectations that I felt about how I *should* be performing. I have had to get to know myself in an honest and sometimes confronting way and adjust my own expectations to be able to not only get through training but also enjoy it.

Although the process was different to what I expected, I sit here happy and proud of what I have achieved over these last few years. I have discovered a love for psychodynamic theory and therapy, and I was fortunate to receive fantastic supervision in my final year of training that gave me the confidence to begin to define my own therapeutic identity and voice. I enjoy being part of a team and have learnt to listen to myself whilst remaining open to other perspectives. I want to always remember that my way of thinking about things and seeing things is only one perspective, it is not a truth. This is a personal and professional journey that I have now started, and I look forward to seeing how things unfold.

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Part A: Doctoral Research Thesis

Women's experiences of living with premenstrual dysphoric disorder (PMDD)

Abstract

Background: Premenstrual dysphoric disorder (PMDD) is a condition that affects 1.6% of women (Reilly et al., 2024). It is defined as a cyclical hormonal disorder that includes emotional and physical symptoms and treatment options are limited. Women face long journeys to diagnosis including frequent misdiagnosis and misunderstanding of their premenstrual symptoms. More needs to be explored about women's experiences of living with PMDD to enrich our understanding of both the individual experience and the wider impact to inform how we support women living with this condition.

Aim: To explore women's experiences of living with PMDD and consider the clinical implications of the study's findings.

Method: Seven women with a diagnosis of PMDD were interviewed and asked to complete written diaries. Women were aged between 18-37 years old. Interviews were transcribed verbatim and combined with the diary data, before being analysed using interpretative phenomenological analysis. Four group experiential themes emerged from the data.

Results: The four group experiential themes each cover different elements of the experience of living with PMDD while also overlapping in ways. **'**Making sense of PMDD: a journey of discovery' explores the journey that women went on as part of receiving their diagnosis of PMDD. 'PMDD and relationships: unheard, dismissed and judged' describes participants experiences of feeling unsupported by professionals when seeking care and by friends and family when seeking support. 'The impossible battle', describes participants' experiences of the day-to-day dealings with PMDD and the impact this has on them. 'Getting through it: finding ways to manage', describes how participants have found different ways to cope with the challenges they face with PMDD.

Conclusion: This study's findings indicate that living with PMDD is a complex and overwhelming experience. Diagnosis provides some relief for women but does not have a long-lasting impact in isolation given the lack of appropriate support available. Further research is necessary to understand what support women living with PMDD need. Implications for clinical practice and future research are discussed

Terminology

The menstrual cycle: The time from the first day of a woman's period to the day before her next period. A cycle lasts for between 21-35 days, with an average of 28 days (NHS, 2023).

The follicular phase: The first part of the menstrual cycle that starts with the first day of the period and lasts until ovulation.

The luteal phase: The second part of the menstrual cycle that starts just after ovulation and lasts until the first day of the period.

Premenstrual syndrome (PMS): physical and psychological symptoms experienced during the luteal phase that have an impact on daily life (Royal College of Obstetricians and Gynaecologists, 2016)

Premenstrual disorder (PMD): a disorder in which symptoms change across the menstrual cycle. Both PMDD and PME sit under this category.

Premenstrual exacerbation of an underlying disorder (PME): when an already existing disorder such as anxiety or depression is exacerbated during the luteal phase and the symptoms do not fully resolve during the rest of the month.

Premenstrual dysphoric disorder (PMDD): "a cyclical, hormone-based mood disorder with symptoms arising during the premenstrual, (International Association for Premenstrual Disorders, 2019).

Chapter 1: Introduction

My original literature review was carried out in 2021 and there have been significant developments in the years since, including several studies published on qualitative research in premenstrual dysphoric disorder (PMDD) with a specific focus on women's experiences of living with the condition. This research did not inform the development of my research study, but I have included it in this introduction as the studies are relevant for the reader to contextualise the topic and this study's findings and discussion.

At the very the beginning of my research journey I believed that the diagnosis of a premenstrual disorder was problematic; that this approach stemmed from a pathologisation of how women coped with changes related to their menstrual cycle and that something "normal" was therefore being labelled as a psychiatric illness. It did not take long for me to change my perspective and accept PMDD as a valid diagnosis as I educated myself about the causes of PMDD and the benefits people felt from being diagnosed.

A large part of my approach as a counselling psychologist is based on the idea that we can make sense of a person's mental health problems using formulation which then guides treatment options. This approach considers how wider contextual factors may contribute to the development and maintenance of mental health problems which I identified was missing from PMDD research. An increased understanding of people's subjective experience of living with PMDD would build on the existing research and contribute new findings to the field.

I begin this introduction chapter by providing an overview of PMDD and other premenstrual disorders including the biological mechanisms of PMDD and the current treatment options. This is followed by a section exploring the current start of women's health research and specifically the menstrual cycle. Following this I present the current available research on premenstrual disorders and then go onto discuss how PMDD is discussed in today's media. Finally, I suggest areas for future research and introduce

this research study in more detail, outlining its relevance to counselling psychology and the study's aims.

Premenstrual disorders

Studies on the topic of PMDD differ in how they define premenstrual change and related premenstrual disorders. There are currently three distinct categories of premenstrual change: premenstrual syndrome (PMS), premenstrual exacerbation of an underlying disorder (PME) and the main topic of this research, premenstrual dysphoric disorder (PMDD). As PMS is not a formal diagnosis there is no single fixed definition, but it is commonly understood to refer to emotional and/or physical changes that women experience during the premenstrual phase. PMS may affect up to 80% of women and symptoms can vary from being mild to severe, however symptoms are manageable without medication and do not have a severe impact on daily life (RCOG, 2016). Some research suggests that the prevalence of PMS is inflated (Romans et al., 2012) as PMS is used to explain away women's normal fluctuations in mood and emotions throughout the month.

PME is not as well-known but is defined as when a person has a condition such as depression or anxiety that is made worse during the premenstrual, or luteal, phase of the menstrual cycle (IAPMD, 2025). The symptoms follow a similar pattern to PMDD but do not resolve at the end of the luteal phase. PME is not classified as a separate diagnosis in the DSM-5 and is an area that warrants further research to better understand the impact and the causes (IAPMD, 2025).

Premenstrual dysphoric disorder (PMDD) is defined as "a cyclical, hormone-based mood disorder with symptoms arising during the premenstrual, or luteal, phase of the menstrual cycle and subsiding within a few days of menstruation" (IAPMD, 2025). Research suggests that PMDD is caused by "a severe negative reaction in the brain to the natural rise and fall of oestrogen and progesterone" (IAPMD, 2025). PMDD itself can be viewed as a spectrum disorder and women can experience mild, moderate or severe symptoms. It is listed in the DSM-5 as a psychiatric diagnosis (American

Psychiatric Association, 2013) and in the ICD-11 (World Health Organization, 2019). Initially included in the DSM-IV in the appendix of mood disorders, it was added as a distinct diagnostic category following a review of the research by a committee of experts (Epperson et al., 2012). Several benefits of its inclusion in the diagnostic manual have been highlighted such as improving research and clinical care as well as validating women's experiences of these distressing symptoms as credible (Epperson et al., 2012). Prevalence of PMDD is estimated to be around 1.6% based on the most recent available evidence (Reilly et al., 2024). The severity of PMDD symptoms varies between women and to receive a diagnosis, a woman is required to track her symptoms for at least two months, meeting 5 out of 11 diagnostic criteria as listed in the DSM-5 (Epperson et al., 2012). At least one of the symptoms experienced must fall under the emotional category which includes "marked affective lability (e.g., mood swings; feeling suddenly sad or tearful or increased sensitivity to rejection), marked irritability or anger or increased interpersonal conflicts, [and] markedly depressed mood, feelings of hopelessness, or self-deprecating thoughts" and at least one symptom must be included from the physical symptoms category which includes "decreased interest in usual activities, subjective difficulty in concentration and lethargy, easy fatigability, or marked lack of energy (Epperson et al., 2012).

While PMS, PME and PMDD are defined here and elsewhere as separate disorders, some research and other sources of information refer to them as being on a spectrum and describe PMDD as a severe form of PMS (Bertone-Johnson, 2014; Hardy & Hardie, 2017). Previous research has shown that there is overlap in the way that women make sense of and construct their experiences of living with PMS and PMDD (Brown et al., 2024; Buys, 2024). Research studies will also group PMS and PMDD together as premenstrual disorders (Labots-Vogelesang et al., 2023) and there is limited research on PMDD only. I will therefore include research that looks at premenstrual disorders including both PMS and PMDD, specifying where possible which part the research is referring to. Much of the research into PMS may still be relevant to this research as it considers the impact of the menstrual cycle and related premenstrual symptoms on different parts of women's lives. I will be drawing on relevant ideas and theories from

PMS research, with the caveat that that there are both similarities and differences between those experiences.

Premenstrual dysphoric disorder

Studies have shown that the premenstrual symptoms in PMDD are caused by an abnormal sensitivity to changes in ovarian hormones during the menstrual cycle (Eisenlohr-Moul et al., 2022). The reasons for this sensitivity to these hormones (*progesterone and oestradiol*) are not fully known however there is evidence that suggests an association between experiences of stress and trauma and the development of PMDD. This could be linked to a sensitive stress response system and a "*dysregulation of the interaction between the hypothalamic-pituitary-gonadal (HPG) axis, which is involved in controlling the release of gonadal hormones, and the hypothalamic-pituitary-adrenal (HPA) axis, the major neuroendocrine stress response system"* (Bencker et al., 2025). Bencker et al.'s (2025) systematic review and meta-analyses found that stress played an important role in the development of premenstrual symptoms, supporting the theory that a sensitive stress system contributes to the development of premenstrual disorders.

Trauma exposure may further contribute this hypersensitivity to hormonal changes and research has shown that there is a high prevalence of traumatic experiences in people with PMDD (Grewal et al., 2024). Repeated exposure to trauma has been shown to trigger changes in neuroendocrine systems such as the HPA axis and the HPG axis leading to mood changes during the menstrual cycle (Grewal et al., 2024).

An increased understanding of the causes and mechanisms involved in the development and maintenance of PMDD can have positive implications for clinical treatment. Given the possible role of stress and trauma outlined above, assessing people with PMDD for experiences of trauma is beneficial in developing a wider understanding of their problems. This can help people with PMDD to formulate an understanding of their PMDD in the context of their past experiences as well as enable

them to develop strategies to manage the psychological, emotional and behavioural problems they have as part of their PMDD (Bencker et al., 2025; Grewal et al., 2024).

Treatment options for PMDD

Although research into treatment options has increased, it remains focused on medical interventions leaving people with limited options. There is a gap to be filled by further research into psychological and holistic therapies. Current treatment recommendations based on results of randomised control trials (RCTs) include:

1. SSRIs or SNRIs (anti-depressants), either luteal or continuous dosing.
2. Hormonal contraceptives.
3. Chemical menopause (GnHRa treatment).
4. Bilateral salpingo-oophorectomy with or without total hysterectomy.

Both continuous and luteal dosing of selective serotonin reuptake inhibitors (SSRIs) are recommended for managing symptoms of PMS and PMDD (Jespersen et al., 2024). Intermittent use of SSRIs has been shown to be effective in managing symptoms of PMDD without the withdrawal symptoms that occur from continuous use and so can be recommended for this population (Reilly et al., 2023).

Recent data suggests that the contraceptive pill is best used continuously for treating symptoms of PMS (Royal College of Obstetricians and Gynaecologists (RCOG), 2016). as it works by suppressing ovulation. Chemical menopause, also called gonadotropin releasing hormone analogues (GnRHa) treatment, eliminates the hormonal fluctuations associated with PMDD and therefore eliminates the symptoms of PMDD. There is evidence that this is an effective treatment for people diagnosed with PMDD and can be used indefinitely when combined with hormone replacement therapy (HRT) (IAPMD, 2025).

According to the RCOG (2016), medical management of PMS is recommended however surgery may be used for people who have not experienced relief from

symptoms. There are various surgical options available however the alternatives for PMDD are a bilateral oophorectomy (removal of the ovaries) or a bilateral salpingo-oophorectomy (removal of the fallopian tubes and ovaries) if a person can tolerate HRT. If not, a total hysterectomy combined with a bilateral salpingo-oopherectomy (removal of the uterus, fallopian tubes and ovaries) is recommended. A bilateral oophorectomy without removal of the uterus risks a return of PMS like symptoms and there is a lack of evidence for this option (RCOG, 2016).

All these treatment options come with associated side effects and consequences as well as not being readily available to most people living with PMDD in the UK. If fortunate enough to be able to access these limited options, women then face a challenging time identifying an appropriate treatment route.

Comorbidities and risk

People with a diagnosis of PMDD are likely to have a comorbid psychiatric diagnosis with rates as high as 70%. The existence of a comorbid diagnosis is often an exclusion criterion for research studies which may suggest to clinicians that PMDD cannot be diagnosed when another diagnosis is present. This is inaccurate and may lead people to miss PMDD as a diagnosis if other problems are identified (Eisenlohr-Moul et al., 2022). A recent study found that participants with a diagnosis of PMDD exhibited patterns of disordered eating that were reflective of diagnoses such as binge eating, bulimia and anorexia (Nkeng et al., 2025). People with PMDD may develop coping strategies such as these to manage the symptoms of their PMDD and their impact (Brown et al., 2024). An additional known risk associated with PMDD is increased suicidal thoughts and behaviours (Brown et al., 2024; Eisenlohr-Moul et al., 2022; Reilly et al., 2024). This risk may be particularly high for people with a comorbid psychiatric diagnosis of post-traumatic stress disorder (PTSD), borderline personality disorder (BPD) and major depressive disorder given the cyclical and chronic nature of the emotional symptoms associated with these disorders (Hartlage & Gehlert, 2001). This research demonstrates how important it is for clinicians to be trained to assess for PMDD and to be aware of the risks associated with this presentation.

Women's health

Women's health problems have been misunderstood throughout history, most famously with the diagnosis of "hysteria", a term that was initially used to diagnose women for a wide range of symptoms that we likely view today as physical diseases such as "epilepsy, anaemia, arthritis, multiple sclerosis… as well as other chronic pain and autoimmune diseases" (Jackson, 2019). The term hysteria was originally thought to be attributed to a wandering uterus (McCulloch, 1969) and despite a change in the understanding of hysteria over time, these archaic ideas seem to persist in the Western societal narrative. Despite substantial progress in changing this narrative, women continue to experience challenges and stigma in relation to their physical and mental health. The term "hysterical" continues to be a term associated with women behaving in ways that do not fit societal expectations (Jackson, 2019) and there is a cultural narrative in western society that women are emotional, unstable, crazy or mad.

This problem partially continues due to the lack of health research focusing on women. Most research is carried out on men and ignores important biological differences contributing to a continued lack of understanding and knowledge on female only health problems (Merone et al., 2022). In the past, menstruation was a reason given for women to not be included in research as it may influence how they respond (Merone et al., 2021) and the stigma of menstruation and the impact that it has on people's attitudes towards them persists (Roberts et al., 2002). All these points have led to a lack of specific knowledge on women's health and the subsequent impact on how women's health problems are treated, both in medical settings and in the wider society. This has been shown to influence how women are treated differently to men in healthcare contexts, leading to long waiting times for treatment, receiving different treatment for the same problem and reporting experiences of being dismissed and ignored by healthcare professionals (Merone et al., 2021). Hoffman and Tarzian (2001) explored the bias against women in the treatment of pain and found that healthcare providers responded differently to women's pain. Recent research has also reported on how women describe feeling dismissed and misunderstood by healthcare professionals. For example, Hildenbrand et al. (2022) found that younger, non-white women were more likely to feel

dismissed by healthcare professionals. Grundström et al.'s (2018) study suggests that women have both positive and negative experiences with healthcare professionals and found that the nature of this experience influenced how they perceived themselves, highlighting the significance of how women are treated when they seek support for health problems. Factors contributing to the continued dismissal and minimisation of women's health problems include a lack of research with female participants (Merone et al., 2021), a mislabelling of physical health problems as mental health problems (Happell et al., 2016) and a familiar and persistent narrative of women being perceived as "difficult" (Merone et al., 2021). Patterns of judgements and dismissal of women's health problems exist across the board and provide some context to women's individual experiences of living with these conditions. Research has shown that women's complaints are more likely to be viewed as linked to emotional and psychosomatic factors compared to men's (Bernstein & Kane, 1981). How women express their emotions has also been shown to be significant, as Barrett and Bliss-Moreau (2009) found that women's emotions were attributed to the fact that they were seen as "emotional creatures", whereas men expressed emotions that were deemed justified by the situation.

Research has found that women describe years of their physical, emotional and behavioural problems related to their menstrual cycle as being minimised as "normal" issues for women. In addition, women have described being ignored by doctors who did not take their problems seriously (Buys, 2024; Chan et al., 2023; Osborn et al., 2020b). Misdiagnosis is a common experience for women with PMDD, who are frequently diagnosed with other mental health disorders such as bipolar disorder (Studd, 2012; IAPMD, 2025), personality disorder or depression and face years of struggles without a correct diagnosis and appropriate treatment and support, leading to the development of other problems such as eating disorders, alcohol and drug use and suicidality (Buys, 2024; Osborn et al., 2020b; Winslow et al., 2022).

We can also look to other areas of women's health to help highlight any potential gaps in the current literature. Endometriosis has faced similar diagnostic challenges to PMDD

resulting in delayed treatment and support leading to a negative effect on women's physical and mental health (Jackson, 2019). There has been an increase in research investigating women's individual experiences from different perspectives including a thematic analysis of the differences in the impact of endometriosis on women's lives across three age groups (Moradi et al., 2014), the notion of biographical disruption to identity in living with endometriosis (Cole et al., 2020) and a retrospective longitudinal study of 15 years of living with endometriosis (Fagervold et al., 2009). These examples show the potential next steps for further qualitative research in this area and highlight some of the current gaps.

The history of how women have been treated in a healthcare context suggests that this is an area that deserves more attention, not only to improve understanding of women's experiences but also to work towards changing the narrative around women's health being less important. By exploring women's experiences in more detail, we can highlight differences in the individual and the group and begin to address some of the disparities in care.

The menstrual cycle

There is a long history of menstruation as being taboo and something to be hidden away from public view. Menstruation is not a topic that is open for discussion in the western world and there is a narrative of shame and needing to hide menstruation that dominates. Teenagers and women describe it as a predominantly negative experience (Burrows & Johnson, 2006; Fahs, 2016) and there is stigma around having a period and talking about it (Johnston-Robledo & Chrisler, 2011). Teenagers describing their experiences of their first period (menarche) and menstruation more generally, experience it as embarrassing and shameful while also thinking about it as an illness (Burrows & Johnson, 2006).

An important aspect of the conversation around menstruation is related to the emotional, physical and behavioural changes that take place during the luteal phase prior to the beginning of the period, also referred to as PMS. PMS is understood in different ways

depending on the theoretical lens employed, with researchers viewing it from biological, biopsychosocial and social constructionist perspectives. Rosvall and Ekholm (2016) found that women mainly described PMS as premenstrual changes due to biomedical causes, with a smaller proportion of their participants attributing it to biopsychosocial causes, factoring in the potential impact of contextual factors. Although there has been some research exploring how women construct premenstrual changes as positive (King & Ussher, 2012), most research shows that women experience these changes as negative and speak about it in that way.

Research has considered different ways of framing premenstrual distress. Ussher & Perz (2014) explore this topic from a feminist perspective, situating premenstrual change as a part of women's experiences that is pathologised and medicalised by society. Perz & Ussher (2006) propose the idea that the self-silencing of women is linked to the symptoms of distress referred to as PMS. PMS is framed as a "rupture" in women's habitual self-silencing, when women are no longer able to maintain the control over their thoughts, feelings and behaviours that society expects of them. They also found that women self-silenced during the luteal phase as a means of self-preservation, pulling away from society so as not to upset others. Not only does this suggest that a "culture of silence" plays an important role in how women manage distress, but that the myths around women's health and menstruation may be maintained by the censoring nature of our language around the female body (Jackson, 2019). Although I agree that it is important to consider the role of social and cultural factors in women's experiences of premenstrual changes, this perspective needs to be considered alongside the existing evidence for the biological mechanisms underlying conditions such as PMDD.

Research into the menstrual cycle has also looked at how women relate to themselves and others in relation to their cycle. Researchers have explored the idea that women employ a dualistic discourse which places premenstrual change and related distress outside the body (Rosvall & Ekholm, 2016). This suggests that women can separate themselves from the PMS "self" and portray themselves as how women should be (Winslow et al., 2022). This has been found to be similar in women with PMDD who

often refer to feeling like there are two versions of themselves, a normal self and a PMDD self (Osborn et al., 2020; Winslow et al., 2022).

Slade et al. (2008) suggest that higher symptom levels of premenstrual distress are related to perfectionism which may have an impact on perceptions of the self and others. Women described lower levels of tolerance for imperfections in themselves and others which may therefore have an impact on how they perceive support available to them. This study also found higher levels of isolation, helplessness and less active problem solving in women with high premenstrual distress. Although this study did not include women with a diagnosis of PMDD, this research provides valuable insight into the impact of symptoms of premenstrual distress with a particular focus on how women with higher symptom levels perceived themselves and others and the impact that his has on their ability to cope. Wethington and Kessler (1986) found that women who perceived support from others were also more able to seek out support from others. Given that women frequently report a lack of support from others when seeking help for PMDD, it may be relevant to consider perceptions of the self and others in relation to women's experiences of seeking and receiving support from professionals and social networks.

Diagnosis

Historically there was a debate on whether PMDD should be defined as a distinct diagnosis, with early feminist critiques protesting the perceived pathologisation and medicalisation of the female experience due to societal and cultural constructs. It has been argued that the categorisation of women's experiences as a psychiatric condition is an unnecessary medicalisation of women's distress (Browne, 2014; Daw, 2002; Offrnan & Kleinplatz, 2004; Ussher, 2003; Ussher & Perz, 2020) however research questioning the validity of PMDD as a diagnosis lacks input from the women experiencing the symptoms, at times potentially undermining the severity of women's symptoms and portraying women who question if their PMS is PMDD as being "afraid of not being perfect, cheerful, serene women" (Chrisler & Caplan, 2002).

In 2013 premenstrual dysphoric disorder (PMDD) was added to the Diagnostic and Statistical Manual of Mental Disorders, 5th ed. (American Psychiatric Association, 2013) as a distinct psychiatric disorder. This has led to an improved understanding of the biological mechanisms in PMDD showing how this label is not purely a medicalisation of the normal female experience (Reilly, 2024). Whilst recognising PMDD as a valid condition that has biological causes is a necessary step to improve understanding and treatment, the diagnostic focus comes with both advantages and disadvantages. Naming a person's experience with a label such as PMDD can help a person to feel validated, taken seriously and can also serve the purpose of guiding treatment and helping a person to access appropriate care for their condition. However, at times, the process of labelling someone's experience in this way can lead to their whole experience not being considered. To receive a diagnosis, a person's experience is likely to be limited to whether they meet the criteria that have been determined by a group of professionals based on the best available evidence. A diagnostic approach in this instance therefore focuses on the biological aspects of PMDD and its medicalisation, reducing a person's experience to a list of symptoms only.

An alternative perspective is taken by contemporary feminist theorists who recognise the real suffering that people with PMDD live with but challenge the notion of pathologisation. Ussher et al. (2002) acknowledge that PMDD has been shown to have biomedical causes, however they uphold the theory that other factors, such as societal pressures and expectations of women, contribute to how they view themselves and their premenstrual distress. An example of this is the application of the material-discursive-intrapsychic framework to PMDD, a woman-centred approach that formulates an understanding of women's experiences of premenstrual change from a critical realist perspective (Ussher et al., 2002). In applying the MDI approach to PMDD, Ussher et al., (2002) are critical of the diagnostic approach and the purely medicalised view of PMDD whilst still moving away from Ussher's more strictly social constructionist position. It brings the materiality of premenstrual changes to the fore, alongside the more classically social constructionist beliefs around the influence of societal and cultural context. The MDI framework does not attribute the challenging experiences people face

to any one issue and does not place the responsibility solely on the individual. This feminist perspective can therefore make a significant contribution to this research field by offering alternative perspectives that include the role of sociocultural contexts and make space for the inclusion of difference and diversity which is lacking from the purely medical model and the current research focus. It is important to consider who defines PMDD, how it is defined and for whose benefit.

Current research on premenstrual disorders

There is extensive research exploring women's experiences of PMS from different perspectives (Perz & Ussher, 2006; Ussher, 2008; Ussher et al., 2002; Ussher & Perz, 2013) however the current body of literature exploring this area for PMDD is more limited. From reviewing the existing research, the majority appears to focus on the topic of diagnosis and the underlying mechanisms of PMDD to improve diagnosis and treatment (Eisenlohr-Moul, 2019; Epperson & Hantsoo, 2017), looking at its prevalence, causal and correlational relationships (Raffi & Freeman, 2017), symptomatology and effective medical treatments (Bosman et al., 2015; Halbreich et al., 2003; Hantsoo & Epperson, 2015; Wittchen et al., 2002). Inconsistent use of different PMDD symptom measures across these studies makes comparisons difficult with both self-report and retrospective measures frequently used. A confirmed diagnosis of PMDD requires prospective daily ratings of symptoms and provisional diagnoses may lead to inflated prevalence data (Reilly et al., 2024).

Studies have been carried out exploring the association between a diagnosis of PMDD and areas such as emotion regulation (Petersen et al., 2016) and anger (Akyol et al., 2013), as well as psychiatric diagnoses including generalised anxiety disorder (Yen et al., 2020) and post-traumatic stress disorder (Pilver et al., 2011). Doğu et al. (2022) compared women with PMDD and PMS on certain measures and found that women with PMDD scored higher on anxiety and depression levels and reported more physical symptoms and lower life satisfaction than women with no PMS and PMS. A recent systematic review of quantitative research investigating psychological features of PMDD suggests that there may be a tendency towards negative thinking and negative

perception of events in PMDD (Henderson et al., 2025). This would be a valuable avenue to explore further to gain insight into how women experience their PMDD and the contributing factors.

Dorani et al. (2020) found that there was a higher prevalence of PMDD in women with ADHD suggesting that there is an association between the two, while there has been conflicting evidence on whether PMDD is more prevalent in autism. A recent study found that there was not a significantly higher prevalence of PMDD in women with autism (Groenman et al., 2021) despite previous research reporting otherwise (Obaydi & Puri, 2008). Report measures differed between the studies so more research in this area may be needed to better understand the prevalence. These studies provide valuable information on co-morbidities and specific psychological or behavioural challenges that women with PMDD experience, however they are limited in what they contribute in terms of understanding women's individual experiences of PMDD due to their specific focus and methodologies used. Further research in this area would be valuable to better understand these possible links and how the experiences of women with PMDD and neurodivergence may differ to those who are neurotypical.

Some studies have been carried out in non-western cultures around the world (De Carvalho, et al., 2018; Islas-Preciado, et al., 2025) however the majority appears to take place in the USA, Europe and Australia. As already discussed, there is a lack of research available in women's health, and this is also reflected in the lack of racial diversity in the research. This racial inequality is seen in PMDD research as well with no systematic reviews that explore racial difference published (Phimpasone-Brady et al., 2023). Research has shown that PMDD is not as prevalent amongst black women compared to white women in the US, however the measures used did not align with diagnostic criteria in the DSM-5 (APA, 2013) so further research is needed. A limited number of studies were available that included women from racial and ethnic minorities and these were limited to women with depression and eating disorders. Similar to the available data on PMDD, women from minority backgrounds reported a lower prevalence of depression and eating disorders in comparison to white women. Despite this, those that did report having these conditions also described having different

symptoms to white women and sometimes higher rates of symptoms (Phimpasone-Brady et al., 2023). This speaks to how people from different racial and ethnic backgrounds may experience similar conditions in different ways and highlights how important it is to recognise those differences. This will not only help with the assessment and identification of mental health disorders in women but also guide appropriate treatment and how it can be adapted.

The individual experience

Since this research study was first proposed in 2021, more qualitative research studies have been carried out and published, contributing new perspectives and ideas to the field with a particular focus on women's experiences of PMDD. A recent systematic review (Brown et al., 2024) included six studies on PMDD, with four studies allowing women to self-report a formal diagnosis, one study requiring completion of the Premenstrual Symptoms Screening Tool (PSST) (Steiner et al., 2003) and one stating that the participants met the criteria for PMDD in the DSM-IV. Prior to this, the evidence was more limited, primarily focused on Osborn et al.'s (2020b) paper exploring women's experiences of receiving a diagnosis of PMDD and exploration into the impact of PMDD in the workplace (Hardy & Hardie, 2017).

