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Exploring Qualitative Experiences of Premenstrual Dysphoric Disorder within the US Healthcare System

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Exploring Qualitative Experiences of Premenstrual Dysphoric Disorder within the US Healthcare System

By

Kiera Chan
Bachelor's of Science
University of North Georgia
2019

Thesis Committee Chair: Cari Jo Clark, Sc.D., M.P.H.

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Global Health
2022

Abstract

Exploring Qualitative Experiences of Premenstrual Dysphoric Disorder within the US Healthcare System

By Kiera Chan

Premenstrual Dysphoric Disorder is a premenstrual condition that affects 3-8% of the US population, yet knowledge on treatment and consistent diagnostic testing is lacking. It is a clinical disorder defined by the presence of cognitive-affective and physical symptoms presented in the week before menses. Historically, PMDD has been a controversial diagnosis due to ambiguity around diagnostic criteria and gaps in provider knowledge, leading to delays in diagnosis. While research concerning the epidemiology and pharmaceutical treatments for this condition has increased, there is a lack of qualitative studies on the experiences of patients who live with this condition. Understanding the main experiences and barriers to diagnosis will lead to an increase of appropriately diagnosed cases and, eventually, the delivery of proper treatment. The aim of this study was to explore the diagnostic and treatment experiences of PMDD patients in the U.S. healthcare system and identify barriers to diagnosis and treatment. This study uses a feminist framework with qualitative phenomenological methods. We recruited participants who identified as having PMDD, regardless of official diagnosis, through online forums within the U.S. PMDD community. The study conducted 32 in depth interviews with participants on their experiences with PMDD diagnosis and treatment. Analysis methods using constructivist grounded theory revealed key barriers within the diagnostic and care process including patient, provider, and societal barriers. This study presents a PMDD Care Continuum that represents the timeline of participant experiences beginning from symptom onset towards official diagnosis, treatments, and ongoing management of the condition. Participant experiences demonstrated that the majority of the diagnostic and treatment process was burdened on the patient, and that successful navigation within the healthcare system was dependent on high levels of self advocacy. This study concluded that an official diagnosis did not result in doctors being able to treat PMDD. Instead, participants had to be reevaluated and diagnosed again with every new provider they saw. This was the first study of its nature to describe the qualitative experiences of patients who identified as having PMDD in the U.S. Further research is needed to refine and operationalize diagnostic criteria and treatment guidelines for PMDD.

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Acknowledgements

This research would not have been successfully completed without the help and collaboration from the International Association for Premenstrual Disorders and the Center for Reproductive Health Research in the Southeast for their support. I would like to thank my thesis advisors, Dr. Cari Jo Clark and Dr. Anna Rubtsova. I would like to acknowledge the participation of all the women in this study, without whom this research would not be possible.

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Chapter 1: Introduction

Statement of the Problem

Premenstrual Dysphoric Disorder (PMDD) is a condition that affects 3-8% of menstruators worldwide, yet knowledge on treatment and consistent diagnostic testing is lacking (Gehlert, 2009; Rapkin & Lewis, 2013). PMDD is defined as a "cyclical recurrence of distressing or impairing affective symptoms" and symptoms must appear 3-4 days before menstrual bleeding (Eisenlohr-Moul, 2019). PMDD is a premenstrual condition that has been officially recognized by clinical and scientific research and is part of the DSM-V (Hartlage, 2014). Quality adjusted life years, or QALY is a measurement that quantifies the burden of disease using life years lived with disease and adjusting with quality of life measurements. Patients with PMDD are considered to experience loss of quality adjusted life years comparable to that of patients with other mental disorders, including major depressive disorder (Yamada, 2017). The Global Burden of Disease (GBD) estimated PMDD to be 0.5, with 0 as perfect health and 1.0 as death, which points to the public health relevance (Halbreich, 2003). Furthermore, both the incidence of PMDD and related suicide reports are increasing globally (Gao et al., 2021).

There is a paucity of literature examining the lived experiences of women with PMDD. Using the experiential knowledge of my participants, I seek to reveal diagnostic and treatment practices from the perspective of patients who have been historically underrecognized in order to reveal underlying barriers to diagnosis of PMDD in the US healthcare system. The research that has examined experiences of women with this condition required an official clinical PMDD diagnosis by a health professional or the completion of the Premenstrual Symptoms Screening Tool (Hardy & Hardie, 2017; Osborn et al., 2020a). In contrast, in this study, I will allow participants to identify whether they have PMDD or not (Evans et al., 2021; Grundstrom, 2018; Osborn et al., 2020; Soucie, 2021; Tomlinson, 2017). To develop an understanding of PMDD from the patient's perspective, this study uses approaches from phenomenology and grounded theory (Annells, 2006). It also uses a feminist approach to explore the lived experiences of individuals who identify as having PMDD (Campbell, 2000). Using a feminist perspective to gain understanding of this condition will disrupt the traditional androcentric biomedical discourse on PMDD. Feminist critiques of research have led to the emphasis on representing the lives of women, who were often ignored or not well represented in research (Smart, 2009). Qualitative research with a feminist perspective seeks to produce research for women rather than on women and recognizes the rights of participants (Henwood & Pigeon, 1995).

There has been an influx of scientific research around PMDD and its etiology and treatment in recent years; however, the specific etiology of PMDD remains contentious, hampering diagnosis and treatment and resulting in negative patient outcomes (Halbreich et al, 2003). Gender bias is prevalent in the healthcare system, leading to barriers in diagnosis and treatment for women (Hamberg, 2008). Given the prevalence of diagnostic or treatment delays or gender discrimination globally, there is a need to study specific women's health disorders from a patient perspective of PMDD (Din et al., 2015; Lyratzopoulos et al., 2013). There is a need to understand the experiences of diagnosis and misdiagnosis among individuals with PMDD due to the high prevalence of healthcare professionals and patients who are unaware of this condition (Freeman. 2003). Understanding the main experiences and barriers to diagnosis will lead to an increase of appropriately diagnosed cases and, eventually, the delivery of proper treatment. The purpose of this study is to determine barriers to diagnosis and condition management of PMDD and examine the strategies patients use to receive or cope with a diagnosis and understand why patients may not receive a diagnosis.

This thesis has two aims:

1) To describe experiences among patients with PMDD
2) To identify barriers to diagnosis and successful treatment of PMDD in the US healthcare system

Significance statement

There is a need to create evidence-based practice guidelines on diagnosis and treatment of PMDD in order to create a formal consensus around the condition. In order to do this, it is crucial to understand the perspectives of the patients with current diagnosis and treatment experiences in the US healthcare system. Improving the healthcare system for women with premenstrual disorders by targeting specific barriers will help to shorten the diagnostic delay and treatment delay. Furthermore, it will help practitioners to understand why patients may not seek treatment or providers may not have the tools to help patients who do seek treatment. There are gaps within the healthcare community around general knowledge of PMDD as well as diagnostic practices. This study will help to bridge those gaps and point to areas of further research and practice. The results of this study will aim to address the knowledge gap around PMDD by providing a qualitative sample of patients' perspectives on their experiences within the US healthcare system, beginning with the first onset of symptoms to current management of the condition.

Although this study will not actually create diagnostic or clinical guidelines, it will help build a better knowledge base around the management of PMDD in our current healthcare system so that further studies around diagnosis or treatment can be conducted to refine existing practices, create new guidelines, or build programs for public health training and patient support.

Chapter 2: Literature Review

Overview of PMDD

PMDD is a cyclical mood and premenstrual disorder appearing in the luteal phase of the menstrual cycle, which is the phase from ovulation to the start of menstruation (Hofmeister & Bodden, 2016; Osborn et al., 2020). The prevalence of PMDD has been found to impact 3-8% of individuals who menstruate, however reported prevalence rates vary widely throughout epidemiological studies due to diverging study definitions of PMDD and disparate symptom criteria (Biggs & Demuth, 2011; Halbreich et al., 2003; Halbreich, 2004). Symptoms must discontinue less than four days after menstrual bleeding to be considered PMDD (Hofmeister & Bodden, 2016). The health-related quality of life (HRQoL) burden of PMDD is greater than that of type 2 diabetes and comparable to rheumatoid arthritis (Yang et al., 2008). Furthermore, the Global Burden of Disease (GBD) estimated PMDD to be 0.5 on a scale from 0 as perfect health to 1.0 as death (Halbreich, 2003). Individuals with PMDD have been found to have a lifetime suicidal ideation prevalence of 45.8% (Obsborn et al., 2021). The impact of PMDD has been found to significantly impair the quality of life of individuals (Carter et al., 2002; Yonkers, 1997). PMDD patients have been found to have comorbidities of other psychiatric disorders, such as PTSD, or having a family history of mood disorders (Yonkers, 1997; Endicott, 2000;

Sepede et al., 2020). Other studies have found PMDD to be a risk factor for postpartum depression (Gao et al., 2021; Fornaro & Perugi, 2010).

Etiology of PMDD

PMDD is characterized by an abnormal response in the brain towards a normal monthly change in hormone levels post ovulation (Eisenlohr-Moul, 2019). PMDD is caused by the dysregulation of levels of allopregnanolone, which is a neurosteroid made from progesterone (Girdler et al., 2001). Specifically, the metabolic pathway that converts progesterone into allopregnanolone is modified. Women with PMDD were found to have greater objective and subjective sensitivity to stress in the luteal phase, due to this allopregnanolone dysregulation and altered HPA axis (The HPA axis is a set of interactions between the hypothalamus, pituitary gland, and adrenal glands, which regulates the body's stress response)(Hantsoo & Epperson, 2020). PMDD has been found to have a genetic association, specifically a variation in the Estrogen Receptor Alpha (ESR1) gene (Huo et al., 2007; Miller et al., 2010; Raffi et al., 2020).

History of PMDD

PMDD has not been recognized in the international medical community as a distinct condition until recent years but has plagued menstruators for centuries. For instance, "hysteria" was first linked to premenstrual symptoms and can be dated from the 5th century BC (Tasca et al., 2012). In the 1950s, the term "premenstrual syndrome" (PMS) began to be widely used throughout society and healthcare (Endicott, 2000). In the 1980s, researchers began to focus on premenstrual mood changes, which led to the National Institutes of Health to hold a workshop in 1983 to address research methodology in this field. This workshop established the criteria for premenstrual symptomatology to be considered a syndrome, or a clinically significant behavioral pattern (Stein, 2010). The DSM is a standardized system for classifying mental conditions (Sanders, 2011). In 1987, the criteria for late luteal phase dysphoric disorder (LLPDD) were published in the Appendix of DSM, Third Edition, Revised (DSM-III-R) (Johnson, 2004). Consistent clinical studies around a clear pattern of symptoms in the luteal phase indicated the need for a distinct diagnosis (Epperson, 2012). In 1993, this condition was changed to "Premenstrual Dysphoric Disorder" in the Appendix of the DSM-IV as a mood disorder not otherwise specified. In 1998, a panel convened to discuss the distinctness of PMDD as a clinical condition, and in 2013 PMDD was included in the DSM-V as a distinct category after much controversy (Endicott, 2000; Hartlage et al., 2013). Controversy included the concern over the lack of a clear definition of PMDD and the possibility of resulting misdiagnoses (Severino, 1996). The inclusion of PMDD in the DSM led to its evaluation and final inclusion in the World Health Organization's (WHO) International Classification of Disease (ICD) 11th edition in 2019. Its primary location is in the chapter on genitourinary diseases and is cross listed in the depressive disorders subgroup (Reed et al., 2019).

Diagnosis of PMDD

The DSM-V requires that at least five of the eleven possible symptoms listed in the manual must be present for most of the luteal phase and absent upon menses (Gehlert et al., 2009; Hantsoo & Epperson, 2015). One must be an affective symptom such as depressed mood and another must be a behavioral symptom, such as low energy or breast tenderness. The second criterion is that these symptoms must interfere "markedly" with school, work, or relationships (Gehlert et al., 2009). The third criterion is that these symptoms cannot be a result of another psychiatric disorder. Furthermore, all of these symptoms must be confirmed by prospective daily ratings for at minimum two consecutive menstrual cycles. The requirement for at least 5 symptoms lacks any supportive empirical evidence for the diagnosis of PMDD (Freeman, 2003). Clinical guidelines stress the difference between PMDD and other mood disorders as the onset of symptoms during the premenstrual phase, which creates a predictable and distinct pattern (Epperson et al., 2012). The DSM-V does not clearly distinguish between PMDD and PME, or Premenstrual Exacerbations of ongoing mental disorders (Keuhner & Nayman, 2021). There are disparities between some requirements for PMDD as well as disparities in diagnostic methods, which has created issues for diagnosis as well as problems for clinical trial inclusion criteria (Halbreich, 2004; Henz et al., 2018).

Controversies with the DSM

Within the DSM itself, there are opposing views over its inclusion as an official psychiatric disorder. For instance, some have concerns regarding the lack of research on PMDD, and its inclusion in the DSM may thus discourage further research (Di Giulio & Reissing, 2006). PMDD is classified as a psychiatric and medical condition, which introduces complexity in the way PMDD is conceptualized and diagnosed (Osborn et al., 2020). Recent studies have discovered neurobiological differences between PMDD patients and controls, which points to PMDD as a genitourinary disease instead of a psychiatric condition (Osborn et al., 2020). Some researchers have posited that placing PMDD in the DSM-V was urged by the agenda of the industry, leading to increased profits for pharmaceutical companies and boards benefitting from the sale of psychiatric medications (Cosgrove & Wheeler, 2013). Because there is no biological marker for PMDD as well as other mental conditions in the DSM, there are controversies surrounding the psychiatric labels that these diagnoses can present due to the subjective nature of the criteria (Khoury et al., 2014). The criteria in the DSM for PMDD have been evaluated as ambiguous, leaving most of the responsibility on the clinician's ability to accurately assess and diagnose (Coveleski, 2019). The DSM in general has been known to leave out women-specific issues, which is derived from a lack of inclusion of women on DSM revision task forces (Wittchen, 2010).

