

**Living with Premenstrual Dysphoric Disorder and Premenstrual Syndrome:
A Qualitative Exploration**

A thesis submitted to the University of Manchester for the degree of
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Thesis Abstract

This thesis explored the lived experiences of women with Premenstrual Disorders (PMDs), including Premenstrual Dysphoric Disorder and Premenstrual Syndrome. Mixed methods were used and are presented as three papers.

The literature view (Paper 1) was a systematic review and thematic synthesis, aiming to explore the psychological impact of PMDs and women's perceived support needs. Seventeen papers were included within the review, synthesising the voices of 479 women, across 31 years of research. Two main themes identified the life controlling nature of PMDs, and the subsequent impact on women's lives. PMDs were described as intense, life changing and life-controlling, women held the responsibility of managing their own condition, whilst advocating for their medical needs and developing coping strategies.

The empirical paper (Paper 2) was the first to explore the prevalence of self-harm, suicidal thoughts and attempts in women with PMDD. Mixed methods were used to analyse multiple-choice survey data and semi-structured interviews. Over 3,600 women with PMDD completed an online survey, the results of which supported the development of a topic guide, which was used to interview 14 women with PMDD. Results showed that 47% of women had deliberately self-harmed, 85% had suicidal thoughts on one or more occasion, and 26% of had attempted to end their own life, during their luteal phase. Three main themes linked women's impaired relationships and time delays in accessing diagnosis and treatment with their damaged self-worth, and therefore suicidal behaviours.

Paper 3 provides a critical evaluation and personal reflections from the author regarding the process of conducting a doctoral level thesis into premenstrual disorders. The strengths and limitations of the work were considered.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Paper 1

The Experiences and Psychological Impact of Living with Premenstrual Disorders (PMDs): A Systematic Review and Thematic Synthesis

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Prepared according to submission guidelines set out in *Frontier in Psychology*.

For ease of reading, APA referencing has been used across the thesis

(see Appendix A for author guidelines).

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Abstract

Introduction: As the psychological impact and decreased quality of life experienced by women living with a Premenstrual Disorder (PMD) has been reported in the literature, the aim of this systematic review and thematic synthesis was to explore a) their experiences and the psychological impact of PMDs, specifically Premenstrual Syndrome (PMS) and Premenstrual Dysphoric Disorder (PMDD), and b) their perceived support needs.

Method: Six databases were searched for publications reporting on qualitative studies, since the database inception. The Preferred Reporting Items for Systematic Review and Meta-Analysis guidelines were followed, and Thomas and Harden's (2008) thematic synthesis method was used.

Results: Seventeen papers reporting on 479 women met the inclusion criteria: ten focused on PMS, six on PMDD and one on PMS and PMDD combined. Two main PMD themes were identified: 1) *controlled by PMDs*, which had three subthemes, and 2) *a women and life left broken*, with five subthemes.

Conclusion: Women's accounts revealed that experiences of PMDs were intense, life changing and life-controlling. Women were left holding the responsibility of understanding and managing their own condition, whilst advocating for themselves in a healthcare setting in which their condition has been little understood. Consequently, women developed coping strategies to lead a functional life, and experienced changes to their sense of self. Clinical recommendations included the need for professionals working with women in crisis, to assess for PMDs and signpost towards specialist services.

Keywords: *Premenstrual syndrome; PMS; premenstrual dysphoric disorder; PMDD; women's health; menstrual cycle.*

1. Introduction

Premenstrual disorders (PMDs) are on a continuum of premenstrual symptoms ranging in severity from Premenstrual Syndrome (PMS) to the more debilitating Premenstrual Dysphoric Disorder (PMDD) (Ismaili et al., 2016), despite being diagnosed separately since 1987 (Goswani et al., 2023). Given this continuum, both PMDD and PMS papers will be included within this review, under the term PMD. Approximately 20-30% of menstruating women experience PMS, whilst only 3-8% suffer symptoms severe enough to be classified as PMDD (Goswani et al., 2023). At present, there is no clear understanding of the aetiology of PMDs; however, theories include genetics, increased sensitivity of the central nervous system to menstrual cycle hormones and psychosocial factors (Hantsoo & Epperson, 2015).

Premenstrual Disorders are defined by the cyclical nature of their symptoms, occurring during the luteal phase and subsiding with menstruation, with a symptom-free period between menstruation and ovulation (Goswami et al., 2023). Symptoms of PMDs include low mood, suicidal thoughts, affective lability, and interpersonal conflicts, as well as physical discomfort, changes to appetite and sleep. According to the DSM-V (American Psychiatric Association, 2022), symptoms must cause an impairment to the individual's daily personal, professional, or social commitments during the luteal phase to meet the threshold for a PMDD diagnosis. PMDD is linked to co-morbidities with depression, anxiety and panic disorders, as well as social phobia and OCD (Santamaria & Lago, 2014).

Treatment options for PMDs are limited, and a cure for PMDD specifically is only truly possible by removing the ovaries (Goswami et al., 2023). However, an individual's day-to-day life can be improved through symptom management, such as prescribing antidepressants or hormone therapies, to reduce the fluctuation of hormone levels (Goswani et al., 2023). For more mild symptoms, non-pharmacological treatment recommendations include cognitive behaviour therapy, dietary intervention, exercise, exposure to sunlight, stop smoking and not drinking alcohol (Takeda, 2023).

In terms of interventions, Kancheva Landolt and Ivanov's (2021) systematic review of 32 peer-reviewed papers found non-pharmacological interventions provided a significant reduction in PMS

symptoms. In addition, Carlini et al.'s scoping review of 113 studies (2022) highlighted that PMS and PMDD symptom reduction was possible with both pharmacological and non-pharmacological interventions, but the authors expressed concern about the quality and methods of some non-pharmacology studies.

The impact of PMDs on a woman's life has been documented by various quantitative studies (e.g., Branecka-Woźniak et al., 2022), and although some women experienced their premenstrual changes positively (Reid, 2017), most literature recognises the negative impact. Experiencing PMDs placed a burden on women's occupation (Hardy & Hunter, 2021) and daily activities (Schiola et al., 2011), and has been associated with depression, stress, sleep disturbances and a poor relationship with food (Yi et al., 2023). Prabhavathi et al. (2023) found that as the severity of PMS symptoms increased, cognition and psychomotor execution decreased, highlighting the impact symptoms had on a woman's functional abilities. Given the vast impact of PMDs, it is unsurprising that data from 500 female students showed a direct association with PMS and decreased quality of life measures (Irshad et al., 2022).

In Osborn et al.'s (2021) review of ten quantitative studies, women with PMDD were noted to be a high-risk group for suicidal ideation; however, the authors did not find women with PMDD to be at a higher risk for suicide attempts. In contrast, Prasad et al.'s (2021) review of 13 papers identified an almost sevenfold increase in risk of suicide attempts. Finally, in the only review of the qualitative literature to date, Moe and Karlsson (2022) identified 12 papers reporting on the experiences of women with PMDD only. Two main themes identified the social, emotional, and professional limitations women experienced due to PMDD and their journey to a diagnosis and treatment options. Although the authors used a comprehensive approach to provide nursing specific clinical recommendations, they did not explore the psychological impact of this particular diagnosis, nor did they highlight how services could support these women.

There is a growing qualitative literature exploring women's experiences of PMDs. Changes to women's body dissatisfaction have been documented across the menstrual cycle, and many women chose

to conceal their body during the premenstrual phase (Ryan et al., 2022). Cosgrove and Riddle (2003) interviewed 30 women with PMS and described the contrast between women's view of themselves with and without their symptoms, leading them to question which was their true identity. Uncertainty about one's own self could be connected to women's reported feelings of loneliness (Slade et al., 2009). These studies provide insight into the affect PMDD has on a woman's self-image and identity but lacked a comprehensive exploration of the wider psychological impact. As previously discussed, PMDs are considered to sit on a continuum of symptom severity (Ismaili et al., 2016), as recognised by Carlini et al. (2022) in their review of interventions. As a synthesis of PMDs experiences could provide novel insights into their psychological impact on women. Therefore, the proposed review of qualitative studies aimed to a) explore women's lived experiences of a PMD's, such as PMS or PMDD, and b) explore their perceived support needs from healthcare services.

2. Method

2.1 Search strategy

The systematic search was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021) and the protocol was registered with PROSPERO in January 2024 (CRD42024505284). The SPIDER tool¹ (Cooke et al., 2012) categories phenomenon of interest (PI), design (D), and research type (R) were used to create search terms (see Table 1). Medical Subject Heading (MeSH) terms identified synonyms, whilst search categories were combined with Boolean operator "AND". Due to diagnostic terminology changing from LLPDD to PMDD in the DSM-IV in 2000 (APA, 2022; Chrisler & Gorman, 2016), the decision was made to include PMD, PMS, PMDD and LLPDD within the search terms, to ensure no eligible papers were omitted. Six databases were searched from inception to March 2024, CINAHL (EBSCO), EMBASE (OVID), HMIC (OVID),

¹ See Paper 3, section 3.2 for further information on the selection of the SPIDER tool and chosen databases.

Medline (OVID), PsycINFO (OVID) and Web of Science. Backwards searching of identified papers' reference lists and papers citing the included papers were also used.

Table 1: Search terms by category and search strategy

	Search terms	
1	(PI) Phenomenon of interest	“Premenstrual dysphoric disorder*” OR PMDD OR “premenstrual syndrome*” OR PMS OR “late luteal phase dysphoric disorder*” OR LLPDD OR “premenstrual disorder*” OR PMD
2	(D) Design	Interview* OR “focus group*” OR questionnaire* OR survey* OR “case stud*”
3	(R) Research Type	Qualitative* OR “mixed method*”
4	2 OR 3	
5	1 AND 4	

2.2 Inclusion and exclusion criteria²

Papers were included if 1) participants experienced PMS or PMDD, with a self-reported diagnosis or diagnosis confirmed by study or medical team, 2) studies aimed to understand the participants' experiences related to their condition, 3) studies which utilised qualitative research methods for data collection and analysis (e.g., interviews), including mixed method studies in which qualitative results were presented separately, and 4) studies written or translated into English. Papers were excluded if 1) participant eligibility was unclear or their diagnosis was vague, 2) participants with and without a diagnosis were recruited, and without findings reported separately, or 3) they reported on secondary research (e.g., conference posters or literature reviews).

2.3 Quality appraisal

The Critical Appraisal Skills Programme (CASP; 2018) tool is a validated checklist used to assess included papers, with ten domains including methodology, ethical issues and results³. As the CASP does

² See Paper 3, section 3.3. for further reflection

³ See Paper 3, section 3.4 for further information regarding selection of CASP tool

not offer a summary scoring system (Long et al., 2020), a numerical system was also used for better comparison across reviews (yes=1, partially agree=0.5, no=0). Total CASP scores were used to categorise methodological quality as high (> 8-10), moderate (6-8) or low (<5; e.g., Harries et al., 2023; Butler et al., 2020). As no accepted guidelines for excluding studies based on quality exist (Dixon-Woods et al., 2006; Thomas & Harden, 2008), all studies were included irrespective of quality appraisal.

2.4 Data extraction and data analysis

All eligible papers were transferred into NVivo software in preparation for analysis and relevant study characteristics (e.g., aims, sample size and recruitment strategy) were extracted and tabulated. Thematic synthesis (Thomas & Harden, 2008)⁴ was used for data analysis and involved three stages: line-by-line coding of the individual papers' findings was completed independently by two of the authors (DB & DMS), codes were then grouped into descriptive themes across and between papers, with the reviewers looking for similarities and differences between the codes. All themes were discussed and finalised by the whole team, allowing different perspectives and judgements of the meaning behind each code.

2.5 Reflexivity statement

All authors were white women and mothers; however, they ranged in age and stage of their careers. The first author (DB) was a trainee clinical psychologist, with experience working with women in secure services and supporting children and families in community services. The second author (DMS) was a Health Psychologist and Senior Lecturer, specialising in exploring pregnancy and behaviour change. The third author (EO) was a Clinical Psychologist working in paediatric services and had an interest in premenstrual disorder research. The fourth author (AW) was a Clinical Psychologist and Senior Lecturer, with an interest in understanding mothers experiencing severe mental health difficulties. As a team, we acknowledged our similarities with the participants as females of reproductive age, whilst holding in mind

⁴ See Paper 3, section 3.5 for further information regarding decision to select thematic synthesis

the potential for power differentials between researchers without a premenstrual condition and participants with a diagnosis. The similarities and differences between the research team supported nuances in interpretation during the synthesis, whilst discussions and reflective diaries were utilised to minimise the risk of biased interpretations.

3. Results

3.1 Search outcome

Initial searches identified 7,496 references. Following the removal of duplicates, the title and abstract of 4,154 papers were screened for eligibility (see Figure 1). The full text of 79 studies was assessed, with 15 selected for inclusion. An additional two papers were included following backwards searches of the citations and references, resulting in 17 included papers⁵. An independent researcher (SH) assessed 10% of the search results against the eligibility criteria: there was a 100% agreement based on the title and abstract and 100% agreement after reading the full papers ($\kappa=1$).

3.2 Characteristics of included studies

Seventeen papers, published from 1993 to 2024 and conducted in ten countries, were identified and synthesised (see Table 2). Sample sizes ranged from four to 83, with a combined sample of 479. Six studies recruited women with a diagnosis of PMDD: four studies allowed participants to self-report their formal diagnosis, one study confirmed diagnosis using the *Premenstrual Symptoms Screening Tool* (PSST; Steiner et al., 2003) and the final study stated that the participants met the DSM-IV criteria for PMDD. One publication used the International Society for Premenstrual Disorders definition of Premenstrual Disorders (PMDs; which includes PMDD and PMS) as eligibility for participation. The other ten studies recruited women with PMS: six accepted self-report diagnosis, two used the PSST, and two stated that researchers confirmed PMS symptoms or diagnosis (see Table 2). Women were recruited

⁵ See Paper 3, section 3.2 for further information.

from a range of settings, including social media, local newspapers, and radio adverts, as well as medical clinics and snowball sampling. Fifteen studies collected data via semi-structured interviews, the remaining two studies used interviews as well as open-ended surveys and a questionnaire followed by case studies. Thematic analysis was the most used analysis method (n=9), two studies used thematic decomposition and two described content analysis. Thematic coding, narrative analysis, the listening guide and a feminist phenomenological approach were each referenced once.

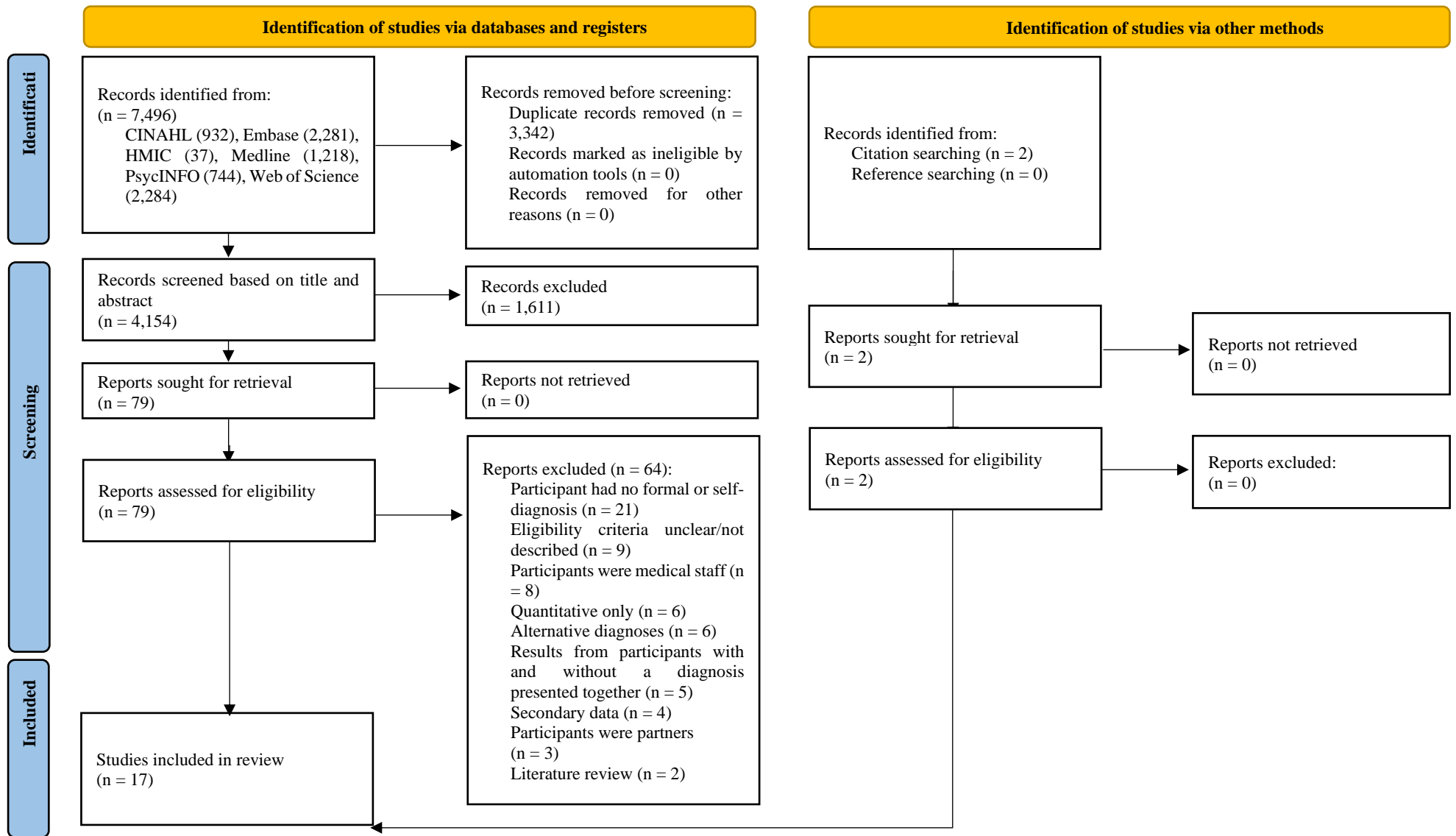


Figure 1: PRISMA diagram of the search strategy

Table 2: Characteristics of included studies

	Study	Aims	Sample size and diagnosis	Participant characteristics	Recruitment and data collection	Methodology and analysis	Findings and themes
PMDD only studies							
1	Buyss (2024) Australia	To explore the transition into recovery, management or transformation of PMDD and how participants understood those narratives	7 Self-diagnosed or reported a formal diagnosis of PMDD, but identified as in recovery, management, or transformation of PMDD	22-45 years old 57% Australian, 28% British, 15% Turkish 85% employed, 15% student Age at onset of symptoms, age at diagnosis and relationship status not reported	Social media adverts and online support groups. Narrative interviews	The Listening Guide (Gilligan & Eddy, 2021; Gilligan et al., 2003)	Two narrative themes; 1) within abjection 2) beyond abjection
2	Chan et al. (2023) USA	To explore the diagnostic and treatment experiences of PMDD patients in the U.S. healthcare system and identify barriers to diagnosis and treatment	32 Self-identified having PMDD (87% reported formal diagnosis)	21-50 years old Experienced PMDD symptoms for a mean of 17.43 years and mean of 5.6 years from symptom onset to diagnosis Age at diagnosis ranged from 16 to 45 94% white, 12% Hispanic, 3% Alaskan native, 3% mixed ethnicity 65% single, 29% married and 6% divorced 86% had attended collage	Online adverts (supported by IAPMD) Semi-structured interviews	Feminist phenomenological approach (Campbell & Wasco, 2000)	Study presents a PMDD Care Continuum that represents five themes as a timeline of participant experiences: 1) PMDD Symptoms 2) Patient delay 3) Diagnosis delay 4) Treatment delay 5) Condition management delay
3	Osborn et al. (2020) England	To explore women's experiences of both having PMDD and of receiving this diagnosis	17 PMDD diagnosis confirmed by the	20-56 years old Average symptom onset of 15 years old Average diagnosis of 35 years old 83% white British	Recruited via two NHS gynaecology clinics.	Reflexive thematic analysis (Braun & Clark, 2006, 2019)	Four themes: 1) A broken woman 2) Misdiagnosis and the lost decades 3) A life transformed