Osborn et al.'s (2020b) paper provides vital data on women's individual and collective experiences of living with PMDD and their journey to receiving a diagnosis. This study contributes valuable information to the field by sharing the impact on their day to day lives, interpersonal relationships, work life and ultimately their identity and sense of self. The women's narratives revealed how a diagnosis of PMDD brought positive experiences of recognition, understanding and hope, as well as highlighting the need for the women to "rebuild" their lives and the personal struggles they had in understanding their new identities following treatment. A limitation of the study is that it uses women's retrospective accounts of PMDD given that they all described receiving effective treatment and were no longer experiencing significant symptoms of PMDD. The fact that all the women had received confirmed diagnoses and were recruited through an NHS setting as well as using the PSST, was both a strength as it ensures that

participants meet the diagnostic criteria providing a valid measurement of PMDD (IAPMD, 2025), and a limitation as this sample represent a small group of women who have been successful in receiving effective and appropriate support. Future studies would benefit from recruiting participants in alternative ways, for example recruiting from the community as well (Moradi et al., 2014) and expanding inclusion criteria. Some research has already begun to address this issue, with Winslow et al. (2022) analysing data from a Reddit thread meaning there was no way to confirm a diagnosis with participants, and Buys (2024) recruiting a sample with both medical diagnosis and self-diagnosis of PMDD. These studies provide valuable insight into the experiences of women with PMDD, building on previous research and contributing novel findings, which speaks to the need for variety in research and to not be overly constrained by diagnostic criteria.

Receiving a diagnosis of PMDD has been shown to bring relief to women, providing them with a way of understanding their struggles and in some cases leading to effective support and treatment (Buys, 2024; Chan et al., 2023; Osborn et al., 2020b; Winslow et al., 2022). Research has shown that PMDD has an impact on interpersonal relationships, leading to women feeling isolated (Osborn et al., 2020b) and struggling to maintain relationships. There is limited research looking at the impact of PMDD on parenting however findings suggest that symptoms of premenstrual disorders are associated with high parental distress (Tutty et al., 2021) and Osborn et al. (2020b) found that women expressed regret at not being the mothers they wanted to be due to their PMDD. Slade et al. (2008) found that that women's relationships with their partners and children were often affected by symptoms of PMS. Women who were mothers did speak about the impact on romantic relationships and partners. Partners may not know how to support those suffering from the condition (Alkattan, 2023) and research suggests that women with severe premenstrual disorders need support to maintain relationships (Westermark et al., 2024).

A fear of stigmatisation has been shared by women when it comes to sharing details of their condition with people in their lives whether that is with their employer or colleagues

(Hardy & Hardie, 2017), friends and family or medical professionals (Osborn et al., 2020b). This links to the idea of self-silencing that has been proposed as a way of understanding women's behaviour in relation to PMS (Chrisler et al., 2014; Ussher, 2004) and has been suggested to play a role in how women construct their experience of PMDD (Buys, 2024). A sense of being out of control has also been described in the research (Brown et al., 2024). Recent studies into women's experiences of PMDD have introduced the idea of agency and the plasticity of PMDD, suggesting that despite its biomedical cause, psychological, social, cultural and contextual factors still play a vital role in a person's experience of PMDD and their ability to have agency and ownership over it (Buys, 2024; Winslow et al, 2022). This area of the research is newer and warrants further research to better understand the generalisability of these findings.

A dominant theme throughout the qualitative research into women's experiences of PMDD is that of the "split self". Described as feeling like two different people, a different version of the self, Jekyll and Hyde or an externalised 'other', it seems that women engage with the idea of making sense of their experience splitting PMDD off from themselves. In Winslow et al.'s (2022) analysis of the r/PMDD reddit thread, they suggested that defining PMDD as an illness helped women to distance themselves from the shame that they felt following the luteal phase. Interestingly, the term "Jekyll and Hyde" has been used by women to describe their experiences of PMS as well (Chrisler & Caplan, 2002) indicating the overlap in how women make sense of their premenstrual changes despite diagnosis and severity.

Hardy & Hardie (2017) carried out semi-structured interviews with women regarding their experiences of PMDD in the workplace specifically. They found that women described noticing the impact of PMDD throughout the month, reporting being absent from work when symptoms were present during the luteal phase and then struggling with guilt and overcompensating for their absence the rest of the month. Other research found similar themes that demonstrated the month-long impact of PMDD, despite symptoms decreasing following the onset of their period, women described having to pick up the pieces following the impact of PMDD during the luteal phase (Osborn et al.,

2020b). Habib et al., (2024) took a different approach to other qualitative research exploring women's experiences of PMDD by incorporating the idea of PMDD as an "episodic disability" and analysing the data using feminist disability theory based. This approach acknowledges how PMDD changes throughout the month and the impact that it has on how women can engage with life day to day during the luteal phase.

An important criticism of using the term 'episodic disability' to describe PMDD is that this definition does not accurately represent the impact of the condition on people's lives. Even though the symptoms of PMDD only occur during the luteal phase, the impact of these symptoms can be felt by women throughout the month. PMDD has been shown to have a similar impact on quality of life as other chronic health conditions, indicating that the term episodic may not accurately communicate how pervasive the impact of PMDD is (Yang et al., 2008). People with PMDD need to evidence that their condition affects them more than 50% of the time and they have shared that this was difficult for them to do when applying for PIP/ADP as PMDD is a fluctuating condition. Symptoms are present for 1-2 weeks every month, but PMDD has a negative impact on all areas of life even when out of the luteal phase. Referring to PMDD as an episodic disability may be harmful as it risks diminishing how debilitating a condition it is and limiting people's access to support, for example welfare support (Campbell et al., 2025).

Additional research has focused on the individual by using an autoethnographic approach, a first-person account of a woman's experience of PMDD in relation to her sense of self (Barker-Smith, 2020). Due to its personal nature, the results of this study are not generalisable to the wider population however this report provides a wealth of information regarding a woman's personal experience of PMDD and the journey of self-awareness and identity reconstruction that she took. The process of diary keeping and reflexive analysis was not clearly outlined, and the study lacks enough detail for others to replicate. However, the author makes a personally valuable connection between her experiences of trauma and PMDD, a connection that echoes previous research that has found associations between abuse and trauma in the development of PMS and PMDD (Bertone-Johnson et al., 2014; Pilver et al., 2011).

PMDD in the media

Recent developments have seen several books published on the topic of the woman's health and the menstrual cycle (Hill, 2019; Jackson, 2019; Morgan, 2019). In addition to this, online support networks such as 'The Vicious Cycle' have been created (www.viciouscyclepmdd.com), providing women with the space and the community support to advocate for themselves, an example being PMDD awareness month in April 2021 driven by the International Association for Premenstrual Disorders **(**www.iapmd.org).

There has also been an increase in discussions in the media about PMDD and its impact, with celebrities speaking up and women sharing their individual experiences. Several news articles have been published in the UK that give voice to women's struggles with PMDD that echo findings in recent qualitative research on women's experiences. Women often described not knowing about PMDD until they were diagnosed and highlighted the importance of speaking about it in public to improve awareness. Women shared stories of being told that their premenstrual symptoms were part of being a woman (Belli & Lloyd-Willams, 2023) and a long road to diagnosis included frequent misdiagnoses of perimenopause (Seal, 2024) bipolar, personality disorder and complex PTSD (Oppenheim, 2024). News articles address important topics such as barriers to receiving care including a lack of training available to GPs, confusion around the nature of the disorder and a lack of research in women's health (Seal, 2024). Young women are reportedly often told that what they are experiencing is a different mental health problem (Collins, 2024) while some women described thinking that depression and suicidal thoughts were normal, perhaps partly due to the taboo nature of periods as a topic and problems being dismissed due to being a teenager or exam stress (Swash, 2024). A narrative around their struggles being dismissed as PMS was commonly described which again reflects findings from qualitative research. One woman described how she found it difficult to explain PMDD as she often struggled to understand and identify it herself (Ro, 2019).

In addition to the conversation around diagnosis and misdiagnosis, reports in the news have addressed the impact of PMDD on women's lives including the loss of work opportunities and the ability to have children (Aslett, 2023). It is important to bear in mind that these articles are predominantly based on the perspectives of women with PMDD and are not empirical science, however, they provide valuable information on the struggles that these women face and demonstrate the growing interest in this area.

Future research

In the United Kingdom, Matthews and Riddell (2023) published a PMDD research agenda, developed using focus groups with a range of stakeholders and summarising five key research areas in PMDD. The first of its kind, this research agenda identified the following research priorities; "diagnosis and management of PMDD, best approaches for psychological support, suicide and self-harm prevention, impact of PMDD on life and support for hormonal 'trigger' events". Other areas were also found to be important including "causes and biology of PMDD; (b) destructive behaviour; (c) surgery and post-surgery support; (d) barriers to support; (e) the 'cost' of PMDD; (f) premenstrual exacerbation of existing disorders; (g) neurodivergence; (h) support from the welfare system; and (i) PMDD education and training."

Based on the current available research presented in this chapter so far and the research agenda described, there are number of gaps in the research that need to be addressed. As the research into women's individual experiences of PMDD has been limited, the participants taking part are not representative of the female population. Further research would benefit from accessing different participant groups including ethnic minorities, younger age groups including teenagers, and women who identify as LGBTQA+. This would also provide more insight into how women from different cultures experience PMDD and contribute to the understanding of PMDD as a social construct.

As previous qualitative research has predominantly used thematic analysis (Chan et al., 2023; Habib et al., 2024; Osborn et al., 2020b; Winslow et al., 2022) alternative qualitative methodologies such as interpretative phenomenological analysis, critical

narrative analysis or grounded theory may contribute new perspectives and findings. The majority of existing studies have used semi-structured interviews for data collection which is appropriate and relevant when examining people's experiences as it provides the opportunity for participants to speak freely and the researcher to use prompts and additional questions where relevant to the topic (Marks & Yardley, 2004). An alternative method such as the use of diaries (Morrell-Scott, 2018) would also be appropriate and add a new perspective, building on the existing findings.

Further research into how women cope with the changes associated with PMDD and how they make sense of themselves and their experience would be of interest to psychologists supporting women with PMDD. There is also scope to explore women's experiences of living with PMDD without receiving successful treatment. Previous studies interviewed women who had received treatment and were reporting their experiences of PMDD retrospectively (Buys, 2024; Osborn et al., 2020b). Recruiting participants who are still struggling with the symptoms of PMDD could offer valuable insight into the day-to-day impact of PMDD and the struggles that women continue to experience following diagnosis or during the process of seeking out treatment.

In conclusion, this literature review has highlighted several research areas that are currently lacking input and would benefit from further exploration. As already suggested, use of additional qualitative methodologies and mixed methods studies would be beneficial to build on what has been done so far. Finally, due to the cyclical nature of PMDD and its chronicity, a longitudinal approach would provide further understanding of how symptoms change over time and women's long-term approaches to coping.

Relevance to counselling psychology

This study is relevant to counselling psychology from both a research and clinical perspective. A fundamental aspect of the counselling psychology field is to help people make sense of their experiences and apply this knowledge and understanding to clinical practice. Deepening our understanding of women's experiences of living with this diagnosis will hopefully result in psychologists being better informed and ultimately

better equipped to support women with the changes and challenges that may occur. Counselling psychology's philosophy is that a person is seen as a whole being, made up of both the body and the mind. The embodied nature of phenomenological research ties in with this view and is well placed to be studied in counselling psychology. I am curious to better understand how the body and mind are connected for these women by taking the approach of seeing them as the whole person, rather than separating out the physical and psychological.

Rationale for the current study

Throughout history the misunderstandings around women's health are evident and this continues to be an area that is dismissed or deprioritised to this day. There is a dearth of research carried out on topics related to women's physical and mental health and as a result women may feel ignored, unsupported and without appropriate care (Osborn et al., 2020b). There is a societal attitude of "get on with it" in the western world and a long history of women being viewed as "hysterical" (McCulloch, 1969). Whilst the psychological research literature in this field is still developing, the research into the biological mechanisms resulting in PMDD has grown and the physical causes of the condition are better understood. What is still lacking is a better understanding of what these women are going through when they are living with PMDD, the impact that this condition has on their lives in general and the clinical implications of these findings.

The qualitative studies discussed in this chapter have formed a foundation for further research to be carried out to build on the findings that women's work, relationships and sense of self are all likely to be negatively affected by this condition (Buys, 2024; Hardy & Hardie, 2017; Osborn et al., 2020b; Winslow et al., 2022). As I reviewed the existing literature on PMDD, I found myself reacting quite strongly to some of the feminist theory around PMS that suggest it is a social construct and a result of patriarchal oppression and self-repression (Ussher, 2008; Ussher & Perez, 2013). Although part of me is open to these ideas and finds them interesting to explore, on reflection my negative reaction was in response to the lack of women's own voices and a deeper exploration into their subjective experience to access their own understanding of what they were going

through. This realisation helped me to focus my topic and develop my interest in how women experience the day to day of living with PMDD and how they make sense of it; with a particular focus on how they make sense of their bodily experiences and "symptoms", interacting with their psychological experiences, the "mind". It is likely that counselling psychologists will encounter clients who are living with this condition, knowingly or unknowingly. It is therefore vital that counselling psychologists develop their knowledge and understanding of women's menstrual cycles and the impact on their physical and mental health as well as their general wellbeing to be able to better support them.

Research aims

The aim of this research is to focus on women's experiences of living with PMDD and how they make sense of it. Counselling psychologists are well placed to support women in managing the challenges associated with living with PMDD as well as supporting them to manage the distress they experience monthly. This study is not looking to form any generalised assumptions about how all women experience PMDD, however my hope is that it will build on previous research and deepen our understanding of the different ways in which women experience the condition and consider appropriate ways to offer support.

Chapter 2: Methodology

Introduction

This chapter describes my chosen methodology and research process. I will explain the theory underlying the study's approach and methodology including my own epistemological and ontological position. I will then go on to outline the research design, data collection and analysis processes in detail demonstrating my transparent and rigorous approach to the research (Yardley, 2000). Finally, I will evaluate the quality and validity of the study according to specific criteria for qualitative research. Throughout the chapter I have included sections on my reflexive process at different stages of the research to demonstrate how I engaged with reflexivity to inform my research in terms of the decisions I made and how it influenced my role in the research (Finlay, 2002; Kasket, 2012).

The research I found at the time of my initial literature review and study design demonstrated a lack of qualitative research exploring women's subjective experience of PMDD with only one study identified at the time (Osborn et al., 2020b). My intention with this study was therefore to build on this research by expanding the recruitment to those in the community rather than from an NHS setting and use a methodology that allowed for an in-depth exploration of the subjective experience.

To work towards these aims I identified the following as the study's main research question: 'How do women make sense of their experience of living with premenstrual dysphoric disorder (PMDD)?'

Using reflexivity

Reflexive analysis is most valuable when embedded within the research from the beginning and Finlay (2002) discusses how to approach each stage of the process in a reflexive way, highlighting the need for the researcher to engage in reflexive questioning during the planning stage, the data collection process and the analysis.

In the planning stage, the researcher reflects on why they have chosen their topic and the processes that took place to start the project. Using reflexive analysis during the analytic process can enable the researcher to identify what their responses to participants may mean, improving their understanding of themselves with the aim to then better understand and interpret the meanings that participants bring (Finlay, 2002). Maintaining the balance of reflexive analysis throughout the research can be challenging, however the benefits of research reflexivity are evident in improving the quality of the research as well as the researcher's ability to remain faithful to the philosophical underpinnings of the research (Yardley, 2000).

The researcher's reflexivity is necessary to engage in the bracketing of IPA, as only by becoming aware of their personal beliefs and assumptions can the researcher set them aside. I have maintained this reflexive approach from the beginning of this project by keeping a reflexive journal on my laptop, noting down ideas, thoughts, doubts and questions as they came up throughout the study design, data collection and analysis. I found this process particularly enlightening during the process of writing up my research, as I was able to reflect on my own experiences and my personal and professional journey since starting this project. I have summarised my reflexive process in different sections throughout this thesis with the intention of offering the reader insight into my own process, how I have managed challenges and the impact on the research.

Theoretical underpinnings

The philosophy of science that underpins research is made up of ontology, epistemology, axiology, methodology and rhetorical structure. As a researcher, identifying one's own philosophical position regarding ontology and epistemology will lead to identifying the research paradigm on which to base the research (Ponterotto, 2005). The research paradigm represents the researcher's worldview that "defines… the nature of the world, the individual's place in it, and the range of possible relationships to that world and its parts" (Lincoln & Guba, 1994). The core of this is based on the individual's ontology, "theory of being" and their epistemology, "theory of

knowledge" (Bergin et al., 2008). In any type of research, the theoretical position of the researcher forms the basis of the study, informing the questions that are asked and the methodology and method that is employed (Ponterotto, 2005). The researcher's **ontological position** deals with what exists in the world and asks, "what is reality?". The **epistemological position** of the researcher is concerned with what is possible to know and asks, "how can we acquire knowledge?".

At first, identifying a theoretical position can be challenging, as it requires the researcher to reflect on their own assumptions and beliefs and make the implicit, explicit. I found myself aligning with different ideas along the continuum of theoretical paradigms from relativism to positivism and struggled to know where I stood most firmly and confidently. I set aside time to intentionally reflect on my theoretical position as I found that I had a sense of what I believed but was not sure how to articulate it. I used the following questions to think about this more explicitly: "What are the assumptions that I make about the (material, social and psychological) world? What kind of knowledge do I aim to create? How do I conceptualise the role of the researcher in the research process? What is the relationship between myself and the knowledge that I aim to produce?" (Willig, 2012).

In summary, I determined that I believe in an objective reality in the world but there is only so much of it that we can access. I was not looking to find out a "truth" or produce an exact type of knowledge as such but rather gain access to a person's experience as much as possible. In thinking about my role as the researcher, I determined that I viewed myself as part of the research, and that the findings are to be created together with the participants and discovered by me. This led me to identify with the critical realist position.

Critical realist position

The critical realist paradigm which combines a realist ontology with a relativist epistemology (Pilgrim, 2019). While a realist ontology assumes that there is an objective reality that exists in the world that is independent of human understanding and

perception, a relativist epistemology assumes that everything that we can know is shaped by contexts.

I felt sure that my beliefs aligned with a realist ontology which assumes that there is an objective reality that exists in the world but that we cannot fully perceive it. I was less sure about my epistemological position and found it reassuring to think about my epistemological position as flexible and changeable. This aligns with my approach as a counselling psychologist as I am not fixed in one way of thinking about the world and one approach when it comes to working therapeutically with clients. As I reflected on this, I thought about how I draw on different models of therapy with different theoretical underpinnings ranging from systemic approaches, cognitive-behavioural and psychodynamic depending on a person's mental health problems and preferences and I wondered if it was possible to approach my research in a similar way? Not necessarily focusing on figuring out where I stand epistemologically in general but for this piece of specific research. This helped me to free up my thinking and consider what knowledge I wanted to produce and my view on the researcher's role.

By taking a critical realist position with this piece of research, I am working with the assumption that PMDD is a real condition that exists outside of our perceptions but that our knowledge about PMDD is shaped by contextual factors such as culture, language and individual interpretation and experience. There is no single truth that exists and that can be discovered through research, instead everyone experiences reality through a subjective lens, and researchers can access some of that experience through an understanding of subjective experiences and interpretations (Clarke et al., 2015). The researcher takes an active role in the creation of the research and is seen as a cocreator with the participants. The researcher attempts to suspend their own beliefs before engaging in the research as a way of ensuring that the participant's experience is at the centre, which is known as "bracketing" (Ponterotto, 2005). In doing so the researcher is attempting to get 'experience close' whilst remaining aware of the fact that it is not possible to fully separate oneself from one's own attitude in the interpretation of

people's experiences (Smith et al., 2022). The research takes a subjective and interactive stance and is reflected in the rhetorical structure of the work. For example, I have used the first person throughout my writing to capture this and demonstrate my involvement in the researcher. I am not a neutral bystander carrying out an experiment, but I have a dual role, "like the participant but also not like the participant" (Smith et al., 2022). In addition, I have included my own reflections on the process, considering the impact of the research on me and my own beliefs and ideas that I bring to the topic (Ponterotto, 2005).

Shifting philosophical stance

As I have progressed with this research my relationship to the topic has changed and this has had an impact on my philosophical stance. Overall, I took the view that my position was that of a critical realist however I have found that my position has shifted back and forth between a critical realist stance and a social constructionist stance. This has created tension in the research as there are key differences in the perspectives of these positions. While critical realism believes that there is a real world that exists independently of thought and language, social constructionism takes the position that reality is socially produced through interaction and discourse. During the analysis stage, I found myself making interpretations that were more focused on the role of society in the construction of that meaning. On reflection I think this changing position is linked to how this research study developed from the very beginning. When I first considered the topic of PMDD for my research I did so with an element of scepticism about the term PMDD and its definition as a psychiatric disorder in the DSM-5 (APA, 2013). I was initially drawn to research literature based on a social constructionist position which challenges the concept of diagnosis and instead prefers to frame PMDD as a social construct. As I engaged more with the topic and met with my participants, I found that my own understanding changed to a position of accepting the existence of PMDD as a diagnosable condition while also acknowledging the limitations of this perspective and seeing the value in bringing in the subjective elements of a critical realist position. In carrying out this piece of research my focus has been on the subjective experience of

women living with a diagnosis of PMDD which both acknowledges that PMDD exists but that people's experiences of it are subjective.

The tension between these two differing positions is reflective of how I felt carrying out this research. I have struggled at times to maintain a strong position and found my perspective shifting, especially given how long I have been working on this project and my own life experiences in that time. I have evolved along with this project, and these changes are reflected in the work. Despite this, I do not believe that this takes away from the important work that I am presenting in this thesis. It is reflective of the dual researcher-participant role that I have held while carrying out this research and benefits from being thought about and reflected on as I have done here. The findings and discussion continue to be relevant and reflective of the participants' experiences while making a significant contribution to this area of research.

Rationale for qualitative design

The aim of this research is to improve understanding of PMDD, increase awareness in clinical practice and help the development of psychological support in future. I hope to increase awareness of PMDD in the counselling psychology field by undertaking research in a lesser-known field, drawing psychologists' attention to a topic that may be unknown to them and providing them with some insight into the personal experiences of living with this condition. Another important aim is to give participants the opportunity for their voices to be heard, to share their experiences and to make a valuable contribution to the body of research on this topic. Given the aims of this research, selecting a qualitative methodology was deemed a good fit. Using a qualitative approach can provide access to the individual's subjective experience and shed light on findings from quantitative studies, demonstrating how qualitative and quantitative research can complement each other (Smith et al., 2022). This approach enables me as the researcher to gather relevant data and analyse it in a way to answer the research question and meet these research aims (Ponteretto, 2005).

I also had a personal interest in carrying out qualitative research as it is a new area for me. In the past I have mainly worked on quantitative research and so I was interested to expand my knowledge and experience of research by exploring a different side to it. I therefore intentionally sought out a research topic and question that aligned with this approach. In addition, in my clinical capacity as a trainee counselling psychologist I am interested in working with people to help them make sense of themselves and their experiences. Engaging with a qualitative methodology aligns well with my personal and professional preferences and supports an authentic relationship to my research.

Choosing the methodology

As my research question focuses on meaning making and the subjective experiences of PMDD, I primarily considered either narrative analysis or interpretative phenomenological analysis (IPA) as methodologies. Both methodologies are interested in how participants find meaning in their lives in different ways. I briefly considered using grounded theory as I thought that it sounded interesting as a methodological approach but rejected this as an option. Grounded theory focuses on developing theories, mainly to explain social processes, and so does not fit with a study that is interested in the subjective experience of the individual related to specific phenomenon (Willig, 2021). A study using grounded theory may have been used if the research question was more focused on social processes, for example investigating the process of gaining social support in PMDD, leading to the creation of a theory around this process.

In narrative analysis, the researcher is interested in how the individual constructs the story of their lives and the meaning that they take from it. The focus is not on discovering an objective truth but on how the narrative is constructed and the social and psychological consequences of that narrative (Willig, 2021). I have experience using narrative therapeutic techniques in the past with clients with eating disorders and so I am familiar with those ideas. A narrative approach is based on a relativist ontology and epistemology that assumes that reality is socially constructed, that there is no objective reality that exists outsides of human perceptions and that knowledge is dependent on contextual factors. I thought this methodology would align with my research question

exploring women's meaning making in PMDD however the social constructionist position made me unsure as it does not sit comfortably alongside a medical diagnosis such as PMDD. As already discussed, a critical realist position is more fitting given that it incorporates both realist and relativist theory. A research question for a narrative methodology may have been: "how do women construct their identities through stories about PMDD?". This question might have led to findings that focused more on the stories that women shared and the role of identity in their experience.

I therefore considered IPA as a methodology. IPA is a phenomenological methodology that aligns with a critical realist position. There is a focus in IPA on meaning making in the individual's subjective experience of a specific phenomenon, linking how someone thinks and speaks about a possible stressful situation and how they respond to it (Smith, 1996). IPA is commonly used in health psychology research for example in studies exploring the experiences of pain (Smith, 2018), Parkinson's (Eatough & Shaw, 2019) and depression (Smith & Rhodes, 2014).

Interpretative Phenomenological Analysis (IPA)

Interpretative phenomenological analysis (IPA) was first developed by Jonathan Smith and has become a popular qualitative methodology in psychology including counselling psychology. The theoretical foundations of IPA are based on three philosophical ideas: phenomenology, hermeneutics and idiography (Smith et al., 2022). Husserl's phenomenological philosophy aims to shed light on the concrete experience of a phenomenon by focusing on the "thing itself" and removing the layers of assumptions, preconceptions and biases people acquire through living their lives (Eatough & Smith, 2017). This is termed 'intentionality' and describes a focused orientation towards something. Hussrl believed that by bracketing off the view of the world that is taken for granted, we can gain access to our perception of the world and therefore our experience of it (Smith et al., 2022). This philosophy is at the core of IPA but moves to incorporate the interpretative stance of hermeneutic phenomenology, originally developed by Heidegger (Langdridge, 2007).

Heidegger believed that to interpret people's experiences was to understand them. Gadamer and Ricoeur went on to add their own ideas stating that it was impossible to transcend the position that we are in and that we will therefore always bring our beliefs, assumptions and preconceptions with us. Heidegger proposed that how we relate to the world is integral to our being in the world as we are always relating to something (Smith et al., 2022). Heidegger argued that bracketing is not fully possible, we inevitably engage with a topic before being able to determine what to bracket off, leading to a cyclical process that takes place in the moment (Smith et al., 2022). This philosophy aligns with the critical realist position that we can only partly know what someone's reality is. In IPA the interpretation is needed to make sense of the experience, and both participant and researcher engage in this process, with the researcher attempting to make sense of the participant's meaning making. It is a collaborative process and a personal process; the interpretation is not based on existing theory but is drawn from the data (Smith et al., 2022).

Merlau-Ponty also contributed to the philosophy underpinning IPA through his interest in the embodied nature of the human relationship with the world (Smith et al., 2022). Merlau-Ponty believed that we communicate with the world through our bodies and we are "body-subjects" above all else. The relationship between the body and the world takes precedence (Anderson, 2003). These ideas feel particularly relevant to the embodied experience of PMDD. Ideas from Sartre, the existential philosopher, have also influenced IPA in considering the importance of present and absent things in our lives and how that presence or absence influences our perceptions of the world and how we make meaning of our experiences (Smith et al., 2022).

IPA's idiographic nature makes it distinctive from other methodologies by focusing on the unique aspects of an individual's experience (Eatough & Smith, 2008). This is not to be confused with a focus on the individual themselves, but it is a focus on the *particular*. This translates into carrying out a detail focused analysis and the commitment to examine how "a particular phenomenon has been understood from the particular perspective of particular people in a particular context" (Smith et al., 2022). Although

this is easily understood to therefore imply that single case studies are key, the idiographic nature of IPA can be maintained with small samples as well. The in-depth analysis of each individual case before bringing the data together and the focus on the convergences and divergences between participant experiences ensures that this element of IPA is maintained (Smith et al., 2022).