Diagnostic Tools and Their Challenges

There is no universal standardized diagnostic measuring tool assessing for PMDD (Wittchen, 2010). There are prospective tools such as the Daily Record of Severity Problems (DRSP) as well as retrospective tools such as the Carolina Premenstrual Assessment Scoring System (Bailey et al., 2019; Schmalenberger & Eisenhlohr-Moul, 2017). Some providers use interviewing, which alone cannot confirm diagnosis, as the most frequent and only method of diagnosis instead of using daily symptom ratings (Accortt et al., 2011; Craner et al., 2014). Using prospective self-ratings as the main method of diagnosis has been debated due to the possibility of patient non compliance and unwillingness of providers to use this screening method (Apperiibai & Alonso-Arbiol, 2020). Diary based diagnostic tools have been found to be more accurate than retrospective screening tools (Śliwerski & Koszałkowska, 2021). Some studies suggest using multiple methods such as both prospective and retrospective screening to increase diagnostic accuracy, however this is not a universally accepted method (Schmalenberger & Eisenhlohr-Moul, 2017). One study found that only 12% of providers used prospective ratings across two cycles to diagnose PMDD (Craner et al., 2014). The requirement for impaired "daily functioning" is ambiguous, leading to the possible misunderstandings (Bailey et al., 2019). The requirement for symptoms to be present during the luteal phase of menstruation is also a vague construct that requires operationalization (Epperson & Hantsoo 2017). The lack of specification of how many days of symptom onset in exactly which days in the menstrual cycle is a methodological flaw (Hartlage et al., 2013). Tracking symptoms across two menstrual cycles may delay diagnosis and treatment, which also poses issues for the diagnosis method (Hantsoo et al., 2022).

Barriers to Diagnosis

Historically, PMDD has been a controversial diagnosis. This has been in part due to areas of ambiguity around diagnostic criteria as well as lack of knowledge around the etiology of the condition. Gaps in provider knowledge continue to hinder the diagnostic process, leading to delays (Osborn et al., 2020). There are no standardized clinical criteria for PMS, which poses problems for clinically distinguishing PMS and PMDD (Bailey et al., 2019). As there are no specific endocrine tests available for most premenstrual disorders, many premenstrual disorders are often unrecognized or misdiagnosed (Mehedintu et al., 2014; Mishell, 2005). Some disorders such as depression may have worsening of symptoms during the premenstrual phase, which could present issue for accurately diagnosing PMDD (Biggs & Demuth, 2011). Due to society's negative attitudes towards PMS and PMDD, patients are less likely to seek treatment due to shame (Johnson, 1987). Other psychosocial factors such as perception of "natural menstrual cycles" may impact patient self awareness of PMS (Warner & Bancroft, 1990).

Gender bias as a Barrier to Diagnosis

Due to society's expectations for women as caregivers, women are more likely to self-silence and not seek treatment (Maji & Dixit, 2019). Medical schools lack an evidence-based evaluation and treatment methodology for PMDD, causing lack of awareness around PMDD among providers (Hantsoo, et al., 2022). The complexity of diagnosis leads women to suffer from untreated PMDD symptoms for many years (Osborn et al., 2020). In general, women have been known to be dismissed and mistreated in the U.S. healthcare system. Overall, women wait longer for medical attention and their pain or symptoms are dismissed compared to men (Carnlof et al., 2017; Hoffman et al., 2001; O'Donnell, 2021; Shabbir et al., 2004). Clinical trials often lack an inclusion of women participants, leading to a lack of research on women specific conditions as well as sexual differences in medicine (Rogers, 2015). Clinical studies on pain have lacked female subjects (8%), with only 4% of studies testing sex differences (Greenspan et al., 2007). Studies have shown that women receive less pain medication but more antidepressants and mental health referrals than men for the same conditions (Samulowitz et al., 2018).

Bias against women in medical schools and in the medical field impacts women's experiences in the healthcare system (Patricia, 2019). Women's health issues and women's bodies have been historically excluded from medical research and texts, which leads to systematic bias in the diagnosis, treatment, and research of women's health issues (O'Donnell, 2021). In one study on women suffering from chronic pain, 83% reported gender discrimination from healthcare providers. Gender bias is apparent in healthcare, especially when looking at healthcare expenditures for men versus women for the same condition (Hamberg, 2008). Medical mistrust, defined as "a lack of trust in the health care system felt by those who have experienced discrimination when receiving care" is prevalent among women who have experienced gender discrimination in healthcare (Jaffee et al., 2021; Sheldon & Botelho, 2021). Although some premenstrual disorders such as endometriosis are more common, impacting up to 15% of reproductive age women, the disease is still poorly understood and underdiagnosed (Mehedintu, 2014). Nonspecific, functional, and somatoform syndromes (NFS) is a diagnostic term for unexplainable symptoms and is more common among women than among men (Claréus & Renström., 2019). Women wait longer to receive diagnoses than men, with women waiting an average of 14.8 days longer in one study (Sun et al., 2020).

Depression is more commonly diagnosed in women than in men (Hamberg, 2008). Even before the creation of the DSM, depression was thought to be more common in women than in men. One reason for this is that symptoms of depression are considered intensified traits of what is considered to be female such as helplessness (Norman, 20014). In the DSM-II, “hysterical personality disorder” was diagnosed among women with the symptoms of “excitability, emotional instability, over reactivity, and self-dramatization (Ussher, 2013).” It was later renamed histrionic personality disorder to avoid connotations with hysteria, but the connotations still remain. Both borderline personality disorder and histrionic personality disorder are considered conditions that stemmed from hysteria and are more commonly diagnosed among women. One study found that women with depression are more likely to be misdiagnosed with histrionic personality disorder than men, even with presentation of the same symptoms (Garb, 2021). Criteria for mental health disorders may be gender biased, which results in a gender difference in diagnosis rates (Widiger, 2000). Furthermore, women continue to be overrepresented in psychiatric care (Määttä, 2009).

Consequences of Underdiagnosis of PMDD

With the result of PMDD lingering in “diagnostic limbo,” women may continue to be misdiagnosed or left untreated (Gehlert, 2009). One study found that certain disorders were more likely to be diagnosed in women, including bipolar disorder, dissociative identity disorder, and depression (Kaplan, 1983). Another study found that 15-27% of women with bipolar also met a diagnosis of PMDD, pointing to the possibility of misdiagnosis or unclear diagnostic criteria (Sepede et al., 2020). There are often high rates of misdiagnosis of psychiatric disorders due to the overlap of symptom criteria (Ayano et al., 2021). The rapid cycling of mood swings in PMDD often mimics those in bipolar disorder, causing misdiagnosis (Iakimova, 2020). Patients with PMDD who were misdiagnosed report reluctance to accept the misdiagnosis, which leads to pressure into treatment compliance (Osborn et al., 2020). Misdiagnosis can cause patients further harm by prescribing incorrect treatments (Coveleski, 2019). Some cases of misdiagnosis lead to attempted suicide and psychiatric hospitalizations, showing the impact of delayed diagnosis or misdiagnosis (Yamauchi et al., 2019). It takes an average of 20 years for women to be accurately diagnosed and treated for PMDD (Osborn et al., 2020). Individuals with undiagnosed PMDD report impairment in work productivity, lost wages, and higher medical expenses (Craner et al., 2013; Heinemann et al., 2010). Furthermore, 30% of individuals with PMDD report suicidal attempts, and women with PMDD are more likely to report suicidal ideation than those with PMS (Eisenlohr-Moul et al., 2019; Osborn et al., 2021).

Treatment of PMDD

Overall, due to the lack of understanding of the etiology of PMDD, lack of ability to test for biomarkers for PMDD, and the complex nature of the behavioral and affective symptoms, there are limited options for treatment of PMDD (Alevizou et al., 2018). Treatment options differ corresponding to the level of severity of certain PMDD symptoms and the type of treatments the patient may tolerate (Steinberg et al., 1999). Selective Serotonin Reuptake Inhibitors (SSRIs) are considered the first-line treatment for PMDD, with some patients being prescribed luteal phase administration and others treated on a continuous basis (Hantsoo & Epperson, 2015; Meir et al., 2006; Rapkin & Lewis, 2013). Efficacy for SSRIs has been shown by response rates of 60-90% compared to 30-40% for the placebo (Cunningham et al., 2009). Another study found that SSRIs demonstrated relief for 50% of symptoms in 60-80% of PMDD patients (Rapkin & Lewis, 2013). Another first line treatment is hormonal oral contraceptives, which have shown symptom relief of 30-59% in controlled trials (Freeman et al., 2012). Oral contraceptives have shown mixed results symptom relief among studies, with evidence pointing to higher efficacy with combined hormone therapy instead of monotherapy (Hantsoo & Epperson, 2015; Johnson, 2004; Laza di Scalea & Pearlstein, 2017). Other non-first line treatments include ovulation suppression methods, such as chemically or surgically induced menopause (Rapkin & Lewis, 2013). Chemical menopause includes the use of gonadotrophin releasing hormones to suppress the ovaries, which has shown effective symptom reduction (Carlini, 2020; Freeman et al., 1997). Surgical menopause is considered a final method of treatment for patients who have failed prior treatment methods and may involve uterus removal as well as bilateral oophorectomy (Cronje et al., 2004; Rapkin & Lewis, 2013). It has a high patient satisfaction rate (Cronje et al., 2004). Some supplements such as Chasteberry, Primrose Oil, Calcium, and B6 have been shown to reduce some PMDD symptoms as well, however low quality studies and primarily anecdotal evidence exist (Hantsoo & Epperson, 2015; Steiner et al., 2006).

Current Issues with Treatment Options

Although there are treatment options for PMDD, they are not modified specifically to this condition and its symptomatology (Coveleski, 2019). Due to the inclusion of PMDD in the DSM, other non-psychiatric medications such as ovulation suppression methods are not considered the primary treatments (Cosgrove & Wheeler, 2013). Although SSRIs are the first-line treatment, symptom relief has reported to be quite low among PMDD patients (Jackson et al., 2015; Rapkin & Lewis, 2013). SSRIs have been shown to often increase impairment due to the high number of side effects (Rapkin & Lewis, 2013). The chronic nature of PMDD causes issues when choosing treatment options, specifically due to the varying symptoms and degrees of severity (Johnson, 2004). For oral contraceptive options, one study found that 53% of patients' symptoms remained after use (Freeman et al., 2012). Among all oral contraceptive options, YAZ is the only one approved for treating PMDD, which points to limited options for patients, particularly if this medication fails (Lopez et al., 2012; Pearlstein et al., 2005). Surgical options are only given to a low number of women, those of whom have failed other treatment options (Dilbaz & Aksan, 2021). Clinicians worry that surgical options may pose no benefits and that patients will not tolerate post operative hormone replacement therapy (Johnson, 2004). There are no clear guidelines such as those proposed by the American Congress of Obstetrics and Gynecologists (ACOG) or American Psychological Association (APA) for PMDD, which prevents the existence of standardized treatment plans (Hantsoo et al., 2022). Further research on treatment methods for PMDD is vital, particularly due to the wide range in symptom clusters among PMDD patients (Kaiser et al., 2018). Patients with PMDD have reported trying multiple treatments over time with failure, which causes them to feel like giving up on finding a treatment that works for them (Osborn et al., 2020).

Barriers to Management

Overall, lack of research on PMDD produces difficulties for obtaining not only a diagnosis but also a plan for treatment (Tamaki et al., 2013). One study found that General Practitioners were ranked lowest among all practitioners when treating PMDD, which raises concerns for patients who have access only to a General Practitioner (Hantsoo et al., 2022). Another study found that the most common reason for not seeking treatment was that women felt that their symptoms were not “severe enough,” with 5-7% of respondents specifically believing their symptoms were a natural part of being a woman (Hylan, 1999). Furthermore, negative attitudes around PMS create barriers for women to seek treatment for their symptoms (Robinson & Swindle, 2000). Women with PMDD who are misdiagnosed are also less likely to seek treatment for PMDD (Osborn et al., 2020).

Mainly, there is a lack of research around women’s health issues, which leads to underdiagnosis, misdiagnosis, and lack of treatment for women. Studies have found that most cases of underdiagnosis among women are those in which providers believe nothing is wrong with the patient (O’Donnell, 2021). In general, PMDD poses a significant threat to productivity and a burden on daily life and relationships (Kelderhouse & Taylor, 2013). There is a lack of research on the specific barriers to management of PMDD, as most studies regarding PMDD tend to focus on the clinical nature of the condition. There is no cure for PMDD and the exact etiology of the condition is not understood. Currently, only one PMDD specific study using qualitative methodology exists using a sample from the United Kingdom, suggesting a need for further research, particularly within the United States (Osborn et al., 2020). This study found that receiving a diagnosis was a transformative process for many patients with PMDD and highlighted the many obstacles within this journey. There is one qualitative study in the United

Kingdom exploring the qualitative experiences of PMDD in the work context, which highlights the impact of symptomology on employment characteristics such as voluntary turnover or absenteeism (Hardy & Hardie, 2017). The consequences of underdiagnosis, delayed diagnosis, and misdiagnosis among PMDD patients is severe, as there is a significant risk of suicide attempts among PMDD patients compared to controls (Yan et al., 2021). Further research on PMDD and the specific barriers to diagnosis and management could lead to the development of effective guidelines, diagnostic protocols, and interventions for the medical community and PMDD patients. There may be significant health benefits for women who are diagnosed earlier, as women who are diagnosed later in life are more likely to attempt suicide (Osborn et al. 2020).