			<i>Premenstrual Symptoms Screening Tool</i> (PSST; Steiner et al. 2003) questionnaire	47% married, 47% single, 6% divorced 53% obtained undergraduate degree or higher 59% mothers	Semi-structured interviews		4) Negotiating the aftermath
4	Marfuah and Barat (2018) Indonesia	To understand the experiences of adolescents with PMDD	6 Met the diagnostic criteria for PMDD with DSM – IV	14-18 years old Age of first menstruation was between 10 and 15years old 100% Javaness 100% Students relationship status not reported	Purposive sampling from one collage Interviews	Thematic analysis (no reference within paper)	Four themes: 1) Symptoms perceived as a change that affects the psychological, behavioural and physical teens 2) Symptoms of intermittent throughout the menstrual cycle 3) Environmental factors and hormones play a role in the emergence of symptoms 4) The symptoms cause discomfort and interfere with social relationships
5	Hardy and Hardie (2017) England	To explore women's experience of PMDD in the workplace	15 Self-reported a formal diagnosis of PMDD	25-49 years old 80% receiving treatment for PMDD Received a diagnosis 6months to 4years prior to the interview 53% British, 40% American, 13% did not disclose 87% employed, 13% unemployed relationship status not reported	Online adverts via social media Semi-structured interviews	Thematic analysis (Braun & Clark, 2006)	Two themes: 1) Phases of PMDD at work and 2) The role of the organisation
6	Jurvanen (2017) Sweden	To understand the subjective experiences of private- and work life for people with PMDD	11 Self-reported a formal diagnosis of PMDD	55% worked full time, 18% worked part time, 27% were freelance Age range, age at onset of symptoms, age at diagnosis, ethnicity and relationship status not reported	Social media adverts Semi-structured interviews	Thematic analysis (Braun & Clark, 2006)	Five themes: 1) The impact of PMDD on work and occupational life 2) PMDD and social life 3) Psychological welfare and PMDD

							4) Medical shortcomings 5) Participants' thoughts
PMDD and PMS studies							
7	Labots-Vogelesang et al. (2023) Netherlands	To improve understanding of the perspectives of women with PMD, their coping strategies and their expectations of the GP	20 Researchers confirmed symptoms met ISPMDD definition of PMD	27-49 years old PMD symptoms started at 14 to 43 years old 95% Dutch, 5% Moroccan 75% married/partnership, 20% single, 5% widowed 80% employed, 15% unemployed, 5% student 60% mothers	Adverts in local newspapers and closed PMS/PMDD Facebook pages. Semi-structured interviews	Thematic analysis (The qualitative data analysis & research software) (Malterud, 2012)	Three themes: 1) Separate female identities 2) A life-controlling condition 3) Differences in coping strategies
PMS only studies							
8	Park et al. (2023) England	What are the lived experiences of women with PMS? To what extent does PMS influence their daily occupations? What are the needs of women with PMS	4 Self-reported PMS symptoms	No participants details reported	Social media adverts. Semi-structured interviews	Inductive thematic analysis (Braun & Clarke, 2006)	Three themes: 1) Occupational disturbance 2) Social impairment and occupational disengagement 3) The importance of self-awareness to engage in occupations
9	Tutty et al. (2022) Canada	To explore the relationship between women's premenstrual symptoms and parenting stress	46 Mothers who self-reported PMS	23-47 years old 72.7% white, 16.4% Indigenous, 3.6% Vietnamese, 3.6% Filipino, 3.6% East Indian 65.5% married or living with a partner, 34.5% lived alone Mothers of between 1 and 6 children, with at least one child under 18 80% attended post-secondary schooling	Adverts placed in local newspapers and public locations, including; libraries, hospitals and child welfare offices. Mixed methods, semi-	Thematic analysis (Braun & Clark, 2006)	Three themes: 1) Effects of PMS on mothering 2) Parenting changes after bad premenstrual phases 3) Strategies to address negative mothering

				51% employed outside of the home, 37.7% not employed outside of the home, 11.3% students 27.2% currently taking anti-depressants Age at onset of symptoms and age at diagnosis not reported	structured interviews		
10	Ussher and Perz (2020) Australia	To examine the role of premenstrual embodiment in women's premenstrual distress	83 Self-reported PMS, symptoms assessed with the <i>PSSST</i> (Steiner et al., 2003) and daily diary measures	Average age 35 years old 100% in a relationship 98% were heterosexual, 2% lesbian Age at onset of symptoms, age at diagnosis and ethnicity not reported	Participants recruited from a larger scale project (Ussher & Perz, 2017). Recruited via social media, local radio, newspapers and women's health centres. Open-ended survey responses and interviews	Theoretical thematic analysis (Braun & Clarke, 2006)	Two themes: 1) Inhabiting the abject premenstrual body 2) Reframing premenstrual embodiment: resisting the self-objectification and dehumanization.
11	Labots-Vogelesang et al. (2019) Netherlands	To explore which symptoms/complaints are considered most disabling and why, what cognitions women have about the cause of PMS and how these affect their help-seeking behaviour	20 Women who met DSM-5 criteria for PMS, confirmed by researcher	27-49 years old PMS symptoms started at 14 to 43 years old 95% Dutch, 5% Moroccan 75% married/partnership, 20% single, 5% widowed 80% employed, 15% unemployed, 5% student 60% mothers	Recruited via local newspapers and social media Semi-structured interviews	Thematic coding (no reference) Consolidated Criteria for Reporting Qualitative Studies (COREQ, Booth et al., 2014)	Three themes: 1) The disturbance in preferred feminine roles of being a good mother and wife 2) PMS as a life-controlling condition 3) Differences in coping strategies
12	Siahbazi et al. (2018) Iran	To discover the experiences of women with PMS, with a focus on quality of life	21 Moderate to severe PMS based on the	15-45 years old 48% married, 48% single, 4% divorced 43% mothers (between 1 and 3) 58% employed, 28%, housekeeper	Purposive sampling Semi-structured interviews	Content analysis (Polit & Tatano, 2014)	Four themes: 1) Physical consequences 2) Psychological consequences

			<i>PSSST</i> (Steiner et al., 2003)	14% students 67% attended higher education, 33% high school education Age at onset of symptoms, age at diagnosis and ethnicity not reported			3) Behavioural consequences 4) Familial-social consequences
1 3	Ussher and Perz (2013) Australia	To identify key themes in women's construction and experience of premenstrual change, and the ways in which women negotiate and cope with PMS, in the context of relationships	60 Self-reported to experience PMS	22-48 years old 98.5% Anglo-Australian, 1.5% Asian 80% in a relationship 66% heterosexual, 34% lesbian 47% mothers 82% employed Age at onset of symptoms and age at diagnosis not reported	Participants recruited from a larger scale project (Ussher & Perz, 2017) Recruited via social media, local radio, newspapers and women's health centres. Semi-structured interviews	Thematic analysis (Braun & Clark, 2006; Ussher, 1999)	Three themes: 1) Self-monitoring and awareness 2) Recognition and acceptance of premenstrual change 3) Coping through self-regulation of premenstrual distress
1 4	Hoga et al. (2010) Brazil	To describe the perceptions of women with PMS regarding the behaviour of their spouses in face of this event	20 Self-report PMS symptoms	19-44 years old 55% single, 35% married and 10% divorced 95% employed Years in education 10-16years Age at onset of symptoms, age at diagnosis and ethnicity not reported	Snowball sampling Semi-structured interviews	Narrative analysis (Riessman, 1993)	Three themes: 1) Difficulties in identifying the syndrome and in adopting care practices 2) Lack of knowledge and sensitivity of men 3) Its impact on the couple relationship
1 5	Mooney-Somers et al. (2008) Australia	To examine the development, experience and construction of premenstrual symptoms across a range of relationship types and contexts	60 Self-reported PMS	22-48 years old Majority Anglo-Australian 80% partnered 66% heterosexual, 33% homosexual 47% mothers Age at onset of symptoms and age at diagnosis not reported	Mixed method Recruited via local media, women's health centres, community groups and	Thematic decomposition (Stenner, 1993), a version of thematic analysis (Braun & Clark, 2006)	Three themes: 1) Naming to explain 2) 'PMS' becoming the only explanation for distress 3) 'PMS' as not a legitimate explanation for distress

					social organizations. Semi-structured interviews		
1 6	Perz and Ussher (2006) Australia	To examine women's subjective experience of PMS, and the negotiation of PMS in the context of relationships	35 (interviews) 2 (case studies) Self-reported to experience PMS	17-49 years old 63% partnered 59.5% heterosexual 76.6% employed 44% mothers Age at onset of symptoms, age at diagnosis and ethnicity not reported	Mixed methods Recruited via local media and women's health centres Questionnaire, narrative interviews, followed by case studies	Thematic decomposition (Stenner, 1993)	Women described PMS similarly, as being characterized by intolerance, irritation, emotional sensitivity, feeling more negative towards others, and feeling overwhelmed in the face of life's demands.
1 7	Burrage and Schomer (1993) South Africa	To examine whether the daily coping processes of women suffering from PMS vary across the menstrual cycle and to investigate the effect that women's coping resources have on the severity of their premenstrual symptom	12 PMS symptoms confirmed by researcher	30-49 years old 83% married, 17% single 33% housewives, 25% secretaries, 8% nurse, 8% musician, 8% part-time worker 8% used oral contraception Age at onset of symptoms, age at diagnosis and ethnicity not reported	Recruited via advert in local newspaper Women completed 8 weeks of daily PMS symptom diaries Three formal semi-structured interviews	Content analysis (Stone et al., 1966)	Interview 1: common PMS experiences and feeling like two different people. Interview 2: difficulty in meeting daily demands and interpersonal conflict. Interview 3: hassles arising from family matters, role conflict and daily workload.

3.3 Methodological quality of included studies

The methodological quality of all 17 studies was assessed as high (n=14) or moderate (n=3), indicating the rigorous analysis and reporting of results presented. Only three studies had sufficiently considered the researcher-participant relationship (Jurvanen, 2017; Osborn et al., 2020; Park et al., 2023); however, all papers provided a clear statement of findings and described the value provided by their results. The CASP quality appraisal ratings can be viewed in Table 3. An independent researcher (SH) independently assessed all papers, there was a substantial agreement (97.3%, kappa=0.74), any discrepancies were resolved through discussion.

Table 3: Overview of CASP scores

	Study	1. Clear Aims	2. Qual method appropriate	3. Research design appropriate	4. Recruitment strategy	5. Data collection	6. Researcher participant relationship	7. Ethical	8. Data analysis	9. Statement of findings	10. Value of research	Quality Score
PMDD only studies												
1	Buy (2024)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	No (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
2	Chan et al. (2023)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
3	Osborn et al. (2020)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (10)
4	Marfuah and Barat (2018)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	No (0)	No (0)	No (1)	Yes (1)	Yes (1)	Moderate (6)
5	Hardy and Hardie (2017)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
6	Jurvanen (2017)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (10)
PMDD and PMS studies												
7	Labots-Vogeleang et al. (2023)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
PMS only studies												
8	Park et al. (2023)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (10)
9	Tutty et al. (2022)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
10	Ussher and Perz (2020)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	No (0)	No (0)	Yes (1)	Yes (1)	Yes (1)	Moderate (7)
11	Labots-Vogeleang et al. (2019)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (8)
12	Siahbazi et al. (2018)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (8)

13	Ussher and Perz (2013)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
14	Hoga et al. (2010)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
15	Mooney-Somers et al. (2008)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (8)
16	Perz and Ussher (2006)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
17	Burrage and Schomer (1993)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	No (0)	No (1)	Yes (1)	Yes (1)	Yes (1)	Moderate (7)
	Percentage of studies rated 'Yes' (1)	100%	100%	70%	94%	100%	18%	88%	94%	100%	100%	
Key												
Yes (1)		Partially (0.5)		No (0)								
High scores: > 8-10		moderate scores: 6-8		low scores: <5								

3.4 Thematic synthesis

Two main themes were conceptualised to capture women's experiences. PMDs were described as life controlling, narratives indicated the psychological symptoms and maladaptive coping mechanisms left women feeling themselves and their lives were broken, and forever damaged. The two themes were 1) *controlled by PMDs* (with three subthemes) and 2) *a woman and a life left broken* (with five subthemes) (see Figure 2).

Themes are outlined below with their respective subthemes and quotes to support. Table 4 presents a matrix of these themes and their respective subthemes, highlighting which themes were endorsed by each of the 17 studies.

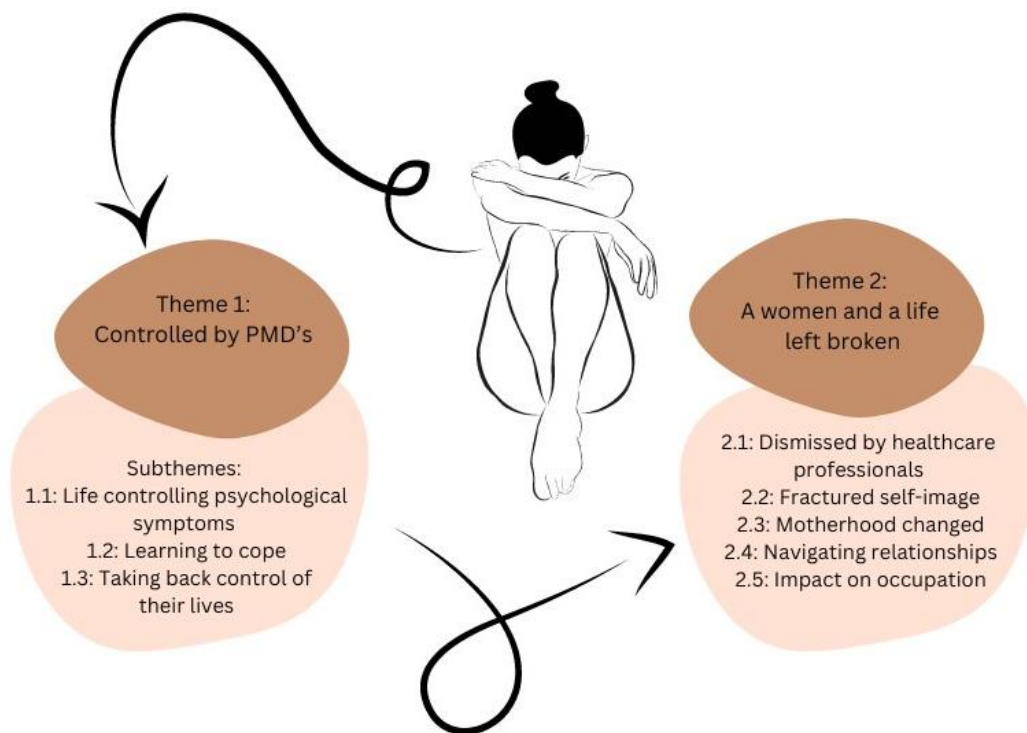


Figure 2: Overview of the two themes and subthemes

Table 4: Matrix of theme representation within the included 17 studies

		Theme 1: Controlled by PMS/PMDD			Theme 2: A woman left broken				
		Life controlling psychological symptoms	Learning to cope	Taking back control	Dismissed by healthcare professionals	Fractured self-image	Motherhood changed	Navigating relationships	Impact on occupation
PMDD only studies									
1	Buyts (2024)	✓	✓	✓	✓	✓	✓	✓	✓
2	Chan et al. (2023)	✓	✓	✓	✓	-	-	-	-
3	Osborn et al. (2020)	✓	✓	✓	✓	✓	✓	✓	✓
4	Marfuah and Barat (2018)	✓	✓	-	-	-	-	✓	✓
5	Hardy and Hardie (2017)	✓	✓	✓	✓	✓	-	-	✓
6	Jurvanen (2017)	✓	-	-	-	✓	✓	-	✓
PMDD and PMS studies									
7	Labots-Vogelansang et al. (2023)	✓	✓	✓	✓	✓	✓	✓	✓
PMS only studies									
8	Park et al. (2023)	✓	✓	-	✓	✓	✓	✓	✓
9	Tutty et al. (2022)	✓	✓	-	✓	-	✓	✓	-
10	Ussher and Perz (2020)	✓	✓	-	-	✓	-	✓	-
11	Labots-Vogelansang et al. (2019)	✓	✓	-	✓	✓	✓	✓	-
12	Siahbazi et al. (2018)	✓	-	-	✓	✓	✓	✓	✓
13	Ussher and Perz (2013)	✓	✓	-	-	✓	✓	✓	✓
14	Hoga et al. (2010)	✓	✓	-	-	-	-	✓	-
15	Mooney-Somers et al. (2008)	✓	✓	-	-	✓	-	✓	-
16	Perz and Ussher (2006)	✓	✓	-	-	✓	-	✓	✓
17	Burrage and Schomer (1993)	✓	✓	-	✓	✓	✓	-	✓

3.4.1 Theme 1: Controlled by PMDs

This theme and its three subthemes captured the perceived control that PMDs exerted over women's lives, and the coping strategies women developed as a result, including active strategies and avoidance. The process of regaining control was framed as separately to coping strategies implemented, and therefore described as a separate subtheme.