Through IPA the aim is to understand a person's lived experience in the context of their lifeworld. Eatough & Shaw (2019) describe the lifeworld as "the world that we experience, that is replete with meaning for us and in which people, events, and so on matter to us." By understanding the meaning that people make of their lived experience we can better understand the experience itself. The meaning of the individual subjective experience may then elucidate other wider areas of psychology, making links between the idiographic and the nomothetic (Yardley, 2000).

As I began to develop my research question, I spoke to an expert by experience who reassured me by saying it was great to have someone who is not living with PMDD interested in carrying research out in this area. This was validating for me to hear in my role as an "outsider" and highlighted for me how important it is to be carrying out this research to help shine a light on this condition.

I initially became interested in this topic when I first heard that PMDD had been given its own distinct diagnosis in the DSM-5 (APA, 2013). For years I have experienced premenstrual syndrome (PMS) and was surprised to hear that a condition related to woman's menstrual cycle was categorised as a psychiatric disorder. When it came to choosing my research topic for this study, I found it difficult to select a topic that I was interested in and felt connected to until I thought about my interest in women's health and specifically PMDD. I felt motivated by the thought that I could contribute to this area and open people's eyes to a condition and experience that most people do not know exists.

My initial reaction to finding out about the classification of PMDD as a diagnosis in the

DSM-5 was one of shock and anger. I was taken aback at the idea that women's premenstrual distress could be pathologised in this way and I was quick to form an opinion on it. I was in a phase of being particularly anti diagnosis, feeling frustrated with the system in which mental health problems are diagnosed and treated, and particularly frustrated with this being a women's issue that was classified in this way based on seemingly limited understanding. Through my own experience of menarche and the PMS that I have struggled with on and off for years, I think I took quite a defensive stance. I do not have a diagnosis of PMDD, and it is not an experience that I fully relate to however I was already worried about people seeing me as crazy or hormonal and at times feeling quite out of control with my mood and the impact of my cycle. I felt resistant to the idea that this was something that could be diagnosed and therefore potentially label me with a problem that set me apart from others. Even speaking about PMS felt shameful in a way, despite some of my friends relating to certain aspects of it, as it did not feel like there was anyone who experienced it to the extent that I did.

Given this experience, I was aware that I was coming to this research with certain beliefs and assumptions about what it meant to be affected by premenstrual changes and what it meant to diagnose these problems as a "disorder". I felt very much on the side of women with premenstrual issues and wanted to give them a voice and help them share their experiences. As I learnt more about the research process and using IPA, I understood how important it was to recognise my role and influence in the production of the research and bracket off where possible, allowing for the participants' experience to be front and centre. Even though the role of the researcher is active and a part of the research in IPA, the participant's sense making takes priority while the researcher's sense making should be in second place (Smith et al., 2022).

As I began to do more research and familiarise myself with the topic through reading and on social media where this is large and active community, I noticed the influence of the wider PMDD discourse on my thinking and that I was struggling to hold onto my

own perspectives. Recognising this, I made the decision to stop following PMDD social media accounts and limit my interaction to research literature relevant to the topic. This helped me to remain open minded to all perspectives and focus on the experiences that my participants were bringing and my own interpretations of those.

Sampling

Recruitment for this study was carried out using purposive sampling as is recommended when using IPA (Langdridge, 2007). Phenomenological research is based on gaining a deeper insight into people's experiences of a specific phenomenon and as such it is important for the sample to be homogenous; consisting of individuals who have experience of this same phenomenon and are similar across demographic measures. This ensures that the research maintains its idiographic nature, meaning that the individual, subjective experience is at the centre of the study (Smith, 2004). My aim was to recruit 6-8 participants for the study to maintain the focus on the individual and to allow for in depth data analysis to be carried out on a case-by-case basis while also providing an appropriate number of data points for a doctoral level research study (Smith et al., 2022).

Before starting recruitment, I submitted my first ethics application which was approved (ETH2122-0352, see appendix A). I originally included completion of the PSST questionnaire as a step in the recruitment process, used in other research (Osborn et al., 2020b) or completion of the C-PASS as a requirement as advised by the IAPMD (IAPMD, 2025) in my research proposal. I received feedback from the academic team via my research supervisor that the use of the questionnaire may sit uncomfortably with the use of IPA. We discussed the tension between me asking them to complete a questionnaire to effectively confirm their diagnosis, while also taking an analytical stance that focused on the individual, subjective experience. I expressed concerns about my research not being taken seriously and not being considered of good quality without this; however following some discussion and personal reflection I concluded that I did not want to ask participants to complete the questionnaire to confirm their

diagnosis. We agreed that I would ask participants to confirm that they had received a diagnosis from a medical professional as part of the screening call to preserve the homogeneity of the sample. I accept that PMDD is a formal diagnosis in the DSM-5 (American Psychiatric Association, 2013) and the ICD-11 (World Health Organisation, 2019) and that this forms part of the sociocultural context of these women's experience which cannot be ignored in this study.

An additional change that was made after my initial research proposal was to the age range of the participants. I initially kept the age range very open at 18 years old and above, however after some further research and discussion with my supervisor, I considered how the different stages of female development and the menstrual cycle may have an impact on experience. Given that PMDD is related to the menstrual cycle, it was necessary that all participants were still actively menstruating. However, I also needed to consider life stage in terms of the perimenopause and the menopause, as women can experience significant fluctuations in oestrogen and progesterone during the perimenopause, with a likely impact on their PMDD symptoms and experience as well (IAPMD, 2025). Given that the average woman starts the menopause at 51 years old, may start it as young as 45 years old (British Menopause Society, 2023), and perimenopause may go on for a few years preceding this, I discussed with my supervisor that setting an age cap of 40 years old would ensure a homogeneous sample and focus the study on women who are not either perimenopausal or menopausal. Making this decision felt difficult as I did not want to exclude anyone from taking part in the study, but at the time I felt confident that this was the right decision for this piece of research. This speaks to the different challenges that women face and the ones that are often not spoken about, such as dealing with the perimenopause and the menopause which are huge life events that are often not considered in women's daily lives and in women's health research. These changes were submitted as amendments to my ethics application, and they were approved (ETH2122-1885, see appendix B).

A final decision that I made that is important to acknowledge here is the decision to only include women who were female at birth and identified as female as adults, also known

as cisgender women. Throughout this research I have chosen to focus on women's experiences of living with PMDD, recognising that this does not include all people with PMDD given its focus on gender. I want to acknowledge that people born with ovaries and who have a menstrual cycle may identify as a different gender and the term AFAB (assigned female at birth) is used. Research that includes people with different gender identities is limited in this field and only recently has this been starting to change (Lowik, 2021; Arshed et al., 2024). My decision to use the term 'woman' throughout this research is based on the research that already exists on this topic which is relevant to those who were born as women and identify as women due to the selection process for participants. Unfortunately, people who menstruate but do not identify as women have been routinely excluded from research in this field. This is not with the intention to exclude anyone but also considers the individual and subjective nature of this research which takes an idiographic position and therefore looks for homogeneity in the participants. This was something that the IAPMD asked me to defend, and I also had a direct question from someone who was interested in taking part as to why people assigned female at birth (AFAB) were excluded from the study. I acknowledge that this was problematic in ways and explained that my decision was based on a need to preserve the homogeneity of the sample given the research methodology I was using.

The exclusion of perimenopausal and menopausal groups and only including cisgender women in my sample were two decisions that I justified at the time, however in hindsight I may have changed these points to be more inclusive. Partly I think this recruitment approach came about because of my inexperience in carrying out research using this methodology. I was focused on ensuring that the participant group was homogenous given the focus on experience and the idiographic nature of IPA. My hypothesis at the time of designing this study was that a person's experience of PMDD may differ greatly dependent on their gender identity given the research so far that suggests that there is a gendered element to people's experiences.

I wonder if I was overly cautious about the differences between the participants that may have arisen and that in fact taking a more inclusive approach would have been

informative and added another layer to this research project by incorporating different voices and perspectives. I recognise that by recruiting in this way I missed the opportunity to acknowledge the perspectives of marginalised groups that are valuable and important to hear.

The final selection criteria are outlined in the table below.

Table 1. Participant selection criteria

Inclusion criteria	Exclusion criteria
• 18 – 40 years old • A confirmed diagnosis of premenstrual dysphoric disorder (PMDD) by a medical professional • Living in the UK • English speaker • Female	• Active risk such as high emotional distress

Recruitment

I contacted the International Association for Premenstrual Disorders (IAPMD) for support with recruitment, and they agreed that I could advertise my study with them. I made this decision as I determined that they would have access to a wide audience of people with PMDD. After receiving final ethics approval, I sent an outline of the study and the recruitment flyer to the IAPMD research team, and they agreed to advertise the study on their website and to post about the study on their social media accounts. I had a significant amount of interest in just a few days of the study being advertised with IAPMD. I asked participants to contact me by email if they met the inclusion criteria and wanted to find out more about taking part. 49 women contacted me, and I began to feel a bit overwhelmed with how many people were getting in touch and found myself worrying about disappointing them if they could not. I decided to contact people in the order that I received their emails, thanking them for getting in touch and attaching a copy of the information sheet for them to review. I asked them to read the information sheet and then confirm if they wanted to go ahead with a screening phone call. I planned on carrying out a screening call to give the potential participants an opportunity to ask any questions they may have, as well as confirming certain details with them before agreeing that they take part.

I carried out screening calls with 6 women. During the screening call I asked a few short questions to confirm that they met the inclusion criteria for the study and that they were available to complete the diary and attend the interview. At the end of the phone call, if we both agreed that they were going to take part, we scheduled an interview time and date and agreed the time period for keeping the diary. For the other women who had been in touch, I thanked them for their interest, explain that I had met the recruitment numbers for my sample at this time and that I would re-advertise the study in future if anything were to change. After the initial recruitment stage, I had a sample of 6 women who I had scheduled interviews with.

There were a couple of timing restrictions that influenced how I recruited and scheduled interviews. Firstly, by asking participants to schedule the diaries during the luteal phase and the interviews during the follicular phase, it meant that there were several weeks between the screening call and the interview for some participants. Secondly, I was carrying out recruitment towards the end of my second year of training just before I was about to interrupt my training for a year to go on maternity leave. This meant that I had to schedule all the interviews before I finished for the year as I was not able to carry out participant facing activities while on interruption. This did not have an impact on the interviews themselves but in the end, for these two reasons, one of the participants was not able to attend the interview before I finished and so, although she completed her diary, she dropped out of the study before the interview stage.

When I returned from maternity leave a year later, I therefore had data for 5 participants. Following a discussion with my supervisor we decided that I would recruit 1-2 more participants to meet my initial planned sample size of 6-8 based on guidance for a doctoral research project (Smith et al., 2022). I contacted the IAPMD, and they generously re-advertised the study on their website. I declined advertising the study on their social media as I was only recruiting 1-2 people. 7 women contacted me; I sent the information out and scheduled screening calls with 2 women who then went ahead and completed the diaries and scheduled the interviews. Following these two recruitment

phases I had a sample of 7 women who completed both diaries and interviews. This met my original aim of 6-8 participants.

To ensure participant confidentiality, all identifying information has been removed and pseudonyms have been used throughout the thesis.

Table 2. Participant demographics (with pseudonyms)

Participant	Age	Ethnicity	Occupation	Relationship status	Diagnosis year
Emma	30	White British	Freelance data analyst	In a relationship	2022
Eleanor	37	Hispanic	PhD student	In a relationship	2021
Nathalie	37	White British	Housewife	Married	2015
Josie	32	White British	User researcher	In a relationship	2022
Nina	18	White British	Student	Single	2020
Lisa	33	White British	Data analyst	Engaged	2023
Danielle	31	White British	Executive journal manager	In a relationship	2023

Limitations

It is important to acknowledge the limitations of my final participant group. Of the seven participants, the majority (six) were White British, therefore the findings presented in this study are representative almost entirely on this perspective and representations of other ethnicities are absent. This is particularly important given the limited research that addresses racial diversity in women's health. This was not intentional at the point of recruitment but may have been better addressed with a more diverse range of

recruitment strategies, for example by using posters to advertise my research study in different community-based locations or reaching out to local organisations.

This limitation also has implications on cultural representation within the participant group. A sample of predominantly White British women living in the United Kingdom (one participants identified as Hispanic but resides in the UK) suggests that their experience of PMDD will be situated within Western, white and British cultural norms about mental health, gender and the menstrual cycle. Their cultural beliefs are likely to influence the meaning that they make of their diagnosis of PMDD and their experience of it. The majority of findings of this study therefore need to be considered from this perspective as the voices of other cultures are missing. This could have been addressed by being more intentional in the recruitment of participants, for example by actively reaching out to community-based organisations or groups to help increase diversity rather than relying on online recruitment only.

I have already discussed how my inclusion and exclusion criteria contributed to a lack of diversity in gender identity as I made the decision to only recruit cisgender women. The final participant group was therefore made up of 7 people who identified as cisgender women. This research therefore presents findings from this perspective and does not include the nuanced experiences of people who identify their gender differently. This limitation could have been addressed by changing my inclusion criteria from the beginning.

Due to these limitations, it is not possible to explore how these different areas such as race, gender and culture intersect with PMDD. It will be important to address this in future research as well and design research studies that recruit more inclusively and allow for more creative exploration of these experiences.

During the screening call with the final participant who took part, she said (I am paraphrasing) how her life wasn't going to change from taking part in this study, so it came down to whether it was helpful for my research for her to take part. I noticed

how I found this quite jarring, and it made me feel uncomfortable and I thought about why. What she said was not inaccurate and I reflected on how it was an unfamiliar position for me to be in. As a trainee counselling psychologist my aim is to help other people, and it felt wrong to be asking for people to do something to help me. Although participants said they wanted to help other people by spreading the word about PMDD, the benefits of taking part were less personal and direct than they might be for someone engaging in therapy with me as a trainee counselling psychologist. This power imbalance in the relationship felt difficult to sit with but important to acknowledge.

It felt like I had more of the power in a way which felt uncomfortable for me, especially as I felt like a bit of a researcher imposter, being a novice qualitative researcher. I wanted to make sure they were the "expert", leaving things very open and hold back from expressing any leading assumptions or judgements. I did not always succeed at this, for example during a screening call when I empathised with what I interpreted as a challenging experience with a medical professional saying, "I don't know the letters" and the participant clarified that it was actually fine and she felt supported. I caught myself and felt silly for making such a basic mistake.

Data collection

I chose to carry out semi-structured interviews and ask participants to complete personal diaries. The intention behind this was to gather richer data than either interviews or diaries would provide alone. The diaries gave access to participants' experiences at different points in their menstrual cycle and therefore did not depend solely on them recalling past experiences at the time of interview (Morell-Scott, 2018).

Participants were asked to keep the diary of their day-to-day experiences of PMDD during the luteal phase of their cycle and to take part in one semi-structured interview with me during the follicular phase. The decision to schedule the interview during the follicular phase was intentional, to ensure that participants felt fully able to take part in an interview without the impact of their PMDD symptoms. Other studies have also

scheduled data collection according to participants' cycles as well (Osborn et al., 2020b). By asking them to keep a diary during the luteal phase this meant that they could share 'in the moment' experiences of PMDD in a way that hopefully felt more manageable. Some of the participants commented on how they appreciated this structure and confirmed that taking part in an interview during the luteal phase would have been too challenging for them.

Diaries

All participants were asked to complete diaries for the luteal phase of their cycle preceding the scheduled interviews and then send it to me before we met so that I was sure that I had both parts of the data following the interview. I was initially unsure whether I would read the diaries before the interviews, however after some reflection I decided against it and I made this clear to the participants when I outlined the details of the study. My decision not to read the diaries was so that I would not be influenced by the diary content during the interviews, as I was concerned that if I had already read about their experience of the luteal phase before the interview, this would perhaps change the questions I asked and influence what they shared as well. This is in line with the 'bracketing off' process that forms part of the IPA methodology, recognising the need to bracket off personal assumptions, judgements and beliefs as much as possible to leave space for focused interpretations of the participants experiences (Smith et al., 2022).

I asked the participants to keep a diary of their day-to-day experiences of PMDD during the luteal phase. The instructions for the diary keeping were simple as I did not want to overly influence how they shared their subjective experience. Most of the participants asked follow up questions about how much to write or what to include and some of them expressed a desire to make sure they were doing it correctly as they wanted to make sure I had the data I wanted. On reflection, I wondered if more structure to the diary keeping would have been helpful, particularly as all the participants spoke about tracking their cycles in the past and that approach tends to be very symptom focused. I wanted to remain consistent with all participants and so clarified that I was interested in

what it was like for them to be living with PMDD during the luteal phase, with a focus on experience and not only on symptoms. I reassured them that there was no right way to do it, and I did not have any fixed expectations for what they would produce but instead was interested in their subjective, individual experience as fitting with this study's aims.

Semi-structured interviews

Initially I considered carrying out a focus group to help determine the questions for the interviews as I wanted to ensure that I was focusing on topics that felt most relevant and important to participants (Breakwell et al., 2020). On reflection, I noticed that this came from a place of me feeling insecure in my role as the researcher and wanting to get it "right" rather than a research need. As I became more familiar with IPA as a methodology, I used the previous literature on PMDD and guidance on IPA to develop an interview schedule that consisted of open-ended questions that I hoped would allow for the participants to share topics that felt important to them whilst remaining aligned with the research study's aims (Eatough & Smith, 2008; Langdridge, 2007; Willig, 2021; Smith et al., 2022). In line with the guidance on semi-structured interviews in IPA (Smith et al., 2022; Willig, 2021) I included additional prompts for the questions to guide the interview as needed, loosely based on topics of interest in this area. Participants were given the option to attend the interview over online video or in person, all the participants chose online via Zoom. The interviews lasted between 45mins – 1 hr.

Following the first interview, I met with my supervisor, and we discussed how the interview had been, reflecting on what went well and where there were some challenges. In semi-structured interviews in IPA, there is space to allow for flexibility in what questions are asked and the interview schedule can evolve over time (Breakwell et al., 2020; Smith et al., 2022). I shared how one of my questions was met with some confusion about how to answer (w*hat does it mean to you to have PMDD?*) and we spoke about what my intention was in asking this question. We agreed on some alternatives which are outlined on the interview schedule (see appendix G).

After each interview I noted down any initial thoughts, feelings and responses I had to aid my reflexive process and the analytic process (Finlay, 2002). This also helped me with bracketing off my own ideas between interviews with participants as it allowed me to retain my initial thoughts and interpretations of the data while also being able to let it go and not allow it to influence how I carried out following interviews.

Data storage

The participant's signed consent forms and contact details were saved and password protected. The diary entries and interview transcripts were stored on the City University one drive which is encrypted, and documents were password protected. Data was de-identified for analysis and personal data was stored separately. In line with the City University Intellectual Property policy the participants' research data and personal data will be stored for 10 years from the end of the project. The personal data will then be destroyed by the Information Services team at City, University of London in line with their destruction policy.

Ethical considerations

This study was carried out in accordance with the British Psychological Society (BPS) code of ethics and conduct (2021) and received ethical approval from the City, University of London ethics committee before commencing. I followed the key ethical principles outlined by the BPS: respect, competence, responsibility and integrity. Below I have outlined the steps I took to ensure that these principles were present throughout the research.

Participants were given a participant information sheet outlining the details of the study as well as a consent form to sign confirming that they had understood what the study involved and consented to the use of their data. Participants also took part in a screening call with me to confirm that they understood the information sheet, to answer any questions they had and to screen for any risk due to the sensitive nature of the topic.

No deception took place as participants were made fully aware of each step of the project.

Before agreeing to take part, the participants were informed of their right to withdraw their data from the study at any time until the data was deidentified for analysis. Once the data was deidentified it was not possible to remove as it was no longer linked to the specific participant; they had one month from the date of their interview to notify me if they wanted to withdraw. This was explained to the participants in the participant information sheet, the consent form and during the screening call. I monitored participants for signs of upset and distress before, during and after the interviews and had a distress protocol in place for how to manage this (see appendix H).

At the end of each interview, I stopped the recording and then had a short debrief with the participants asking them how they had found the interview and if they had any concerns or issues that they wanted to raise. Participants who consented to being contacted with the study's findings will be sent a summary of the publishable findings and offered an opportunity to discuss these with me as the researcher (Hintz & Dean, 2020). All participants wanted to be contacted with the findings following the completion of the research and confirmed this on the original consent form that they signed before completing the diary and interview.

Reflexivity at the data collection stage of research can help clarify the impact of the researcher-participant relationship and the methods on the data (Gough, 1999). During the data collection phase, I took notes after each interview with my initial thoughts and reflections about the process, the content and my personal experience of the interview to aid the reflexive process. There were specific quotes that I picked out that made me think about how my own reactions and judgements in the moment may have influenced the research and specifically how the interviews unfolded.

During the interviews I sometimes found myself questioning how I should react, particularly in the first couple of interviews. Do I react as I would with a therapeutic

client? Or as I would in a normal conversation? Or do I need to be more restrained and distanced to not overly influence what they say? On the one hand I felt pressure to know exactly what I was doing as I was the researcher and the "expert", but on the other hand I was conscious of ensuring that they not feel too directed by me and were able to communicate their experience in a way that felt right for them. In a couple of the interviews, I found that I used a lot more prompting questions with the participants whereas with others they spoke more freely. At the time I was concerned that I was asking too many questions or maybe not the right questions, however when I was analysing the data the difference was not noticeable to me in the data that emerged.

Data analysis

New IPA terminology has recently been developed by senior IPA researchers which has been described as more intuitive and representative of the analysis taking place (Smith et al., 2022). The analytic procedure in IPA is not prescriptive, meaning that the researcher can move back and forth between phases as needed, allowing for a flexible and creative approach to the analysis. Due to its idiographic nature, a key part of the data analysis in IPA is on a case-by-case level; once this has been completed the researcher will bring the cases together and analyse them as a group. As this was the first time I was using the IPA methodology, I consulted the most recent textbook on IPA (Smith et al., 2022) for guidance on the analytic process. I also used the group sessions with my peers and a member of the doctoral teaching team to learn more about the analytic process, gain some input on my data and get some insight into how other people approached their data analysis. I found it helpful to see how other people were analysing their data as it helped me to think creatively about how to approach my own analytic process.

After completing the interviews with the participants, I transcribed each of the recordings verbatim according to guidelines (Smith et al., 2022). I listened back to the recordings 1-2 times before beginning the transcription to familiarise myself with the content, the tone and the way in which the participants spoke. I noticed how there were certain things that

the participants said that sparked my interest and made me excited about the next stage of the analysis.

Once the transcriptions were finished, I began the next phase of the analysis which was working towards experiential statements for each participant. The first part of this is to make exploratory notes going through the data line by line, and then create experiential statements based on the exploratory noting and the data. I referenced the textbook on IPA (Smith et al., 2022) for advice on how best to approach this and discussed this with my supervisor. I created a document with the content from the diary and the interview transcript in one column with a blank column to either side (see appendix I). I printed this out and then worked through the data making notes. I felt quite overwhelmed with how much data there was and found myself worrying about what to include as I was anxious that I captured the participant's experience accurately. To provide some structure I focused on the descriptive, interpretative, linguistic and conceptual elements of the data as outlined by Smith et al. (2022). I tried colour coding the notes as I had seen other people do but it was not intuitive to me and made it more confusing and time consuming. I decided to focus on making notes on what I understood to be important and relevant.

I then read through the exploratory notes, linking them to the diary and interview data and then came up with experiential statements that I felt captured the participant's experience. For the first participant I produced over 100 statements which became cumbersome to work with at the next stage, so with following participants I focused on condensing these down. It helped me to do one round of statements and then go back over the data and combine statements where it made sense and remove others that felt excessive. This meant that the process took longer but was reflective of the iterative process of IPA analysis which encourages the back-and-forth process of interpretation (Smith et al., 2022).

I experimented with doing the exploratory noting and experiential statements on the computer but found that the formatting made it difficult to keep my work aligned and so

went back to the combined approach of printing out the transcripts and making notes by hand. When it came to producing the personal experiential themes (PETs), I wrote each statement out by hand on a card and laid them all out on the floor to get an overview of them. I began to group them together according to similarities and tried to filter out any repeated statements I had. For the first participant I had a lot of statements and so this process took quite a long time, and I struggled to get an overview of the data and make links. I persevered and ended up with several GETs that I then received feedback on from my supervisor. I realised that this approach needed some adjusting as it was quite labour intensive to write them out by hand and I realised I did not have any record of the statements on my computer which meant it was difficult to track the statements and the related quotes. For following participants, I added an additional step where I created a document for each participant where I added the experiential quotes and associated quotes. I then printed these out and cut the statements up so that I could lay these out and move them around to figure out the PETs for each case. This process of moving back and forth between computer and paper worked well for me, helping me to track each step of the analysis and giving me ample space to work iteratively with the data, staying close to the participant's experience as I attended to the data at every stage but also allowing me to input my own interpretations.

At times I noticed how I was drawn to grouping certain statements together and perhaps seeking out certain themes that I had identified with other participants or even ideas that I had picked up on at an earlier stage of the analytic process. I took time to notice this and reflect on where this thinking was coming from. At these points I found it helpful to take some time away from the data and come back to it with fresh eyes so that I could bracket off any preconceived ideas or assumptions I was making.

For each participant I produced a spreadsheet with several PETs and sub-themes. There were some experiential statements that were excluded, either if they were very similar to others already included or if they did not clearly fit into any of the final themes. I was careful to keep a note of these statements and the reasons for why they were

excluded so that I could remember my thought process but also in case I changed my mind about including them at any point.

At times I found myself feeling happy with several PETs for a participant but feeling a bit stuck with one or two that did not feel quite right. For these, I went back to the initial stage of grouping together the experiential statements, taking the printed cut out statements that were remaining and redid the process of grouping them together. This helped me to get unstuck and view the statements more objectively again. This stage of the process took longer than I expected and for each participant there were moments where I felt like I was drowning in data and that there was no way I would be able to finish.

I felt intimidated by the final stage of the data analysis which involved producing the group experiential themes. Up until this point I had been able to retain the individual experience for each participant, and I was concerned that I would lose important aspects of their experiences by grouping them together. This pressure that I put on myself to remain as faithful as possible to the participants experience was important and helpful in maintaining the idiographic nature of the analysis, but I also found that it could get in the way at times as I doubted decisions I made. Use of research supervision helped me to be aware of this and remind me of the focus in IPA on both similarities and differences between participants as a way of keeping the idiographic approach and the subjective experience even as the analysis progressed to the development of the group experiential themes.

I put the PETs into one spreadsheet with a different sheet for each participant and then slowly went through, reviewing each of the PETs and beginning to mark each one where I saw similarities across participants by colour coding. I then grouped these PETs together and began the back-and-forth process of moving them around and seeing how things fit together. I did all of this on my computer as I thought that it would be too difficult to work with such a large amount of data in paper form and it worked well for me. Instead of moving between paper and working on my laptop, I created new

spreadsheets for each stage of this part of the analysis and moved between these to be able to think creatively and move things around while holding onto the structure. At this point in the analysis, I found colour coding a helpful tool to keep track of the different themes as this helped me to have an overview of how the different PETs fit together (see appendix J). This shows how important it was for me to take a fluid and creative approach to this analysis, adapting how I analysed the data at each stage so that it fit best with what I needed to do. The flexibility of a methodology like IPA allows for this and although this may give ammunition to criticisms of IPA due to its lack of fixed structure, it adds value in giving the researcher the ability to make their own personal interpretations of the participants meaning making, which is at the core of experiential qualitative research such as this (Willig, 2021). This process of analysis also reflects the hermeneutic philosophy of the IPA methodology and the hermeneutic circle which describes the significant relationship between the whole and the part in interpretation and understanding. Only by looking at the whole can you understand the part, and you need to look to the parts to understand the whole (Smith et al., 2022). This iterative process is integral to the analytic process in IPA, and I found that it came quite naturally to me as I worked with the data.

I felt overwhelmed at the prospect of producing the group experiential themes (GETs) due to the challenge of figuring out how the data worked together while also retaining the idiographic nature of the analysis. I held this in mind while working and found it helpful to go back and remind myself of the context of certain quotes as I was working so that I could remember who the participants were and what their individual perspectives were. I noticed how I wanted to change certain experiential statements, sub-themes or PETs after having some time away from the analysis. This can be part of the analytic process in IPA (Smith et al., 2022) however I took my time with this and made sure to go back and review data before making any changes so that I remained faithful to what it was that I understood my participant wanted to express and was not too focused on my own personal interpretation. I wanted to ensure that the participants' meaning making came first and my own meaning making came second as it should in IPA (Smith et al., 2022).