Methodological Framework

This study uses a feminist framework with qualitative phenomenological methods. Phenomenology is a qualitative methodology that seeks to answer the question, "What is it like to experience this phenomenon or event (van Manen, 2017)?" Phenomenology has been used to study health phenomena such as chronic illness, pain, disability, and pregnancy (Abrams, 2014; Carel, 2016; Kusch & Ratcliffe, 2018; LaChance Adams & Burcher, 2014). Feminist frameworks can be used in health research to understand how gender inequalities can impact women's health status (Ballantyne, 1999). Feminist phenomenology seeks to understand the gendered dimensions of lived experiences and embodiment of those experiences, which offers a view against the universalizing or privileged views of the majority within research (Lajoie, 2019). Feminist phenomenology has been used to uncover the embodied experiences of vulnerable populations and provide nuances that other methodologies would not have been able to capture (Oksala, 2016; Weiss, 2017; Young, 2009). Feminist phenomenology can provide a framework in which to study a gendered phenomenon within a male hegemonic structure such as the U.S. healthcare system (Goldberg et al., 2009). Phenomenology itself has been used as a methodology within health research sciences to disrupt traditional biomedical approaches of understanding illness by differentiating between subjective and objective views of the medical condition (Rodriguez & Smith, 2018). Using phenomenology to study women's health conditions can place a third person's description of an illness into a first-person account, as most clinicians are trained to discount patients' narratives in order to achieve a diagnosis and treatment (Cook & Brunton, 2015). This study uses both phenomenology approaches to collect and analyze the data, which has been proven useful in uncovering a complex human phenomenon such as a poorly understood medical condition (Annells, 2006).

Chapter 3: Study Methods

Population and Sample

The study context for this project was chosen as the United States patient population of PMDD. The eligibility criteria for this study included: 1) anyone who identifies as having PMDD regardless of official diagnosis, 2) anyone who is active in the PMDD community, which is defined by attending a PMDD virtual event or summit, participating in an online forum, or has received treatment or services through a PMDD provider or a Non-Profit; 3) able and willing to provide informed consent; 4) able to complete interview in English language; 5) US residents aged 18 years and older. Participants who identified as having PMDD, regardless of diagnosis were eligible as this study aimed to explore the common pathways to diagnosis in the U.S. healthcare system and thus needed a variety of diagnostic experiences. Participants were recruited in partnership with the Non-Profit, International Association for Premenstrual Disorders (IAPMD). Online advertisements were posted by Non-Profit communication managers on closed support group pages. Snowball sampling was also used to recruit participants through current participants and Non Profit members. The Non Profit approved and provided feedback on the interview guide prior to data collection.

Procedures

Data Collection

32 participants were recruited in the study in July 2021. Interviews were conducted over a two-week period in July 2021. Each confidential interview lasted about one hour and was conducted over Zoom or a phone call. Participants were asked a series of questions pertaining to their experiences with PMDD, their process of self diagnosis or provider diagnosis (if relevant), their past and current methods of treatment, and their experiences in the US healthcare system. The interviews followed a semi-structured interview guide consisting of 25 questions (please, see the Interview Guide in Appendix A). Prior to the interview, oral consent was received. The interviews were recorded over Zoom, even in cases in which an interview via phone call was used. They were then transcribed by trained research study members, deidentified, and stored in a password protected OneDrive folder. The audio recordings were deleted immediately post transcription. Descriptive demographic information was taken for each participant and is presented in Table 1 in the results. Each interview began with the participant agreeing to the confidential nature of the discussion and each participant was made aware of their ability to skip any questions during the interview. The data collection was conducted by lead researcher, Kiera

Chan, who was made aware of the potential for distress among participants during the interviews. All participants were directed towards resources and support services from the International Association for Premenstrual Disorders after the completion of the interview. Most participants were eager to participate and spoke positively about their interview experience and ability to contribute to research for PMDD.

Analysis

This study used a feminist phenomenological approach to explore the themes generated from the in-depth interviews to understand the lived experiences of patients with PMDD. By allowing participants to subjectively define whether they identified as having PMDD, phenomenology was used to understand the perspective of the patient within the healthcare system. A feminist framework intends to understand a phenomenon through the eyes of marginalized groups, as it recognizes that marginalized locations are epistemically superior in that they can deconstruct privilege and unveil previously unknown facts (Campbell, 2000).

The collaborative, semi structured interview allowed participants to generate their own ideas about the barriers that impacted their diagnosis and treatment of PMDD, as well as comment on the positive and negative experiences with providers. The interview guide and codebook both were organized in a few key themes that derived from both inductive and deductive methods. These themes included diagnosis experience, treatment experience, encounters with providers, and impact of PMDD on participants. A codebook was created using inductive methods by reading the transcripts, writing memos on emerging themes, and revising the codebook accordingly. Deductive codes were generated from previous literature on the patient experience and barriers to diagnosis. Themes were listed in the codebook with succinct definitions and were reviewed by an independent coder to ensure understanding of the codes. To avoid data being forced to fit into a codebook, a naive coder was assigned to code an initial transcript. The codebook was discussed and revised post preliminary coding. All de identified transcripts were uploaded into MaxQDA software.

5 coders were trained and were given the codebook. In order to achieve intercoder agreement, all coders coded one transcript and any discrepancies were discussed and until consensus was built prior to coding the entire dataset. The team continued this coding practice until agreement was reached. A total of 6 coders split the 32 transcripts evenly and coded simultaneously. Intercoder reliability was assessed through a comparison of coded transcripts from two independent and blinded coders. For the development of the codebook, a close read of the transcripts and memos were created by these two independent coders as well prior to the intercoder agreement. The codebook was then refined and reliability was assessed with the total of 6 coders. Intercoder reliability scores were not calculated. The coding team communicated regularly and collaborated across any discrepancies in coding. Furthermore, the conceptual model (described in the next section) was validated by continually returning to the data to confirm themes, patterns, and supported links across participant experiences. The broad themes that emerged from the conceptual model were confirmed constantly by going back to participant narratives, repeating data searches, and reviewing codes. The analysis process was reviewed by qualitative expert, Dr. Anna Rubtsova throughout to examine the interpretations and concepts developed from the data.

Analysis involved using grounded theory and phenomenology approaches to extract meaning and themes from the participants' narratives. Analysis comprised of coding data by inductive and deductive themes, as mentioned previously, conducting structured comparisons across the sample, developing thick descriptions, categorizing themes, and developing a conceptual model to explain these developing themes. Preliminary case summaries were created for each participant. A case summary template was used to create standardized summaries across the sample. Thick descriptions were written from the resulting codes. Narrative analysis was used to analyze themes and processes within each cases. Then, themes were assessed across all cases. Both case- and code-based analysis resulted in generation of conceptual themes. Types of cases such as participants who experienced misdiagnosis, self diagnosis, or diagnosis directly by a provider were created. Themes across these types of demographic cases were compared to create experience groupings. Conceptual codes were then created for a second round of coding, which resulted in relational analysis between codes and a final conceptual framework derived from the data. The coding process ended once saturation was reached or no new information was found in the data. Relational analysis derived from MaxQDA Code Relations Browser and Code Intersectional analysis tools. This analysis process involved reviewing associated codes to explore the nuances and depth of themes and concepts that emerged from participant narratives. Constantly overlapping codes were analyzed in relation to each other, creating a matrix across types of cases.

Development of a Conceptual Model

Thematic summaries of processes within the data were used to find patterns across the sample, describing the properties of each conceptual code and resulting process. Analytic memo writing was maintained throughout the analysis process as well as referring to quotes as evidence. From this analytic process, a conceptual model was created using the experiences of the participants, building upon a model derived deductively from a tuberculosis care continuum. The model builds off a conceptual model published in a study that explores barriers and delays in tuberculosis diagnosis and treatment (Yang et al., 2014). This conceptual model creates a PMDD care continuum that has never before been presented in prior research. This PMDD Care Continuum is characterized by overlapping barriers that cause specific delays in the patient's care continuum as well as certain feedback loops as patients move through the healthcare system. This model was derived inductively from the participants' experiences as shown by the feedback loop, but deductively as shown in the types of categorical delays above the continuum. This conceptualization of PMDD in light of separate overlapping barriers causing delays in presentation of symptoms to healthcare provider and initiation of treatment fit well with the narratives of the participants in the sample. Participants described their PMDD journey in terms of their ability to detect their symptoms and present them to a provider as well as the provider's ability to treat or detect symptoms. This entire process was described as an iterative process of presentation to health providers and initiation of treatment until the patient could find a provider and treatment method that helped to manage their condition effectively.

Ethical Considerations

This analysis was determined by the Emory IRB to be exempt, because it meets the criteria for exemption under 45 CFR 46.104(d)(2). All data was deidentified prior to analysis. Prior to data collection, all portions of the study materials were reviewed by the Emory IRB (ID number 00002906). The exemption was determined on July 23rd 2021.

Chapter 4: Results

Table 1.
n = 32

Variable	Age Range	M(SD) or %
Age	29 years [50-21]	33.9 (7.99)
Employed		71%
Female		100%
White		94%
Alaskan native		3%
Mixed		3%
Hispanic		12%
Some college (undergraduate)		19%
Bachelor's Degree		45%
Master's Degree		13%
Beyond Graduate School		3%
Completed High School		6%
Graduate School in Progress		6%
Single		65%
Married		29%
Divorced		6%
Household income <=25,000		32%
Household income >25,000 and <=50,000		32%
Household income >50,000 and <=75,000		6%
Household income >75,000 and <=100,000		6%
Household income >100,000		23%
How many years have you suffered from PMDD?		17.43 (8.86)
Official PMDD Diagnosis		87%
Years since official diagnosis		5.56 (5.63)

Notes: “unemployed” includes students

Figure 1. The PMDD Care Continuum

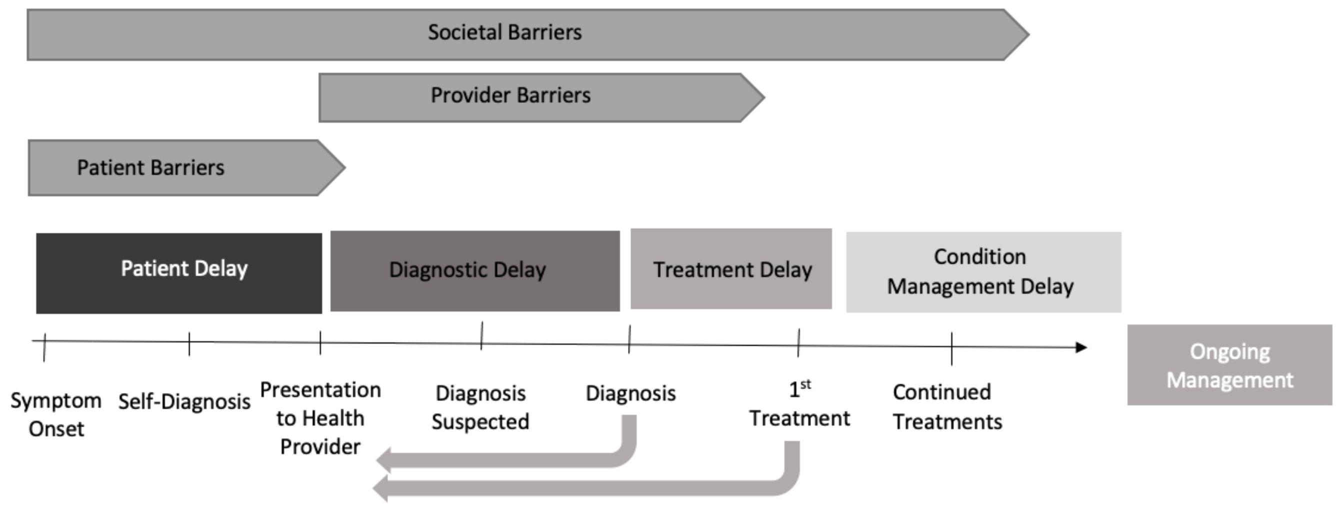
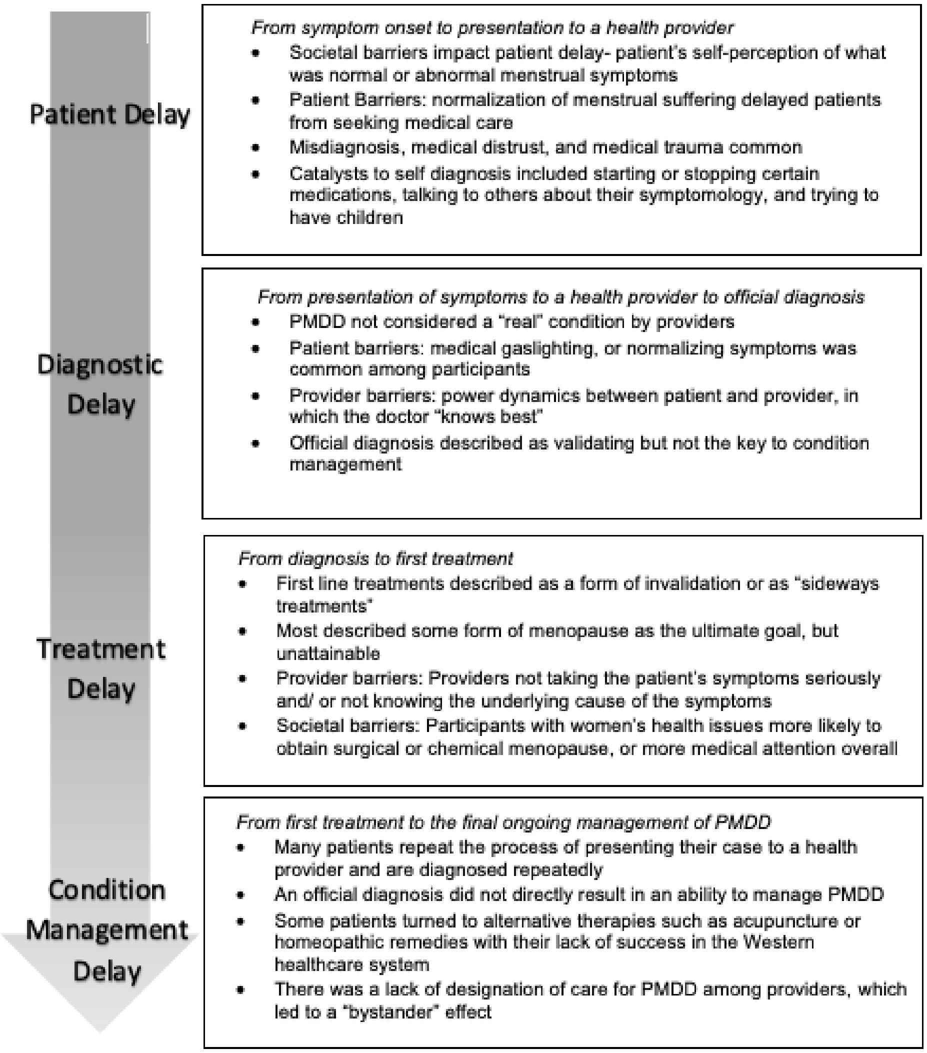


