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Women's experiences of living with premenstrual syndrome (PMS) or premenstrual dysphoric disorder (PMDD): A scoping review

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ABSTRACT

Premenstrual syndrome (PMS) and premenstrual dysphoric disorder (PMDD) are conditions related to hormonal fluctuations that occur during the luteal phase of the menstrual cycle. Understanding the experiences of women with these conditions is vital to providing appropriate and effective care. A scoping review was undertaken to explore available global literature on women's experiences of living with PMS or PMDD, highlighting gaps in the literature. Nineteen studies were included in the scoping review, and all studies were qualitative or had a qualitative component. Four main themes were identified by the authors: (1) Lack of understanding or support, (2) Dual identity, (3) Impact on relationships, and (4) Difficulties in reaching the diagnosis of PMS/PMDD. The literature highlights a lack of understanding from family, friends and medical practitioners. We suggest increased training for health care professionals, across interdisciplinary fields, on PMS and PMDD so women can be better supported and understood.

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Background

Premenstrual syndrome (PMS) is a constellation of physical, mood and behavioral symptoms that are limited to the luteal phase of the menstrual cycle, cause problems for the woman, and are not better explained by another diagnosis (Johnson, 2004). Premenstrual dysphoric disorder (PMDD) is a complex and potentially disabling condition that affects women of reproductive age, often characterized by severe physical and psychological symptoms that occur cyclically and remit following the onset of menses (Cunningham et al., 2009). PMDD accounts for the most severe form of PMS and is characterized, in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM 5), as a major depressive disorder

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(American Psychological Association, 2013). Researchers have shown, through meta-analyses, pooled prevalence rates of around 47% for PMS (Direkvand Moghadam et al., 2013; Direkvand-Moghadam et al., 2014), and of 3%–8% for PMDD (Halbreich et al., 2003). Researchers have indicated a large variance of prevalence rates between countries for PMS, however the potential causes for this are yet to be accurately investigated or explained (Direkvand-Moghadam et al., 2014; Hantsoo et al., 2022).

Premenstrual syndrome (PMS) or premenstrual dysphoric disorder (PMDD) have been the focus of biomedical research including work on etiology, treatment, and risk factors (Gao et al., 2021). This biomedical focus and the inclusion of PMDD in the DSM 5 manual in 2013 as a depressive disorder has been critiqued by feminist theorists who emphasize the socially constructed nature of PMDD and PMS and highlight the over-medicalization and stigmatization of women's premenstrual phase (Gagné-Julien, 2021; Ussher, 2003; Ussher & Ussher, 2011). By framing these experiences as medical conditions, such as PMS or PMDD, women's natural bodily processes are medicalised, necessitating medical intervention. This phenomenon, as explained by several feminist scholars, may pose significant challenges for women's well-being (Ussher & Ussher, 2011).

Foucault's concept of the medical gaze puts emphasis on how medical professionals tend to interpret patients' experiences through a biomedical lens to fit a biomedical paradigm (Misselbrook, 2013). This becomes problematic for nosology of PMS/PMDD as it can lead to an overemphasis of biological factors, gender bias, stigma, and medicalization of normal experiences (Ussher, 2013; Ussher & Ussher, 2011). Consequently, the pervasive 'expert' bio-medical 'gaze' and the medicalization of bodies in health care have resulted in the neglect of womens' lived experiences of PMS and PMDD.

PMS and PMDD can have significant impacts which are often not well understood through a biomedical lens (Ismaili et al., 2016; Ussher, 2003). Research that captures lived experience, therefore, is important as it can provide insight into women's own experiences and the meaning that they give to these experiences - leading to a more holistic understanding, beyond what can be offered by bio-medical models and clinical symptomology. Moreover, supporting the voices of a wide range of women to be heard can illuminate how categories of identity (for example, disability, ethnicity, religion, social class, and gender) intersect and impact on their experiences.

The authors aim, in this scoping review, to explore and map the existing literature on the experiences of women living with PMS/PMDD and elucidate prevalent themes, identify patterns, and pinpoint gaps in the literature. By undertaking this review, we seek to contribute to a deeper understanding of the multifaceted dimensions inherent in womens' lived experience of PMS and PMDD. This review holds particular significance due to its potential to shed light on crucial aspects of women's health that may be overlooked within the

confines of the biomedical model. By prioritizing the voices and narratives of women themselves, we endeavor to move beyond the limitations of a purely medicalised perspective and offer insights that can inform more holistic and patient-centred approaches to care.

Materials and methods

Scoping reviews are effective at pinpointing and analyzing gaps in knowledge (Munn et al., 2018). This methodology allows for a comprehensive exploration of existing evidence, aiding in the refinement of focus and methodology for subsequent studies. While distinct from traditional systematic reviews, the scoping review approach maintains rigorous methodology, incorporating transparent processes that empower readers to evaluate the conducted work within the targeted area of research. A scoping review is, therefore, an appropriate method for two reasons: (1) to explore and map the extent of the published literature on women's lived experiences of PMS and PMDD and (2) to identify research gaps in the published literature for future research (Munn et al., 2018; Peters et al., 2020).

For this scoping review we were guided by the six-step framework recommended by Levac et al. (2010) *and* the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). The first five steps were used in this review's methodology as the sixth is optional. This approach facilitates the fusion and presentation of data derived from studies of various designs and sources. The protocol for the scoping review was registered, by the authors, on Open Science Framework (https://osf.io/xvq5s).

Stage 1: Identifying the research (review) question

Levac et al. (2010) recommends considering the target population (women with premenstrual syndrome or premenstrual dysphoric disorder), the outcomes of interest (experiences of living with PMS or PMDD), and the core concept (women's encounters with PMS or PMDD) when formulating the review question. The eligibility criteria were developed, by the authors, following the 'Participants, Concept and Context (PCC)' approach as recommended by Joanna Briggs Institute for scoping reviews (Peters et al., 2015).

1. *Participants*: Women of all ethnicities and ages who are menstruating
2. *Concept*: Lived experiences of PMS or PMDD including their experiences of diagnosis and treatment, the impact on social and emotional relationships, their wellbeing, and their self-image/identity
3. *Context:* Global review of published and grey literature

Review question: What is the available qualitative evidence on the lived experiences of women with PMS or PMDD?