After repeating this moving around process, four GETs emerged from the data that I thought represented the main themes and sub-themes for the participants. I created mind maps for each GET with the sub-themes outlined so that I could visualise how they fit together and begin the process of focusing on these parts of the data for the rest of the project. I then began the process of writing up the findings chapter.

I found it helpful to engage with the reflexive process during the analysis as it helped me to manage some of the feelings of overwhelm that I experienced, as well as helping me to identify how I was interacting with the data and the participants experiences. I felt a real responsibility to include everything that the participants were sharing with me as it all felt important and I found it difficult to know what to include at times. This was particularly challenging when the data was very rich, and I wanted to include more. On reflection I think I also felt this responsibility because of the experiences that the participants shared about how they had been misunderstood by other healthcare professionals. I'm not sure that they necessarily saw me in that way, but I wondered if there was a desire to prove that their experience was valid and credible to me. When I first asked participants in the interview why they wanted to take part there was also a shared motivation to help other people with PMDD so that they did not have to struggle like they had. Given this experience I noticed how I wanted to make sure they got their message across but needed to balance this with my own interpretations. Going back and forth between the data helped me with this, getting distance from it and then getting close again allowed me to see the wood for the trees.

Taking this time to reflect also helped me to catch myself in the moment and ask, "am I interpreting something based on what the participant is bringing or am I bringing too much of my own perspective into it?". It was more difficult to for me to engage with the data and bracket off my own assumptions, beliefs and judgements when I was experiencing my own symptoms of PMS during the luteal phase. I decided to take a break from analysis during this time to allow me to separate my own experience from

those of my participants as much as possible. I found myself really empathising with these women.

Engaging in this process also helped me to work out what helped me with bracketing and engaging thoroughly with the data and the analytic process. Taking frequent breaks and listening to classical music during the analysis helped me to focus. Practicing a brief mindfulness exercise before starting with a new participant helped me to stay with the experience of each individual and maintain the idiographic nature of my analysis.

I reflected on the above with my research supervisor, particularly discussing the responsibility I felt towards the participants and my desire to accurately report their experiences. Getting an outside perspective was helpful and reminded me to use my reflexive journal to record this. The double hermeneutics in IPA allows for the researcher's interpretations and perspectives and I am unable to communicate the participants' objective reality in this way.

Generalisability

Qualitative data is often dismissed as ungeneralisable as it does not fit the criteria for generalisability used for quantitative research however it requires a different approach to measuring it. As already outlined in this chapter, when it comes to a methodology such as IPA the aim is not to discover an experience that is shared by everyone; the focus is on the similarities and differences across subjective experiences of the same phenomenon (Smith, 2017). In fact, research that focuses on the idiographic experience can complement nomothetic research and link the particular to the general (Smith et al., 2022).

Two types of generalisability criteria have been considered for this study's findings; naturalistic (also known as representational) generalisation and analytical (also known as idiographic) generalisation (Smith, 2017). Naturalistic generalisation asks whether the experiences shared in the findings reflect people's personal experiences when they

read it. It is not possible to determine whether this is the case prior to publication, but I believe that this study's findings do have the potential to be generalisable in this way. I have included examples of the rich data that the participants shared with me and detailed descriptions of my own interpretations which provides people with the opportunity to consider whether their experiences are reflected in the findings. Given that the findings also replicate findings from previous research with similar populations, this provides further evidence for this study's potential generalisation.

Analytic generalisation considers how the findings contribute to refining, extending or challenging existing theories. The theories explored in the discussion chapter are generalisable and have been shown to be used with other populations and contexts. These ideas are therefore generalisable outside of this specific research and could be thought about for other populations for example, women with other health problems.

Validity

Yardley (2000) outlines characteristics of good qualitative research in her paper 'Dilemmas in qualitative research'. These flexible criteria are designed to evaluate the quality and validity of research that aligns with qualitative methodologies as opposed to incorrectly attempting to apply criteria designed for quantitative methodologies. These criteria include 'sensitivity to context', 'commitment and rigour', 'transparency and coherence' and 'impact and importance'. I have outlined how I have met each of these below.

Sensitivity to context

It was important for me to consider my role as the researcher in this study, given the inevitable impact on the development of the study and my relationship with the participants. I identify as a white British woman, I have a menstrual cycle and my own experiences of premenstrual change, and I am in my 30s. On the one hand I felt quite closely aligned with most of the participants who shared these attributes. On the other hand, I was aware of my role as both a researcher and a trainee counselling

psychologist and considered how these different roles might have influenced the nature of our interactions. This reflective and reflexive process is described throughout the thesis at different stages and shows how I considered these elements throughout this piece of research.

I also considered the wider context of the participants' experiences, for example considering the role of women in today's western society and particularly the role of millennial women and the agency myth (Carian & Johnson, 2022) which will be discussed in more detail in the discussion chapter. Contextualising the findings in this way is important as it aligns with the IPA methodology in terms of always considering people's experiences in the context of their lifeworlds (Brook, 2015).

Commitment and rigour

As already discussed, I have been interested in this topic for a long time and spent a significant amount of time researching it, demonstrating my commitment to this area. Through my reflexivity I have shown how committed I was to carry out a thorough analysis. I used peer feedback on my analysis to develop my analytic skills and worked hard to refine my approach in way that worked well for me, for example experimenting with different techniques at the initial stages of analysis and not being too rigid if something was not working well.

I demonstrated rigour in the data collection process by using interviews and diaries and therefore added a new perspective to the data. Throughout my analysis I have engaged with the data on multiple levels, for example looking at the language participants used and thinking about different meanings of specific words, considering how the participants used metaphors to communicate their experiences and thinking about how pauses and laughter may be interpreted to access a person's subjective experiences.

Transparency and coherence

I have been fully transparent and open in how I have carried out the research process from start to finish, detailing each step of the process, sharing my thinking throughout and using reflexivity to openly work through my own process. I have also included visual examples of different steps of the analytic process in the appendices to demonstrate this process in more detail and ensure that I am not withholding anything from the reader.

This study demonstrates coherence in how the research study was designed. The research question was about how women make sense of their experience of PMDD, which involved finding out about their subjective experience with a focus on the meaning making involved. Both the use of diaries and interviews as a method of data collection and IPA as a methodology align well with this research question and allowed me to access the necessary data and analysis to attempt to answer this question as much as possible.

Impact and importance

Finally, it is necessary to consider the impact and importance of the study to evaluate its validity. This research contributes to the current body of research by offering new perspectives on the subjective experience of PMDD and considers how these findings link to current theory and practice. Deeper interpretations of these women's experiences of PMDD offer new insights into their embodied experience. It also considers the role of diagnosis in a new light, as something that is both helpful and challenging. Diagnosis marks the beginning of a new journey of meaning making for these women and highlights this time as a priority for multidisciplinary care and tailored support. These findings are important as they focus our attention on the time "in-between", after diagnosis and before recovery. I hope that this study can also demonstrate the value in working with both a diagnosis and formulation in mind, considering the biological experiences as well as the psychological and contextual.

As I read the literature and think about the discussion and my findings, I found myself reflecting on how there seem to be two distinct sides to PMDD and the available research. One is the medicalised or diagnostic approach, and the other is a feminist and social constructionist approach. I see this piece of work as an attempt to bring some of these ideas together, recognising how the participants make sense of their own experiences in a multitude of ways which include biological, social and psychological factors. I am aware of how I hold these two ideas in my mind as I analyse and develop my findings and that this will have influenced my interpretations of the participants' sense making. What is interesting is how well this aligns with my critical realist position and the use of IPA. This was not as clear to me as I began this process as I was unfamiliar with IPA as a methodology, and I learn best by putting something into action. I have learnt more about IPA and its theoretical underpinnings by applying it and learning as I go. Therefore, as I have progressed through the different stages of the project and learnt how to use IPA, I have been motivated and reassured by how good a fit the theory, methodology and topic was.

Chapter 3: Findings

This section presents the findings from my data analysis as described in the methodology chapter. Four group experiential themes (GETs) emerged from the data:

- Making sense of PMDD: A journey of discovery
- PMDD and relationships: Unheard, dismissed and judged
- The impossible battle
- Getting through it: Finding ways to manage

Each of these GETs is explored in detail using relevant quotes from the participants and is broken down into sub-themes. The first GET, 'Making sense of PMDD: A journey of discovery' describes how the participants experienced learning about PMDD, receiving a diagnosis and the journey they took to make sense of their PMDD. The second GET, 'PMDD and relationships: Unheard, dismissed and judged' describes participants experiences of feeling unsupported by professionals when seeking care and by friends and family when seeking support. The third GET, 'The impossible battle', describes participants' experiences of the day-to-day dealings with PMDD and the impact this has on them. The fourth and final GET, 'Getting through it: Finding ways to manage', describes how participants found different ways to cope with the challenges of PMDD. Although I have presented the themes separately, they are not wholly independent of each other and the different GETs and sub-themes are interconnected.

Table 3. Group experiential themes (GETs)

Group experiential themes	Sub-themes
1. Making sense of PMDD: A journey of discovery	1.1 Making sense of the problem through diagnosis
	1.2 Forced to navigate the journey alone
	1.3 Blaming myself: Is it me or is it PMDD?

2. PMDD and relationships: Unheard, dismissed and judged	2.1 Met with ignorance rather than knowledge
	2.2 Judged and misunderstood
3. The impossible battle	3.1 The moment it changes
	3.2 The fight is exhausting
	3.3 Powerless to escape it
	3.4 Loss of the self: “It’s like I’m not here”
4. Getting through it: Finding ways to manage	4.1 Coping through connection
	4.2 Withdrawn from the world
	4.3 A state of resolution

GET 1: Making sense of PMDD: A journey of discovery

This theme explores how the participants made sense of PMDD from before diagnosis to after diagnosis. All the participants shared how they did not understand what they were going through at times. This theme describes the ways in which the participants attempted to understand what it meant to have PMDD.

The theme is broken down into three sub-themes which each emerged out of the sense making process shared by the participants. The three sub-themes capture how they made sense of their experiences at different times of the month and at different points in their PMDD journey. This reflects the cyclical nature of PMDD and how the experience is ever changing. The first sub-theme ‘Making sense of the problem through diagnosis’ explores how receiving a diagnosis of PMDD helped participants to understand what they were going through. The diagnosis validated their experience and eased their worries and fears about what was wrong with them. The second sub-theme ‘Forced to navigate the journey alone’ describes how several participants were left to their own devices and had to figure out what was wrong and how to help themselves. The responsibility was on the participants to explain what they needed to healthcare professionals and there was little support available. The final sub-theme ‘Blaming myself: Is it me or is it PMDD?’ explores how participants seemed to blame themselves for struggling during the luteal phase. They questioned whether what they were

experiencing was real even after being diagnosed and judged themselves for not coping better.

1.1 Making sense of the problem through diagnosis

Most of the participants shared how receiving a diagnosis of PMDD was a validating experience and that it helped them to make sense of what they were experiencing month to month. The participants expressed how confused they felt about what they were going through prior to being diagnosed. This lack of knowledge led to them questioning themselves and wondering whether there was something wrong with them as a person rather than a medical concern. They shared how it helped them to understand what was happening to them and to talk to other people about it.

Josie describes the confusion and lack of understanding before diagnosis:

> *Mmhm yeah and I just, I think, so part of it is before you're diagnosed you don't understand why your brain's acting a certain way, why are you so angry, why's things happening, whereas now I um, one I avoid the triggers so that includes like not going into office, like having more working time where I'm just working on my own um... but also includes things like telling myself "oh I'm angry because I've got PMDD, not just because I'm an angry person".*

Josie's choice to speak about her experience by using "you" rather than "I" is interesting. It may be that this gives her some distance from what she is speaking about and makes it feel less personal, making it clear that it is not just her experience but one that she shares with others. Another interpretation of this is that she wants to convey her experience to me in a way that I can more easily access. By generalising, this may be a way for her to communicate how common this experience is and give it more validity. There is a change in how she speaks about her experience from before diagnosis and after; before diagnosis it was confusing and hard to understand, while after diagnosis

she is more aware of what she needs, perhaps feeling more empowered as a result of having a label for her experience.

Other participants spoke specifically about the feeling of relief that diagnosis brought for them. Nina shares this aspect of her diagnosis in the interview:

> *A bit of a relief, that it's gone that you're not by yourself in the sense that you're not- I was just happy that I wasn't insane. And as much as it sounds kind of like, with PMDD it is slightly physiological because it's your sensitivity to hormones, so knowing that there is some sort of kind of like physical side to it and this physiology, rather than it just being mental health. And there was- and there's actually triggers, it was kind of reassuring to me to know that I wasn't crazy.*

It seems like the idea that Nina may be "insane" or "crazy" was a worry for her. A diagnosis reassured her that she was not alone in feeling this way and there was something physical to attribute her experience to rather than it "just being mental health". It may be that if PMDD was solely a mental health problem without a clear biological explanation, Nina might have found that scarier and more overwhelming. Perhaps this would have made it more difficult to accept as something that she was not in control of. Nina chose to start chemical menopause which reduced her PMDD symptoms significantly. If what she was experiencing had not had the same biological underpinnings, then a treatment option such as this would not have been available.

Eleanor shares how being diagnosed was a relief partly because it explained why she was struggling to make changes on her own.

> *Uuuh it was very relieving, I felt heard, it made sense because there was some points where I was putting a lot of effort in and still I was feeling very unmotivated and depressed and... And I just felt like I*

was going crazy, like I was thinking like there's no reason why this happens all the time. Yeah, it was. It was a relief. It was.

Like Nina, Eleanor also uses the term “crazy”, stating that she was worried she was going crazy as nothing was changing in how she was feeling. I wonder if that feeling came from not being able to make sense of what she was going through and nothing was adding up. What should have helped in her mind (putting a lot of effort in), was not helping. This also touches on the pressure that Eleanor seems to be putting on herself to be able to deal with things on her own. Her diagnosis explained it and brought about a feeling of relief, as if it took the pressure off and it was ok that things were not working as they should.

Emma describes having mixed feelings about her diagnosis:

... it was, it was positive, because you have a bit of an explanation um, and validation and it’s kind of like being seen and heard and understood a bit. There’s an explanation for feelings and behaviour but then that’s also sad because what it is, is something that is probably going to happen every month depending on whether there isn’t, there isn’t really or as far as I’m aware there isn’t really a pure straight up treatment.

The explanation for what she is experiencing leaves her feeling validated and understood, but with an element of sadness as she faces the fact that there is no straightforward solution. It may be that it is disappointing for Emma to realise that although she now understands what is happening to her, it feels like there is little that can be changed.

Later in the interview, Emma speaks about how being diagnosed with PMDD helped her to reflect on her past experiences and make sense of them:

It just puts all the pieces together and again gives me more validation and makes me feel more ok with it.

Emma refers to how her diagnosis “put all the pieces together”. My initial interpretation when analysing this quote was that her experience of PMDD up until that point may have felt like an unsolved puzzle and having the diagnosis meant she could put the puzzle together and have a complete picture to show to other people. As Emma did not use the word puzzle or refer to other people at all it is important to consider alternative interpretations. I think I may have over interpreted this quote. On reflection I wondered whether an alternative interpretation could be that up until the point of diagnosis it felt like there were lots of “pieces” of different experiences in her past that she could not make sense, there was not anything tying them together. Being diagnosed meant that she was able to gain clarity about a lot of different things in her whole life and gain clarity over what was happening in those moments.

1.2 Forced to navigate the journey alone

Participants shared how they had to figure things out alone in different ways. Some found that it was only when they did their own research that they worked out that they had PMDD and went to the doctors with that information. Others described the extensive research they did on their own to find treatment options following a diagnosis and the burden this put on them. Throughout this sub-theme there seems to be common experience amongst participants of feeling like they did not have any choice. There was not enough understanding from doctors which left them forced to be responsible for identifying their problems and finding solutions.

Eleanor was asking for help for her physical symptoms and psychological symptoms in different places, treating them as separate. It was only when she figured out herself that they were linked that she gained some clarity:

I was treating them as two different things. Uh, but then I realised that they were, they were always the same, in the same day.

One way to look at this is that Eleanor stepped back to look at the whole picture to make sense of the parts. By not treating her mind and body as separate she was able to make sense of her experience in a way that had been impossible up until that point.

Nina was also left to her own devices as her doctor attributed her mood changes to “being a teenager”. Nina took things into her own hands and worked out that there was something else going on:

> *...it wasn't until I kind of started doing my own research when I was around about 16 and realised that there are other people like this, it's not just me and it's not just being a teenager.*

I wonder if it was also perhaps disappointing for Nina to feel pushed to do her own research, particularly at such a young age. After hearing people attribute her severe PMDD symptoms to “just being a teenager”, learning about PMDD was likely reassuring and validating. For Nina it was learning that other people were having a similar experience that helped her to gain some clarity about her experience.

Lisa spoke about how hopeful she was after first being diagnosed and how hard she worked to find the thing or things that would help. Lisa describes here how that initial hope slowly dissipated as nothing changed:

> *Because I've been constantly searching for answers or searching for this one thing or multiple things that if I do them and I do them religiously and I work hard enough then this will be resolved and not be as severe um and and then trying all of those things and not not yet finding anything that really does make a huge difference. Or does make a huge difference and doesn't give me any other symptoms to then deal with um, has been really difficult because I think before knowing, and before the severity was at what it was, I guess... I*

guess I've gone through a point of having a little bit of hope and then the more I try things feeling a little bit less hope each time one of them doesn't work. Because you feel like you're kind of running out of options and that's really tough.

Without a clear treatment plan from a doctor, Lisa was left trying to find her own way and taking on all the responsibility for figuring out a solution. The added burden of doing this on her own seems to reinforce the pressure she is putting on herself to find the right answer. There may be some underlying fear for Lisa as well, as she speaks about "running out of options". The future for Lisa seems to feel uncertain and there is a sense of hopelessness about it.

Nathalie also spoke about how much research she did herself and the different things that she tried after unsuccessful attempts to get treatment from her doctor.

... I carried on sort of researching it myself and I tried all sorts of home remedies, I mean I've tried vitamin B um... all the obvi- my brain has gone blank now but evening primrose, agnus castus, I've tried every herbal thing there is, thinking I could perhaps help myself.

The last sentence of this quote suggests that she no longer feels able to help herself. She seems to be looking back on a past self when she thought it was a possibility but that is no longer the case. There is a sense that Nathalie has lost the hope that she once had and that she is feeling like there is no one that she can rely onto help her, not even herself anymore.

Danielle's attempts to get help left her feeling responsible for her own care:

I've seen the GP, I've seen a gynaecologist, I went privately as well and no one really knew what would be the best course of action and they were like, what do you want to do?... why in my life is a doctor

coming to me and saying what do you want to do? I don't, I don't know. What what should I be doing? You should be telling me and I feel like I've done more of the research. And more than I really want to have done. So which is why I think I keep searching for things and I don't come back with very much.

Danielle lists the different doctors she has seen, emphasising how much she has tried to get professional help. There seems to be some frustration from Danielle's side that the onus has been put on her to say what she wants to do. She is unwillingly being put in the driving seat and forced to do things she does not want to do (the amount of research for example). I interpret this as Danielle feeling like she cannot rely on others to help her and that she has been pushed into a position that she does not feel comfortable with. This may feel disappointing and potentially quite scary to be figuring out on her own. Despite this, she persists and continues to do research but without much success.

1.3 Blaming myself: Is it me or is it PMDD?

Several of the participants spoke about how they blamed themselves for not coping better and doubted the validity of their experiences during the luteal phase. This led to questions about whether they were driving their PMDD symptoms and if there was in fact something they could be doing differently. The way that the participants spoke about this suggests that PMDD feels intangible. It seemed hard for them to hold onto the reality of it, perhaps partly due to the cyclical nature of the disorder which makes it almost seem to appear and disappear overnight.

Josie finds herself questioning whether she is doing this to herself and in fact falsely attributing her tiredness to her PMDD.

Should I like, should I be trying to get up and doing more and then I'll be trying if I did that, like am I giving myself PMDD symptoms, like so it's like, so that's similar with the diary you really have, you

find yourself really questioning yourself, like am I actually tired? Am I more tired than usual?

By paying attention to her symptoms and her cycle she questions whether she is experiencing PMDD symptoms or whether she is connecting the two because that is what she expects at that time of the month. Not only does she doubt whether what she is feeling is accurate, but she is also blaming herself for the PMDD symptoms, as if she is in control and choosing it.

Emma describes a similar experience when she takes time off from work during the luteal phase and the guilt she feels as a result.

So even if I am taking time off for it, it still feels bad and I still feel so guilty because I'm not working and should I be working... or am I just lazy and using it as an excuse to not work?

This suggests that there may be two layers to the guilt, one being that she "should" be working despite not feeling able to, while the second leads to her questioning whether she is in fact just lazy and using it as an "excuse". There may be some judgements that she is making about herself considering the expectations that she has of herself, but also the expectations that society has based on productivity. Emma seems to be struggling to know how to gauge the severity of what she is experiencing and feeling uncertain about who she is and her values. One way to interpret this quote is that her questioning comes across as tentative. It may be that she is not looking for an answer in herself but that she is seeking some external reassurance to justify her choices.

Lisa also wrote about how she doubts how real her experience is when she is feeling better. This suggests that when she is in the midst of the luteal phase, Lisa struggles to hold onto her diagnosis and what she knows about her PMDD, instead making sense of how different she feels by wondering if she is making it up.

> *...today I feel ok-ish and it's makes me feel like sometimes I'm making it up.*

Feeling differently on one day seems to lead to her questioning her whole experience, suggesting that it feels impossible to hold onto anything outside of her immediate experience during the luteal phase. This relates to another group experiential theme, 'The impossible battle' which explores the participants' experience of feeling powerless when faced with the changes that PMDD bring. This theme is discussed in more detail later in this chapter.

This idea of "making it up" is again shared by Josie, who describes the freedom she felt when she went through treatment that took away her PMDD symptoms and gave her a sense of hope that it might not return. She goes on to say how she also thought that she made it up and that maybe she never had it.

> *There was a period of time where when I finished my chemical menopause last time I was like, oh, maybe it won't come back! Maybe it won't come back. And I was like, maybe I made it up, maybe I didn't have it ever.*

This suggests that having this distance from her symptoms makes it difficult to imagine how real her symptoms were prior to treatment. This seems to lead to Josie doubting whether it was ever real. Initially I wondered if Josie was suggesting that she made it up in a self-blaming way, that she was making a problem out of nothing. An alternative way to interpret this is that Josie may have felt hopeful at this point; almost wishing that she had made it up so that she did not have to experience it again. In both interpretations Josie seems to find it hard to believe that what she had experienced was real when she was no longer experiencing it, highlighting again how challenging PMDD is to live with as the symptoms come and go.

Nathalie described a similar experience of questioning herself:

And I wouldn't even know where to begin, trying to get a disability for this, and to be honest I don't think I could advocate for myself because in the second, in the good part of my month I sometimes look back and think "well what was the problem?". I even underestimate my, you know I even play it down and think "well why on earth can't you pull yourself together and..." you know? So I don't always even take myself seriously (laughs). Um... it's so hard to explain to people. And as I say in the good part, I feel like a different person so... I even look back and think well, why can't you just do this or why can't you do better at this or try harder at this or whatever.

There is a sense that Nathalie does not even take herself seriously so she cannot expect other people to either. This quote seems to demonstrate how difficult it is for Nathalie to believe in her experience of PMDD, despite having a diagnosis of PMDD and understanding the biological mechanisms underlying the condition. This leads to her being self-critical and questioning why she could not "do better".

Eleanor shares a similar experience saying that she just needs "to like have a better outlook":

I still struggle like I I I I can see it every month umm... The symptoms are still there, I just need to like have a better outlook (laughs) I don't know maybe.

This suggests that on some level Eleanor may believe that she holds the responsibility for things to feel better or easier and that if she were to see things differently then she would be able to cope better. She laughs as she says this, as if she thinks that this suggestion is ridiculous, and then says "I don't know maybe" as if there is a part of her that recognises it is ridiculous but another part of her that thinks it is true. Eleanor

describes seeing “it every month” and “the symptoms are still there”; this suggests that she may be viewing her PMDD from the outside and that it feels separate to her. When reading this I pick up on an underlying feeling of self-criticism and failure in Eleanor’s description. It may be that she believes that she should not allow herself to be so affected by this ‘thing’ and that she should be able to resist it.

Lisa shared similar feelings about herself:

> *I cried to my partner and told him I felt pathetic for not being able to work today. He hugged me and told me it was fine but nothing has made me feel better. I feel like a failure for finding it too much.*

She wrote how she felt “pathetic”, which suggests that she may feel weak and ashamed for not being able to work. Lisa describes how her partner offered support and reassurance but “nothing has made [her] feel better”. Lisa shared that the feeling of failure is related to finding it overwhelming and not being able to cope better with what she is going through. This suggests that she feels that she should be able to cope with life differently to what she is doing and that it feels difficult to accept how hard it is without the thoughts of failure and self-criticism taking over.

GET 2: PMDD and relationships: Unheard, dismissed and judged

This theme explores the participants’ relationships with others, and the interaction between the external world and their experience of living with PMDD. Relationships came up in the diaries and interviews in different ways however this theme focuses on the challenges that came about as part of those relationships.

This theme is split into two sub-themes that each explore different relationships that the participants spoke about. The first sub-theme ‘Met with ignorance not understanding’ describes how participants experienced their interactions with healthcare professionals as unhelpful and dismissive. Participants shared how they did not receive adequate support and guidance and found that professionals did not always understand what

PMDD was. The second sub-theme ‘Judged and misunderstood’’ describes how participants experienced relationships with friends, family and peers. Several participants shared similar experiences of feeling judged or pressured by others and spoke about the impact this had on them.

2.1 Met with ignorance not understanding

Several participants shared how their experience of care from health professionals was disappointing; they didn’t feel listened to and the help that was available felt useless and irrelevant. This sub-theme explores that relationship, one where it often took a long time to be listened to. When the participants reached out for help, they were met by medical professionals using incorrect language and offering little guidance.

Lisa describes how she reached out for help from the doctor when she was struggling every month and there was no information.

> *I'd called the doctors and said it was getting really bad, and I was really struggling with my mood every month and they didn't say a lot. They said, here you can try some birth control and, and I'm already on the implant and they gave me the pill and I just, they gave me no information. Um so that wasn't a very nice experience...*

Lisa may have felt dismissed by the doctor as they were suggesting generic treatment options and did not appear to be considering her individual situation. Lisa goes onto say it “wasn’t a very nice experience...” which seems to downplay it somewhat. This quote suggests that she may have felt dismissed, ignored and unsupported at a time when she was “really struggling” and asking for help.

Nathalie had seen a close family member go through a similar experience and knew that she needed help. After doing her own research she went to the doctor but was not taken seriously.

I first went to my GP uum I think I must have been about 18, so it was really quite early on and said something's wrong here, and he did not take it seriously he... I mean he didn't even give it a name really to be honest, I mean they just said it was PMT.

Nathalie says he "didn't even give it a name" and then goes onto say "they just said it was PMT". In a sense the doctor is naming her experience but doing so incorrectly and, it seems, without much exploration and thought. It seems that Nathalie may have felt dismissed by the doctor which highlights how important correct terminology is.

When Nathalie eventually did get diagnosed and was offered treatment there was still a lot of uncertainty about what worked and what did not.

Then, I was treated with the progesterone only injection, again three months of wanting to die (laughs)... and it was me that again said to them [the GP] look, I think I'm sensitive to progesterone, this is not helping.

She repeats the word 'again', suggesting that she felt somewhat resigned to the repetition of this process of her feeling worse and not being given constructive support. Nathalie laughs after saying "three months of wanting to die". Her laughter seems to highlight how ridiculous and extreme her experience was and its repetitive nature. This description of her experience suggests that she may have felt frustrated with not getting anywhere and not being listened to the first time. It needed to get so bad that she wanted to die before they heard what she was saying.

Josie described a somewhat similar experience of her treatment for PMDD being "trial and error".