Subtheme 1.1: Life-controlling psychological symptoms

Psychological and behavioural symptoms of both PMS and PMDD were reported as negatively influencing quality of life more than any physical symptoms. The psychological impacts were defined as "*life-controlling*" (Labots-Vogelèsang et al., 2019, p.5), with examples including emotional sensitivity, feeling overwhelmed and negatively towards others. At their most extreme, women reported suicidal thoughts and attempts to end their life and "*monthly admissions to emergency department each time they reached crisis point*" (Osborn et al., 2020, p.7). For some women, the time without symptoms was spent preparing for and worrying about their next premenstrual phase, highlighting the life-controlling nature of the condition.

"I'm actually always thinking about it. And when I feel good, I'm already preoccupied with it, like: 'Oh, I hope I won't feel bad again'" (Labots-Vogelèsang et al., 2019, p.5).

Subtheme 1.2: Learning to cope

A wide variety of coping strategies to manage the symptoms and impacts of their undiagnosed PMDs were described, ranging from active approaches to avoidance. Although many papers referenced isolation, there was an interesting contrast in framing: some describing avoidance of "*emotional labour*" (Perz & Ussher, 2006, p.297), whilst others reported being alone as a form of self-care.

“I just want to lock myself in a room and hide under a duvet and not talk to or see anyone. And I'm completely disengaged and don't take initiatives” (Jurvanan, 2017, p.25).

Many women had developed maladaptive coping strategies; for example, substance misuse, self-harm or disordered eating as a way to maintain control or as a form of self-harm. Secondary mental health difficulties were also described; eating disorders and suicidal thoughts or attempts to end their lives.

“And so at some point I [...] would also feel the urge to end it all” (Labots-Vogelansang et al., 2023, p.5).

Whilst some women lacked the energy to implement any coping strategies, others actively engaged with activities to look after their own body and prioritise themselves; *“taking the time-out to recognize my own needs has been very useful”* (Ussher & Perz, 2020, p.15).

Subtheme 1.3: Taking back control of their lives

Shared amongst some participants was the sense of women taking back control of their lives, in contrast to feeling controlled by their PMDs, after receiving a diagnosis and/or treatment. This subtheme was more prevalent within the PMDD papers (see Table 5). Examples included women *“adjusting [their] lifestyle completely”* (Buys, 2024, p.11) and the ability to plan their lives around their menstrual cycles, rather than work against it. Although some women struggled to accept their diagnosis and were reluctant to take medications, others described validation from finally being given a diagnosis and/or treatment. Participants described their treatment as *“life changing and life-saving”* (Osborn et al., 2020, p.8).

3.4.2 Theme 2: A woman and a life left broken

Women described the length of time between their first symptoms and their eventual diagnosis, and the responsibility they held to advocate for themselves throughout this process. Advocating for themselves across a significant length of time when feeling repeatedly dismissed by healthcare impacted women's sense of self, and other key life domains. Five subthemes were developed.

Subtheme 2.1: Dismissed by healthcare professionals

On many occasions women visited healthcare professionals seeking advice and help, but they left feeling “dismissed” (Osborn et al., 2020, p.7), with one individual being told her symptoms were “in their head” (Chan, Rubtsova & Clark, 2023, p.4). Professionals were deemed to have minimal knowledge regarding the symptoms or treatment options for PMDs, thus requiring women to be the expert and advocate for themselves.

“I realised that I basically have to treat myself” (Park, Murphy & Cezar De Cruz, 2023, p.643).

Women described spending months completing symptom diaries only to have doctors decline to read them, which they experienced as particularly frustrating because the DSM-V specifically highlights symptom diaries as a necessary part of the diagnostic process (APA, 2022). If treatments were offered, these focused solely on physical symptoms, therefore not targeting most distressing psychological symptoms (as per theme 1, subtheme 1).

“You can no longer turn to a doctor because [...] they had no answers either” (Labots-Vogelesang et al., 2023, p.5).

Subtheme 2.2: Fractured sense of self

Across the majority of studies, women used an array of terms to define and differentiate themselves with and without symptoms, as if they were two separate entities and described “*feeling like two different people*” (Burrage & Schomer, 1993, p.113). Examples included “*alter-ego*” (Osborn et al., 2020, p.5) and “*Jekyll and Hyde*” (Hardy & Hardie, 2017, p.294). This finding appeared to be in response to the guilt and fear women experienced regarding their “*out of character*” (Hardy & Hardie, 2017, p.295) behaviours, whilst in the luteal phase. One consequence of a fractured self-image was a decline in self-esteem and self-confidence.

“I lost my confidence and I stopped saying what I really felt and what I really thought”
(Buys, 2024, p.8).

Specifically, women described a self-objectification and annihilation of their “*sense of being attractive*” (Ussher & Perz, 2020, p.7), and used derogatory terminology to describe themselves: “*frumpy*”, “*disgusting*” and “*unattractive*” (Ussher & Perz, 2020, p.7). Women chose to conceal their body during their premenstrual phase by wearing looser fitting clothes, or by simply not leaving the house.

Subtheme 2.3: Motherhood changed

For participants who had children, a majority spoke about the distress and impact of their symptoms on their children, and recognised being “*quite unreasonable with them*” (Tutty et al., 2022, p.90) during their luteal phase. Women described the difficulties fulfilling their role as a mother and the impact this had; “*I feel like I’m not being a good mom*” (Park, Murphy & Cezar De Cruz, 2023, p.643). Some women felt dominated by the needs of their family and described a feeling of resentment and internal conflict. Some women bravely shared their guilt of using physical chastisement with their children, such as spanking, when experiencing symptoms, something they would not typically do. Intense feelings of guilt then followed and women

overcompensated with their children afterwards or choose to isolate themselves during their luteal phase to avoid contact with their family to protect them.

“For women who were mothers, they talked about having felt unable to care for their children and their deep regret for not having been able to be the parent that they wished to have been” (Osborn et al., 2020, p.7).

Subtheme 2.4: Navigating relationships

Maintaining relationships through menstrual cycles was a common challenge, women spoke of volatile relationships and repeated conflicts with partners, and experienced guilt for not fulfilling their own role as a supportive partner. Many spoke about their difficulties in having to rely on someone else for support and recognised the responsibility of having to educate their partner. Some women had a perception that their male partners did not understand their intense symptoms and they had a *“perception that men did not understand the suffering of women”* (Hoga et al., 2010, p.375). Relationships became fractured as partners told women that they *“cannot rely on you”* (Siahbazi et al., 2018, p.288), resulting in women having to apologise for their behaviour during their luteal phase. However, when partners did recognise the difficulties, women generally felt more understood and supported. This perceived lack of understanding resulted in some heterosexual women never choosing to tell their partner when they were experiencing symptoms related to their menstrual cycle.

“Very unfair that every month I have to say to my partner ‘no I’m, it’s the week that I’m getting my bad days so, you know, I’m just telling you now’ it’s a bit embarrassing” (Mooney-Somers, Perz & Ussher, 2008, p.6).

Subtheme 2.5: Impact on occupation

As participants were working or were in education the term occupation was used to cover both activities. A common theme across studies was that maintaining an occupation whilst experiencing life-controlling symptoms was perceived to be a near impossible task. Women described regular absences, terminated employments and withdrawal from higher education: “*school was shattered*” (Maruah & Barat, 2018, p.223).

“I feel I can't do the 8 hours a day, 5 days a week job. I really don't think I could manage that mentally or physically. Because, if I look back at times I've been working, I have many days of absence. At least 2-3 days every month, and they always happen the days before menstruation” (Juraven, 2017, p.23).

Some women described feeling less motivation to engage in occupations during their luteal phase, whilst others acknowledged their careers had been impacted by their symptoms of emotional dysregulation.

“Women often thought colleagues were talking about them and perceived them as being unable to do their job. Communications could often be misperceived as negative or a personal attack on them” (Hardy & Hardie, 2017, p.294).

Avoidance was used by some women to manage at work, as well as recognising they held a more negative view of colleagues; “*I find I get more annoyed by other people... especially at work*” (Ussher & Perz, 2020, p.915) Although some individuals felt comfortable sharing their experiences with their employer, this came with its own complexities, including facing disciplinary action and justifying the chronic impact of PMDs.

4. Discussion

This systemic review of 17 studies was the first to explore and thereby report on the psychological impact of living with PMDs. Key themes highlighted PMS and PMDD were experienced as life controlling,

women felt required to repeatedly advocate for themselves during appointments with medical professionals who failed to recognise their PMD, and they had to explain their condition to their family and work colleagues, who did not understand their symptoms' psychological impact. The weight of this responsibility was with women who already experienced debilitating symptoms each month, which reduced their psychological resilience. Women positioned themselves as the expert, researching and educating others, including medical professionals. As a result of these demands, combined with living with life-controlling symptoms and developing and learning coping strategies to lead a functional life, women viewed themselves and their lives as broken.

The current review expands upon the findings of Moe and Karlsson's PMDD review (2022), the findings from both reviews support the impact PMD's had on a variety of life domains, including family, relationships, and occupation. However, novel insights were provided by the current review into the relationships women held with others. Themes described the difficulties women had fulfilling their roles as a mother and partner, and the subsequent guilt and regret experienced. Additionally, as Moe and Karlsson's review (2022) included six papers in which the participants' diagnosis was not verified or was questionable, the current review provided a more diagnostically robust synthesis of qualitative studies relating to PMDD as well as PMS. Thus, only six studies from Moe and Karlsson's review of 12 studies were included in the current review.

To manage their enduring symptoms and maintain a functional life, women developed various maladaptive coping strategies, including disordered eating, as indicated by Coban et al. (2021) and Yi, Kim and Park (2023). A strong association between suicidal ideation and PMDD was previously seen in Osborn et al.'s (2021) and Prasad et al.'s (2021) reviews, and reflected in the current review, in which a monthly crisis point was reached by many women. Given the level of risk highlighted, further research should focus specifically on understanding the relationship between PMDs and thoughts and attempts of suicide.

Whilst the contrast between women's self-image with and without PMS symptoms has been documented (Cosgrove & Riddle., 2003), the current review noted that women's sense of self appeared to be fractured with women describing themselves as two separate entities. Changes to identity in response to a physical health illness draw on narrative identity theory to understand the mismatch perceived identity (Walker & Rogers, 2017). Current themes connected this fracture in identity to the guilt women felt for their behaviour during their luteal phase, and the self-objectification which followed.

Although the psychological impact PMD symptoms had on women's quality of life has been quantified in the literature (Branicka-Woźniak et al., 2022; Irshad et al., 2022), the current review extends these observations by recognising that even during non-symptomatic periods, women were still worrying about their next menstrual cycle. Despite the combination of PMS and PMDD diagnoses in this review, these findings were seen across all studies.

4.1 Strengths and limitations of synthesised papers

This review recognised the omission of relevant demographic information within the synthesised papers; 11% failed to document the participants' age and 41% did not report their ethnicity. This omission limits the transferability of results to other groups and settings. Only five papers reported on the length of time women had experienced symptoms, or their age at onset of symptoms or diagnosis, meaning nuances within the data and psychological impact could not be explored in depth. Of note, Park et al. (2023) provided no participant demographic information, and two papers did not reference the author of the chosen method of analysis. Similarly, the CASP rating scores (see Table 3) highlighted a notable trend of authors failing to reflect on the researcher-participant relationship (item 6), and how their own position could impact the analysis.

Whilst conducting scoping searches, the authors noted published titles which referenced a PMD; however, the methodology indicated that women without a formal diagnosis were recruited. As documented in Figure 1, a total of 21 papers were removed because they focused on non-clinical levels

of premenstrual symptoms, and a further nine were removed due to unclear or undefined participant eligibility criteria. It is argued that this practice continues to blur the lines of what are typical premenstrual symptoms versus the severity of diagnosable PMDs. Transparency and clarity of participants' symptoms and/or diagnosis are needed in future research.

4.2 Strengths and limitations of review process

This review of 17 papers was conducted in a systematic, transparent way, using an established analysis approach and synthesised the voices of 479 women across 31 years of research. Searches were independently analysed for eligibility; assessment of each paper was conducted using the validated CASP (2018) checklist and initial coding was conducted separately by the two authors independently to increase credibility and minimise risk of bias. However, the decision to only include academic papers written in English raised the possibility of language, location and publication biases.

As PMS and PMDD sit within a continuum (Ismaili et al., 2016), studies were combined under the term PMD to develop a comprehensive picture of women's experiences. Although it was a strength to combine qualitative PMD studies, it could also be argued that nuances of symptom severity could not be drawn out appropriately. At present PMS and PMDD are diagnosed independently; however, PMDD has only been a separate entity since 2013 (Goswani et al., 2023), and hence more qualitative studies are emerging only since then. The matrix of theme representation (see Table 4) strengthened the decision to combine PMS and PMDD studies, as only one of eight subthemes was solely represented by both diagnoses. All seven remaining subthemes represented the experiences of women with both PMS and PMDD, highlighting the similarities of their psychological impact.

Another strength of this review was the clear specification of PMS and PMDD symptoms/diagnosis within included papers, ensuring that the synthesised data captured the experiences of women with clinical levels of symptoms, as opposed to the general population of menstruating women.

Papers excluded for this reason were unlikely to represent the experiences of women with a clinically diagnosable level of symptoms.

4.3 Clinical implications

The difficult experiences women had seeking support from healthcare professionals were highlighted, adding to the concerning reality that healthcare professionals were less likely to take women's experiences seriously (Hoffmann & Tarizan, 2001), especially when their symptoms were related to their reproductive health (Grundström et al., 2018; Osborn et al., 2020). Consequently, women with a suspected or diagnosed PMD must continue to advocate for themselves and discuss their symptoms with their family and social support network. Clinicians should consider the psychological impact of PMDs and the associated impact on quality of life, recognising the potential need for referral to clinical psychology services for therapeutic support with processing of diagnosis and psychological impact, to reduce psychological distress.

Owing to the frequency of suicidal experiences described, additional training for healthcare staff to assess PMDs and signpost women to appropriate services is required. Increased understanding of PMDs would be beneficial in healthcare services where women in crisis may present, for example, emergency services, general practitioners, and mental health teams. Once diagnosed, many women described only being offered treatment for physical symptoms. Therefore, premenstrual training for healthcare professionals is needed to have an updated understanding of the growing research into the range of evidence-based treatment options (see Nevatte et al., 2013 for further exploration of treatment options) and recognise the need for therapeutic interventions targeting the psychologically distressing symptoms.

5. Conclusion

For the first time, qualitative papers exploring the psychological impact of premenstrual disorders (PMS and PMDD) were synthesised in one systematic review. Women described PMDs as life-changing and

life-controlling, they were often left holding the responsibility for understanding and managing their own symptoms, whilst advocating for themselves in a world which did not recognise their experiences. Key recommendations included the need for medical professionals working with women in crisis, to assess for PMDs and signpost towards specialist services, including psychological interventions.

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

Not applicable

Competing interests

All of the authors declare no conflict of interest.

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Authors contributions

All authors participated in the design of this study. DB undertook the literature search, DB and DMS both independently coded and synthesised the literature. All authors reviewed the findings and final manuscript.

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Paper 2

Women with Premenstrual Dysphoric Disorder (PMDD) Experiences of Suicidal Thoughts and Behaviours: A Mixed Methods Study

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Abstract

Background: Women with Premenstrual Dysphoric Disorder (PMDD) experience debilitating psychological symptoms during each luteal phase of their menstrual cycle. Although women's increased risk of suicidal thoughts and attempts to end their lives has been highlighted, little is as yet known about women's own narratives. Therefore, this study aimed to explore the prevalence and the experiences of self-harm, suicidal thoughts and attempts in women with PMDD.

Method: In this mixed methods study, women's experiences of living with PMDD were captured via an online survey exploring risk and via semi-structured interviews with questions informed by survey results. Data were analysed using descriptive statistics and reflexive thematic analysis.

Results: Over 3,600 women completed the survey between January and March 2020 and 14 women were subsequently interviewed in 2022. The survey revealed that just under half of women had deliberately harmed themselves during a PMDD crisis, 82% had suicidal thoughts on one or more occasions during their luteal phase, and 26% of women had attempted to end their own life. Three main themes, which related to suicidal ideation in the context of PMDD, were generated from the interview data: 1) *personal relationships and social connections affected by PMDD*, 2) *the increase in suicidal experiences caused by diagnosis delays* and 3) *self-worth damaged by PMDD*.

Conclusion: Women living with PMDD are at high risk of self-harm, suicidal thoughts and attempts to end their lives each month, narratives highlighted the damaging impacts PMDD had on relationships. Risk was increased by delays in appropriate medical support and women reported internalising their experiences as their problem.

Keywords: *women's health, mental health, women, qualitative, quantitative.*

1. Introduction

Premenstrual Syndrome (PMS) is cyclical and characterised by psychiatric and somatic symptoms (Hofmeister & Bodden, 2016; Kessel, 2000), peaking in the luteal phase, and resolving after the onset of menstrual bleeding (Kessel, 2000). Approximately 50-80% of women of reproductive age have mild PMS, and 30-40% report a severity of symptoms requiring treatment (Ryu & Kim, 2015). In 1987, the DSM-III (American Psychiatric Association, 1980) categorised a severe form of PMS, originally titled Late Luteal Phase Dysphoric Disorder and later changed to Premenstrual Dysphoric Disorder (PMDD; Yonkers et al., 2008). PMDD affects 5-8% of women of reproductive age (Wittchen et al., 2002; Yonkers et al., 2008) and is a complex, disabling condition believed to be associated with the fluctuation of hormones during the luteal phase of the menstrual cycle (di Scalea & Pearlstein, 2017). Women living with PMDD report various cognitive, psychological and somatic symptoms; some women experience increased stress, depression, anxiety and even psychotic episodes (American Psychological Association, 2013; Hantsoo & Epperson, 2020; Mohib et al., 2018; Studd, 2012).