Stage 2: Identifying relevant studies

The definitive searches were conducted, by the authors, in June 2023 in the following nine databases: Academic Search Premier, MEDLINE, Psychology and Behavioral Sciences Collection, APA PsycInfo, CINAHL Plus with Full Text, APA PsycArticles, AMED - The Allied and Complementary Medicine Database, SPORTDiscus with Full Text, eBook Collection (all accessed through EBSCOhost). Please see Table 1 below for the key words searched.

Stage 3: Study selection

The authors identified 2014 papers which were transferred to Endnote and duplicates removed ($N = 1017$). Two researchers (CHZ/JM) independently screened the abstracts and titles of the remaining 997 papers for eligibility according to the inclusion/exclusion criteria (Table 2).

Nine hundred and forty-five ($n = 945$) papers were excluded by the authors; full texts ($n = 52$) were then screened independently by CHZ/JM, to identify the final papers according to the inclusion and exclusion criteria above. The two researchers reviewed each other's full text screening and reached consensus regarding which texts under full text review should be excluded and which should be included. Nineteen ($n = 19$) papers were retained for the final review. Discussions took place throughout with authors LD and LG. The process of study selection is demonstrated in

Table 1. Keywords.

(PMDD OR 'premenstrual dysphoric disorder' OR PMS OR 'premenstrual syndrome')
AND
(phenomenolog* OR 'experience*' or embodi* or perception*)

Table 2. Inclusion and exclusion criteria.

Inclusion criteria:
1. Primary published research which reports on the lived experiences of women of any age and ethnicity with diagnosed or self-reported PMS or PMDD
2. Qualitative empirical research or mixed methods with a substantial qualitative component.
3. No time limit, search until June 2023
4. Text available in English
5. Must include women's perspectives/experiences
Exclusion criteria:
• Written in a language other than English
• Research that does not specifically look at experiences of PMS or PMDD experiences
• Studies that include health care providers perspectives/experiences
• Resources that do not focus on lived experience of women
• Quantitative only studies and non-qualitative scoping reviews or systematic reviews
• Any books which summarize previous research

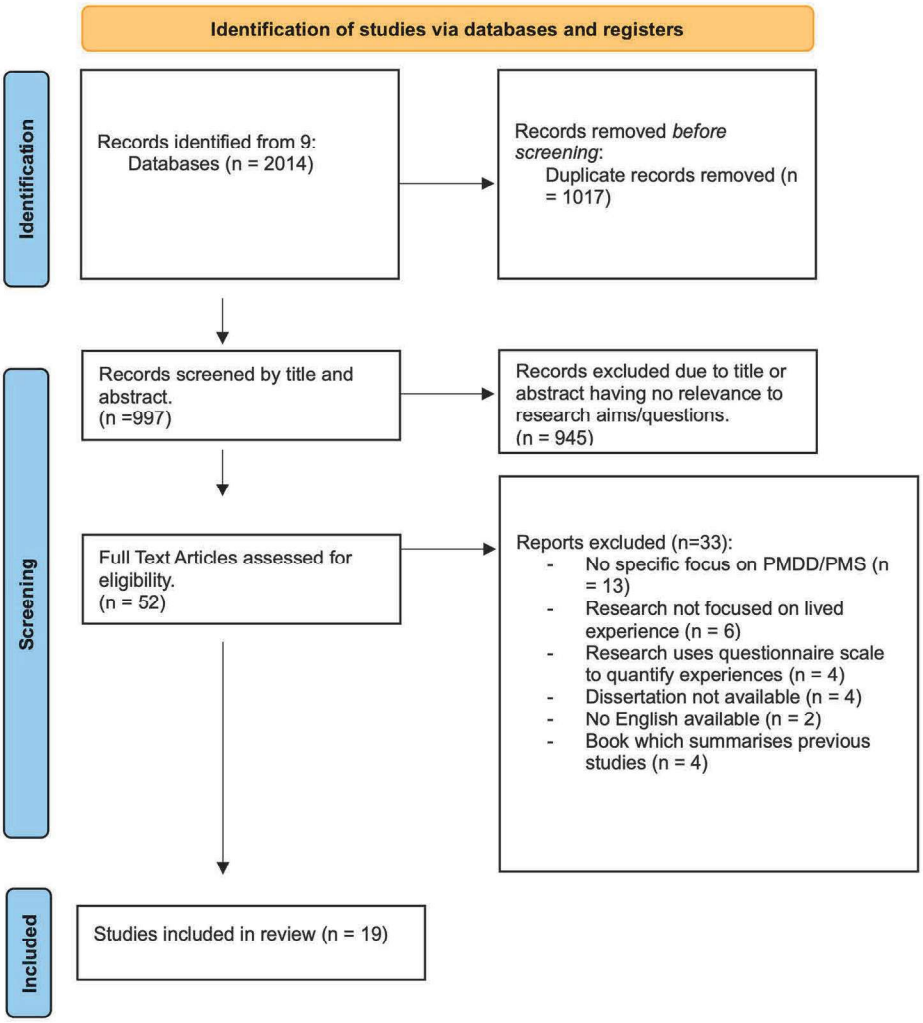

Figure 1. PRISMA flow diagram detailing method of study selection.

the PRISMA diagram in Figure 1 and reasons for exclusion discussed. As the aim of this scoping review was to map out main themes from existing literature, provide an overview of key concepts and identify gaps in the evidence, critical appraisal was not a primary focus.

Stage 4: Charting the data

Study design including sample size and setting, diagnosis, main results, PMS or PMDD experiences and participant demographic data were extracted independently into a matrix (CHZ) and then checked by the second author (JM) onto a prepared data extraction chart. Braun and Clarke's Reflexive Thematic Analysis (Braun & Clarke, 2021) was used, by the authors, to guide the data analysis. Two authors (CZ and JM) became

familiar with the data and independently coded the themes across the findings. Themes were generated inductively, by the authors, using Reflexive Thematic Analysis of the findings from the articles, which were cross checked and negotiated. Please see Table 3 for an overview of the included papers.

Stage 5: Collating, summarizing, and reporting the results

The three distinct steps in stage 5 of Levac et al.'s (2010) framework, demonstrate the standard reporting sequence of Results, Discussion, and Conclusions and Recommendations.