The GP has been relatively proactive, she tried a few things um, I think the whole treatment plan for PMDD is just trial and error and a

> *bit crap. Um... the local gynaecologist was quite a horrific experience um... they use chemical menopause as a diagnostic tool which then makes their mindset in a way that "oh all we want to know is, is she still having PMDD symptoms or not, we don't care what else happens to this girl who's going through chemical menopause".*

Josie echoes other participants' experiences of there not being a clear treatment plan and doctors taking a symptom focused approach. This may have made Josie feel that there was a lack of care and that they did not see her as a whole person who needed support but as a problem to solve.

Eleanor shared her own attempt to get help from her GP. She felt he was quick to dismiss her concerns as stress.

> *I tried to go to the GP and in this particular like occasion like this, doctor was very mean (laughs). Like I I I even went there crying saying I don't know what's happening, like I feel, like help me like this is not, it's not OK and there's something wrong in my head and he said like "you're just stressed". He sent me links of uuh meditation (laughs).*

One interpretation of this quote is that Eleanor is desperate for help here, describing how she "even went there crying" as if she expected a different reaction because of that. Eleanor laughs at two different points while telling this story, both after describing how the doctor behaved towards her. This makes me wonder how it felt for her to be treated this way when she made herself so vulnerable. It may be that laughter helps to keep some distance from the upsetting feelings she had in response to this doctor. An alternative interpretation may be that she laughs at these points because of how absurd it seems to her that he would behave in this way.

In Nina's instance she shared how her mother was the one who was doing a lot of research and speaking to the doctors in the beginning, likely due to Nina's young age.

> *I remember my mom thinking she went, remem- she had the conversation that she thought uuh that maybe I might be bipolar just because, but then she, cos she did so so much research into bipolar, thinking that- but then she realised you don't go from that extreme, the episodes were too short. And then spoke to the GP, who just kind of brushed it off and just said "Ohh no, it's just teenage anxiety, it'll be fine".*

The GP refused to take her mother seriously and dismissed it as "just teenage anxiety". Similar to other participants' experiences, the doctor seems to minimise what Nina is going through. In this scenario the GP is attributing it to the life stage she is in rather than acknowledging the severity of her concerns. This may have led to Nina questioning whether her symptoms were "real" or whether she was overreacting to something that she should be able to manage better.

Danielle had a different initial experience of going to the doctor to the other participants and acknowledged this as her being "incredibly lucky".

> *I've been incredibly lucky with my PMDD journey. Like I went to the doctors because I'd been putting off going to the doctor's um and I had, I don't know if this is why, but I had a young female doctor and and she immediately went "it sounds like PMDD". And I know that that's not the case from everybody.*

She mentions that her doctor was young and female as a possible explanation for why she was able to identify it so quickly. Danielle acknowledges how this is not the case for everybody, highlighting how rare her experience is. This initial experience may have changed how she made sense of her PMDD and helped her to believe in the reality of

her experience in a way that other participants struggled to do. Danielle did not express the same experience of self-blame as other participants in this study.

2.2 Judged and misunderstood

This sub-theme explores the participants' experiences with people in their lives, with a specific focus on other people's expectations of them and the judgements and assumptions that people make about them and their condition. Participants shared feelings of guilt and shame for what they went through during the luteal phase and spoke about what it felt like for people to see them struggling.

Lisa describes the shame that she feels after taking time off work during the luteal phase:

> *So then I will kind of go back to work and I feel... (sigh) a little bit of kind of shame that I've gone through that and that I've- that people have had to see me that way. Uum like I feel, not embarrassment just, I think shame is probably the right word. Yeah, just that people have observed me just without that control uum.*

She specifies that it is shame she feels rather than embarrassment, which suggests that she thinks or feels like she has done something wrong. Shame feels deeper than embarrassment and more personal. It may be that it feels like she has lost the respect of those people who have seen her struggling. Lisa goes on to say that she feels ashamed of people observing her "without that control" suggesting that she may be worried about how people perceive her based on this; that she is doing something wrong by needing to take time off work and not being in control of her feelings and behaviours, and that this says something negative about her as a person and her character. Lisa does not reference anything specific that people say or do towards her so there may be some internal judgement taking place here and internalisation of societal expectations of what is acceptable or not. Struggling during the luteal phase

becomes her losing control, rather than Lisa experiencing a difficult time due to her condition.

Emma shared a similarly difficult experience of taking time off work while she is in the luteal phase, describing how she feels guilty about it:

> *I just feel guilty and there's all like stigma around not working and not wanting to be a woman having issues with her cycle.*

In addition to experiencing personal guilt about taking time off work, she speaks about the stigma in society about not working. The way that Emma describes "a woman having issues with her cycle" suggests this is an identity or a role that people are familiar with and judgemental of. I may interpret this "woman" as someone she does not want to be associated with, perhaps there is a risk of being ostracised by society for not fulfilling her obligations as a working woman if she is seen in this way. Not only does she struggle with how she is feeling in herself, but there are also worries and fears she experiences in relation to how other people view her.

Nina described how other people misunderstood what she was experiencing while at college and the judgements that came because of that:

> *...it was kind of like a lot of my friends, they just they didn't- I- it affects a lot of my relationships in high school because they all just kind of thought I'm a bit– you- kind of weird, I'd say, and I'm a bit unstable.*

She describes how her friends saw her as "weird" and "unstable" which suggests that Nina may have thought that people saw her as different, and unpredictable. This may have led to Nina feeling isolated and misunderstood by others which then meant her friendships changed. Nina was unaware of what was making her feel and act differently at this time and her peers were the same. Nina did not explicitly describe how the

relationships changed but one interpretation of this change could be that they distanced themselves from her because they did not understand what was happening.

Nina goes on to describe how family members reacted to her diagnosis of PMDD and her subsequent decision to go through chemical menopause:

> *I remember my mum speaking to some of my aunts and she was like they just pretended they didn't hear it because it's like they just why on earth has that happened, it can't be that bad or they say, oh, we all get our period, it's not that bad.*

In this instance, Nina's family are being told directly about what she is going through, and their response is to pretend to not hear it or dismiss it as something that everyone goes through. This experience gives an indication of some people's views of women's health problems and the possible impact that this may have on women who are struggling. Elsewhere in her interview Nina spoke about how supportive her very close family members were, and it may be that this support acted as a protective factor and helped Nina to stand her ground when faced with these comments. Hearing "it's not that bad" may have felt dismissive of Nina's experience and led to Nina feeling the need to be more secretive about her experience. Nina spoke about how she was selective in who she talked to about her PMDD and that having a diagnosis helped her to do so in a way that felt comfortable for her, by referring to it as a "hormonal disorder".

Another participant, Nathalie, shared how she had tried to speak to friends about her experiences but was met with resistance:

> *I've explained to my friends, and they just look a bit glazed and hope that you don't talk about it most of the time.*

It is unclear whether Nathalie's friends explicitly say that they do not want her to talk about her PMDD, but there is something about their glazed looks and demeanour that

leaves Nathalie feeling unsupported. They seem to be disconnecting and pulling away from her when she opens up to them. I imagine this may leave Nathalie feeling quite vulnerable and lead to her distancing herself from others as she loses trust in their support.

In her diary Nathalie shared an interaction with her husband during the luteal phase when he makes a mess at home repairing something.

> *I'm crying uncontrollably now. I think he looks angrily at me. PMDD time is not a good time for him to choose to do this, why doesn't he see that?!*

Nathalie seems to be expressing frustration at what he is doing and at the fact that he cannot see that this is a bad time. It may be that she feels that he does not understand her needs and that he is judging her for crying. She describes how she thinks he looks angrily at her, indicating that she may understand that this is her own interpretation of what is happening but there is still a sense that he does not fully understand her needs at this time.

Danielle shared her experience of navigating how people speak about PMDD as her mum referred to what she was experiencing as “a wobbly”.

> *And I said I need you to stop saying it's a wobbly because a wobbly suggests there’s negative connotations here. Like I have PMDD, I'm going to struggle occasionally and it's not a wobble.*

She describes it as having negative connotations and that this suggests there is something wrong or bad about her struggling, similar to the shame and guilt that other participants described experiencing in relation to other people’s views of their experience. Danielle shares how she was able to express this to her mum and clarify the distinction between a “wobble” and her having PMDD. This suggests that she may

feel able to separate other people's judgements from her own feelings and thoughts about her PMDD.

Eleanor's description of people sharing their opinions on how to manage suggests that she did not find it helpful and that it felt dismissive.

> *Um, even even even like people said like, oh, you know already what is gonna happen, you just don't book things like important in those weeks... I don't know, but yeah, it's not as simple. Basically, it's not as simple.*

She repeats "it's not as simple", emphasising this point and how the oversimplification of people's suggestions misses a lot of the complexity of her experience but also the impact of what this change to her life would mean. This may suggest a feeling that her experience is not being fully understood or that she should be dealing with it differently.

GET 3: An impossible battle

This theme encompasses the ideas of struggle and loss that make up the participants day to day experiences of living with PMDD. Participants described similar experiences of feeling powerless in the face of their PMDD symptoms and the exhaustion and frustration they felt as they attempted to navigate their symptoms.

This theme is broken down into four sub-themes which explore different aspects of this theme focusing on the battle that these women face each month. The first sub-theme, 'The moment it all changes', explores how participants experience the sudden shift between the two phases of their cycle. Some of the women described a feeling of symptoms building and building to suddenly then overwhelm them, pulling them down into the depths of the luteal phase. The second sub-theme, 'The fight is exhausting', describes the tiring experience of keeping up a fight against PMDD while they try to keep the symptoms at bay and hold onto a sense of normality. The third sub-theme "Powerless to escape it' focuses on exploring the feeling of powerlessness that

participants described and this idea that they are unable to escape what is happening to them. They feel forced to surrender to their PMDD and describe feeling more sensitive to things going on around them and unable to change how they feel. The final sub-theme 'Loss of the self: "It's like I'm not here"' describes the participants' shared experience of losing themselves during the luteal phase of the month. Several of the women who took part described how they felt like a different person at this time of the month and that there was a sense that they lost themselves and returned to themselves as their periods started. This sub-theme also incorporates an element of losing control which is evident through this GET; the women shared how they lost control of themselves and were taken over by something else.

3.1 The moment it changes

This sub-theme explores how participants experience the moment when PMDD descends upon them.

In her diary, Nathalie describes the changes in her mood during the luteal phase, leading to a sudden change in how she feels about her surroundings at home.

> *All of a sudden the chaos around my whole house since the renovation feels like a crushing weight. I have so many jobs to do and I just don't know how to handle all this. It's too much. I don't know where to start and I feel so alone despite people all around me.*

The chaos around the house is not new so this change in how she is feeling may represent a sudden inability to tolerate these things, as well as a feeling of being unable to control or manage how she is feeling in that moment. Nathalie's description of the chaos in her house as feeling like "a crushing weight" suggests that it may feel so overwhelmingly heavy that it could hurt or damage her somehow.

Eleanor references an entry in her diary where she describes having an "outburst":

> *... I shouted at someone just because it's just like an outburst, it just, I don't know how to call it, it's just like an explosion like, AH! Like you just get mad about stupid stuff and and you just hurt people you like and you love and... I, I, I always des- describe it as I feel, especially during those weeks, I feel like there's something like building up like uhh like restlessness, something like that.*

She describes the changing moment as being "an explosion like, AH!" which suggests that Eleanor may feel out of control in that moment. Everything comes out at once and with a great deal of force. Eleanor speaks about how there is a feeling of restlessness building up in the preceding weeks which suggests that she can sense it coming before it all boils over and overwhelms her. This description of her experience evokes a real sense of feeling it physically in her body; the restlessness suggests a feeling of physical anxiety perhaps, shakiness, and a nervous energy that needs to be released. This then provides fuel for the fire and gets to the point where she cannot keep it together and the explosion happens, and no one is safe from it as she says, "you just hurt people you like and you love".

Lisa wrote in her diary that "the fog is starting to get" her:

> *It feels like the fog is starting to get me know and I don't want to feel like this. At the start I don't know if I'm just upset or in a mood for a real reason but the longer it lasts I know it's the PMDD and I shouldn't have to feel like this but I do.*

This description of Lisa's PMDD creates quite a sinister image. There is something insidious and intangible about fog; it creeps in, you cannot stop it, and it impairs visibility and perspective. Being stuck in fog can be a dangerous experience and this may give some indication of Lisa's experience that she is describing here. Lisa may feel scared of it, that she will get lost in it and not be able to see outside of her own internal experience. She describes being unsure about whether she is upset for a "real reason" suggesting

that she does not see her PMDD as a real reason. I wonder if this relates to the feeling of not being able to do anything about it, while she may be able to act to change how she is feeling if it is a "real reason". If it is the PMDD then she is being forced to feel something that she does not want to feel and should not have to feel.

Emma describes the moment things change for her by using an evocative metaphor:

> *I'm in a boat on top of it and I can feel that there's like this shark below the water... and it just, completely came, comes over me and I'm like, ugh, ok, I'm in it.*

The shark below the water might suggest a feeling of a threat lurking below the surface; I imagine the shark circling the boat just waiting for the moment to strike. The way that Emma speaks about being "in a boat on top of it" recalls an image of Emma in a small boat on a vast sea, small and vulnerable, surrounded by nothing for miles. The moment that it changes, and she is "in it" is sudden. She can see it coming as she knows the shark is there below the water, and then it comes over her, like a wave that sweeps over and takes her down into the water. The "ugh, ok, I'm in it" suggests a sense of resignation, like there is no doubt about it and it is now a matter of just getting through it.

3.2 The fight is exhausting

This sub-theme explores the exhausting and frustrating experience of dealing with PMDD each month. About half of the participants spoke about a similar feeling of fighting against the symptoms and the exhaustion that they experienced as a result.

Lisa speaks about the "mental effort" it takes to try to "hold on". She does not specify what it is she is trying to hold onto, but my interpretation is that she is trying to hold onto normality or a feeling of being herself.

> *I think it's the effort, I think it's the mental effort of just, yeah. Like I'm just trying to hold on, but something's like pulling me.*

She describes how it feels like “something’s like pulling me”, suggesting that PMDD is pulling her into the luteal phase and that there is a physical aspect to it. She speaks about the mental effort but there is a real feeling of physical and mental exhaustion in this description.

Later in the interview, Lisa shared more about how it felt for her to be in the luteal phase:

> *I stop walking and I'm just kind of like... I don't know there's nothing, there's, there's nothing to walk for, there's nothing to be here for. It's just too much. It's too big. It's too overwhelming. And I can't, yeah, can't literally put one foot in front of the other.*

Lisa describes physically stopping in her tracks when it feels “too much”. As she says “there’s nothing to walk for, there’s nothing to be here for” this brings to mind a sense that she has lost all motivation to keep going and that she is powerless to keep moving forward physically and psychologically. One interpretation of this is that she is frozen in place, and it is as if she is looking ahead of her and seeing her PMDD as an insurmountable mountain that is “too just much... too big... too overwhelming”. This is a powerful image that portrays the overwhelming powerlessness that Lisa faces when just trying to get through her day during the luteal phase.

Danielle described her experience of how tired she felt all the time and the repetitive cycle of feelings mirrored in her repetition of “month after month after month”.

> *I was tired all the time. I- and I think it was making me more tired doing it month after month after month because you'd be so low for five days and then you'd feel guilty because you'd have to cancel plans and you'd have to- Then you drag yourself out of the hole to then... well, straight after that you'd have your period.*

This suggests that there was no opportunity for recovery at all. Danielle says, “you drag yourself out of the hole”, which suggests that it takes an immense effort to keep going and pick herself up after feeling low during the luteal phase. As with Lisa’s experience there is a very physical element to this description, which speaks to this as an embodied experience.

Later in the interview Danielle spoke about this pattern again and the idea of dragging herself out to “begin to feel normal”. She speaks in a more generalised way at this point, saying “you” and then swaps to her personal experience. This gives a sense of being closer to the true experience and focuses in on her specific experience when she was so tired that she thought “I don’t know if I’ve got the energy to do this again”.

> *And to do that consistently every month and you drag yourself out, you begin to feel normal and then it's, I feel like shit again. And you can't- I just got so tired that the last time, I remember getting in the shower saying I don't know if I've got the energy to do this again. And as soon as that worrying thought came in and like, I was like, I can't. I cannot think like that.*

Thinking “I cannot think like that” was a turning point for her in seeking help and making changes to how she was living her life. It suggests that the exhaustion may have been at the point where she did not want to keep going which scared her.

Emma shared this experience of tiredness and exhaustion, writing in her diary during the luteal phase:

> *I am exhausted, and it is just exhausting and frustrating to think and feel that way all the time.*

Like other participants Emma describes feeling exhausted in that moment, and how exhausting and frustrating the relentless nature of living with PMDD is, as she thinks and feels “that way all the time”. This suggests that there may be different layers to the exhaustion that she is experiencing, both in the moment but also a continuous experience that never seems to end. When Emma writes “I am exhausted” it suggests that she is very tired but also, if we look at the other use of the word, it can mean that she feels like all her resources are used up. There is a sense that it feels exhausting and frustrating to think in this way for Emma as it is unnatural, that it is not how she wants to be feeling.

Nathalie spoke about a different type of overwhelm and exhaustion to others but one that evokes a similar experience being overwhelmed and trying to push against the symptoms of PMDD.

> *Feeling wired with energy again today but can't seem to focus...*
> *Feeling overwhelmed. Work until exhaustion and beyond.*

Nathalie describes “feeling wired” and struggling to focus which suggests that the symptoms of PMDD are building. Writing “work until exhaustion and beyond” suggests that she was pushing herself to keep going despite feeling overwhelmed and not able to focus and it takes her to a place where she so tired that she goes past exhaustion. She works herself into the ground trying to keep going despite the impact of the PMDD.

3.3 Powerless to escape it

This idea of feeling resigned and getting through it is explored in more detail in this sub-theme which focuses on how the participants feel powerless in the face of PMDD. Several participants shared experiences of feeling unable to stop what they were feeling and thinking related to their PMDD.

Eleanor expressed a desire to stop what she is doing:

I wish I could stop this. It is depressing to have tried for so many years and still, I keep doing it.

Initially I thought that Eleanor may be contradicting herself by referring to her PMDD when she said, “I wish I could stop this” and viewing it as something that was happening to her that she wanted to stop, while then later saying that it was something she was doing, “I keep doing it”. My interpretation was it may have felt confusing to know how much control she had over her PMDD. However, on reflection, I wonder if she does view it as if she is fully doing this to herself, particularly when she is in the luteal phase. She may feel responsible for feeling and thinking this way and powerless to make any changes to it as she has “tried for so many years”.

Lisa spoke specifically about not being able to escape her feelings, suggesting that she feels powerless to stop them:

Um I think when I'm in those feelings, it's just kind of... (sigh) like there's no escape to experiencing it, it's just, it's almost just on repeat in my head.

This suggests that it may feel like she has been taken over by these feelings and she is being forced to listen over and over as they are on repeat in her head. The way she describes this experience as being “in those feelings”, suggests to me that the feelings are so all consuming that they are not only felt internally and but that she feels surrounded by them, as if she enters the feelings and cannot leave.

Lisa spoke in her interview about a moment where she describes a sudden feeling of sadness coming up and that she “couldn’t hold it in”.

I suddenly just felt it all kind of come up and it was like I couldn’t hold it in and it was just sadness and it was loud in my head. And it was like, yeah, just really loud like, again I think I wrote this in my

diary, it's like having loads of TV's on. Like I've got so many thoughts and so much is going on in there like I can't even really hear any of it, but it's really loud.

Lisa's description of how she "felt it [the sadness] all kind of come up" suggests that it has been lying under the surface, and she has been able to keep hold of it until this point where it came up without warning. She uses a metaphor of loads of TVs being on to communicate how loud it is. This evokes a strong image and gives a sense of how overwhelming the experience is but also how isolated she is in it. No one else has insight into what is going on for her as it is internal.

In her interview, Emma used a metaphor of feeling like a "kite off in a hurricane" to describe her experience of being in the luteal phase.

I'm just sort of like a kite off in a hurricane and I can't grab onto anything and just can't ground myself again.

This metaphor suggests a feeling of being flimsy and light in a storm, giving Emma no chance to gain control as she is completely at the mercy of the winds. My interpretation of this is she that she feels at the mercy of her PMDD and feels powerless to do anything to help herself in the moment. When she says "I can't grab onto anything" I imagine that she feels like she is flying by things that might help. Initially I thought that she may be able to see things that she wants to grab onto but not feel strong enough to hold on, however when I reflected on this, I thought it may be impossible to do that in a hurricane. Instead, I wonder if she feels so overwhelmed by her PMDD that the world around her is blurry, and she cannot see anything around her, all she can focus on is where she is in that moment, amid her PMDD.

Nathalie's description of her experience presents a certain level of acceptance or a feeling of being resigned to what needs to happen.

It just has to, it has to play out and I have to do the time so to speak..

Saying “it has to play out” suggests that she may feel powerless to change what is happening to her. Her choice of the words “I have to do the time” suggests the idea of doing time in prison and emphasises a feeling of being imprisoned, trapped and powerless to do anything. There is no escape, and she feels forced to live through something that she has not chosen and cannot change.

Later in the interview Nathalie spoke about the likelihood that her daughters have PMDD when they get older and how she wished she could save them:

...I'm just sort of on tenterhooks waiting really to... I wish I could save them from it to be honest.

All she can do is wait and see. The way that she describes this process of waiting as being “sort of on tenterhooks” suggests that she feels agitated about the uncertainty of not knowing what is coming but also the danger that her children may be facing. She wishes she could “save” them from it, which suggests a desire to rescue them from something terrible that may be about to happen to them. Sadly, she knows that she cannot, and she is powerless to do anything but wait. This suggests that she may feel frustration or sadness about being in this situation and watching helplessly as to see what happens for her daughters.

Josie described a similar feeling of powerlessness and as if someone else was in control of her PMDD. This is in relation to her partner not fully understanding how out of control she feels when she is the luteal phase.

Where like if someone had anger and actually, I think they might be able to stop themselves first, with PMDD it's almost like it's someone else in there controlling the strength sort of thing.

This suggests that Josie may feel like she has no chance to change anything for herself because it feels like someone else is in charge during her luteal phase. Josie may feel like she does not have a say and she is at the mercy of someone else (PMDD).

3.4 Loss of the self

This sub-theme explores hoe the powerlessness and exhaustion of the daily battle of living with PMDD leads to losing the self. Most of the participants described a sense of feeling like a different person, that there were two versions of them and that they were not themselves during the luteal phase. Emma and Nathalie both used the same specific reference, describing how they experience the switch between the two versions of them as being like Jekyll and Hyde.

Emma describes this here:

> *Um super social throughout that whole time, building up to ovulation and things and just cracking on, getting on, lots of energy, both with work and things outside of work, and helping friends and seeing friends and booking in seeing friends when, when the other half I just don't want to do that at all. So it's kinda like Jekyll and Hyde it feels like...*

Nathalie describes how she becomes a different person:

> *Ok so um I'm pretty regular and from day 1-14 I'm good tempered, good natured, you know, fairly positive, fairly good mum, I'm active and busy and um... everything's normal. And then I ovulate day 14 usually, I can feel that so I know I do, I get like sort of pain um... and then yeah it's like, I call it my Jekyll and Hyde (laughs) I just become a different person.*

Neither of them explicitly describes this other version of them as evil, but the comparison to Jekyll and Hyde suggests that their experience is that one version of them is good and one version of them is bad. In the story of Dr Jekyll and Mr Hyde, Dr Jekyll is a scientist who transforms himself into his evil alter ego, Mr Hyde, to experiment with being a character that shows no remorse for his actions. Dr Jekyll is initially able to control this other part of him but ultimately Mr Hyde takes over and they both die. The use of this reference suggests that there may be a feeling that the version of themselves that they are during the luteal phase is someone they have created who behaves in ways they never would and that who they are during that period is in conflict with how they view themselves otherwise. There may also be a fear or a feeling that here is a risk that they will lose themselves completely and PMDD will take over completely.

Eleanor struggles to explain how she experiences the loss of herself but describes it as feeling like she is “not there”. It may feel like she has disappeared, or to be more specific, the version of herself that she recognises and knows has disappeared.

> *It's just like I'm not, it's like I'm not there, I don't know how to explain it, it's just very very weird.*

This experience feels uncanny, it is a bit eerie and odd, and this is reflected in how she struggles to describe it. She says, “I don’t know to explain it” before describing the experience as “weird”. This suggests that she does not understand what she is experiencing in those moments, and it feels confusing. There is a dissociative element to this description, she is aware of how she is not connected to herself in this moment.

Several participants spoke about the feeling of coming back to themselves and noticing how they can function again. This return to the self highlights the difference between these two versions and everything that they lose during the luteal phase of the month. I wonder if it feels easier to speak about how they feel when they are themselves rather

than put words to how it feels when they are the other version. It may be that they are unable to see outside their experience in the moment when things are bad.

Josie spoke about coming back into the real world and the changes that brings for her:

> *... so the main thing I guess that impacts me a lot for the moment is brain fog, so coming into, back into the real world sort of being able to, my brain to work, um, being able to... to talk to people, not get angry and just... it's just a completely different world and it feels like you're a different person.*

Not only does she describe feeling like a different person, but she also describes the world as "completely different". This suggests that how she interacts with the world changes and that she notices a difference in how she responds to external factors. This may amplify thoughts and feelings that she has depending on where she is in the month and suggests that she does not feel able to change that of her own free will. Her description of the "real world" suggests that there is a feeling of not only two versions of her but also two versions of the world, one in which she is real, the world is real, her life is real, and the other world, which is false, perhaps implying that the self that is there is false as well and her life there is false. There is a rejection of this other self who does not function as she wants to.

Lisa shared how different she felt in each part of her cycle by comparing how she felt at the time of the interview to her at her "worst":

> *I feel normal now and I don't feel myself when I'm at my worst. It doesn't really feel like me.*

This suggests a feeling of conflict between who she is when she feels like herself and who she is the rest of the time. This is likely to be an unsettling experience for her. There is some ambiguity about what she means by saying "when I'm at my worst"; it

may be that this refers to her being her worst self or at her worst with her PMDD. Lisa refers to how she feels “normal” which suggests that she feels like herself, and the way that she expects to feel. This idea of “me” is interesting, as it relates to the idea of identity and the idea that there is one version of the self that is correct and acceptable. By splitting the self, participants seem to be able to reconcile themselves with the idea that they are not the problem and that there is distance between their two selves. There seems to be an element of this that feels like it is forced upon them while also a part of it that feels like they are reinforcing this separation to make sense of the extreme changes they experience.

Nina also refers to feeling normal again after treatment and how other people noticed the change:

> *...once I kind of got stabled on the chemical menopause, it was just, even all my teachers, they saw the impact it was having, how in college I came back to this normal smiley person before the whole incident I was in hospital and my friends just saw it, how I was more like smiley and just more myself.*

The change was so stark that “even” her teachers saw the impact of her being in chemical menopause. Nina describes how she goes back to being “smiley” which suggests that she felt happier and more at ease with expressing this to others.

Danielle focused on sharing the joy that she feels when she comes back to herself at the end of the luteal phase:

> *I just feel like I can do anything, it's lovely to be frank. So we had a date night last night and I was like, oh, it’s me! I'm back.*

The way that Danielle says, “oh it’s me!” suggests that she is almost taken by surprise by her return, like she’s saying, “oh there you are, where have you been?” The way she

says “I’m back” suggests that it feels like she went away somewhere, like she left the world briefly and has now returned. She is back in life and is ready to live again, to do things again, to be in her relationship again and enjoy herself. This may suggest that during the luteal phase, she does not feel present in life and is unable to engage with life in the way that she wants to.

GET 4: Getting through it: Ways to manage

This theme explores the different ways that participants manage the physical, emotional and behavioural challenges that arise from living with PMDD. Some of the participants spoke about how they relied on support from other people to help them feel less alone, while they also spoke about choosing to pull away from people at certain times of the month when things felt too much. There is both convergence and divergence within this theme, and I have chosen to split it into three sub-themes, each of which explores a different way that the participants manage.