Figure 2. Care Continuum Delays



From symptom onset to presentation to a health provider

- Societal barriers impact patient delay- patient's self-perception of what was normal or abnormal menstrual symptoms
- Patient Barriers: normalization of menstrual suffering delayed patients from seeking medical care
- Misdiagnosis, medical distrust, and medical trauma common
- Catalysts to self diagnosis included starting or stopping certain medications, talking to others about their symptomology, and trying to have children

From presentation of symptoms to a health provider to official diagnosis

- PMDD not considered a "real" condition by providers
- Patient barriers: medical gaslighting, or normalizing symptoms was common among participants
- Provider barriers: power dynamics between patient and provider, in which the doctor "knows best"
- Official diagnosis described as validating but not the key to condition management

From diagnosis to first treatment

- First line treatments described as a form of invalidation or as "sideways treatments"
- Most described some form of menopause as the ultimate goal, but unattainable
- Provider barriers: Providers not taking the patient's symptoms seriously and/ or not knowing the underlying cause of the symptoms
- Societal barriers: Participants with women's health issues more likely to obtain surgical or chemical menopause, or more medical attention overall

From first treatment to the final ongoing management of PMDD

- Many patients repeat the process of presenting their case to a health provider and are diagnosed repeatedly
- An official diagnosis did not directly result in an ability to manage PMDD
- Some patients turned to alternative therapies such as acupuncture or homeopathic remedies with their lack of success in the Western healthcare system
- There was a lack of designation of care for PMDD among providers, which led to a "bystander" effect

Sample Description

As shown in Table 1, there were a wide range of demographic characteristics throughout the sample. Although the sample was not diverse in terms of race, it was diverse in regards to socioeconomic status. The average years from symptom onset to official diagnosis was 5.6 years. Overall, most participants (87%) in the sample had received an official diagnosis. The sample was highly educated, with over half having completed some college. The average age was 33.9 years, with the youngest participant being 21 years old and the oldest participant 50 years old.

Over half of the sample was single. Most participants were employed. Participants suffered PMDD for a mean of 17.43 years and experienced a mean of 5.56 years from symptom onset to official diagnosis.

PMDD Symptoms/ Experiences

There were a range of experiences of PMDD across the sample. Most patients suffered onset of symptoms during their first menses. Older participants described larger gaps to self-diagnosis or formal diagnosis. Most younger participants experienced diagnoses earlier on in life, saw at least 2-3 providers for PMDD, with some having seen 10 or more providers, depending on access to medical care. The youngest patient was officially diagnosed was at age 16 and the oldest was at age 45. A couple of participants had never been able to receive an official diagnosis. 5 participants described being sent to a psychiatric institution specifically for PMDD. A few participants described suicide attempts as a result of worsening PMDD symptoms. More participants may have experienced hospitalizations or suicide attempts but were not directly probed on this topic. One participant stated:

> Well, I have attempted suicide, and then in the U.S. after you attempt suicide, you're required to go to a psychiatric ward… They didn't really do anything at all in the psychiatric ward. I mean, I wasn't surprised, but it was useless. I mean they didn't do anything about the PMDD. They didn't, you know- I mean they actually took me off all my medication which was crazy. *Katrina, Age 36, 16 Years PMDD Sufferer*

Almost all 32 participants experienced suicidal ideation as a part of their monthly PMDD symptomology. Some participants described experiencing support from family or friends for their PMDD symptoms, and others experienced not being able to maintain relationships with family, friends, or partners as a result of PMDD. Although not specifically asked in the interview guide, many participants brought up that they were single, unemployed, or even lacked housing due to PMDD. Others mentioned that they were unable to complete their schooling or pursue the type of career they aspired to as a result of their condition impairment. Several participants described having to quit college, move back home, or live with friends when they experienced severe PMDD symptoms and had yet to be diagnosed or treated. Most participants took at least a few years since diagnosis to find a treatment or manage their PMDD symptoms. Many participants were prescribed around 5 different medications for PMDD. Most participants also tried at least one lifestyle change such as diet, meditation exercises, or alternative therapies such as dietary supplements. 6 participants experienced surgical menopause for PMDD and 2 participants underwent chemical menopause. A few participants used alternative therapies for PMDD symptom management, whereas other participants used only clinical treatments. Some patients did not have access to insurance or experienced cost related barriers, which impacted their ability to diagnose and manage PMDD. 20 out of 32 participants mentioned a comorbidity of an unrelated medical condition such as autoimmune, 13 of which were women’s health conditions. 6 out of the 13 women’s health conditions were endometriosis. Very few participants mentioned mental health comorbidities, unless it was misdiagnosed for PMDD.

PMDD Care Continuum

The results from this study revealed several themes and experience groupings that are represented in a continuum presented above in Figure 1. The results below are organized as following, “Patient Delay,” “Diagnostic Delay,” “Treatment Delay,” and “Condition Management Delay.” Several key themes in the process of diagnosis and treatment within the continuum are highlighted within each section. Types of barriers including societal barriers, provider barriers, and patient barriers were elicited from the participants’ experiences to represented the main barriers that impacted delays in diagnosis and care among the sample.

Figure Overview

This conceptual model (Figure 1), “The PMDD Care Continuum” describes the pathways found in the sample from symptom onset to condition management. The continuum captures the common pathways to diagnosis and treatment among participants. In this paper, the term “care continuum” will be used to describe the patient’s pathway in reference to the figure. The continuum starts with the onset of symptoms, leading to self diagnosis, the presentation of symptoms and self diagnosis to a health provider, followed by formal diagnosis, treatments, and eventually ongoing management of PMDD. Above the continuum are overlapping barriers that cause the delays to diagnosis, treatment, and condition management. Arrows at the bottom of the model describe the continuing cycle within the continuum until a patient can reach ongoing management.

Patient Delay

“Patient delay” describes the portion of the PMDD Care Continuum from symptom onset to presentation of PMDD to the patient’s health provider. Normalization of PMDD symptoms, such as part of being a woman or being equated with PMS, delayed self diagnosis and presentation to health provider. Many patients presented their symptoms to providers, but providers failed to recognize PMDD symptoms and would tell patients that it was “in their head.” Some patients believed their doctors when they were told their symptoms were normal or that they were making them up. Particularly when patients were younger, they were told that teenage girls were dramatic and that many teenage girls experienced severe PMS, so patients believed that their PMDD symptoms were normal. As shown in Figure 1, societal barriers impacted patient delay, specifically towards patients’ self-perception of what was normal and what was considered abnormal menstrual symptoms. Participants stated that this internalization of the normalization of menstrual suffering delayed them from seeking medical care. Participants also stated that menstruation was described as something women just have to suffer through. They stated that in older generations, there was no cure for menstrual suffering, so we still often have this same mindset that women should just suffer and there is nothing we can do about it. Patient barriers were personal factors that limited their ability to seek care or manage their PMDD in the healthcare system. For instance, one participant stated that women are taught to be selfless, and thus should take care of others, which encouraged them to further suffer in silence.

Misdiagnosis

Overall, nine participants experienced misdiagnoses, five of which experienced later PMDD self-diagnoses and the rest were diagnosed officially with PMDD later by a provider. 7 participants out of the 32 total participants received a PMDD diagnosis by a doctor. Most participants were misdiagnosed with bipolar or borderline personality disorder. Other misdiagnoses included schizophrenia, chronic fatigue, fibromyalgia, Post Traumatic Stress Disorder, and Cluster B Personality Disorder. Patients described bipolar and other common misdiagnoses as more readily available diagnoses for providers, because it has been a more established condition for longer and more people are aware of it. Some patients were so desperate for answers and treatment that they accepted their misdiagnosis, even if it did not necessarily fit them. One participant received a diagnosis of bipolar even with her PMDD diagnosis, and her mother assured her that the label was not important, that getting provider attention and the opportunity for treatment was key. Most patients who were hospitalized in a psychiatric ward came out with a bipolar diagnosis, even if they already had an official PMDD diagnosis prior to hospitalization. Patients shared that they have been to so many different providers, that it is likely that the disorganisation and lack of communication lead to misdiagnosis. Patients stated that providers did not spend enough time with the patient, which may also lead to misdiagnosis and not seeing the full picture. Other patients described a lack of awareness and understanding around PMDD as a reason for misdiagnosis:

> I think it's just, a lack of… understanding of PMDD, and people just, not willing to accept that PMDD is the way it is. I think people just don't want to believe that hormones can do that, and they just want to find any other reason to pinpoint it. And so bipolar is the most logical answer for them. *Rachel, Age 29, 18 years PMDD Sufferer*

One patient described why she might have been misdiagnosed:

> They explored bipolar, but I didn't meet the bipolar diagnosis because I didn't have the mania. So, I didn't have that. I didn't have the major depression because it wasn't sustained. And so, it was just like... I never really fit into a good box, I guess. Which makes sense because the box wasn't really established until 2017. *Sarah, Age 34, 21 Years PMDD Sufferer*

Participants shared the consequences of misdiagnosis, many having suffered health impacts from being on the wrong medications for so long and many struggling to get off of these medications once they realize they have PMDD and should not be on certain medications. One participant stated that she was on antipsychotic medications since she was 15, even though they never helped to relieve her symptoms. A few patients struggled to remove the misdiagnosis from their medical chart, and would have to explain repeatedly to doctors that it was a previous misdiagnosis and that their legitimate diagnosis was PMDD. Patients with misdiagnoses were likely to get official PMDD diagnoses much later in life. Participants described doctors being hesitant to see past the misdiagnosis to diagnose the PMDD symptoms. Furthermore, if a patient was misdiagnosed with bipolar or another mental health condition, providers automatically were more likely to discredit them, assuming that they were mentally unstable. As shown in Figure 1, patient barriers also impacted patient’s ability to seek care. For instance, if patients had been dismissed or had negative experiences such as with misdiagnosis or being hospitalized, this caused medical trauma and distrust of doctors which prevented them from seeking further help for PMDD. Furthermore, participants stated that their role as patient was to accept the provider’s diagnosis and treatment plan, so some did accept their misdiagnosis.

Catalysts to Self Diagnosis

Many patients experienced events that caused them to realize that their symptoms were not normal, which caused them to research and self diagnose. Several patients talked to other women about their menstrual cycles and would realize that other women do not experience PMDD symptoms. Other patients would start or stop certain medications, which would either exacerbate or relieve their PMDD symptoms. For instance, starting or stopping certain hormonal birth controls caused this phenomenon, which led patients to realize that they were experiencing cycle related symptoms, which led them to research PMDD. Some patients self diagnosed by attempting to have children. A few patients visited fertility doctors, which led them to identify their PMDD symptoms. A few other patients stopped their hormonal birth control to try to have children, which caused severe PMDD symptoms that had been previously alleviated by the birth control. Other patients would come to the epiphany that they had been suffering for a while with their PMDD symptoms and decided not to suffer anymore or take no (from doctors) as an answer.

> And so, you know, my mind- it was just, this is just how life is. We just hurt and it sucks, but it is what it is and I'm not willing to take that as an answer anymore. *Olivia, Age 33, 14 Years PMDD Sufferer*

Self Diagnosis

19 out of the 32 total participants self diagnosed, 17 of whom later received official diagnoses from providers. Three other participants were diagnosed by a partner or parent (mother). Thus, self diagnosis was a common occurrence in the data. Many described self diagnosis as a relief,

but almost all participants stated that the care continuum could not stop there, because a doctor was required in order to get prescription medication and other necessary treatments to manage PMDD. Patients who self diagnose either realize that their symptoms are right before their period or realize that their symptoms are only part of the month. Hence, either patients identified the occurrence of symptoms or used a process of exclusion to discover their self diagnosis. Patients have a lot of curiosity regarding their symptoms, and know that if they had not googled their symptoms, they would have suffered for much longer.