Results

Study characteristics

Of the 19 included studies, seven were from Australia (Mooney-Somers et al., 2008; Perz & Ussher, 2006; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013, 2020a), six from England (Barker-Smith, 2020; Hardy & Hardie, 2017; Osborn et al., 2020; Slade et al., 2009; Swann, 1995; Ussher, 2002), and one took place in both Australia and England (Ussher, 2004). Two studies were based in the USA (Chan et al., 2023; Cosgrove & Riddle, 2003), one study was a social media based analysis of Reddit with the researchers based in America (Poladian et al., 2022), one from the Netherlands (Labots-Vogelesang et al., 2023) and one from Northern Ireland (Reilly & Kremer, 1999). All studies were qualitative or had a qualitative component; 15 were solely interview based, nine used semi-structured interviews (Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023; Reilly & Kremer, 1999; Slade et al., 2009; Swann, 1995; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2020a) and six used in-depth interview methods (Chan et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Ussher, 2002, 2004; Ussher & Perz, 2013), with one of those six being a phenomenological study (Chan et al., 2023).

Two studies used mixed methods including questionnaires and different forms of interviewing (Cosgrove & Riddle, 2003; Perz & Ussher, 2006), one was an auto-ethnographical study (Barker-Smith, 2020) and another used data from the website Reddit© (Poladian et al., 2022). Of the 15 interview studies, all used purposive and/or snowball methodology to recruit participants. Sampling was predominantly achieved through media/newspaper advertisement, however, two studies recruited patients attending their clinical appointments for PMS/PMDD (Osborn et al., 2020; Swann, 1995). Ten [23,25,27,31–37] of the 19 studies were carried out by J.M. Ussher as one of the authors (Mooney-Somers et al., 2008; Perz & Ussher, 2006; Swann, 1995; Ussher, 2002, 2004; Ussher et al., 2007, 2014; Ussher

Table 3. Description of included studies.

Author(s) Year Country Title	a. Methodology b. Sampling c. Data Capture d. Data Analysis	1. Sample:*N* 2. Age (mean and/or range) 3. Diagnosis	Main emerging themes (in order of prominence)
Barker-Smith, H 2020 England Navigating the menstrual landscapes: From the darkness to the light. (Barker-Smith, 2020)	a. Autoethnography b. NA c. The author writes about their own experiences, weaving memories, insights, and theory to offer the reader a flowing account. d. Critical reflexivity of personal experience. Grounded through memory, which is informed by epistemology, methodology and autobiographical data.	1. $N = 1$ 2. In their 'fifties' 3. Identified as having PMDD	Lack of understanding/support Difficulties in reaching the diagnosis of PMS/PMDD
Chan, K., A.A. Rubtsova, and C.J. Clark 2023 USA Exploring diagnosis and treatment of premenstrual dysphoric disorder in the U.S. health care system: a qualitative investigation. (Chan et al., 2023)	a. Feminist Phenomenology b. Snowball sampling was also used to recruit participants through current participants and Nonprofit members. c. In-depth interviews d. Feminist phenomenological approach.	1. $N = 32$ 2. 29 years (21–50) 3. Identified as having PMDD	Difficulties in reaching the diagnosis of PMS/PMDD Lack of understanding/support Clashing with the female stereotype identity
Cosgrove, L. and B. Riddle 2003 USA Constructions of Femininity and Experiences of Menstrual Distress. (Cosgrove & Riddle, 2003)	a. Mixed methods b. Participants were recruited by posting flyers in urban and suburban communities of a large East Coast city. c. Menstrual Distress Questionnaire and narrative interviews. d. A discourse analytic approach and thematic decomposition was used to analyze the quantitative data.	1. $N = 30$ 2. 20 to 45 years ($M = 28.87$) 3. Experiences of PMS	Dual Identity (during PMS/PMDD and when experiencing no symptoms) Lack of understanding/support Clashing with the female stereotype identity Negative perception of self
Hardy, C. and J. Hardie 2017 England Exploring premenstrual dysphoric disorder (PMDD) in the work context: a qualitative study. (Hardy & Hardie, 2017)	a. Semi-structured interviews b. Adult women with PMDD. c. Semi-structured one-to-one interviews. d. Transcripts analyzed using an inductive (bottom-up) thematic analysis approach.	1. $N = 15$ 2. 25-49 years 3. PMDD diagnoses 6 months to 4 years prior to the interview.	Lack of understanding/support Impact on relationships Dual Identity (during PMS/PMDD and when experiencing no symptoms)
Ussher, J.M. 2002 England Processes of appraisal and coping in the development and maintenance of Premenstrual Dysphoric Disorder. (Ussher, 2002)	a. Interview, open-ended questions/dialogue. b. One hundred and eight women. c. Narrative interviews. d. Thematic narrative analysis.	1. $N = 36$ 2. $M = 38$ 3. Women who met the diagnostic criteria for PMDD.	Dual Identity (during PMS/PMDD and when experiencing no symptoms) Impact on relationships Negative perception of self

(*Continued*)

Table 3. Continued.

