



# **Exploring the Health-related Quality of Life of women with Premenstrual Dysphoric Disorder**

by  
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## DECLARATION

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## ABSTRACT

Premenstrual Dysphoric Disorder (PMDD) is a condition marked by its cyclical nature in symptom expression during the late luteal phase. Approximately 2 % - 8% of the adult female population have PMDD. Quantitative studies have shown the impact of PMDD symptoms on quality of life (QOL), but there are no qualitative studies reporting on this. In this presentation, I present findings of the first qualitative study that explored QOL among women with PMDD. Participants were 27 females with self-reported PMDD. Data were collected using a phenomenological research approach where semi-structured interviews were conducted. Interviews were transcribed and analysed in ATLAS t.i. Thematic analysis was used to explore women's Health related quality of life (HRQoL) and four main themes emerged; (1) Culture surrounding premenstrual distress disorders, (2) Psychological functioning and PMDD, (3) Interpersonal relationships and PMDD, and (4) Healthcare and PMDD. The findings highlight the impact of PMDD on a number of factors associated with HRQoL particularly women's self-concept, interpersonal relationships, occupational responsibilities and psychological well-being. The results also highlight the importance of diagnosis in women's PMDD journey as it facilitates in self-awareness, interpersonal relationship understanding and contributes to better healthcare experiences. Several findings of this study are not apparent in current research which indicates the need for additional research evaluating the impact of PMDD. The findings provide insight into the female experience of PMDD and recommendations for healthcare and mental health practitioners are provided.

## OPSOMMING

Premenstruele disforiese versteuring (PMDD) is 'n toestand wat tydens die laat luteale fase gekenmerk word deur sy sikliese aard in simptomeuitdrukking. Ongeveer 2% - 8% van die volwasse vroulike populasie het PMDD. Kwantitatiewe studies het die impak van PMDD simptome op gesondheidsverwante lewenskwaliteit (HRQoL) getoon, maar daar is geen kwalitatiewe studies wat hieroor verslag doen nie. In hierdie tesis bied ek bevindinge aan van die eerste kwalitatiewe studie wat HRQoL onder vroue met PMDD ondersoek het.

Deelnemers was 27 vroue met self-gerapporteerde PMDD. Data was ingesamel deur gebruik te maak van 'n fenomenologiese navorsingstegniek waar ek semi-gestruktureerde onderhoude gevoer het. Onderhoude is getranskribeer en ontleed in ATLAS t.i. Ek het tematieses analyses gebruik om vroue se HRQoL te verken en vier hooftemas het na vore gekom; (1) Kultuur rondom premenstruele noodversteurings, (2) Sielkundige funksionering en PMDD, (3) Interpersoonlike verhoudings en PMDD, en (4) Gesondheidsorg en PMDD. Die bevindinge beklemtoon die impak van PMDD op 'n aantal faktore wat met HRQoL geassosieer word, veral vroue se selfkonsep, interpersoonlike verhoudings, beroepsverantwoordelikhede en sielkundige welstand. Die resultate beklemtoon ook die belangrikheid van diagnose in vroue se PMDD-reis aangesien dit in selfbewustheid, interpersoonlike verhoudingsbegrip fasiliteer en bydra tot beter gesondheidsorgervarings. Verskeie bevindinge van hierdie studie is nie duidelik sigbaar in huidige navorsing nie, wat dui op die behoefte aan bykomende navorsing wat die impak van PMDD evalueer. Die bevindinge bied 'n insig in die vroulike ervaring van PMDD en aanbevelings vir gesondheidsorg en geestesgesondheidspraktisyns word verskaf.

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*Philippians 4:13 "I can do all things through Christ who strengthens me".*

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To my knights of the round table, I love you all so much. I am so blessed to have you in my life and I extremely excited to see each of you flourish in your chosen fields. Here's to our existential sushi dates and copious amounts of hot chocolate which carried us through our most difficult moments. I am in awe of all of you and it has been a privilege and an honour to know and work with each of you.

Finally, I am so grateful for the funding support from the Ithemba Bursary Foundation and Dr Rizwana Roomaney.

## **DEDICATION**

I dedicate this thesis to every women diagnosed and undiagnosed with PMDD. I hope this research allows you to feel seen and heard. Let the words of your fellow warriors bring you comfort and enlighten you on your individual journeys. I truly hope I have captured the essence of the PMDD experience.

## TABLE OF CONTENTS

DECLARATION.....	2
ABSTRACT.....	3
OPSOMMING.....	4
ACKNOWLEDGMENTS.....	5
DEDICATION.....	6
TABLE OF CONTENTS.....	7
LIST OF TABLES.....	11
LIST OF APPENDICES .....	12
LIST OF ABBREVIATIONS.....	13
Chapter 1: Introduction, Rationale, and Aims.....	14
1.1 Introduction.....	16
1.2 DSM-V Criteria of PMDD .....	16
1.3 Culture and Menstruation.....	16
1.4 A Contextual Model of HRQoL.....	17
1.5 Rationale.....	18
1.6 Research Aims and Objectives.....	19
1.7 Thesis Outline.....	20
Chapter 2: Literature Review and Theoretical Framework.....	22
2.1 Introduction.....	22
2.2 Qualitative Research on PMDD.....	22
2.2.1 PMDD in the Work Context.....	22
2.2.2 PMDD in the Healthcare Context.....	23
2.2.2.1 Osborn et al., (2020).....	23
2.2.2.2 Chan et al., (2023).....	25
2.2.3 Gap in the existing research.....	26
2.3 Menstruation in the social context.....	27
2.3.1 Culture and Menstruation.....	28
2.3.2 Socio-ecological Factors and Quality of Life.....	29

2.4 Female complaints with the healthcare context.....	31
2.4.1 Female healthcare experience.....	31
2.4.1.1 Endometriosis and PCOS.....	33
2.4.1.2 PMDD and PMS.....	35
2.5 PMDD'S impact on quality of life.....	37
2.5.1 Psychological well-being.....	37
2.5.1.1 PMDD and suicidality.....	38
2.5.2 Interpersonal relationships.....	39
2.5.2.1 Romantic and familial relationships.....	39
2.5.2.2 Social Relationships.....	40
2.5.3 Academic Performance.....	41
2.6 Theoretical Framework.....	43
2.6.1 The Contextual Model of HRQoL.....	43
2.7 Chapter Summary and Conclusion.....	45
Chapter 3: Research Methods.....	46
3.1 Introduction.....	46
3.2 Research Design.....	46
3.3 Participants.....	46
3.3.1 Inclusion Criteria.....	47
3.3.2 Exclusion Criteria.....	47
3.4 Participant Recruitment.....	47
3.5 Data Collection.....	49
3.6 Data Collection.....	50
3.7 Trustworthiness.....	52
3.8 Ethical Consideration.....	54
3.9 Reflexivity.....	55
3.10 Conclusion.....	57
Chapter 4: Findings and Discussion.....	58
4.1 Introduction.....	58



4.2 Demographics of Participants.....	58
4.3 Culture and Premenstrual Distress Disorders.....	61
4.3.1 Menstrual taboo.....	61
4.3.2 The hysterical woman.....	65
4.4 Psychological functioning and PMDD.....	72
4.4.1 “I can’t trust my judgment”.....	72
4.4.2 The PMDD monster.....	77
4.4.3 PMDD – Abused or Abuser.....	81
4.4.4 Suicidal ideation.....	85
4.4.5 The role of self-awareness.....	88
4.4.6 PMDD anger and rage.....	91
4.5 Interpersonal relationships and PMDD.....	94
4.5.1 PMDD’s impact on employment.....	94
4.5.1.1 PMDD symptoms led to job loss.....	97
4.5.2 Romantic relationships and PMDD.....	100
4.5.2.1 PMDD anger and rage in romantic relationships.....	103
4.5.2.2 PMDD’s impact on my partner.....	104
4.5.3 Familial and social relationships.....	107
4.5.3.1 Mom guilt.....	109
4.6 Healthcare in the PMDD context.....	112
4.6.1 Medical gas-lighting.....	113
4.6.2 Doctor shopping.....	117
4.6.3 Access to healthcare.....	121
4.6.4 Advocating for myself.....	124
4.7 Conclusion.....	128
Chapter 5: Conclusion, Limitations and Recommendations.....	130
5.1 Introduction.....	130
5.2 Research Objectives and Findings.....	130
5.2.1 Functional areas of HRQoL.....	130

5.2.2 Occupational responsibilities.....	131
5.2.3 Psychological well-being.....	131
5.2.4 Interpersonal relationships.....	133
5.2.5 Socio-ecological and cultural influences.....	134
5.3 Study Limitations.....	135
5.4 Recommendations.....	136
5.4.1 Future Research.....	136
5.4.2 Clinical and mental health practitioners.....	136
5.5 Conclusion.....	137
REFERENCES.....	139
Appendix A.....	151
Appendix B.....	153
Appendix C.....	154
Appendix D.....	155
Appendix E.....	156
Appendix F.....	157
Appendix G.....	161
Appendix H.....	163

## LIST OF TABLES

Table 1.....	44
Table 2.....	59
Table 3.....	60

## LIST OF APPENDICES

Appendix A: DSM V Criterion for Premenstrual Dysphoric Disorder.....	151
Appendix B: Recruitment flyer .....	153
Appendix C: Healthcare practitioner information flyer .....	154
Appendix D: Ethical approval certificate .....	155
Appendix E: Amendment approval letter .....	156
Appendix F: Information pack and consent form .....	157
Appendix G: Interview questions .....	161
Appendix H: Interview schedule .....	163

## **LIST OF ABBREVIATIONS**

HRQoL	Health-related Quality of Life
PCOS	Polycystic Ovarian Syndrome
PD	Postpartum Depression
PMDD	Premenstrual Dysphoric Disorder
PMS	Premenstrual Syndrome
QoL	Quality of Life

## Chapter One

### Introduction, Rationale, Aim of Study

#### 1.1 Introduction

Premenstrual Dysphoric Disorder (PMDD) is a condition which presents with both psychological and physical symptoms and affects menstruating women (Bhatia & Bhatia, 2002; Cunningham et al., 2009; Lanza di Scalea & Pearlstein, 2017). Studies have reported that approximately 2% - 8% of women have PMDD (Cunningham et al., 2009; Roomaney & Lourens, 2020; Tschudin et al., 2010; Yonkers & Simoni, 2018). PMDD is often referred to as a severe form of Premenstrual Syndrome (PMS), but differs in the severity of symptoms and impact it has on women's ability to function optimally (del Mar Fernández et al., 2019). The characteristic feature of both PMS and PMDD is that symptom expression takes place specifically in the late luteal phase of the menstrual cycle (Cunningham et al., 2009; Yonkers & Simoni, 2018). Physical and psychological symptoms associated with PMDD include lethargy, suicidal ideation, marked affective lability, hypersomnia or insomnia, rumination, bloating, breast tenderness, anxiety and marked changes in appetite (American Psychiatric Association, 2013; Cunningham et al., 2009; Yonkers & Simoni, 2018;). The combination of these physical and psychological symptoms are what causes impairment in women diagnosed with PMDD (Cunningham et al., 2009; Grady-Weliky, 2003; Lanza di Scalea & Pearlstein, 2017; Yonkers & Simoni, 2018).

Both quantitative and qualitative studies have shown the negative impact PMDD and other related premenstrual complaints can have on a woman's academic performance, physical body health, occupational competency and psychological well-being (Beddig et al., 2019; Hardy & Hardie, 2017; Hussein Shehadeh & Hamdan-Mansour, 2018; Issa et al., 2010; Sahin et al., 2018). Psychological and physical symptoms of PMDD can affect the social areas of women's lives (Cunningham et al., 2009; Eldeeb et al., 2021; Thakrar et al., 2021). A

qualitative study conducted by Hardy & Hardie (2017), described the experiences of working women with PMDD. The researchers found that employed women with PMDD expressed a need for increased awareness of PMDD and that employers offer support for employees with PMDD (Hardy & Hardie, 2017). Adding to this, PMDD symptoms were found to impact quality of work beyond the period of PMDD symptom expression (Hardy & Hardie, 2017). Moreover, symptoms associated with PMDD were shown to affect women beyond the symptom expression period, showing how severity of symptoms had ability to impact quality of occupational life for working women with PMDD (Hardy & Hardie, 2017). This study highlighted not only the need for more research and knowledge in order to increase awareness of PMDD but also emphasised the negative impact a lack of awareness has on women with PMDD (Hardy & Hardie, 2017).

Literature assessing the effects of severe premenstrual complaints on quality of life, found that quality of life scores were lower when compared to women without severe premenstrual complaints (Thakrar et al., 2021). Research conducted by Thakrar et al., (2021) found that women with PMS/PMDD described being vulnerable to absenteeism from work, increases in medical care visits, impaired relationships and lower quality of life as a result of PMS/PMDD. These findings are further supported by PMS/PMDD quality of life research that PMS/PMDD has a negative impact on quality of life (Delara et al., 2012; Siahbazi et al., 2018). These studies also expressed the need for more support options for women with the disorder (Delara et al., 2012; Siahbazi et al., 2018).

Studies assessing the prevalence of PMDD and PMS support further research into PMDD (de Carvalho et al., 2018; Eldeeb et al., 2021; Hussein Shehadeh & Hamdan-Mansour, 2018; Roomaney & Lourens, 2020; Tschudin et al., 2010). Prevalence studies further support the premise that descriptions regarding living with PMDD is essential as it could easily describe PMDD and increase help-seeking behaviours for women presenting

with severe premenstrual complaints. These findings supports the need for further research to be done assessing PMDD.

## **1.2 DSM-V Criterion for PMDD**

PMDD is listed under the DSM-V criterion as a depressive disorder (please refer to Appendix A for the DSM-V criterion) (American Psychiatric Association, 2013). According to the DSM-V, in order to be diagnosed with PMDD symptoms must be present during the late luteal phase, improve once menstruation has begun and be minimal or absent after menstruation (American Psychiatric Association, 2013). Psychological symptoms associated with PMDD are listed as mood swings, irritability and anger, depressed mood and anxiety (American Psychiatric Association, 2013). Physical symptoms described by the DSM-V to be associated with PMDD are sleep disturbances, lethargy, changes in appetite and eating habits, feeling overwhelmed or out of control, breast tenderness, bloating or weight changes and joint and muscle discomfort, (American Psychiatric Association, 2013). Symptoms presented should not be attributed to alternative depressive disorders or effects of substances and should cause clinically significant distress or impairment and interfere with ability to maintain relationships, social activities and academic and occupational responsibilities (American Psychiatric Association, 2013). Finally, symptom severity and prevalence should be confirmed by use of symptom tracking for a minimum of two menstruation cycles (American Psychiatric Association, 2013).

## **1.3 Culture and menstruation**

PMDD is related to menstruation therefore menstruation is an important theme to include in order to appropriately assess Health-related quality of life (HRQoL) of women with PMDD. Several socio-economic, cultural and religious factors impact women's experiences and understanding of premenstrual complaints (Aflaq & Jami, 2012; Betsu et al., 2023; Bramwell & Zeb, 2007; Çevirme et al., 2010; Hawkey et al., 2017; Mccammon et al.,



2020; Padmanabhanunni et al., 2017; Padmanabhanunni & Fennie, 2017). Research highlighting the impact of socio-ecological factors on experiences of menstruation found that menstruation was viewed as stigmatizing to women and as a burden (Mccammon et al., 2020; Padmanabhanunni & Fennie, 2017). A study by Padmanabhanunni & Fennie (2017), found that women from rural, single parent, unemployed households were more likely to describe menstruation as a debilitating experience than those who were from urban locations. This finding indicates a relationship between low socio-ecological backgrounds and negative experiences of menstruation.

Cultural and traditional backgrounds can influence the experience of menstruation and premenstrual complaints (Çevirme et al., 2010; Padmanabhanunni et al., 2017) Research shows that religious backgrounds can influence the attitudes and symptom experiences associated with menstruation (Bramwell & Zeb, 2007). Thus, it is pertinent to incorporate cultural, traditional and religious factors when exploring HRQoL of women with severe premenstrual complaints.

Literature has shown that stigma regarding menstruation has a negative impact on the experiences of menstruating women (Mccammon et al., 2020). Additionally, studies have shown that factors such as lack of education, shame and not being allowed to discuss topics relating to menstruation may impact negatively on women's knowledge and experiences of menstruation (Hawkey et al., 2017; Jalan et al., 2020; Mccammon et al., 2020).

#### **1.4 A contextual model of HRQOL**

Cultural, spiritual and socio-ecological factors have been shown to impact on women's knowledge and experiences of menstruation (Betsu et al., 2023; Çevirme et al., 2010; A. Hawkey et al., 2022; Jalan et al., 2020; Padmanabhanunni et al., 2017). PMDD is a disorder which is expressed during women's late luteal phase, a part of the menstrual cycle

(Cunningham et al., 2009; Yonkers & Simoni, 2018). Therefore, using a framework which incorporated socio-ecological and cultural factors in assessing HRQoL was essential in appropriately describing the experiences of women with PMDD. The Contextual model of HRQoL developed by Ashing-Giwa (2005), takes on a holistic approach when assessing an individual, their pathology and the environment in which they exist. Older models of HRQoL only took into account psychological, sexual, spiritual, functional, social and socio-ecological areas of life (Bowling, 2001). The contextual model was established in order to facilitate a better understanding of the individual as opposed to only understanding the individual and the context in which they exist (Ashing-Giwa, 2005). By understanding the person, their belief structures and socioeconomic backgrounds, we would better understand the impact of the disorder and recommend methods of support for individuals. The contextual model of HRQoL allows us to incorporate factors such as religion and culture which are not present in other quality of life models and was used as the theoretical framework in the current study.

## **1.5 Rationale**

Literature has shown that PMDD has an impact on the quality of life of women with the disorder (Petersen et al., 2016; Siahbazi et al., 2018). More specifically, studies assessing women with PMDD in Universities found that PMDD negatively impacts on academic performance, sport performance and overall university experience (Hussein Shehadeh & Hamdan-Mansour, 2018; Issa et al., 2010; Minichil et al., 2020; Teng et al., 2005).

Research assessing PMDD in Africa evaluates prevalence, impact of PMDD in universities and the impact of premenstrual distress on academia (Hernandez et al., 2019; Hussein Shehadeh & Hamdan-Mansour, 2018; Roomaney & Lourens, 2020; Thakrar et al., 2021). However, studies have not sufficiently explored women's experiences with PMDD. It is important to qualitatively explore the impact of PMDD on interpersonal and social relationships, socio-ecological and cultural factors associated with menstruation,

psychological well-being, occupational self-efficacy and functional areas of life.

Furthermore, present research regarding PMDD is predominantly quantitative, which leaves a shallow understanding and minimal descriptions of the experience of women who have PMDD.

The HRQoL model developed by Ashing-Giwa (2005) assesses the role of multiple factors, such as social relationships, socio-ecological context, demographics variables, cultural/religious background and healthcare systemic contexts, on an individual's ability to function optimally (Ashing-Giwa, 2005). Current qualitative PMDD research explored women's experiences within occupational and healthcare settings (Chan et al., 2023; Hardy & Hardie, 2017; Osborn et al., 2020). However, existing qualitative studies does not discuss PMDD women's narratives as it pertains to their HRQoL, specifically with regards to socio-ecological and cultural/religious factors. Therefore, the motivation for this thesis was to explore the HRQoL of women with PMDD.

## **1.6 Research aim and objectives**

The aim of this study was to explore the HRQoL of women with PMDD. The objectives of this study were:

- 1) To explore the impact of PMDD on functional areas of life in women with PMDD.
- 2) To explore how PMDD impacts occupational self-efficacy and overall work experience in women with PMDD.
- 3) To explore how PMDD impacts on the psychological well-being of women with PMDD.
- 4) To explore the impact of PMDD on interpersonal relationships in women with PMDD.  
(social/interpersonal).
- 5) To explore how socio-ecological and cultural factors associated with menstruation and menstrual related complaints impact women with PMDD.

## 1.7 Thesis outline

**Chapter one** introduced the topic that this thesis researched and provided a brief overview of the topic and definitions of key terms. The theoretical framework was flagged and the chapter contained the rationale, research aims and objectives and structure of the thesis.

**Chapter two** contains the literature review and a description of the theoretical framework for this study. In the chapter I report on and evaluated current PMDD research relating to HRQOL.

**Chapter three** describes the research methods and parameters of the study. It includes the research design, participant recruitment procedures, ethical considerations and data analysis process. I also reflect on my experience as a researcher throughout the process.

**Chapter four** contains the findings and discussion of the study. These are based on the aims and objectives stipulated in chapter one and literature review in chapter two. Each theme is supported with the inclusion quotes.

**Chapter five** contains the conclusion, how this research will be beneficial for healthcare practitioners and recommendations for future studies.

## **Chapter Two**

### **Literature Review and Theoretical Framework**

#### **2.1 Introduction**

In this chapter, I describe and critically evaluate the current women's health research and relate it to central factors of my research. Firstly, I conduct an in-depth evaluation of the existing qualitative research regarding PMDD. By evaluating the current qualitative PMDD research I will demonstrate the relevance of this thesis by highlighting how it will fill the gap in the existing research. Following this, I describe menstruation in the social context and explain its relevance and risk factors as it pertains to the experience of premenstrual distress symptoms. Then, I discuss women's healthcare experiences, demonstrating the barriers to care and how negative healthcare experiences result in a decrease in women's health-seeking behaviours. Thereafter, I discuss the potential impact of premenstrual distress symptoms on HRQoL as it is explored in current research. I focus particularly on the impact of PMDD and PMS symptoms on academic and sport performance and interpersonal relationships. Subsequently, Finally, I conclude this chapter by outlining the Theoretical Framework which served to guide my research.

#### **2.2 Qualitative Research on PMDD**

From my review of current literature, there are three qualitative studies relating to PMDD. These studies consisted of women with diagnosed PMDD (Chan et al., 2023; Hardy & Hardie, 2017; Osborn et al., 2020). In this section, I will critically assess each study and explain the shortcomings of each one and illustrate where my study will fill the research gap.

### **2.2.1 PMDD in the work environment**

From my review of the literature, there was only one study assessing the impact of PMDD on occupational responsibilities and workplace experience (Hardy & Hardie, 2017). The researchers conducted semi-structured telephonic or Skype interviews with fifteen women where women were required to have received a clinical diagnosis for PMDD prior to participating in the study (Hardy & Hardie, 2017). In addition, women had to either be employed at the time of the interview or had to have employment experience in order to participate in the study. A realist philosophical position was used and data was analysed using inductive thematic analysis and two main themes were developed namely: 1) Phases of PMDD at work; and 2) The role of the organization (Hardy & Hardie, 2017).

Hardy and Hardie (2017), investigated the experiences of women with PMDD in the workplace and found that common symptoms women experienced which negatively impacted on their occupational responsibilities and overall work experience included difficulty concentrating, self-doubt, paranoia, fatigue, tearfulness, heightened sensitivity to the environment and people, outbursts, and trouble socializing during the luteal phase (Hardy & Hardie, 2017). According to Hardy and Hardie, (2017) premenstrual symptoms impacted negatively on a variety of factors associated with occupation namely; occupational responsibilities, productivity, work attendance, women's professional relationships, and career paths. During times of PMDD symptom expression, women reported absenteeism from work, which negatively impacted on the quality of their work and overall job performance (Hardy & Hardie, 2017). Additionally, emotional dysregulation experienced during times of PMDD symptom expression led to further emotional outbursts at work (Hardy & Hardie, 2017). As a result, participants reported more conflict with colleagues during times of PMDD symptom expression than when they were not experiencing symptoms which led to feelings of guilt post-PMDD-episode (Hardy & Hardie, 2017).

Women reported that stigma towards mental illness led to them withholding their PMDD diagnosis from colleagues and work bosses in fear of being stigmatized or labelled (Hardy & Hardie, 2017). Consequently, mental health stigma negatively impacted women's health-seeking behaviours within their work environments and therefore indicates the role of stigma for women with mental illness, thus highlighting the need for awareness (Hardy & Hardie, 2017). A consistent sentiment shared by the participants of this study was that awareness regarding PMDD in their workplace would positively influence their experience and management of their PMDD symptoms during an episode (Hardy & Hardie, 2017). This shows the possible benefit of workplaces and organizations increasing of awareness of PMDD within occupational contexts.

This study noted the importance of organizational and workplace engagement in destigmatizing discussions and perceived impact of premenstrual complaints on women's ability to function optimally within the workplace (Hardy & Hardie, 2017). From this research we may conclude that occupational areas of life are an essential aspect of HRQoL to investigate in order to appropriately understand the extent to which PMDD affects multiple areas of HRQoL.

### ***2.2.2 PMDD in the Healthcare Context***

From my review of current literature women's health, two studies qualitatively discuss PMDD within the healthcare context (Chan et al., 2023; Osborn et al., 2020). In this section, I will critically analyse these studies.

**2.2.2.1 Osborn et al., (2020).** The study conducted by Osborn et al. (2020), aimed to explore both women's overall experiences associated with PMDD and their experiences of receiving a PMDD diagnosis. This study consisted of seventeen women with diagnosed PMDD from the United Kingdom (Osborn et al., 2020). The inclusion criteria for this study

were: 1) English speaking women; 2) aged 18 years or above; 3) previously diagnosed with PMDD by a medical specialist; and 4) met the clinical criteria for PMDD using the Premenstrual Symptoms Screening Tool (PSST) (Osborn et al., 2020). Women who did not meet these criteria were excluded from the study. Data were collected using semi-structured interviews which were recorded and later transcribed (Osborn et al., 2020). Data were analysed inductively using reflexive thematic analysis and was supported by a critical realist perspective (Osborn et al., 2020). Four main themes emerged during data analyses namely: 1) A broken woman; 2) Misdiagnosis and the lost decades; 3) A life transformed; and 4) Negotiating the aftermath.