Diagnostic Delay

Very few patients had one doctor that followed them through their entire PMDD Care Continuum. Thus, many patients found a doctor to diagnose, but had to switch providers to receive treatment. Most patients were diagnosed by a therapist, Primary Care Physician, or Naturopathic or holistic doctor. Most patients who received a confirmation diagnosis, a provider diagnosis after self diagnosis, were from OBGYNs, because this was the type of provider most patients wanted to seek help from after their PMDD self diagnosis. Patients described PMDD as being a condition that required a great deal of self advocacy and “work” on the patient’s side. Most patients had to do their own research on PMDD symptoms and treatments. Many had to explain what PMDD was to each new provider they saw. Many patients, even after receiving an official diagnosis from a provider, could not bring this diagnosis with them to their next provider, as each provider had to reevaluate and some providers did not “believe” in PMDD. Patients stated that because PMDD was a relatively “new” condition as it was recently added to the DSM, most providers did not think it was real. They also stated that because PMDD is a women’s health and mental health condition, doctors doubted its reality. For instance, participants described depression as something patients are told to “get over,” which is also a common occurrence for any type of PMS like symptom. In Figure 1, the patient barriers occurred as patients often were dismissed or experienced medical gaslighting. Patients described medical gaslighting, as shown in the participant’s quote below, as impacting their ability to distinguish their symptoms as well as advocate for themselves in the healthcare system. Medical gaslighting referred to doctors normalizing or dismissing patients’ symptoms. For example, many patients were told that their symptoms were normal by providers, so they believed the doctor and did not bring it up again in later consults or seek further help. One participant described this experience of medical gaslighting as follows.

> And if it- if it makes them- if they- most doctors don't know how to say, ‘I don't know let's try to figure something out, or let's get more help’, so that's where they fall short, I guess. They have a- an issue saying, ‘I need to learn more about this-’. But instead -- instead they'll say, ‘no you're wrong because I don't know about it.’ And that's pretty gaslightly, you know. Medical gaslighting is a real thing, especially in Women's Health.
> *Kai, Age 29, 12 Years PMDD Sufferer*

Official Diagnosis

Many patients described receiving an official diagnosis as a validating experience. Many patients who had been self diagnosed for some time did not receive an official diagnosis until much later in their PMDD care continuum. Patients who were diagnosed by a doctor instead of coming to a doctor with a self diagnosis considered themselves “lucky” that their doctor recognized the

PMDD symptoms and was aware of the condition. Common pathways to diagnosis included women recognizing the cyclical nature of their symptoms, researching PMDD, and finding a doctor to diagnose. Other participants know they are suffering, so they bring their symptoms to a doctor and keep reaching out to different doctors until they receive a diagnosis. Some patients saw up to 10 different providers before receiving an official diagnosis, which took years. Barriers to diagnosis included doctors struggling to distinguish PMS from PMDD, and assuming that all women experienced some form of PMS. Many participants experienced PMDD symptoms and took these symptoms to their provider in their teenage years. However, many providers put teenage girls on oral contraceptives as a method to regulate irregular menstrual cycles, without finding out what the cause was or diagnosing PMDD. This led to many participants being unaware about PMDD and struggling to find a proper management or doctor to manage their symptoms. Some doctors asked patients to track their symptoms across their cycle, however there were many cases that did not. Some patients pointed out that doctors tended to misdiagnose, just because they wanted to give the patient an answer, even if the patient did not fit the diagnostic criteria. For instance, one participant was misdiagnosed with fibromyalgia before her PMDD diagnosis, but she did not believe the diagnosis, because she knew it did not fit.

> But even when the doctor said he suspected I had Fibromyalgia, there's like specific points on the body that you press that the doctor will press and see if you have pain there to really like make sure that that's what it is. Well, he did that test and I didn't have pain in those spots, but he still told me I had he's like well I still think it's this. So there was

> nothing like he didn't go beyond that to try and figure out what it was. *Julia, Age 43, 28 Years PMDD Sufferer*

Some patients thought an official diagnosis was meaningful, because they could pursue certain treatments for PMDD with an official diagnosis. Others did not think an official diagnosis was as significant, because they still had to gain new PMDD diagnoses from every other doctor post official diagnosis. Others did not think it was significant because the official diagnosis did not result in any type of treatment, because the diagnosing physician did not know how to treat PMDD. Some patients had experienced medical gaslighting for so long that when they received their diagnosis, it took some time and effort to process it.

> It took me a few months to believe it. You know, every month I would say, ‘No it is not PMDD. My diagnosis is ‘I’m a bitch’ [laughs] or I'm just miserable and I'll die miserable’ and yada, yada, yada, you know. So, it took several months for me to finally be like, ‘Wow there really is quite a pattern to this!’ *Maria, Age 34, 15 Years PMDD Sufferer*

Overall, there were many “Provider Barriers” (Figure 1) that limited providers’ ability to correctly diagnose PMDD. Patients described the power dynamic between doctor and patient as a barrier, as providers were expected to be knowledgeable and should be the ones to diagnose, instead of the patient. This power dynamic between the patient and provider resulted in many providers not listening to the patient. For instance, several patients tracked their cycles and symptoms and brought these documents to their provider, but the provider did not even look at these documents. Some participants described not being asked further about their menstrual cycle, when brought up. A few participants stated that providers did not want to meddle with menstrual issues, as the menstrual cycle was a phenomenon less understood and thought of as “mysterious” or complicated.

Type of Provider

Overall, participants felt that doctors only wanted to deal with what they are familiar with, so patients stated that PMDD was often left undiagnosed, because doctors were not familiar with it. As shown in Figure 1, the provider barriers prevented providers themselves from being able to diagnose PMDD. Some participants stated that doctors did not have the tools or knowledge to diagnose or treat PMDD. For instance, gynecologists were described by one participant as only performing surgeries and delivering babies.

> Well, I mean so, the problems with psychiatrists is that they only know medications. They only know medications. They know nothing else like most psychiatrists don’t even do talk therapy, like all they do is see you for 15 minutes and you say, ‘I like my meds’ or ‘I don’t like my meds’ and they fix your meds like that’s all they freaking do. So they're worthless in the treatment of PMDD, from my perspective. My PCP... the only thing she actually treats potentially is diabetes, everything else she refers out. Right, so PCP do nothing except they're just, they’re like a hub. They just like send you to other people, and if they don't have people to send you to that are evidence-based, they have nothing for you. And then... OB/GYN I don’t know, I actually don’t know anymore, what should have happened on that end, but to be fair I really didn’t take these symptoms to my

> provider. Um... great surgeon! [laughs] But uh not great for PMDD. *Charlie, Age 34, 15 Years PMDD Sufferer*

Participants discussed that General Practitioners were more likely to normalize and diagnose PMDD as PMS. Because General Practitioners could easily prescribe oral contraceptives, this was often described as a common reaction from General Practitioners towards PMDD patients. Gynaecologists were described as seeing cycle related issues all day, so they often did not empathize with PMDD patients. Overall, patients had the most negative experiences with gynaecologists. Patients described gynaecologists as only performing pap smears and conducting STI testing, but any other requests were often dismissed. Gynecologists tended to treat menstrual issues only related to physical abnormalities such as uterine fibroids, so all other cycle related issues were normalized or dismissed. Endocrinologists were described as thinking in black in white, so if hormone panels came back negative, then they assumed that there was nothing hormone related for the patient. One participant stated:

> Some of ‘em said… like… that’s out of my wheelhouse [laughs] like, not my specialty. And then there was one, who was in fact a reproductive endocrinologist who I sought out because I was like, ‘there’s something wacky with my hormones,’ who had basically told me, like, it’s all in my head and I can’t possibly still be having symptoms while I’m on birth control. *Mia, Age 43, 30 Years PMDD Sufferer*

Most of the positive experiences patients described with providers were with mental health professionals. Specifically, therapists were often described supportive, because they listened to the patient and were more likely to research PMDD if the patient brought it to their attention. Other providers were less likely to research PMDD or find out treatment options for the patient and were more likely to dismiss them or refer them to a psychiatrist. Psychiatrists, however, were not described as helpful, because they were often dismissive, and could only do so much in terms of treatment such as prescribe SSRIs.

Female vs Male Doctors

Participants stated that they had different experiences with female and male providers. With female providers, participants said that they often lacked empathy, because female providers experienced menstruation as well, but did not suffer from PMDD symptoms.

> And so, they think, 'Oh my hormones don't do that, so your hormones don't do that.' I mean, women's health in general is extremely stigmatized, and women usually aren't believed… with women, I think it's, because their periods are normal, they think we're, like, making it up, you know what I mean? 'Oh, my periods aren't like that, so why are yours like that?' *Rachel, Age 29, 18 Years PMDD Sufferer*

9 different participants described female providers normalizing women's symptoms as something all women had to deal with during their periods. 5 participants described a female provider not listening to their case as a form of dismissiveness. 4 participants stated that a female provider implied that they were "making it up." Some female providers assured patients that they themselves also experienced those same symptoms and brushed them off as PMS. Some female doctors that did understand that the patient was suffering from PMDD did not think that it

was a condition that was severe enough to be treated, because they thought that it was just something they should "deal with." Male doctors, on the other hand, stereotyped PMDD patients as being hysterical or overly emotional and dismissed their symptoms. Overall, male doctors were described by participants more often in dominant characteristics, such as implying that they knew more about the patient's symptoms or experience than the patient themselves. Overall, male doctors tended to be unempathetic, because they lack understanding about menstruation, because it is not something they themselves experienced or could fathom. Participants thought that male doctors tended to think that menstruation was not an area they were comfortable diagnosing or treating. 8 different participants described a male provider being disrespectful, making a rude or misogynistic comments towards them. For instance, one male provider described the participant as living "like a rat," and a separate participant was told her uterus was "mad at her" for not having children. More participants described male providers as "clueless" regarding PMDD compared to female providers.

> When it comes to men, they just don't understand in any way, shape, or form, because their hormones are constantly level. They don't understand the ups and downs, highs and lows. So, I think, it has to take a very compassionate, patient man… to see—to see our side of it. So, I think that's why with men it's really hard. It's 'cause they just--they have no idea--they will never go through anything in their life that even comes close to what we go through. *Rachel, Age 29, 18 Years PMDD Sufferer*

Treatment Delay

Many patients felt hat they must prove to doctors how severe their symptoms are in order to warrant the treatment they request. Some patients used prior hospitalizations in a psychiatric ward as proof or support for the severity of their condition. Others were hesitant to tell their provider about their suicidal ideation, because they were afraid they would be hospitalized or not taken seriously. Several patients stated they had to prove that they not only have PMDD, but needed the corresponding treatment, or else providers do not take them seriously. One patient described her experience:

> Like I've written down all these notes to show the OB/GYN so they kind of understand how severe it is. I have to keep- I have to stress that to people over and over again for them to get it. *Jan, Age 36, 16 Years PMDD Sufferer*

Patients shared that they had to jump through many hoops in order to receive the type of treatment they wanted. Some patients had already tried one type of treatment, and stated that it was previously unsuccessful. When they visited a new provider, a few participants were forced to try this treatment again as it was considered a first line treatment. Many patients stated that providers were unaware of how to treat PMDD and, even if they did, they only provided first line treatments as the options. One participant shared:

> Like they acknowledge that I said it, and that’s about it. It’s almost like they… they’ve heard of it, but don’t really know what to do about it… and they don’t quite know what it means. *Mia, Age 43, 30 Years PMDD Sufferer*

Type of Treatment

Participants had varying experiences with types of treatment they received for PMDD over the course of their PMDD care continuum. Most patients had to go through first line treatments such as oral contraceptives or SSRIs, before trying other types of treatments such as chemical or surgical menopause. Three participants received chemical menopause treatments and five participants underwent surgical menopause in the sample. Many patients described some form of menopause, whether chemical or surgical as the ultimate goal, however most described it as an unrealistic or unattainable goal. Some patients described being prescribed first line treatments as a negative experience. Most patients tried several types of first line treatments before finding a treatment that helped them manage their PMDD symptoms. Patients had trouble with providers wanting them to try the same or yet another type of birth control or SSRI, even after they have already had negative side effects or worsening symptoms with prior similar treatments. SSRIs were described as easily prescribed due to the assumption that PMDD patients are mentally unstable or merely depressed. One participant stated:

> Women have historically not really spoken up for themselves, so if you're in a room with a gynaecologist who is a male, or any kind of a doctor who is a male, and they say, ‘oh no honey let me just like give you some antidepressants, and, you know, no, no you're just making all of that up. *Bianca, Age 46, 30 Years PMDD Sufferer*

Most patients experienced partial or temporary relief from some types of SSRIs, and others experienced the exacerbation of symptoms or suicidal ideation from SSRIs. 29 out of 32 participants reported being prescribed some type of antidepressants or SSRIs. Overall, patients described negative experiences or side effects with most first line treatments, but many were forced to go through these treatments repeatedly. Birth control was described as a standard treatment for anything hormonal or cycle related, so many patients were also prescribed this type of treatment easily, even without a PMDD diagnosis. Many patients had tried birth control earlier in life and had experienced negative side effects, which led them to hesitate once doctors tried to prescribe birth control again. Most common side effects were described as worsening depression. As birth control was one of the main treatments for PMDD, many patients agreed to be put on it out of desperation rather than genuine desire for the medication. Many patients were told that there were no further options after they unsuccessfully tried the SSRIs or birth controls that the provider prescribed. One patient described most treatments, particularly first line treatments such as birth control or SSRIs as "sideways treatments," because they did not specifically address the PMDD or the root symptoms.