Author(s) Year Country Title	a. Methodology b. Sampling c. Data Capture d. Data Analysis	1. Sample:*N* 2. Age (mean and/or range) 3. Diagnosis	Main emerging themes (in order of prominence)
Labots-Vogelesang, M.S., et al. 2023 Holland Perspectives of Dutch women on premenstrual disorder. A qualitative study exploring women's experiences. (Labots-Vogelesang et al., 2023)	a. Qualitative study with in-depth semi-structured interviews. b. Dutch women with symptoms of premenstrual disorder were recruited through local newspapers in the town of Nijmegen and the North-Holland region and *via* social media. c. In-depth semi-structured interviews.Thematic analysis of interviews underpinned by Grounded Theory.	1. *N* = 20 2. 27-49 years (*M* = 38.6) 3. Symptoms of premenstrual disorder.	Dual Identity (during PMS/PMDD and when experiencing no symptoms) Impact on relationships Negative perception of self
Mooney-Somers, J., J. Perz, and J.M. Ussher 2008 Australia A complex negotiation: Women's experiences of naming and not naming premenstrual distress in couple relationships. (Mooney-Somers et al., 2008)	a. Interview data from a large mixed method study. b. Questionnaire sample comprised 327 women, and of these 60 women participated in an individual interview. Purposive sampling. c. Individual interviews d. Thematic decomposition	1. *N* = 60 2. Aged 18 or older. 3. Self-identified as PMS sufferer	Lack of understanding/support Impact on relationships
Osborn, E., et al. 2020 England Women's experiences of receiving a diagnosis of premenstrual dysphoric disorder: a qualitative investigation. (Osborn et al., 2020)	a. Qualitative, individual interview design. b. Recruitment took place at two NHS gynecology clinics. c. Individual interviews. d. Reflexive Thematic Analysis	1. *N* = 17 2. 18 years or older 3. Women were screened using the Premenstrual Symptoms Screening Tool (PSST). The PSST is a questionnaire which presents the categorical DSM-IV diagnostic criteria for PMDD.	Difficulties in reaching the diagnosis of PMS/PMDD Lack of understanding/support Dual Identity (during PMS/PMDD and when experiencing no symptoms Negative perception of self
Perz, J. and J.M. Ussher 2006 Australia Women's experience of premenstrual syndrome: a case of silencing the self. (Perz & Ussher, 2006)	a. Mixed method design. b. Recruited through advertisements placed in local media and women's health centers. c. Questionnaires and qualitative analysis of two case studies d. Correlational analyses and Thematic decomposition	1. *N* = 257 completed questionnaires. 2 case studies. 2. 17-49 (*M* = 34.12) for online questionnaire. Case studies aged 38 and 43. 3. Women who experienced PMS to take part in a research project on premenstrual experiences and relationships.	Impact on relationships Lack of understanding/support Dual Identity (during PMS/PMDD and when experiencing no symptoms Negative perception of self

(*Continued*)

Table 3. Continued.

Author(s) Year Country Title	a. Methodology b. Sampling c. Data Capture d. Data Analysis	1. Sample:*N* 2. Age (mean and/or range) 3. Diagnosis	Main emerging themes (in order of prominence)
Poladian, N. et al. 2022 World-wide website. Unmet needs discussed on Reddit by women with Premenstrual Dysphoric Disorder. (Poladian et al., 2022)	a. Obtaining qualitative data from online website Reddit. b. Searched the subreddit "r/PMDD" for posts from January 2020 through November 2021. Three of the authors jointly read all the posts and affiliated comments that met the inclusion and exclusion criteria. c. Qualitative analysis. d. Thematic saturation of posts and comments	1. N=The subreddit search term "r/PMDD" yielded over 800 posts; 250 posts met inclusion and exclusion criteria. 2. NA 3. Those women who made posts and comments in the PMDD section with a score of at least +5 and had a minimum of three comments.	Lack of understanding/support Impact on relationships Difficulties in reaching the diagnosis of PMS/PMDD
Reilly, J. and J. Kremer 1999 Northern Ireland A qualitative investigation of women's perceptions of premenstrual syndrome: implications for general practitioners. (Reilly & Kremer, 1999)	a. Semi-structured interviews. b. Purposeful sampling technique. c. Individual and group interviews/discussions d. Data were analyzed using a grounded analysis technique.	1. *N* = 13 interviewed individually, 33 participated in group discussions 2. 20-42 years for individual interviews. 3. With and without self-reported pre-menstrual syndrome.	Lack of understanding/support Difficulties in reaching the diagnosis of PMS/PMDD
Slade, P., A. Haywood, and H. King 2009 England A qualitative investigation of women's experiences of the self and others in relation to their menstrual cycle. (Slade et al., 2009)	a. Semi-structured interviews b. Women were drawn from a subsample of a larger community sample of women with young children who were participating in a quantitative study undertaken in conjunction with this work. c. One-on-one semi-structured interviews d. Template analysis	1. *N* = 16 women (9 with 'low' and 7 with 'high' symptom levels) 2. 27 to 39 years (*M* = 31 years) 3. Identified as experiencing low or high premenstrual symptoms from daily diary accounts taken over 2 consecutive months.	Impact on relationships Clashing with the female stereotype identity Negative perception of self

(*Continued*)

Table 3. Continued.

Author(s) Year Country Title	a. Methodology b. Sampling c. Data Capture d. Data Analysis	1. Sample:*N* 2. Age (mean and/or range) 3. Diagnosis	Main emerging themes (in order of prominence)
Swann, C., Ussher, J. 1995 England A discourse analytic approach to women's experience of premenstrual syndrome. (Swann, 1995)	a. Qualitative interviews b. Women attending their first appointment at the PMS clinic at a London Hospital c. Semi-structured one-on-one interviews d. Discourse analytical approach. Grounded theory approach.	1. *N* = 14 2. 26-44 years. 3. Self-report or self-diagnosis of PMS.	Impact on relationships Lack of understanding/support Dual Identity (during PMS/PMDD and when experiencing no symptoms) Clashing with the female stereotype identity
Ussher, J.M. 2004 Australia and England Premenstrual Syndrome and Self-policing: Ruptures in Self-Silencing Leading to Increased Self-Surveillance and Blaming of the Body. (Ussher, 2004)	a. Qualitative interviews b. Women were randomly selected from a larger group, who were taking part in a controlled clinical trial. c. One-on-one narrative interviews. d. Thematic narrative analysis.	1. *N* = 34 from Australian sample and 36 from British sample. 2. *M* = 36 years. 3. Australian Sample: Women who were taking part in a self-help treatment for PMS. British Sample: women who reported a 30% increase in premenstrual 'symptoms'.	Dual Identity (during PMS/PMDD and when experiencing no symptoms) Lack of understanding/support Clashing with the female stereotype identity
Ussher, J.M. and J. Perz Australia 2008 Empathy, Egalitarianism and Emotion Work in the Relational Negotiation of PMS: The Experience of Women in Lesbian Relationships. (Ussher & Perz, 2008)	a. Qualitative interviews b. Women were recruited from advertisement in the media and women's health centers; online chatrooms and email lists; Relationships Australia (a counseling organization); and a lesbian mother–baby network. c. One-on-one semi-structured interviews. d. Thematic decomposition.	1. *N* = 15 2. *M* = 36 years. 3. Experiencing PMS.	Lack of understanding/support Impact on relationships
Ussher, J.M. and J. Perz Australia 2020 'I feel fat and ugly and hate myself': Self-objectification through negative constructions of premenstrual embodiment. (Ussher & Perz, 2020a)	a. Qualitative interviews b. Women were recruited from a range of contexts, including social media, sexual and reproductive health clinics, local radio and newspapers, and women's health centers. c. Semi-structured one-on-one interviews d. Theoretical thematic analysis using an inductive approach.	1. *N* = 30 2. *M* = 35 3. Premenstrual Symptoms Screening Tool (PSST) with confirmation by daily diary measures.	Lack of understanding/support Negative perception of self Clashing with the female stereotype identity

(*Continued*)

Table 3. Continued.