Suicide is a global problem, occurring throughout the lifespan and across diverse backgrounds (World Health Organisation, 2021). Statistics show that women were three times more likely to attempt suicide than men (Nock et al., 2010). In addition, a significantly higher prevalence of PMDD has been found among women hospitalised for attempting to end their lives (Baca-Garcia et al., 2014; Shams-Alizadeh et al., 2018). Three large cohort publications examining correlations found significant relationships between PMDD and suicidal ideation, suicide plans and attempts (Hong et al., 2012; Pilver et al., 2013; Yan et al., 2021). In their systematic review of ten studies, Osborn et al. (2021) also noted that PMDD was associated with suicidal thoughts, plans and attempts. Furthermore, survey data indicated that women with PMDD reported higher rates of self-injurious thoughts and behaviours, when compared to

population averages for women without PMDD (Eisenlohr-Moul et al., 2022). This finding was based on 599 women with a prospectively confirmed diagnosis of PMDD. However, no association between suicide attempts and different phases of the menstrual cycle for women with PMDD was identified by Osborn et al. (2021), as would have been anticipated. These discrepancies in studies may reflect differences in the severity of PMDD symptoms and diagnostic methods used for its identification (Osborn et al., 2021). Osborn et al. (2020) noted that it could take 20 years for a women's PMDD symptoms to be accurately diagnosed and treated, increasing the importance of further research to understand the psychological impacts that living with PMDD has on women's experiences of suicidal thoughts and behaviours (Shams-Alizadeh et al., 2018) both before and after diagnosis.

There is a growing literature aiming to explore the experiences of women with a premenstrual diagnosis. In order to understand the psychological impact of living with a premenstrual disorder (PMD), Brown et al. (2024) conducted a metasynthesis of 17 qualitative papers and identified two themes 1) "*controlled by PMDD's*" and 2) "*a woman and a life left broken*". In their review of 12 qualitative papers, Moe and Karlsson (2020) focused on PMDD only and identified two themes: 1) "*limitations due to PMDD*" and 2) "*attempts to manage life with PMDD*". However, Moe and Karlsson's review presented recommendations for nursing. Despite insightful findings, neither review (Brown et al., 2024; Moe & Karlsson, 2020) captured women's perspective of self-harm, suicidal thoughts or suicide attempts, in the context of their PMDD. However, Osborn et al. (2020) interviewed 17 women regarding their journey to receiving a PMDD diagnosis and identified that feeling hopeless in the context of their PMDD appeared to be linked to suicidal ideation and sometimes to women's attempts to end their lives.

To date, no study has focused solely on women's experiences of self-harm and suicidal ideation in the context of their PMDD. Thus, the aims of this study were twofold: 1) to examine

how many women with PMDD reported the experiences of self-harm, suicidal thoughts or attempted suicide and 2) to explore women's lived experiences of PMDD, with a focus on their experiences of self-harm, suicidal thoughts and behaviours.

2. Method

2.1 Design and ethical approvals

A mixed methods design was chosen to explore the above-mentioned aims. Utilising quantitative and qualitative methodologies (Wasti et al., 2022) enabled the development of an enhanced understanding of the impact of PMDD on women.

The survey was granted ethical approval via the British Broadcasting Corporation (BBC) internal processes, including a review by the BBC data protection team who provided a privacy notice to be presented alongside the survey⁶. A data sharing agreement was signed between the BBC and University of Manchester (see Appendix B). Ethical approval for the interviews was granted by the University of Manchester in March 2022 (Ref: 2022-12850-22464, see Appendix C). Due to risk concerns and the potential need to get medical or psychological support for an individual, ethics for the interviews was only granted for the additional recruitment of women currently living in the UK.

2.2 Survey overview

In 2020, BBC news aired a PMDD documentary called "*My periods made me suicidal*" (British Broadcasting Corporation, 2020). During the production of the show a survey was completed by thousands of women internationally. The survey was designed by the BBC to

⁶ See Paper 3, section 4.2 for more information regarding the BBC survey dataset

capture information regarding the wider impact of PMDD on a woman's life. The present study utilised sections of the BBC dataset.

2.3 Survey participant eligibility and recruitment

Participants were women aged ten years and over, who reported receiving a formal diagnosis of PMDD from a healthcare professional. As the survey was available online, it was accessible worldwide. The survey was advertised via social media accounts managed by the BBC and the *International Association for Premenstrual Disorders* (IAPMD, 2024).

2.4 Survey procedure

Potential participants were presented with an electronic information sheet followed by 14 multiple-choice questions, with consent implied by the completion of the survey (see Appendix D for full survey). For the purpose of the current study, only data relating to demographic information (e.g., age and years since diagnosis) and questions relating to self-harm, suicidal thoughts and attempted suicide were selected for analysis.

2.5 Survey data analysis

Six multiple-choice questions were selected from the larger anonymous survey dataset: three questions gathered demographic information (e.g., age and years since diagnosis) and three questions related to self-harm, suicidal thoughts, and attempted suicide. Survey responses were made available within Microsoft Excell and descriptive statistics were used, with data tabulated.

2.6 Interview overview

In the qualitative part of this mixed methods study, women were interviewed to collect lived experience data, which were analysed using reflexive thematic analysis (Braun & Clarke, 2006). This method allows for further exploration of participant experiences and perspectives, beyond the quantitative data available from the survey. The survey findings informed the development of the qualitative topic guide used in the subsequent interviews with British women.

2.7 Interview participant eligibility and recruitment

All participants were English speaking women, over 18 years old, living in the UK, who reported receiving a formal diagnosis of PMDD, their symptoms were tracked for a minimum of two months by their medical doctor⁷. Participants were recruited via a social media advert shared online and within premenstrual disorders forum pages between April and September 2022 (Appendix E). Potential participants, who contacted the research team to express interest, were emailed a copy of the information sheet and consent form (Appendices F and G).

2.8 Interview development and data collection

Although the survey captured the data from a large number of women with PMDD, it included pre-defined multiple-choice questions. To understand the wider ranging impact of PMDD on women, a topic guide (Appendix H) was developed based on the survey results, which included questions and prompts related to experiences of self-harm, suicidal thoughts and suicide attempts. Additionally, a demographic questionnaire (Appendix I) was developed to record their use of symptom trackers, estimated age of symptom onset and age of diagnosis.

⁷ See Paper 3, section 4.3 for further information regarding inclusion criteria

2.9 Interview procedure

Interviews were completed via video call, once the participant had provided written informed consent and completed the short demographics questionnaire. A semi-structured topic guide was followed, and interviews were recorded, securely stored and transcribed verbatim.

As participants were not recruited through a medical team, all participants provided their GP details and consented to them being contacted, in case there were any risk or safeguarding concerns raised during the interviews. All participants were made aware they had two weeks after the interview date to withdraw, after this time all data would be anonymised and could not be identified. Due to the emotive topic, a distress management plan and debrief sheet were developed to protect their wellbeing (Appendices J and K).

2.10 Interview data analysis

The analysis of the qualitative data was guided by the six stages of Braun and Clark's reflexive thematic analysis (Braun & Clark, 2006; Braun et al., 2018). This method was chosen to understand the participants' experiences with theoretical freedom.

Two authors (DB and DMS) familiarised themselves with the interview dataset, taking an inductive approach to code line-by-line and separately generate initial semantic codes, before jointly reviewing preliminary latent codes (phase 2). Both NVivo and paper post-it notes were used to collate comparable codes and construct themes to conceptualise patterns of shared meaning shown by the participants (phase 3). Once latent themes were described, further analysis of the dataset was undertaken (by DB and DMS) to ensure the themes represented and reflected the experiences of the participants (phase 4). Themes were then defined and named (phase 5) through consultation with the research team, before the written report was produced (phase 6).

2.11 Reflexivity and rigour

The first author (DB) was a Trainee Clinical Psychologist, with a history of working with children, families and working in complex, challenging environments, such as secure services. The second author (DMS) was a Health Psychologist and Senior Lecturer, with a background in exploring pregnancy and behaviour change. The third author (EO) was a Clinical Psychologist working within paediatric services and had a specialist research interest in premenstrual disorders. The fourth author (AW) was a Clinical Psychologist and Senior Lecturer, whose clinical work involved supporting mothers with severe mental health difficulties therapeutically. The authors had varying levels of qualitative research experience and of clinical support of women with premenstrual conditions. As all authors were women and mothers, these roles could have impacted how they viewed the data, given all participants were also women and many, but not all, were mothers⁸. To reduce bias during analysis, the first author kept a reflective journal, which she used to write down thoughts and impressions during interviews, transcription, and coding, as well as methodological decisions. These reflections were shared with all authors, when appropriate, and discussed during coding and theme generation, allowing a secondary level of reflection and consideration. The variety of experience and clinical backgrounds allowed for authors to challenge each other's assumptions and pre-conceptions.

3. Results

3.1 Survey participant characteristics

Overall, 3,906 women with a reported diagnosis of PMDD from a healthcare professional completed the survey between January and March 2020. The age of participants ranged from

⁸ See Paper 3, section 4.5 for further reflections.

ten to over 60 years old and the majority were non-UK residents. Whilst most women received their diagnosis in the last nine years, some women reported receiving a diagnosis over 30 years ago (see Table 5 for further details).

Table 5: Demographic characteristics for survey data⁹

		N (%)
Country	UK Resident	1,547 (40%)
	Non-UK Resident	1,979 (51%)
	Unknown	380 (9%)
Age	Under 19	85 (2%)
	20 – 29	970 (25%)
	30 – 39	1,733 (44%)
	40 – 49	1,002 (26%)
	50 – 59	109 (3%)
	Over 60	2 (<1%)
	Unknown	5 (<1%)
Years since diagnosis	0 – 9 years	1,825 (47%)
	10 – 19 years	1,213 (31%)
	20 – 29 years	663 (17%)
	Over 30 years	143 (4%)
	Unknown	62 (2%)

3.2 Survey findings

Of 3661 women, 47% reported to have self-harmed, at least once during a PMDD crisis (see Table 6). Specifically, 9% regularly self-harmed, whilst 31% had self-harmed on occasion and 7% reported only one instance of self-harm related to their PMDD. The remaining women had self-harmed at a different time in their menstrual cycle (3%) or had never self-harmed (49%).

⁹ No further demographic information was collected by the BBC.

Table 6: To what extent had PMDD led to self-harm?

1. To what extent had PMDD led to self-harm?	Number (%)
I regularly self-harm during PMDD crises	322 (9%)
I have self-harmed on occasion during PMDD crises	1150 (31%)
I have self-harmed once during a PMDD crisis	274 (7%)
I have self-harmed but at a different time/s in my menstrual cycle	116 (3%)
No, I have never self-harmed basis just before my period	1799 (49%)
	3661

In total, 3768 women responded to question 2; 82% had experienced suicidal thoughts, on one or more occasion during their luteal phase (see Table 7). Of these, 6% of women reported suicidal thoughts once, and 36% had experienced suicidal thoughts on occasion. Forty percent of respondents experienced suicidal thoughts monthly.

Table 7: To what extent had PMDD led to suicidal thoughts?

2. To what extent had PMDD led to suicidal thoughts?	Number (%)
I have suicidal thoughts on a monthly basis just before my period	1511 (40%)
I have suicidal thoughts on occasion just before my period	1364 (36%)
I have had suicidal thoughts once just before my period	244 (6%)
I have had suicidal thoughts but at a different time/s during my menstrual cycle	286 (8%)
No, I have never had suicidal thoughts	363 (10%)
	3768

Of 3670 women, 13% reported to have attempted suicide more than once and 13% had attempted suicide once during a PMDD crisis (see Table 8). Two percent of women responding had attempted suicide at different times in their menstrual cycle, unrelated to their PMDD and 72% had never attempted suicide.

Table 8: To what extent had PMDD led to attempted suicide?

3. To what extent had PMDD led to attempted suicide?	Number (%)
I have attempted suicide more than once during PMDD crisis	479 (13%)
I have attempted suicide once during a PMDD crisis	477 (13%)
I have attempted suicide but at a different time/s in my menstrual cycle	69 (2%)
No, I have not attempted suicide	2645 (72%)
	3670

3.3 Interview participant characteristics

Thirty-three women contacted the researcher, three women were not living in the UK and were therefore unable to participate, in line with ethical approval. Fifteen individuals did not respond to follow up emails. Thus, 14 women consented to take part and were interviewed between May and September 2022. Their ages ranged from 24 to 54 years, and they were all White British. Although the mean age of symptom onset was 22 years old, the mean age of diagnosis was not until 42 years old. All 14 women had received specialist treatment previously, eight were biological mothers of children ranging from three to 26 years old, one woman had stepchildren (see Table 8 for further demographics).

Table 9: Demographic characteristics of interviewed participants

		N (%)
Age	Under 19	0 (0%)
	20 – 29	3 (21%)
	30 – 39	2 (14%)
	40 – 49	7 (50%)
	50 – 59	2 (14%)
	Over 60	0 (0%)
Ethnicity	White	14 (100%)
Highest level of education	No school attended	0 (0%)
	Primary school	0 (0%)
	Secondary school	2 (14%)

	Collage University Other...	3 (22%) 9 (64%) 0 (0%)
Marital Status	Single In a relationship Co-habiting Married Divorced Other...	3 (21%) 0 (0%) 5 (36%) 5 (36%) 1 (7%) 0 (0%)
Estimated age of symptom onset	Under 19 20 – 29 30 – 39 Over 40	11 (79%) 2 (14%) 1 (7%) 0 (0%)
Age when diagnosed	Under 19 20 – 29 30 – 39 40 – 49 Over 50	0 (0%) 5 (36%) 3 (21%) 7 (50%) 0 (0%)
Currently receiving treatment	Yes No	12 (86%) 2 (14%)
Previously received treatment	Yes No	14 (100%) 0 (0%)
Have children	Yes No	9 (64%) 5 (36%)

3.4 Thematic analysis themes

Three themes were developed from women's narratives that reflected the psychological impact PMDD had on them, including their experiences of suicidal ideation and attempt (see Figure 3 for a conceptual diagram). The experiences captured within themes one and two had a direct impact on women's self-worth, as described in theme three. The three themes will be presented below with related subthemes (n=7) and pseudonymised quotes from the transcripts.

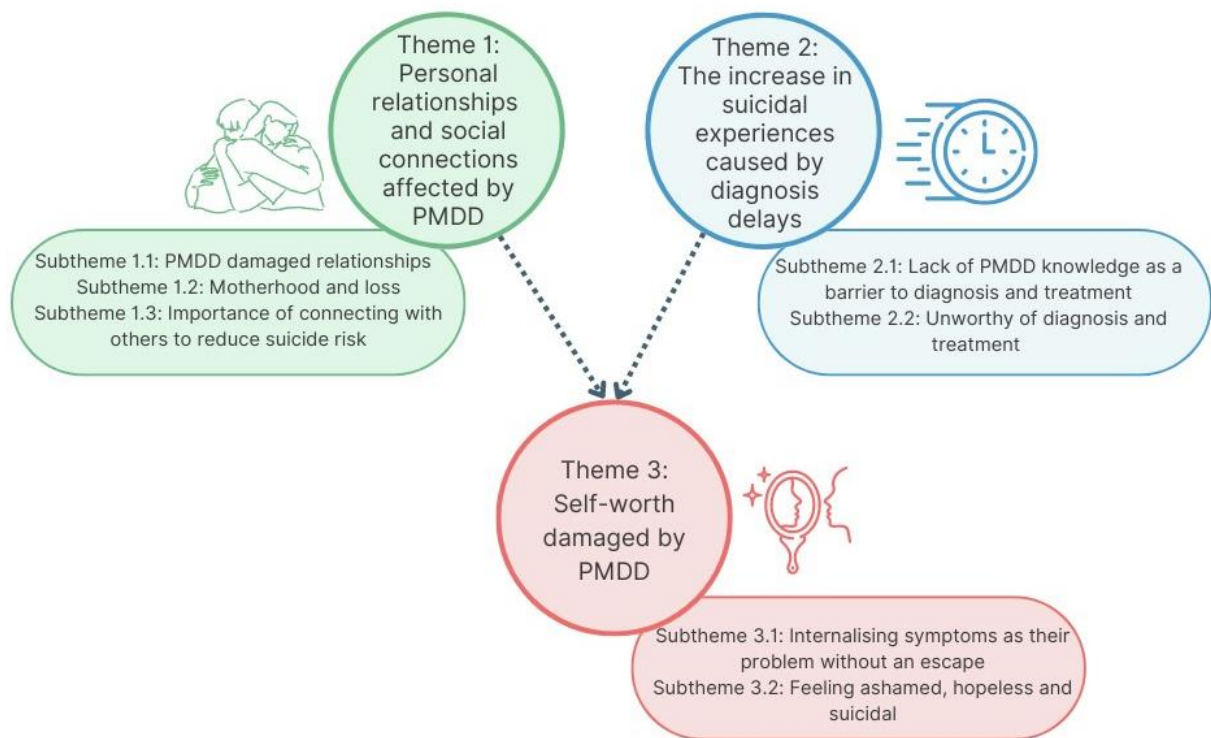


Figure 3: Diagram of themes from interviews

Theme 1: Personal relationships and social connections affected by PMDD

Women's narratives revealed numerous attempts of engaging in personal relationships and social connections whilst living with PMDD and associated suicidal thoughts each month or during a crisis. These experiences were described as complex and at times chaotic. Women recognised their relationships being negatively impacted or damaged, contributing to emotional isolation, and this in turn contributed to their experiences of suicidal thoughts or attempts. Women spoke about their romantic relationships, family members and friendships; however, they particularly highlighted the greater impact PMDD had on their role as a mother, or their ability to become a mother. This main theme consisted of three subthemes.