Other less common types of treatments were chemical menopause and surgical menopause. Only two participants were on medications to induce chemical menopause, which were described as difficult to get. Three participants were able to get hysterectomies, and two participants had full hysterectomies and ovariectomies. Surgical menopause was described as a treatment that most providers were unwilling to even consider, because it impacted women's fertility, was invasive, and may cause long term health impacts such as osteoporosis. Many patients experienced issues with doctors prescribing treatment, because most providers did not know what types of medication to prescribe PMDD patients. Patients had to conduct their own research and advocate for the treatment they wanted or find a different provider. In one case, a participant was suffering from PMDD and did not have health insurance, so she agreed to let a community health doctor prescribe her the Mirena IUD instead of the Copper IUD. Her symptoms worsened considerably, causing a complete mental breakdown, and eventually she was able to have it taken out. She felt bad later about not advocating for herself more or knowing that PMDD patients should not be on the Mirena but Copper IUD instead (non-hormonal).

Co-morbid Conditions

In some cases, having another condition helped patients get treatment. For instance, one patient had a disability in conjunction with PMDD, so they were able to get treatment right away because they had a large care team for their disability. Also, their PMDD symptoms were taken more seriously because they had a disability that could be impacted by the PMDD symptoms. If patients had another women's health condition, particularly one that impacted fertility such as endometriosis or uterine fibroids, they were more likely to get surgical menopause or just more attention towards their symptoms. Four out of the five participants who received surgical menopause also had other female conditions. In other cases, some patients experienced barriers to treatment due to another health condition. As shown in Figure 1, "Societal barriers" described by participants were a lack of discussion or awareness about menstruation, leading many providers to become wary about menstrual related issues. Participants described society only putting emphasis on women's fertility, so because PMDD does not impact women's fertility, it is a condition that is often ignored or left untreated. PMDD symptoms were ignored in patients who experienced another women's health condition, because the other condition was seen as more pressing. One patient attempted for years to get a hysterectomy and ovariectomy for PMDD, but was unsuccessful, so she switched to using her endometriosis as a method to gain this treatment. She was successful, but right before her surgery the doctor chose to leave one ovary, due to the risk of osteoporosis. She was eventually successful in getting the surgery when she presented her endometriosis as the main reason for surgery.

> I think the bone density thing is just BS, honestly, because that's the whole point of hormone therapy, replacement. And they say, oh, it'll like, you know, shorten your lifespan. There's so many women that have had hysterectomies and had everything removed and there's, you know, they still lived long lives. So I think it's just an excuse, but…I - for me it was. *Rachel, Age 29, 18 Years PMDD Sufferer*

Condition Management Delay

Overall, participants had trouble finding a provider and a treatment option for them to manage their condition. Even after years with an official PMDD diagnosis, patients still struggled to find a provider to treat them or find a treatment that would work for them. Some patients were able to find a treatment within two years of their diagnosis, others took 14 years, and still others had not found any relief. In Figure 1, the feedback loops show that many patients repeat the process of finding a health provider and presenting their case after their official diagnosis or after having no success with their first treatment. This cycle continues until patients can find a provider to help manage their condition. Patients have to be diagnosed again by the new provider, as some providers do not “believe” in PMDD. For instance, a couple of participants received misdiagnoses even years after their official PMDD diagnosis. Many participants had to advocate for themselves, researching treatments, bringing in their cycle and symptoms they had charted, and finding specialists who were known for treating complex women’s health conditions. Some patients found that receiving an official diagnosis still did not result in doctors accepting PMDD as their condition, as a few participants experienced misdiagnoses such as bipolar even after receiving an official PMDD diagnosis years prior. Patients found that receiving an official diagnosis only brought them so far in the care continuum, because receiving certain treatments such as chemical or surgical menopause could not be approved for the diagnosis of PMDD, only for conditions such as endometriosis. Some patients blamed themselves for not noticing that their symptoms were linked to their menstrual cycle sooner. One participant stated:

> Made me sad to see that I had wasted so many years of my life, um, feeling broken, feeling unaccepted, unacceptable, and feeling unlovable, and then it made me angry because, it's um, I feel like um, menstruators have been failed, you know, that people with PMDD have been failed by the health industry, and, well yeah, it is an industry, um, that nobody talked about this openly, so there's no chance of you ever really finding out until you just have no other way out. *Bianca, Age 46, 30 Years PMDD Sufferer*

Many participants described PMDD as a difficult and complex condition, because it did not fall in a simple category that providers could easily diagnose and treat. Furthermore, the lack of research and treatment options significantly limited both patients and providers. One participant described:

> It's a woman's issue which already gets tossed aside and it's a mental health issue which also gets tossed aside. It's just- it's a double whammy of bad luck and they just don't want to take it seriously for whatever reason. And I think it being mental health that is caused

> by the body also really blows their mind. Because they think, you know, oh it's their brain and it's like no, no, no. It's my ovaries and the ovaries are causing this to happen. And they just- I don't know. They just don't want to connect that it could be both at the same time. They just wanna think it's either brain issue or it's a reproductive system issue and they can't seem to connect that it's- they're both. They're tied into each other. And that the body is making the brain feel this way. *Rachel, Age 29, 18 Years PMDD Sufferer*

Within the sample, most participants described being “lost” in the cycle of the healthcare system, being passed from one provider to the next, lacking continuity of care, and repeat the process of diagnosis and treatment repeatedly with each new provider. Many providers quit on PMDD patients, stating that they could no longer help them. Participants described the lack of holistic treatment among providers, which led to providers pushing off PMDD into another specialty as it was not “in their lane.” Without a clear designation of diagnosis, patients were forced to be responsible for themselves, as no one took responsibility for their condition and treatment. Because no one was responsible for PMDD as it did not fit into a clear category, most providers did not screen for it or even know how to screen and diagnose. Patients were then caught in the middle, because they were forced to diagnose themselves, but providers often dismissed their symptoms. This lack of designation led to providers not researching PMDD or its symptomology, which patients stated would have been helpful for them and their case. One participant described this phenomenon as the “bystander effect.”

> Especially since it is such a complex issue that combines so many different specialties it- everybody can just kind of kick it to someone else's court and say oh go see your

> primary, oh go see your OB/GYN, oh go see a psychiatrist. Um, so it’s not squarely in one specialty. So I think that it’s almost like the bystander effect, So like oh somebody else can handle it and it’ll be fine. *Jessie, Age 28, 14 years PMDD Sufferer*

Many patients who experienced successful management of PMDD had tried many different types of medications, visited a variety of providers, and took several years to experience this success. Successful management was defined by patients as being able to manage their PMDD symptoms so that they can function. However, most participants still experienced a PMDD “hell week” before menstruation that could interfere with daily functioning. Most participants planned their daily lives around this “hell week.” Seven participants described lack of success with finding a method to manage their condition. One participant, who described herself as “lucky” was able to get a complete hysterectomy and oophorectomy at age 23, with no other premenstrual condition. This was an extremely unique situation, as the participant was referred to an OBGYN who was known for performing surgeries and who happened to be familiar with PMDD. Patients found that many doctors could turn away or give up on PMDD patients. One participant described why this was possible:

> Because more patients will keep coming in. You know what I mean, like it's okay to give up on one person because you know there's a whole line of people outside of the door that's waiting to see you, and you can just as easily see them, and you know, still go home at the end of the day happy that they were able to prescribe medications and help some people if not everybody. *Leah, Age 32, 18 Years PMDD Sufferer*

A few participants felt hopelessness in finding a strategy to cope with the PMDD symptoms and with their age coming closer to menopause, they stated that they would just wait until menopause for relief of symptoms. Other patients turned to non-traditional methods such as the use of alternative therapies to manage their symptoms, if they had previous lack of success or negative experiences in the healthcare system. Patients described alternative therapies as last resorts if they could not find any other treatments to help them. Others sought out alternative therapies if they have no access to health insurance to seek “traditional” help. Two participants managed their condition by microdosing with psilocybin, and a few others used other methods such as reiki, marijuana, acupuncture, and homoeopathic treatments to complement their other methods of biomedical treatments. One participant claimed that she was “self healed,” using nontraditional methods of therapy such as meditation, diet, supplements, and other holistic measures to manage her condition, without a doctor.

Conclusion

Overall, participants described being “lost” in the loop of the medical system, being passed on from one doctor to the next without any doctor taking responsibility for PMDD. As shown in Figure 1, participants described having to start over the diagnostic process and treatment process, starting again with first line treatments with new providers they sought out. The PMDD Care Continuum conceptualizes the process of diagnosis and treatment within the U.S. healthcare system, pointing to the major barriers that interact to generate the patient’s overall experience. Most patients are forced to advocate for themselves, because doctors are unlikely to figure out that patients have PMDD, due to the lack of awareness and attention to the menstrual cycle. Once patients are diagnosed, they still shared experiences of having to advocate for themselves, because they must research providers to find one that can help treat them and research the treatments that can help them. Providers tended to dismiss patients’ symptoms as normal or patients as mentally unstable, or tell them that they cannot treat them. Providers hesitated to prescribe any other treatment than first line treatments, either because they were unaware of what other treatments to prescribe, were wary of more serious treatment methods, or doubted that more serious methods were necessary for PMDD, because they did not take the condition of PMDD seriously. Patients described positive experiences with providers as those who believed the patient, conducted further research on PMDD, and thought outside of the box for treatment methods. Delayed diagnosis and delayed treatment caused patients to suffer for years, even resulting in increased hospitalizations and suicide attempts. Patients described the ultimate goal for them to be able to manage their PMDD symptoms so that they can function, which some were able to do and other still struggled to do.

Chapter 5: Discussion

In this study, I report the healthcare experiences of patients with PMDD using a conceptual model that describes the delays to diagnosis and treatment. Overall, this study found that a multitude of societal, provider, and patient related barriers cause delays to diagnosis and treatment starting from symptom onset to condition management. Misdiagnoses and normalization of women in general and their own personal menstrual suffering delayed symptom presentation to a healthcare provider for an official PMDD diagnosis. Providers were not perceived to be equipped to treat menstrual related issues, which led to them giving up on their patient. The PMDD Care Continuum reported in the results reflected the cyclical nature of this process as patients became caught up in the healthcare system. This was particularly true for patients who already tried first line treatments and did not experience relief from PMDD symptoms. The most compelling finding from this study was that an official diagnosis did not result in doctors being able to treat PMDD. Participants had to be reevaluated and diagnosed again with every new provider they saw. This was the first study of its nature to describe the qualitative experiences of patients who identified as having PMDD in the U.S.. This study found that patients were burdened with their untreated PMDD symptoms, which were normalized by providers, preventing them from seeking medical help. Patients were further burdened by being responsible for their own diagnosis, seeking out numerous providers and treatments to help manage their symptoms, and advocating for themselves in the healthcare system.

One significant finding from this study was that patients felt that they were often dismissed and their symptoms were normalized. This phenomenon was described by a few participants as “medical gaslighting.” This phenomenon has also been observed in other studies on premenstrual disorders (Evans et al., 2021). Medical gaslighting is described as the act of providers minimizing the patients’ symptoms (Sebring, 2021). Diagnosis is a process in which the provider largely dominates the narrative and is the “purveyor of treatment” (Jutel, 2015). Results from this study indicated the large gaps in doctor and patient communication, particularly when providers are expected to be the source of knowledge about the patient’s condition and the patients are the consumers of this knowledge (Ong et al., 1995). Another prominent finding was that providers stated that patients’ symptoms were normal or PMS related. This confirms another study that found providers were more likely to normalize patients’ menstrual symptoms compared to other types of symptoms (Grundstrom, 2018).

This study found that women had varying self perceptions of PMS, which was further complicated by a lack of medical definitions of PMS which created problems between distinguishing PMS from PMDD (Reilly, 1999). Furthermore, participants stated they were taught to not be impacted negatively by their hormones due to PMS related stigma, which has also been cited in other studies (Kendall, 1991; Sveinsdottir, 2002). Other studies on premenstrual disorders such as endometriosis or PCOS have also found common themes in the recurring dismissal of patient symptoms by providers and lack of empathy from providers (Soucie, 2021; Tomlinson, 2017; Grundstrom, 2018; Evans et al., 2021). Consistent with previous research on premenstrual disorders, this study also found that women were not taken seriously unless their symptoms impacted their fertility (Franklin et al.. 2019).

Although one study has noted the recent increase in alternative medicine use among women, there has been no qualitative research pointing to women turning to alternative medicine to manage their premenstrual symptoms as a result of unsuccessful prior biomedical treatments in the Western healthcare system (Adams, 2003). This finding is particularly salient for providers as women are turning to methods in which they have more autonomy over their bodies such as microdosing with psilocybin and in which case treatments have less negative side effects compared to first line PMDD treatments. The next finding was that many patients did not have success on first line treatments due to many side effects. This correlates with findings that patients tend to have worse psychosocial outcomes on hormonal contraceptives (Zethraeus et al., 2017). Providers tended to overprescribe hormonal contraceptives for any type of menstrual related issue, regardless of PMDD. Most patients were on hormonal contraceptives since a young age, some even since the onset of their first menses. Doctors tended to prescribe any type of hormonal contraceptive, with few patients being prescribed YAZ, the only FDA approved hormonal contraceptive for PMDD, suggesting a need for additional medical education among providers. This also correlates with one study that suggests providers prescribed contraceptives even for those who were not medically eligible (Grove & Hooper, 2011). Overall, this study found that few providers were willing to prescribe any treatment other than SSRIs or oral contraceptives, and would make patients try the same medication again even if tried in a previous encounter with a different provider.