Author(s) Year Country Title	a. Methodology b. Sampling c. Data Capture d. Data Analysis	1. Sample:*N* 2. Age (mean and/or range) 3. Diagnosis	Main emerging themes (in order of prominence)
Ussher, J.M., J. Perz, and E. May Australia 2014 Pathology or source of power? The construction and experience of premenstrual syndrome within two contrasting cases. (Ussher et al., 2014)	a. Case study comparisons. b. Women were recruited from a range of contexts: advertisement in the media and Women's Health Centers; online chatrooms and email lists; a relationship counseling organization and a lesbian mother–baby network. Two contrasting accounts, Judith and Sophia. c. One-on-one semi-structured interviews. d. Case analysis. Thematic decomposition.	1. *N* = 2 2. 39 and 28 years. 3. 2 case studies from people who identify as having experienced PMS.	Lack of understanding/support Impact on relationships Dual Identity (during PMS/PMDD and when experiencing no symptoms Difficulties in reaching the diagnosis of PMS/PMDD Clashing with the female stereotype identity Negative perception of self
Ussher, J.M., J. Perz, and J. Mooney-Somers Australia 2017 The experience and positioning of affect in the context of intersubjectivity: The case of premenstrual syndrome. (Ussher et al., 2007)	a. Qualitative interviews b. Recruited through advertisements placed in local media and women's health centers. c. Semi-structured one-on-one interviews d. Thematic decomposition.	1. *N* = 59 2. 22-46 (*M* = 34) 3. Women who have experienced PMS.	Lack of understanding/support Dual Identity (during PMS/PMDD and when experiencing no symptoms Impact on relationships Negative perception of self
Ussher, J. and J. Perz Australia 2013 PMS as a process of negotiation: Women's experience and management of premenstrual distress. (Ussher & Perz, 2013)	a. Qualitative interviews. b. Women were selected for interview from a larger mixed-methods study. Range of relationship types (lesbian/heterosexual) and contexts (presence of children; single vs. cohabitation). c. One-on-one interviews. d. Thematic analysis.	1. *N* = 60 2. 22-48 years (*M* = 35) 3. Women who reported three or more psychological premenstrual symptoms, and scored a six out of ten or more, were purposefully selected.	Impact on relationships Lack of understanding/support Negative perception of self Clashing with the female stereotype identity

& Perz, 2008, 2013, 2020a) and from those ten, seven were in Australia, two in England and one in both Australia and England.

All researchers used thematic analysis and decomposition analysis, aside from two: one researcher used discourse analysis and grounded theory approach (Swann, 1995), and the researcher of the auto-ethnographical study used critical reflexivity (Barker-Smith, 2020). Gaps included a lack of research from countries in Asia, South America, or Africa and the use of methodologies such as intersectional analysis, in-depth phenomenological studies, and digital ethnography.

Thematic analysis

Four main themes were identified by the authors of this paper: *Lack of understanding or support, Dual identity, Impact on relationships* and *Difficulties in reaching the diagnosis of PMS/PMDD*. Two sub-themes arose during discussions between the authors of themes which were embedded within some of the main themes: Conflicting with the female stereotype' and 'negative perception of self' were found within *Dual identity*. Verbatim quotes from studies are used below by the authors to support the voices of women in line with the focus on lived experience.

Theme 1: Lack of understanding/support

Lack of understanding/support was present in all 19 papers (Barker-Smith, 2020; Chan et al., 2023; Cosgrove & Riddle, 2003; Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Reilly & Kremer, 1999; Slade et al., 2009; Swann, 1995; Ussher, 2002, 2004; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013, 2020a). This recurring theme identified that women with PMS/PMDD experienced a lack of understanding or support from people they interacted with including their male partner (Mooney-Somers et al., 2008; Perz & Ussher, 2006; Poladian et al., 2022; Reilly & Kremer, 1999; Swann, 1995; Ussher, 2002; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013), family (Labots-Vogelesang et al., 2023; Osborn et al., 2020; Ussher, 2002, 2004), work (Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023), friends (Barker-Smith, 2020; Reilly & Kremer, 1999; Ussher & Perz, 2013), and those who provide professional support, for example, doctors (Chan et al., 2023; Osborn et al., 2020; Poladian et al., 2022; Reilly & Kremer, 1999). Women highlighted that their experiences of PMS/PMDD were misunderstood by their partners and families, and that partners' and families were unable to handle the emotions/symptoms that resulted from having PMS/PMDD. Women

experienced an overall lack of knowledge and understanding from medical professionals. One study looked at the difference between female and male doctors and found female providers to lack empathy while male doctors were described as 'clueless' and 'disrespectful' (Chan et al., 2023). Experiencing this 'lack of understanding/support' regarding their feelings and symptoms of PMS/PMDD, affected women's mental health (Barker-Smith, 2020; Chan et al., 2023; Labots-Vogelesang et al., 2023; Osborn et al., 2020; Poladian et al., 2022), relationships (Barker-Smith, 2020; Osborn et al., 2020; Perz & Ussher, 2006; Slade et al., 2009) and overall quality of life (Barker-Smith, 2020; Chan et al., 2023; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Ussher & Perz, 2013). The impact on their mental health and emotions materialized as sadness, anger and irritability for PMS with more severe impacts for PMDD, such as suicidal thoughts, depression and rage. There was an overall greater lack of understanding for women's symptomology and experiences of PMDD (Barker-Smith, 2020; Chan et al., 2023; Hardy & Hardie, 2017; Poladian et al., 2022; Ussher, 2002) than to PMS (Cosgrove & Riddle, 2003; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Reilly & Kremer, 1999; Slade et al., 2009; Swann, 1995; Ussher, 2004; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013, 2020a).