Osborn et al. (2020), were able to identify that prompt diagnosis of PMDD was essential in preventing long-term and detrimental psychological distress in women with PMDD. Additionally, Osborn et al., (2020) highlighted the vulnerability of the PMDD community as a result of healthcare practitioners overlooking premenstrual symptoms, leading to misdiagnosis and missed diagnosis of PMDD. These findings are similar to that found in women's health research (endometriosis and Polycystic Ovarian Syndrome (PCOS)) where women documented the negative impact dismissal of symptoms and negative healthcare experiences had on their psychological well-being (Ismayilova & Yaya, 2020, 2023; Mikesell & Bontempo, 2022; Wren & Mercer, 2022). A potential effect of these misdiagnoses was women experiencing secondary difficulties such as eating disorders, substance misuse, and suicidal ideations (Osborn et al., 2020).

After receiving a PMDD diagnosis, both a life and identity reconstruction had to take place in order for participants to adapt to their new reality (Osborn et al., 2020). Participants reported having to make changes to life as a result of their PMDD diagnosis in order to compensate for changes to their mental health (Osborn et al., 2020). Furthermore, after receiving a PMDD diagnosis, women stated that therapeutic support was recommended to



assist in the task of re-evaluating themselves and their lives (Osborn et al., 2020). The study indicates the severity of potential misdiagnoses, missed diagnosis as well as symptoms of PMDD being overlooked by healthcare practitioners. Furthermore, these findings may indicate the negative psychological effects not being diagnosed can have on a woman's self-concept and further, her self-image.

**2.2.2.2 Chan et al., (2023).** According to Chan et al., (2023) women reported barriers in their healthcare system when attempting to receive a diagnosis for their severe premenstrual symptoms, such as diagnostic delay and predominantly relying on self-advocacy. This study aimed to explore the healthcare and treatment experiences of patients with PMDD in the United States of America healthcare system in order to identify barriers to women receiving a PMDD diagnosis and appropriate treatment (Chan et al., 2023). This study explored the healthcare experiences of thirty-two women with self-identified PMDD and data were collected by using in-depth semi-structured interviews (Chan et al., 2023). Data were analysed using both inductive and deductive coding methods and a feminist phenomenological approach was used to explore themes generated during data analysis (Chan et al., 2023). From the data collected, Chan et al., (2023), were able to develop a PMDD care continuum which represented the timeline of participants' healthcare experiences starting from symptom onset, receiving a PMDD diagnosis, PMDD treatment and ending with ongoing management of PMDD.

In this study, women reported experiencing a number of barriers in attempting to attain a diagnosis and recognition for their severe premenstrual symptoms such as societal barriers related to stigma associated with premenstrual disorders (Chan et al., 2023). The second barrier causing a diagnostic delay was labelled as patient barriers, which pertained to women not speaking up when they felt they were misdiagnosed, barriers in accessing appropriate healthcare and not discussing abnormal symptoms with others (Chan et al.,

2023). Negative healthcare experience, such as dismissal of symptoms and misdiagnosis, resulted in women feeling distrustful of doctors, and caused women medical trauma. These negative experiences in turn resulted delays in health-seeking behaviour and resulted in delayed diagnosis and pro-longed struggles with women's severe premenstrual symptoms (Chan et al., 2023).

Prolonging diagnosis and treatment resulted in women's PMDD symptoms worsening, which caused psychological distress and lead to suicidal ideations and suicide attempts (Chan et al., 2023). These findings demonstrate the detrimental impact negative healthcare experiences and delayed diagnosis may have on women's psychological well-being. Research assessing experiences of women with PMDD, PCOS and endometriosis found similar findings as those described by Chan et al., (2023) (Ismayilova & Yaya, 2020, 2023; Mikesell & Bontempo, 2022; Osborn et al., 2020; Wren & Mercer, 2022).

### ***2.2.3 Gap in the existing research***

The existing qualitative studies excellently depict the experiences of women with PMDD with regards to diagnosis, experience, healthcare and work-contexts. Nevertheless, majority of the participants in these studies, 83% in Osborn et al. (2020) and 53% in Hardy & Hardie (2017), were recruited in the United Kingdom. Additionally, all participants in Chan et al., (2023) study were recruited from the United States of America. Although these findings offer a good indication of the experiences of women within the majority demographic experience, experiences of women from different countries may allow for a richer, more diverse understanding of the PMDD experience. This makes the diversity of each study's participant pool minimal, therefore these studies cannot provide a holistic view of the experiences of women with PMDD.

None of the studies qualitatively assessing PMDD took cultural or socio-ecological factors into account in their interpretation and presentation of female experiences with PMDD. Although Chen et al., (2023) notes the role of stigma regarding discussing premenstrual symptoms as a societal barrier causing delayed diagnosis, the impact this may have on women's HRQoL is not discussed. Similarly, Hardy & Hardie (2017), noted stigma as a factor against women's help-seeking behaviours and contributed to women withholding their diagnoses from colleagues. Additionally, factors such as menarche and menstruation were not taken into account in the explanation or interpretation of PMDD related experiences in any of the current qualitative studies. As shown in previous sections, cultural and socio-ecological factors have been shown to impact on the experience and understanding of menarche and menstruation (Betsu et al., 2023; Hawkey et al., 2017; Padmanabhanunni & Fennie, 2017). The menstruation taboo, which encompasses women staying silent regarding their menstrual experiences, may impact negatively on health-seeking behaviours when experiencing premenstrual symptoms. Additionally, as a result of a lack of menstrual and menarche education (Hawkey et al., 2017; Jalan et al., 2020), menstruating women may not be appropriately knowledgeable in abnormal symptoms associated with premenstrual disorders, which could potentially lead to further delays in health-seeking behaviours. It was therefore important to conduct a study which assessed the influences of socio-ecological and cultural factors in women's experiences with PMDD.

### **2.3 Menstruation in the social context**

In order to best assess the impact of a disorder on an individual, the context in which they exist should be considered (Ashing-Giwa, 2005). Several studies have found that socio-ecological factors influences women's perceptions and experiences with menstruation (Çevirme et al., 2010; Hawkey et al., 2017; Jalan et al., 2020; Padmanabhanunni & Fennie, 2017). In addition, individuals' environments may give an indication as to the behaviour or

understandings they hold regarding menstruation, premenstrual disorders and menstruating women (Betsu et al., 2023; Jalan et al., 2020; Padmanabhanunni et al., 2017; Ussher & Perz, 2020). For example, studies have shown that women's cultural and religious beliefs impact on their experiences and knowledge regarding menstruation and how they perceive menstruating women (Çevirme et al., 2010; Padmanabhanunni et al., 2017). Therefore, to appropriately understand the experience and impact of a disorder, it is essential to evaluate the social, cultural and socio-ecological contexts of individuals, how these factors affect disorder experience and how the disorder effects existing within those contexts (Ashing-Giwa, 2005). In this section, I explore two factors in relation to menstruation and how it may affect women with premenstrual disorders. These are: 1) Culture and menstruation; and 2) Socio-ecological factors and quality of life.

### ***2.3.1 Culture and menstruation***

As explained above, socio-ecological and cultural influences are essential factors when assessing HRQoL as it may give insight into potential influences on the experience of a disorder (Ashing-Giwa, 2005). Research shows that cultural practices and women's ethnic backgrounds have an impact on how women experience and understand menstruation (Betsu et al., 2023; Padmanabhanunni et al., 2017). Padmanabhanunni et al., (2017) investigated the menstruation experiences of women and students in South Africa and found that ethnic culture had an impact on the experience and understanding of menstruation. 'Ethnic culture' was not defined within their study however cultural practices and menstrual experiences of women belonging to the ama-Xhosa ethnic group were described (Padmanabhanunni et al., 2017). Padmanabhanunni et al., (2017) explored the experience of menstruation for twenty ama-Xhosa women and found that traditional practices relating to menstruation were linked to experiences of shame and discomfort. Women reported both positive and negative narratives when describing the impact of cultural practices on their experiences of

menstruation. Some cultural practices (e.g. taboos around discussing menstruation, not cooking food while menstruating) were reported to be a burden, as restrictive and provoked feelings of shame for women regarding the experience of menstruation (Padmanabhanunni et al., 2017). However, some women described their cultural practices as a positive as it allowed them to feel more connected to their ancestors (Padmanabhanunni et al., 2017).

Cultural, ethnic and religious constructions regarding menstruation were often reported to impact women's psychological well-being by invoking feelings of shame for menstruating women (Hawkey et al., 2017; Padmanabhanunni et al., 2017). Hawkey et al., (2017) investigated how socio-cultural factors influenced the construction and understanding of eighty-two migrant and refugee women's narratives regarding both menarche and menstruation. Menarche refers to women's first period (Hawkey et al., 2017). Menarche was described by participants as a pivotal point of womanhood, marking the transition between girl to woman (Hawkey et al., 2017). In this study, menstruation was often constructed as a negative experience, with women describing it as shameful and something which needed to be hidden (Hawkey et al., 2017). However, when women were given appropriate information regarding menstruation before menarche, they reported their experiences more positively than women who were not given sufficient menstrual information prior to menarche (Hawkey et al., 2017). This shows the important role education plays in the understanding and experience of menstruation.

### ***2.3.2. Socio-ecological Factors and Quality of Life***

Research has shown that certain socio-economic factors influenced how women experience menstruation (Çevirme et al., 2010; Padmanabhanunni & Fennie, 2017). Socio-ecological factors which were listed in research as impacting on knowledge and views of menstruation were level of education, access to education, employment status and household

dynamics (Çevirme et al., 2010; Hawkey et al., 2017; Jalan et al., 2020; Padmanabhanunni & Fennie, 2017). Padmanabhanunni and Fennie (2017) investigated the experience of menstruation for South African students and found that socio-economic factors impacted on students experiences of menstruation. Women of lower socio-ecological status (e.g. rural area, single parent household, unemployed) were more likely to describe menstruation as debilitating than their counterparts (Padmanabhanunni & Fennie, 2017). Similarly, Çevirme et al., (2010) found a statistically significant relationship between participants (n=586) experiences of menarche, age and level of education ( $p < 0.05$ ). This study's findings showed that it was more likely for women who were aged 30 and above and whose highest level of education were primary and secondary school to recognize that menarche was an unpleasant experience (Çevirme et al., 2010).

As explained above, education regarding menstruation impacts on the experience and understanding of menstruation, especially when this information is provided prior to menarche (Hawkey et al., 2017; Jalan et al., 2020). In a study conducted by Hawkey et al., (2017) women described that there was no discussion and limited sources of education regarding menstruation and menarche. Reasons for the lack of resources on menstruation and menarche were described to be as a result of shame and that the topic of menstruation was considered to be disrespectful and inappropriate. As a result of these narratives surrounding menstruation, women reported not feeling comfortable engaging in conversations and reported being excluded from discussions regarding menstruation and menarche as a result of the stigma of shame surrounding the topic (Hawkey et al., 2017). Similar findings are discussed by Jalan et al., (2020) where a sample of forty-four women from India were interviewed regarding their experiences with menstruation. In this study, women reported that information regarding menstruation was often minimal or incorrect because of the stigma of shame surrounding the discussion of menstruation. In addition, as a result of the lack of

access to accurate educational resources discussing menstruation and menarche, women reported relying on the advice and guidance of matriarchal figures within their families (Jalan et al., 2020).

Socio-ecological factors such as religion, ethnicity, socio-economic status, cultural background and social contexts were listed in a variety of studies as factors which impact on women's experiences and understanding of menstruation (Çevirme et al., 2010; Hawkey et al., 2017; Jalan et al., 2020; Padmanabhanunni et al., 2017; Padmanabhanunni & Fennie, 2017; Ussher & Perz, 2020). This illustrates the necessity in incorporating socio-ecological factors when assessing HRQoL. It is therefore appropriate to conclude that socio-ecological factors are an essential part in understanding the lived experiences and HRQoL of women with premenstrual disorders.

## **2.4 Female Complaints within the Healthcare Context**

In this section I discuss the female healthcare experience as it is represented in current women's health research. As there are minimal studies describing the healthcare experiences of women with PMS and PMDD, I have included studies assessing endometriosis and PCOS patients' healthcare experiences as these both represent female reproductive health issues. In this section I start by exploring female healthcare experiences in general, then describe the healthcare experiences of patients with endometriosis and PCOS and conclude by reporting on the healthcare experiences of patients with PMDD and PCOS.

### **2.4.1 *Female Healthcare Experience***

Studies comparing gender differences in patient experiences within healthcare contexts showed that women experienced notably poorer and unfavourable care compared to their male counterparts (Chen et al., 2022; Elliott et al., 2012; Teunissen et al., 2016).

In a 2022 study conducted by Chen et al., (2022), gender differences in patient experiences of care in the emergency room showed that women (n=1926) reported worse experiences of care compared to men (n=1196). Women reported worse emergency department experiences to men in all measures assessing patient experience (Chen et al., 2022). Some results from this study suggested that female complaints were taken less seriously than those from men, as women reported worse experiences in receiving timely care ( $p < 0.001$ ) and men were attended to faster than women ( $p < 0.05$ ) (Chen et al., 2022). In addition, women reported that doctors were more likely to not discuss test results with them in comparison to male patients ( $p < 0.05$ ) (Chen et al., 2022), which may indicate a dismissive attitude from healthcare practitioners towards female patient needs.

Studies discussing gender differences in experiences of inpatient care reported similar findings to Chen et al., (2022), as women reported low scores associated with inpatient care experiences in comparison to their male counterparts (Elliott et al., 2012; Teunissen et al., 2016). In both studies, women reported less satisfactory health-care experiences in comparison to men (Elliott et al., 2012; Teunissen et al., 2016).

In a cross-sectional survey study conducted by Teunissen et al., (2016) inpatient experiences between men (n=897) and women (n=814) were compared in order to assess quality of care during individuals hospital stay at a university medical centre in the Netherlands. In this study, researchers surveyed inpatient experiences using the survey tool Consumer Quality index (CQ-index). Researchers found that women rated their hospital experiences significantly lower than men ( $p < 0.01$ ) and reported the behaviour of the nursing staff was unfavourable towards them while receiving treatment ( $p < 0.05$ ). Similar to the findings of Chen et al., (2022), 6% more women reported time delays in receiving care or assistance in comparison to their male counterparts during their hospital stay ( $p < 0.001$ ) (Teunissen et al., 2016).



According to Elliot et al., (2012), women were found to have less positive healthcare experiences in comparison to men. In their study, data was analysed from the Consumer Assessment of Healthcare Providers and Systems Hospital Survey (HCAHPS) collected from 3 380 acute care hospitals (Elliott et al., 2012). Data from both male (n=823 714) and female (n=1 147 918) patients were analysed in order to assess patient experiences after they were discharged from hospital care (Elliott et al., 2012). Elliot et al., (2012), found that women reported less positive experiences relating to treatment communications, hospital cleanliness and discharge information than men ( $p < 0.001$ ). These are similar to the findings explained by Chen et al., (2022), and Teunissen et al., (2016). Conversely, Elliot et al., (2012) found that women (91.1%) reported more favourable experiences regarding communication from healthcare practitioners in comparison to men (90.5%). The researchers concluded that women's healthcare experiences were notably worse than men's, specifically noting discrepancies in timely patient care, communication regarding medication, treatment and diagnosis and behavioural treatment from healthcare practitioners (Chen et al., 2022; Elliott et al., 2012; Teunissen et al., 2016).

**2.4.1.1 Endometriosis and PCOS healthcare experiences.** PCOS is a female endocrine disorder which is characterized by hyperthyroidism, polycystic ovaries and a range of symptoms resulting in reproductive problems and changes in women's physical appearance (Wolf et al., 2018). Endometriosis is a gynaecological disorder where endometrial tissue grows outside of the uterus, causing inflammation, severe pelvic pain and reproductive complaints (Culley et al., 2013; De Graaf et al., 2013). Studies assessing the healthcare experiences of women with PCOS have shown a pattern of symptom dismissal where women with PCOS symptoms sought medical intervention and support with their symptoms but were consistently overlooked by healthcare practitioners (Ismayilova & Yaya, 2020, 2023; Rea et al., 2020; Wren & Mercer, 2022). Therefore, PCOS and endometriosis research shows

barriers in healthcare and repercussions of which are similar to the struggles women with premenstrual symptoms experience. It is for this reason that PCOS and endometriosis research will be discussed in order to provide perspective on the universal experiences of women within healthcare contexts.

According to Ismayilova and Yaya, (2023) PCOS patients (n=25) reported that negative healthcare experiences led to women withdrawing from seeking medical treatment and distrusting healthcare practitioners. Women reported that they did not receive sufficient medical guidance, experienced a lack of empathy and weight bias from healthcare practitioners and that mental-health related symptoms experienced as a result of PCOS were ignored by doctors (Ismayilova & Yaya, 2023). Additionally, Ismayilova and Yaya, (2023) found that women who were older were provided with minimal guidance regarding post-menopausal treatment options. These findings are similar to those described in Ismayilova and Yaya, (2022) which indicated that 66% of participants (n=296) were dissatisfied by the PCOS information healthcare practitioners provided them and dissatisfied with medical therapies (38%) provided at the time of them receiving a PCOS diagnosis. In addition, 42% of participants reported not receiving any form of information regarding lifestyle management or medical therapy (28%) regarding management of their PCOS symptoms.

Similar healthcare experiences are described by endometriosis patients, where research has found that women with endometriosis often experienced dismissal of their symptoms and medical mistrust negatively impacted on their health-seeking behaviours (Rea et al., 2020; Wren & Mercer, 2022). For example, Wren and Mercer, (2022) described experiences of women (n=9) with endometriosis where women reported prolonged diagnostic experiences as a result of age bias and ineffective clinical practices. Similarly, in a study conducted by Rea et al., (2020) women (n=25) described delayed diagnosis and consistent dismissal of their symptoms by healthcare practitioners. Additionally, the delayed diagnosis of endometriosis

negatively impacted on women's QoL, adversely affecting women's social lives and causing self-isolating behaviour (Rea et al., 2020).

**2.4.1.2 PMDD and PMS.** PMS and PMDD symptoms have been shown to cause significant disturbances in women's occupational, social, academic and interpersonal areas of life (Hardy & Hardie, 2017; Osborn et al., 2020; Park et al., 2023). Studies assessing women with PMDD healthcare experiences have shown evidence of symptom dismissal, medical mistrust, patients needing to self-advocate and delays in health-seeking behaviours as a result of negative healthcare experiences (Chan et al., 2023; Osborn et al., 2020). According to an assessment of premenstrual disorder literature assessing the prevalence, impact and burden of PMS and PMDD, in order for women to be better treated within healthcare settings, premenstrual complaints need to be better acknowledged within healthcare settings (Halbreich et al., 2003).

Osborn et al., (2020), found that women with PMDD reported diagnostic delays for their severe premenstrual symptoms as a result of healthcare practitioners not being sufficiently informed regarding the diagnostic criteria for PMDD. In addition, women reported being misdiagnosed and as a result received incorrect treatments for their severe premenstrual symptoms by healthcare professionals (Osborn et al., 2020). Moreover, participants reported feeling repeatedly dismissed by healthcare practitioners when they raised concerns regarding possible misdiagnosis and treatments that were not working (Osborn et al., 2020). These negative healthcare experiences and delays in diagnosis and treatment for participants severe premenstrual symptoms negatively impacted on women's psychological well-being, resulting in women questioning the severity of their symptoms and the validity of their experiences (Osborn et al., 2020). Upon receiving a diagnosis for their severe premenstrual symptoms, women reported that their diagnosis positively impacted on

their psychological well-being as they were better able to understand themselves and experienced relief at receiving recognition and an answer for their symptoms.

According to Chan et al., (2023), societal, provider and patient barriers were described as barriers in patients not receiving appropriate care for their severe premenstrual symptoms. Participants described that societal barriers associated with women's health focusing predominately on fertility caused their severe premenstrual symptoms to be disregarded and left untreated within the US healthcare system (Chan et al., 2023). Patient barriers were described as barriers preventing patients from discussing their symptoms with healthcare practitioners, speaking up against possible misdiagnosis, not disclosing their severe premenstrual symptoms to others and not being able to access healthcare (Chan et al., 2023). Patient barriers were found to be impacted by societal barriers where menstrual stigma limited women's ability to discuss struggles relating to menstruation (Chan et al., 2023). This is similar to the findings discussed in menstrual taboo research (Betsu et al., 2023; Padmanabhanunni et al., 2017). Lastly, provider barriers were described as healthcare practitioners' reactions to patients' severe premenstrual symptoms (Chan et al., 2023). Women reported that their symptoms were often dismissed and reported experiences relating to medical gas-lighting, which is described as healthcare practitioners normalizing the chronic dismissal of patients' symptoms (Chan et al., 2023).

From these findings it is possible to conclude that a diagnosis for severe premenstrual symptoms may have a positive impact on women's psychological well-being as it is able to facilitate in self-awareness, understanding and possibly acceptance during the premenstrual phase.

## 2.5 PMDD's Impact on Quality of Life

Related QoL research describes the impact of premenstrual disorders on women's psychological, functional areas of life and interpersonal relationships (Delara et al., 2012; Siahbazi et al., 2018). More specifically, studies have shown the impact of PMDD and PMS on academic performance, occupational responsibilities, interpersonal relationships and psychological well-being (Delara et al., 2012; Hussein Shehadeh & Hamdan-Mansour, 2018; Park et al., 2023; Petersen et al., 2016; Siahbazi et al., 2018). This will be discussed further in the following section. In this part of the review I will discuss PMS and PMSS research on (1) Psychological well-being; (2) Interpersonal relationships; and (3) Academic performance. Since there is limited research on quality of life among patients with PMDD, I have included research on PMS.

### 2.5.1 *Psychological Well-being*

Psychological well-being can be described as an individuals' emotional and mental state and includes characteristics of anxiety, self-esteem, depression, and life meaning (Ashing-Giwa, 2005; Tang et al., 2019). Many studies report the negative impact PMDD and PMS symptoms have on women's psychological well-being and health (Delara et al., 2012; Park et al., 2023; Petersen et al., 2016; Siahbazi et al., 2018). Additionally, women who met the diagnostic criteria for PMDD scored statistically worse in markers relating to emotional regulation, social functioning and overall psychological well-being than women who did not experience PMDD like premenstrual symptoms (Delara et al., 2012; Petersen et al., 2016). In a study conducted by Delara et al., (2012) female students who met the diagnostic criteria for PMDD (n=224, 37.2%) scored significantly lower in all categories of QoL (social functioning, bodily pain, emotional well-being and role physical) besides physical functioning ( $p < 0.274$ ) in comparison to women who did not meet the criteria for PMDD ( $p < 0.0001$ ). QoL was measured using the Short Form Health Survey (F-36) and students and

PMDD was determined using the DSM-5 diagnostic criteria. Similarly, in a study conducted by Park et al., (2023) women reported that their PMS symptoms resulted in occupational impairment, resulting in lack of self-care and levels of productivity during the menstrual phase as a result of anhedonia.

Negative healthcare experiences for women presenting with premenstrual symptoms were often reported to negatively impact on women's psychological well-being (Chan et al., 2023; Osborn et al., 2020). According to Chan et al., (2023), worsening PMDD symptoms resulted in women experiencing suicidal ideations and suicide attempts. Additionally, Osborn et al., (2020) reported that experiences relating to misdiagnosis and medical dismissal lead to women doubting their symptom experiences. Moreover, Osborn et al., (2020) reported that women experienced mild forms of dissociation in order to cope with their PMDD symptoms. Women stated identifying their PMDD as “monster” and “alter ego” in order to distinguish between when they were and were not experiencing their PMDD symptoms (Osborn et al., 2020, p. 5)

From this we can conclude that psychological well-being is a multi-faceted factor which is acted upon by both internal (PMDD/PMS physical and psychological symptoms) and external factors (symptom dismissal, emotional medical trauma, persistent self-advocacy).

**2.5.1.1 PMDD and Suicidality.** Studies have reported on women with PMDD and their experiences with suicidality (Chan et al., 2023; Osborn et al., 2020; Wikman et al., 2022; Yan et al., 2021). In a study conducted by Wikman et al., (2022), it was found that 39.1% of women with PMDD (n=110) reported suicidal ideation. A further 18% expressed acute suicidal ideation. PMDD was diagnosed using the DSM-5 criteria for PMDD and suicidal ideation was measured using the Montgomery-Åsberg Depression Rating Scale self-

rated version (MADRS-S) (Wikman et al., 2022). In addition, women who reported having undergone previous psychological treatment were more likely to report suicidal ideations during times of PMDD symptom expression than women who had not undergone previous psychological treatment (Wikman et al., 2022). Moreover, women who reported experiencing suicidal ideation were also more likely to have higher depressive scores than women who did not report experiencing suicidal ideation during the late luteal phase (Wikman et al., 2022).

According to a systematic review conducted by Yan et al., (2021), PMDD was associated with suicidal ideation and suicide attempts in comparison to their healthy counterparts. The systematic review and meta-analysis focused on six studies (from 2002 until 2014) with 8 532 patients who can be considered to have a provisional diagnosis of PMDD (Yan et al., 2021). The evidence presented by all six article allowed reviewers to conclude that women with provisional diagnosis of PMDD were more likely to experience suicidal ideation and were at a greater risk of attempting suicide than the healthy controls (Yan et al., 2021). Moreover, in qualitative PMDD studies, women with PMDD reported experiencing suicidal ideations and some expressed attempting suicide as a result of the severity of their PMDD symptoms (Chan et al., 2023; Osborn et al., 2020). From these findings it can be deduced that PMDD has a profoundly damaging effect on women's psychological well-being.