One unique finding from this study was that participants experienced negative outcomes with both male and female providers. Patients had different experiences with both types of gender, but a female provider did not result in positive interactions. Studies have shown that women receive better care from female doctors than males (Ganguli et al., 2020; Tsugawa et al., 2017; Wallis et al., 2021). Women are more likely to choose female doctors, however there are debates whether this leads to better patient satisfaction than with male doctors (Adams et al., 2007; Schmittdiel et al., 2020). Participants in this study demonstrated a variety of strategies used to navigate the healthcare system. Self advocacy was a significant finding from this study, as most of the burden of diagnosis and treatment rested on the patient. Within women's health, other studies have confirmed women's self advocacy and strategies used to negotiate in healthcare encounters (Hagen et al., 2017; Lombardo, 2014; Thomas et al., 2021). Other studies have found that the age of the internet has resulted in an increase in self diagnosis and medical research by the patient (Angela & Wilson, 2008; Farnood et al., 2020; Gioia & Boursier, 2020; Lupton & Jutel, 2015; McMullan, 2015). As most official diagnoses in this study were a result of a previous self diagnosis from the patient, most of the burden rested on the patient to find their diagnosis and even their own treatments.

This study is to our knowledge unique, as it describes the lived experiences of patients with PMDD. One qualitative study on PMDD studied the experiences of patients in the work context and the other qualitative study examined experiences of patients with diagnosis of PMDD in the UK (Hardy & Hardie, 2017; Osborn et al., 2020). The study on women's diagnosis experiences in the UK by Osborn et al showed that invalidation by providers, misdiagnosis, and the lost years of not being diagnosed were also common themes, as confirmed by this study in the U.S. However, the study by Osborn did not look into specific barriers within the healthcare system or treatment experiences. Although not specifically mentioned in the study, medical gaslighting was alluded to in various participant narratives. The results from this paper provide novel insight into how patient-practitioner communications act as barriers to diagnosis and management of PMDD. A strength of this study is that it is the first of its nature to focus on the healthcare encounters of women in the United States who identify as having this disorder. The qualitative nature of this research provided rich detail from a perspective of the women who experience PMDD, which a quantitative survey would not have captured. Compared to biomedical research, this study provides a different perspective on PMDD, as the results were grounded in the experiences of women themselves. This study used both inductive and deductive methods to capture themes among participants with diverse experiences of PMDD in the U.S. healthcare system.

There were several limitations to this study. The sample comprised of women who responded to the advertisement on the select number of online sites that it was posted on. The sample included those who were self-selected, which may have resulted in different characteristics among the sample who responded to the advertisements versus patients who did not respond. There was a lack of diversity in race or socioeconomic status in the sample. There were difficulties in recruiting patients without an official PMDD diagnosis in order to reveal a diverse range of diagnostic experiences. As the interviews were based off of memory, there may have been recall bias in dates of diagnosis and other necessary facts regarding PMDD experience. Since SES and race can impact the patient's ability to access healthcare, it is crucial that future studies include more diverse samples of participants to capture the full understanding of barriers in the US healthcare system. Future research should include the perspectives of providers on their experiences with diagnosis and treatment of PMDD, to supplement findings from a patient perspective.

Several key points are salient to researchers and practitioners. First, participants described a lack of coordination among healthcare providers and specialties, which resulted in further misdiagnosis or patients having to repeat treatments that had previously not been successful. Thus, we recommend that providers be trained in effective interprofessional communication (MacArthur et al., 2016). We also recommend that providers interact with each other and coordinate services as has been recommended for patients with serious medical conditions (Storm, 2020). Studies have shown that a lack of coordination of care can result in serious medical complications for the patient (Jones et al., 2015; Kripalani et al., 2007; Tiwary et al., 2019). Participants in this study indicated large gaps in provider knowledge around PMDD diagnosis guidelines and the absence of a clear treatment plans for PMDD. Our findings also suggest gaps in patient awareness around menstrual health issues, such as a lack of knowledge of what menstrual symptoms would be considered normal and what could be significant to present to a health provider. Further training for providers and general conversations around what normal or abnormal menstrual symptoms in consults are recommended for this purpose.

This study highlights the gaps in diagnosis and treatment in the U.S. healthcare system. We recommend up to date resources be provided for healthcare workers regarding premenstrual conditions so that it can aid in diagnostic practices and early intervention or treatment. Medical schools should provide further training on premenstrual disorders, PMDD, and the clinical distinction between abnormal premenstrual symptoms and other symptoms. Although the data suggests that self-advocacy is a key part of the process of diagnosing and managing PMDD among patients, these strategies are limited as patients in our study struggled to gain a diagnosis or the preferred method of treatment. Thus, more research on the providers' side of diagnosis and treatment is needed to gain a full understanding of the gaps in knowledge around PMDD in the healthcare system. Given the present lack of knowledge on the treatment and etiology of PMDD, it is suggested that further funding towards clinical research is needed to create better diagnostic and treatment criteria for PMDD.

Chapter 6: Conclusion

This study concludes that patients with PMDD experience numerous barriers to diagnosis and treatment in the U.S. healthcare system. Findings from the data showed that patients with PMDD are often caught in a cycle of diagnostic and treatment delay within the US healthcare system. We recommend further research on the diagnostic practices of PMDD as well as gaining the perspective of healthcare providers in regard to diagnosis of PMDD. These findings contribute to the overall body of research on premenstrual disorders as well as diagnosis literature on women's health conditions, because it presents a unique conceptual model on delays and barriers to condition management. Conclusions from the data point to the usefulness of a feminist perspective to gain understanding of the experiences of participants who have historically been unheard or under researched. Barriers to participant’s ability to reach overall management of their chronic condition included barriers at the societal as well as the patient and provider levels. These overlapping barriers at levels of the healthcare system can indicate several types of public health interventions to improve the patient and provider experience for diagnosing this type of medical condition. These findings will provide the basis for further research on the operationalization and refining of diagnostic criteria for PMDD.

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Appendix A: Interview Guide

Time: 1 hour | 15-25 questions

Interview on Experiences with Premenstrual Dysphoric Disorder

Date:
Start Time:
Stop Time:
Participant study ID____________________

INTRODUCTION AND CONSENT

Hello,

Thank you for taking part in this interview. My name is…. I am a Master's of Public Health student at Emory University working on my thesis project. For this study, I would like to learn about the experiences of individuals with Premenstrual Dysphoric Disorder. I am interested in learning about personal experiences, attitudes and opinions on diagnosis or treatment, and challenges within the healthcare system for people with PMDD or providers who treat PMDD. During this interview, you will be asked questions around personal or general experiences or attitudes on PMDD and how it is experienced within the healthcare system. Your responses may help inform the PMDD community on how to create more support services and potentially help others with PMDD or medical providers better understand how to treat individuals with PMDD. You are the expert here and I'm thankful that you are sharing your perspective with me. Do you have any initial questions for me?

[Perform oral consent *(See Informed Consent document)*.]

With all of this information, would you like to participate in the interview today?
Do I have your permission to record our discussion?
Are you ready to proceed?

Socio Demographic Questions

1. What is your age?
2. What is your occupation?
3. What is your sex? What gender do you most identify with?
4. What is your race?
5. Are you of Hispanic origin?
6. What is your education?
7. What is your marital status?
8. What is an annual income before taxes of your household?
    0. <=25,000
    1. >25,000 and <=50,000
    2. >50,000 and <=75,000
    3. >75,000 and <=100,000
    4. >100,000
9. How long have you suffered from PMDD?__________________________
10. Have you received an official PMDD diagnosis? Yes/No   If yes, when?___________

Initial Experiences with PMDD

“So, let’s start off with you telling me a little about yourself and how you became involved in the PMDD community.”

1. When was the first time you ever heard about the condition, PMDD?
    0. How did you come to know about PMDD?
2. If you personally had experiences with PMDD, could you tell me a little about your first manifestations?
    0. What have been your main symptoms?
    1. How have these symptoms impacted your daily life?
    2. How have they impacted your relationships?
    3. How have they impacted your ability to work or function in society?
3. If you do not want to talk about personal experiences, what have you heard about other community members’ first experiences or how they came to know about PMDD?
4. What have been your experiences with the PMDD community so far?
    0. Have you been treated in the medical community?
    1. Have you been treated by alternative medical therapists?
    2. Have you participated in online events or any support groups?
    3. Have you helped to provide PMDD related services to others?

Experiences With Diagnosis

“Now I’d like to learn a little bit about how you or other people you may know have been diagnosed with PMDD.”

1. Earlier you said that you have (have not) received PMDD diagnosis.
    0. If so, would you mind explaining your experience with the diagnosis process?
    1. If you have not received the diagnosis, then why?

2. In your opinion, what is the usual experience with getting diagnosed with PMDD?
    0. Is the process easy? How so?
    1. Is the process hard? How so?
3. If you haven't received a diagnosis or do not want to talk about your own experience, would you describe someone else's experience with diagnosis?
    0. This could be a fellow PMDD member's experience.
4. How did you feel/ how do people usually feel when you/ they receive a diagnosis?
    0. Would you describe this feeling?
    1. What kind of emotions are brought on with a new diagnosis with PMDD?
5. Does receiving a diagnosis change one's experience with PMDD?
    0. How so?
    1. Prompts: changes in treatment of symptoms, changes in effects on daily life.
6. Have you ever had any problems with misdiagnosis?
    0. Have you heard of others experiencing misdiagnosis?
7. What do you think was something that helped you receive a diagnosis?
    0. Or- if you have not received a diagnosis, what would help you or others receive one?
8. What do you think hindered you to receive a diagnosis?
    0. What do you think would have hindered others to receive a diagnosis?
9. The average time to diagnosis for individuals with PMDD is 9 to 13 years. Why do you think this is so?

Experiences in the Healthcare System

"Now we are going to dive deeper into any specific experiences you or others you may know have had within the healthcare system."

1. What have been your general experiences with patient-doctor communication around the topic of PMDD?
2. Compared to other conditions, have you had better, worse, or the same type of experiences with doctors around PMDD?
    0. How so?
    1. Why do you think that is?
3. Have you ever felt listened to or "heard" by doctors when discussing PMDD?
    0. Have not felt "heard" when discussing PMDD with providers? Please describe one such experience.
4. PMDD already causes much emotional distress due to its impact on mental health and hormonal imbalance. How do you think the typical experience of PMDD in the healthcare system impacts this type of distress?
5. Have you ever had anyone not believe your symptoms or make you doubt your symptoms?
    0. Have you heard of others experiencing this in the healthcare community as well?
    1. Why do you think this happens? Do you think this happens to other people who do not have PMDD?
6. What have been your positive experiences within the healthcare system related to PMDD?

    0. What have been your negative experiences within the healthcare system?
7. How have your previous experiences within the healthcare system with PMDD impacted later experiences in the healthcare system?
8. What have been your experiences with treatment of PMDD within the healthcare system?

Suggestions

“Now we are going to talk about any suggestions you may have for the treatment or diagnosis of future PMDD patients.”

1. In your opinion, what could healthcare providers do to create a better experience with the diagnosis or treatment process with PMDD?
2. If you could do anything different about your experience with diagnosis or treatment, what would you have wanted to be changed?
3. Do you have any other suggestions for how people could receive a diagnosis quickly for PMDD?
4. Do you have any other suggestions for how PMDD could be treated?

“Thank you so much for your time today and for sharing your story with me. Do you have anything else you would like to add before we finish?”

Closing

“Please remember that this entire interview and its information will remain confidential. The audio recording will be typed up into a transcript and any identifying information will be removed. If you choose to withdraw your interview from the study, please let me know. If you have any additional questions later, feel free to contact me- you have my email address.”

Interview Notes:

Appendix B: Codebook

Diagnosis		
Pathways to Diagnosis	This code is applied to any description of the experience the participant had to reach their diagnosis. This should	*P: So, I umm... was back n the fall of... I’m trying to think what year, I think it was 2018, umm... and I just like started to have umm...a... like a lot of depression*

	accurately describe what the participant's journey looked like to gain a diagnosis. Any experience after the diagnosis should be coded under "Post Diagnosis." Even if the participant has self-diagnosed but hadn't received an official diagnosis yet, code their experience until diagnosis under this category. Double code this with "Post Diagnosis" if the participant's story overlaps with a mention of how they felt after they were diagnosed (for context). Situations even after diagnosis until finding the right provider should also apply in this code. This should only apply to lived experiences. When asked how many doctors they have been seen for PMDD, apply this code.	*umm and anxiety and I immediately linked it to my cycle because I've had issues with severe pain for a long time and I've always had like hormonal acne and just different things, so different hormonal problems, and I very quickly linked that, like depression and anxiety, to umm my uhh menstrual cycle. So it got to be like pretty bad, pretty debilitating, and I quickly diagnosed myself, via, you know internet searches, and I was like confident that's what I had 'cause it matched exactly. So that was kinda how I first found out about it.*
Misdiagnosis	This code should directly apply to any experiences relating to misdiagnosis of PMDD. If the participant states that they had a previous diagnosis before PMDD or a doctor almost misdiagnosed them with a different disorder, apply this code. This can be hypothetical or lived experiences.	*That was the first time because, because previously all of my symptoms had been assigned to bipolar um.. And I will say that um.. [sigh] so yeah, so really I never even brought it up to my gynecologist except to tell them the meds that I was on. And I've used hormonal birth control since college.*
Post Diagnosis	This code applies to any feelings or change of perception after they received a diagnosis. The participant's experience after their diagnosis, whether they felt validated or understood why they suffered with PMDD symptoms years before their diagnosis. Any acceptance of the condition must also be	*I didn't have health insurance and I was spending a thousand dollars a month on meds. A thousand dollars! Like are you kidding me. And then the other piece that's been really frustrating I have- had all of these like [air quotes] chronic pain issues. But they flare up once a month! And of course- and I kick myself now for not seeing these sort of patterns but I've probably spent ten thousand dollars on physical therapy,*

	coded with this code. This should only apply to lived experiences. Any grieving over lost years after their diagnosis is included in this code. Apply this code if the participant mentions years lost after being misdiagnosed or not being diagnosed for so long. This can apply to any type of "PTSD" the patient may have when going to doctors after having bad experiences with previous ones.	*massage, acupuncture like you name it. Trying to- and seeing I've had cat scans. Ive had MRIs. I've seen surgeons. To try and figure out how to cure this back pain. And now that I'm treating PMDD. <u>I have no back pain.</u>*
Designation of Diagnosis	Any discussion of how PMDD should be diagnosed, who should diagnose it, and any difficulties that current providers have with designating diagnosis or care of PMDD should apply to this code. This code applies to the label of PMDD as a diagnosis, PMDD in the DSM, or any types of difficulties in diagnosis such as lack of testing available. If the participant mentions type of provider (OBGYN, Psychiatrist) but only in a hypothetical context of who should treat or diagnose, only code that statement under this code and do NOT code under "OBGYN" or other specialty code. Any problems with current methods of diagnosis should be applied here. This can apply to hypothetical or lived experiences.	*And what I asked for was for them to have empathy you know really think about it from our perspective where many of us have gone through a lot of our life with this disorder without knowing what it was, with being misdiagnosed, with being you know put in this loop in the medical system where your gynecologist tells you to go see a psychologist and your psychologist tells you to go see a gynecologist who then tells you to see and endocrinologist, and you're just lost in this loop because nobody really knows how to treat it because it is such a multi system disorder..*
Specialty		
OBGYN	Any mention of OBGYN or Gynecologist, including interactions or experiences should be applied to this code.	*It's easier to talk to OB/GYN's about cycle related issues because it comes up, and just like a standard, um, primary care provider setting they say 'Okay,*