Evidence of poor understanding of PMS/PMDD by medical professionals, family members and peers was embedded in all the studies under review. This was also evident among health care professionals, many of whom demonstrated limited understanding when identifying or diagnosing PMS/PMDD (Barker-Smith, 2020; Chan et al., 2023; Osborn et al., 2020; Poladian et al., 2022) and there were inconsistencies in providing adequate support (Chan et al., 2023; Poladian et al., 2022; Reilly & Kremer, 1999). Examples of these inconsistencies included an incomplete understanding of PMS/PMDD, various doctors giving different diagnoses, and a lack of consistent treatment after diagnosis. These inconsistencies led women to seek alternative forms of support such as online communities (Poladian et al., 2022), engaging in self-care practices (Ussher & Perz, 2020b), or advocating for themselves within their personal and work relationships (Hardy & Hardie, 2017; Ussher & Perz, 2013). The Reddit© website study (Poladian et al., 2022) which gathered responses from women with PMDD across the world illustrated that there was a lack of support from doctors who were less likely to take PMS/PMDD seriously:

> The state-run therapies near me specialize in drug and alcohol addiction/recovery and PMDD/PME (premenstrual exacerbation) is an unknown or 'made up' mental health issue. … 'The docs don't take me seriously. I just want a doctor to help me.'
>
> [(Poladian et al., 2022, p. 811]

Theme 2: Dual identity

The theme of dual identity was mentioned in all 19 studies. Women identified differences between their 'symptomatic self' and their 'non-symptomatic self' or a 'real me/not me' dichotomy (Swann, 1995; Ussher et al., 2000).

> It's just like being two different people….as I said earlier only the one that's shouting is enjoying it… and yet the normal side of me is standing next to me thinking WHY [her emphasis] are you doing this.
> [(Swann, 1995), p. 8]

Experiencing the symptoms of 'PMS/PMDD identity' was linked with negative thoughts/feelings (Barker-Smith, 2020; Chan et al., 2023; Cosgrove & Riddle, 2003; Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Slade et al., 2009; Swann, 1995; Ussher, 2002, 2004; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013, 2020a) and unwanted behaviors (Barker-Smith, 2020; Cosgrove & Riddle, 2003; Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Slade et al., 2009; Swann, 1995; Ussher, 2002, 2004; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013). Feelings such as being irritated and volatile as well as experiencing sadness and anger were described. Unwanted behaviors were reported such as becoming withdrawn, nagging, and uncontrollable crying during premenstrual symptomatic times.

These dual identity experiences were described as an unrecognizable 'other' (Barker-Smith, 2020; Chan et al., 2023; Cosgrove & Riddle, 2003; Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023; Osborn et al., 2020; Poladian et al., 2022; Reilly & Kremer, 1999; Slade et al., 2009; Swann, 1995; Ussher, 2002, 2004; Ussher et al., 2007; Ussher & Perz, 2008, 2013) or being destructive (Barker-Smith, 2020; Chan et al., 2023; Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Swann, 1995; Ussher et al., 2007; Ussher & Perz, 2013, 2020a). In the five studies which looked at PMDD experiences (Barker-Smith, 2020; Chan et al., 2023; Hardy & Hardie, 2017; Poladian et al., 2022; Ussher, 2002) there was both an unrecognizable 'other' and behaviors reflecting depression and anger. Whereas, when dual identity was displayed in PMS experiences both features were not always present simultaneously (Cosgrove & Riddle, 2003; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Reilly & Kremer, 1999; Slade et al., 2009; Swann, 1995; Ussher, 2004; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013, 2020a). Thus, PMDD's dual identity experiences were widely associated with more severe negative thoughts and behaviors.

Sub-theme: Conflicting with the female stereotype

Amongst mentions of dual identity, eight studies showed internal experiences of conflict between the 'symptomatic self' and gendered stereotypes (Chan et al., 2023; Cosgrove & Riddle, 2003; Labots-Vogelesang et al., 2023; Perz & Ussher, 2006; Swann, 1995; Ussher, 2002; Ussher et al., 2014; Ussher & Perz, 2013, 2020a). During symptomatic periods women felt that they no longer were seen to embody the 'perfect' women because of difficulties in regulating emotions including being angry, violent, irritable, and lacking patience (Cosgrove & Riddle, 2003; Labots-Vogelesang et al., 2023; Perz & Ussher, 2006; Swann, 1995; Ussher, 2002; Ussher et al., 2014; Ussher & Perz, 2013). Two studies specifically showed experiences of the 'symptomatic self' being the reason for not being a 'good wife' or 'good mother' (Ussher et al., 2014; Ussher & Perz, 2013). This conflict and self-policing of the female stereotype was seen in both PMS and PMDD experiences.

Sub-theme: Negative perception of self

A 'negative perception of self' was also identified within the 'dual identity' theme and was present in seven (Cosgrove & Riddle, 2003; Labots-Vogelesang et al., 2023; Osborn et al., 2020; Perz & Ussher, 2006; Ussher, 2002; Ussher et al., 2007; Ussher & Perz, 2013) of the 19 studies. Women viewed their symptomatic identity as the root cause of their negative emotions and feelings which led to decreased psychological wellbeing: behaviors included frustration with self (Slade et al., 2009; Ussher, 2002), being an inner critic (Barker-Smith, 2020; Ussher & Perz, 2013, 2020a) and fighting an inner battle with their own body and mind (Osborn et al., 2020; Ussher et al., 2007). The negative perception of self, seen in the reviewed research, is reflective of decreased mental and physical wellbeing seen similarly in both PMS and PMDD.

> I just feel so….frustrated with myself and hate myself so much that I just get aggressive and then the tiniest the teeny-weeny bit sort of start an argument and no apparent reason (referring to her PMS) obviously [laughs].
> [(Ussher, 2002), p. 316]

Theme 3: Impact on relationships

This theme was present in 15 of the 19 studies (Barker-Smith, 2020; Cosgrove & Riddle, 2003; Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Slade et al., 2009; Swann, 1995; Ussher, 2002; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013).

The impact on relationships would vary depending on multiple factors. For example, within heterosexual relationships there was a lack of understanding for PMS/PMDD shown from the male partner and this would result in anger and irritation central to the experience (Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Swann, 1995; Ussher, 2002; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013). Women also reported the relationship with their children being affected during symptoms by being snappier with them (Labots-Vogelesang et al., 2023; Perz & Ussher, 2006; Ussher, 2002; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013) and avoiding them (Ussher et al., 2007; Ussher & Perz, 2020a).