## **2.5.2 *Interpersonal Relationships***

**2.5.2.1 Romantic and Familial Relationships.** Research discussing the impact of premenstrual symptoms on interpersonal relationships are limited. However, studies have shown that premenstrual symptoms negatively impacted on familial relationships, specifically romantic and parental relationships (Osborn et al., 2020; Siahbazi et al., 2018). According to Siahbazi et al., (2018), sexual dysfunction formed part of women's PMS symptoms and was

reported to have a negative impact on their romantic relationships (Siahbazi et al., 2018). Sexual dysfunction related to decrease in sexual libido, a disinterest in sexual intimacy, reduced intensity of orgasm and painful intercourse were reported as reasons why women did not want to participate in sexual activities during times of PMS symptom expression (Siahbazi et al., 2018). These findings are similar to those discussed in Osborn et al., (2020) where researchers illustrated that women's romantic relationships were negatively impacted on by participants PMDD symptoms. More specifically, women described a "breakdown" of their romantic relationships as a result of their PMDD symptoms (Osborn et al., 2020, p. 7).

In relation to parenting, women with PMS reported that their symptoms negatively impacted on their relationship with their children during times of PMS symptom expression (Siahbazi et al., 2018). These findings are similar to that described in Osborn et al., (2020) where women with diagnosed PMDD reported not being able to appropriately care for their children as a result of their PMDD symptom during times of PMDD symptom expression.

**2.5.2.2 Social Relationships.** Women's health research has shown that female complaints impact negatively on women's social relationships and overall social functioning (Cole et al., 2021; Delara et al., 2012; Osborn et al., 2020; Park et al., 2023; Rea et al., 2020). Social relationships refers to relationships and friendships outside of the individuals family who provide support (Ashing-Giwa, 2005).

PMS research suggests that women experience social disengagement during their premenstrual phase (Park et al., 2023). In this study, four women who reported experiencing PMS symptoms were interviewed and reported on the impact of their symptoms on occupational participation and engagement (Park et al., 2023). According to Park et al., (2023), women with PMS reported that their PMS symptoms negatively impacted on social activity attendance and their social relationships. In addition, women reported participating in



self-isolating behaviours during their premenstrual phase in an attempt to reduce interpersonal relationship conflicts (Park et al., 2023). These findings are echoed in current PMDD research where women reported the negative impact their PMDD symptoms had on their friendships resulting in self-isolation during times of PMDD symptom expression, cancelling plans with friends and for some losing their friendships altogether (Osborn et al., 2020).

### **2.5.3 Academic Performance**

Studies have shown that PMDD and PMS symptoms have an impact on functional areas of life, illustrating that these symptoms impacted negatively on class attendance, academic scores and test participation (Hussein Shehadeh & Hamdan-Mansour, 2018; Minichil et al., 2020; Padmanabhanunni & Fennie, 2017). According to studies, symptoms resulted in a decrease in academic performance were menstrual pain, emotional dysregulation, lethargy, sleep difficulties, bodily discomfort and appetite changes (Hussein Shehadeh & Hamdan-Mansour, 2018; Minichil et al., 2020; Padmanabhanunni & Fennie, 2017).

In terms of physical discomfort associated with menstruation, according to Padmanabhanunni and Fennie (2017), 51% of South African students (n=255) reported menstruation as debilitating and a further 58% reported menstruation as a burden (Padmanabhanunni & Fennie, 2017). In addition, students who reported that menstruation had a negative impact on their academic responsibilities were more likely to describe menstruation as debilitating ( $p < 0.01$ ) in comparison to students who did not miss lectures as a result of menstruation (Padmanabhanunni & Fennie, 2017). Similarly, in a study conducted by Minichil et al., (2020), 386 students at University of Gondar in Ethiopia were surveyed on the magnitude and perceived impact of severe premenstrual symptoms. Of the sample of 386

students, there was an 84.6% response rate and overall the magnitude of students who met the criteria for a PMDD diagnosis, which was measured using the DSM-5 criteria for PMDD, were 34.7%. The development of PMDD was found to be 2.31 times higher in the students who found that their academic performance was negatively impacted on by their menstrual pain (Minichil et al., 2020). Academic performance was reported to be impacted on negatively by students who met the criteria for PMDD when compared to students who had no menstrual pain, where the impact of their menstrual pain led to students missing classes (72.5%), missing tests (7.9%), a decrease in academic results (13.2%) and for some dropping out of their university programs (6.5%) (Minichil et al., 2020).

Hussein Shehadeh and Hamdan-Mansour, (2018), researched the prevalence of PMS and PMDD among 858 university students and evaluated and compared the impact of symptoms on academic performance. The prevalence of PMDD was 7.7%, where PMS with high risk of PMDD was 49.1% (Hussein Shehadeh & Hamdan-Mansour, 2018). Academic performance was measured by using students' involvement scale developed by Sharkness and DeAangelo, (2011). When comparing self-determination levels, there was a statistically significant difference between students who met the criteria for PMDD and PMS ( $p < 0.001$ ), in terms of the Academic Motivation Scale (AMS-C 28) (Hussein Shehadeh & Hamdan-Mansour, 2018). This illustrates the impact of premenstrual symptoms on academic performance (Hussein Shehadeh & Hamdan-Mansour, 2018). This may potentially signifying that the impact of PMDD on academic performance is more severe in comparison to women with PMS.

These studies describe the impact of PMDD, PMS and menstrual physical and psychological symptoms impact on academic performance (Hussein Shehadeh & Hamdan-Mansour, 2018; Minichil et al., 2020; Padmanabhanunni & Fennie, 2017). It is therefore

possible to conclude that these symptoms impact negatively on HRQoL by inhibiting women from reaching full academic potential, specifically during times of symptom expression.

## **2.6 Theoretical Framework**

I have used the contextual model of HRQoL developed by Ashing-Giwa, (2005) as the theoretical framework for this study. The theoretical framework was used to develop this study's aims and objectives, interview questions and guided identification and organizing of themes during the data analysis process. The HRQoL model allows one to introduce cultural and socio-ecological factors when assessing the impact of a disorder. This framework was particularly relevant to my study as the literature discussing menstruation and female complaints showed a relationship between specific socio-ecological factors and experiences of female complaints, particularly in how it impacts on women's health-seeking behaviours (Çevirme et al., 2010; Chan et al., 2023; Hawkey et al., 2017; Jalan et al., 2020; Padmanabhanunni & Fennie, 2017).

### **2.6.1 *The contextual model of HRQoL***

The contextual model of HRQoL includes eight contexts which Ashing-Giwa (2005), stipulates is essential in assessing the HRQoL of individuals. The first context is labelled as the macro-systemic level which includes cultural, demographic and healthcare factors (Ashing-Giwa, 2005). More specifically, the macro-systemic level includes individuals' socio-economic and life burden factors such as income, level of education, employment status, living environment (Ashing-Giwa, 2005). Following this is the cultural context, which is unique to Ashing-Giwa's (2005), HRQoL model. The cultural context includes individuals' ethnic background, social environment, spiritual beliefs, language and social media they are exposed to (Ashing-Giwa, 2005). Next is the demographic context, which includes individuals' age and gender. After this is the health care system context, which describes individuals' monetary healthcare concerns and access to healthcare. Following this is the

individual level which includes general health, medical factors, health efficacy and psychological well-being contexts (Ashing-Giwa, 2005). More specifically, the individual level assess level of psychological functioning, illness co-morbidities, age at diagnosis and individuals healthcare practices and ability to maintain treatment plan. Factors associated with the contextual model of HRQoL are described below, in table 1.

**Table 1**

*The contextual model of HRQOL (Ashing-Giwa, 2005)*

Context	Components	Sub-components
Macro/systemic level	Socio-economic status Life burden	Income, education, employment Living situation, neighbourhood character & resources, day-to-day strain
Cultural	Social support Ethnicity Ethnic identity Acculturation Interconnectedness Worldview Spirituality	Emotional, instrumental, social networks Region of ancestral origin(s) Level to which ethnicity & cultural heritage defines self Language, choice of media, social network and practices Quality & pressure of family life & social relationships Attitudes and beliefs Faith based beliefs and practices
Demographic Health care system	Chronological age gender Access to health care Quality of health care Quality of relationship	Cost, insurance, availability of tx centres State of the art, satisfaction with care Compassion, communication, involvement
Individual level		
General health	Health status	Disease status, comorbid illness(es)
Medical factors	Cancer characteristics Age at diagnosis	Stage, surgery, chemotherapy, radiation Age at diagnosis
Health efficacy	Motivation & know-how	Health practices, utilization, perceived health efficacy, medical adherence
Psychological well-being	Level of functioning	Depression, anxiety, meaning, resolve

In a study conducted by Ashing-Giwa et al., (2004) the contextual model of HRQoL was tested using Structural Equation Modelling. In order to appropriately determine the utility and relationship among the HRQoL Model's factors, it had to be assessed using a large multi-ethnic population (Haase and Braden, 1998). In this study, female breast cancer survivors (n=703) were recruited which consisted of 135 African American women (19%), 206 Asian-American women (29%), 183 Latina-American women (26%), and 179 European-American women (26%). The findings of this study lead researchers to conclude that the measures postulated in the contextual model of HRQoL were reliable in assessing diverse female populations of breast cancer survivors.

## **2.7 Chapter Summary and Conclusion**

From this literature review it is apparent that no qualitative study has broadly researched HRQoL as it pertains to women with PMDD. Factors such as social context, menarche, cultural influence, ethnic back-ground, religious beliefs and socio-economic status are not sufficiently acknowledged within qualitative research assessing PMDD. Additionally, it has been noted that premenstrual complaints could create an impairment in a women's ability to function optimally. This alongside studies showcasing potential prevalence of PMDD in certain communities shows the necessity for a study to evaluate HRQoL.

In the following chapter I outline the research methods I used in order to appropriately conduct this study. I further explain how these research methods were used in order to accomplish the aims and objectives I described in Chapter one.

## **Chapter Three**

### **Research Method**

#### **3.1 Introduction**

In this chapter I outline the methods used in this research study. This chapter comprises of the research approach, participant recruitment, data collection procedures, data analysis, trustworthiness of the research conducted, ethical considerations and reflexivity.

#### **3.2 Research approach**

The aim of this qualitative study was to explore the quality of life of women with PMDD and understand the way in which PMDD affected different areas of their lives. The findings of this study provide qualitative insights into the experience of PMDD. I used a descriptive phenomenological research design as my intent was to qualitatively describe the quality of life associated with a specific disorder. Descriptive phenomenology is based on the writings of Husserl and allows for deeper understanding of the personal experiences of individuals who experience a specific phenomenon (Giorgi et al., 2017; Giorgi & Giorgi, 2008). I collected data using semi-structured interviews via Microsoft Teams and Zoom with women who reported having a clinical diagnosis of PMDD and analysed the data using thematic analysis.

#### **3.3 Participants**

Participants were twenty-seven women who self-identified and were diagnosed by medical or mental health professionals as having PMDD. Of the twenty-seven participants five were from South Africa and twenty-two were from various countries such as the United Kingdom, the United States of America, Romania, Denmark, Sweden, Australia, Canada and India. A description of participants' demographic information is available in chapter four. Recruitment of participants took place across 11 months (August 2021 to June 2022).

### **3.3.1 Inclusion Criteria**

Women were eligible to participate in this study if they met the following criteria:

1. Eighteen years and older
2. Able to understand and comfortably communicate in English.
3. Diagnosed with PMDD by a mental or medical health professional.

### **3.3.2 Exclusion Criteria**

Women were excluded from this study if they:

1. Did not have a clinical diagnosis of PMDD and self-diagnosed.
2. Had PMS related symptoms or who experienced premenstrual complaints not classified as PMDD.

## **3.4 Participant Recruitment**

I chose to use convenience and snowball sampling to recruit participants as these methods fit most appropriately with the demographic of participants for this study.

Convenience sampling is a method used where participants are recruited from a platform which is easily accessible to the researcher (Bryman, 2016). This study had a set of inclusion criteria for participants and I recruited candidates from the population and platforms which were easiest for me to access. Therefore convenience sampling was necessary. The snowball sampling method works by having recruited participants assist in recruiting additional participants for the study (Bryman, 2016).

Medical and mental health practitioners were contacted via email explaining the study and asking for the help in participant recruitment. Attached in each email was the study flyer (please refer to Appendix B for the flyer), which provided a basic description of the research study, the inclusion criteria for participants and my contact details. I also attached a second

flyer (please refer to Appendix C for the flyer) explaining the study to healthcare practitioners which the email recipient was able to share with colleagues or professional mailing lists to further aid in participant recruitment. The final attachment in the email was the letter of ethical approval (please refer to Appendix D for the ethics approval certificate). These medical and mental health practitioners shared the flyer with clients who fit the inclusion criteria of the study. These clients then contacted me via email or WhatsApp messenger if they were interested in participating in the study.

I also recruited participants online. The flyer with the study details and inviting candidates to participate was also posted on Facebook support groups for women with PMDD (Appendix B). Before I was allowed to post on the PMDD support group Facebook pages, the study advert were screened by the PMDD support group page administrators before it was permitted to be posted on the page. The advert was posted on a total of six Facebook pages, one of which was a mental healthcare practitioners group. The advert was posted in two cycles. The first instance being when this study received ethical clearance where the advert was posted on three Facebook pages twice. The second instance being after an amendment (please refer to appendix E for the amendment approval certificate) was submitted for this study to include international participants, where the advert was posted on five PMDD Facebook support group pages one time. Majority of the final participants (twenty-two participants) came from the study flyer being posted on Facebook PMDD support groups. Women then contacted me via Facebook messenger, email and WhatsApp messenger to take part in the study. Upon being contacted by women wanting more information about the study, I discussed the study details with them and made the study information package and consent form (please refer to Appendix F for the information pack and consent form) available to them to read through by emailing it or sending it through WhatsApp. When candidates agreed to participate in the study, I discussed a date, time and



appropriate online platform to conduct the interview. Before starting the virtual interview, I discussed ethical issues and explained what can be expected from the interview.

### **3.5 Data Collection**

This study took place during the COVID-19 Pandemic therefore, all interviews were conducted on an online platform. Five interviews were conducted on Zoom and twenty-two were conducted on Microsoft Teams. The interviews were conducted in my study at home which gave me enough privacy to conduct the interviews in an ethical and comfortable way. The interviews lasted between forty-five minutes to a hundred and five minutes. Before each interview commenced, each participant was required to send me their completed consent form. One participant who had trouble sending me the document before the interview expressed this in the interview and sent me their completed consent form directly after our first interview session. In an email which described the nature of the study, the information pack and consent form were attached for the potential participants to read through in order to make an informed decision. Every participant consented to the interview by sending a copy of the signed consent form. Interviews were recorded on the online platforms (Zoom and Microsoft teams) as well as audio recorded on my cellular phone as a back-up.

Semi-structured interviews were used for the data collection method. Questions were formulated under the guidance of my research supervisor and were based on the health-related quality of life framework developed by Ashing-Giwa (2005) (please refer to Appendix G for the interview questions). Ashing-Giwa's (2005), framework of quality of life incorporates the individuals' religion, culture and social context, which is unique to frameworks assessing QoL. I chose this framework as it allowed for more factors to be taken into consideration when assessing QoL with relation to a disorder than traditional frameworks. The first set of questions asked for the demographic details of the participants. After this, I asked the participants about the process they went through being diagnosed with

PMDD and their overall experience with the health-care system. Following this, I asked questions relating to their self-image their interpersonal relationships and how PMDD has impacted on their occupation. In the final set of questions I asked the candidates about how societal and cultural factors may have impacted on their experience of PMDD. I asked follow-up questions which related to points that the candidates would bring up within the interview. Questions associated with interpersonal relationships, such as familial, romantic and social relationships and how PMDD influenced these areas of life were asked and discussed. This study had global participants which meant that the healthcare system experience varied and involved both public and private healthcare.

After each interview was completed, I thanked the participant for answering the call to participate in the study. I asked them if they had any questions for me regarding the study or any comments they would like to make about their experience being interviewed. This was often followed by a friendly conversation and display of interest and enthusiasm regarding PMDD related research being done by the participant. I then followed up with each participant after the interview was done via email thanking them and again presenting them with a R50 data voucher and R100 Takealot voucher (or Amazon voucher for the international participants if that was requested) as a token of appreciation. All recordings of the interviews were uploaded onto Stellenbosch University OneDrive as well as the participant consent forms and transcriptions of each interview.

### **3.6 Data Analysis**

I used thematic analysis as the data analysis method for this study. Thematic analysis was used as my intent with this study was to describe women's lived experiences with PMDD. The goal of thematic analysis is to understand and assess the patterns provided from participants lived experiences (Sundler et al., 2019). In addition, thematic analysis allows the researcher to better position themselves within the research as it is necessary for the

researcher to describe and contextualise the meanings in the experiences described by participants (Sundler et al., 2019). Before starting data analysis I recruited research assistants to transcribe the interviews I recorded. Before being allowed to work on the data, each transcriber completed and signed a non-disclosure agreement in order to maintain confidentiality for the participants of this study. I set up a folder on OneDrive and made separate folders for each data transcriber and allocated a certain amount of interviews for them to transcribe. The folders were identified by the data transcriber's name. Each transcriber was instructed to only access the interviews and raw transcriptions in their allocated folder and not that of the other transcribers. A template was made for the transcriber to use when transcribing so that all work would look the same. Upon receiving the completed transcription I listened to the interview and read through the transcript. After checking the transcription, the data transcriber was paid the agreed upon amount.

I followed Braun and Clarke's (2020), updated guidelines in using thematic analysis throughout the data analyses and theme development process. Conducting the research interviews was my first step in familiarising myself with the data. Additionally, after receiving each completed transcript I listened to the interview while reading the transcript in order to further immerse myself in the data. According to Braun and Clarke's (2020), this was an essential first step in the data analysis process. While listening to the interview and reading through the transcriptions I also made sure to have my notes that I took during each interview in order to note any themes or important points I wrote down during the interview. During this process I then further added to my interview notes on any points I found relevant to the aims and objectives of this study.

Part two of the data analysis process was coding data gathered through interviewing. I used ATLAS t.i. version 22 the coding software for this study. I participated in a training workshop in the use of this software before starting with my data collection in order to

properly prepare myself for the data analysis and coding processes. A coding workshop was also offered by my supervisor where we discussed which coding methods I would be using and coding techniques. Both inductive and deductive coding methods were used as analysis was driven by the content of the data and the data was being interpreted by myself as the primary researcher.

I developed an interviewing list as suggested by my supervisor in order to start coding with interviews which in my view had the richest data. Following this I generated codes on ATLAS t.i. These codes were made while being guided by my interview notes, coding workshop notes and interview questions. In addition to this, I took notes while coding each interview, noting points of interest and within each interview. These notes also described unique codes I developed as preparation for the results and findings chapter of this thesis. I developed an initial code book of 784 codes from nine interviews. From this point, I had regular check-ins with my supervisor on the quality of the coding and the methods relating to my coding procedures. I adjusted my coding method as advised by my supervisor and generated a total of 471 codes. Data collection was stopped at twenty-seven interviews.

From the final codes, I developed themes by grouping similar codes and reviewed these with my supervisor in order to form appropriate data themes. Following this, I continuously refined the codes and ultimately established the final set of themes which I then named and defined appropriately. I developed themes from the outlined data analysis process was able to depict an accurate representation of the health-related quality of life of women with PMDD internationally.

### **3.7 Trustworthiness**

In order to uphold trustworthiness in this study, I used Lincoln and Guba's (1985) four guidelines for trustworthiness. According to Lincoln and Guba (1985), trustworthiness

an integral part of the researchers task in establishing whether or not their research findings are valuable enough for academic consumption. In my task to uphold trustworthiness in my study it was firstly essential to be properly trained in interviewing skills. As a novice researcher, the guidance of my supervisor was an essential part in making certain my conduct in interviews would render the most authentic responses from my research participants. My supervisor arranged an interview training session where we discussed appropriate ways to ask questions and how to best conduct myself during an academic interview. Additionally, we discussed how to actively take notes during the interview and Dr Roomaney advised me on how best to stay present during the dialogue as this was an essential practice for a Phenomenological approach was chosen for this study. Once the data collection process began, I set up an OneDrive folder where I uploaded my interview recordings and shared this folder with my supervisor. Dr Roomaney listened to these recordings and gave me feedback on how I could better myself in conducting research interviews. In our bi-weekly meetings we discussed any concerns had regarding interviewing. I was then appropriately advised by my supervisor on how to overcome any concerns. I also participated in a postgraduate workshop for public speaking which was offered by the university as I felt I needed additional preparation in communication and speaking skills. My supervisor listened to my interviews and gave me feedback on my interviewing skills.

According to Lincoln and Guba's (1985) guidelines, it was important to use four strategies, namely credibility, dependability, confirmability and transferability for the study in order to uphold the value of the study. Qualitative research maintains credibility when it is able to accurately display the research findings truly based on the accounts of the participant (Lincoln & Guba, 1986; Nowell et al., 2017). Credibility was ensured by consistently discussing my data collection and data analysis process with my supervisor and making updates where necessary in order to better conduct and report my research. Transferability is

described as the generalizable I ensured transferability of my research to other environments and research by including demographic components of my participants in my study. The following demographics were ascertained by each participant of this study: age, number of children, marital status, number of people in household and occupation. As this study includes international participants, I also made the decision to add the participants' country as a demographic factor. This process extended into dependability as I often consulted with my supervisor on the study progress and method procedures. During data analysis, my supervisor checked my coding and gave me feedback and advice on further progress. By making sure that the findings of the study were backed up by existing research, I ensured confirmability for the study.

### **3.8 Ethical Considerations**

This research study received ethics approval from the Health Research Ethics Committee (HREC) of Stellenbosch University (Project ID: 22309) (S21/05/095) (please refer to Appendix D for ethical approval certificate). No data collection or participant recruitment took place before ethical approval for the study was received. All participants were tasked to read through the study information pack and only sign the form once they felt comfortable to do so. I also made sure to answer any questions the candidates had about the consent for and study if they requested of me. All participants within this study consented to participating and signed the consent form. With the commencement of every interview I explained to the participant that participation in the study was voluntary. They were also informed that if at any time in the interview they wished to end the interview, they were within their rights to do so. It was also explained to them that if there was a question which they did not feel comfortable with answering, they would need to communicate that to me and did not have to answer that question. A referral for distress was made available for any participant who stated that they felt they needed extra counselling after the interview.

Welgevallen Clinic associated with Stellenbosch University gave permission for their contact details to be used as a referral for distress in my study. The clinic's contact details were made available to both South African and international participants of this study. This information was also made available to participants in their information pack and consent form. However, no participant was perceived to be of danger to themselves or pointed out needing further therapeutic support. Furthermore, each participant was assigned a pseudonym to protect their identity and maintain anonymity. All interviews were shared between myself and my supervisor as well as myself and my data transcribers via Stellenbosch OneDrive.

Transcribers signed a non-disclosure. The data collected for this study will be stored for a total of five years after the study is complete and will be destroyed after this time period has lapsed.

### **3.9 Reflexivity**

Phenomenology was the research approach of this study which called for the researcher to remain in a state of reflection, as this is proposed to be an essential part of the research process (Eberle, 2013; Usher & Jackson, 2017). This research method called for continuous introspection and self-awareness, as being knowledgeable of my own biases and preconceived ideas about QoL and PMDD was necessary to stay objective during both the data collection and data analysis processes. Therefore, practicing phenomenological constructs in my research supplemented my ability to identify and express the experience of women with PMDD as realistically as possible.

My interest in Women's Health, and further PMDD, came from my own experiences with gynaecological related complaints. I set out to understand QoL as I found my experiences were often closely related to other women who experienced female complaints and yet were not appropriately discussed within research. Therefore, it was important for me to remain aware of my subjectivity by using phenomenological related reflexive methods. I

chose to journal before interviews to remain aware of any preconceived ideas I may have regarding the interview questions and themes potentially presented by the participants during the interviews. Additionally, during the interviewing process I made sure to remain in the interview space with the participant by attentively listening to answers, taking notes of points needing to be explored further and being appropriately lead by my interview guidelines and questions. By doing this, only the experiences relating to the participant being interviewed were discussed and I remained cognisant of my own experiences in order to maintain objectivity. I remained empathetic and impartial during each interview while staying aware of my position as a researcher and not a mental health practitioner. Moreover, I made sure to discuss any concerns or barriers I felt were significant with my supervisor in order to better my interviewing abilities. My supervisor and I made sure to regularly discuss the interviewing process and Dr Roomaney would make suggestions on my interviewing methods. I adjusted my interviewing approach based off of recommendations made during discussions.

I believe that my experiences with gynaecological related complaints allowed me to create a safe space where participants were able to feel comfortable and explain their experiences with PMDD. Additionally, I made sure to maintain the boundary of creating a safe space for participants and remaining professional during interviews. I believe I accomplished this as participants stated feeling heard, supported and grateful that research into PMDD was being done as they struggled to find credible information regarding the disorder. Participants were also appreciative for the opportunity to add to research about PMDD and stated that they would be waiting in anticipation to read the research that they took part in. Listening to each woman's experiences with PMDD humbled me and further fuelled me to look at my research as both academic and as a catalyst in bettering the lives of women with PMDD.



### **3.10 Conclusion**

In this chapter I described the research methods I used. I described the procedures associated with participant recruitment. Alongside this, data collection processes were explained including the manner in which the interviews were conducted and how communication with participants took place. Data analysis techniques were described and the research method this study was based on was defined with relation to data analysis. I then further expressed my personal interest in this topic and identified how I maintained trustworthiness and reflexivity throughout the research process. The next chapter, Chapter four, will describe the results of my data collection and data analysis procedures.

## Chapter Four

### Findings and Discussion

#### 4.1 Introduction

In chapter four I present my findings and discussion. I constructed five main themes during data analysis namely: 1) Culture surrounding premenstrual distress disorders; 2) Psychological functioning and PMDD; 3) Interpersonal relationships and PMDD; and 4) Healthcare and PMDD. In each theme, there are sub-themes which further describe the nuances of the main theme. Firstly, I outline the demographic information relevant to the participants of my study. Thereafter, I describe and define the main themes and their sub-themes. Additionally, each theme and subthemes description will be supported using quotes directly from participant interviews and data analysis.