The first sub-theme, ‘Coping through connection’, explores how participants connect with other people in their lives and find solace in sharing similar experiences. The second sub-theme, ‘Withdrawn from the world’, describes how participants avoid other people and distance themselves both emotionally and physically. The third sub-theme, ‘A state of resolution’, is a smaller sub-theme that describes the experience of two of the participants regarding how they manage their PMDD. Despite this not being relevant for more of the participants, it felt important to include their experiences here. They shared how they reached a place of acceptance with their PMDD and spoke about integrating the PMDD into their lives.

4.1 Coping through connection

This theme explores the strength and power of relationships in people’s lives. The way that the participants speak about these relationships suggest that they have a profound impact on their experience and can stop things getting worse, to change the outcome and offer comfort and reassurance that they are not alone and not “weird”. When they

are feeling powerless against PMDD, they can look to others to feel powerful and able to cope.

Emma describes how a small act, like reading about someone else having a similar experience can evoke a resounding sense of understanding and connection:

> *Whether that's just reading someone else's experience of it and going "oh myyy god, yes, yes, thank you, yes, that resonates".*

Her joy at hearing a similar experience is palpable in this quote. The way that she says, "thank you" suggests that she is grateful for being able to connect with the community in this way. By saying that it resonates with her, it suggests that what she read is meaningful and feels true to her. It is like she has struck gold, finding this in that moment and it is a bit of a 'hallelujah' moment.

Other participants shared similar experiences of connecting with other members of the PMDD community in these ways. Danielle spoke about how joining online support groups initially helped her to feel seen after she was diagnosed.

> *I think they definitely have their place and for sure when I first got diagnosed, they were a salvation in, Oh my God, like, I'm not weird like this- I felt seen. I felt like ohh like this is, I'm ok.*

She describes the groups as a "salvation", suggesting that they saved her from harm. She goes on to say, "I'm not weird" and "I'm ok", as if the groups helped her to realise this, that she was not alone and there was not something wrong with her as a person. Although Danielle does not specifically reference any religious meaning here, one way to interpret the use of the word salvation and her use of "oh my God" could be that this felt like a religious experience for her. Salvation means "the deliverance from the power and effects of sin". This could be understood as her having been saved and protected from something dangerous and scary.

Josie shared a similarly powerful experience of the support groups:

> *Because I think with PMDD, because a lot of it's mental you question yourself, you start gaslighting yourself and that in itself makes things worse. I think having someone else going "Oh no, I feel like that as well" ... some of these people like really read up on it that supports like amazing just to understand that you're not going crazy and it can stop you really spiralling and it just it's someone there to just sort of speak to, who understands what you're going through. So, it's it's really invaluable even it's just a simple, "Yeah, me too" sort of thing.*

Josie describes how the support helps her to make sense of her experience, repeating this fear or belief that we have seen in other themes that she is crazy. The significance of this support for Josie is clear as "it can stop you really spiralling". What she describes as a "simple 'Yeah, me too'", can change her perspective on what she is going through, making it more manageable and stopping it in its tracks. There may also be something about appreciating the effort that these people put into reading up on it and understanding what PMDD is and what they are all experiencing, not just because they are going through it too but because they are experts on the topic. This is in stark contrast to the majority of these women's experiences with the healthcare system and suggests that having this experience of encountering experts who know what they are talking about can make a positive difference to how Josie feels about her struggles in PMDD.

Nathalie also shared that it helped her to know that she is not alone in her experience and resorted to doing her own research to find and connect with this community.

> *Researching it, researching. I did a lot of research into PMDD and that helped, um... so, I know I'm not alone. I follow you know, a few*

things on Facebook and Instagram so that helps to feel less alone as well.

This suggests that there is something meaningful about knowing that she is not the only one experiencing this. It may be that this helps her to better understand what she is going through as she sees her own experiences reflected in other people's.

Other participants described how the understanding and support from friends and family made all the difference when they were struggling. Nina describes how the support from people in her life led to her being successful at college despite her illness and absences. This suggests that for Nina, this support was integral to being able to cope with her PMDD journey and that she could not have done it alone.

...knowing that if I didn't have the support from teachers and really close friends and really close family as well as that amazing consultant, it wouldn't have been kind of like the same outcome.

Lisa spoke about a more specific example of how her close family member offered support:

And I've felt so much guilt for not being able to do those things that she kind of reminds me that it's ok like, you don't have to feel guilt- no one's expecting anything of you um... So yeah, it just feels, I don't know. It's like a big hug (laughs).

Lisa speaks about the guilt she feels for not being to do things during her luteal phase and how helpful it is to get support from her loved one. It seems like hearing from someone else in this way helps her to see thing from a different perspective and touch base with "reality". This is a helpful reminder of what other people think and helps her to reflect on the contrast between what she is feeling in those moments, "so much guilt", and other people's experiences of it. Lisa describes it as feeling "like a big hug",

suggesting that receiving this support may feel warm and comforting and that she is being taken care of.

4.2 Withdrawing from the world

This sub-theme describes how participants withdraw from the world, particularly during the luteal phase, to cope more easily with what they are going through but also as a direct response to their experience in the moment. Some of the participants spoke about feeling alone, wanting to be alone, not having any desire to engage with other people or even with themselves, as a way of stopping themselves from being triggered by other people and feeling worse.

Danielle speaks about keeping things hidden from others due to feeling pressure to be ok but in the context of family and friends rather than the workplace.

> *But I want to keep this week of concern in. Does it make it more real if I let it become a talking point? I think I feel more pressure to be ok when he or family say, "You've got this".*

She seems to be trying to figure out why she does this as well, asking if it makes it more real. By describing it as a potential "talking point", it is as if she is deciding whether or not she wants other people to weigh in on it and make it a discussion. There is also a question about whether speaking about it makes it more real. Danielle speaks elsewhere about not making her whole life about PMDD and this suggests that an important element of this for her may be that she chooses when and what she shares.

Josie shared some of the things that can exacerbate how she feels during the luteal phase:

> *Yeeah, so things like, like having to talk to too many people at work or I have too many big presentations or I get feedback or um... things like that or if I can recognise that someone else is in a bad mood, you*

know steering clear of them, things like that. Um, yeah, or like even just like having my camera off on a meeting, things like that. Um... so where like I can just like have a moment to myself and then I'm not feeling like I'm having to keep everything in or put a smile on my face sort of thing, so it's sort of reducing that I think.

By identifying these things as triggers, Josie can avoid interactions that may cause her problems, for example avoiding someone in a bad mood. Describing it as "steering clear" brings to mind a feeling of intention, that she must be on high alert and looking out for possible hazards that she can avoid. As I read this back, I can see how there may be different interpretations of Josie's experience. My own interpretation is that although on the one hand it may feel helpful to be able to recognise what exacerbates her symptoms and adapt accordingly, it may also be challenging to make happen in terms of how much this has an impact on her life and what she is able to manage and control. There may also be some frustration and upset when she is not able to avoid these things and must deal with the consequences, whether that is the impact on relationships or on her own wellbeing. It seems important to Josie to be able to relax and not have to pretend to be ok, suggesting that it is hard work putting on an act for other people and that she may feel some fear of judgements from others or some pressure to "be ok".

During Nathalie's interview, she described her intrusive thoughts as "so huge", as if there was no escape from them at all and the best solution is to "lay low".

I tend to just avoid people during the bad part um, and also because even if I do spend time with my friends in the bad part of my cycle, I will be thinking "they hate me, they're thinking this about me, they're thinking that" because the intrusive thoughts are so huge that I imagine everybody hates me at that point, and everything I say is stupid, ridiculous and you know... so it's best just to lay low and not you know...

This suggests that in her experience, the only way to prevent these intrusive thoughts from building and spiralling is to take herself out of any kind of situation that might trigger them. At a time when she is struggling, she seems to feel unable to connect with others and get support. There also may be a belief that other people do not want to be around her as she is having thoughts of everyone hating her. By withdrawing she is "protecting" herself from feeling worse but also protecting other people from having to be around her and hear all the "stupid" and "ridiculous" things she has to say.

Nathalie also wrote in the diary that she kept during the luteal phase:

> *I don't want to be touched. I don't want to be talked to.*

The way she writes this in two short sentences communicate a firmness and a certainty about how she is feeling. The tone also suggests a sense of wanting to keep people at a distance, as if people can pick up on her energy and want to stay away from her as well.

Emma shared a similar experience in her diary of almost feeling repulsed at the idea of being close to anyone:

> *Couples look VERY unappealing and I'm feeling like I want to crawl out of my own skin.*

It may be the idea of being in a couple that is unappealing, emphasising the feeling that she has of not wanting to be close to other people. I interpret this as being both physically and emotionally close with someone as there is something more intimate about being in a couple, rather than looking at groups of people as unappealing. The physical aspect is then built on by her description of feeling like she wants to "crawl out of [her] own skin". One interpretation of the word "crawl" is that she wants to move slowly and close to the ground, perhaps as a way of not being seen by other people. I

also think about the idea of something making your skin crawl, which evokes a sense of overwhelming disgust.

Later Emma wrote how these feelings continued during the luteal phase:

> *Isolating. Paralysed. Frozen. Didn't want to see anyone.*

The style of writing in short sentences made up of one descriptive word suggests that Emma may not feel able to say more, that it may feel difficult to come up with more to say or that it feels too much to describe her experience in more detail. Her choice of words "paralysed" and "frozen" suggest that she is feeling stuck and unable to do or say more. This quote is very effective in communicating her experience. I think it is worth noting that she writes "paralysed" and "frozen" that suggests that she herself is in those states yet writes "isolating" which I interpret to mean that the situation she is in feels isolating. This suggests that being in the luteal phase feels isolating and she is identifying here how her experience of going through this makes her feel alone in it. There is something about her distancing herself from others but also the PMDD imposing this isolation upon her.

Eleanor spoke about her own experience during the luteal phase of not interacting or engaging with her partner:

> *Uuuh sometimes I don't even answer to my boyfriend. He, he, he, has noticed a, a few uuuh... He has witnessed a few events that when I, I don't even want to talk to anyone like he called me and I'm just completely silent because it's, it's difficult I don't know how to explain it. It just feels... Sad and depressed, and I just don't want anything (laughs).*

Eleanor describes how she does not want anything when she feels "sad and depressed" and this includes not wanting to talk to anyone, even her boyfriend. She says that she

does not want it and there may also be an element of not feeling able to. A lack of motivation to do something may make it feel like she cannot.

Lisa describes a similar experience of disconnection but in a slightly different way:

> *So yeah, it was a very different experience and later on in the day, kind of when everyone was dancing and that kind of stuff, I just felt, like I could see all this joy around me and I couldn't feel joy. I knew that it existed, but it didn't exist for me. It sounds so dark, doesn't it? Just like. But yeah, that's that was my experience of it, yeah.*

Lisa described attending a friend's wedding and how she felt disconnected from the joy around her. There seems to be a block between what she knows and what she feels, as if she is conscious of it in her mind but cannot connect with the joy experientially. Lisa describes it as sounding "so dark", as if describing it to me in the interview made her hear that in a way that she may not have acknowledged. This experience of distance and disconnection from what is going on around her suggests that there may be a feeling of being isolated, and like she is on the outside of something looking in. This makes me think of how valuable the sense of community can be for people with PMDD and suggests that there may be a link between this feeling of being isolated and disconnected from the world, and the reassurance and comfort that participants spoke about feeling when hearing about people's similar experiences.

4.3 A state of resolution: Understanding what is needed

This sub-theme explores an experience that was shared by two participants. It felt important to include this in the analysis because of the relevance of these findings. Both Nina and Danielle described accepting their PMDD as a part of them and learning how to live their lives with it rather than fighting it. It is important to say that at the time of interview, Nina and Danielle had both found different ways to manage and decrease the symptoms of their PMDD during the luteal phase, whether through medical treatment

and/or alternative therapies, suggesting that this may have played an important part in them reaching the state of resolution or integration that is explored here.

Danielle spoke about how her perspective on her PMDD shifted:

> *And I don't see- it's taken a year, well, it probably took six months of it for me to see that actually, my life isn't over because I've got PMDD, I just have to live a certain way.*

Danielle shared how the changes that she made required her to find a way to live with PMDD that set her apart from other people. Danielle chooses to say no to things like alcohol and events, she must eat a certain way and prioritise doing things that she needs like taking naps. This quote suggests that Danielle went through a process of acceptance and changed her perspective on her diagnosis “to see that actually, my life isn’t over”. The “actually” suggests an element of surprise in discovering this while the realisation that her “life isn’t over” suggests a profound turn around; from feeling like her life is over to feeling like she has a life to live again.

Later in the interview Danielle spoke about how this felt for her:

> *Terrifying. But also refreshing. It's- I do feel like having to find a way to live with PMDD feels like you're pushing against the tide a bit.*

This suggests that the process of finding a way to live with PMDD sets Danielle apart from other people and makes her feel different. The image of “pushing against the tide” is powerful and suggests that it takes an immense amount of effort and determination to do what is needed to find a way to live with PMDD. As Danielle describes it as “refreshing”, I understand this to mean that although it is "terrifying”, it is not a negative experience. The word “refreshing” suggests that this journey to live with PMDD has given Danielle energy and strength, leading to a stronger and more integrated sense of

self. She is choosing to live in a way that is right for her and dares to go against how other people live.

The second participant who spoke about her experience of PMDD as more integrated was Nina:

> *I kind of, I just view it as it's just another part of me if that makes sense, but it doesn't kind of like define me.*

The way that Nina speaks about PMDD being a part of her, rather than defining her, suggests that she does not feel like it has the power to overwhelm her or take over. By describing it as a part of her as well, I understand this to mean that she does not view her PMDD as an 'other' or the cause for her to turn into a different person. This suggests that she has been able to reach a state of resolution where she can live with her PMDD rather than losing herself to it.

Nina went on to say:

> *I kind of view it very similar to like my dyslexia. It can have an impact on my life, but it's, but it's, I've got coping strategies, it's well, very well coped and it doesn't have a profound impact on my life.*

It is there, and it is not going anywhere but she knows how to cope so that it is manageable. By comparing it to her dyslexia she seems to be able to normalise it and make sense of what it means to her. Recognising that it is there, and she needs to accept it, to then be able to adapt accordingly and live her life.

Chapter 4: Discussion

In this final chapter, I will summarise and contextualise the study's key findings presented in chapter 3. The areas of the analysis that stood out for me are the following:

- Diagnosis alone is not enough.
- The embodied experience of PMDD.
- PMDD is not an isolated experience, the social context is significant.
- Rebellion as a means of resolution.

I interpreted these areas as important to the participants as well as making important contributions to the field. These findings tell us that exploring the individual experience of living with PMDD is important. While previous research has found that diagnosis is a gateway to change (Buys, 2024; Osborn et al., 2020b), this study has shown that this was not the case for these women as they still struggled with the symptoms of PMDD and the associated feelings of shame and self-blame. This is a significant finding that despite the progress in diagnosis that has been made, there is a lot more work to be done to support people with PMDD subsequently. This study also provides valuable insight into the embodied experience of PMDD, moving beyond a symptom focused approach and engaging with the qualitative experience of living with PMDD. This is important, as it is fundamental in moving towards an understanding of the impact on women's daily lives. The role of social support was a key finding as it highlighted how these women's experiences were not in a bubble; their interactions with other people had a significant impact on how they made sense of their experience. Finally, reaching a place of resolution with PMDD was framed as an act of rebellion in this study which provides a new perspective. This tells us that a shift in how women frame their experience of PMDD can be one which is less about trying to adapt to society and more about making society work for them.

In the second half of this discussion chapter, I discuss how these findings link to wider theories and research literature, focusing on what stood out for me and the clinical

implications. I have chosen to focus on the following topics as they are both relevant to the above-mentioned key findings and to current discussions:

- Defining PMDD and the clinical implications
- Diagnosis of PMDD and related challenges
- Post-diagnostic support for PMDD sufferers

In the final section I will summarise my ideas for future research and the limitations of this study, ending with a conclusion and by closing my reflexive circle.

Context

As already outlined in the introduction chapter, there has been an increase in qualitative research studies in this area including studies exploring the experiences of receiving a diagnosis of PMDD (Osborn et al., 2020b), the role of the PMDD community (Winslow et al., 2022), life after diagnosis (Buys, 2024) and PMDD as episodic disability (Habib et al., 2024). This section of the discussion will briefly summarise each of the GETs from my analysis chapter and make links between this study's findings and the existing research. I will show how my study has replicated findings from previous research and has contributed novel ideas to the field.

GET 1: Making sense of their PMDD: a journey of discovery

For most of the women I interviewed, diagnosis brought a sense of relief and was a tangible way for them to hear that what they were experiencing was not their fault and that they weren't "crazy". It confirmed for them, albeit briefly, that there was an acceptable reality to their experience and their symptoms were real. This reflects findings from previous research that diagnosis brings validation, relief and an understanding of what they were experiencing (Buys, 2024; Chan et al., 2023; Osborn et al, 2020b). However, most of the participants shared how they were left with the burden of figuring things out themselves following diagnosis. They described being left to advocate for themselves, take a lead on their treatment and educate themselves to be able to educate others, including their doctors. This also replicates findings from

other studies in similar areas (Chan et al., 2023; Osborn et al., 2020b) and shows how this lack of consistent care and support post diagnosis is a shared experience in the existing literature.

Other research has explored women's experiences of self-blame during PMDD but described it as being part of the pre-diagnosis experience and explored it retrospectively (Osborn et al., 2020). Women described blaming themselves for their situation, believing that there was something fundamentally wrong with them as nothing else made sense (Osborn et al., 2020). What sets this current study apart is that these findings show women continued to experience intense self-doubt and self-blame even *after* diagnosis, suggesting that diagnosis alone was not enough to move away from these self-critical beliefs. To illustrate, a few of the participants shared how they felt like they should not find it so difficult to work and that there must be something wrong with them. The self-blame seems to be connected to societal expectations and pressures that women in Western society encounter such as being productive and useful, questioning their self-worth when they do not meet these ideals (Chrisler, 2012). These findings replicate previous research that found that women's lives were significantly impacted in all areas including work (Hardy & Hardie, 2017; Osborn et al., 2020b).

Experiences of feeling dismissed and misunderstood were also present prior to diagnosis and remind us of the long journey to reach that point (Osborn et al., 2020b). In contrast to previous research, this study found that receiving a diagnosis was only one part of the journey of making sense of PMDD and did not necessarily represent the beginning of an end to their PMDD. This differs from previous studies whose participants experienced diagnosis as a significant turning point in their PMDD leading to them either having effective treatment and a change in their identity (Osborn et al., 2020b) or finding their own way to a place "beyond abjection" (Buys, 2024).

As the majority of women in this study were still struggling with the symptoms of their PMDD, this research gives important insight into how women make sense of their experience when they are in the midst of the most difficult times of PMDD and give

access to the ‘here and now’ experience. Their experience is ongoing and so offers a new angle on the experience of PMDD by engaging with their ‘hot cognition’, the meaning making in the moment which involves a lot of activity emotionally and cerebrally (Smith, 2018). As the symptoms of PMDD come and go in a drastic way, it feels like the diagnosis comes and goes as well, feeding into the self-doubt around what is real and what is not.

GET 2: PMDD and relationships: unheard, dismissed and judged

All the participants in this study experienced challenges when interacting with doctors in their attempts to get a diagnosis and access support and treatment. These findings replicate previous PMDD research that found women repeatedly feeling dismissed and ignored by health professionals (Brown et al., 2024; Osborn et al., 2020b) and align with wider issues regarding women’s health not being prioritised.

Women were silenced and left to manage on their own due to incorrect terminology and misunderstanding what is normal. These findings support previous research including Buys (2024) who described a theme of “the voice silenced” and Osborn et al., (2020b) who presented the theme as “an unheard voice”. This experience was felt by participants in this study with family and friends as well, through being actively ignored and silenced. The focus in previous research has been on how women experienced the support they received from healthcare professionals; this study expands this by demonstrating how women experienced similar feelings of being dismissed and silenced by friends and family. Several of the participants shared experiences of shame and guilt at how they behaved during the luteal phase. At times this was explicitly expressed by the participants, but I also made my own interpretations of their experiences. This has been found in previous research on PMDD where shame, guilt and self-criticism are commonly described by women (Buys, 2024; Osborn et al., 2020b; Winslow, et al., 2022). McHugh (2020) presented interesting ideas on the concept of menstrual moaning and shame which evokes similar ideas to some of the themes in this study. Using a shame resilience framework (Brown, 2004), McHugh explored the idea that speaking about menstruation negatively is common practice and suggests that this

perpetuates a culture of shame around the menstrual cycle, leading to women connecting with other women through shared problems and otherwise maintaining silence around their experiences. The author suggests that women have learnt how to speak about menstruation negatively and she refers to this as “menstrual moaning” suggesting that women only know how to focus on the negatives of menstruation. By shifting to a more balanced and positive talk around menstruation, women could develop shame resilience through connection.

Despite having a medical condition diagnosed by a medical professional, it seems that these women continue to experience shame around not coping better and associate having a problematic menstrual cycle with other people viewing them negatively. These findings suggest that having PMDD influences not only how these women view themselves, resorting to self-blame and self-attacking when struggling, but also how others perceive them and their beliefs about how others perceive them. The impact this has on their relationships is evident and perpetuates feeling different to others, being misunderstood and isolated in their experiences. Research in this area has demonstrated how women’s premenstrual distress continues to be misunderstood (Winslow et al., 2022), while a combination of little knowledge about illnesses and the view of women as hysterical may be linked to less social support (Johnston-Robledo & Chrisler, 2011).

This study’s findings build on previous research on the impact of PMDD on relationships and the impact of relationships on women’s experience of PMDD. There has been previous research carried out looking at a cognitive behaviour therapy approach (CBT) for couples (Ussher & Perz, 2017) and found that it was effective in supporting women with premenstrual disorders. This is evidently an area that deserves further attention based on the research so far.

GET 3: The impossible battle

This study replicates previous research that explored how women felt as if they were engaging in an inner war (Osborn et al., 2020b). Women described fighting to resist

PMDD and the physical and mental exhaustion that came about as a result. PMDD is experienced on a psychological and physical level, and this highlights the importance of thinking about the embodied experience of PMDD. Several of the participants shared evocative descriptions of the moment that it changed for them, suggesting that there is a fear of danger involved in the fight with PMDD. The use of metaphors is a powerful way of communicating an experience (Shinebourne & Smith, 2009) and the participants in this study employed metaphors during the luteal phase. Four of the participants used metaphors to convey this experience; feeling a “crushing weight” (Nathalie), having an outburst like and “explosion” (Eleanor), like the fog was starting to “get her” (Lisa) and a shark circling underwater (Emma). This relates to the genuine risk of self-harm and suicide that women with PMDD encounter and reflects the all-encompassing nature of their experience (Osborn et al., 2020a).

A shared experience in PMDD research is one of feeling out of control during the luteal phase and feeling powerless in relation to their PMDD (Buys, 2024; Osborn et al., 2020b). My findings mirror a dominant theme in the literature which describes the feeling of a split self, a sense that there are two versions of the self or even going so far as to describe themselves as Jekyll and Hyde (Osborn et al, 2020b; Buys, 2024; Winslow et al., 2022). Using a metaphor such as this may allow participants to distance or detach themselves from their other self (Shinebourne & Smith, 2009). Winslow et al. (2022) reported participants describing multiple self-states including externalising PMDD as a separate being entirely. The researchers discussed how the dissociation of PMDD was used as a way to cope with going through something that did not fit with a person’s own view of themselves. It could also be a way of distancing themselves from the potential stigma and shame that comes from experiencing emotional distress and mood changes during the premenstrual phase. I found that similar themes emerged in this research around multiple self-states and the experience of PMDD as an external being which reflected other previous research (Buys, 2024; Osborn et al., 2020b; Winslow et al., 2022). This study’s findings build on this previous research by exploring participants’ immediate experience of what losing themselves to PMDD, powerfully captured within some of the above metaphors.

This study also contributes a new perspective by considering how it is to experience two versions of the external world; it is not just the self that changes during the luteal phase but also the world around them. This speaks to the widespread impact that PMDD has and reinforces how challenging it feels to have a sense of control over it. This highlights again how important it is to consider the individual experience in context (Smith & Rhodes, 2014).

GET 4: Getting through it: finding ways to manage

The theme of coping through connection reflects previous findings. Women connect with others as a means of coping and making sense of their experience. Alternative ways to cope that have been discussed in other research include taking time out for themselves, avoidance, substance misuse and self-harm amongst others (Brown et al., 2024a). My findings suggest that women sought reassurance and comfort from other people going through a similar experience leading to them feeling less alone and confused. Like Winslow et al.'s research (2022), the participants spoke about how connecting with support groups and other women with PMDD online was a valuable resource. Social support has been shown to be protective by giving the individual a meaningful role and purpose in life (Theofilou, 2023). Despite this, participants also coped by avoiding other people as this removed any perceived external pressure to be ok. This links in with Ussher's ideas around self-surveillance and self-silencing in premenstrual change and has been replicated in other PMDD specific research (Buys, 2024; Winslow et al., 2022).

This experience of connection and acceptance diverges from the previously discussed theme focusing on the experience of feeling isolated, judged and misunderstood by others. This demonstrates how IPA allows both converging and diverging experiences to emerge from the data. These findings replicate a recent study looking at women's experiences of suicidal thoughts and behaviours in PMDD (Brown et al., 2024b) where women shared their experience of a "push and pull" in relationships, recognising that social support was helpful but still isolating themselves when things were difficult. This

study's findings build on this research by demonstrating how the participants engaged in these behaviours in other situations unrelated to suicidality or self-harm.

A physical, embodied urge to withdraw and pull away from others also emerged, with some of the participants expressing disgust at the idea of being touched by someone else. Previous research has found that women's withdrawal and isolation during the luteal phase had an impact on their relationships (Ussher & Perz, 2013) and this study is able to build on these findings with this theme around the visceral reactions that these participants shared in response to connecting with others. This provides further insight into the embodied experience of PMDD.

A final significant finding of this study is one that was experienced by a small number of participants but is linked to previous research and so is worth including. Reaching a state of resolution with PMDD and developing agency in managing their PMDD was a significant experience for two of the participants. Previous studies have presented themes around transformation after diagnosis, with a focus on receiving treatment and undergoing an identity transformation (Osborn et al., 2020b). More recently, Buys (2024) found PMDD to be "plastic" in the context of treatment and recovery, showing how women gained agency over their PMDD through knowledge, helping them to reach a place "beyond abjection". The findings in this study build on the research so far by adding a new perspective to the transformation process. Neither of the women in this study saw their PMDD as threatening, an illness or an alien being, a "not me" (Svenaeus, 2011). Nielsen (2022) suggested that illness brings about an "epoché", disrupting life and forcing a more "conscious engagement with one's life". PMDD brought about a change in how all these women lived their lives, no longer able to take things for granted but suddenly conscious and paying attention to their bodies, minds, lives and relationships to others due to the natural order being "breached" (Smith & Rhodes, 2014). In this study, these two women have taken something disruptive and consciously engaged with it to adapt. These findings provide valuable insight into how women may make sense of their experience of PMDD and how counselling

psychologists can support women clinically to develop more autonomy, agency and ultimately compassion for themselves and their experiences.

The wider discussion

In this section I will bring in theories and literature from the wider research field and consider how my findings are relevant to these current topics. Firstly, as the experience of receiving a diagnosis of PMDD was significant to the participants it felt important to focus on this and how it ties in with wider discussions on diagnosis. I identified the current discussion around the role of diagnosis without appropriate treatment options as particularly pertinent and wanted to explore that in more detail. I will therefore consider the role of diagnosis in women's treatment of PMDD and the clinical implications of this study's findings in the context of current research.

Secondly, it felt important to explore in more detail how a condition such as PMDD is experienced as one that is fluctuating and non-visible. I will consider how we may frame a person's experience of living with PMDD and how it may influence the support they receive. For example, one perspective has suggested that PMDD can be described as an "episodic disability". I will further explore this idea and relate it to this study's findings.

Finally, given this study's findings that none of the participants found that they were given appropriate support following their diagnosis, I will discuss suitable options for post-diagnostic support for women with PMDD and consider how they can be developed and made available. This includes an approach based on a material-discursive-intrapsychic (MDI) framework (Ussher et al., 2002) and the more well-known model of therapy, compassion focused therapy (CFT) (Gilbert & Simos, 2022).