Women in lesbian relationships highlighted that their partners showed recognition and understanding of the symptoms that they were experiencing (Mooney-Somers et al., 2008; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2020a), resulting in experiences of support which led to feeling less guilt during symptomatic phases (Ussher et al., 2007; Ussher & Perz, 2008). However, there were also reports of difficulties of PMS/PMDD impacting lesbian relationships when women had the same menstrual cycle as their partner (Ussher et al., 2014). Whilst there were experiences which showed that women in lesbian relationships could lack support from their partner, this was more common in heterosexual relationships (Ussher et al., 2007).

Impact on social relations were also reported due to PMS/PMDD symptoms (Barker-Smith, 2020; Labots-Vogelesang et al., 2023; Osborn et al., 2020; Poladian et al., 2022; Slade et al., 2009; Ussher, 2002, 2004; Ussher et al., 2014; Ussher & Perz, 2013). Studies showed individuals withdrawing from social situations due to misunderstanding and misjudgement (Labots-Vogelesang et al., 2023). On the other hand, relationships with supportive friends during symptomatic periods were also reported to be beneficial and provided comfort and understanding (Ussher & Perz, 2013). One PMDD study showed friendships to be lost because of PMDD symptoms (Osborn et al., 2020), whereas for PMS studies there were no reports of loss of friendships.

Work relationships are also shown to be affected. Having anxiety and colleague-related stresses due to their PMS/PMDD symptoms would lead women to temporarily leave the workplace and this impacted work relationships (Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023). Having to interact with others in the workplace during symptomatic stages caused distress, and the need to withdraw from or avoid work colleagues. Symptomatic behaviors such as crying (Osborn et al., 2020), social withdrawal (Labots-Vogelesang et al., 2023; Perz & Ussher, 2006), and avoidant coping (Labots-Vogelesang et al., 2023; Ussher & Perz, 2013) were reported

to negatively affect relationships at work with a more profound effect for women with PMDD.

The experiences of PMS/PMDD symptomology impacted on emotions which in turn impacted on relationships (Barker-Smith, 2020; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Ussher, 2002; Ussher & Perz, 2008). These emotions included feelings such as irritability (Cosgrove & Riddle, 2003; Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Ussher, 2002, 2004; Ussher et al., 2014; Ussher & Perz, 2013, 2020a), anxiety (Hardy & Hardie, 2017; Labots-Vogelesang et al., 2023; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Ussher, 2004) and depression (Barker-Smith, 2020; Chan et al., 2023; Cosgrove & Riddle, 2003; Labots-Vogelesang et al., 2023; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Reilly & Kremer, 1999; Swann, 1995; Ussher, 2004; Ussher et al., 2014; Ussher & Perz, 2020a). The presence of these emotions impacted women's relationships by leading to misunderstandings and conflicts (Labots-Vogelesang et al., 2023; Poladian et al., 2022; Slade et al., 2009; Ussher, 2002, 2004; Ussher & Perz, 2013). Those who were close to the women would find it difficult to navigate these heightened emotions during PMS/PMDD symptoms leading to embarrassment (Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Poladian et al., 2022) or arguments (Labots-Vogelesang et al., 2023; Mooney-Somers et al., 2008; Osborn et al., 2020; Perz & Ussher, 2006; Slade et al., 2009; Swann, 1995; Ussher, 2002, 2004; Ussher et al., 2007, 2014; Ussher & Perz, 2013).

Theme 4: Difficulties in reaching the diagnosis of PMS/PMDD

Six studies highlighted a lack of accurate and timely diagnosis for PMS/PMDD (Barker-Smith, 2020; Chan et al., 2023; Osborn et al., 2020; Poladian et al., 2022; Reilly & Kremer, 1999; Ussher et al., 2014). The time spent searching for an accurate diagnosis negatively impacted women's experiences of quality of life (Barker-Smith, 2020; Chan et al., 2023; Osborn et al., 2020; Reilly & Kremer, 1999; Ussher et al., 2014) and emotions (Barker-Smith, 2020; Osborn et al., 2020; Reilly & Kremer, 1999; Ussher et al., 2014). Receiving an accurate diagnosis was shown to be more difficult for PMDD (Barker-Smith, 2020; Chan et al., 2023; Osborn et al., 2020; Poladian et al., 2022) than for PMS (Reilly & Kremer, 1999; Ussher et al., 2014) (29,35) with PMDD more likely to be misdiagnosed (Chan et al., 2023; Osborn et al., 2020). Women with PMDD were more likely to be diagnosed with bipolar disorder (Chan et al., 2023; Osborn et al., 2020), depression (Barker-Smith, 2020; Chan et al., 2023), borderline personality disorder (Chan et al., 2023), schizophrenia (Chan et al., 2023),

chronic fatigue (Chan et al., 2023; Osborn et al., 2020), fibromyalgia (Chan et al., 2023), Post Traumatic Stress Disorder (Chan et al., 2023), Cluster B Personality Disorder (Chan et al., 2023), and Myalgic Encephalomyelitis (Osborn et al., 2020). These misdiagnoses, and doctors failing to understand what the women were experiencing, resulted in women feeling dismissed and not heard (Barker-Smith, 2020; Chan et al., 2023; Osborn et al., 2020; Poladian et al., 2022). These feelings would arise when their symptoms were not taken seriously by professionals and when told that anti-depressant medication would improve their mood, which professionals considered to be part of a 'normal' female experience (Chan et al., 2023; Osborn et al., 2020; Poladian et al., 2022).

A number of reasons for misdiagnosis and not being taken seriously by medical practitioners were identified, including the rigidity of the medical model which tended to not effectively consider social, economic, political and cultural experiences (Barker-Smith, 2020), difficulty in correctly assessing and identifying PMDD cycles (Barker-Smith, 2020; Osborn et al., 2020; Poladian et al., 2022), medical professionals' difficulty in diagnosing PMDD (Chan et al., 2023; Osborn et al., 2020; Poladian et al., 2022) and health care providers not listening and thinking that PMDD is not real (Chan et al., 2023; Osborn et al., 2020; Poladian et al., 2022). The failure to recognize PMDD as 'real' meant women were left unheard and without an accurate diagnosis. This was shown specifically in one of the PMDD studies which dedicated a chapter to 'Misdiagnosis and the lost decades' (Osborn et al., 2020) where the authors explain that women were left crying for help from professionals, over many years.