Subtheme 1.1: PMDD damaged relationships

In all cases, woman described a perceived link between their experiences of suicidal thoughts and the key relationships with other adults in their lives. A common view amongst the women was a recognition that these relationships were reciprocal for approximately three weeks each month. But when in a PMDD crisis and experiencing associated suicidal thoughts, this dynamic changed. One woman described the difference in her interacting with her loved ones during each luteal phase as "*unreasonable*" (Sally). Women spoke of ending their romantic relationships monthly, long-term friendships being broken and struggles to maintain connections with colleagues, all of which left them hopeless.

"Demons just came out and suddenly that that friendship was never the same"
(Catherine).

Relationships and friendships were categorised by push-pull patterns, with women trying desperately to repair the damage caused by their suicidal thoughts linked to their PMDD crisis, whilst knowing they did not have long until the same pattern repeated itself. Upon recognition of this pattern, women reported increased feelings of hopelessness and subsequent

suicidal thoughts or attempts. Women described that living with them was like living with a “roller coaster” (Katie), and that they noticed psychological distress being experienced by their partners. According to women, partners often particularly struggled to understand the unpredictable changes and suicidal experiences expressed by them.

“He used to say I just didn't know what I was going to come home to. Said you'd be fine I'd walk out the room, and I'd come back in and your face would have changed and you'd be raging about nothing and everything. Erm and at my worse he didn't know if he was going to come home and find me having killed myself” (Katie).

Subtheme 1.2: Motherhood and loss

A women's role as a mother was described with more importance, different dynamics, and expectations to their other relationships, as detailed in the previous subtheme. Motherhood was an emotive topic discussed by all the women and was often underpinned with feelings of loss. Whilst some women described their monthly suicidal experiences as robbing them of the opportunity to be a mother, those who had children recognised the loss of the mother they had wished to be.

Furthermore, worrying about the impact PMDD would have on their children was a common experience, and some women made the difficult decision not to have children, instead choosing to have a hysterectomy and, hopefully, live a functional life. There was recognition that not being able to have children impacted on their current or future partners.

“I chose not to have kids because it was so bad and I thought I really don't want to, you know, I really don't want to hurt, and it's awful because I love kids” (Hannah).

Another concern women spoke of was how they would be able to prioritise taking care of a child, when they did not feel able to care for themselves for a period of time each month.

Many women also expressed worries about the psychological impact PMDD would have on their future children.

“I was really worried about like emotional blueprint and transference, and what happens and how traumatic potentially the child’s first twelve, twenty-four months could be, ‘cos even if I had the child, then what happened about the attachment and things like that, and I was like, it’s one thing having, needing like psychiatric care and ending up in a mother and baby unit potentially, when you don’t know, but if you anticipate that that is what’s gonna happen, and you think that’s likely, I was like I don’t, I don’t think I can do that to a child” (Natalie).

Experiencing suicidal thoughts whilst parenting left women with indescribable guilt, and worry for the impact this could, or did have, on their children. Some women described what their children witnessed as trauma and worried about the possibility of their daughters also being diagnosed with PMDD.

“Erm, it’s then it’s the guilt pressure of you know you feel low and you’re shutting down on people, but you can’t help it and being a mum, you’ve got the mum pressure of, you know, needing to be there for your children and not wanting them to see you in that kind of frame of mind, but you can’t do anything about it, it just completely takes over” (Elisa).

Subtheme 1.3: Importance of connecting with others to reduce suicide risk

Women’s narratives offered ideas on what might help them cope during a mental health crisis related to their PMDD. They emphasised the importance and value of being able to connect with at least one person. Women valued this connection and viewed it to reduce the risk of acting on their impulses to self-harm or attempt to end their lives.

“I’m feeling really low, like I just feel like I could just literally just end it, erm, and she just stayed with me and just talked to me and just listened and that kind of got me through the crisis point” (Ellie).

Unfortunately, women’s suicidal thoughts were described as creating an emotional barrier, preventing women from connecting with other people the way they wished to.

“Because of how you are and what you’re struggling with, so that, I think makes you feel even more lower, and more likely to feel suicidal because you just think, everyone’d be so much better off without me, because nobody understands what you’re going through” (Ellie)

Women described feeling emotionally isolated in their experiences: their friends and family rarely understood their diagnosis of PMDD, their suicidal thoughts or why their behaviour would change so drastically each month. Feeling isolated meant that women did not disclose their suicidal thoughts, perpetuating the experience of isolation. . Some women described comparing their premenstrual symptoms to those of their friends, the recognition of differences left women feeling *“alone”* (Catherine).

“Nobody feels like this, nobody feels the way I do, nobody knows how I feel” (Antonia).

Theme 2: The increase in suicidal experiences caused by diagnosis delays

The process of seeking a diagnosis and treatment for their PMDD symptoms was prolonged due to repeated visits to different medical professionals, who were often unaware of PMDD. Such difficult medical appointments left women feeling both dismissed and unworthy of help because they left no closer to a diagnosis or treatment plan than before they sought help. The length of delay also drastically increased perceptions of risk for women; the longer women waited, the more menstrual cycles and suicidal thoughts they had and the number of healthcare appointments increased. Two subthemes supported this main theme.

Subtheme 2.1: Lack of PMDD knowledge as a barrier to diagnosis and treatment

Delays in receiving a diagnosis and suitable treatment plan prolonged the hopelessness women reported feeling, which women linked this to an increased risk of suicidal thoughts. They described their journey to diagnosis and treatment as characterised by repeated visits and referrals to a wide variety of services, most of which had minimal knowledge or awareness of PMDD.

“Sort of reflecting on it all, I think, with that lack of support, without that understanding, etc, it put me so, so much lower, and more at risk of self-harm and suicide” (Ellie).

Women described having had appointments with multiple different services regarding their undiagnosed PMDD, including, general practice doctors, community mental health teams, outpatient crisis teams, personality disorder services and some were inpatients on acute mental health wards. Each referral returned the women back to an indefinite wait for support they perceived a diagnosis or treatment would bring, whilst living with significant risk of self-harm or suicidal behaviours each menstrual cycle. *“PMDD just, kind of as a tsunami just washing over me, just month after month” (Stephanie).* These referrals also required women to voice their thoughts and plans to harm themselves, which was reported as incredibly traumatic, and was only made worse by the lack of appropriate support which often followed.

“Everything takes such a long time, doesn’t it, so you’re waiting, waiting, waiting, which makes everything worse and it makes, probably makes you more angry and more tense and more anxiety and depression, because you’re currently waiting and waiting” (Scarlett).

Subtheme 2.2: Unworthy of diagnosis and treatment

When seeking support for their PMDD symptoms, including thoughts to harm themselves, from healthcare professionals, women described feeling dismissed. They recounted stories of being called a “*hypochondriac*” (Lauren), “*told to go away*” (Sally) and left appointments feeling “*pathetic*” (Catherine) that they were not able to manage their symptoms. Interactions with healthcare professionals left women feeling their experiences did not deserve a diagnosis and they were not worthy of the clarity women hoped a diagnosis could provide.

“She didn't know what to do, she found my suicide letter phoned the ambulance, and when I was down there a nurse said what is she doing here, she was safe in her house, she's wasting our time, so they then left me for 12 hours of my own, while waiting for the community mental health to come out and assess me” (Katie).

Many spoke about being misdiagnosed: “*bipolar*” (Hannah), “*chronic fatigue*” (Sally), “*borderline personality disorder*” (Mandy) or “*eating disorder*” (Natalie). A misdiagnosis was also given despite women bringing symptom trackers, which evidenced the cyclical nature of their symptoms, to appointments. Receiving a misdiagnosis left women feeling invalidated and frustrated. Women expressed how their thoughts to harm themselves or end their lives would increase following those appointments. Women reported perceiving that they knew more about PMDD than their doctor did.

“I would go into the doctor surgeries and be like look I've done some research now I've been coming to you on and off every month for the last few years, with the same symptoms, I think I have PMDD and they would just be like oh what's that, I'd be like what you're not, you don't know what PMDD is and how, it would just be so debilitating because then I would have to explain my own possible condition to people that know a great deal more than me” (Catherine).

During conversations about the treatment options for PMDD, women also reported medical doctors included the cost as one of the most important factors to consider. Often the cost was prioritised above the clinical indication, the women's own wishes or their desire to have children. Other women reported their only option to access treatment was to seek private medical treatment.

"I'd sell anything it's not about money. What price are you going to pay for your life"

(Hannah).

Theme 3: Self-worth damaged by PMDD

The risk of harm to themselves was ever present in women's accounts of their personal relationships and interactions with healthcare professionals, as evidenced by the previous two themes. The culmination of these experiences, for most women over many years, was described as damaging to their self-worth. Women framed their symptoms as their problem and that they were flawed due to the emergence of suicidal thoughts on a monthly basis, subsequently women reported to experience extreme guilt and shame. Being overwhelmed by these emotions increased the sense of hopelessness, risk of self-harm, suicidal thoughts, and attempts. The suicidal experiences of women varied, with some reporting one past experience of suicidal ideation, and others describing monthly attempts to end their life. This final theme was supported by two subthemes.

Subtheme 3.1: Internalising symptoms as their problem without an escape

Women stated that after years of damaged relationships and difficult interactions with healthcare professionals, they had internalised their experiences as their "*problem*" (Molly) or their "*fault*" (Stephanie). Others questioned the sudden desire to harm themselves each month:

“I was like, why am I like this, I don’t understand” (Sally). Some women described that they were failing at simply being a woman, and they were worthless.

“It was like, great, another thing that I’m shit at, basically” (Laurie).

The perceived association between internalising symptoms and increase in risk of self-harm was expressed by women. The risk was framed as something they had to manage themselves at home, with minimal professional help. Internalising their PMDD experiences was described by women to lower their self-worth and damage how they perceived themselves.

“I wasn’t good enough, and, you know, my inner voice was just so negative” (Mandy).

For a smaller proportion of women, this internalising was somewhat alleviated after receiving a diagnosis, and helped women to recognise they were not to blame.

“PMDD has made me feel like I’m such an awful person, erm along with getting used to masking putting faces on so people didn’t really know the pain and it was kind of a relief erm to actually find out that I wasn’t just vile and there was something out my control erm a reason for it” (Katie).

Subtheme 3.2: Feeling ashamed, hopeless and suicidal

As a result of internalising their experiences, women spoke of an intense “guilt” (Elisa) and shame, specifically for thoughts of self-harm or suicide during their luteal phase and for acting on these impulses. At times this shame was so intense it would stop them seeking support.

“I have quite big scars on my arms, from where I hadn’t gone to hospital, I hadn’t had stitches ‘cos I feel so ashamed of what I’ve done” (Stephanie).

Women described the distress and upset their self-harm caused their family and friends, and subsequently feeling “ashamed” (Mandy). Additionally, once their menstrual cycle started and their symptoms reduced, women described almost immediately feeling ashamed about

their behaviours, which, unfortunately, often led to a perceived increased risk of self-harm, suicidal thoughts and attempts to end their lives.

“You also feel like a burden as well, to everybody, because of how you are and what you’re struggling with, so that, I think makes you feel even more lower, and more likely to feel suicidal because you just think, everyone’d be so much better off without me, because nobody understands what you’re going through” (Ellie).

4. Discussion

This study was the first to examine how many women with PMDD reported experiences of self-harm, suicidal thoughts and attempts, whilst also capturing women’s lived experiences, associated with their PMDD. Over 3,600 women with PMDD responded to the online survey; just under half of the women had deliberately harmed themselves during a PMDD crisis, 82% had suicidal thoughts on one or more occasion during their luteal phase, and 26% of women had attempted to end their own life. These results support previously reported rates in the literature for self-harm (51%; Eisenlohr-Moul et al., 2022), suicidal thoughts (72%; Eisenlohr-Moul et al., 2022) and suicide attempts (14%; Hong et al., 2012; 30%; Eisenlohr-Moul et al., 2022). Differences in rates reported may be linked to notably differing sample sizes (59 in Hong et al., 2012; 599 in Eisenlohr-Mour et al., 2022) or variations in terminology used (e.g., suicidal thoughts versus active suicidal ideation). Therefore, authors should be clear and specific with their choice of terminology. Additionally, cultural differences may be affecting the rates reported, because our survey was open to women worldwide; however, Hong et al. (2012) included women living in Korea only.

The potential link between the experiences of PMDD and self-harm, suicidal thoughts and attempts was examined in more detail through interviews. Women outlined that relationships were disrupted on a regular basis because of their PMDD, its associated

symptoms and deterioration in their mental health. Our finding that medical delays and lack of PMDD knowledge within the medical profession, was described as having significant negative impacts on their self-worth and thoughts of ending their lives. These findings complement those by Osborn et al. (2020) and Chan et al. (2020), who explored the journey to diagnosis within the UK and US healthcare systems, respectively. Both sets of authors highlight the detrimental impact of time delays, with Osborn et al. (2020) reporting an average delay of 20 years before PMDD was diagnosed. Delays in receiving diagnosis and treatment were linked to feeling unworthy and hopeless within these findings, the internalising of PMDD symptoms was perceived as fundamental to women's risk of self-harm, suicidal thoughts and attempts to end their lives. Interestingly, specific focus was placed on motherhood and women reported markedly different dynamics in other relationships related to their PMDD.

The role of social isolation and loneliness in increasing the risk of suicide and in contributing to poorer health outcomes has been reported (e.g., mental health issues, heart attacks, stroke; Holt-Lunstad, 2021). However, novel insights were presented as women struggled to connect with people who rarely understood their PMDD experiences, their perceived emotional isolation intensified, and they expressed thoughts of self-harm and suicide. NICE guidance for preventing suicide and managing self-harm, and for the diagnosis and treatment of PMS, including PMDD, are reported on separately (National Institute for Health Care Excellence, 2018; 2019; 2022). Recommendations include suicide prevention plans, family involvement in treatment planning, and multi-agency working. However, NICE guidance fails to account for women with PMDD, whose self-harm and suicidal thoughts are nuanced and cyclical. Additionally, the benefits of safety planning interventions for individuals presenting at emergency departments expressing "suicide-related concerns" (Stanley et al., 2018, p.895) have been documented. Future research and guidance specifically supporting the cyclical risk associated with PMDD should be explored.

4.1 Clinical implications and wider recommendations

The perceived increased risk associated with delayed access to medical support highlights the clear priority to ensure women are diagnosed in a timely fashion, and therefore receive treatment and mental health support during periods of crisis. Initiatives for all individuals presenting with risk of suicide within the Nation Health Service (NHS) have been recommended (Brown et al., 2020). However, as these do not recognise the nuances of PMDD. Routine screening for PMDD and additional training regarding PMDD awareness and signposting should be implemented within services supporting women in crisis, such as paramedics, accident and emergency, mental health services, general practice doctors.

Current findings emphasise the importance of personal relationships, both for general support and at times of crisis. Following diagnosis, healthcare services should consider ways to support women's families, for example, via information leaflets. Additionally, as social connection is a protective factor against risk to self (Holt-Lunstad, 2021), services may consider post-diagnostic support groups, creating a space for mutual understanding and sharing experiences.

The relationship between shame and increased risk of suicidal behaviours has been described within this study and wider literature; services diagnosing PMDD should consider referrals to psychological services, so that women could gain support regarding risk and the shame experienced. For example, ACT (Acceptance and Commitment Therapy; Dindo et al., 2017) or CFT (Compassion Focused Therapy; Millard et al., 2023).

Education regarding menstruation is included in the UK school curriculum; however, premenstrual disorders, such as PMDD, are not specified. Many women in our study (79%) estimated their symptoms started whilst they were school age; however, 71% were not diagnosed until they were over 30 years old. If girls were educated about PMDD in school, is it possible that those who develop symptoms would recognise their experiences sooner and

seek medical advice. Additionally, inclusion of PMDD within the school curriculum would increase awareness and understanding within the general population.

4.1 Strengths, limitations and suggestions for future studies

A strength of this study was the mixed methods approach, in which findings from the survey data were followed up by in-depth interviews. A mixed methods design enabled the aims to be studied from different perspectives: the strengths, and weaknesses of each approach complemented the other (Regnault et al., 2018).

As the online survey was open to women worldwide, diagnosis of PMDD could not be verified. This limitation was reduced in the interview study in which the researcher verbally confirmed diagnosis and the use of symptom trackers with each woman as part of their diagnostic assessment. Alternatively, prior to interviews a screening tool could have used (such as the PSST (Steiner et al., 2003)).

Although the samples of women for the survey and the interviews were diverse in terms of age and years since diagnosis, all the interviewed women were White British and most (86%) had accessed higher education, leading to a possible bias in that study. There is also a possibility of selection bias because both the survey and interviews required internet access to participate, thereby limiting recruitment to those with computer literacy skills and those who had an awareness of social media as a means recruitment (Im & Chee, 2004).

5. Conclusions

Women's experiences of self-harm, suicidal thoughts and attempts in the context of their PMDD were explored in this mixed methods study. Survey data drawn from over 3,600 responses demonstrated prevalence rates as high as 82% for suicidal thoughts, while women's narratives further illustrated the role of that emotional isolation, delayed diagnosis and feeling

unworthy, had on women's suicidal experiences. These findings underscore the need for more timely diagnosis of PMDD, better public awareness of the condition and improved health service support for women once diagnosed.

Declarations

Ethics approval and consent to participate

Ethical approval was granted by University of Manchester Research Ethics Committee (Appendix C) and the survey was approved by the British Broadcasting Corporation's internal ethical approvals. All participants gave informed consent prior to participation.

Consent for publication

All interview participants gave prior information consent for publication of their pseudonymised interview transcript.

Availability of data and materials

The datasets generated and analysed that support the findings of this study are not publicly available due to privacy and ethical restrictions. However, data could be available via request to the corresponding author.

Competing interests

The authors had no potential conflicts of interest, including research, authorship and/or publication of the article.

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Authors contributions

All authors participated in the design of this study, DB co-ordinated the interview recruitment and data collection. Both DB and DMS conducted the reflexive thematic analysis, all authors reflected on the theme development, findings and conclusions.

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Paper 3

Critical Evaluation

Brown, D.

Word count: 4,039 (excluding references)

This paper is a reflective piece and not intended for publication.

1. Introduction

This paper outlines the author's critical evaluation and personal reflections of conducting a thesis into premenstrual disorders. Considerations of how both the literature review and empirical paper sit within the wider context are summarised, alongside challenges and strengths.