#### 4.2 Demographic information of participants

My study sample consisted of 27 women aged between 19 and 50 (average age 32) as displayed in the demographic information table below. The participants in this study were recruited internationally from South Africa (n=5), the United Kingdom (n=3), United States of America (n=11), Romania (n=1), Denmark (n=2), Sweden (n=1), Australia (n=2), Canada (n=1) and India (n=1) via the participant recruitment methods discussed in Chapter 3. As evident in Table 2 below, most women were between the ages of 31-35 (n=6), were married (n=12), did not have children (n=14) and were either full-time students or employed (n=24).

Participants were not explicitly asked about comorbidities alongside their PMDD. However, depression, ADHD, anorexia and bulimia were mentioned as separate diagnoses participants received which were not related to their PMDD.

**Table 2**

*Description of participant demographics*

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Demographic	Total
Age	n
18 – 25	3
26 – 30	3
31 – 35	8
35 – 40	4
41 – 45	7
46 – 50	2
Current Relationship Status	
Single	7
Committed Relationship	7
Married	12
Divorced/Separated	1
Children	
Yes	13
No	14
If Yes, how many?	
1	8
2	2
3	2
No. of People in Household	
1	5
2	8
3	8
4	4
5	2
Current Employment	
Student/Employed	24
Unemployed	3

In the following section I outline the themes and sub-themes which were developed during data analysis. Table 3 provides an overview of each theme and sub-theme explored.

**Table 3**

*Description of data themes and sub-themes*

Themes and Subthemes
Culture Surrounding Premenstrual Distress Disorders
Menstrual Taboo
The Hysterical Woman
Psychological Functioning and PMDD
“I can’t trust my judgment”
The PMDD monster
PMDD – Abused or Abuser
Suicidal Ideation
The role of Self-awareness
PMDD anger and rage
Interpersonal relationships and PMDD
PMDD’s Impact on Employment
PMDD Symptoms lead to job loss
Romantic Relationships and PMDD
PMDD anger and rage
PMDD’s impact on my partner
Familial and Social Support and Understanding.
Mom guilt
Healthcare in the PMDD context
Medical Gas-lighting and the Importance of a Diagnosis
Access to Healthcare
Advocating for Myself

### **4.3 Culture Surrounding Premenstrual Distress Disorders**

Culture and socio-ecological contexts forms an integral part of the theoretical framework of this thesis. More specifically, participants reported that religion and culture were two factors of HRQoL which most impacted their psychological well-being and overall experience both before and after being diagnosed with PMDD. Stigma relating to menstruation and menstruating women within participants' social contexts emerged as an important factor as stigma resulted in feelings of shame for participants. In addition, feelings of shame were also described by participants and said to occur because of the stigma attached to premenstrual complaints. Moreover, participants reported that stigma and stereotypes surrounding premenstrual symptoms and menstruating women shaped their understanding of premenstrual disorders prior to their PMDD diagnosis. This theme consists of two sub-themes, namely: 1) Menstrual Taboo; and 2) The Hysterical Woman.

#### **4.3.1 *Menstrual taboo***

Menstrual taboo can be described as stigma and negative stereotypes relating to menstruation which may negatively impact on women's psychological well-being by creating feelings of shame and harmful narratives surrounding menstruating women. For most participants these stigma and negative stereotypes were similar, irrespective of participants' social contexts. Stigma associated with menstruation and menstruating women was reported to negatively impact on the HRQoL of women with PMDD. More specifically, participants reported that experiences related to menstrual taboo was frequently linked to a decrease in health-seeking behaviours while experiencing severe premenstrual symptoms prior to their PMDD diagnosis. Many participants reported that menstrual taboo manifested itself in participants not feeling comfortable to openly discuss menstruation with their support structures and healthcare practitioners. As a result, menstrual taboo led women to withhold

their struggles with their severe premenstrual symptoms. This is illustrated in the following quote by Morgan, a 32-year-old user researcher from the United Kingdom:

*“I think that the taboo of talking about menstruation and periods 100% and I particularly like I grew up in a village and it was mostly men around me. And it was just seen as you got on with it. Like, I think that's just a general in this country [United Kingdom]. It's just something you have to deal with, so that I think impacted me into thinking like if I had known or talked about it a little bit more or had more education might have known that it wasn't normal and maybe to like not even learning to track your symptoms like or not even tracking your period, that wasn't a thing. And so that was a big thing and yeah that taboo of hiding what you're doing with and around your period I think probably had the biggest impact...”*

In the quote above, Morgan described the negative impact menstrual taboo had on her psychological well-being and health-seeking behaviours prior to her PMDD diagnosis.

Morgan stated “and it was just seen as you got on with it”, which may indicate that Morgan’s social context did not provide a supportive environment for discussions on menstruation and premenstrual complaints. As a result, Morgan reported feeling as though she had to hide her experiences with severe premenstrual symptoms prior to her diagnosis with PMDD because of the social stigma regarding menstruating women within her social context. In addition to social stigmas, Morgan stated that she felt that if she had more education regarding “normal” premenstrual symptoms, she may have known to seek help sooner. This may point out that Morgan was not appropriately educated on menstruation and premenstrual symptoms to be able to distinguish between when symptoms could be considered as abnormal or not. As a result, Morgan questioned whether this lack of education may have resulted in a delay in health-seeking behaviours while she experienced severe premenstrual symptoms.

Participants reported that menstrual taboo and stigma relating to menstruating women negatively impacted on their health-seeking behaviours. In addition, participants reported avoiding discussions about PMDD with others for fear of being stigmatized. Most participants reported feeling relieved when they were diagnosed with PMDD. However, as a

result of stigma surrounding menstruation and female hormonal complaints, participants reported reluctance in openly discussing their diagnosis. Similar to Morgan, Rachel, a 27-year-old environmental scientist, explained how menstrual taboo negatively impacted on her health-seeking behaviours when she experienced severe premenstrual symptoms.

*“I feel like because PMDD is inherently a feminine issue. It is. Of course, affected by the culture I was raised in and the culture I live in. It's contributed to me not seeking help and not taking it seriously. It definitely adds stigma. It's the reason I don't talk about it with a wide group of people and I pick and choose. [...] but because PMDD isn't talked about. No one knows, so that means talking to someone about it involves also educating them about it, which means also being comfortable talking about. Menstruation periods. Hormonal cycles. Most people I have to talk to in code. Oh well, I have a feminine hormone cycle. And I am constantly worried that someone I bring it up with is either gonna be uncomfortable talking about it or not believe me. And so I just don't.”*

In the quote, Rachel described PMDD as “inherently a feminine issue” and how this concept contributed to her silence regarding her struggles with her severe premenstrual symptoms. In addition, this statement may demonstrate an internalization of menstrual taboo as it appears Rachel asserts that the burden of illness (PMDD) falls solely on the woman. Rachel explicitly stated that stigma resulted in her not seeking help or taking her struggles severe premenstrual symptoms seriously. Rachel’s reluctance to discuss her experiences with severe premenstrual symptoms and PMDD could be attributed to her internalizing menstrual taboo and stigma surrounding premenstrual disorders. Furthermore, Rachel described that menstrual taboo and stigma negatively impacted on her health-seeking behaviours prior to her PMDD diagnosis, further showcasing the negative impact of menstrual taboo.

In addition to menstrual taboo, women of this study reported that stigma regarding menstruating women, mental illness and premenstrual complaints negatively impacted on their HRQoL. This will be discussed in the following sub-theme “The Hysterical Woman”.

Menstrual taboo can be described as stigma, negative stereotypes and narratives surrounding menstruation which may result in feelings of shame concerning experiencing or discussing menstruation (Betsu et al., 2023; Hawkey et al., 2017; Jalan et al., 2020). Current women's health research fails to discuss the impact of menstrual taboo on the experiences of premenstrual disorders. Women in the current study reported that experiences relating to menstrual taboo negatively impacted on their health-seeking behaviours. However, women's health research discusses the impact of menstrual taboo on the psychological well-being of women (Betsu et al., 2023; Hawkey et al., 2017; Jalan et al., 2020; Padmanabhanunni et al., 2017), which will be discussed in relation to the findings of this thesis.

Studies have shown women's narratives regarding menstruation were often positioned as negative, where women described menstruation as being shameful, a burden and embarrassing (Betsu et al., 2023; Hawkey et al., 2017; Padmanabhanunni et al., 2017). According to Betsu et al., (2023), schoolgirls who had experienced menarche (a female's first period) reported feeling fearful and embarrassed regarding experiencing menstruation. Additionally, Betsu et al., (2023) reported that the information available to girls regarding menstruation are encumbered with inaccuracies and social taboos. Moreover, studies have shown that certain cultural practices and social taboos resulted in silencing of women when menstruating (Betsu et al., 2023; Hawkey et al., 2017; Padmanabhanunni et al., 2017). Although these studies do not specifically discuss menstrual taboo, the social taboos that are described relate closely to the stigma and stereotypes regarding to menstruation and menstruating women described by participants of this thesis. Therefore, these findings may be related to that of this thesis as women reported feeling reluctant to discuss their severe premenstrual symptoms as a result of menstruation and social taboo's within their social contexts.



The silence explained by participants related to both feelings of shame and internalizing expectations that menstruation should not be discussed openly. These findings are similar to that of current women's health research (Hawkey et al., 2017; Padmanabhanunni et al., 2017). For women of this thesis, taboo's surrounding discussing menstruation impacted on their health-seeking behaviours when women began experiencing severe premenstrual symptoms. According to Padmanabhanunni et al., (2017), menstruation experiences of South African women were negatively impacted on by cultural taboos regarding menstruation, specifically regarding taboos on discussing menstruation. Similarly, Hawkey et al., (2017), found that migrant and refugee women also experienced cultural taboos and shame regarding discussing menstruation. In addition, women reported that the expected silence regarding taboos around discussing menstruation caused a considerable amount of distress, especially when needing to rely on male family members in accessing sanitary products (Padmanabhanunni et al., 2017). These findings are similar to that of this thesis as women reported taboos regarding discussing menstruation lead to a reluctance to seek help when they were experiencing their severe premenstrual symptoms. Although Padmanabhanunni et al., (2017) and Hawkey et al., (2017), do not discuss the long-term impact of menstrual taboos on women, these findings showcase the negative impact menstrual taboos have on women's psychological well-being and their experience of menstruation.

#### **4.3.2 *The hysterical woman***

This sub-theme explores the stigma and stereotypes participants stated existed within their social contexts and how this affected their experiences with PMDD and their psychological well-being. Many participants reported that social culture surrounding menstruating women and premenstrual disorders impacted on their experiences with PMDD. Participants often described how they understood the concept of menstruating women within

their social contexts. Terms such as “hysterical”, being in “hysterics” and “crazy” were described as labels associated with menstruating women in participants’ social contexts. In addition, silence was described as a reoccurring construct in two ways, as an expected way to cope with premenstrual disorders, imposed on women by society and a chosen way to hide struggles with PMDD for fear of being stigmatized. In the quote below, Heather, a 26-year-old student from the United States of America, described how she believed menstruating women were perceived in her social context.

*“... socially, people see women as crazy anyway, like when it comes to menstruating. And it's like, you know, a lack of understanding again, that, you know, you can be a little bit deeper than that, and a lot of people have like misconceptions about mental health, and general society, about women and how, you know, our periods can really mess up our bodies and a lot of people don't understand it. [...] femininity as well. You know, being quiet and not really being vocal about issues that are going on. People want women to, you know, be quiet and, you know, that kind of thing.”*

In this quote, Heather also described the first concept of silence, as an expected attitude towards dealing with female related complaints. In addition, Heather described a “lack of understanding” which she perceived to be present within her social contexts towards female complaints. Heather explained how there were “misconceptions” present regarding menstruation and its ability to affect the female body, which may express that Heather experienced obstacles regarding explaining her diagnosis with PMDD. It may also describe that experiences relating to struggles with menstruating, such as PMDD, may be dismissed within Heather’s social context.

Social culture surrounding menstruating women and premenstrual complaints was often described by participants to be stigmatizing and therefore disadvantaged women diagnosed with PMDD. As a result of certain terms (“hysterics”, “hysterical”, “crazy”), participants described that social stigma around premenstrual disorders and menstruating women impacted negatively on their psychological well-being. Furthermore, participants

stated feeling apprehensive about discussing their PMDD experiences as a result of the stigma attached to menstruating women and premenstrual disorders. This is demonstrated in the following quote by Kathleen, a 31-year-old student and catering assistant from the United Kingdom.

*“I think that again it's [PMDD] something that's kind of joked about and mocked and obviously it's [PMDD] seen as a kind of weakness, isn't it? You know, there's jokes made about. I don't trust anything that bleeds for a week and doesn't die kind of thing. That kind of joke. It can be a very misogynistic attitude towards periods and hormones and mood swings are often just dismissed as being overly emotional or being unable to cope and so there's that embarrassment of, actually talking about it [PMDD] and it [PMDD] being treated seriously by people. Because of the way that women are thought of. I mean, obviously there's a history of women being labelled as hysterical”*

In the quote, Kathleen described the negative connotations attached to menstruating women within her social context. The joke which Kathleen described in her quote, “I don't trust anything that bleeds for a week and doesn't die”, is a graphic depiction of the understanding of menstruating women present within Kathleen's environment. Additionally, Kathleen stated how her experience with conversations around menstruation and hormones were often misogynistic, dismissive, and labelled women in a negative way. As a result of this stigma, Kathleen reported feeling reluctant to discuss her severe premenstrual symptoms and her PMDD diagnosis with others. From Kathleen's quote I infer that there may be a relationship between menstrual taboo, stigma and the possible shame of being diagnosed with PMDD. Moreover, Kathleen's quote may demonstrate how misogynistic attitudes are a driver of stigma in women's social contexts, may contribute to a reluctance to share experiences with PMDD, particularly in professional settings. This may indicate that social stigma led to Kathleen experiencing feelings of shame and suppressing her severe premenstrual symptoms for fear of being stigmatized. Kathleen also acknowledged the labelling of menstruating

women as “hysterical”, which was a common term participants of this study used when describing how menstruating women were labelled within their social contexts.

Quinn, a 39-year-old self-employed cleaner from Denmark, had similar descriptions of menstruating women within her social context. Quinn explained how these social stigma may have created a barrier in healthcare when she sought assistance with her severe premenstrual symptoms.

*“And I was treated like that, like I'm a hysterical woman. It wasn't like, oh, you're ill. It's just like, yeah. Which, I don't know, I'm just this type of mad woman that exists, you know? I'm guessing a lot of women were in the mad house because of it. [...] The lack of control, yeah. It's sort of losing all. This unrestraint, you know? Not being able to, or behaving in ways that I would not want to behave, or say things they wouldn't... But yeah, I don't know. There's not much compassion towards strong emotions in women. Like it seems like it's not taken seriously, as a real thing. It's feels more like it's a fault or something wrong with them, but not in a kind of way that is medical.”*

In the quote, Quinn described being treated like a “hysterical woman” and “mad woman” when seeking treatment and a diagnosis for her severe premenstrual symptoms. These labels may illustrate the stigma associated with the representation of menstruating women and women with premenstrual symptoms in Quinn’s social context. Quinn described her experiences relating to the lack of recognition given to women within women’s health. In addition, the lack of compassion Quinn described in the quote could lead to women feeling ostracized and potentially further contribute to feelings of distress. Quinn described feeling as though her symptoms were not taken seriously because they were of a premenstrual nature, which may indicate a systemic problem within Quinn’s healthcare system. Moreover, this quote may illustrate prejudices resulting from social stigma pertaining to premenstrual complaints and how this may affect healthcare for women with PMDD. Furthermore, it may be deduced from this quote that stigma regarding menstruating women could negatively affect the quality of care for women with premenstrual distress disorders.

Similarly, Freja, a 47-year-old copywriter from Denmark, described how menstruating women were negatively labelled within her social context and how this impacted on her experience with PMDD.

*“... females that are menstruating that just you know, we have a saying in Denmark. Uh, she's just not in hysterics. [...] she's just being... Extreme negative in a negative way. They would go right in a negative way, labelled negatively. [...] It's given me a lot to think about in terms of opening up to specifically manager [work]. Because I feel so, I leave myself very vulnerable yeah [work], it's linked with, you know, no job security. If I mention I have these issues, will they [work] uh, you know, just if I experience other problems into relational problems with colleagues, will they just put it down on me. Because they know that I have PMDD it's so easy, you know, to resolve an issue just going. It's Freja. She's in the wrong because she has this disorder.”*

In this quote, Freja described how menstruating women are often labelled as being “in hysterics”, which could illustrate the negative stigma attached to menstruating women within her social context. As a result of these labels, Freja reported being hesitant to discussing her diagnosis with her manager and work colleagues as she feared being labelled as a result of her disorder. In the sub-theme “Occupation and PMDD” Freja further explained how she lost her job as a result of her PMDD symptoms.

Participants reported that social stigma also caused a reluctance in opening up to others about their PMDD diagnosis after they were diagnosed. Although majority of participants reported feeling relieved at receiving a diagnosis for their severe premenstrual symptoms, the reality of social stigma now being attached to them proved to impact negatively on their psychological well-being. Some participants reported that stigma associated with mental illness negatively affected them seeking emotional support from social and familial relationships. Some women reported fearing being labelled or misunderstood as reasons behind not seeking support when struggling with their PMDD from

their social and familial relationships. An example of this is illustrated in the following quote by Natalie, a 31-year-old medical doctor from South Africa.

*“... again, the mental health stigma. I don't think there will be an understanding from a male point of view and just him who, as I know, not just as a male, but as I just know, as a human, who I don't think may necessarily take, um, mental health can I say seriously was real. As, as I do, even before PMDD, I was always a, like, I understand my attached stigma...”*

In this quote, Natalie responded to a question regarding why she felt she could not discuss her PMDD diagnosis with her brother. Natalie explained that she feared she would be labelled and misunderstood by her brother regarding her PMDD diagnosis and therefore chose to not discuss her diagnosis with him. The statement “I understand my attached stigma” is complex and may be understood in two ways. Firstly, this statement may allude to how Natalie understood she was perceived by society as an individual with a mental illness as a result of the mental illness stigma which exists in her social context. Secondly, this statement could also illustrate Natalie understanding that mental illness stigma is attached to her as someone with diagnosed PMDD, which may indicate that Natalie had internalized the social stigma regarding mental illnesses. This quote may showcase the destructive impact of social stigma concerning mental illnesses on women with PMDD’s psychological well-being. Furthermore, Natalie’s quote is an example of the second form of silence described by women of this thesis; choosing to stay silent regarding their struggles for fear of being stigmatized. Natalie stated later in the interview that she only disclosed her PMDD diagnosis to very close friends and family whom she felt would not label her because of her PMDD diagnosis.

Social stigma regarding both mental illnesses and premenstrual symptoms were described by participants to be stigmatizing. Participants reported that jokes, misogynistic attitudes towards and labelling of menstruating women lead them to suppressing their

experiences with their severe premenstrual symptoms, resulting in a reluctance to discuss their premenstrual complaints. This is similar to the sentiments expressed in an article by Greenhalgh (2022), where gender biases within Western medicine is explored. According to Greenhalgh, (2022) women's experiences of consistent misdiagnosis and dismissal of symptoms can be attributed to gender based bias within the healthcare system. Additionally, Greenhalgh (2022), suggests that women's exclusions from clinical research trials and the male-centred perspective in Western medicine adds to gender discrimination within healthcare. Furthermore, stigma regarding mental illness and women's health were described in several studies as a barrier to care (Ismayilova & Yaya, 2020; Mikesell & Bontempo, 2022; Osborn et al., 2020).

Research discussing stigma with regards to endometriosis is under-studied and barely discussed in recent literature (Sims et al., 2021). Sims et al., (2021), provided a brief overview of current endometriosis research and demonstrated how understudied endometriosis related stigma is. Additionally, their brief overview gave insight into the endometriosis related stigma by discussing how it could contribute to diagnostic delay, delays in treatment and impact on women's psychosocial well-being and overall QoL (Sims et al., 2021). Furthermore, the findings of a brief overview by Sims et al., (2021) is similar to the experiences expressed by women in the current study as stigma was found to negatively impact on participants health-seeking behaviours and their overall HRQoL.

When seeking assistance for their severe premenstrual symptoms, women often reported feeling dismissed and being labelled with some form of feminine hysteria, resulting in delayed diagnosis. Similar findings are discussed by Osborn et al., (2020) where women reported that stigma attached to mental illness and women's health resulted in delayed diagnosis and dismissal of their severe premenstrual symptoms. Additionally, women were reportedly viewed as being dishonest by healthcare practitioners when reporting the impact of

their PMDD symptoms on their psychological well-being and overall QoL (Osborn et al., 2020). However, Osborn et al., (2020), made minimal indication that experiences relating to dismissal of symptoms were as a result of being labelled as the hysterical female, which was a common narrative for women in this thesis.

Research discussing endometriosis and PCOS shows similar findings (Ismayilova & Yaya, 2020; Mikesell & Bontempo, 2022). Both Ismayilova & Yaya, (2020) and Mikesell & Bontempo, (2022) reported on the experiences of women with PCOS and endometriosis as being chronically dismissed by healthcare practitioners and the negative impact this chronic dismissal had on their psychological well-being. In addition, the chronic dismissal of female complaints resulted in delayed diagnosis (Ismayilova & Yaya, 2020; Mikesell & Bontempo, 2022). These findings may indicate a systemic problem with regards to how women's premenstrual complaints are dealt with in the medical field. In addition, the dismissal of women's severe premenstrual symptoms could demonstrate an additional barrier to care, similar to those discussed in the in further detail in the theme "Healthcare and PMDD".

#### **4.4 Psychological functioning and PMDD**

Psychological functioning refers to psychological well-being, social behaviours, and an individual's overall mental health. Participants reported that their PMDD symptoms negatively impacted on their psychological functioning. In this theme, I describe psychological functioning in the context of PMDD by using the following sub-themes: (1) "I can't trust my judgment"; (2) The PMDD monster; (3) PMDD – Abused or abuser; (4) Suicidal ideation; (5) The role of self-awareness; and (6) PMDD anger and rage

##### **4.4.1 *"I can't trust my judgment"***

Majority of women in this study reported that they felt anxious as part of their PMDD symptoms. Participants reported experiencing a variety of emotions such as feeling



overwhelmed, agitated and being easily aggravated and associated these emotions with their PMDD anxiety. In addition, participants stated that they experienced other symptoms such as intrusive thoughts and rumination which they linked to their PMDD anxiety. Participants reported that these symptoms negatively impacted their ability to function optimally by adversely affecting rational decision-making, concentration and causing mild dissociations. In the quote below, Penelope, a 25-year-old mental health consultant in South Africa describes how she experienced her PMDD anxiety. For Penelope, her anxiety manifested in symptoms such as overthinking, feeling overwhelmed and an inability to concentrate on current tasks.

*“[...]and then yeah from an emotional point of view I just start to have so much anxiety, so I start to overthink things, I start to have more like obsessive and intrusive thoughts and I struggle to be in the moment so my mind is just consumed with anxiety and stress...”*

Penelope described being “consumed” by anxiety and stress as a result of her PMDD symptoms. This description may illustrate the severe impact Penelope’s anxiety type PMDD symptoms had on her mental state. During PMDD symptom expression Penelope reported struggling to maintain focus “in the moment” which may demonstrate how her PMDD anxiety had an impact on her concentration. Furthermore, Penelope’s inability to stay “in the moment” can be interpreted as experiencing a lack of enjoyment during PMDD symptom expression, as the only emotions Penelope could focus on were her anxiety and stress. This explanation may exemplify the harmful impact the PMDD anxiety and related symptoms had on Penelope’s psychological well-being. This quote demonstrates how PMDD anxiety can impair women’s ability to function optimally during times of symptom expression by causing impairment in their cognitive abilities and negatively impacting on their psychological well-being.

Some participants who experienced anxiety as a symptom of their PMDD reported that they could not identify a trigger for the anxiety. Not knowing this trigger often caused participants notable distress and discomfort as there was no warning for when anxiety would be experienced. An example of this is illustrated in the quote below by Bethany, a 33-year-old editor from the United States of America. Bethany reported that the worst characteristic of her PMDD anxiety was its unpredictability. The erratic nature of Bethany's PMDD anxiety often led to unpredictable anxiety attacks which resulted in her experiencing a generalized state of anxiety during times of PMDD symptom expression.

*“Anxiety is the big one [symptom]. I started getting extremely anxious. The biggest thing is that I have symptoms and I cannot attribute it to anything, so I will get really anxious. I'll feel really tense. [...] My heart's racing and just like I don't know why I'm anxious.”*

Participants who reported experiencing anxiety as a symptom of their PMDD often stated that this symptom affected their rational thought processes by causing paranoia, rumination and obsessive thoughts. Additionally, symptoms of paranoia, rumination and obsessive thoughts were linked by participants to experiencing a skewed interpretation of reality during times of PMDD symptom expression. An example of this is illustrated in the quote below by Liezl, a software developer from South Africa.

*“...so I became increasingly, um, needy [...] Which did not bother my, um, wife too much, but I think it was expressing the feeling of insecurity. Um, and I, I felt that. My wife doesn't love me or that maybe she's cheating on me. Um, you know, all sorts of thoughts that, I never think of now that just came up for no reason. There was no, no reason to suspect any of this stuff, but it was always there.”*

In the quote Liezl described how her PMDD symptoms resulted in paranoia and mistrust in her marriage. Liezl outlined that feelings of insecurity and mistrust were not related to real occurrences but may have been a manifestation of her paranoia during times of PMDD symptom expression. These symptoms further led to feelings of insecurity, which

negatively impacted Liezl's marriage. However, Liezl reported that when she received treatment for her PMDD symptoms, her symptoms of paranoia stopped.