Discussion

Our objective in this scoping review was to narratively outline existing research regarding women's experiences of living with PMS/PMDD. We found several themes that are consistent across this area of research with some sub-themes which can reveal the essence of experiences for those with PMS/PMDD: (1) *Lack of understanding/support*, (2) *Dual Identity* with sub themes of 'Clashing with the female stereotype identity' and 'Negative perception of self', (3) *Impact on relationships*, and (4) *'Difficulties in reaching the diagnosis of PMS/PMDD'*. These themes begin to address the knowledge gap by mapping the features of experiencing PMS/PMDD, including the lack of understanding from others.

Our review highlights that many women who experience PMS/PMDD simultaneously experience a lack of understanding and support from their relationships with others, including family, friends, and partners. The experience of not being heard and understood or feeling dismissed by

health care providers was a consistent feature in women's narratives and created detrimental impacts on women's well-being. These negative experiences chime with previous research which highlights how PMS/PMDD experiences are dismissed and not taken seriously by doctors (Chan et al., 2023; Osborn et al., 2020; Perz & Ussher, 2006; Poladian et al., 2022; Ussher, 2002) resulting in 'lost decades' (Osborn et al., 2020). These experiences which are negative and have potential for dismissal may be exacerbated by the current ambiguity surrounding diagnosis and treatment for PMDD, including a lack of knowledge of the phenomena which can potentially lead to mis/overdiagnosis and incorrect medical intervention (Bhatia & Bhatia, 2002; Chan et al., 2023; Osborn et al., 2020).

Stigma attached to women's mental health (Hoffmann & Tarzian, 2001) and specifically women's menstruation (Grundström et al., 2018) is an aspect that needs to be considered when attempting to improve women's experiences of PMS/PMDD. When combined, these stigmas may result in doctors believing and informing women that PMDD/PMS is not real and that women are exaggerating, imagining or faking their symptoms (Chan et al., 2023; Grundström et al., 2018; Hoffmann & Tarzian, 2001; Osborn et al., 2020; Poladian et al., 2022). This 'gaslighting' also affects, for example, people with chronic pain (Bean et al., 2022), women with postnatal illness (Edwards &Timmons, 2005), and people with inflammatory bowel disease (Edwards & Timmons, 2005; Guo et al., 2020). Particularly, cis-gendered male doctors are shown to dismiss and ignore women who have menstrual-related concerns (Edwards & Timmons, 2005; Grundström et al., 2018; Osborn et al., 2020).

The embodied experience was a dominant feature when reviewing the research exploring women's experiences of PMS/PMDD, with women experiencing a dual identity 'split' of the usual self and the symptomatic self (Labots-Vogelesang et al., 2023; Swann, 1995; Ussher, 2004; Ussher & Ussher, 2011). However, the embodied and subjective experiences varied across individuals and were influenced by societal interaction, gender expectations and partner's sex or gender (Ussher, 2003, 2006; Ussher et al., 2007; Ussher & Perz, 2020b; Ussher & Ussher, 2011). These factors can shape women's experiences and identity, as women may feel pressure to minimize or hide their PMS/PMDD symptoms and conform to societies expectations of a 'good' woman (Chrisler, n.d.; Ussher & Perz, 2020a). Moreover, there were some differences in support levels between heterosexual and lesbian partners, which may be due to a higher likelihood of understanding and empathy provided by a female partner who has had similar experiences. Increased empathy and understanding have been shown to benefit the symptomatic individual experiencing PMS/PMDD (Mooney-Somers et al., 2008; Ussher et al., 2007, 2014; Ussher & Perz, 2008, 2013). Moreover, PMS/PMDD and mental health stigma can begin to be remedied

by education (Byrne, 2000), indicating the potential for additional medical education among providers (Chan et al., 2023) and family and friends on the phenomenon. Limitations of this scoping review include the possibility of missing articles as only articles in English were included and this may not have covered the full breadth of literature.

Implications for practice and research

In terms of future research, we identified a lack of research in countries other than England and Australia thus more research is needed globally which can explore the impact of cultural context on the experiences of PMS/PMDD. Moreover, most of the qualitative studies in the review utilized semi structured interviews and thematic analysis or discourse analysis. Future research which utilizes more in-depth methodologies like hermeneutic phenomenology, could be useful for exploring the essence of the phenomenon across this lived experience. We also found a lack of research utilizing digital ethnography as a methodology. Poladian et al. (2022) study of 'Reddit©' highlights how internet sites can provide rich and insightful data of experiences, suggesting there is wealth of opportunity to explore PMS/PMDD *via* online routes.

In relation to practice, our analysis highlights a lack of understanding from significant others including medical practitioners. To better support women with PMDD/PMS, we suggest that attempts must be made to increase health care professionals' understanding of the experiences of women as well as increased training on PMS/PMDD. Increased training may enable earlier and more accurate diagnosis of PMS/PMDD and in turn lead to more effective and earlier support being offered to women. The uniqueness of PMS/PMDD to females can result in gender bias and this must be addressed when increasing education and awareness around the topic of PMS/PMDD. Population-level health promotion activities which focus on PMS/PMDD would be useful in relation to supporting women who experience the symptoms but also may increase population health literacy supporting understandings around PMS/PMDD of family and friends.

Conclusions

Premenstrual syndrome (PMS) and premenstrual dysphoric disorder (PMDD) have significant impacts on women who experience them. The findings from our scoping review highlight that women who experience PMS/PMDD may be faced with delays in diagnosis, mis-diagnosis, and inadequate understanding and support from medical practitioners, and from family and friends. Moreover, experiencing PMS/PMDD can have

significant impacts on relationships as well as women's sense of self. More support and increased understanding of PMS/PMDD and the impact that it has on women's lived experience is thus needed.

Authors' contributions

Caspian Haidarieh-Zadeh led the conception and design of the review, conducted the literature search, screening, data charting and synthesis, and drafted the manuscript. Julia Morgan assisted in the screening, data charting and synthesis of themes. Liz Gale and Lesley Dibley provided methodological guidance, contributed to interpretation of the findings and critically revised the manuscript. All authors read and approved the final manuscript.

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No potential conflict of interest was reported by the author(s).

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Ethical approval was not required for this study as it is a scoping review of previously published literature and did not involve the collection of primary data from human participants. Patient consent was not required as this study is a review of previously published literature and did not involve human participants.

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