2. General reflections

Premenstrual Syndrome (PMS) and Premenstrual Dysphoric Disorder (PMDD) are considered to sit along a continuum (Ismaili et al., 2016). Although the topic area is considered under-researched (e.g., Hardy & Hardie, 2017; Osborn et al., 2020; Robinson et al., 2024), a bibliometric analysis of quantitative PMS and PMDD studies published between 1945 and 2018 described the number of annual publications following an upwards trend (Gao et al., 2021). The bibliometric highlights the contrast between quantitative and qualitative studies, supporting the use of a mixed methods designs of the empirical study. Findings from the literature review presented within this thesis specifically evidenced the lack of qualitative exploration of women's experiences of suicidal experiences, a gap the empirical aimed to address.

Premenstrual Dysphoric Disorder is a premenstrual condition, and as such, affects individuals who are biologically female. During interviews, all participants described themselves with she/her pronouns, and literature reviewed used female terminology. Thus, this terminology was adopted throughout. However, it feels important to recognise that some individuals who menstruate may prefer alternative pronouns (Strousma & Wu, 2018).

The author's clinical experience prior to the clinical psychology doctorate shaped her interest in this project. When working in a female prison, women regularly spoke about how their hormones impacted their behaviour, and some individuals had noticed the cyclical nature

of their experiences. Therefore, on becoming a Trainee Clinical Psychologist and having the opportunity to choose a thesis project, the author was very interested in further exploring the menstrual cycle and its associated risks.

3. Paper 1: Literature review

3.1. Rational for review topic

It is estimated that 20-30% of menstruating women experience PMS, and 3-8% meet the diagnostic criteria for PMDD (Goswani et al., 2023). Although the author was aware of PMS, she was surprised to learn about the severity of PMDD symptoms during the initial stages of this review.

Initial scoping searches highlighted few previous reviews; two quantitative reviews aimed to outline the risk profile for suicidal experiences (Osborn et al., 2021; Prasad et al., 2021). At the time of writing there was only one qualitative review (Moe & Karlsson, 2022), which synthesised 12 papers exploring the experiences of women with PMDD, and therefore did not capture the data for women with PMS. However, Moe and Karlsson's review did include six papers which reported on menstruating women, but their symptom severity was not specified. It is also worth noting that Moe and Karlsson's review was an unpublished dissertation, for a nursing university qualification, which heavily influenced the discussion and recommendations. Wanting to honour the breadth of the PMD continuum. The author decided to focus the review on the qualitative exploration of women with a PMD.

3.2. Literature searches

Despite having relative clarity regarding the topic area, preparing a search strategy to capture the relevant qualitative literature was both challenging and imperative to the project. The author used the SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type;

Cooke et al., 2012) and PRISMA guidance (Page et al., 2021) to support the process. Alternatives to the SPIDER tool were considered; however, as the SPIDER tool has high specificity across multiple databases, it was chosen (Methlay et al., 2014).

As scoping searches highlighted the vast array of titles and key words used by target papers, the decision was made to only include three elements of the SPIDER tool to create search terms: phenomenon of interest (PI), design (D), and research type (R). Prior to 2000, PMDD was termed Late Luteal Phase Dysphoric Disorder (LLPDD; Chrisler & Gorman, 2016). As our searches did not have a limitation on the publication date, and relevant papers published prior to 2000 would have used LLPDD terminology, it was important to include LLPDD within the search terms.

The challenges of conducting qualitative database searches (Evans et al., 2002) include the databases' indexing practices and the content of the title and abstract not including methods employed within the paper. To improve databases searches, a variety of search strategies were tried out. This strategy has been shown to reduce the potential for relevant papers to be missed (Shaw et al., 2004), including using thesaurus terms, free-text terms, and broad-based terms.

Six databases were selected based on their area. As this project covered mental health, physical health, women's health, medicine and psychology, the author aimed to select databases which covered these different topics and disciplines. Initial scoping searches were conducted during the database selection process to ensure relevant papers were found.

Following the initial database searches, the author conducted backwards searches of the reference lists of included papers, and searches of papers which cited the included papers. Two additional papers which met the inclusion criteria were found (Jurvanen, 2017; Marfiah & Barat., 2018). Exploring the reasons why these papers were not found by database searches, the author noted that one paper had no mention of qualitative research methods in the title, and the abstract and key words were first presented in Indonesian. The second paper was an

unpublished thesis from Sweden, which had not been made available on the grey literature database selected.

3.3 Inclusion/exclusion criteria

One criterion for inclusion was the transparency of women's diagnoses as reported in the paper, and specifically, how the researchers had confirmed the diagnosis. Of the final 17 papers, ten allowed women to self-report receiving a formal diagnosis, the remaining seven papers confirmed the diagnosis, often via a one-off measure of symptoms such as the *Premenstrual Symptoms Screening Tool* (Steiner et al., 2003). Papers in which the experiences of women with and without a formal diagnosis were combined, and analysis was unable to be separated, were also excluded. The author recognised the risk of excluding papers which recruited diagnosed women, but authors had failed to specify this within their reporting. However, the eligibility criteria ensured that the data reviewed captured a clinically meaningful level of PMS or PMDD symptoms, as opposed to the general population of menstruating women, who experience menstruation-related aches and pains.

The aim of this review was to understand the participants experiences, specifically related to their PMDs. In order to capture papers focusing on the psychological impact, the inclusion criteria were relatively broad, and it is possible that contributed to the large number of papers identified from searches (7,496), compared to those selected for inclusion (17). Similarly, given the aim of this review was to explore women's perspectives, qualitative research was the most appropriate method to meet that aim. Mixed methods papers were included for analysis only if the qualitative and quantitative results were presented separately.

The eligibility criteria limited inclusion to studies written, or translated, into English creating a potential for language and publication biases. However, included papers represented studies from ten countries, indicating cultural variations could be included (Australia, England,

Netherlands, USA, Indonesia, Canada, Iran, Brazil, South African, and Sweden). The decision was made to search for grey literature, as well as papers published in peer reviewed journals, minimising the potential for publication bias.

3.4. Quality rating

The Cochrane Handbook for Systematic Reviews of Interventions supports the use of a quality rating tool as an important part of a qualitative literature review (Noyes et al., 2008), whilst others debate whether the quality of qualitative papers should be assessed at all (Thomas & Harden, 2008). The *Critical Appraisal Skills Programme checklist* for qualitative papers (CASP; 2018) was chosen as a suitable tool to appraise the quality of all papers included within the review. It provided a transparent and rigorous assessment, within which key issues regarding validity, rigour and relevance were explored. An independent researcher assessed all 17 of the included papers using the CASP checklist, the results were compared to that of the author. There was a substantial agreement, supporting the validity of the checklist and the ease with which included papers could be compared.

The CASP summary table (see section 3.3 of paper 1) highlighted a commonality amongst the included papers; only three included a reflexivity statement which described how their position as researcher may have influenced the findings (Jootun et al., 2009). Lack of clarity regarding the authors positions and perspectives could indicate that during their data collection and analysis, the authors did not adequately recognise and account for their own unconscious bias and how this affected interpretation of participants responses. At the time of writing, no accepted guidelines existed to exclude papers from the review based on their quality (Dixon-Woods et al., 2006; Thomas & Harden, 2008). Therefore, all papers were included.

3.5. Data synthesis

The inclusion of 17 papers provided large amounts of data to be synthesised, the author familiarised themselves with the data through reading each paper multiple times. The Cochrane RERAT criteria (Booth et al., 2018) was used to consider the most appropriate qualitative evidence synthesis approach. All seven domains were considered, with the review question, epistemology and type of data proving the most important in the selection of an appropriate synthesis approach. A thematic synthesis was chosen to transform the primary data into third order constructs and produce new findings (Noyes et al., 2018), moving beyond interpretation made by the authors of the primary studies. Thomas and Harden's (2008) thematic synthesis approach was used and provided the author with clear stages to follow. The author enjoyed the process of immersing herself in the data and recognising the impact PMDs have on every aspect of a woman's life, but the author also recognised the responsibility to adequately represent the distress women live with through the synthesis.

4. Paper 2: Empirical paper

4.1. Rational for topic

Premenstrual Dysphoric Disorder is a cyclical, disabling condition, in which women experience cognitive, psychological and somatic symptoms during the luteal phase of the menstrual cycle (American Psychological Association, 2013; di Scalea & Pearlstein, 2017). Arguably one of the most challenging experiences women with PMDD face is a monthly deterioration in mood, and increased risk of self-harm, suicidal thoughts, and attempts to end their lives (Eisenlohr-Moul et al., 2022; Hong et al., 2012).

Across the span of a woman's reproductive years, they will have between 400 and 500 menstrual cycles and in total, a woman may spend four to ten years of their lives experiencing premenstrual symptoms (Stoddard et al., 2007), highlighting the vast potential for women with

PMDD to experience life-impacting symptoms and increased risk profile. Unfortunately, limited treatment options exist for PMDD, with a cure only truly possible by removing the ovaries (Goswami et al., 2023). Therefore, understanding the women's perspective of the psychological impact of and underpinnings of risk related to PMDD is crucial to support women during a PMDD crisis.

The literature review searches highlighted the variety of ways PMDD impacts a women's life, for example, career (Hardy & Hardie, 2017), daily activities (Schiola et al., 2011), school (Marfauh & Barat, 2018), sleep disturbances and poor relationship with food (Yi et al., 2023). As well as the difficult process to receive a diagnosis (Osborn et al., 2020). Given all of these areas had been explored, even if only by one paper, the author was struck by the lack of studies exploring the suicidal experiences of women with PMDD. Therefore, it was paramount that PMDD and the associated risks to women were further explored and understood.

The author endeavoured to verify the PMDD diagnosis of participants as much as possible. Survey question 4 asked "*have you been diagnosed with PMDD?*", only respondents who indicated "*yes, by a doctor*" were selected for analysis with (Appendix D). Women recruited to the interview reported a formal diagnosis, including the use of symptom trackers for a minimum of two months. Whilst the author recognises alternative options were available, the unfortunate reality of the current risk literature base means that both PMS and PMDD separately, and combined are under researched, particularly papers using qualitative approaches.

4.2. Survey dataset

One of the project supervisors (AW) had previously conducted research into PMDD with one of their ClinPsyD students (See Osborn et al., 2020; 2021). A British Broadcasting Corporation

(BBC) representative, who had worked on the PMDD survey used to inform the documentary *My periods made me suicidal* (British Broadcasting Corporation, 2020), contacted the supervisor with the offer of exploring the dataset in more depth. Following a data sharing agreement between the University of Manchester and the BBC, survey responses were shared with the research team within an excel spreadsheet. Upon receipt, the author spent time familiarising themselves with the questions, and using the filter function to understand the approximate proportions of responses to specific questions. The author considered how best the survey data could be best incorporated into a wider project.

Unfortunately, due to staffing changes at the BBC in 2020 when the project was in development, the initial weblink and information sheet were not accessible. The author recognised the possible challenges and ethical concerns raised; however, the initial researchers had gained internal BBC ethical approvals. All survey responses were anonymised prior to sharing. In total, 7,406 individuals completed the survey, which included women with and without a formal diagnosis, and who lived across the world. The author and supervision team recognised that not analysing this data may be unethical and a missed opportunity. Therefore, supervisors are in discussion for how this dataset may be re-analysed for future papers, something this research area needs.

4.3. Interview dataset

The author remains grateful to the population of women with PMDD in the UK, who shared the research advert and were keen to engage with research. In total, 14 women were interviewed by the author, and no recruitment challenges were experienced.

The optimum strategy to ensure a formal diagnosis prior to research participation is under debate. Whilst Osborn et al. (2020) chose to use the *PSST (Premenstrual Symptoms Screening Tool*; Steiner et al., 2003) in their exploration of women with PMDD receiving a

diagnosis, the validity of retrospective questionnaires has been challenged (Eisenlohr-Moul, 2019). For the empirical paper, the decision was made to allow women to confirm that they received a formal diagnosis without the need to check their medical records. For additional assurance of their diagnosis, women were asked about the use of symptom trackers prior to beginning their interview. The DSM-V specifies a minimum two months in which women use symptom trackers to document the cyclical nature of their experiences, before they can be considered for a diagnosis of PMDD (American Psychiatric Association, 2013). Alternatively, the author could have recruited women via an NHS clinic or hospital; however, this would have resulted in a population bias, limited the generalisability of the findings. Based on papers included within the literature review, 58% of papers allowed women to self-report a diagnosis, compared to a researcher confirming their formal diagnosis through retrospective questionnaire or medical notes. Therefore, both options are somewhat equally used.

The social media adverts shared online, and the information sheet sent to potential participants specified that women had to have both a formal diagnosis and experience of suicidal thoughts and/or behaviours. No further clarification of this terminology was provided to the potential participants, the author recognises the potential for individuals to have differing understanding of these terms and the meaning. For example, someone may have experienced feeling hopeless and wishing to no longer be alive, but not recognised that this could be described as suicidal thoughts.

4.4. Analysis and the combining of datasets

The survey results were analysed and informed the development of a topic guide, in which women were asked to reflect on the onset and frequency of their self-harm, suicidal thoughts and behaviours. Questions regarding stressors, which affected the frequency of behaviours, coping strategies and impact on other life domains were also asked. The author aimed to capture

the perspectives and understanding which participants think of when answering multiple choice survey questions, as with the first part of the empirical paper.

Reflexive thematic analysis (Braun & Clark, 2006; Braun et al., 2018) was utilised for the analysis of the interview data. In comparison to other approaches, reflexive thematic analysis allowed for patterns and themes to be described with theoretical freedom (Braun & Clark, 2006). The reflexive approach is considered accessible for novice researchers and provides a robust and structured framework for coding and theme development (Braun & Clarke, 2006; 2019). To support the author's familiarity with the interview data, she conducted all 14 interviews in 2022, prior to going on maternity leave. The decision to use an external transcriber was made due to time constraints when returning from maternity leave in October 2023. The author transcribed 43%, with the remaining 57% being transcribed by a University of Manchester approved transcriber. The author recognises the potential benefits from transcribing all interviews themselves (Halcomb & Davidson, 2006; Wolff et al., 2019), therefore she spent time reading and re-reading the transcripts to ensure that she was emersed in the data.

Mixed methods were chosen for the empirical paper based on the research aims, and access to the significant survey dataset shared by the BBC. Utilising both methodologies provided an enhanced understanding and exploration of the impact of PMDs on women's lives (Regnault et al., 2018; Wasti et al., 2022). Although the combination of these datasets proved a challenge, the mixed methods approach allowed the author to gain research skills in two different areas, which she can continue to use within her future work. Ultimately, the combination of data felt important for the author, who became aware of the unresearched experiences of women with PMDs during the entire research process.

4.5. Personal reflections

During the interview process, the author recognised feeling pulled towards their role as a clinician, as opposed to a researcher. Remaining neutral felt particularly difficult as women spoke of their memories of traumatic experiences, for instance, related to trauma as a child or young adult, or when talking about their difficult decision not to have children. A structured topic guide was important to support the author to remain within their researcher role, as opposed to a clinician, and allowed flexibility yet provided a clear overview of what topics to explore.

At the time of interviewing (between April 2023 and September 2024) the author was pregnant and due to go on maternity leave within the next couple of months. The author was mindful that the decision to be a mother was difficult for some women with PMDD and therefore she felt conscious to make sure her stomach was not visible during the video calls, as such a parallel felt emotive. At times the author felt guilt for the ease of which the decision to try for a child had been made. Although the author recognises parallels with the participants, as described above, they remain positioned as an outsider, a researcher who was studying a group they were not a member of (Dwyer & Buckle, 2009). Reflecting on the author's inclination to lean into their role as a clinician, with a strong desire to support women when sharing such vulnerable information, and recognising their position as an outsider, the author made an effort to best use reflect spaces, such as supervision. For example, after the first two interviews, the author transcribed both verbatim, and brought the transcripts to supervision, prior to completing any other interviews. During this supervision the author and supervisor (DMS) reflected on the topic guide and the authors interview style, for instance, asking the participant to clarify what a colloquial phrase means to them, for the purpose of clarity.

Following nearly a full year of maternity leave the author returned to work (October 2023) and began the transcription of interviews as a new mother, which gave a different

perspective to the transcripts, especially stories of the guilt women felt for their child experiencing their low moments and distressing psychological symptoms. For the author, this held a new deeper meaning, as a mother they could not help but compare their experiences of motherhood. Specifically, an emotive pull was felt during the writing up of the themes, for instance, the motherhood subtheme (theme1, subtheme 3). The author had to disentangle the important data which reflected the theme, whilst recognising the desire to include every emotive quote related to motherhood. The robust and systematic framework of reflexive thematic analysis (Braun & Clarke, 2006) provided the author with a structure to ensure their personal perspective to reduce bias. Similarly, attempts to minimise bias by having the paper's second author independently code, and the third and fourth authors meet to discuss theme development. Throughout this process the author also used supervision and a reflective journal to help stay grounded in their role as a researcher.

Women were recruited on the understanding that they had “experienced suicidal thoughts and/or behaviours previously”; however, in interviews the range of these experiences varied, with some women reporting one past experience of suicidal ideation, and others having monthly attempts to end their life. The author discussed and reflected on the comparability of these women's experiences in supervision but recognised the differences in severity were also seen within the survey responses and are reflective of the range in severity of PMDD.

Reflecting on the interviews, the author recognised their own perceptions of self-harm, suicidal thoughts and attempts impacting their expectations prior to interviews. The author had previously worked within forensic and secure mental health services, in which most of the service users had an extensive risk history. It was important for the author to use supervision and reflection to ensure all experiences of risk were captured appropriately and without judgement, for instance, one participant spoke of intentionally starting romantic relationships with volatile and abusive men as a form of self-harm.

5. Dissemination

The author is committed to disseminate the findings of both the literature review and empirical paper to a wider audience. Both papers will be submitted for publication in June 2024, and relevant conferences will be sought to disseminate findings. A lay summary of findings will be shared with all interviewed participants and staff who participated in the research. As the BBC provided the survey data, the author will send them a summary of the results directly. The IAPMD (the International Association of Premenstrual Disorders) have in-depth specialist knowledge and oversight of the literature, and consulted on the research aims during the development of this project. The author will share findings with the IAPMD, and following publication both articles will be submitted for their support with dissemination, for example, via the IAPMD website or IAPMD email newsletter.