Participants reported that when they experienced paranoia and obsessive thoughts they felt as though they could not trust themselves or their judgment. As a result, participants introduced coping strategies during PMDD symptom expression to mitigate the impact of their PMDD symptoms on their HRQoL. An example of this is shown by Micaela, a 41-year-old teaching assistant from the United Kingdom. Micaela stated that she asked her husband to make important decisions when she was experiencing her PMDD symptoms:

*"Sometimes I trust him [husband] if I'm not in a good place, and I need to make a decision about something. I have to turn to him [husband]. And because I can't trust my judgment, sometimes you see reality in very different ways when you're in an episode of PMDD. It's a bit like a psychosis. The way people talk to you, you hear it differently. You might pick up on something that people might glance between themselves, when you're like, what was that? They're talking about me. You get paranoid, you get obsessive. So I have to be really careful about making some life decisions."*

Micaela's statement "I can't trust my judgment" illustrates how her symptoms of paranoia, anxiety and rumination may have negatively impacted on her interpretation of reality. In addition to experiencing anxiety, Micaela reported that her paranoia affected her social relationships and often skewed her interpretation of peoples' actions towards her. This quote demonstrates how emotional symptoms of PMDD negatively impacted on women's perception of reality and their ability to make rational decisions.

Feelings of guilt and being self-critical were reported to be common emotional states for participants both during and after experiencing PMDD symptoms. Many participants reported developing a negative self-perception and self-esteem because of the negative impact their PMDD symptoms had on their psychological well-being. This is explored in the following sub-theme "The PMDD monster".

Participants of this study reported that their psychological symptoms associated with their PMDD impacted most negatively on their HRQoL. This finding is echoed in current qualitative PMDD research (Osborn et al., 2020). However, Bansal et al., (2023), reported that physical symptoms (91.4%) were more commonly reported by women who met the criteria for PMDD in comparison to women who did not meet the criteria for a PMDD diagnosis. This difference could be explained because participants of Bansal et al., (2023), were not diagnosed with PMDD and were not expressly questioned regarding the impact of symptoms, but rather the prevalence of symptoms.

Women in this study reported that anxiety affected their rational decision-making abilities, concentration and caused mild dissociation during times of PMDD symptom expression. Bansal et al., (2023), reported that 79.3% of participants who met the diagnostic criteria for PMDD reported anxiety/tension during their late luteal phase, which could demonstrate the prevalence of this symptom in women who meet the diagnostic criteria for PMDD and diagnosed PMDD. These symptoms often resulted in women feeling overwhelmed, aggravated, agitated and experiencing intrusive thoughts and rumination. I was not able to find research which appropriately demonstrated similar findings. Some participants stated that during times of PMDD symptom expression their anxiety had no identifiable trigger, resulting in distress and discomfort at pre-empting the anxiety. These findings are similar to those found in Osborn et al., (2020), as women of this study reported dramatic and sudden mood fluctuations and reactions being disproportionate to their situation. These obstacles were specifically related to symptoms of anxiety, frustration and anger (Osborn et al., 2020).

Anxiety and related symptoms were reported to cause paranoia and obsessive thoughts, resulting in a skewed interpretation of reality during times of PMDD symptom expression. Furthermore, in order to combat the negative impact of these symptoms,

participants reported introducing coping strategies as a means of managing their skewed interpretation of reality and inability to trust their judgment during times of PMDD symptom expression. I was not able to find women's health research which reported similar findings.

#### **4.4.2 The PMDD monster**

This theme, the PMDD monster, describes how PMDD made participants feel about themselves. Moreover, participants described that the psychological impact of their PMDD symptoms often led to feelings of shame towards themselves. Participants reported that symptoms such as unhealthy eating habits, avoiding mirrors, suicidal ideation, emotional dysregulation, intrusive thoughts, rumination, mild dissociation, anhedonia and anxiety and depressive symptoms had a negative impact on their self-image and self-esteem. In the quote below, Liezl described her emotional experience during times of PMDD symptom expression before her diagnosis of PMDD. In addition, Liezl described her intrusive thoughts and the effect these thoughts had on her psychological well-being.

*“There's a feeling of insecurity, um, a feeling that I'm yeah. And that's why I thought it was maybe depression. Mm-hmm, feeling insecure, feeling incompetent, all of a sudden feeling that I don't deserve anything. And then for all of that, just to go away three, three days later, it is so weird [...] A rollercoaster feeling [...] it takes time to acclimate (post PMDD symptom experience) When you feel better, you, you start thinking about why, why, why did I feel this way? You know, you're concerned about yourself. Yeah. So, so it's not, it's not that you feel on top of the world, all of a sudden...”*

Liezl used terms such as “insecure” and “incompetent” to define how she felt about herself while experiencing intrusive thoughts during PMDD symptom expression. The phrase “I don't deserve anything” could indicate the negative impact of Liezl's PMDD symptoms on her self-worth. Moreover, Liezl described feeling concerned post PMDD symptom experience because of the “rollercoaster feeling” she experienced. This could demonstrate that the impact of PMDD symptoms are able to impact individuals' psychological well-being after periods of PMDD symptom expression.

As shown above, participants self-esteem and self-worth were affected by the impact of psychological symptoms associated with their PMDD both pre and post PMDD symptom expression time periods. In addition to participants' self-esteem and self-worth, psychological symptoms were also reported to have a negative impact on participants' self-image.

Participants often used language dissociating themselves from the person they were when they experienced their PMDD symptoms. This resulted from participants finding it difficult to accept their PMDD-selves. As a result, participants reported that they had to separate their "normal selves" from their "PMDD selves" to cope with their symptoms. Additionally, destructive behaviour caused as a result of participants PMDD symptoms was reported to be one of the main reasons for using dissociating language. However, some participants stated that this mild dissociation often led to feelings of confusion and emotional distress. This is illustrated in the quote below by Lucy, a 41-year-old Project Leader from Sweden.

*"For me it's like feeling alien in yourself. Like, you know, it's like you're wearing someone else's skin for a couple of days a weeks because it doesn't feel like you anymore. [...] Nowadays it's like it isn't me, but it's still part of my personality because I don't know what I would be like without it. I don't know. It's a hard question."*

In the quote, Lucy responded to a question inquiring about how her PMDD symptoms affected her self-image and self-esteem. Lucy described feeling overwhelmed by her PMDD symptoms and made a distinction between herself during periods when she experienced her PMDD symptoms and when she did not. Moreover, the term "alien" may have been used to separate herself from her PMDD symptoms by describing her symptoms as a foreign entity to herself. Lucy described the experience of her PMDD symptoms as "wearing someone else's skin" which may illustrate the mild form of dissociation reported by other participants in this study. From Lucy's description, it may be deduced that her PMDD symptoms negatively impacted on her psychological well-being and self-image.

Participants who described their PMDD as an entity foreign to themselves were more likely to be self-critical when experiencing PMDD symptoms than participants who did not. One of the potential indicators to differentiate between participants who were more critical from those who were not was the language used to describe themselves within the context of experiencing PMDD symptoms. This is evident in the following quote by Anna:

*“So it's like, did you become a \*\*\*\*\* [bad person]. You know, you become this evil person, your alter-ego. [...]it's a monster that's coming out from you. And you cannot control it. Like I feel like you need to train that monster, in order to survive.”*

In the quote, Anna created a separation between herself and who she was when experiencing her PMDD symptoms. Similar to Lucy's experience of PMDD, this quote illustrates a mild form of dissociation. Anna described herself as having an “alter-ego” when experiencing her PMDD symptoms and described her PMDD as “that monster” which may showcase the lack of control she felt over her PMDD symptoms and fear for that lack of control. Additionally, Anna labelling her PMDD symptoms as “the monster” could indicate her feelings of powerlessness towards her PMDD symptoms. Anna's description of her PMDD is a powerful description of how her symptoms impacted on her self-image.

Women in this study often used dissociative language when describing themselves during periods of PMDD symptom expression. Dissociative language was used as linguistic separation between participants and who they were when experiencing PMDD symptoms because of the negative impact their PMDD symptoms had on participants' self-esteem, self-worth and overall psychological well-being. Research assessing PMDD, endometriosis and PMS reported similar findings (Cole et al., 2021; Osborn et al., 2020; Ussher & Perz, 2020).

In a study conducted by Osborn et al., (2020), women with diagnosed PMDD used dissociative language when describing the psychological changes that took places at the beginning of PMDD symptom expression. In addition, Osborn et al., (2020) stated terms such

as “alter-ego” and “monster” were highlighted as being used by participants when describing themselves during times of PMDD symptom expression. These findings are similar to those of this thesis as women used the same adjectives when describing themselves during times of PMDD symptom expression.

Ussher and Perz (2020), illustrated how women with self-identified PMS used language describing their premenstrual bodies as separate from themselves when experiencing physical symptoms related to their PMS. Moreover, women positioned their premenstrual bodies as the cause of their psychological and premenstrual distress when experiencing PMS. Although Usher & Perez (2020) focused primarily on how women used dissociative language because of their physical PMS symptoms, women’s construction of their premenstrual bodies as separate entities relates to how women of this thesis used dissociative language when describing themselves during times of PMDD symptom expression. Similarly, Cole et al., (2021) reported that endometriosis negatively impacted on women’s body image and gender identity. Women stated that they felt unfamiliar to themselves as a result of their endometriosis for reasons such as infertility and changes in physical appearance and bodily functions (Cole et al., 2021). Their findings relate to this thesis as women reported that endometriosis impacted negatively on their physical body and emotionally, regarding how they felt about their body. This is similar to the findings of this study as participants reported that PMDD negatively impacted on the way they felt about their bodies.

This theme explored how participant’s PMDD symptoms often led to them having a negative sense of self. As a result of this, participants negatively labelled their PMDD. This is discussed in the following sub-theme “PMDD – Abused or abuser”.



#### 4.4.3 PMDD – Abused or Abuser

As discussed in the above sub-theme, participants often made a distinction between themselves and who they were when experiencing their PMDD symptoms. Participants' descriptions of their experience with PMDD often carried a harmful tone. This occurred as their behaviour, which resulted from PMDD symptoms during periods of PMDD symptom expression, was often characterised as destructive. The destructive behaviour was described as a result of PMDD symptoms because of two reasons namely; how PMDD made participants treat themselves and how PMDD made them treat other people. This sub-theme explores the personification of PMDD as participants' abusers and participants as the abusers themselves.

The relationship between participants and their PMDD was often described as damaging. Moreover, the negative impact of PMDD symptoms on participants' HRQoL resulted in participants having a negative relationship with their PMDD symptoms. Participants often reported dreading experiencing their PMDD symptoms. Anticipation caused by this dread often triggered an emotional distress response for participants when they were not experiencing PMDD symptoms. This is demonstrated in the following quote by Anna a forty-two-year-old business analyst from Romania.

*"I actually live with my aggressor every month. It's like every month somebody comes and kicks you. Sometimes it beats the \*\*\*\* out of you and it puts you into hospital. It's like it's that bad. Sometimes it just gives you some bruises. Sometimes it just gives you a slap and you hurt and you get over it. And that's why I think the suicidal thoughts come through. Because you don't see a way out, it always, always comes back. You know that everything that you build in two weeks gets destroyed like a sandcastle in the next two weeks and you feel like you can grow anything, like a business, like a child, like a pet, like anything. Because in two weeks you flip and you're somebody else and you don't believe in yourself anymore."*

The personification of Anna's PMDD symptoms as an "aggressor" can be interpreted as her feeling trapped within a distressing and abusive cycle of being physically and

emotionally acted upon by her symptoms. Similar to the power dynamics in an abusive relationship (Walker, 1979), the PMDD is in control which seems mimic the cycle of violence in abusive relationships. The cycle of violence normally begins with a honeymoon phase when things are good, then the tension starts building and eventually there is the expression of violence. This parallels the PMDD cycle. The honeymoon phase can be seen as the time period where women are not experiencing PMDD symptoms, the tension build-up is the week before women experience their PMDD symptoms and the expression of violence occurs when PMDD symptoms are experienced. The quote illustrates the impact Anna's PMDD symptoms had on her ability to function optimally while she is experiencing her symptoms.

Five out of the twenty-seven participants interviewed for this study reported participating in some form of self-harm. Forms of self-harm reported were participants cutting themselves on various places on their body, hitting themselves, banging their heads against a surface and pulling their hair. These were reported to be done with the intention to inflict harm on their bodies. Majority of participants who participated in self-harm stated that their self-harm occurred before their diagnosis. This may demonstrate the importance of a PMDD diagnosis as participants who participated in self-harm reported stopping after receiving their diagnosis. Moreover, upon self-reflection after being diagnosed with PMDD, these participants attributed their self-harm behaviours to their PMDD symptoms, further showing the negative impact PMDD symptoms had on participants' psychological well-being. Courtney, a 21-year-old videographer from United States of America, describes how she self-harmed as a coping mechanism. It is important to note Courtney self-harmed after her diagnosis with PMDD.

*"But then before I was talking with her [spiritual support person] I would self-harm. I just thought that I need to express, you know, like that was a good point for me. Like I said, cutting myself in a way distracts my mind enough that my thoughts aren't that bad. [...] Yes,*

*it was after my diagnosis. [...] And I would like hit myself, but I never cut myself. [...] Not just like hitting myself, yeah. I don't really know how to describe it, just like hit my leg or something. I'd be like oh I'm the worst."*

In the above quote, Courtney described that she participated in self-harm as a coping mechanism in order to deal with her PMDD symptoms. The physical pain Courtney experienced when participating in self-harm may have given her relief from the negative impact her symptoms had on her psychological well-being. Moreover, Courtney reported feeling more self-critical and an increase in negative thoughts associated with times of PMDD symptom expression. An example of the negative self-talk is when Courtney stated "I'd be like oh I'm the worst", which could illustrate Courtney's negative self-talk during times of PMDD symptom expression. Courtney's self-harm behaviour can be interpreted as a physical act of abuse on her body as a result of her PMDD symptoms.

Participants were often self-critical and expressed feelings of guilt when assessing the impact of their PMDD symptoms on their interpersonal relationships. Rachel, a 27-year-old Environmental scientist from United States of America, labelled herself as an abuser when experiencing her PMDD symptoms.

*"I need to be apart [from my partner] or I'm going to harm our relationship [...] I feel like an abuser sometimes ... It's hard to not. [...] You feel like a different person on PMDD you feel. Someone else's inside of your brain, making all the decisions. And then there's still this part of me watching in the back watching it happen and just screaming like not to do it. And I still make decisions. I would never if I was in my right mind. And it makes me feel like a horrible person watching myself. Not be, not just like, not be there for someone I love, but even being cruel and harmful."*

I interpret Rachel's description of herself as an abuser as her feeling guilty about her actions towards her fiancé during times of PMDD symptom expression. Additionally, it can be seen in the quote that Rachel felt shame when reflecting on her PMDD symptoms because of the negative impact her actions had on her romantic relationship. Moreover, Rachel also

described having a lack of control over herself during times of PMDD symptom expression. In fact, it may appear as though she was controlled by the PMDD. This quote may illustrate the mild dissociation some participants reported on when affected by their PMDD symptoms.

As discussed in “The PMDD Monster”, women of this thesis personified their PMDD in order to describe it as an entity outside of themselves, one which they did not have control over. Women’s health research shows evidence of women personifying disorders in order to create a separation between themselves and their disorders (PMDD and PMS) as a result of the disorders negative impact on women’s psychological well-being (Osborn et al., 2020; Ussher & Perz, 2020). According to Osborn et al., (2020, p. 5) women with PMDD described the impact of PMDD on their psychological well-being by using words such as “monster” and “alter ego”. Additionally, participants reported that, upon experiencing their PMDD symptoms, they felt as though they changed into someone they did not recognize which prompted women to use personifying language when describing their PMDD symptoms (Osborn et al., 2020). Similarly, Ussher and Perz (2020), reported on how women used personifying language to separate between themselves and their premenstrual bodies. Women personified their premenstrual bodies as though they were being acted upon by their premenstrual symptoms, illustrating the negative impact their PMS symptoms had on their psychological well-being (Ussher & Perz, 2020). These findings are similar to those described by women in this thesis.

One of the most severe personifications of PMDD were participants’ connection between living with PMDD and an abusive relationship. Participants in this thesis made a connection between the power dynamics of an abusive relationship and how PMDD impacted on their psychological well-being, often labelling the PMDD as an “aggressor” and participant’s themselves as an “abuser”. More specifically, women in this thesis described their experiences with PMDD in two distinct ways namely; (1) women as the abuser as they

inflicted violence on others as a result of their PMDD and (2) PMDD as the aggressor and women with PMDD as the victims of said aggressor. Self-harm was represented as physical violence on participants' bodies as a result of their PMDD symptoms. Self-harm was not noted in current women's health research as a maladaptive coping mechanism. These are novel findings and therefore I did not find research discussing PMDD or personifications of disorders in this manner.

As a result of the negative impact of participants PMDD symptoms on their psychological well-being, some participants reported experiencing suicidal ideation and participating in self-harm. This will be discussed in the following theme "Suicidal ideation".

#### **4.4.4 Suicidal Ideation**

Suicidal ideation manifested in participants contemplating suicide, participating in self-harm and expressing a disinterest in living. A total of 13 participants reported symptoms associated with suicidal ideation as a result of their PMDD. It is important to note that no participant reported appeared to be a danger to themselves during the interview or reported needing therapeutic support after the interview. Participants were not expressly asked about suicidal ideation but rather reported it when asked about their PMDD symptoms. Participants who reported experiencing suicidal ideation attributed this to the negative impact their PMDD symptoms had on their HRQoL. In addition, Participants who stated that they experienced suicidal ideation reported that these symptoms left them debilitated and often unable to fulfil necessary daily tasks. An example of this is shown in the following quote by Kayla, a mother of three from United States of America.

*"... there was a period umm right before the pandemic started where I was basically suicidal daily I was. I was just I could not. I couldn't tolerate life. I was always crying. [...] I almost I hate to say it, but I almost can't describe it to you because it was so bad."*

In the quote, Kayla described how before the Covid-19 pandemic, she experienced severe suicidal ideation because of her PMDD symptoms. Kayla reported symptoms of weepiness, an inability to function optimally while experiencing her PMDD symptoms and hopelessness. The phrase “I couldn’t tolerate life” can be interpreted as Kayla describing how her PMDD symptoms overwhelmed her and negatively impacted on her psychological well-being and cognitive functioning. Later on in the interview, Kayla described contemplating admittance into an inpatient program because of her poor state of mental health as a result of her suicidal ideation, demonstrating the severity of the impact of Kayla’s PMDD symptoms on her HRQoL.

Majority of the participants in this study reported that the burden PMDD symptoms had on their HRQoL led them to experience self-deprecating thoughts, weepiness and feelings of hopelessness. Moreover, when experiencing PMDD symptoms participants reported an increase in paranoia, negative self-talk, being obsessive, acts of self-harm (discussed in the sub-theme “PMDD – Abused or Abuser”) and suicidal ideation. Participants reported their PMDD symptoms affected their behaviour by having a negative impact on how they understood their reality. The following quote by Freja, a 47-year-old copywriter from Denmark, demonstrates that she did not want to commit suicide however the feelings of hopelessness and self-deprecating thoughts she experienced as a result of her PMDD symptoms led to her suicidal ideation.

*“But before that [diagnosis] I was just like, what is going on with me because my intrusive thoughts were about...Not good enough. If this is the way I have to feel, I might as well not be here. I didn't wanna commit suicide, but the thought was there. I knew as well. I didn't wanna kill myself, but I just felt so hopeless.”*

Similarly, Courtney, a 21-year-old videographer from United States of America, expressed a similar sentiment as Freja when asked about her suicidal ideation. Freja and

Courtney both reported experiencing suicidal ideation but did not want to actively commit suicide.

*“Then I’ve definitely had some self-deprecating thoughts. I’ve never like, actively tried suicide, previously, but there’s been times that I would have thoughts of like I wish I wasn’t alive. Though never thoughts about how I would kill myself, but I’ve definitely had those.”*

In the quote above, Courtney explained how her self-deprecating thoughts, which she reported to be a symptom of her PMDD, led to her experiencing suicidal ideation. Courtney also explained how she began to internalize her intrusive thoughts of self-deprecation, which led her to further feelings of hopelessness. Additionally, suicidal ideation may have occurred as a result of the impact of intrusive thoughts on Courtney’s self-esteem. Furthermore, this quote demonstrates the negative impact of PMDD symptoms on Courtney’s psychological well-being and overall HRQoL. Courtney’s experience of suicidal ideation led to a diminished interest in self-preservation. The impact of PMDD on interpersonal relationships is explored further in the following theme “The role of self-awareness”.

Women of this thesis reported participating in self-harm, experiencing suicidal ideation and anhedonia as a result of their PMDD symptoms. In addition, women of this thesis reported their PMDD symptom left them feeling debilitated and unable to fulfil necessary daily tasks. In a study conducted by Chan et al., (2023), most of the participants (n=32) reported suicidal ideation as a PMDD symptom they experienced while a smaller number of participants reported suicide attempts because of worsening PMDD symptoms. However, Chan et al., (2023) did not report any participants engaging in self-harm, which women of this thesis stated doing as a result of the impact of their PMDD symptoms on their psychological well-being. I was not able to find research discussing maladaptive coping or self-harm in relation to PMDD. In A study conducted by Bansal et al., (2023) it was found that less than 60% of women who met the criteria for PMDD reported anhedonia type

symptoms during their late luteal phase. The impact of said symptoms on women's HRQoL were not reported on in Chan et al., (2023) and Bansal et al., (2023).

For some participants of this study, self-harm practices were reported to be a form of maladaptive coping during times of PMDD symptom expression. Moreover, the burden of women's PMDD symptoms led to self-deprecating thoughts, weepiness and feelings of hopelessness. These findings are similar to those found in qualitative PMDD research (Osborn et al., 2020). Osborn et al., (2020), reported in their study that women reported feelings of hopelessness and weepiness during times of PMDD symptom expression. Maladaptive coping strategies were not addressed in their study, however, women expressed attempting to find coping mechanisms because of distressing experiences related to their PMDD. These coping strategies were not elaborated on.

#### ***4.4.5 The role of self-awareness***

Participants often reported that having knowledge and awareness of their PMDD symptoms and the impact it had on their HRQoL played an integral role in the management and acceptance of the disorder. This understanding often came from the knowledge gained by being diagnosed with PMDD. A PMDD diagnosis offered participants the opportunity to inquire by their healthcare practitioners for more information on PMDD and research about the disorder. Participants reported that receiving a PMDD diagnosis was empowering as this knowledge allowed participants to be self-aware during periods of PMDD symptom expression. Moreover, a PMDD diagnosis offered women control over how they experienced their PMDD symptoms and therefore PMDD was reported to have had less control over them. As a result, a PMDD diagnosis was reported to be the main motivator for many participants' self-awareness during time periods of experiencing PMDD symptoms.



Self-awareness was reported by many participants to be liberating and an asset to their ability to combat the effects of their PMDD symptoms during times of PMDD symptom expression. Participants who reported that their self-awareness supported them during times of PMDD symptom expression were able to make a separation between themselves and their PMDD symptoms without experiencing distress. It is important to note that this occurred as a result of participants receiving their PMDD diagnosis. Additionally, cycle tracking was also noted to be an important method used by participants to prepare for their time period where PMDD symptoms were experienced. In the quote below Shahara, a 27-year-old Engineer from South Africa, describes how understanding her cycle gave her agency over her distress associated with experiencing her PMDD symptoms. Shahara also used cycle tracking to predict when she will be experiencing her PMDD symptoms.

*“... if I’m having like a very bad episode, like this month or if I’m having, getting like within like seven days before my period or like five days and I find that I’m getting moody, I feel like how I used to, then I go to my calendar and I see OK fine, I’m in that period of time where I am experiencing this so I don’t feel like oh no, it’s me. I’m the problem. My personality is a problem. But it’s like OK fine, this is what’s going on, it’s a chemical imbalance, it’s not my fault.”*

Similarly, Penelope, a 25-year-old mental health consultant in South Africa, described how her PMDD diagnosis allowed her to understand her body and how PMDD affected her. In this quote, Penelope illustrates the control her PMDD diagnosis gave her by describing that she felt more powerful and insightful as a result of the diagnosis. This quote shows how a PMDD diagnosis can provide acceptance of PMDD and lead to a decrease in feelings of overwhelm and hopelessness during PMDD symptom expression. Moreover, Penelope’s description can be interpreted as her being less self-critical of herself when she is experiencing her PMDD symptoms.

*“...and that self-awareness and being able to understand and know that there is an underlying biological explanation to this as well it’s not me just going crazy, there’s a reason*

*why this is happening in my body [...] I feel like I have much more control and like insight into my life you know I haven't taken it as a negative I see it as a positive because to go through these episodes without knowing what is going on, you have no hope or understanding"*

It is important to note that this was not an experience all participants shared and some participants still struggled with their self-image and self-criticism after being diagnosed with PMDD. In addition, some participants stated that their PMDD diagnosis was not helpful as it negatively impacted on their relationships and occupations. These participants narratives will be discussed in the theme "PMDD and Relationships".

A tool majority of participants of this study reported using as a positive coping mechanism and as a tool for receiving a PMDD diagnosis was cycle tracking. Cycle tracking has been noted in current PMDD research as a coping mechanism and facilitator in receiving a PMDD diagnosis (Hantsoo et al., 2022; Osborn et al., 2020). Cycle or symptom tracking can be described as women documenting the prevalence and severity of premenstrual symptoms during their late luteal (American Psychiatric Association, 2013; Osborn et al., 2020). In addition, for majority of the women of this study, a PMDD diagnosis facilitated in a deeper understanding of themselves, allowing them to better create a separation between who they were when experiencing PMDD symptoms and when they were not.

Current women's health research has showed that a diagnosis and knowledge regarding their disorder often had a positive impact on the QoL of the women receiving their diagnosis (Ismayilova & Yaya, 2023; Osborn et al., 2020). According to Osborn et al., (2020), women who received a PMDD diagnosis felt relief at having an answer for their symptoms in the form of a diagnosis and having their experiences acknowledged. Conversely, Ismayilova & Yaya (2023), stated women who received a PCOS diagnosis at an early stage were not supported as a result of lack of practitioner knowledge on PCOS.