A diagnosis of PMDD

As a trainee counselling psychologist working in the NHS, I regularly see how women seek out diagnoses to make sense of their experiences with an increase in requests for assessments for ADHD, autism and personality disorders. There are valid concerns within research and the healthcare system that this approach risks reducing women's

experiences to a list of symptoms and that there is too much value put on diagnosis alone. This risks putting an enormous amount of focus on getting the right diagnosis, adding more diagnoses to give people answers without enough attention given to the follow up care. Without appropriate treatment, a diagnosis of any condition loses its value and does not provide the resolution that people hope for (Sullivan, 2025).

This increased focus on diagnosis could be linked to the growing interest in wellness and self-care, and the belief that individuals have control over their destinies. The "agency myth" is particularly prevalent in millennials (people generally born between 1980-1995) (Carian & Johnson, 2022). Given that 6 out of 7 of the participants in my study fall within this bracket, I found it interesting to consider how this preoccupation with being self-sufficient, independent and taking responsibility for the self plays a part in their experiences and how they conceptualise PMDD. The narrative developed by this group enabled them to and seek out help but also led to self-blame when they inevitably continued to struggle. The belief that they should be able to manage and control all aspects of their health and behaviour held them back and is both a generational issue as well as a gendered one.

Although there may be a risk of overdiagnosis and associated implications, a diagnosis can provide relief, understanding and access to support that is otherwise unavailable. A diagnosis also legitimises distress; without it a women's distress is more likely to be dismissed as a female problem and misattributed to longstanding prejudices of being too emotional or another psychiatric disorder that is better known. For example, women are more likely to be diagnosed with depression than men even when scores on standardised measures are similar and are more likely to be prescribed psychiatric medication (Morgan, 2019). This speaks to a widespread issue of not understanding women's distress specifically. Women in this study described testimonial injustice (Fricker, 2007) when seeking help for their problems, with doctors and family members not taking them seriously. They were not viewed as women who were reliably capable of identifying the experience they were having but instead as women who were overreacting and not coping with the normal female experience of premenstrual change.

Menstruation has long been associated with being ill or incapable of functioning "normally" (Appignanesi, 2008). In this instance, it seems that this led to an accurate diagnosis being withheld from women which not only deprived them of potential treatment but also maintained ongoing prejudices against women as overreacting and unable to cope due to their menstrual cycle.

As discussed in the introduction chapter, there has been an improved understanding of the biological mechanisms that underly PMDD, proving a clear link between the different stages of the menstrual cycle and the symptoms of PMDD. Prior to these developments there was some debate around the validity of PMDD as a diagnosis suggesting that it was a social construct and reflective of the pathologisation of women's problems (Ussher, 2008; Ussher & Perez, 2013). These ideas have now been discounted and our understanding of PMDD has evolved as a result. This study shows the benefits of having this knowledge, as women felt relief and validation in hearing that there was a legitimate biological reason for their experiences. Participants in this study described the physical, emotional and psychological changes as a sudden shift and felt powerless to stop them, often blaming themselves for not being able to cope better and hearing that it was not something directly within their control gave them some respite from this.

This study found that how the participants in this study experienced these biological changes was influenced by their individual situations and contexts; their relationships with other people, how they viewed themselves, how they viewed their condition and their experience of how they were treated by others. This study shows that it is beneficial to consider wider contextual factors when assessing and formulating women's distress related to living with a medical condition such as PMDD. The Power Threat Meaning Framework (Johnstone & Boyle, 2018) has been developed to understand people's problems in a way that is not based on psychiatric diagnostic criteria but is trauma informed and focuses on the question "what has happened to you?" rather than "what is wrong with you?". Whilst this is a move away from a purely medical approach which can feel unfamiliar and uncomfortable to many, especially in a society where we have seen how a medical diagnosis has become the norm, taking a wider view of

psychiatric disorders means there can an opportunity for change without medical intervention or in addition to it. While diagnosis focuses on fixing something within the individual, an approach that formulates a person's distress in the context of their life experiences promotes the idea that multiple factors contribute to the development of a person's distress and that there may be different ways to approach the treatment of it. When it comes to women's distress in particular, history shows that women have always been treated differently based on their gender and this continues today (Showalter, 1985; Scull 2009). In the past, women rebelling and behaving in ways that were deemed inappropriate for women, for example taking an interest in education, was seen as insanity (Showalter, 1985). In this study, the participants who reached a place of resolution did so by taking ownership of their lives following their diagnosis and rebelling against social norms as well as engaging with more traditional treatment options such as SSRIs and chemical menopause. This was done without much support and relied on the participants doing a huge amount of independent research and investing in their own care.

This study's findings demonstrate that there is clear value in receiving a diagnosis but that there is also limited support available afterwards. One of the main arguments for giving someone a diagnosis is for it to provide access to evidence-based treatment (O'Sullivan, 2025) however this was not the case for these women. Treatment options are limited and their availability is limited as well, with few specialist services in the UK. Without the follow up care, the diagnosis becomes somewhat redundant and risks leaving people blaming themselves for not managing better, isolation and frustration at the lack of help. Identifying the problem is the first step and it is then vital that people are provided with access to evidence-based treatment to improve their quality of life and reduce the risk of suicidal and self-harm behaviours.

Living with PMDD

Feminist disability theory and critical embodiment theorists both argue against treating the mind and body as separate entities (Habib et al., 2024). No matter how much we speak about the mind and body connection in counselling psychology, a divide between

how we understand and treat mental health and physical health in the Western world is still the norm. This research highlights how important it is to understand the embodied experience of PMDD; it is unsettling, overwhelming and at times scary, leading to a feeling of disconnection from the self and surroundings.

Given this study's findings that participants experienced PMDD as both changeable and chronic, it felt important to explore PMDD's temporal nature. Based on these experiences I considered how one could frame PMDD as a fluctuating condition and a chronic condition. PMDD could be categorised as a chronic condition given that it is long lasting, it will not resolve on its own and is rarely completely cured (Dowrick et al., 2005). The participants themselves did not refer to PMDD as a chronic illness however this was one of my interpretations of what emerged from the data as the participants expressed feeling like it would never change and they would live with it forever, not as something that could be cured. This idea of it being a chronic condition lends itself to certain types of treatment, with a focus on acceptance and management of symptoms rather than working towards eradicating symptoms. This will be explored later in this thesis in relation to post-diagnostic support.

A fluctuating condition is one that is underlying and has variable symptoms and functional effects over time (Department for Work and Pensions, 2024). A recently published paper proposed the idea of framing PMDD as an episodic disability (Habib et al., 2024). Episodic illness and episodic disability can be similarly defined as conditions that consist of phases of illness and wellness (Charmaz & Rosenfeld, 2006; Habib et al., 2024). The experiences of living with other episodic conditions are similar to those described in this study, in how confusing and unsettling it is to have symptoms that come and go. The fluctuations in symptoms lead to self-doubt and make it difficult for people to explain the condition to other people as they feel like they are making it up when they are not in the midst of it.

An added challenge to living with this condition is that the symptoms of PMDD and the impact on daily life are most commonly not visible to other people. These types of

conditions are described as being invisible, or non-visible, and previous research has shown how women living with invisible conditions such as ADHD (Morgan, 2023), endometriosis (Kocas et al., 2023) and long Covid (Ireson et al., 2022; O'Brien et al., 2023) have similar experiences in delays in diagnosis due to lack of knowledge and understanding (Ireson et al., 2022), challenges in receiving support due to not recognising women's symptoms (Kocas et al., 2023) and experiences of shame and stigma (Charmaz & Rosenfeld, 2006; McLeod, 2023).

The combination of the episodic nature of a condition with a non-visible presentation compounds these challenges and is an important element to consider when thinking about the phenomenological experience of illness and disability. Habib et al. (2024) suggest that episodic and non-visible disabilities face similar challenges as they do not meet the criteria for what is defined as a disability according to binary Western norms, that there is a "right" way to be and a "wrong" way to be. A person is either able bodied or disabled, healthy or unhealthy, neurotypical or neurodivergent. This certainly fits with the Cartesian dualism that underpins much of our understanding of the world (Thibaut, 2018) and is reflective of the experiences my participants shared. Habib et al. (2024) suggests that framing PMDD as an episodic disability provides an opportunity for off-label treatment, an approach to treatment that does not prescribe a one size fits all approach to reflect how changeable and individual PMDD is as a condition.

However, describing PMDD as "episodic" risks diminishing the severity of the widespread impact of the condition. The symptoms of PMDD do fluctuate, as to be diagnosed with PMDD it is a requirement that the associated symptoms are only present during the luteal phase of the menstrual cycle. If viewing PMDD through a purely positivist lens one could perhaps argue that the absence of symptoms during the rest of the month would indicate that the person is well and healthy. This view discounts the wider impact of the condition and does not align with my own stance or this study's findings. Although the measurable symptoms of PMDD occur during the luteal phase, the impact of the condition on people's lives is constant as shown by the participants experience in this research and previous studies. Participants spoke about returning to

themselves when their period started but were then left with pressure to mend relationships and catch up on work when they felt able to while others were still unable to work at all. People are never “well” or free from PMDD as the impact is continuous throughout the month and affects people’s ability to function in all areas of their lives. Therefore, the term episodic may be used to highlight how the *nature* of the condition is changeable, but I would argue that this study and other research have shown that the impact of PMDD goes beyond the luteal phase and is widespread and long lasting. Understanding PMDD in this way can then inform how support is designed and developed.

Post-diagnostic support

The key message from this study’s findings is that receiving a diagnosis of PMDD alone is not enough. Given the significant impact of PMDD on people’s lives, it is essential that more work is done to develop the care that is given to these people. I have taken this opportunity to explore what these options could look like from a psychological perspective based on this study’s findings and the other research in this field.

As discussed in the introduction chapter, research has shown an association between previous experiences of trauma and PMDD (Bencker et al., 2025; Grewal et al., 2024; Kulkarni et al. 2022) which indicates that a trauma informed approach to assessment and care is beneficial. A trauma informed approach promotes safety, empowerment, collaboration, trust and choice (Office for Health Improvement and Disparities, 2022) for people with PMDD, all of which is currently lacking in how people are treated as shown by this study’s findings. A recent paper published on the use of a dialectical behaviour therapy (DBT) informed model for women with PMDD (Oliveri et al., 2025) argues for taking a trauma informed approach. The DBT informed sessions that they offer provide women with education and skills development on PMDD symptoms. The authors explain that the focus is not on changing the symptoms themselves but working towards acceptance and adaptive coping which is well suited to a condition such as PMDD. While this study is of interest it did not provide any evidence of outcomes for people who have taken part in the therapy and so further research is needed in this area.

I have considered alternative therapy models based on this study's findings. Holding in mind the idea of "off-label treatment" for women with PMDD (Habib et al., 2024) I wanted to explore approaches that allow for individualisation. A woman centred model of therapy developed by Ussher et al., (2002) based on the MDI framework brings together ideas based on principles of CBT and narrative therapy. Originally developed as an individual therapy, it has been adapted for couples therapy (Ussher & Perz, 2017) and self-help/guided self-help (Ussher & Perz, 2006) and encourages women to consider a range of factors that contribute to problems with premenstrual change including material factors (biological factors, inequality in relationships, previous history of trauma), social and linguistic factors (language, culture, power) and intrapsychic elements (psychological factors related to the individual).

The MDI model is a move away from Ussher's previous work which takes a feminist perspective and a social constructionist position. While that approach is critical of diagnosis and PMDD as a psychiatric disorder, the MDI framework acknowledges that the biological symptoms that women report in relation to their menstrual cycle are real and valid. The MDI framework therefore takes a critical realist position and considers the role of biological factors alongside other important factors in person's experience of PMDD. What sets this apart from other positivist biopsychosocial models is that it does not rely on hierarchy and no single element is privileged over another (Ussher et al., 2002). Therefore, by employing this framework it allows us to expand our understanding of a person's life with PMDD away from being a purely biological disorder that is defined by symptoms and treated medically (a medical perspective) or purely a social construction (a feminist perspective). This approach aligns with my own position in the context of this research as the participants experiences of living with PMDD were made up of many different elements beyond the biological symptoms they described. I suggest that by introducing the MDI model based on the findings of this study we can acknowledge the important role of diagnosis in validating a person's experience and verifying their biological experience, alongside acknowledging the important role that other material, social, linguistic and intrapsychic elements also have on how PMDD is

experienced. This comprehensive understanding of PMDD can then better inform how we support people with this condition.

The MDI model of therapy integrates theory and skills that are accessible to mental health professionals with a formulation-based approach. It allows for flexibility in interpretations of experience by exploring personal meaning and does not attempt to attribute one fixed view of the world but allow them to explore and reflect on the interaction between themselves and the world.

Some of the key elements of Ussher's model of therapy include:

- A focus on stress management and relaxation techniques
- Considering the role of relationships
- Developing assertiveness in relationships
- Integrates narratives around social expectations of women
- Looking after the self
- Use of vicious cycle to establish patterns
- Personal meaning of premenstrual change

A possible limitation in the model itself and its research base is the exclusion of other aspects of identity such as ethnicity and cultural differences. As already discussed in this chapter, this study has highlighted a gap regarding intersectionality in the current PMDD research given the focus on stigma related to gender (Crenshaw, 1991). It is also important to consider how this model would apply to people with PMDD whose gender identity does not fit the stereotypical female role and identity.
The approach also speaks about premenstrual change in general. This aligns with the model's critical realist epistemology but risks undermining the severity of PMDD.

Implementing a novel approach such as this requires time, interest and money that are dedicated in this area to produce the relevant research and make it widely available. This links back to the already much discussed issue of women's health as being low priority, with a lack of dedicated funding and research activity on issues that affect

women and AFAB (assigned female at birth) individuals. Ussher (2005) herself outlined this, acknowledging how this perspective may seem “a utopian analysis”. The continuing financial struggles of the NHS in the UK suggest that this will continue to be a challenge and so I am conscious that suggesting an implementation of a model such as this may not be realistic and reflective of the current climate.

As already discussed, therapeutic approaches such as cognitive behaviour therapy (CBT) (Weise et al., 2019) and dialectical behaviour therapy (DBT) (Schmalenberger et al., 2017) have been proposed for people without PMDD but there is little empirical evidence of their effectiveness. Based on this study’s findings that the participants experienced shame and self-blame relate to their PMDD I propose that compassion focused therapy (CFT) be considered as a viable option for therapy. A third wave cognitive behavioural therapy (CBT) model, CFT is based on evolutionary psychology, neuroscience and Buddhism and has a focus on reducing shame and self-criticism while increasing self-compassion. This model is based on the idea that there are three emotion regulation systems that interact: the threat system, the drive system and the soothe system, with the aim to strengthen the soothe system and achieve balance across the three systems (Gilbert & Simos, 2022).

Shame is linked to self-criticism (Gilbert & Procter, 2006) and compassion focused therapy (CFT) has been shown to decrease self-criticism and increase self-soothing (Vidal & Soldevilla, 2022) with a focus on compassionate acceptance (Gilbert & Simos, 2022). CFT has been shown to be effective in reducing shame and self-stigma and increasing self-compassion in a group format (Cuppage et al., 2017; McManus et al., 2018) and has been used to help people with posttraumatic stress disorder (PTSD) (Luo et al., 2021).

The similarities between the MDI model of therapy and CFT are:

- Both based on CBT framework
- Use mindfulness and relaxation techniques
- Both about caring for the self in different ways

- Monitoring of thoughts feelings behaviours

What CFT lacks is the tailored element to women and premenstrual change, and this is clearly a significant argument for the introduction of the MDI model. However, as shown by the recent paper on DBT, these elements can be added into the programme to offer a more tailored approach. In addition, the three emotion regulation systems focus the treatment on the individual and do not consider the social context the way that the MDI approach does.

The two models do not serve the same purpose but are two alternatives that meet the needs of women with PMDD according to the findings of this study. Given the current lack of research in this area and lack of funding and focus on women's health, I suggest that CFT is a more widely available option currently to consider when working with this client group. As shame and self-criticism was a shared experience, it is likely that women could benefit from support in addressing some of these challenges and gaining tools to increase self-soothing and self-compassion. Any therapeutic approach needs to be trauma informed and formulate the person's problems in the wider context whilst also providing education on PMDD. This will require a multidisciplinary approach as an initial assessment and diagnosis is likely to be carried out by a GP while further treatment can then be provided by specialist services and/or mental health services.

Summary of implications

This study's findings demonstrate the importance of timely diagnosis for women with PMDD and highlight how clinicians need to be trained in assessing and diagnosing PMDD and associated risks. A diagnosis of PMDD brings clarity, validation and certainty to people who have often been struggling with unidentified problems for years. A great deal of progress has been made in this field to define PMDD and recognise its existence as a distinct diagnostic category in both the DSM-5 (APA, 2013) and the ICD-11 (WHO, 2022) however, what this study's findings also highlight is the lack of strong evidence for effective treatment that goes beyond the medical management approaches outlined in the introduction chapter. Considering that one of the main arguments for

getting a diagnosis is that it opens doors to treatment and support, the system is failing patients in this regard as it is evident from this study and previous research that women with PMDD do not have access to treatment that works for them. Given this is the current status, it is vital that adequate post-diagnostic support is developed and researched as a priority, to improve the quality of life of people with PMDD and to reduce the associated risks such as suicidal thoughts and behaviours as previous research has shown how common suicidality is amongst this group (Brown et al., 2024).

I have identified two models of therapy that may be beneficial for women with PMDD based on this study's findings: compassion focused therapy (CFT) and the model of therapy based on the material-discursive-intrapsychic framework. Both models provide ways of making sense of the problems that women face as part of their experience of living with PMDD provide them with strategies to manage in problem areas. Psychologists would be well placed to offer these interventions as both models are based on psychological theory that most psychologists are already trained in. Additional training that would be necessary would be on the causes and mechanisms of PMDD, associated risk factors and an understanding of common experiences shared by people with PMDD to allow for relevant psychoeducation on the diagnosis. Important areas to include based on this study's findings are the impacts on relationships, common experiences of shame, self-blame and feeling misunderstood by others.

Due to the lack of diversity in this study's sample, it is important to acknowledge that the clinical implications discussed here are based on the findings generated by this research and therefore reflect the experiences and needs of mostly white, pre-menopausal cis-gender women. Further research will need to be carried out with participants from minority backgrounds to determine how their experience differs and how treatment can be adapted for their specific needs.

I have also discussed the role of epistemic injustice as there is a lack of diversity in this study's sample which is reflective of the wider body of research in this area. More research into the role of epistemic injustice in women's experiences and intersectionality

is needed. I have discussed how gender may play a part in testimonial injustice; what is this like for people who identify as a different gender, a different ethnicity, a different socioeconomic status (SES) or level of education? Women in this study were predominantly university educated, white British women with support networks who felt able to advocate for themselves. An important question to ask in future research is "what might this experience look like for women who come from backgrounds without those same privileges?" This is a vital discussion to have and to continue having, as there needs to be more consideration of different backgrounds and identities for people with PMDD in general. People's ethnicity and culture may influence how they make sense of a phenomenon such as PMDD and how their experience is shaped and expressed. As already mentioned in this thesis, gender diversity also matters in PMDD research as this recognises the impact of gender identity on a person's experience of living with PMDD. Considering the intersection of the different identities that a person holds (race, gender, sexuality, disability and class amongst others) is important not only because it shapes their experience and how it feels to have PMDD, but also because it influences how supported they are by the systems around them. PMDD is often misdiagnosed or undiagnosed, and so it is important to better understand the impact and reasons for this for people from all backgrounds. Marginalised communities are more likely to not receive a diagnosis of PMDD and by better understanding their experience of PMDD and seeking care, approaches to improve diagnosis for everyone can be addressed. A more inclusive approach to researching PMDD will mean that everyone's experience can be better understood and lead to improved treatment for all.

Strengths and limitations

A strength of this study is that it replicates findings from previous research into women's experiences of PMDD while also offering new insights. This is the only study that I am aware of that has carried out an analysis using IPA with a sample of women with a self-reported confirmed diagnosis of PMDD. In addition, the recruitment was not through the NHS which means that participation was not contingent on being seen by a specialist service, an option that we know is not readily available to most women. This offered

new insights into the experience of being diagnosed but struggling to access post-diagnostic support, an experience which is a key finding in this study.

The combined use of interviews and diaries as data collection is another strength as it provided data points throughout the month and represented the full cycle of the PMDD experience as a result. Other studies have relied on either interviews (Osborn et al., 2020b; Buys, 2023; Habibi et al., 2024) or the written word in social media forums (Winslow et al., 2022) but not combined the two. In addition, writing things down as well as speaking about their experiences gave the women different modes of communication, bearing in mind that people have different preferences for how they express themselves.

Despite the strengths of this study, it is not without its limitations, and I have outlined these here as they should be considered when interpreting the findings of this study. Firstly, there is a lack of expert by experience involvement in the study design. I consulted with a member of the IAPMD team who was an expert by experience in the very initial stages of this project which was beneficial and provided some insight into how my study fit in with areas of interest for people with PMDD, however on reflection I believe that more in depth consultation would have strengthened the study and contributed to managing the power imbalance between researcher and participant that I felt at times.

Secondly, there is a lack of diversity in my sample in ethnicity, race and gender identity. I have discussed this elsewhere and explained my rationale for recruiting a sample of cis-gender women which I have reflected on and recognised how I could have improved in hindsight. Although it is important to have a homogenous sample when using IPA to retain the idiographic nature of the analysis, 6 out of 7 participants came from a white British background and this was not intentional on my part. I was open to recruiting women from any background but in hindsight I realise that this approach allowed for inequality in my sample and is a clear weakness in this study. Purposely recruiting a more diverse sample of women from black, Asian and minority ethnic (BAME)

backgrounds would have strengthened the study by providing different perspectives that are otherwise unheard.

Thirdly, the recruitment process was limited in that I only contacted the IAPMD for support with recruitment and they advertised their study on their website and social media. This may have limited access to the study information to people who were actively engaging with the IAPMD website and seeking out involvement in research. Several of the participants came from academic backgrounds which may have contributed to their seeking out research participation. There is nothing wrong with this per se but could be linked back to my discussion points on privilege in the experience of managing PMDD. Diversifying the recruitment approach may have opened the study up to different perspectives.

Finally, this study has methodological limitations due to IPA's focus on language and the researcher's subjective interpretations of what is said. Introducing another element to data collection such as an item that represented something important to them, or a piece of art would have made use of different senses and considered how the embodied experience of PMDD could be reflected in the methodology and analysis (Rose, 2023).

Directions for future research

As this area of research is still in its infancy there are countless opportunities for valuable research to be carried out and contribute to the research base. This study has helped to identify some key areas which would be particularly relevant to investigate further. Research exploring the role of women's intersecting identities and their experience of PMDD is necessary to broaden our understanding of the subjective experience beyond that of predominantly white British women.

In addition, I have discussed conceptualising PMDD as an episodic disability or illness and the impact this has on how women make sense of their experience. Further research in this area may be valuable to pursue given the related shame and stigma that stems from its non-visible nature, as well as considering the high co-occurrence

with other non-visible conditions such as autism and ADHD. This idea stems from research showing that there is considerable overlap in the prevalence of these conditions with PMDD as well as in how women make sense of these experiences and the significant crossover regarding experiences of diagnosis and treatment and the associated shame and stigma they experience.

Finally, further research needs to be done to investigate options for post-diagnostic support that go beyond medical treatment, with the aim to develop an evidence base that supports an individualised approach. This may involve carrying out research into the use of Ussher et al.'s (2002) feminist model of therapy for premenstrual disorders with women with PMDD and consider how this model could be adapted for use with a range of populations and particularly in the NHS in the UK. I would be interested to know more about how this model would apply in different cultures or people with different ethnic backgrounds given the research that suggests that premenstrual disorders are a social construction in the western world and that these experiences are not reflected in other parts of the world.

Carrying out this research has been a transformative process, pushing me to develop not only my research skills but also my reflexive and reflective practice. I predicted that I would struggle at times with the duality of my role, professionally as a researcher and a trainee counselling psychologist and personally as both an insider and outsider. I came to this project with what felt like quite strong beliefs about being on the side of women and outrage at how women are treated regarding their health but found myself challenging myself on certain judgements and assumptions I found myself making about women and their menstrual cycle.

On reflection I focused so much on <u>what</u> I was doing and <u>how</u> I was doing it, that I rarely thought about the "so what and now what?". My own clinical practice while writing up reminded me of the importance of this in our work and the practice of asking myself these questions helped me to bring my thinking full circle. Reflecting with others was particularly helpful when I felt stuck. This comes more naturally when

working clinically but I felt quite alone with this project at times and so sharing my ideas with my supervisor and thinking out loud was valuable and helped me to produce this piece of work.

Conclusion

This study set out to explore how women made sense of their diagnosis of PMDD, with the aim to better understand the subjective experience of living with PMDD and inform what support is developed. The findings of this study confirmed what was discussed at the beginning of this thesis; that diagnosis of PMDD is important and significant to women with PMDD. What also became clear is that there is a distinct lack of knowing what is helpful and a lack of appropriate support available to these women. This demonstrates how diagnosis itself is not problematic but that in isolation it does not provide women with the resolution that they hoped for.

In the time that I have been working on this research there have been significant developments in the field which align with the study's findings and suggestions for future research. In 2026, the UK branch of IAPMD launched bringing with it more of a focus on research into PMDD and PME in the UK. A collaborative research project at King's College London, 'Towards Better Outcomes for Premenstrual Dysphoric Disorder (PMDD) has also recently been announced which will aim to map policy and practice changes. These steps towards advancing our understanding of PMDD and improving outcomes for those living with PMDD demonstrate that this is an area that needs investment and this is now being recognised.

In the introduction I discussed how my position regarding PMDD as a diagnosis had changed from when I first heard about it to when I carried out the research. I originally questioned the benefits of PMDD being classified as a psychiatric diagnosis due to concerns I had about pathologising women's problems, and that labelling women with a diagnosis could perpetuate ideas that women are crazy or overly emotional. As I better understood the biological mechanisms of PMDD and the existing research on PMDD my perspective changed and I saw the value in the PMDD diagnosis and its benefits.

Although as a counselling psychologist I remain unsure of the utility of some psychiatric diagnoses, I recognise now that there is nuance in diagnosis and not all diagnoses can be viewed in the same way. This research study has shown how a diagnosis of PMDD helped women to gain clarity about their problems and help them to feel less alone. Carrying out this research has helped me to become more open to considering multiple perspectives and it confirms for me how people's subjective experiences offer a type of knowledge that can sometimes be overlooked by health professionals. Listening to these different perspectives has not only broadened my clinical understanding of PMDD but also highlighted the importance of hearing from people with lived experience, to understand these experiences as much as possible and inform support that is relevant and appropriate. These findings have also strengthened my commitment to ensuring that women receive the support they need following a diagnosis. The value of a diagnosis depends, in part, on what follows.

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Appendix A: Initial ethics approval

Ethics ETH2122-0352: Miss Sophie Grant (Medium risk)

Date Created	25 Oct 2021
Date Submitted	16 Dec 2021
Date of last resubmission	15 Feb 2022
Date forwarded to committee	21 Dec 2021
Academic Staff	Miss Sophie Grant
Student ID	190046338
Category	Doctoral Researcher
Supervisor	Dr Holly Kahya
Project	Women's experiences of living with premenstrual dysphoric disorder (PMDD).
School	School of Health & Medical Sciences
Department	Psychology
Current status	Approved after amendments made

Appendix B: Ethics amendment

Ethics ETH2122-1885: Miss Sophie Grant (Medium risk)

Date Created	22 Jun 2022
Date Submitted	22 Jun 2022
Date of last resubmission	22 Jun 2022
Date forwarded to committee	22 Jun 2022
Academic Staff	Miss Sophie Grant
Student ID	190046338
Category	Doctoral Researcher
Supervisor	Dr Holly Kahya
Project	Women's experiences of living with premenstrual dysphoric disorder (PMDD).
School	School of Health & Medical Sciences
Department	Psychology
Current status	Approved

Appendix C: Recruitment flyer

Department of Psychology
City, University of London

PARTICIPANTS NEEDED FOR RESEARCH IN WOMEN'S EXPERIENCES OF *PREMENSTRUAL DYSPHORIC DISORDER*

We are looking for volunteers to take part in a study exploring women's experiences of living with diagnosed premenstrual dysphoric disorder (PMDD).

As a participant in this study, you would be asked to share your personal experiences of living with PMDD. Your participation would involve writing a diary about your experiences as well as an individual interview (in person or remotely, this will take 45 mins – 1 hr of your time).