6. Conclusions

This thesis had been both academically challenging, emotive and rewarding, and the culmination of the entire doctorate journey. Intense privilege is felt when recalling the many difficult life stories participants shared. Throughout this thesis, the author has learnt about premenstrual disorders, and felt the weight of responsibility for women to understand their own bodies. The author recognises the accelerated development in their decision-making skills and role as scientist-practitioner, which they will take into their onward career.

Given an overarching aim of the project was to share the stories of women who feel unheard, the author wishes to end this paper with a story shared by one interview participant, which highlights the importance of this research. Scarlett (pseudonym) was in her late 40's and had struggled with suicidal thoughts her entire life; however, she had never been diagnosed and reported to have received minimal support. During a particularly challenging luteal phase, Scarlett made a plan to drop her son at his father's house at the weekend, and then end her life.

That same week her niece watched the BBC documentary *My periods made me suicidal* (BBC, 2020), and called her to say “*I think you have PMDD*”. Scarlett described her entire life changing, because subsequently she got a diagnosis and received appropriate support. PMDD symptoms continued to create challenge in her life, but overnight she went from feeling at her lowest to having a diagnosis and a community of women experiencing the same difficulties as her, who she could turn to for support and understanding. Scarlett’s story highlights the importance of research, and clinical understanding of PMDs, as well as the need for the general population to have an awareness and understanding of PMDs.

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Appendices

Appendix A: Author guidelines for Frontiers in Psychology

Taken from: <https://www.frontiersin.org/guidelines/author-guidelines>

Original Research

Original Research articles report on primary and unpublished studies. Original Research may also encompass confirming studies and disconfirming results which allow hypothesis elimination, reformulation and/or report on the non-reproducibility of previously published results. Original Research articles are peer-reviewed, have a maximum word count of 12,000 and may contain no more than 15 Figures/Tables. Authors are required to pay a fee (A-type article) to publish an Original Research article. Original Research articles should have the following format: 1) Abstract, 2) Introduction, 3) Materials and Methods, 4) Results, 5) Discussion.

Systematic Review

Systematic Review articles present a synthesis of previous research, and use clearly defined methods to identify, categorize, analyze and report aggregated evidence on a specific topic. Included in this article type are meta-syntheses, meta-analyses, mapping reviews, scoping reviews, systematic reviews, and systematic reviews with a meta-analysis. Systematic Review articles are peer-reviewed, have a maximum word count of 12,000 and may contain no more than 15 Figures/Tables. Authors are required to pay a fee (A-type article) to publish a Systematic Review article. Systematic Reviews should: clearly define the research question in terms of population, interventions, comparators, outcomes and study designs (PICOS), and state which reporting guidelines were used in the study. For design and reporting, systematic reviews must conform to the reporting guidelines (e.g., PRISMA, Cochrane, Campbell), and include the PRISMA flow diagram <http://prisma-statement.org/prismastatement/flowdiagram.aspx> (if applicable), as well as funding information (if no specific funding to carry out the research, please state so). Systematic Reviews should have the following format: 1) Abstract, 2) Introduction, 3) Methods (including study design; participants; interventions; comparators; systematic review protocol; search strategy; data sources; study sections and data extraction; data analysis), 4) Results (including a flow diagram of the studies retrieved for the review; study selection and characteristics; synthesized findings; assessment of risk of bias), 5) Discussion (including summary of main findings; limitations; conclusions). Systematic Reviews must not include unpublished material (unpublished/original data, submitted manuscripts, or personal communications) and may be rejected in review or reclassified, at a significant delay, if found to include such content.

Title

The title should be concise, omitting terms that are implicit and, where possible, be a statement of the main result or conclusion presented in the manuscript. Abbreviations should be avoided within the title.

Authors and affiliations

All names are listed together and separated by commas. Provide exact and correct author names as these will be indexed in official archives.

Correspondence

The corresponding author(s) should be marked with an asterisk in the author list. Provide the exact contact email address of the corresponding author(s) in a separate section. Example: Max Maximus* maximus@iuscience.edu If any authors wish to include a change of address, list the present address(es) below the correspondence details using a unique superscript symbol keyed to the author(s) in the author list.

Abstract

As a primary goal, the abstract should make the general significance and conceptual advance of the work clearly accessible to a broad readership. The abstract should be no longer than a single paragraph and should be structured, for example, according to the IMRAD format. For the specific structure of the abstract, authors should follow the requirements of the article type or journal to which they're submitting. Minimize the use of abbreviations and do not cite references, figures or tables. For clinical trial articles, please include the unique identifier and the URL of the publicly-accessible website on which the trial is registered.

Keywords

All article types require a minimum of five and a maximum of eight keywords.

Text

The entire document should be single-spaced and must contain page and line numbers in order to facilitate the review process. The manuscript should be written using either Word or LaTeX.

Nomenclature

The use of abbreviations should be kept to a minimum. Non-standard abbreviations should be avoided unless they appear at least four times, and must be defined upon first use in the main text. Consider also giving a list of non-standard abbreviations at the end, immediately before the acknowledgments.

Sections

The manuscript is organized by headings and subheadings. The section headings should be those appropriate for your field and the research itself. You may insert up to 5 heading levels into your manuscript (i.e.,: 3.2.2.1.2 Heading Title). For Original Research articles, it is recommended to organize your manuscript in the following sections or their equivalents for your field.

Introduction Succinct, with no subheadings.

Materials and methods This section may be divided by subheadings and should contain sufficient detail so that when read in conjunction with cited references, all procedures can be repeated. For experiments reporting results on animal or human subject research, an ethics

approval statement should be included in this section (for further information, see the 'Bioethics' section of our policies and publication ethics.)

Results This section may be divided by subheadings. Footnotes should not be used and must be transferred to the main text.

Discussion This section may be divided by subheadings. Discussions should cover the key findings of the study: discuss any prior research related to the subject to place the novelty of the discovery in the appropriate context, discuss the potential shortcomings and limitations on their interpretations, discuss their integration into the current understanding of the problem and how this advances the current views, speculate on the future direction of the research, and freely postulate theories that could be tested in the future.

Acknowledgments This is a short text to acknowledge the contributions of specific colleagues, institutions, or agencies that aided the efforts of the authors. Should the content of the manuscript have previously appeared online, such as in a thesis or preprint, this should be mentioned here, in addition to listing the source within the reference list.

Scope statement When you submit your manuscript, you will be required to summarize in 200 words your manuscript's scope and its relevance to the journal and/or specialty section you're submitting to. The aim is to convey to editors and reviewers how the contents of your manuscript fit within the selected journal's scope. This statement will not be published with your article if it is accepted for publication. The information will be used during the initial validation and review processes to assess whether the manuscript is a suitable fit for the chosen journal and specialty. We encourage you to consider carefully where to submit your manuscript, as submissions to an unsuitable journal or specialty will result in delays and increase the likelihood of manuscript rejection. If you are submitting to a Research Topic, please also clarify how your submission is suited to the specific topic.

References

Frontiers' journals use one of two reference styles, either Harvard (author-date) or Vancouver (numbered). Please check our help center to find the correct style for the journal to which you are submitting.

Appendix B: BBC and The University of Manchester data sharing agreement

DATA SHARING AGREEMENT

BETWEEN THE BRITISH BROADCASTING CORPORATION

a public corporation incorporated by Royal Charter under the laws of England and Wales whose principal office is located at Broadcasting House, Portland Place, London W1A 1AA

AND

THE UNIVERSITY OF MANCHESTER

*(acting in this instance through its Division of Psychology and Mental Health, School of Health Sciences)
Oxford Road, Manchester M13 9PL*

The amalgamated findings of BBC Research into PMDD and Severe PMS owned by the BBC are shared by the BBC with the University of Manchester for the purpose described below.

The sharing of the BBC Research with the University of Manchester is restricted to one PhD project from the ClinPsyD Department.

The University of Manchester will only use the BBC Research to the extent necessary to carry out the ClinPsyD doctoral research as set out in this Agreement and will not use or copy (whether temporarily or permanently) BBC Research for:

- 1.1 text and data mining;
- 1.2 training of or use with any AI/machine learning technology;
- 1.3 for any purpose other than do the research as detailed in this Agreement;
- 1.4 use the BBC Research for commercial purposes.

To ensure the quality and completeness of the data for use in this work, the BBC will make available the amalgamated findings from its research into PMDD and Severe PMS (gathered by the BBC in June 2020 and broadcast in July 2020). The University of Manchester has the right to use data filters, or other tools, to review the data.

The Parties acknowledge and agree that, otherwise, it is not intended for the BBC to share Personal Data with the University of Manchester for the purpose of this project. If the findings shared with the University of Manchester contain any Personal Data the University of Manchester will be legally obliged to inform the BBC of such disclosure, immediately erase or return any Personal Data disclosed, and handle any Personal Data according to the requirements of the Data Protection Legislation.

For the avoidance of doubt, Data Protection Legislation means the Data Protection Act 2018 (DPA), the General Data Protection Regulation 2016/679 ("GDPR"), the Privacy and Electronic Communications Regulations (EC Directive) 2003, and any legislation that repeals, replaces, supersedes or amends any such legislation relating to the processing of personal data and/or e-privacy. The terms "Controller", "Data Subject", "Personal Data", "Personal Data Breach", "Processor" and "Supervisory Authority" shall have the meanings given to them in the Data Protection Legislation.

For the BBC's contribution, the University of Manchester will acknowledge the BBC for contributing the data on all publications resulting from this analysis and include Georgie Bevan, the BBC Producer, as the named author for the BBC Research.

The University of Manchester will not share this BBC Research with any others or use or retain it for any purpose other than the work described above. Following the completion of this work, the BBC can require the University of Manchester to delete stored copies of the data.

At all times, the BBC retains ownership of the data.

If you agree to the terms of this Agreement, please arrange for this letter to be signed by a duly authorised signatory of your organisation and return for our files.



Signed:

Name: Dr Andrew Walsh

Position: Director of Research and Business Engagement

Date: 29 January 2021

On behalf The University of Manchester



Signed:.....

Position: Georgie Bevan, BBC News Producer

Date: 29th January 2021

On behalf the BBC

Appendix C: The University of Manchester ethical approval



The University of Manchester

Research Governance, Ethics and Integrity
2nd Floor Christie Building
The University of Manchester
Oxford Road
Manchester
M13 9PL
Email: research_ethics@manchester.ac.uk

Ref: 2022-12850-22464

28/03/2022

Dear Miss Danielle Brown, Dr Anja Wittkowski

Study Title: Premenstrual Dysphoric Disorder (PMDD) and women's experiences of suicidal thoughts and suicidal behaviours: a qualitative study.

University Research Ethics Committee 5

I write to thank you for submitting the final version of your documents for your project to the Committee on 14/03/2022 09:51. I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation as submitted and approved by the Committee.

Please ensure you review the [Research Ethics website](#) throughout the duration of your project to keep up to date on current UoM guidance and best practice.

Please see below for a table of the title, version numbers and dates of all the final approved documents for your project:

Document Type	File Name	Date	Version
Participant Information Sheet	BBC and University of Manchester Data Sharing Agreement 29.01.2021	29/01/2021	1
Additional docs	Research Subcommittee Approval 19.07.2021	19/07/2021	1
Distress Protocol/Debrief Sheet	Distress Protocol V2 08.03.2022	08/03/2022	2
Default	Demographics Questionnaire V2 10.03.2022	10/03/2022	2
Advertisement	Social Media Advert V2 10.03.2022	10/03/2022	2
Additional docs	Debrief Sheet V2 10.03.2022	10/03/2022	2
Participant Information Sheet	Participant Information Sheet V2 11.03.2022	11/03/2022	2
Consent Form	Consent Form V2 11.03.2022	11/03/2022	2
Default	Topic Guide Draft V2 13.03.2022	13/03/2022	2
Data Management Plan	Data Management Plan V2 13.03.2022	13/03/2022	2
Additional docs	Danielle Brown- Letter to UREC 13.03.2022	13/03/2022	1

This approval is effective for a period of five years however please note that it is only valid for the specifications of the research project as outlined in the approved documentation set. If the project continues beyond the 5 year period you will be required to submit a new ethics application.

If you wish to propose any changes to the methodology or any other specifics within the project, including the dates of data collection, an application to seek an amendment must be submitted for review. Failure to do so could invalidate the insurance and constitute research misconduct.

You are reminded that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a secure university computer or kept securely as a hard copy in a location which is accessible only to those involved with the research.

Reporting Requirements:

You are required to report to us the following:

1. [Amendments](#): Guidance on what constitutes an amendment
2. [Amendments](#): How to submit an amendment in the ERM system
3. [Ethics Breaches and adverse events](#)
4. [Data breaches](#)
5. [Notification of progress/end of the study](#)

Feedback

It is our aim to provide a timely and efficient service that ensures transparent, professional and proportionate ethical review of research with consistent outcomes, which is supported by clear, accessible guidance and training for applicants and committees. In order to assist us with our aim, we would be grateful if you would give your view of the service that you have received from us by completing a **UREC Feedback Form**. Instructions for completing this can be found in your approval email.

We wish you every success with the research.

Yours sincerely,

Miss Kate Hennessy

Secretary to University Research Ethics Committee 5

Appendix D: Full BBC Survey

This questionnaire aims to gather the experiences of those who suffer/ed from PMDD (Premenstrual Dysphoric Disorder) in the UK and beyond. All responses will remain anonymous and kept secure in line with the BBC's Privacy Policy.

1. Where do you live in the UK?

Choose from the following:
Scotland
Northern Ireland
Wales
England - North East and Cumbria
England - North West
England - Yorkshire
England - Hull and Lincs
England - West Midlands (B'ham, Shropshire, Worcs, Warks, Staffs, H'fordshire)
England - East Midlands (Leics, Notts, Derbyshire)
England - East (Norfolk, Suffolk, Essex, Cambs, Herts, Beds, Northants)
England - London Boroughs
England - South East (Kent, Surrey, Sussex)
England - South (Oxon, Berks, Bucks, Hants, Dorset)
England - West (Glos, Somerset, Bristol, Wilts)
England - South West & Channel Islands
Non UK resident

Choose from the following:

2. If you are a Non-UK resident, where do you live?

Choose from the following:
Africa
Asia
Australia and New Zealand
Caribbean
Central America
European Union
Eastern Europe
Middle East
North America
South America

Choose from the following:

3. How old are you?

Please select your age group
10 - 14 yrs
15 - 19 yrs
20 - 24 yrs
25 - 29 yrs
30 - 34 yrs
35 - 39 yrs
40 - 44 yrs
45 - 49 yrs
50 - 54 yrs
55 - 60 yrs
More than 60 yrs

Please select your age group

4. Have you been diagnosed with PMDD? Please select one of the following options:

- Yes, by a doctor
- No, but I am undergoing investigation
- No, but I suspect I have it
- Don't know
- Not Applicable

5. If you have been diagnosed, how many years did you have symptoms before being diagnosed?

Please select the number of years 123456789101112131415161718192021222324252627282930
 years or more Don't know Not applicable

Please select the number of years

6. Without treatment, to what extent does PMDD/symptoms affect your activity? Please select one or more of the following options:

	Frequently every month	Several days every month	Several days some months	Several days in a year	Not affected
I reduce my activity	I reduce my activity Frequently every month	I reduce my activity Several days every month	I reduce my activity Several days some months	I reduce my activity Several days in a year	I reduce my activity Not affected
I'm off work/college	I'm off work/college Frequently every month	I'm off work/college Several days every month	I'm off work/college Several days some months	I'm off work/college Several days in a year	I'm off work/college Not affected
I take to my bed	I take to my bed Frequently every month	I take to my bed Several days every month	I take to my bed Several days some months	I take to my bed Several days in a year	I take to my bed Not affected

7. Without treatment, to what extent does PMDD/symptoms affect your mood?

Please select one or more of the following options:

	Frequently every month	Several days every month	Several days some months	Several days in a year	Not affected
I become tired and emotional	I become tired and emotional Frequently every month	I become tired and emotional Several days every month	I become tired and emotional Several days some months	I become tired and emotional Several days in a year	I become tired and emotional Not affected
I become depressed and anxious	I become depressed and anxious Frequently every month	I become depressed and anxious Several days every month	I become depressed and anxious Several days some months	I become depressed and anxious Several days in a year	I become depressed and anxious Not affected
I become angry and erratic	I become angry and erratic Frequently every month	I become angry and erratic Several days every month	I become angry and erratic Several days some months	I become angry and erratic Several days in a year	I become angry and erratic Not affected
I have suicidal thoughts	I have suicidal thoughts Frequently every month	I have suicidal thoughts Several days every month	I have suicidal thoughts Several days some months	I have suicidal thoughts Several days in a year	I have suicidal thoughts Not affected

8. To what extent has PMDD/symptoms affected your education and school experience? Please select one of the following options:

- It's had an extremely negative impact
- It's had some negative impact
- It's had no impact
- It's had some positive impact
- It's had an extremely positive impact
- Don't know
- Not applicable

9. To what extent has PMDD/symptoms affected your career and job opportunities? Please select one of the following options:

- It's had an extremely negative impact
- It's had some negative impact
- It's had no impact
- It's had some positive impact
- It's had an extremely positive impact
- Don't know
- Not applicable

10. To what extent has PMDD/symptoms affected marriage/partnerships? Please select one of the following options:

- It's had an extremely negative impact
- It's had some negative impact
- It's had no impact
- It's had some positive impact
- It's had an extremely positive impact
- Don't know
- Not applicable

11. To what extent has PMDD/symptoms lead to suicidal thoughts? Please select one of the following options:

- I have regular suicidal thoughts
- I have had suicidal thoughts on occasion
- I once had suicidal thoughts
- I have never had suicidal thoughts
- Don't know

12. To what extent has PMDD/symptoms lead to attempted suicide? Please select one of the following options:

- I have attempted suicide more than once
- I have attempted suicide once
- I have never attempted suicide
- Don't know

13. To what extent has PMDD/symptoms lead to self harm? Please select one of the following options:

- I have self harmed often
- I have self harmed on occasion
- I have self harmed once
- I have never self harmed
- Don't know

14. To what extent did your local doctor/GP know about PMDD? Please select one of the following options:

- Good knowledge
- Some knowledge
- No knowledge but knew about extreme PMS
- No knowledge
- Don't know
- Not applicable

PRIVACY NOTICE: All responses to the survey will remain anonymous as the survey does not ask for any personal data that can identify you directly or indirectly. The BBC will share the information you have provided in the survey with SmartSurvey, the third party provider hosting the survey on our behalf. For information on how the BBC processes personal data, please go to: <http://www.bbc.co.uk/privacy>

Appendix E: Social media advert

Have you been diagnosed with
Premenstrual Dysphoric Disorder (PMDD)
and
experienced suicidal thoughts or behaviours?