	Apply this code even if the participant refers to the doctor with a pronoun such as “she/ he/ they did this…” Do not apply this code to hypothetical situations.	*when was your last period?’, and that was, and that's usually it for that line of questioning. Um, they are not asking ‘Well, are you having painful periods?, or are you having any of these other symptoms?’ Um, they don’t really go into... asking about the menstrual cycle beyond, ‘are you having a period?, are you pregnant?’ unless you bring it up very intentionally. So, I think it’s a little easier to work it into... um, an OB/GYN visit* <u>because</u> *they tend to ask more of those in-depth questions related to the menstrual cycle.*
Endocrinology	Any mention of Endocrinologist, Reproductive Endocrinologist, etc - including interactions or experiences should be applied to this code. Apply this code even if the participant refers to the doctor with a pronoun such as “she/ he/ they did this…” Do not apply this code to hypothetical situations.	*It was always a struggle there, so I don’t know, this is kinda indirectly answering your question, but the like my hormones would look fine, umm, and so the OBGYNs and endocrinologists and all like they would just feel it’s not their field.*
General Practitioner	Any mention of General Practitioner, including interactions or experiences should be applied to this code. Any Family Practice Doctor, Primary Care Physician, Pediatrician, or Physician’s Assistant should be included. Apply this code even if the participant refers to the doctor with a pronoun such as “she/ he/ they did this…” Apply this code to other mentions of general doctors also. This code can apply to hypothetical or lived experiences.	*P: My current umm physician’s assistant. Umm Who has drawn y’know multiple blood panels, has helped... umm... y’know she put me on like 10 thousand of vitamin D. Which really helps some things. It just like.... all those little things that most providers would skip over. That was really helpful for me. Umm, and she was working in conjunction with my psychotherapist, and that was, like that was it for me.*
Mental Health	Any mention of Mental Health Practitioner, including interactions or experiences should be applied to this code.	*The problem with psychiatrists is that they only know medications. They only know medications. They know nothing else like most psychiatrists don’t even do talk*

	Any instances of Psychiatry, therapist, counselor, or psychotherapist should be included. Apply this code for experiences in mental health institutions as well. Apply this code even if the participant refers to the doctor with a pronoun such as “she/ he/ they did this…” Apply this code if the interviewee mentions PMDD as a mental health condition or they were told by doctors that is psychological. This can be hypothetical or lived experiences. Apply this code to any mental health related stigma as well. SSRIs or any mental health treatments should not be included here but instead under “Treatment.”	*therapy like all they do is see you for 15 minutes and you say, I like my meds I don’t like my meds and they fix your meds like that’s all they freaking do so their worthless in the treatment PMDD from my perspective.*
Negative Interactions	This code should apply to any negative interactions with providers. Any instances of doctors not believing them, pushing treatment off to someone else, invalidating the patient, stating that a condition is normal when it is in fact not normal, and forcing the patient to prove themselves to the doctor should be applied. This code should also describe any negative instances with providers that impact later experiences (trauma). Apply this to both lived and hypothetical situations.	*Um, they would [chuckles] just blow me off and... tell me I was a hypochondriac, which I'm not [slight offensive tone].* *I, I legitimately have an alphabet soup of stuff that takes a lot of effort to manage so... I, I think I may have... put some of those fears that were instilled in me by my parents on to talking to those providers.*
Positive Interactions	This code should apply to any positive interaction with providers. Any hypothetical situations in which participants would like to be heard by providers should be applied here.	*My current umm physician’s assistant. Umm Who has drawn y’know multiple blood panels, has helped... umm... y’know she put me on like 10 thousand of vitamin D. Which really helps some things. It just like.... all those little things that most providers would skip over. That was*

		really helpful for me. Umm, and she was working in conjunction with my psychotherapist, and that was, like that was it for me.
Coping		
Self Advocacy	This code applies to any instance of the participant having to advocate for themselves in the healthcare system. Apply this code when a patient must figure out their own health, fight for their diagnosis, and research their treatments on their own. Apply this code to descriptions of self-diagnosis.	*I: Right. And how did it feel to, y'know, almost diagnosis yourself, and you have to be confident in your own diagnosis and confident, you have to find your own providers, and almost find your own treatments, I mean, you're having to be your own provider pretty much.* *P: Yes! Yes. It, yeah. Umm, it is really an awful experience, umm, and it is extremely stressful. Umm, you really are, yes, your own provider. Umm, and then you know, you'd have no more than two appointments with the doctor and then become extremely discouraged and move to the next one, and just, yeah, umm, that also I think increases the severity of the symptoms. Because your stress- your stress levels are so high.*
Treatment	Apply this code to any type of treatment that the participant has tried in the past, is currently on, or has considered. This can apply to any type of treatment, whether they have tried or not. Apply this to any testing as well (as this is a pathway to treatment).	*P: umm, again, she's never mentioned it, even though I would, I would like describe exactly, y'know, to her. Cause for me it was like, day 13 or 14, umm all the way to day 5, so you know I'd just get maybe a week, if I was lucky, of relief. Umm But it was, yeah, it was terrible. Umm and again, it was just, it was just said to be normal. Umm and So it was very invalidating, umm... and very much just stick you on a umm the run-of-the-mill treatment which is standard birth control. Whatever formula, y'know, whichever formula is covered by your insurance that's cheapest. Like that kind of thing, so-*
Non Traditional	Apply this code for any type of non traditional providers, treatments, or methods of healthcare. This can refer to functional doctors, holistic treatments, supplements, yoga, and non western medical	*P: Yeah, I think a lot of people have had to find alternate sources, um something that I'm also a huge advocate for psilocybin. I started doing a regular regimen, where I would take under 1/2 gram, I believe, I mean it's the tiniest amount, um every four days and you're*

	treatments. This can also include non traditional therapies such as RTT (double code under “Mental Health.”) Double code this under “Treatment” if the patient has actually tried or is currently on this type of treatment.	*not experiencing the psychedelic effects that people think of or talk about when they talk about like a mushroom trip. When you're taking a micro-dose…the noise in my head stops, and I noticed that it lasts for day, I'll go days without having that constant rattle in my head, um I feel more connected with everything, I just feel more connected with nature, I see so much more beauty in things and the depression almost disappears.*
Barriers		
Impact of PMDD	This code applies to descriptions of symptomology and the impact of PMDD on the individuals’ or other PMDD suffers’ lives. This should describe the individual experience of PMDD. If the patient experience includes provider interactions, include this under the codes of “Specialty” instead. This can be positive or negative influences of PMDD on their life. This code can apply to lived or hypothetical situations.	*You know whether that be because of the different sensory issues and emotional issues that it makes thriving in society difficult, or because you're simply trying to preserve your relationships and avoid those moments of rage, or you know, not feeling comfortable in your emotions, not feeling comfortable in your body [chuckles], um you know, the the body aches, the migraines, the the joint pains.*
Access to Treatment	This code applies to any type of barriers to access treatment such as cost, availability, and lack of support. If Covid has impacted access to treatments, code this only under “COVID Influence” instead. This can be perceived or lived discussions or experiences. Apply this to access to care or providers as well.	*But I also don’t think that individuals turning to eastern medicine is all- is the answer either right because most people don’t have scientific training and so they assume that if it works for them, this is what I should tell everyone to do as opposed to having someone actually guide you through a process that is at least informed by more than one person’s experience um so I- and- and so for me I continue to be pissed off about this right because I spend $600 a month right now to see this person right I- she charges me $400 to walk into her office and I’m spending about 200$ a month on supplements and that is not sustainable*

		and that is 100% out of reach for most people.
Unawareness	This code applies to any lack of education, ignorance, or unawareness about PMDD. If any participant mentions the lack of understanding for the condition, apply this code.	*Um, and with PMDD they just ignore it because they don't know what to do with it. They don't process it like doesn't fit anywhere so they just like [throwing hand motion] I don't have a spot for you on my wall so I'm going to discard you.*
PMS vs PMDD	This code applies to any discussion of PMS versus PMDD, whether the differences between them or doctors mentioning PMS instead of PMDD as a cause of PMDD symptoms.	*I think PMS is... more of something that—it's kind of like, um, the difference between, like, baby blues and postpartum depression, you know? Like, it's definitely more severe and you can't just, like, turn it off. It lasts longer, I feel like, and there's, um, more—more symptoms that go along with it.*
Misogyny	When a participant describes any type of sexism or role as a woman in society that may impact PMDD or diagnosis and treatment for PMDD, apply this code. If a provider mentions that someone is overemotional because she is a woman, include this code. Apply this code for any menstrual related stigma or women's health related stigma. Any type of description of misogyny should apply as well. Apply for lived or hypothetical situations.	*There's part of that cultural conditioning that, 'No no, put everyone else first. You- you- you do the bare minimum for yourself. Take care of everyone else.' And it's really hard, um... to overcome that conditioning with time, with resources, um... and even like giving yourself the time and attention* <u>*you*</u> *need to take care of yourself. It's impossible to take care of anyone else if you're falling apart.*
Suffering		
Suicidal	Any time a participant mentions suicidal ideation, suicide attempts, or risk of suicide from PMDD, apply this code. Apply this code even for hypothetical situations.	*And it's the same thing with PMDD. The... suicide risk is so high but, you know, because they don't... think that they themselves only them can treat it, then they're like 'Oh okay, I'll just refer you to someone else', but you're referring someone who is high risk of death.*
Future Recommendations		

Support for PMDD	Apply this code for any mentions of support needed for PMDD. Apply it also when a participant mentions family, friends, doctor, or PMDD community support they received. Any support they wished they had should also be applied here. Research for PMDD should also be included here.	*Um... but being able to give people their lives back, um, with research and science, that’s the ultimate goal because these people need... help. You cannot do it on your own. It’s just impossible.*
Recommendations	Apply this code for any description of recommendations for how PMDD should be diagnosed or treated. This code is also applied for how they wish PMDD would ideally be approached in the healthcare system. This can include recommendations for future PMDD sufferers or doctors as well.	*P: Oh, thank you, no I think um, in I mean in so many things, um I think it should be the case, you know I think that for really extreme illness, yes you do have a care team. Um you have you know, for cancer patients, you have many people in your treatment, right? But with diseases that aren’t as big of a problem, there’s just something lacking, um I think it’s really up to the patient then to piece things together. Which, in some cases, maybe the patient wants to piece things together and have more control over their healthcare, um and some cases, it probably is…you know, is devastating.*
Other Factors		
Other Condition	This code should be applied for any description of a medical condition other than PMDD. Any premenstrual condition or medical condition that the participant may have, a family member may have, or any hypothetical situation regarding a non PMDD condition should be applied here.	*People know what PCOS is. They understand that. They can look at you and see, ‘Oh yeah! You- you have a lot of hair [chuckles] on your face.’ Or ‘Yeah, I see a hump between your shoulders, and the extra weight, and we know what to do for that. Here’s some birth control, here’s some metformin, here’s some diet advice that will help with your condition. Here you go. Here’s all the resources in the world.’ And then PMDD, they’re like, ‘Uh... we can give you antidepressants, which one do you want to try?’ [laughs] Like, really! Because they hear depressed, upset, crying, anxiety. It’s like, okay, that fits this script we have for anxiety and depression.*
COVID Influence	Apply this code when any impact of the COVID-19	*I think it's changing I think it's starting, just even in the past year with COVID*

	Pandemic on anything PMDD related is described in the interview.	*and the mental health crisis that we all saw, I think it's opened up everybody's eyes a lot more to all of the issues that we're experiencing, not just in mental health but also in female health.*
Childbearing	Apply this code to any mention of child bearing, pregnancy, or fertility in relation to PMDD. For instance, if a participant describes that a doctor only cared about women's health in relation to child bearing instead of menstrual problems, apply this code.	*But then, it's... there was a time when umm he basically just said "I can't help you anymore", umm and then he said some very invalidating things. Umm, including like, just kind of off the cuff, like well you know you'd have to see if you would even be able to have biological children, and that's not the kind of thing that you just throw at a 19-year old girl, you know? So, umm, yeah, just kind of weird things like that. Umm, so I- I can't really trace a complete, like trend in male versus female.*