However, women stated that knowledge and self-education about PCOS facilitated in their management of the disorder (Ismayilova & Yaya, 2023). In addition, endometriosis research has demonstrated that the absence of a diagnosis negatively impacted on women's HRQoL and that upon receiving a diagnosis, women felt relief (Cole et al., 2021a; Rea et al., 2020). These findings are similar to that of this study as women stated knowledge and self-awareness as a result of their PMDD diagnosis allowed them to gain a deeper understanding of themselves and led to them feeling relieved. Furthermore, women of this study reported that after receiving their PMDD diagnosis they were able to properly separate themselves from who they were when experiencing their PMDD symptoms which positively impacted on their psychological well-being and coping during times of PMDD symptom expression.

#### **4.4.6 PMDD anger and rage**

Anger and rage were two common psychological symptoms participants associated with their PMDD. These symptoms have been grouped together in this sub-theme as they affected participants' interpersonal relationships in the same manner. Participants differentiated between 'normal' anger and PMDD anger and rage by explaining the physical effect this symptom had on their bodies. Most participants who described experiencing anger and rage as psychological symptoms of PMDD also attributed these symptoms to an increase in irritability, mood swings, impatience and sensitivity to rejection or criticism. Furthermore, participants reported that PMDD anger and rage negatively affected their psychological well-being because of how it adversely affected their interpersonal relationships. This is demonstrated in the following quote by Kathleen, a 31-year-old student and catering assistant from the United Kingdom.

*"[...] but I felt a lot of rage and a lot of irritability and then obviously feeling that way, potentially being snappy and short with people, you feel guilty for that. [...] I would, you know, feel the rage building up inside me. It would be like this firing thing and probably, like, clench my teeth. So yeah, I wish I could laugh, but at the time it was quite difficult."*

In this quote, Kathleen described her body's physical response to her PMDD anger and rage. Kathleen described previously in the interview that she experienced an increase in irritability and being more susceptible to acting on her anger during her PMDD symptom expression time period. Additionally, Kathleen acknowledged the impact of her symptoms on both herself and the people around her. This may express a level of self-awareness regarding the impact of her symptoms on those she is in contact with during times of PMDD symptom expression. As a result, Kathleen reported feeling guilty and confessed to how hard it was for her to manage her symptoms and to deal with the reality of her symptoms consequences, being that she often engaged in conflict with her partner during times of PMDD symptom expression. This quote illustrated the negative impact PMDD anger and rage may have on participants' psychological well-being as a result of the destructive way it could affect their interpersonal relationships.

Similarly, Rachel illustrated how her PMDD anger and rage symptoms led to her experiencing suicidal ideation which may illustrate the severe impact PMDD anger and rage could have on women's psychological well-being.

*"...primary symptom, mine was rage. [...] Horrible rage. Anger. Anxiety. Suicidal ideation. So consuming. I was seeing things. Like I said, I'd have vivid daydreams where I was living through hurting myself. I would get so angry. I talked to my partner about feeling like rage in my forearms, like I could physically feel it in my blood, and I all I wanted. Sorry, it's might be pretty triggering. All I wanted to do was just cut my arms open and like just watch my blood like and I could see it. I would close my eyes and I would do it to myself in my head. [...] one is more prominent and mine is anger and irritability and sensitivity to rejection. Really bad that plays into romantic relationships, of course."*

Rachel described that her "primary symptom" was PMDD anger and rage. In this quote, Rachel illustrated physically "feeling like rage in my forearms", which is similar to Kathleen's representation of how her rage physically manifested. As a result, Rachel

illustrated that she often ruminated on self-harm, which may be interpreted as a coping mechanism she used to manage her PMDD anger and rage. This quote is a graphic description of the possible effects of PMDD anger and rage on participants' psychological functioning, potentially leading to suicidal ideation, rumination and self-harm. Furthermore, Rachel reported at the end of the quote that her "anger and irritability and sensitivity to rejection" impacted most notably on her romantic relationship.

Women of this study reported that anger and rage were symptoms of their PMDD that significantly impacted on their psychological well-being because of how it negatively impacted on their relationships. Anger and rage symptoms were reported to lead to an increase in interpersonal relationship conflicts during times of PMDD symptom expression. Studies describing anger and rage symptoms in women's health literature are limited and therefore only prevalence of anger and rage symptoms (Bansal et al., 2023) and PMDD research (Osborn et al., 2020) will be discussed.

The impact of women's anger and rage symptoms were only realized post-PMDD-episode as participants reported being more able to understand the consequences and impact of their symptoms after they experienced their symptoms. Osborn et al., (2020), reported similar findings in their study as participants reported reacting disproportionately to stimuli during times of PMDD symptom expression as a result of anger, rage, and anxiety symptoms. This resulted in an increase in interpersonal relationship conflicts during times of PMDD symptom expression. However, the manner in which this increase in relationship conflict impacted on participants psychological well-being was not reported on by Osborn et al., (2020).

According to Bansal et al., (2023), anger and irritability was the second most common symptom reported by women who met the diagnostic criteria for PMDD, which indicates the

prevalence of the symptom. Understanding that anger and rage have a high prevalence for women who meet the diagnostic criteria for PMDD allows us to recognize that these symptoms are frequently experienced. This reflects findings similar to those of this study as most of the participants who reported conflicts in their relationships attributed it to their PMDD anger and rage symptoms.

As stated above, PMDD anger and rage were also attributed to other PMDD symptoms such as sensitivity to rejection and criticism. This symptom was often reported to impact on participants' occupational relationships and responsibilities. This will be discussed further in the following theme, "Interpersonal Relationships affected by PMDD".

#### **4.5 Interpersonal Relationships affected by PMDD**

All participants reported that their PMDD symptoms affected their interpersonal relationships, a dimension of HRQoL. Romantic, occupational, social and familial relationships were reported to all be affected by participants' PMDD symptoms. Additionally, the manner in which participants PMDD symptoms affected their relationships were reported to negatively affect their psychological well-being, causing self-isolating behaviours and overall emotional distress. This theme explores participants' accounts of how their PMDD symptoms affected their interpersonal relationships and the impact of this on their psychological well-being. This theme consists of several sub-themes: (1) PMDD's Impact on Employment (*PMDD symptoms lead to job loss*); (2) Romantic Relationships and PMDD (*PMDD Anger and Rage* and *PMDD's; Impact on my Partner*) and (3) Familial and Social Support and Understanding (*Mom Guilt*).

##### **4.5.1 PMDD's impact on employment**

Twenty four participants reported being employed at the time of their interview. These participants reported that their PMDD symptoms negatively affected their occupational

functioning. Symptoms reported to impact on occupational areas of HRQoL were increased irritability, PMDD anger and rage, sensitivity to rejection or criticism, fatigue, brain fog and anxiety and depressive symptoms. Employed participants reported that their PMDD symptoms negatively affected their ability to work, leading to difficulty meeting occupational deadlines and negatively affecting the quality of work produced during times of PMDD symptom expression. Additionally, some participants reported an increase in absenteeism from work during times of PMDD symptom expression. An example of this is demonstrated in the following quote by Morgan:

*“I usually feel when I'm actually taking the time off [from work], I feel guilty. Very guilty. When I'm actually taking time off. Like, if I can't do a presentation or, you know [...] And so it depends on how I'm working where I'm working and how big of a cog I am in the project sort of thing and but yeah, I do realize that I do need to take the time off and it makes me sad I think that I've lost all of that time to PMDD like I've lost a lot of my career to PMDD like, and that makes me really sad”*

In this quote, Morgan explained how she felt guilty as a result of not being able to fulfil her occupational responsibilities during times of PMDD symptom expression. At the end of the quote, Morgan illustrated how remorseful she was at the impact of her PMDD symptoms on her career path and how she's lost career opportunities to her struggle with PMDD. This quote may demonstrate the severe negative impact PMDD symptoms have on ability to cope with occupational responsibilities and the potential negative long-term effects PMDD symptoms may have on women's career trajectory. Similarly, Abigail, a 45-year-old tourism administrator from Canada, described how after she received her PMDD diagnosis, she felt confident enough to discuss the impact of her PMDD symptoms on her occupational responsibilities with her work bosses and colleagues.

*“I was able to talk to my bosses and my colleagues and say, there's certain times in the month that I'm not right, and I can't do certain things. I'm quite functional, I can still work, but certain things, I can't do. So if I'm writing, I have to write a big proposal, I can get it*

*down in bullet points what I need to get across, but putting the flowery prose on it and writing it to a level that I would normally be happy with, I couldn't do. And it took me a while to get to that point of struggling for days to try like, why can't I? And I finally realized that I just cognitively can't put those words together right now"*

It may also be interpreted from Abigail's quote that her bosses and colleagues supported her with her struggles with PMDD which may have made it easier for Abigail to communicate her constraints during the time of PMDD symptom expression. Abigail also described how, during PMDD symptom expression, she struggled with concentration which made it difficult for her to appropriately communicate necessary information to her colleagues. This quote may also demonstrate the importance of a supportive and understanding workplace environment for women who have PMDD symptoms that impact on their occupational responsibilities.

Participants reported that a supportive work environment positively influenced their ability to cope with their PMDD symptoms during times of PMDD symptom expression. Participants reported feeling less guilt regarding absenteeism associated with PMDD symptoms when they were positively supported by their workplace colleagues and bosses. An example of this is illustrated in the quote below by Penelope, 25-year-old a mental health professional from South Africa. In this quote, Penelope explained how valuable her workplace support was in managing her symptoms and occupational responsibilities during times of PMDD symptom expression:

*"I will get a lot more anxiety around that time of the month and that will affect work. And my energy levels like I don't have that much motivation during that time but the company that I work for and the relationship with my boss he's incredibly supportive and he knows all about my struggle with PMDD. So much so that he also decided to make period leave available for all the women in the company uhm if they need it. So he realized you know how it can affect [work responsibilities]."*



Participants reported that their PMDD symptoms impacted so negatively on their occupational responsibilities that it resulted in job loss. This is explored further in the following section “PMDD symptoms led to job loss”.

**4.5.1.1 PMDD symptoms led to job loss.** Some participants reported that their workplaces were not supportive or understanding of their PMDD symptoms and diagnosis. Five participants reported losing their jobs as a result of their PMDD symptoms. Participants reported different reasons for their dismissal such as feeling as though they were discriminated against for their PMDD symptoms and acting out as a result of their PMDD symptoms. Moreover, some participants stated that their PMDD diagnosis and symptoms was not understood by their superiors, resulting in a break in communication leading to occupational conflicts. In the quote below Grace, a 42-year-old marketing director from United States of America explained how she was fired from her job as a result of her PMDD. Grace stated that her mental health practitioner suggested she apply for short-term disability leave because of the extent to which her PMDD symptoms impacted her psychological well-being. Grace was the only participant of this study to state that her PMDD diagnosis did not have a positive impact on her life because she felt that the diagnosis led her to job insecurity.

*“I was working an extra, crazy amount of hours. So I started to prioritize my life. Like my boss didn't take it well. [...] So it was difficult. I mean, in the end, I had to make some of the, you know, conversations but it's not easy to have it with your male boss, like explaining to him like what the disorder is. So what happened was, that was in November, December. And during that time, the company neither accepted my FMLA [short-term disability], nor my short-term disability. And they ended up firing me in February.”*

For some participants, the negative impact of their PMDD symptoms on their ability to fulfil their occupational duties led them to resigning from their jobs. Catherine, a 44-year-old part-time teacher, reported that she had to step down from her teaching position as a result of her PMDD symptoms impact on her ability to fulfil her occupational responsibilities.

*“It’s [PMDD] just such a big impact on my life like workwise. I stepped down from teaching. I was only doing it three days a week, teaching at the time because I’d had that my children. [...] before I was diagnosed, I did take six months leave like I took long service leave, cause thought maybe it was depression. Maybe I, you know, maybe I’m having burnout. I just need a break kind of thing. Uhm but obviously the [PMDD] symptoms were still there [...] I didn’t think till I started getting into playgroups and then having the same problem like I was still missing days of work”*

Catherine’s case of job loss is different to Grace’s in that Catherine chose to step down from her teaching position. However, this quote still relates to loss of occupation as a result of PMDD symptoms. In the quote, Catherine explained how her PMDD symptoms unknowingly impacted on her ability to work. Catherine described how her PMDD symptoms felt similar to burnout and depression and resulted in her being unable to cope with occupational responsibilities, such as participating in playgroups, and absenteeism from work. After her PMDD diagnosis, Catherine advocated for and received a bilateral oophorectomy, removal of both ovaries, as treatment for her PMDD symptoms.

Participants in this study reported that their PMDD symptoms negatively impacted on their occupational responsibilities. PMDD symptoms that impacted negatively on participants occupational responsibilities were increased irritability, PMDD anger and rage, sensitivity to rejection or criticism, fatigue, brain fog and anxiety and depressive symptoms. Moreover, these symptoms were reported to lead to higher rates of occupational conflicts, absenteeism and an inability to fulfil occupational responsibilities during times of PMDD symptom expression. Similar findings were discovered in current PMDD and PMS research (Hardy & Hardie, 2017; Park et al., 2023; Pekçetin et al., 2022).

Both physical and psychological symptoms associated with PMS and PMDD were reported by women to negatively impact on their occupational responsibilities and work relationships (Hardy & Hardie, 2017; Park et al., 2023; Pekçetin et al., 2022). According to Park et al., (2023), women with self-identified PMS reported that emotional dysregulation,

lack of motivation and fatigue were symptoms which caused occupational disturbances. Additionally, Pekçetin et al., (2022) found that women with PMDD experienced more occupational disturbances during times of PMDD symptom expression when compared to women without PMDD. These findings are similar to those of this thesis as women reported emotional dysregulation, manifesting in anger, sensitivity to rejection and irritability, negatively impacted on their ability to fulfil their occupational responsibilities.

Hardy & Hardie, (2017) found that women diagnosed with PMDD experienced mood related outbursts, which increased work related conflicts during times of PMDD symptom expression. In addition, women reported feelings of guilt post-PMDD-episode as a result of their inappropriate behaviour towards colleagues and inability to fulfil occupational responsibilities during times of PMDD symptom expression (Hardy & Hardie, 2017). Post-PMDD-episode guilt was related to overcompensating in the workplace, resulting in further distress (Hardy & Hardie, 2017). Women in this study did not report to overcompensate in the workplace post-PMDD-episode however, women reported feelings of guilt similar to those described in Hardy & Hardie (2017).

As a result of women's emotional dysregulation and PMDD physical symptoms, women in this study reported job loss in the form of voluntarily resigning and being fired from their occupations. Participants reported voluntarily resigning as they could not optimally fulfil occupational responsibilities. These findings are similar to that found in Hardy & Hardie, (2017) where women reported deciding to leave their occupations as they could not cope with their occupational responsibilities. Some participants reported being asked to leave their jobs and attributed this to possible workplace discrimination (Hardy & Hardie, 2017). This is similar to the findings of this thesis as some women attributed losing their jobs to workplace and mental-health discrimination because of their PMDD diagnosis.

#### 4.5.2 Romantic relationships and PMDD

Participants in this study who were in romantic relationships at the time of their interview reported that their PMDD symptoms negatively affected these relationships. Participants reported an increase in romantic relationship conflict as a result of their PMDD symptoms. PMDD symptoms such as increased irritability, rumination, intrusive thoughts, depressive symptoms and PMDD anger and rage were reported to most contribute to romantic relationship conflict. Moreover, participants reported that these symptoms affected their romantic relationships because their partners formed part of their immediate interpersonal network. An example of this is presented in the quote below by Penelope:

*“I find myself in that [PMDD episode] time, I become very unaffectionate, I withdraw completely, uhm yeah I don’t want affection I don’t want to be touched, I don’t want to be hugged, I just want to be left alone, I can become very irritable, I become quite passive aggressive or actually just pretty angry in general, so like lose patience completely. [...] I’d start to feel anxiety and then I’d start to like question the relationship. I feel so shi\*t, I feel horrible and I think I want to try and find a reason for why I am feeling so horrible and I think obviously, the first thing is either work is making me feel sh\*tty or my relationship is making me feel sh\*tty. And I tend to go through these like episodes of complete doubt like am I doing the right thing? Am I with the right person? I don’t know if this is right for me.”*

In the quote, Penelope described the PMDD symptoms which she felt most impacted on her interpersonal relationships and her romantic relationship. In the first sentence of this quote, Penelope described feeling “unaffectionate” and not wanting to be touched, which may relate to a decreased interest in sexual intimacy during times of PMDD symptom expression. Also, Penelope stated experiencing symptoms relating to PMDD anger and rage by becoming quite “passive aggressive” and “pretty angry” while experiencing her PMDD symptoms which could lead to an increase in interpersonal relationship conflict during times of PMDD symptom expression. Penelope described how her anxiety, which she related to her PMDD symptoms, often led to her questioning her romantic relationship and her partner which she later reported led to an increase in interpersonal relationship conflict during times of PMDD

symptom expression. Additionally, Penelope described how she often directed her frustrations and feelings of confusion toward her boyfriend. Penelope described experiencing these symptoms as “episodes” which may exemplify that these feelings were felt during every PMDD episode. This could relate back to and further demonstrate the “cycle of violence” discussed in the sub-theme “PMDD –Abused or Abuser”.

In addition to an increase in interpersonal relationship conflicts, some participants reported a decrease in sexual libido, which also negatively impacted their romantic relationships. Participants reported that not wanting to be touched, low self-esteem and an overall disinterest in intimacy were the main contributing factors to a decrease in sexual libido during times of PMDD symptom expression. An example of this is illustrated in the following quote by Kathleen, a 31-year-old catering assistant from Scotland.

*“So it affects my sex life as in, it becomes non-existent, and I don't want to be seen. I don't want to even see myself. It affects how much I would shower, you know, like I wouldn't even want to see myself. I wouldn't look after myself in that way. And so yeah, it affected like a physical relationship, as well as, an emotional relationship because I would just be irritated by him. So yeah, and obviously we wouldn't go out anywhere or do anything, so then you just start to think, well, what's the point? They'd be better off with somebody else.”*

In this quote Kathleen explained how she found it difficult to be intimate with her partner during times of PMDD symptom expression. Kathleen described how she struggled to take care of her physical health during times of PMDD symptom expression and experienced low self-esteem which contributed to her disinterest in romantic intimacy. Kathleen stated that her feelings of irritation, which she attributed to her PMDD symptoms, further aggravated her relationship with her romantic partner. Kathleen stated thinking “they’d be better off with someone else” which may illustrate Kathleen feeling guilty towards how her PMDD symptoms impacted on her romantic relationship and her partners’ well-being. In addition, this may also indicate low self-esteem on Kathleen’s part. This quote illustrates how

PMDD symptoms impact on women's psychological well-being as well as their romantic relationships.

Some participants reported better romantic partner understanding regarding their severe premenstrual symptoms after they were diagnosed with PMDD. Better romantic partner understanding was linked to the PMDD diagnosis giving necessary information regarding the cause of participants' severe premenstrual symptoms. In addition to a PMDD diagnosis, possible treatment plans and discussion regarding medical interventions were reported to grant relief for both participants and their partners. Participants reported that their romantic partners found comfort in their PMDD diagnosis as conflicts caused during times of PMDD symptom expression were understood to be from PMDD symptoms and not relationship, romantic partner or participant's behaviour. As result, better partner understanding was reported to cause a decrease in romantic relationship conflicts during times of PMDD symptom expression. This is illustrated in the following quote by Morgan, a 32-year-old User Researcher from the United Kingdom:

*"So essentially just him understanding that it wasn't like it wasn't just my behaviour. I think that was what I main thing. So, him understanding that it was a chemical reaction in my brain that it wasn't just me acting out or misbehaving or like I literally could say like, this is what's happening. I think that helped and him sort of understand that a little bit more, but also that... me sort of being able to say to myself, right, it's the PMDD."*

Similarly, Abigail described that her severe premenstrual symptoms had a negative impact on her marriage prior to her receiving a PMDD diagnosis. Abigail described constant conflicts in her marriage because of an increase in irritability when she experienced her severe premenstrual symptoms. In addition, Abigail reported that prior to receiving her PMDD diagnosis, her severe premenstrual symptoms negatively impacted on her marriage, which led to Abigail and her husband attending marriage counselling. After receiving her PMDD diagnosis, Abigail stated that her husband experienced "relief" and that they both felt

more capable in dealing with her symptoms with the knowledge that came from her PMDD diagnosis. This quote may indicate the positive impact a PMDD diagnosis could have on romantic relationships as it allows for partner understanding during times of PMDD symptom expression.

*“So before the diagnosis, it was rough, right? It was every month, once a week, every month, he's wrong all the time, right? So in my mind, he's the wrong all the time, no matter what he does, it's his fault. So before the diagnosis, like if I'm affected like this, you must have done something to irritate me so, it's you, you, you. So we were going to a marriage counsellor. We were going to marriage therapy because things were so rough. But after the diagnosis, I think he felt some relief too, of just like, OK, so we can deal with this.”*

Many participants described how specific PMDD symptoms most affected their interpersonal relationships during times of PMDD symptom expression. One of such symptoms was PMDD anger and rage. This will be described further in the following section, “PMDD Anger and Rage in romantic relationships”.

**4.5.2.1 PMDD Anger and Rage in romantic relationships.** Participants reported that the manner in which PMDD anger and rage affected their interpersonal relationships negatively affected their psychological well-being. This often came post-PMDD-episode as participants were able to more consciously assess the effects of their symptoms on their interpersonal relationships. An example of this is illustrated in the following quote by Morgan, a 32-year-old User Researcher from the United Kingdom, illustrated how PMDD anger and rage affected her relationship, her romantic partner and her psychological well-being. At the time of the interview, Morgan was in a fourteen year long relationship with her romantic partner and expressed that both her and her partner felt the impact of her symptoms during times of PMDD symptom expression.

*“...but I think the main impact for me is not the low mood, it's more the anger. But the like, the rage because you snap at people and also like there's a bunch of like anxiety. [...] but I think the anger has a bigger impact on my relationships, that anger, and the sort of rage and*

*anxiety because it just has a bigger impact. [...] Whereas when you're anxious and you know you're angry and you've got rage, you take it out another person. So you think that it has a bigger impact. I think on my relationship both at home and at work."*

In the quote, Morgan explained that she believed her PMDD anger and rage symptoms had a significantly negative impact on her romantic relationship. In addition, Morgan's statement "because you snap at people" may be interpreted as there being an increase in interpersonal relationship conflict because of her PMDD anger and rage. Morgan's first sentence may illustrate that she felt her anger had a greater impact on her HRQoL in comparison to her other PMDD symptoms. Morgan stated how she believed her PMDD anger and rage symptoms most affected her romantic relationship and occupational areas of HRQoL.

Many participants reported that one of the most regrettable effects of their PMDD symptoms was the perceived impact of their PMDD symptoms on their romantic partners' psychological well-being. This will be discussed further in the following section "PMDD's impact on my partner".

**4.5.2.2 PMDD's impact on my partner.** Many participants reported on the perceived impact of their PMDD symptoms on their partners' psychological well-being. Some participants reported experiencing feelings of guilt after periods of PMDD symptom expression as a result of this perceived negative impact. With regards to romantic relationships, participants reported often needing to make amends and participate in some form of relationship reconciliation after PMDD symptom expression because of the impact their symptoms had on their romantic relationships and romantic partners. However, these reconciliation efforts were occasionally met with resentment from participants' romantic partners. In the quote below, Kathleen described the impact of her PMDD symptoms after PMDD symptom expression.



*“You know, you feel a bit lighter. You’ll maybe initiate something, but then they are holding on to when you rejected them, so it can still have an impact on the relationship like oh, but when I tried to do that you weren’t interested. How come? I’m never allowed to initiate anything, it’s always you? And then you just feel like, Oh well, I’ll give up then, you know? So even after it when you’re in a better mood, it doesn’t necessarily mean that there’s not damage done there. [...] Because their self-esteem has been affected because you’ve rejected them so many times.”*

Kathleen described that she felt “a bit lighter” after her PMDD symptom expression, which could illustrate the negative impact PMDD symptoms had on her psychological well-being. However, Kathleen recognised the negative impact her PMDD symptoms had on her romantic partner because of her symptoms of low sexual libido and an overall disinterest in romantic intimacy. Additionally, Kathleen’s acknowledgment of the impact her PMDD symptoms had on her partner may indicate the prolonged effects and damage of PMDD symptoms post PMDD symptom expression. This quote illustrated the prolonged impact of PMDD symptoms on participants’ romantic relationships and their romantic partners subsequent to time periods of PMDD symptom expression.

Participants often related their feelings of guilt to self-isolation during times of PMDD symptom expression. Self-isolating behaviours were reported to negatively affect participants’ social and familial relationships. Additionally, participants reported that self-isolation was used as a protective mechanism in preventing relationship conflicts. This will be discussed further in the following sub-theme “Familial and Social Support”

Women in this thesis reported that their PMDD symptoms negatively impacted on their romantic relationships. More specifically, participants reported that during times of PMDD symptom expression they experienced more relationship conflicts than when they were not experiencing their PMDD symptoms. PMDD symptoms participants associated with negatively impacting on their romantic relationships were irritability, rumination, intrusive thoughts, depressive symptoms and PMDD anger and rage. Women’s health research

demonstrates similar findings describing how disorders such as endometriosis and PMDD impacted negatively on intimate partner relationships (Cole et al., 2021; Osborn et al., 2020; Rea et al., 2020).