We're recruiting for a confidential research study:

Who?

- Women diagnosed with PMDD living in the UK
- Have experienced suicidal thoughts or behaviours previously
- Over 18 years old
- Able to read and write in English
- Have access to a computer, tablet or mobile phone with video and a stable internet connection for an interview via videocall. Or access to a phone if you wish to be interviewed via a phone call.

What?

The study will involve completing a short questionnaire and an interview about your experiences lasting roughly 60 to 75 minutes.

(NOTE: all interviews will be completed via Zoom video call)

Why?

There has been little research to understand the experiences of women with PMDD and we'd like to help their voices be heard. We hope the study findings will help services and staff support those diagnosed with PMDD. All information shared will be anonymised within any publications.

If you would like more information, please contact Danielle Brown:
danielle.brown-2@postgrad.manchester.ac.uk

Appendix F: Participant information sheet



The University of Manchester

Participant Information Sheet

Premenstrual Dysphoric Disorder (PMDD) and women's experiences of suicidal thoughts and suicidal behaviours: a qualitative study.

We would like to invite you to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve.

We will give you a minimum of 24 hours to read the information carefully before deciding whether to take part. Please read it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this information sheet.

If we have not heard from you one week after you received this information sheet, we will contact you to see if you have any questions.

Overview

In 2020 the BBC did a documentary about Premenstrual Dysphoric Disorder (PMDD), they asked over 7,000 women complete a survey. The BBC have kindly shared these survey responses with us. We're inviting between 15 and 20 women to take part interviews, where the questions will be guided by the BBC survey responses.

What would I be asked to do if I took part?

If you would like to take part, a researcher will organise to a time that is convenient for you to meet to talk about your experiences. This meeting could be via a video call (using software such as Zoom or Microsoft Teams) or via the telephone. You will also be sent a consent form via email.

At the beginning of the interview, we will go through the consent form with you. If you're happy to go ahead, they will ask you to sign the consent form. Once the researcher receives the consent form via email, they will complete a brief questionnaire with you. This will ask for general demographic details such as your age and ethnicity, as well as some information about when and how you were diagnosed with PMDD.

At this point the researcher will begin recording the interview and you will be asked a number of open-ended questions about your experiences of PMDD and suicidal thoughts and/or behaviours. This is referred to as a semi-structured interview. It is expected this will take between 60 and 75 minutes. The information you provide will be anonymised.

What is the purpose of the research?

PMDD affects 5% to 8% of women of reproductive age. Unfortunately, some of these women suffer PMDD-related distress and they may try to take their own lives. In general, women are

three times more likely to take their own lives than men. Right now, there is no research to help us understand how these women feel, so it is important that we do this study and listen to these women. We hope to use the findings to help services support those diagnosed with PMDD.

Am I suitable to take part?

We're inviting people who are:

- Women over age 18 living in the UK
- Have a formal diagnosis of PMDD by a healthcare professional and able to provide details and confirmation that prospective charting methods were used during diagnosis (Please note: the research team are happy to chat with you if you are unsure whether charting was used to diagnose you)
- Have experienced suicidal thoughts and/or behaviours previously
- Are able to read and write in English
- Have access to a computer, tablet or mobile phone with video and a stable internet connection for an interview via videocall. Or access to a phone if you wish to be interviewed via a phone call.

What are the possible benefits of taking part? Will I be compensated?

Many participants in research find it helpful to share their views and provide feedback about their experiences. However, we do not anticipate any direct clinical benefit of taking part in the interview, the information you provide will help the evidence base of PMDD and therefore experiences of other women diagnosed. Unfortunately, we are not able to provide any monetary compensation for your time.

What are the possible risks and disadvantages of taking part?

A disadvantage of taking part is the time commitment of giving up roughly 60-75 minutes of your time for the interview.

In addition, some people find it difficult talking about their experiences and these topics can be sensitive and personal. Talking about experiences of suicidal thoughts and/or behaviours may bring up strong emotions. The research team and interviewer will hold this in mind and only proceed if you wish to. We will remind you that you can change your mind and withdraw from the study at any time.

Who will conduct the research?

This study is being conducted by Trainee Clinical Psychologist, Danielle Brown, as part of the Doctorate in Clinical Psychology at the University of Manchester. The study is overseen by Dr Anja Wittkowski and Dr Debbie Smith, who are based at the University of Manchester.

Who has reviewed the research project?

The study has been reviewed by the Research Ethics Committee at the University of Manchester.

Will the outcomes be published?

Once all the interviews have taken place and analysed, the researchers will write up the results which will be published in an academic journal. Results will also be shared with other women, healthcare professionals and other researchers at conferences. All information you provide will be anonymised so that no individual participants can be identified.

We will also write a summary of the findings for participants. If you take part in the study, you will be given the option to receive a copy of this summary. In order to send this summary we will need to retain your name and email address. However, this would be stored separately from any interview transcripts and your contact details would be destroyed once we have sent the findings.

What happens if I do not want to take part or if I change my mind?

It is up to you whether or not you wish to take part. If you do decide not to take part, you do not need to do anything further.

If you begin the interview but change your mind, you're able to withdraw from the study. You do not need to give a reason for withdrawing and there will be no detriment to yourself. No further data would be collected from the moment you withdraw and the recording will be stopped immediately. At this point you will be given two options:

- Option 1: all the information you have provided, including the already recorded interview, will be retained and analysed within the study.
- Option 2: all the information you have provided will be removed from the study and the interview recording will be deleted.

If you complete the interview, you will have two weeks to change your mind and request to remove your data from the study. After this time your information and interview recording will be completely anonymised, meaning it is no longer possible to identify which data is yours in order to remove it.

Data Protection and Confidentiality

What information will you collect about me?

For you to participate in the study, we will need to collect information that could identify you. Specifically, we need to collect:

- Name and contact details
- Age
- Ethnicity
- Level of education
- Marital status
- Details about your PMDD symptoms and diagnosis
- A recording of your interview
- GP details

Under what legal basis are you collecting this information?

All personal identifiable information we are collecting and storing is done so in accordance with the UK data protection law which protects your rights. These laws state we must have a specific reason, also known as a legal basis, for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

What are my rights in relation to the information you will collect about me?

Under data protection law you have a number of rights regarding your personal information. For example, you can request a copy of all information we hold about you, including recordings or transcripts. If you would like to know more about your different rights or the way we use

your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#).
<https://documents.manchester.ac.uk/display.aspx?DocID=37095>

Will my participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following ways:

- All information you share with the research time will be treated with strict confidentiality. There may be instances where we need to break your confidentiality, this would only happen if you tell us anything which makes us think you or anyone else is at risk of harm. We would have to share this information in order to keep yourself or other individuals safe. We will collect your GP details for this purpose.
- The interview will be recorded on an audio recorder if the interview is completed via telephone or on the video-call software (for example Zoom or Microsoft Teams). This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third-party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection.
- Two weeks after your interview your data will be anonymised, meaning we will no longer be able to identify specific participants if necessary. Beyond this time, you would no longer be able to withdraw from the study as it would not be possible to identify your data from anyone else's.
- Once anonymised, the interview will be transcribed by the researcher, the Clinical Psychology Doctorate departmental secretary (an employee at The University of Manchester) or a University of Manchester approved transcription service. As the interview recording will be anonymised before transcription, the transcriber will not see any of your personal identifiable information, such as your name.
- Following transcription, all recordings will be permanently deleted and all electronic data, for example the interview transcription, will be stored on a University of Manchester secure server.
- Any personal data, such as consent forms, will be retained for 5 years after the end of the study and will then be securely destroyed. Within any publications of the study results we may use direct quotes; however, these will not reveal your identity.

- The study data and material may be looked at by individuals from the University of Manchester, from regulatory authorities for monitoring and auditing purposes. All of these staff will have a duty of confidentiality to you as a participant.
- Within the consent form, you will be given the option to consent for your details to be stored for us to share a results summary, once it is available. We will only contact you once to provide the summary, following this your details will be confidentially destroyed. If you do not wish to be contacted regarding the results you can opt out, without any impact on your ability to participate in the study.

What if I have a complaint?

If you were to have a minor complaint, please contact the principal researchers in the first instance. Contact details for Danielle Brown and Dr Anja Wittkowski are on the last page of this document.

If you wanted to make a formal complaint or were not satisfied with the response you gained from the researchers in the first instance, then please contact the Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning **0161 306 8089**.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office](#) about complaints relating to your personal identifiable information by telephoning **0303 123 1113**.

Contacts for further information:

<p>Dr Anja Wittkowski Chief Investigator and Senior Lecturer in Clinical Psychology</p> <p>The University of Manchester School of Health Sciences Division of Psychology and Mental Health 2nd Floor Zochonis Building Brunswick Street Manchester M14 9PL Tel: 0161 3060400 Email: anja.wittkowski@manchester.ac.uk</p>	<p>Danielle Brown Researcher and Trainee Clinical Psychologist</p> <p>The University of Manchester School of Health Sciences Division of Psychology and Mental Health 2nd Floor Zochonis Building Brunswick Street Manchester M14 9PL</p> <p>Email: danielle.brown-2@postgrad.manchester.ac.uk</p>
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Appendix G: Consent form



Consent Form:

Premenstrual Dysphoric Disorder (PMDD) and women's experiences of suicidal thoughts and suicidal behaviours: a qualitative study.

If you are happy to participate, please initial each statement and sign the consent form below.

	Please Initial
1. I confirm that I have read and understand the attached participant information sheet (Version 2, 11/03/2022) for the above study. I have had the opportunity to consider the information and ask questions and have these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected, until two weeks after my interview when my interview is anonymised. I agree to take part on this basis.	
3. I understand that there may be instances where, during the course of the research, information is revealed which means the researchers will be obliged to break confidentiality and this has been explained in more detail in the information sheet.	
4. By signing this consent form, I declare that I have provided accurate identity details (full name and electronic signature).	
5. I understand that the interview will be recorded and the recording will be written out in full (transcribed). I understand that transcription may be completed by the researcher, the secretary for the Clinical Psychology Doctorate at the University of Manchester or a University of Manchester approved transcription service.	
6. I agree that any anonymised data collected may be made available to other researchers for the purposes of future study and analysis.	
7. I understand and agree that anonymous quotes may be published as part of the research project and that my identity will not be revealed in any publication.	
8. I understand that relevant sections of my data collected during the study may be looked at by responsible individuals from the University of Manchester or from regulatory authorities, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data.	
9. OPTIONAL I would like to receive a summary of the study results once they are available, and agree for the University of Manchester to store my name and email address for this purpose. I understand that my details will be destroyed once this has been sent to me.	
10. I agree to take part in the above study	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with UK data protection law as explained in the Participant Information Sheet and the [Privacy Notice for Research Participants](#).

Name of Participant Signature _____
Date

Name of the person taking consent Signature _____
Date

When completed: 1 copy for participant, 1 copy for researcher site file.

Appendix H: Topic guide



The University of Manchester

Topic Guide

What follow is an interview schedule of the topics that are likely to be covered in the participant interviews in order to explore their experiences of self-harm, suicidal thoughts, and suicidal behaviours. Some topics may emerge spontaneously, meaning the question order and exact content may vary during the interview.

Topic	Initial Question	Further Probes
Experiences of Self-Harm	Can you tell me about any experiences of self-harming?	Consider thoughts of self-harm as well as actions
		Onset/first incident they can recall
		Frequency
		Severity
		Stressors
		Any coping strategies
		Impact on life domains (e.g., education, career, family, relationships, mood, sense of self)
Suicidal thought and/or behaviours	Can you tell me about any experiences of suicidal thoughts or behaviours?	Onset/first incident they can recall
		Frequency
		Severity
		Stressors
		Any coping strategies
		Impact on life domains (e.g., education, career, family, relationships, mood, sense of self)
Reflections of PMDD & self-harm/suicidal thoughts/behaviours	How do you feel the experiences of self-harm/suicidal thoughts/behaviours are related to your diagnosis of PMDD?	Have they noticed correlations with these experiences and menstrual cycle
		Any changes following diagnosis
		Any changes after treatment (if applicable)
Summary / Reflections	Do you have any further points that you would like to make? Is there anything that I have not asked you, which you feel is important in your experiences of PMDD and self-harm/ suicidal thoughts/behaviours? Do you have any questions?	

In addition to the above, prompt questions such as *please tell me more* and *can you give me an example of this* may be used within the interviews.

Appendix I: Demographics questionnaire



The University of Manchester

Title of Project: Premenstrual Dysphoric Disorder (PMDD) and women's experiences of suicidal thoughts and suicidal behaviours: a qualitative study

Participant ID	
Date of Interview	

This questionnaire is designed to gather some more information about you. Please ask the researcher if you would like anything explained further.

Age:	
Ethnicity:	White Mixed or multiple ethnic groups Asian or Asian British Black, Black British, Caribbean or African Other.....
Highest level of education:	No school attended Primary school Secondary school Collage University Other.....
Marital Status:	Single In a relationship (but not co-habiting) Co-habiting Married Divorced Widowed Other.....
Phone number	
GP Name and address NOTE: this will only be used by the research team if we have any concerns about your well-being.	
Estimated age of PMDD onset	
Age when PMDD diagnosed	
Did you track your symptoms are part of your PMDD diagnosis (e.g., using a symptom tracker app or prospective charting sheets)	Yes / No If yes, for how many cycles?
Any other medical conditions or diagnosis:	
Are you currently receiving treatment for	Yes / No

PMDD from a medical specialist?	
Have you previously received treatment for PMDD from a medical specialist?	Yes / No
Do you have any children?	Yes / No If yes, what are their ages?
If applicable, date of last menstrual cycle:	Day/Month: /
Please provide a brief outline of your PMDD symptoms:	

Appendix J: Distress management plan



Distress Protocol **Premenstrual Dysphoric Disorder (PMDD) and women's experiences of suicidal thoughts and suicidal behaviours: a qualitative study.**

If during the interview a participant shows signs that they are experiencing distress, the researcher will follow the below procedure:

<p>Distress: The researcher notices the participant displaying signs they are experiencing distress and/or the participant verbalises they are experiencing distress. The researcher will seek support and guidance from their supervisors regarding participant wellbeing throughout the process.</p>
<p>Step 1:</p> <ul style="list-style-type: none">• Researcher will sensitively stop the interview and pause the recording to ensure the participants distress is not unnecessarily recorded.• The researcher will ask the participant how they're feeling, listen with empathy and offer support.• Participants will be allowed to take as many breaks as they wish without any detriment to their participation.
<p>Step 2:</p> <ul style="list-style-type: none">• The participant has been given adequate time before being asked if they wish to continue with the interview.• If returning to the interview the participant will be offered continued support, reminded of their right to stop at any time and offered further breaks.• If they wish to end their participation the researcher will give the participant the choice to withdraw all data collected prior to stopping the interview. If the participant is happy for their data to remain within the study, the demographics questionnaire and interview prior to stopping will be retained for analysis.
<p>Step 3:</p> <ul style="list-style-type: none">• Following the termination or completion of all the interviews participants will be debriefed by the researcher to ensure that no-one leaves in a distressed state.• All participants will be given the debrief sheet which details supportive organisations that participants can contact or access at any time.• The researcher will also use this time to assess any distress and risk:<ul style="list-style-type: none">○ Mild distress: Encourage the participant to speak to their GP for support.○ Moderate distress: Support the participant to immediately inform a close family member or friend and request they come to see the participant (if this person does not live in the same household). The researcher will also contact the participants GP.○ High distress: Researcher will phone the police/ambulance/mental health services for assistance.• Should the participant leave the call at any time, the researcher will attempt to contact the participant via phone call to discuss the next steps.
<p>Step 4:</p> <ul style="list-style-type: none">• Any participant who has displayed distress will be offered a follow-up telephone call within 24 hours. During this call the researcher will check on the participant's wellbeing and provide further signposting to helpful resources, if necessary. The researcher is a trainee clinical psychologist and is experienced in dealing with distress as well as risk issues.

Appendix K: Debrief sheet




Participant Debrief Sheet

Premenstrual Dysphoric Disorder (PMDD) and women's experiences of suicidal thoughts and suicidal behaviours: a qualitative study.

Thank you for taking the time to participate and tell us about your experiences. We hope you have found it interesting and have not been upset by the topic discussed. However, if you have found any part of the process distressing and you wish to speak to the researchers, please contact:

Danielle Brown (Researcher and Trainee Clinical Psychologist)

 0161 306 0400

 danielle.brown-2@postgrad.manchester.ac.uk

We would always encourage you to contact your GP if you need support. In addition, listed below are some of the professional and voluntary organisations you can contact to get help if you feel you need further support.


If you are concerned that your life or someone else's life is in immediate danger you should visit your nearest **Accident and Emergency department (A&E) or call for an ambulance by dialling 999.**

NHS 111

 111

Available 24 hours a day, 365 days a year and calls are free from landlines and mobile phones. You can call NHS 111 if you think you need urgent care, if you don't know who to call or don't have a GP. NHS 111 can also help if you need health information or reassurance about what to do next. If NHS 111 advisers think you need an [ambulance](#), they will immediately arrange for one to be sent to you.

Samaritans

 116 123

www.samaritans.org

Samaritans phone line is available 24 hours a day. They offer confidential, non-judgmental support and a safe place for you to talk any time you like, in your own way and about whatever's getting to you.

The International Association for Premenstrual Disorders (IAPMD)

www.iapmd.org

IAPMD a lifeline of support, information, and resources for women with Premenstrual Dysphoric Disorder (PMDD) and other premenstrual conditions. They offer video, email, Facebook and forum-based support groups.