Travel expenses will be reimbursed.

For more information about this study, or to volunteer to take part please contact:

Sophie Grant (researcher)

Email: [redacted]

Holly Kahya (research supervisor)

Department of Psychology

This study has been reviewed by, and received ethics clearance through the Psychology committee, City, University of London.

If you would like to complain about any aspect of the study, please contact the Secretary to the Senate Research Ethics Committee on 020 7040 3040 or via email: [redacted]

City, University of London is the data controller for the personal data collected for this research project. If you have any data protection concerns about this research project, please contact City's Information Compliance Team at dataprotection@city.ac.uk

Appendix D: Participant information sheet

Participant information sheet

REC reference number: ETH2122-1885 amended from ETH2122-0352
Version 4, dated 22nd June 2022
Title of the study: Women's experiences of living with premenstrual dysphoric disorder (PMDD)
Name of researcher: Sophie Grant

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You will be given a copy of this information sheet to keep.

What is the purpose of the study?
This study is being carried out as part fulfilment of the Doctorate in Counselling Psychology at City, University of London. The main aim is to understand how you experience living with PMDD and how you make sense of it. The study will be completed by September 2023 when it will be submitted as a final thesis.

Who is carrying out the study?
The researcher, Sophie Grant, is a trainee counselling psychologist at City, University of London. Sophie has an interest in the interaction between women's physical health and mental health and has chosen this area as the focus for her doctoral research. In this instance, Sophie is recruiting participants for the study to take part for research purposes only and this will not include any direct therapeutic support. However, if you

do feel that you need further psychological or emotional support before, during or after taking part in the study then please make the researcher aware as we will be able to support you with accessing this.

Why have I been invited to take part?

You have been invited to take part as you have a confirmed diagnosis of premenstrual dysphoric disorder from a doctor, and you are between 18 and 40 years of age.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate in part of or all of the project. It is up to you to decide whether to take part. If you do decide to take part, you will be asked to sign a consent form and return this to the researcher.

What will happen if I decide to take part?

Research participants will be expected to attend an individual interview with the researcher to speak about their experience of living with a diagnosis of PMDD. The interview will take place in person at City, University of London or remotely via video. Participants will also be asked to complete a written diary for two weeks prior to the interview documenting their experiences of living with PMDD.

- You will be asked to sign the consent form. Following this, you will have a screening phone call to discuss what taking part will involve, answer your questions, and discuss next steps. If you would still like to take part, you will then agree on an interview date for your individual interview with the researcher.
- The semi-structured interview will take place either in person or over the internet. You will be asked a series of open-ended questions that the researcher will have prepared in advance. You will be able to answer these questions freely. The interview will be scheduled during the follicular phase of your menstrual cycle when there is a reduction in the symptoms commonly experienced by people with PMDD. This is to ensure that you feel well enough to take part.

- In addition, you will be asked to write a diary for two weeks before the interview, documenting your experiences of living with PMDD and the symptoms that you experience during the luteal phase.
- The research method for this study is called ‘interpretive phenomenological analysis (IPA). This means that the content of the diaries and interviews will be analysed, common themes will be identified and then interpreted by the researcher to build up a rich account of people’s experiences.
- The study is due to be completed by September 2024 with submission of a final thesis. This is subject to change if circumstances change.
- If you decide to take part, you will be able to withdraw at any time until 1 month after your interview takes place. The content of the interviews and diaries will be de-identified at this point in the research, and the researcher will no longer be able to extract your individual data from the study once the analysis begins. Withdrawal will not result in participants being penalised or disadvantaged in any way.

What are the possible disadvantages and risks of taking part?

Taking part may involve discussing upsetting information or experiences which could trigger an emotional response for you.

What are the possible benefits of taking part?

By taking part in the study, you will be helping to increase the knowledge and understanding of PMDD in the counselling psychology community and the wider community of health professionals.

Expenses and Payments

Travel expenses will be covered by the researcher.

How is the project being funded?

Any costs that arise as part of the study will be covered by the researcher.

Conflicts of interests

No conflicts of interest to be declared.

What should I do if I want to take part?

Please email Sophie Grant, the researcher, at [redacted] to confirm that you would like to take part in the study.

Data privacy statement

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. The legal basis under which your data will be processed is City's public task.

Your right to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personal-identifiable information possible (for further information please see https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/).

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose. The only person at City who will have access to your identifiable information will be Sophie Grant. City will keep identifiable information about you from this study for 10 years after the study.

You can find out more about how City handles data by visiting https://www.city.ac.uk/about/governance/legal. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (IOC) https://ico.org.uk/.

Will my taking part in the study be kept confidential?

- The researcher will be the only person with access to personal data before de-identification takes place. All transcription will be completed by the researcher.
- Confidentiality will be ensured; no personal identifiable information will be recorded, and quotes will be either anonymized, for example using a pseudonym, or paraphrased to exclude identifying information.
- Audio recordings will be upload from the recording device onto a password-protected laptop and then deleted from the device.
- The researcher may need to share their own experiences of conducting interviews with their own supervisor, confidentiality will be kept by the supervisor as well.
- If you share anything that concerns the researcher related to risk of harm to yourself or others, confidentiality may be broken to ensure the safety of you and others.

What will happen to the results?

The results will be written up as part of the researcher's final doctoral thesis to be submitted to City, University of London. In future, the study may be published in professional journals. The researcher will share the publishable results with you if you are interested. You will be able to opt in or opt out of receiving feedback on the findings by ticking the relevant box on the consent form.

Who has reviewed the study?

This study has been approved by City, University of London Psychology Research Ethics Committee.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name

of the project is ‘Women’s experiences of living with premenstrual dysphoric disorder (PMDD)’.

You can also write to the Secretary at:
Anna Ramberg
Research Integrity Manager
City, University of London, Northampton Square
London, EC1V 0HB
Email: [redacted]

Insurance
City holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone’s negligence, then you may have grounds for legal action.

Further information and contact details

Researcher contact details: Sophie Grant,[redacted]

Research supervisor contact details: Dr Holly Kahya,[redacted]

Thank you for taking the time to read this information sheet, please do not hesitate to get in touch if you have any questions at all.

Appendix E: Screening call protocol

Protocol for screening phone call with participants

This is Sophie Grant from City, University of London psychology department. Thank you for your interest in my study and for taking the time to speak with me today.

The purpose of today's phone call is to discuss what you have understood about the study so far and answer any questions you may have about what taking part will involve. I will also ask a couple of questions about you and your wellbeing at the moment, to ensure that you feel able to take part in both the interview and diary keeping sections of the study and that you feel supported to do so. Finally, if you decide to go ahead and take part in the study we can discuss next steps which will involve scheduling the interview. How does that sound?

I would like to remind you that taking part in this study is entirely voluntary and that you are able to withdraw your consent to participate at any time. Do you have any questions about that?

Because taking part in this research involves discussing your experience of PMDD, we understand that this may be a sensitive topic and might bring up difficult feelings for you. We are therefore advising people who are experiencing a high level of stress or emotional distress to consider whether participation in the study is right for them at this time. Is it alright if I ask you some questions to determine if there are any reasons that participation might be particularly difficult for you? [If no, thank for time and interest. If yes, conduct screening interview.]

Screening questions

Have you read and understood the participant information sheet, including the information on the focus of this study?

Can you confirm that you have received a formal diagnosis of PMDD from a medical professional? [If yes, continue with the screening call. If no, enquire further about this and explain that this is a requirement of taking part and thank for time and interest]

Do you have any questions about the study and what your participation may involve?

Are you experiencing a high level of stress or any emotional distress currently?
If yes, follow-up questions to determine whether the distress is currently interfering with the person's life in a significant way. For example: *can you tell me a little bit more about what you are experiencing? What is the current impact on your life day to day?*

Are there any reasons you can think of that might make participating in an interview and keeping a diary about your experiences of PMDD too difficult for you?

If yes, follow-up questions to determine whether anything can be done to mitigate this, or whether participation at this time does not seem appropriate.

Appendix F: Participant consent form

Participant consent form

Name of principal researcher: Sophie Grant

REC reference number: ETH2122-1885 (amended from ETH2122-0352)

Title of study: Women's experiences of living with premenstrual dysphoric disorder (PMDD).

		Please tick/ initial box
1	I confirm that I have read and understood the participant information dated 22nd June 2022 (version 4) for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.	
2	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any point until the analysis has commenced, as it will not be possible to withdraw individual data after this point. Participants will be able to withdraw up to 1 month (4 weeks) after the interview has taken place. Withdrawal will not result in participants being penalised or disadvantaged in any way.	
3	I agree to the interview being audio recorded.	
4	I agree to direct quotes from the interview being used in the researcher's final thesis.	
5	I agree to direct quotes from the diary entries being used in the researcher's final thesis	
6	I would like to be informed of the results of this study once it has been completed and understand that my contact details will be retained for this purpose.	
7	I understand that my data will be de-identified meaning that no identifiable personal data will be published.	
8	I agree to City recording and processing this information about	

	me. I understand that this information will be used only for the purpose(s) explained in the participant information and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	
9	I agree to take part in this study	

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Name of Researcher	Signature	Date

Appendix G: Interview schedule

Demographic questions

How old are you currently?

What is your ethnicity?

What is your current occupation?

What is your current relationship status?

When were you first diagnosed with PMDD?

Interview questions

What motivated you to take part in this study?

How was your experience of writing the diary?

How was your experience of being diagnosed with PMDD?

Prompts: How did it make you feel, how did you make sense of it? What happened? What were you thinking? How did you feel emotionally? How did you feel physically/in your body? How did you cope?

Can you take me through a typical month?

Prompts: Changes in physical/mental health, relationships with others, relationship with self. (What were you thinking, feeling, doing?)

How supported have you felt by others?

What does it now mean to you to have PMDD? - Alternatives “where are you at with this now? How have you come to terms with having PMDD? How do you understand PMDD for you?

Prompts: How do you make sense of the changes you experience throughout the month?

As we’re coming to the end of the interview, is there anything else you’d like to share with me?

Appendix H: Distress protocol

Distress protocol for interview – risk escalation

If the interviewer determines that a participant's distress reflects what would be expected in an interview on a sensitive topic:

a) Interviews may be paused and support offered, and the participant provided an opportunity to regroup, continue or stop the interview.

If a participant indicates they are experiencing a high level of stress or emotional distress OR exhibits behaviours suggestive that the discussion/interview is too stressful such as crying, shaking etc.:

a) Stop the interview.
b) Offer immediate support.
c) If researcher is appropriately trained, consider assessing mental status:

E.g. Tell me what thoughts you are having?
Tell me what you are feeling right now?
Do you feel you are able to go on with your day? Do you feel safe?

d) Consider having a mental health professional on call (if possible the research supervisor), to intervene and refer the participant to appropriate services.

For participants who are experiencing acute distress but are not at risk of imminent danger, consider terminating the interview and the following actions;

a) Encourage the participant to contact their GP/ mental health/ wellness support services.

b) Offer, with participant consent, for the researcher to do so.

c) Offer a follow-up call from the researcher/ psychologist research supervisor, requesting the individual's phone number for this purpose.

d) The option to call the researcher if they feel that their distress worsens after the interview can be offered,

If the researcher judged that the participant is in **imminent danger,** consider the following actions:

(a) Request the participant's address to call emergency services.

(b) If in person, offer to take the participant to A&E.

(c) Offer a follow-up call from the researcher/ psychologist research supervisor, requesting the individual's phone number for this purpose.

Regardless of distress during interview, check in with all participants after the interview, and considered the above should any distress be expressed.

Distress protocol for diary keeping – risk escalation

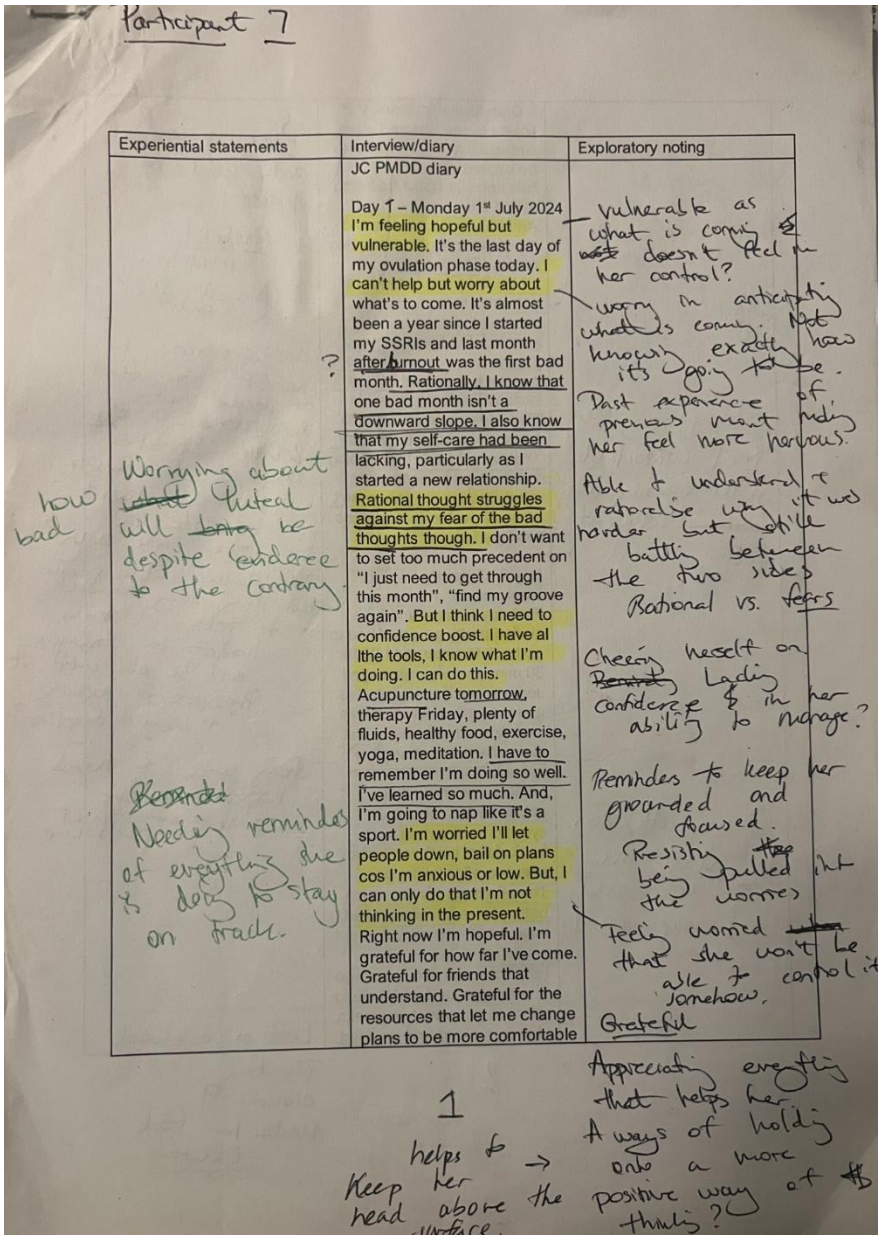
Participants will be asked to keep personal diaries of their thoughts and experiences of living with PMDD for two weeks prior to the one-to-one interview. As this process may bring up some distress for participants, the researcher will minimise this by:

(a) Discussing the risk of distress during the initial screening phone call (see 'Screening call protocol').
(b) Providing information and contact details for additional support should they feel the need to reach out during that time (see 'Diary protocol').
(c) Encouraging participants to keep their diaries in a way that feels easiest and most accessible for them. This could be in the form of note taking, paper diaries or voice recordings.

(d) Reminding participants that they can withdraw their participation at any time.

See ‘Diary protocol’ document for further information on diary keeping guidelines and information and additional resources to be sent to participants to help manage distress.

Appendix I: Exploratory noting and experiential statements (an example)



Participant 7

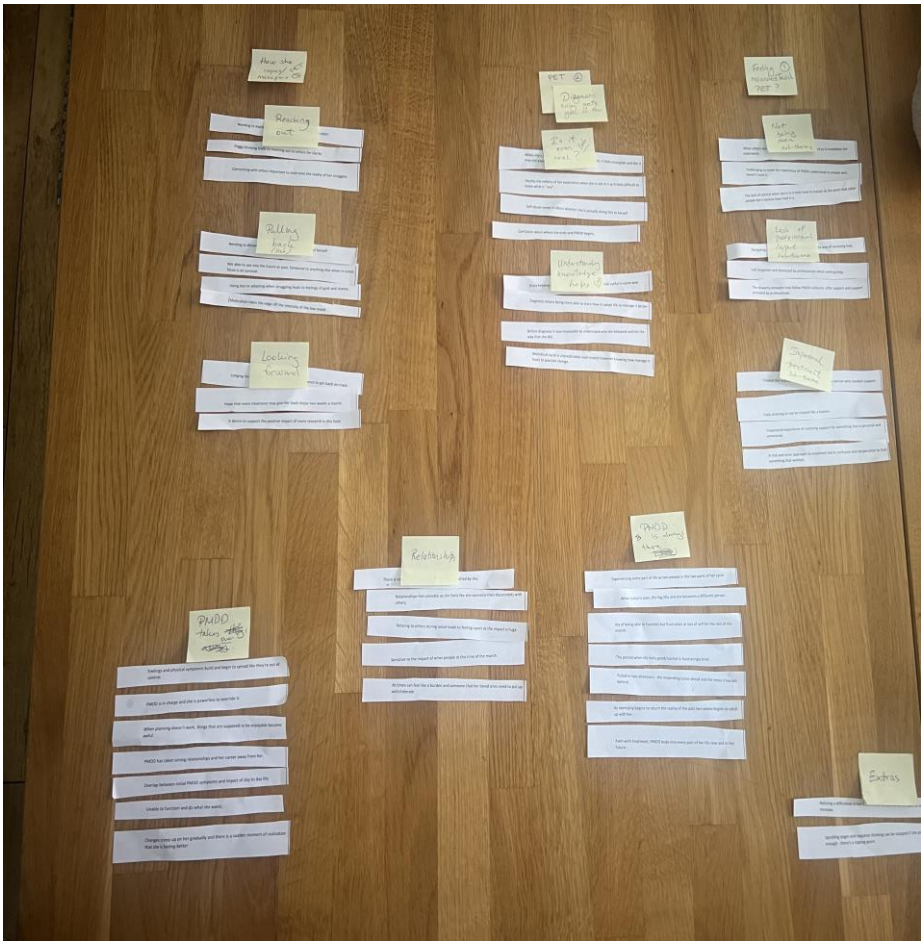
Experiential statements	Interview/diary	Exploratory noting
	JC PMDD diary Day 1 – Monday 1st July 2024 I'm feeling hopeful but vulnerable. It's the last day of my ovulation phase today. I can't help but worry about what's to come. It's almost been a year since I started my SSRIs and last month after burnout was the first bad month. Rationally, I know that one bad month isn't a downward slope. I also know that my self-care had been lacking, particularly as I started a new relationship. Rational thought struggles against my fear of the bad thoughts though. I don't want to set too much precedent on "I just need to get through this month", "find my groove again". But I think I need to confidence boost. I have al lthe tools, I know what I'm doing. I can do this. Acupuncture tomorrow, therapy Friday, plenty of fluids, healthy food, exercise, yoga, meditation. I have to remember I'm doing so well. I've learned so much. And, I'm going to nap like it's a sport. I'm worried I'll let people down, bail on plans cos I'm anxious or low. But, I can only do that I'm not thinking in the present. Right now I'm hopeful. I'm grateful for how far I've come. Grateful for friends that understand. Grateful for the resources that let me change plans to be more comfortable	Vulnerable as what is coming doesn't feel in her control? worry in anticipating what is coming. Not knowing exactly how it's going to be. Past experience of previous must make her feel more nervous. Able to understand & rationalise why it was harder but still battling between the two sides Rational vs. fears Cheering herself on Lady confidence & in her ability to manage? Reminders to keep her grounded and focused. Resisting being pulled into the worries Feeling worried that she won't be able to control it somehow. Grateful
Worrying about what if Luteal will be despite evidence to the contrary how bad Needing reminders of everything she is doing to stay on track.		

1

helps to Keep her head above the

Appreciating everything that helps her
Ways of holding onto a more positive way of thinking?

Appendix J: Developing the PETs



Appendix J: Developing the PETs (contd.)

PET 1: Diagnosis brings clarity and acceptance	
Sub-theme: Uncertain if experience is real without the evidence	
1. The menstrual cycle can be summarised using dates and symptoms	*Day 1 (period starts) 29th July and lasted 4 days, normal flow and duration. p.1*
87. The scientific evidence proves the validity of her experience	*It's almost like having evidence-based acceptance. p. 28*
32. Diagnosis is an external confirmation of what is real	*You have a bit of an explanation um, and validation. p. 10*
Sub-theme: Understanding PMDD makes sense of the past	
91. Before diagnosis, life was a puzzle that needed to be completed	*It just puts all the pieces together and again gives me more validation and makes me feel more ok with it. p. 31*
47. Making connections between past and present	*I think looking back, historically there's been lots of periods where I've gone "oh I feel really trapped in myself". p. 16*
29. Confusion and doubt about her past experiences	*…wondering if I'd had um BPD this, this whole and you know I've had that in the past and... p. 9*
Sub-theme: Understanding is a privilege	
86. To understand is a privilege	*I am really fortunate to have that in a way and to now understand a lot of these, that these things aren't just me and aren't unexplained. p. 28*
22. Disbelief at the delay in diagnosing PMDD	*...it was like woah, this is this is crazy. p. 8*
PET 2: Coping with PMDD	
Sub-theme: Coping through connection with people and nature	
80. Supporting other women is a way of taking back control	*Being proactive and taking part in things like this, um helps me a lot. p. 26*
85. Connecting with other people leads to acceptance	*Whether that's just reading someone else's experience of it and going "oh myyy god, yes, yes, thank you, yes, that resonates". p. 28*
41. Being understood by someone brings a sense of relief	*… he was like "hm ok" and then I just come out of it. p. 14*
89. Social media and the internet has opened up connection and communication	*We didn't have social media in the way that we do now where it can be tailored towards connection about these things. p. 30*

Participant 1 (Emma) | Participant 2 (Nathalie) | Participant 3 (Josie) | Participant 4 (Eleanor) | Participant 5 (Nina) | Participant 6 (Joanna) | Participant 7

PET 1: Anger at the lack of knowledge and guidance		
Anger at there not being enough tangible help available	*Um, so for my life for like the last few years, to literally have revolved around this and then not be anything that is particularly helpful to me is... to be frank, I'm quite pissed off about it (small laugh). But yeah, it's it's annoying, yeah.*	12
Unhappy with having to take a lead on her treatment	*why in my life is a doctor coming to me and saying what do you want to do? I don't, I don't know. What what should I be doing? You should be telling me and I feel like I've done more of the research. And more than I really want to have done.*	13
Frustrated at the lack of helpful and relevant research	*I was like are there any? and and I did just happen to look and I think I joked to you that I'd seen more studies on chicken food than I had on PMDD that would be relevant to me.*	10
PET 2: When it feels like PMDD takes over		
Sub-theme: Fearful of what may happen		
Anxious about always having PMDD and its impact in the back of her mind	*I am- I can- or if I think about it enough, I can get anxious about the thought about being anxious.*	19
Worrying about how bad luteal will be despite evidence to the contrary	*Rational thought struggles against my fear of the bad thoughts though.*	1
Slipping backwards is the biggest, overarching fear	*But, because it's such a sensitivity because I am almost so terrified of being that low again, it's always the thing which I then become most paranoid about.*	22

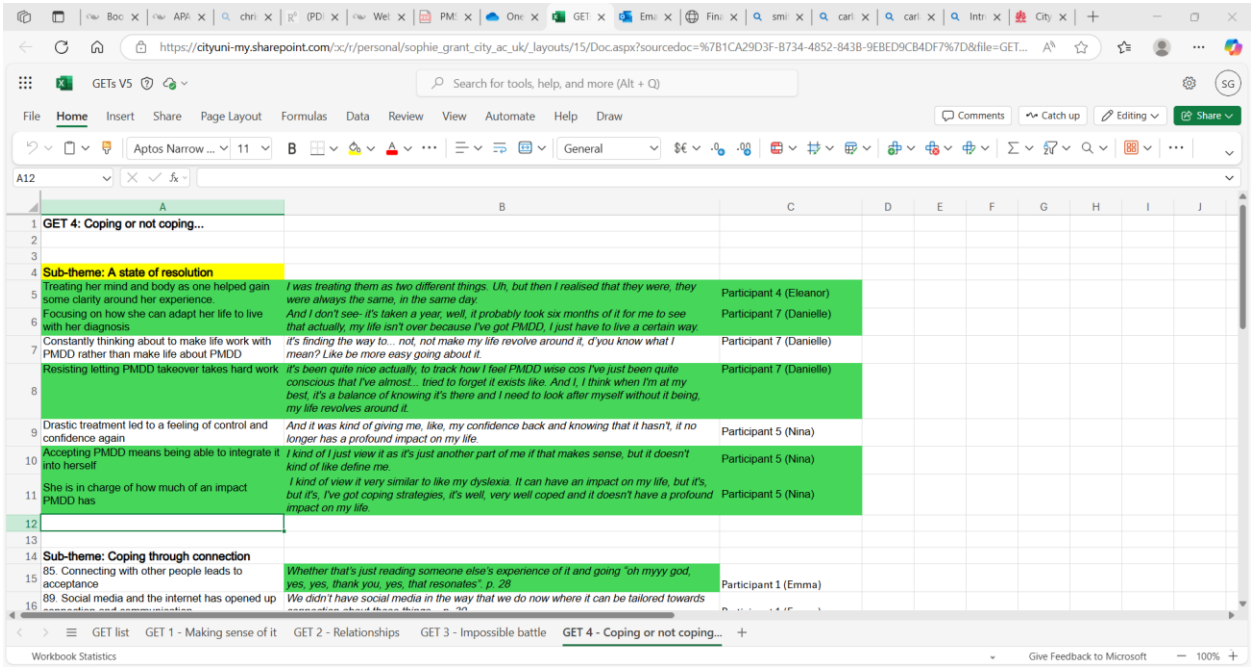
Experiential statements | PETs | +

Appendix K: Developing the GETs

GET 2 - Relationship with the external world

Sub-theme: Relationship with professionals - no guidance	**Not enough knowledge, not the right language, dismissing, no clear treatment, misunderstood by those who are supposed to help**	
Speaking up when a lack of expertise led to significant deterioration.	*p.18 "Then, I was treated with the progesterone only injection, again three months of wanting to die (laughs)... and it was me that again said to them look, I think I'm sensitive to progesterone, this is not helping.*	Participant 2 (Nathalie)
Reaching out for help felt pointless as nothing came from it	*I'd called the doctors and said it was getting really bad and I was really struggling with my mood every month and they didn't say a lot. They said, here you can try some birth control and and I'm already on the implant and they gave me the pill and I just, they gave me no information. Um so that wasn't a very nice experience...*	Participant 6 (Joanna)
Anger at there not being enough tangible help available	*Um, so for my life for like the last few years, to literally have revolved around this and then not be anything that is particularly helpful to me is... to be frank, I'm quite pissed off about it (small laugh). But yeah, it's it's annoying, yeah.*	Participant 7 (Danielle)
Women's health is misunderstood and leads to normalising of extreme symptoms	*I remember feeling really, really anxious and I just thought ohh, everyone feels like this because obviously women's health isn't really talked about much and it's like not someth- this all this like periods thing, you don't really go and talk to your friends about it, it's just like such a taboo subject, so I thought it was normal.*	Participant 5 (Nina)
Risking misdiagnosis by seeing things from one perspective	*And then from, like, a mental health perspective, they saw it as how had she had kind of like some sort of psychotic episode.*	Participant 5 (Nina)
The pattern of symptoms was there but no one could see it or understand it.	*And it took me about... Maybe five years um to get to a point where I was listened to. Like uh, I I I at the beginning I was having like... I couldn't understand what was happening like I just felt that I had this, like ups*	Participant 4 (Eleanor)

GET list | GET 1 - Making sense of it | **GET 2 - Relationships** | GET 3 - Impossible battle | GET 4 - Coping or not coping...



Part B: Publishable paper

Navigating life after a diagnosis of PMDD: A diagnosis alone is not enough

This article was prepared with the intention of submission for publication in the Psychology of Women Quarterly.