Studies assessing QoL for women with endometriosis reported on how endometriosis and pelvic pain negatively impacted on sexual activity (Cole et al., 2021; Rea et al., 2020). More specifically, the lack of sexual activity as a result of women's endometriosis and pelvic pain caused distress in women, their romantic relationships and self-consciousness in the caused by a perceived inability to satisfy their partners (Cole et al., 2021; Rea et al., 2020). However, for women in this thesis, a disinterest in sexual intimacy was linked to a disinterest in intimacy and low self-esteem during times of PMDD symptom expression. This disinterest in intimacy and lack of sexual activity was reported to add to romantic partner conflicts and to negatively impact on participant's romantic partners psychological well-being. This is different to findings shown in endometriosis research as the decrease in sexual activity was not as a result of psychological symptoms or a disinterest in sex but rather were attributed to pelvic pain (Cole et al., 2021; Rea et al., 2020). I was unable to find research showing how PMDD caused a disinterest in sexual activity or a decrease in sexual libido during times of PMDD symptom expression.

Women in this study often reported on the perceived impact of their PMDD symptoms on their partners' psychological well-being. According to Osborn et al., (2020), women with diagnosed PMDD reported that their PMDD symptoms negatively impacted on their romantic relationships, leading to a breakdown of the relationship. This is similar to findings of this thesis as women reported their PMDD symptoms often lead to romantic relationships ending or having to attend marriage counselling in order to preserve the marriage. Moreover, women reported feeling guilty and anguish as a result of the impact their PMDD symptoms had on their relationships (Osborn et al., 2020). These findings are similar

to that of this thesis as women often reported feeling remorse towards the perceived impact of their PMDD symptoms on their romantic partners

Women in this study reported that a PMDD diagnosis was vital in developing better partner understanding and protective structures during times of PMDD symptom expression. Moreover, women reported that a PMDD diagnosis allowed their romantic partners to understand their behaviour as resulting from PMDD and not the women themselves. Similar findings are reported in current women's health research where authors described the importance of a diagnosis for better partner understanding and in the development of coping mechanisms when symptoms were being experienced (Cole et al., 2021; Osborn et al., 2020; Rea et al., 2020).

#### **4.5.3 Familial and social relationships**

Many participants reported that their PMDD symptoms affected their familial and social relationships. Similar to the impact of PMDD symptoms on participants' romantic relationships, some participants reported an increase in familial and social relationship conflicts during times of PMDD symptom expression. This was reported to be as a result of participants PMDD symptoms negatively impacting on their relationships, as well as family and friends not understanding what PMDD is. An example of this is illustrated in the quote below by Heather, a 26-year-old student from the United States of America.

*“Well, you know, some days I get a little like agitated and like, you know, one day I'll be really happy, and next week, like, just leave me alone. I guess, with my mom, because me and my mom like bicker a lot. And then because some days I will talk to her and then the next few hours I just, you know, don't want to be bothered with her. [...] She's like, what's wrong with you? I'm like, nothing, you know, but like it just happened so quickly. I didn't know why it was like happening so fast. Yeah.”*

In the quote, Heather described how during times of PMDD symptom expression she and her mom would “bicker” more often. PMDD symptoms described by Heather in this

quote are anxiety and mood swings, as she stated feeling “agitated” and shifting between feeling “really happy” and sociable one moment and after a few hours wanting to not “be bothered”. In addition, Heather also described self-isolating behaviours as a result of her symptoms and how they caused an increase in interpersonal relationship conflicts. Heather stated her mothers’ response to Heather’s changes in behaviour during times of PMDD symptom expression was “what’s wrong with you”, which may indicate a lack of understanding by Heather’s mother towards Heather’s experiences with PMDD. Heather’s mother was aware that she was diagnosed with PMDD. Furthermore, this lack of understanding concerning Heather’s PMDD symptoms by her mother may contribute to interpersonal relationship conflicts during times of PMDD symptom expression.

Some participants reported fearing the impact of their PMDD symptoms on their familial and social relationships. As a result, participants reported self-isolating during times of PMDD symptom expression as a way of protecting their familial and social relationships. Some participants reported to self-isolate to protect these relationships by preventing conflict and confrontation during times of PMDD symptom expression. Moreover, participants feared impacting negatively on the psychological well-being of their loved ones as a reason why they self-isolated during times of PMDD symptom expression. In addition, self-isolating behaviour was reported to be used during times of PMDD symptom expression for fear of how participants would be perceived while experiencing their PMDD symptoms. An example of this is presented in the quote below by Prajna, a 42-year-old content writer from India.

*“Well, now for example, for example, my friends know that, I made it very clear two weeks in the month is going to be something. If I commit to something and I don't end up coming, they know generally that it's, I've cancelled because I'm not well, you know? And I've sat down and explained it to them and they understood it that way. But yeah, it's affected my ability to network. It's affected my ability to have said confidence in myself in terms of... Connecting with people who I I'm not... Close friends with or you know”*

Prajna reported informing her friends when she started experiencing her PMDD symptoms. This could demonstrate a coping mechanism which Prajna implemented in order to protect her social relationships during times of PMDD symptom expression. Additionally, this could illustrate how supportive Prajna's friends were during times of PMDD symptom expression. Prajna described that her PMDD symptoms also affected her confidence, showcasing the affects her symptoms had on her psychological well-being. As a result, Prajna also explained how she was unable to attend social events during times of PMDD symptom expression. Prajna later described that her PMDD symptoms affected her ability to develop connections with individuals which negatively impacted on both her social and occupational relationships.

**4.5.3.1 Mom guilt.** Thirteen participants reported having children at the time of their interview. These participants stated that their PMDD symptoms impacted on their relationship with their children, both during and after times of PMDD symptom expression. PMDD symptoms such as irritability, PMDD anger and rage and sensitivity to sounds and touch were reported to most affect participants' relationships with their children. As a result, participants' who had children reported that their relationships with their children were strained during the time of PMDD symptom expression, often as a result of PMDD anger and rage. An example of this is illustrated in the quote below by Elaine, a 35-year-old mother of twins from United States of America:

*"...the rage will show up in that I become like physically sensitive. I don't want to be touched. [...] And they [children] are three and a half and they want to be on mommy's lap. And I'm just like, get off of me, like, just leave me alone. And I mean, like I've never been abusive towards anybody, but just feeling that feeling of being out of control and then feeling like finally getting them to bed and then like, oh God, I need to apologize for being so angry with them because they were being three and a half. So, that's a big source of grief, I think, like the relationship I am fostering with my children."*

In the above quote, Elaine described how her PMDD symptoms of irritability and being touch sensitive affected her relationship with her children. Elaine stated feeling “grief” after putting her children to sleep because she acted in an unaffectionate and irritable manner towards them. I interpreted this as Elaine feeling guilty because of the perceived impact her PMDD symptoms had on her relationship with her children. In addition, Elaine described experiencing sensitivity to touch and sound during times of PMDD symptom expression. Elaine reported that this sensitivity further exacerbated her relationship with her children because it led to an increase in irritability and self-isolating behaviours. This quote illustrated how PMDD anger and rage may impact on psychological functioning both during and after PMDD symptom expression.

Some participants stated that their PMDD symptoms affected their ability to maintain their chosen parenting style during times of PMDD symptom expression. As a result, participants who were mothers often stated being concerned for the long-term impact their PMDD symptoms would have on their children’s psychological well-being as well as their future relationships with their children. This concern often resulted in prolonged feelings of guilt which extended beyond times of PMDD symptom expression. Similar to Elaine, Julie, a 36-year-old stay-at-home-mom of two from the United States of America, reported feeling guilty as a result of the impact of her PMDD symptoms on her children’s well-being.

*“It makes me feel like a crap mom sometimes because, like I said, I would just like, start screaming, because, of course, they don't understand what's going on and even if I'm trying to say, mommys not feeling great or my anxiety stuff, and they just keep acting like kids, you know. I've just been yelling and yelling, and I just hated that. And at the same time, as I'm yelling, like, I'm then feeling horrendous for doing that and so guilty”*

In this quote, Julie described feeling like “a crap mom sometimes” as a result of her behaviour towards her children during times of PMDD symptom expression. Julie described herself in the interview as an “attachment style” parent, which may describe a responsive and

physically present parent. However, during times of PMDD symptom expression Julie explained how difficult it was to maintain “attachment style” parenting because of her symptoms of anxiety and irritability. Additionally, in multiple areas of this quote, Julie described feeling guilty and acknowledged that her behaviour was often disproportionate to the behaviour of her children during times of PMDD symptom expression. The guilt Julie stated experiencing post-PMDD-symptom expression may illustrate the long-term effects of PMDD symptoms on women’s psychological well-being.

Women of this thesis reported that their PMDD symptoms negatively impacted on their familial and social relationships. Participants reported an increase in interpersonal relationship conflict as a result of participants PMDD symptoms. Moreover, participants reported that a lack of understanding towards their experiences and struggles with PMDD caused strain in their relationships, further isolating participants from their familial and social relationships. The impact of PMDD symptoms on familial and social relationships were found to be similar to the impact on participants’ romantic relationships. However, the main difference was participants’ reports of self-isolating and avoiding contact with familial and social relationships during times of PMDD symptom expression. Similar findings are demonstrated in current women’s health research (Cole et al., 2021; Osborn et al., 2020; Park et al., 2023; Rea et al., 2020).

Participants of this study reported partaking in self isolating behaviours in the form of avoiding social and family events during times of PMDD symptom expression to preserve relationships. Current women’s health research demonstrates similar findings (Cole et al., 2021; Osborn et al., 2020; Park et al., 2023; Rea et al., 2020). Osborn et al., (2020), found that women with PMDD reported self-isolating as a protective factor in order to preserve their familial and social relationships during times of PMDD symptom expression. Similarly, endometriosis research demonstrated comparable findings as women reported their

endometriosis symptoms negatively impacted on their social and familial relationships and resulted in women participating in self-isolating behaviours (Cole et al., 2021; Park et al., 2023; Rea et al., 2020). Although the cause of self-isolation for women with endometriosis was related to pelvic pain, it was also linked to a lack of understanding of women's experiences with endometriosis, which is similar to the accounts of women of this thesis.

“Mom guilt” was a common phrase used by women of this thesis when describing the impact of their PMDD symptoms on their relationship with their children. Participants reported that their symptoms made it hard to be present parents during times of PMDD symptom expression. This often resulted in feelings of guilt post-PMDD-episode as participant's reported to reflect on their destructive behaviours towards their children during times of PMDD symptom expression. Osborn et al., (2020), discovered similar findings where women with diagnosed PMDD reported feeling unable to appropriately care for their children during times of PMDD symptom expression. In addition, participant's reported feelings of guilt and remorse as they reported not being the parents they wished they could be because of the impact of their PMDD symptoms on their psychological functioning (Osborn et al., 2020). In current PCOS and endometriosis research, statements regarding parenting and motherhood were related to infertility and fears of not being able to become a mother (A. Hawkey et al., 2022; Rea et al., 2020; Soucie et al., 2021) and did not demonstrate these disorders ability to negatively impact on parenting.

#### **4.6 Healthcare in the PMDD context**

In this study, healthcare refers to interactions between patients, doctors and other medical and mental health professionals. For participants, healthcare experiences were an important part of women's PMDD journey. Additionally, healthcare was related to several other aspects of HRQoL, such as their financial and psychological well-being. This theme



consists of four subthemes, namely: (1) Medical gas-lighting and the importance of a diagnosis; (2) Doctor shopping; (3) Access to healthcare and (4) Advocating for myself.

#### **4.6.1 Medical gas-lighting and the importance of a diagnosis**

The term medical gas-lighting was presented to me by one of my participants, Kayla, who was a mother of three and lived in the United States of America. Medical gas-lighting refers to the invalidation of patient experiences by healthcare professionals. The vast majority of participants spoke about their experiences of medical gas-lighting. Examples of medical gas-lighting were dismissive attitudes of doctors towards patients' severe premenstrual symptoms, doctors not acknowledging PMDD as a valid diagnosis for patients and doctors disregarding patient experiences by attributing their severe premenstrual symptoms to PMS. Participants stated that medical gas-lighting made them feel unseen, unimportant, disregarded and dismissed by healthcare professionals. Medical gas-lighting was an important part of participants' experiences of PMDD. Many participant's indicated that they considered that medical gas-lighting played a role in their delayed diagnosis and also resulted in them becoming reluctant to seek medical assistance. Medical gas-lighting was interpreted for some as a lack of support from the healthcare system. In the following quote, Kayla described her experience of medical gas-lighting:

*"...but practitioners that do not believe that this is a real thing because it's not very, you know, it's not visible [...] Medical gas-lighting is a really good term here. That's hard, that's really hard."*

Similarly, this phenomenon was demonstrated through the experience of Liezl, a software developer from South Africa. In the quote below, Liezl described her negative healthcare experience with a male gynaecologist:

*"...my PMS symptoms are quite hectic. And his [doctor] response was you don't have to react to those feelings. And he was saying it in a very dismissive, like. Just take control of, of,*

*of your life sort of way. Um, yeah, just deal with it sort of way. And that feeling sticks with me. Like you [doctor] don't understand, and obviously you [doctor] don't believe that these hormones have an effect that is so severe that we feel that we need help or we, we cannot control it by ourselves anymore."*

Liezl's statement illustrated how her experience was dismissed by her healthcare practitioner and how this impacted her psychological well-being. The healthcare practitioner seemed to convey to Liezl that her experience was something that she could control, and Liezl viewed this interpretation of her PMDD as dismissive and illustrated to the lack of empathy from the doctor.

Participants reported that being diagnosed with PMDD was an important part of their PMDD journey, as diagnosis was needed for treatment. Furthermore, diagnosis was seen as an acknowledgement of their experiences and in some ways participants reported that diagnosis made them feel validated. In the following quote, Micaela, a 41-year-old Teaching assistant from Yorkshire, United Kingdom, described how she felt after being diagnosed with PMDD:

*"I just felt validated. Like everything, it [diagnosis] allowed me to look back at my life and actually makes sense of a lot of life changes that I've made that I was very impulsive about. And it kind of, yeah, it [diagnosis] helped us [family] make sense of everything. And there was also a feeling of being cared for, really. That someone did care, that I mattered. That there were people out there who were looking into this illness [PMDD]. And I only found out about it [PMDD] six months before, so it was all really new to me. I was learning so much. And I cried a lot. There was pure relief, really, that actually, I wasn't going crazy."*

Micaela's quote showcased how important her PMDD diagnosis was for her and also the role the diagnosis played in supporting her psychological well-being. Micaela described how she came to better understand herself and her past experiences and behaviours as a result of the PMDD diagnosis. It is my interpretation that Micaela may have viewed her PMDD diagnosis as a catalyst for her healing, acceptance and understanding of herself. Furthermore,

the value of being understood and having her premenstrual symptoms validated appeared to result in Micaela feeling supported by the healthcare system and her healthcare providers.

However, some participants reported that they did not feel satisfied when they received their PMDD diagnosis. This dissatisfaction was related to their internalisation of medical gas-lighting. For instance, Vanessa, a 22-year-old student who from Australia described in the statement below that when she received a conclusive PMDD diagnosis she felt like an imposter and struggled to accept her diagnosis. I interpret Vanessa's struggle to accept her PMDD diagnosis to her years of experiencing medical gas-lighting associated with her severe premenstrual symptoms.

*“Yeah, I think it [diagnosis] was just underwhelming. Like, I was just a bit like. Yeah, I I... I think it it didn't... I like I wanted to go back and say to people like, OK, I actually know what this is now. Like I have PMDD, but I almost felt a little bit like. Not guilty. I don't know the word, but like, I felt like a bit of, like, an imposter saying it...”*

The findings of this study demonstrate that women often had negative healthcare experiences associated with the diagnosis of their severe premenstrual symptoms and treatment of their PMDD. These negative healthcare experiences were commonly associated with medical gas-lighting. Although there is limited literature on medical gas-lighting within recent women's health and PMDD research, medical gas-lighting can be described as healthcare practitioners minimizing and invalidating patients symptoms and experiences, potentially leading patients to second guess the impact of those symptoms on their QoL (Chan et al., 2023; Fraser, 2021; Tormoen, 2019). QoL and healthcare studies among women with PCOS and endometriosis showed similar findings, with participants also reporting medical gas-lighting (Ismayilova & Yaya, 2020; Mikesell & Bontempo, 2022; Soucie et al., 2021).

Within PMDD research, Chan et al., (2023), explained that healthcare providers were recognized as a barrier for women with severe premenstrual symptoms not receiving appropriate care within their healthcare systems. Provider barriers were defined as healthcare practitioners chronically dismissing patients symptoms and medical gas-lighting (healthcare practitioners normalizing dismissing patient symptoms and experiences) (Chan et al., 2023). Medical gas-lighting was reported to negatively impact on patients' ability to advocate for themselves within their healthcare systems and caused an inability for patients to differentiate between their symptoms (Chan et al., 2023). These findings are similar to the healthcare experiences described by women in this study.

PCOS patients in the UK reported that the dismissive and judgmental behaviours of their doctors resulted in diagnostic delays (Soucie et al., 2021). Women in my study described the same experience when attempting to receive a diagnosis for their severe premenstrual symptoms. For women in the current study, the dismissive and judgmental behaviour of healthcare practitioners led to participants questioning their symptom experiences. While Soucie et al., (2021) did not specifically refer to medical gas-lighting in their study, participants reported that negative diagnostic encounters had a severe negative impact on their emotional and psychological well-being, which is similar to the reports of healthcare experiences linked to medical gas-lighting for participants of the present study.

The delay in medical acknowledgment for women's severe premenstrual symptoms led to a delay in diagnosis of PMDD for participants in this thesis. In addition, participants reported negative healthcare experiences that adversely impacted on their health-seeking behaviours. In a multi-method study conducted by Ismayilova and Yaya (2020) women reported that their PCOS concerns and symptoms were chronically dismissed by doctors. This chronic dismissal of patients concerns led to women receiving delayed diagnosis for PCOS (Ismayilova & Yaya, 2020). These findings are similar to those of this thesis as

women's severe premenstrual complaints were often dismissed and overlooked by their healthcare practitioners, leading to a delay in PMDD diagnosis. However, women in this thesis also reported that some healthcare practitioners dismissed their complaints after receiving a PMDD diagnosis. This may be as a result of a lack of practitioner knowledge regarding PMDD. Delayed diagnosis was linked to participants' experiencing emotional distress and in turn, this emotional distress caused conflicts within their interpersonal relationships.

Mikesell & Bontempo, (2022) reported in their study that patients with a self-reported clinical diagnosis of endometriosis had their symptoms and experiences relating to endometriosis ignored. In addition, women in their study described healthcare practitioners as "insensitive" and "uncaring" towards symptoms (Mikesell & Bontempo, 2022, p. 5). This resulted in participants feeling invalidated by their healthcare practitioners (Mikesell & Bontempo, 2022). This is similar to the findings of this thesis as women often described their healthcare practitioners invalidating their symptom experience both before and after receiving their PMDD diagnosis. These findings showcase a pattern of dismissive behaviour by healthcare practitioners towards women's health concerns and severe premenstrual symptoms.

Some participants in this study stated experiencing dissatisfaction after receiving their diagnosis of PMDD. The dissatisfaction was not as a result of the PMDD diagnosis but rather participants attributed their dissatisfaction to their experience of prolonged medical gas-lighting. I was not able to find research which demonstrated similar findings.

#### **4.6.2 Doctor shopping**

As illustrated in the above sub-theme, the importance of a PMDD diagnosis prompted participants' health-seeking behaviours. However, in seeking a concrete PMDD diagnosis

and treatment, participants found that not many doctors knew enough about PMDD to diagnose or treat the disorder. Additionally, participants found that healthcare practitioners' medical knowledge of PMDD impacted on the quality of care they received from that practitioner. As a result, participants stated that an important part of their PMDD treatment journey was finding a healthcare practitioner sufficiently knowledgeable of PMDD to support their psychological well-being and treat their severe premenstrual symptoms. This process is best described as doctor shopping. Doctor shopping entails visiting multiple healthcare practitioners to find a practitioner who was knowledgeable of PMDD enough to appropriately support them medically and emotionally. Doctor shopping is demonstrated in the following quote by Anna, a forty-two-year-old business analyst from Romania. In this quote Anna described how she consulted a total of five healthcare practitioners in an attempt to properly diagnose and treat her severe premenstrual symptoms.

*“Ever since I've been going to the gynaecologist and I've been asking them [gynaecologist] if they [gynaecologist] know about it [PMDD], one of them didn't it, even after I told her the Romanian word, she just wrote something else because she didn't even have the notion. But three months ago, I met an endocrinologist who actually knew about it... I've asked, you know, a psychiatrist, one month ago, who told me, PMDD is not a real diagnosis. And so I told her, but it is in the DMS-IV... she [psychiatrist] told me, “I [psychiatrist] haven't really read the DSM since it was in the third edition...”*

Anna not only described her efforts in seeking medical help for her severe premenstrual symptoms but also explained the lack of knowledge and understanding of PMDD within the health system she has access to. Anna's interaction with the psychiatrist at the end of the quote also demonstrated one of the main reasons why women in this study engaged in doctor shopping, namely the lack of practitioner knowledge on PMDD. In Anna's example, it is concerning that a psychiatrist was not able to provide adequate care because of their lack of knowledge of PMDD.

The process of doctor shopping was reported by participants to have a negative impact on their psychological well-being. Some participants reported feeling frustrated and demotivated when attempting to seek a diagnosis and treatment for their severe premenstrual symptoms. Additionally, participants indicated that the negative experiences they encountered when doctor shopping negatively impacted on their health-seeking behaviours. In some cases, participants abandoned seeking a diagnosis. In the following quote Lucinda, a thirty-four-year-old mother of one from the United States of America, described how after a difficult experience with her healthcare practitioner she stopped seeking help for her severe premenstrual symptoms. Lucinda was later diagnosed with PMDD by a nurse practitioner.

*“So when I first talked to that doctor, the one that I mentioned who just was like here, I can give you an antidepressant and that's pretty much it. I felt like that was very cold and clinical and I felt like it didn't...it wasn't the support I felt like I needed at the time [...] So I felt like it just felt so transactional, like transactional medicine, and that really deterred me from seeking uhm clinical support again for a long time. Like I said, until it got really, really bad. It did impact me getting the actual diagnosis and it impacted me getting treatment and help for it. And really embracing it...”*

Participants stated that receiving understanding and validation for their severe premenstrual symptoms by healthcare practitioners made them feel heard and seen. Additionally, most participants stated that when they found a doctor who was able to diagnose them, they felt relieved. This is demonstrated in the following quote by Melinda. Melinda is a forty-seven-year-old self-employed entrepreneur from the United States of America.

*“...this wonderful doctor diagnosed me, found in the DSM. [...] And he said, you know, I've never had this before. I've never seen this before, but this is a new thing and I think this is what you're diagnosed with, this is what you have. [...] So, it just kind of woke me up, like, oh, it's not me and my bad character. It's not me and my negative thinking, it's this thing that I need to find some more answers to. ”*

In the above quote, Melinda explained how valuable her diagnosis was to her understanding of herself during the times she experienced her PMDD symptoms. Melinda's description of a 'wonderful doctor' that diagnosed her shows that she had a positive relationship with the healthcare practitioner who diagnosed her. Additionally, the quote also showed the importance of a PMDD diagnosis.

The majority of current research on the term 'doctor shopping' discusses opioid or drug addiction. Doctor shopping is thus often related to the practice of visiting multiple doctors in order to attain multiple prescriptions for opioids so that individuals may maintain their addiction (Randy et al., 2012; Young et al., 2019; Zykova et al., 2022). For the purposes of this study, doctor shopping was defined as patients seeking out multiple clinicians for purposes ranging from knowledge of disorders to unpleasant healthcare practitioner bedside manner. Doctor shopping can also often be associated with patient dissatisfaction regarding their healthcare experiences (Randy et al., 2012). This definition of doctor shopping more accurately describes how this phenomenon manifested itself for women in this study.

Participants in this study reported needing to visit multiple medical practitioners in order to receive recognition and acquire a diagnosis for their severe premenstrual symptoms. Reasons why participants in this study reported doctor shopping were patient dissatisfaction, healthcare practitioners being dismissive of severe premenstrual symptoms, seeking diagnosis for severe premenstrual symptoms and difficulties finding a healthcare practitioner knowledgeable on PMDD. In a study conducted by Ismayilova & Yaya (2020), 41% of participants reported consulting three or more doctors before they received a diagnosis of PCOS. Additionally, women reported that encountering healthcare practitioners who were not appropriately knowledgeable in PCOS to diagnose them was a barrier in receiving a diagnosis (Ismayilova & Yaya, 2020). These findings are similar to the accounts of women in this thesis when seeking diagnosis for their severe premenstrual symptoms.



Women in this thesis stated that a PMDD diagnosis was a valuable asset to have as patients. Participants reported that a diagnosis gave them recognition for their personal struggles with severe premenstrual complaints. In addition, upon receiving a PMDD diagnosis, majority of participants reported feeling relieved and validated. This is similar to the findings described in current PMDD research by Osborn et al., (2020) and Chan et al., (2023) as participants in both these studies reported to feel relieved when they were diagnosed with PMDD. This indicates a pattern that diagnoses relating to women's health conditions validate women's experiences of healthcare and symptom struggles prior to their diagnosis. Furthermore, women in this thesis reported that the relief accompanied by receiving their PMDD diagnosis offered them validation for their symptom experiences, more so for those women who experienced medical gas-lighting.

This sub-theme illustrates both the phenomenon of doctor shopping for women with PMDD and the reason why patients needed to doctor shop; because of the lack of knowledge around PMDD within their health system. Furthermore, the search for medical support can have a negative impact on a woman's psychological well-being and financial capabilities. This is further investigated in the following sub-theme, "Access to healthcare".

#### **4.6.3 Access to healthcare**

As discussed in the theme above, healthcare played an essential part in supporting the HRQoL of women with PMDD. Negative healthcare experiences may also have the ability to impact the experience of PMDD. Many participants stated that they could not access healthcare. Their access to healthcare was limited by costs and logistics as they often consulted with several healthcare practitioners and specialists.

A lack of access to healthcare practitioners knowledgeable about PMDD and premenstrual related complaints was identified as a significant hurdle in seeking diagnosis

and healthcare support. Examples of accessibility issues for participants in this study were doctors' location, financial costs, medical aid scheme rules and healthcare practitioner expertise. For some, the lack of accessibility related to healthcare services being geographically out of reach. In the quote below, Bethany described her logistical and financial difficulties relating to seeking appropriate treatment to support her PMDD. Bethany, a thirty-three-year-old from United States of America, belongs to the indigenous Tlingit tribe and works as an editor.

*“So I live in a pretty small town. It's like 40,000 people and we're surrounded by mountains and ocean, so we don't have a lot of options... So I did not pursue a different psychiatrist because I really don't have any other options here without spending a lot of money. [...] they [healthcare system] also do not often wind up with the best or most experienced providers and it's for a couple of reasons. I think one is pay. I think these are often people who have just graduated and are just starting out and so they often are able to get positions here more easily”*

Logistically, Bethany lived in a remote town with a small choice of both public and private healthcare practitioners. Financially, she could not afford to seek healthcare outside of the public healthcare system and the doctors closest to her were not knowledgeable about PMDD and premenstrual distress disorders. Thus, she did not receive optimal treatment, but received the best treatment that she could afford.

The financial burden of ineffective treatments, doctor shopping, consulting with practitioners, travel costs and access to health services proved for some participants to be too much. Some participants reported that they had health insurance but that healthcare practitioners covered by their health insurance were not knowledgeable in PMDD. This may have resulted in less than optimal treatment. These participants stated that they were forced to either pay for the healthcare services themselves (out of pocket) or withdraw from seeking medical support altogether and attempt to treat their PMDD symptoms themselves. Moreover, some participants noted that they needed to seek support within the private

healthcare system to get effective treatment. Additionally, some participants stated that acquiring healthcare support was difficult as a result of lack of accessibility. One participant in particular, stated that she had stopped attending therapy and taking her medication as a result of this financial burden. Grace, who was a single pet-lover from the United States of America, described her despair relating to struggles in accessing therapeutic support below. It is important to note that these struggles occurred after Grace was diagnosed with PMDD.

*“Trust me, like I had to fight and fight and fight, for over two years to find a gynaecologist (who understood PMDD)... It's horrible. So right now, I cannot even find a psychiatrist to help me, because there is none that is covered by my healthcare. And right now, I cannot afford it and I need a psychiatrist, and I haven't been able to find one because the ones who specialize in PMDD like cost \$500 per session.”*

In the above quote, Grace described how she was not able to properly treat her PMDD symptoms as a result of her current financial situation. In the quote we can see the urgency with which Grace required medical support. Appropriate treatment of PMDD symptoms is an integral part of supporting the HRQoL of women with PMDD. This need for appropriate treatment is further elaborated on in the following sub-theme, “Advocating for Myself”.

Participants of this study reported a variety of barriers in relation to accessing appropriate healthcare to support their PMDD. Health practitioners’ location, financial costs, medical aid scheme rules and healthcare practitioner expertise in PMDD were reported to be the main barriers for participants attempting to access healthcare. In current women’s health research, barriers to healthcare were reportedly linked to financial costs, medical insurance and healthcare practitioner expertise (Cardoso et al., 2021; Chan et al., 2023).

Cardoso et al., (2021), conducted a study assessing healthcare experiences of women in North Carolina, United States of America. Out of the eleven women who participated in the study, ten participants reported insurance and medical costs as barriers when accessing

healthcare (Cardoso et al., 2021). Moreover, women reported that insurance and monetary availability dictated medication choices and often resulted in delays in health-seeking behaviours (Cardoso et al., 2021). In addition to monetary barriers, eight participants reported negative healthcare experiences as a barrier to healthcare which negatively impacted on patient trust, switching healthcare practitioners and affected participants overall experience with their healthcare system (Cardoso et al., 2021). Participants of this thesis reported insurance and monetary barriers when attempting to access healthcare for their severe premenstrual symptoms and PMDD. Similarly, Chan et al., (2023), reported that a lack of healthcare provider knowledge on PMDD was a significant barrier in patient care for women with self-reported PMDD in the United States of America. A lack of access to adequate healthcare for premenstrual disorders could lead to women stopping treatment because of monetary constraints or a delay in health-seeking behaviours, which was demonstrated by the participants of this thesis.

As a result of limited literature, I could not find relevant data describing location or spatial-proximity as a significant barrier to women's healthcare with regards to premenstrual disorders or alternative women's health conditions. However, studies assessing access to healthcare facilities for women in rural areas reported location as a primary barrier for women in accessing appropriate healthcare (Alamneh et al., 2022; Dotse-Gborgbortsi et al., 2022; Statz & Evers, 2020). These studies describe maternal and women's healthcare, mentioning spatial barriers and medical mistrust as prominent barriers to accessing healthcare (Alamneh et al., 2022; Dotse-Gborgbortsi et al., 2022; Statz & Evers, 2020).

#### ***4.6.4 Advocating for Myself***

As previously mentioned, participants stated that medical gas-lighting played a role in their delayed diagnosis. Participants stated that they often had to consult more than one healthcare practitioner before having their premenstrual symptoms acknowledged or being

diagnosed with PMDD. Many participants reported that they had to advocate for themselves to get a diagnosis and appropriate treatment for their PMDD. In the quote below, Quinn described how she brought her self-diagnosis of PMDD to her general practitioner to receive a clinical diagnosis with the disorder. Quinn is a thirty-nine-year-old self-employed cleaner from Denmark.

*“I searched again. I was like, something has got to be here, like I've got to be able to find what's wrong with me. And that's where I just stumbled across something about PMDD and I've, you know, I'd looked, every, I don't know, probably few months, few years, I'm not sure, for, you know, answers, and then I never found anything and no doctors ever said anything about that. That could be related to my hormones or anything. So I basically self-diagnosed and then went to the doctor.”*

After years of misdiagnosis and frustration because of unsupportive healthcare practitioners, Quinn reported that she had stopped looking for an answer to her severe premenstrual symptoms. Finally, after doing her own research and finding PMDD, Quinn consulted with a doctor and they agreed to the diagnosis of PMDD. This demonstrated the importance of self-education in participants' attempts at receiving a PMDD diagnosis. From the quote we are able to see that what drove Quinn was the urgency for an answer after years of struggling with her severe premenstrual symptoms. Additionally, we see that because Quinn continued to advocate for herself, she was able to have her severe premenstrual symptoms diagnosed. This quote also shows how important a PMDD diagnosis can be for women battling with severe premenstrual complaints.

In seeking treatment and medical support for PMDD, participants reported often needing to advocate for themselves with their medical practitioners and overall within the healthcare system. Advocating for themselves included asking their doctors for referrals to specialists as their doctors did not deem their experiences severe enough to write a referral. Furthermore, participants stated that they had to provide evidence of PMDD to their

healthcare practitioners to have their symptoms be treated and diagnosed. This need for providing evidence resulted in participants tracking their cycles and researching possible treatments they could ask for when consulting with their doctors. Cycle tracking as a means of collecting data as proof of severe premenstrual symptoms was used by Vanessa in her struggle for validation and recognition of her severe premenstrual symptoms. Vanessa was diagnosed with PMDD as a result of her cycle tracking. Vanessa also described how she was more intentional with her choice of healthcare practitioner with the results of her cycle-tracking, which related to her experiences of medical gas-lighting and the impact of doctor-shopping.

*“So, I started tracking with the ... [IAPMD] uhm, symptom tracker. And did two months of that and then took that to my GP. And I think I went to like, I went to one that's of like female health... Uhm Mental health sort of specialist. And she she like it wasn't. It wasn't that she was like, Yep, you've 100 got 100% got PMDD. So, it was just like, yeah, this is cyclic like. These are the treatments...”*

Some participants reported feeling as though their treatment plans were not working effectively. As a result, they prompted discussions around modifying their treatment plans with their practitioners. Some of the treatment strategies women suggested to their doctors included surgeries such as a hysterectomy, oophorectomy and chemical menopause treatments. These medical strategies were suggested in an attempt to lessen the impact of PMDD on their HRQoL. However, treatments such as surgery and chemical menopause were very scarcely offered to women as a treatment option. Participants stated their healthcare practitioners' reservations against more aggressive treatments were either not clearly discussed with them and that there appeared to be an incongruence between patient and practitioner goals. The following quote by Freja, a 47-year-old copywriter from Denmark, describes how she attempted to have her PMDD be treated more aggressively:

*“Because I'm really trying to improve my life, my quality of life, and I'm like. What are my options? And I said to him. So can we put me in chemical uhm, menopause? And he said no. And you still have lots of, you know, he was very about the sexual active side. [...] I was upset. I was sad. I felt demotivated again because I just can't come to the I just can't settle that this is the way I'm going to [live] and it's only just gonna get worse. That's what he said.”*

Freja's experience with her healthcare practitioner showed how the treatment goals of her doctor trumped the needs of the patient. It is my interpretation that the barrier between patient and practitioner understanding resulted in a break in trust that further reduced patients' belief in doctors' ability to advocate for them. Additionally, this break in trust can negatively impact on the psychological well-being of a patient which, as discussed in the sub-themes above, can lead to despair towards being diagnosed with PMDD. Freja was not helped with an alternative treatment method.

Women's health research reports that self-advocacy and persistent behaviours are common practices in women's attempts to gain diagnosis for symptoms, accessing specific treatments, accessing specialists and combating dismissive healthcare practitioners (Ismayilova & Yaya, 2023; Mikesell & Bontempo, 2022; Wren & Mercer, 2022).

Women in this thesis reported needing to advocate for themselves with healthcare practitioners in order to receive appropriate PMDD treatment and diagnosis of their severe premenstrual symptoms. In addition, participants stated that experiences related to medical gas-lighting, dismissive attitudes from doctors towards their severe premenstrual symptoms and ineffective treatments were reasons for advocating for themselves within their healthcare systems. These findings are similar to existing women's health research (Ismayilova & Yaya, 2023; Mikesell & Bontempo, 2022; Wren & Mercer, 2022). For example, Wren & Mercer (2022) reported that participants emphasized the importance of remaining persistent when attempting to have their concerns acknowledged by healthcare practitioners and in gaining

access to necessary medical specialists in efforts to receive a diagnosis for their endometriosis-related symptoms.

Mikesell & Bontempo (2022) indicated that participants often needed to self-advocate in healthcare settings by suggesting endometriosis as a diagnosis, proposing alternative treatments and attempting to access specialists knowledgeable in endometriosis. These findings may illustrate women's need for self-education, as knowledge regarding disorders was essential to self-advocating for diagnosis and specific treatments. Participants of this thesis reported that cycle tracking, presenting proof of symptoms and self-education were useful tools in bringing attention to their severe premenstrual symptoms with healthcare practitioners. Mikesell & Allyson (2022) and Ismayilova & Yaya (2023) reported similar findings. Ismayilova & Yaya (2023) reported that twenty-two participant's (n=25) stated self-education supported their understanding of their PCOS diagnosis and finding alternative treatments to present to healthcare practitioners. In addition, eleven participant's reported that self-advocacy was essential when confronted with healthcare practitioners who were not sufficiently knowledgeable in PCOS and practitioners who were hesitant in providing patient referrals to specialists (Ismayilova & Yaya, 2023).

#### **4.7 Conclusion**

In this chapter I described participants' experiences with PMDD and discussed these findings in relation to existing women's health research. The findings in this chapter present on all key objectives displayed in chapter one and demonstrated the extent of the impact of PMDD on women's HRQoL. Participants shared experiences demonstrating PMDD's negative impact on women's psychological well-being, interpersonal relationships, occupational and parental responsibilities, self-esteem and self-concept. Each sub-theme was discussed in relation to existing women's health research. PCOS and endometriosis research was included as PMS and PMDD research were not sufficient in discussing the findings of



this thesis. In instances where I could not find relevant research to support my findings, I demonstrated the existing gap within women's health research where my findings are positioned in.

## Chapter Five

### Conclusion, Limitations and Recommendations

#### 5.1 Introduction

In this chapter I will provide an overview of the findings discussed in Chapter four with relation to this studies objectives. Each objective will be described and I will discuss how each objective was reached within this study. Following this, I will report on and discuss the limitations of this study. Thereafter, I describe recommendations for future research and healthcare practitioners on the topic of PMDD and women's health.

To my knowledge, this study is the first to assess the HRQoL of women with PMDD. It attempts to fill the gap within existing PMDD research on the impact of PMDD on women who are diagnosed. Additionally, this study provides insight into the intricacies of the women who exist with a disorder which is not appropriately recognized within the medical field and invisible to those who do not experience it. Participants in this study are diverse as they represent several countries and this study provides key insights into the experience and impact of PMDD not present in current PMDD research. Therefore, I believe these findings are both novel and a necessary addition to the current body of PMDD research.

#### 5.2 Research objectives and findings

##### 5.2.1 *Functional areas of HRQoL*

The findings of this study provide a detailed and rich description of women's experiences with PMDD. Overall, women in this thesis reported that PMDD impacted on all functional areas of life namely, psychological well-being, interpersonal relationships, occupational responsibilities, career trajectory and parental responsibilities. These are key dimensions of HRQoL and are explained in further detail in the objectives below.

### **5.2.2 Occupational responsibilities**

Employed participants reported that their PMDD symptoms negatively impacted on their occupational responsibilities. Moreover, women reported that during times of PMDD symptom expression they experienced more inter-colleague conflicts and difficulty meeting occupational deadlines. In addition, women reported that PMDD impacted negatively on their career trajectories, resulting in women either choosing to leave their occupations or being fired from their jobs. This ultimately negatively impacted on participants' psychological well-being as they felt as though their PMDD symptoms created a significant obstacle in order to achieve their occupational goals. Furthermore, participants reported that they were unable to take on additional occupational responsibilities and reported taking leave from work during times of PMDD symptom expression. Participants who reported being fired from their employment believed that they were either discriminated against as a result of their PMDD diagnosis or reported that their dismissal was as a result of conflicts with their colleagues.

Women who were not self-employed reported that a supportive work environment was an integral factor in the management of their PMDD symptoms and work responsibilities. Participants reported feeling less guilty when their work environment was supportive to their PMDD struggles, indicating that occupations may hold a supplementary role to assist women with PMDD in the workplace. These findings add to the existing body of PMDD research discussing PMDD women's occupational experiences.

### **5.2.3 Psychological well-being**

All participants reported that their PMDD symptoms negatively impacted on their psychological well-being. Participants reported that their PMDD symptoms lead to them experiencing suicidal ideations. Additionally, some participants reported participating in self-harm as a means of coping with their PMDD symptoms, illustrating the severe impact women's PMDD symptoms had on their psychological well-being.

Women reported that they felt they could not trust themselves as they experienced mild forms of dissociations during times of PMDD symptom expression. Additionally, participants reported experiencing intrusive thoughts and ruminations, which lead to mild forms of dissociation. As a result, participants reported putting in place certain protective factors, such as relying on their partners more to make decisions and self-isolating during times of PMDD symptom expression. These findings have, to my knowledge, not been discussed in current PMDD research meaning my study is the first to report on this.

Participants used language personifying their PMDD. Women in this study described their PMDD as a “monster” or as an “abuser” as a result of the negative impact PMDD had on their HRQoL. More specifically, participants stated that their PMDD symptoms had a negative impact on their self-esteem and self-concept, causing psychological distress. As a result, women attempted to make a separation between who they were during times of PMDD symptom expression and who they were when they were not experiencing their PMDD symptoms. This was done both as a coping mechanism and as a means of preserving participants’ self-image. As similar findings are discussed in PMDD research, these outcomes could be considered as a valuable contribution to current PMDD research

PMDD anger and rage emerged as a significant symptom pertaining to women’s psychological well-being. Some participants explained the physical reaction anger and rage symptoms had on their bodies, which may indicate the level of physical and psychological distress PMDD anger and rage had on women’s bodies. Additionally, some participants explained that anger and rage symptoms negatively impacted their interpersonal relationships, leading to an increase in conflict during times of PMDD symptom expression. Current research does not discuss PMDD anger and rage as a significant PMDD symptom, therefore this study may be the first to discuss anger and rage in this manner.

Finally, self-awareness was described as one of the biggest benefits to receiving a PMDD diagnosis. Women reported that receiving a PMDD diagnosis facilitated in them better understanding themselves. Additionally, the information they received regarding PMDD allowed them to feel more in control and better able to handle their symptoms during times of PMDD symptom expression. These findings add to existing research discussing the value in women receiving a diagnosis for their severe premenstrual symptoms.

#### **5.2.4 *Interpersonal relationships***

Majority of participants reported that their PMDD symptoms negatively impacted their interpersonal relationships. Women in this study stated that, during times of PMDD symptom expression, their symptoms led to an increase in interpersonal relationship conflict, a disinterest in sexual intimacy, and difficulties in maintaining an emotional connection with their children. As a result of the negative impact of participants PMDD symptoms on their interpersonal relationships, women reported participating in self-isolating behaviours in order to preserve and protect their interpersonal connections.

With regards to participants' romantic relationships, women reported that their PMDD symptoms lead to an increase in romantic relationship conflicts. Women reported difficulties in maintaining their romantic relationships, reporting break-ups and attending marriage counselling, as a result of their PMDD symptoms. Additionally, women reported on the perceived impact that their PMDD symptoms had on their partners' psychological well-being. Participants were not explicitly asked regarding the impact of their PMDD symptoms on their romantic partners. However, women stated that their PMDD symptoms negatively impacted on their partners' psychological well-being and described often needing to make amends post-PMDD-episode.

Participants reported that their PMDD symptoms had a negative impact on their social and familial relationships. Women reported this to be as a result of their PMDD symptoms and social and familial members not understanding their PMDD diagnosis. As a result of this negative impact, participants reported self-isolating to preserve and protect their social and familial relationships.

Mothers reported that their PMDD symptoms negatively impacted on their ability to parent and emotionally connect with their children during times of PMDD symptom expression. In addition, participants reported not being able to maintain their chosen parenting style during times of PMDD symptom expression. As a result, participants with children described experiencing feelings of guilt and remorse post-PMDD-episode. Furthermore, participants stated being concerned at the long-term effects of their PMDD symptoms on their children's psychological well-being, which was not a finding described in current PMDD research.

#### ***5.2.5 Socio-ecological and cultural influences***

The final objective of this study was to explore whether or not socio-ecological and cultural factors had an impact on women's experiences with PMDD. Overall, the women in this study reported that menstrual taboo and stigma relating to menstruating women and mental illness present within their social contexts negatively impacted on their experiences with PMDD. Stigma relating to mental illness, premenstrual complaints and menstruation caused women to delay seeking help for their severe premenstrual symptoms. Additionally, women described that stigma regarding menstruating women disadvantaged them within their healthcare systems as their premenstrual symptoms were often disregarded, resulting in medical mistrust and delayed diagnosis. Moreover, women's social contexts did not allow for open discussion regarding premenstrual symptoms, leading women to feel obligated not to

discuss their severe premenstrual symptoms. Women reported that their PMDD diagnosis was a pivotal point in the PMDD journey.

Majority of the women who expressed that mental illness stigma and menstrual taboo negatively impacted on their experiences with PMDD stated that the stigma lead to feelings of shame. As a result, women reported not disclosing their PMDD diagnosis to certain family members and friends for fear of being labelled and discriminated against. These findings provide evidence that cultural factors negatively influenced women's experiences with PMDD. These experiences are not well reported on in current PMDD literature which suggest that my research fills a potential gap within existing PMDD research.

### **5.3 Study Limitations**

The first study limitation pertains to language which interviews were conducted in. As my study was predominantly self-funded and I was the only researcher conducting interviews, interviews could only be conducted in English and Afrikaans as these are the languages I am fluent in. Although all participants stated being comfortable communicating in English, there were some instances where the language barrier became eminent, specifically when discussing participants socio-cultural experiences related to PMDD.

The final limitation was that participants often found it difficult to describe their experiences relating to how socio-ecological factors impact on their experiences with PMDD. Majority of participants confessed to never thinking about this as no one had inquired about socio-ecological or cultural factors impacting on their experiences with PMDD before. When this occurred, participants would pause, reflect on their experiences and answer as best as they could. Few participants reported being religious and no participant reported that their religious beliefs impacted on their experiences with PMDD. Therefore, this thesis was not

able to appropriately investigate all aspects of HRQoL as described in the theoretical framework.

## **5.4 Recommendations**

### **5.4.1 *Future Research***

For future research I recommend the following:

1. This thesis was intended to evaluate the HRQoL experiences of women within the South African context. However, as a result of low rates of participant recruitment, this study was amended to recruit international participants. It would be beneficial to explore women's experiences with PMDD in specific countries as socio-ecological factors would be more reliable to report on and compare.
2. Women's healthcare experiences emerged as an important theme in understanding women's HRQoL with PMDD. Therefore, further studies into healthcare experiences comparing private and public healthcare could give additional insight into the healthcare experiences of women with PMDD. Additionally, partnering with organisations and health services locally which focus on women's health could potentially provide an avenue to implementing practical change and creating interventions to combat negative increase awareness of PMDD and combat women's negative healthcare experiences.
3. Women reported that their PMDD symptoms negatively impacted on the psychological well-being of their partners. For this reason, research describing the experiences of partners to women with PMDD could provide valuable and additional insight into the impact of PMDD.



### **5.4.2 *Clinical and Mental health practitioners***

In this section I will make recommendations for clinical and mental health practitioners based on the data I have collected. Firstly, women often reported that healthcare and mental health practitioners were not well-informed on PMDD, causing delays in diagnosis and receiving treatment. Therefore, I recommend that both clinical and mental health practitioners become well-versed in the symptoms and recent treatment suggestions for women with PMDD. In addition, practitioner knowledge regarding PMDD could influence more research regarding treatment options for women with PMDD. Moreover, many women reported that showing evidence of the cyclical nature of their symptoms were what prompted a PMDD diagnosis. It is consequently essential for mental and healthcare practitioners to be knowledgeable of the cyclical nature of PMDD and that symptoms are most prominent during women's late luteal phase of menstruation as this may lead to early diagnosis and better treatment experiences.

Secondly, many women reported negative healthcare experiences regarding their symptoms being chronically dismissed, severity of symptoms ignored and expressed experiences of medical gas-lighting by healthcare practitioners. Some participants were met with doctors denying the existence of a disorder such as PMDD, further delaying patient treatment and diagnosis. As a result of this, women reported delaying seeking help for their symptoms which resulted in worsening of symptoms and feelings of medical distrust. Therefore, it is essential that women presenting with severe premenstrual symptoms are better treated and acknowledged within the healthcare field. Furthermore, women should be treated as the experts of their symptoms and diagnosis and treatment should be guided by the patients' narratives.

## **5.5 Conclusion**

The findings of this study demonstrate the overall negative impact PMDD has on women's HRQoL, leading to self-isolating behaviours, increases in interpersonal relationship conflicts and negatively impacting on women's self-esteem and self-concept. In addition, the findings of this study demonstrate the importance of understanding patient experiences and explained the psychological, interpersonal and functional impacts of PMDD. Moreover, the methods used in this thesis proved to provide participants with a cathartic experience, as this thesis offered participants a platform to discuss their PMDD journey, an opportunity many stated they were not provided with before. I would therefore suggest that it would be valuable for my recommendations to be incorporated into healthcare practices.

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## **Appendix A: DSM V Criterion for Premenstrual Dysphoric Disorder**

### **Premenstrual Dysphoric Disorder**

#### **Diagnostic Criteria**

625.4 (N94.3)

A. In the majority of menstrual cycles, at least five symptoms must be present in the final week before the onset of menses, start to improve within a few days after the onset of menses, and become minimal or absent in the week post-menses.

B. One (or more) of the following symptoms must be present:

1. Marked affective lability (e.g., mood swings: feeling suddenly sad or tearful, or increased sensitivity to rejection).

2. Marked irritability or anger or increased interpersonal conflicts.

3. Marked depressed mood, feelings of hopelessness, or self-deprecating thoughts.

4. Marked anxiety, tension, and/or feelings of being keyed up or on edge.

C. One (or more) of the following symptoms must additionally be present, to reach a total of five symptoms when combined with symptoms from Criterion B above.

1. Decreased interest in usual activities (e.g., work, school, friends, and hobbies).

2. Subjective difficulty in concentration.

3. Lethargy, easy fatigability, or marked lack of energy.

4. Marked change in appetite; overeating; or specific food cravings.

5. Hypersomnia or insomnia.

6. A sense of being overwhelmed or out of control.

7. Physical symptoms such as breast tenderness or swelling, joint or muscle pain, a sensation of “bloating,” or weight gain.

Note: The symptoms in Criteria A-C must have been met for most menstrual cycles that occurred in the preceding year. D. The symptoms are associated with clinically significant distress or interference with work, school, usual social activities, or relationships with others (e.g., avoidance of social activities; decreased productivity and efficiency at work, school, or home).

E. The disturbance is not merely an exacerbation of the symptoms of another disorder, such as major depressive disorder, panic disorder, persistent depressive disorder (dysthymia), or a personality disorder (although it may co-occur with any of these disorders).

F. Criterion A should be confirmed by prospective daily ratings during at least two symptomatic cycles. (Note: The diagnosis may be made provisionally prior to this confirmation.)

G. The symptoms are not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication, other treatment) or another medical condition (e.g., hyperthyroidism).



**Appendix B: Recruitment Flyer**

EXPLORING THE HEALTH RELATED  
QUALITY OF LIFE OF WOMEN WITH

# **PREMENSTRUAL DYSPHORIC DISORDER: A QUALITATIVE STUDY**

You have been invited to participate in a research study that I am conducting as part of my MA Research psychology degree at Stellenbosch University. In this study I will explore how PMDD has impacted your quality of life, such as your relationship with others and self-image.

## **ELIGIBILITY FOR THIS STUDY**

*You are eligible to take part in this study if you:*

- Have been diagnosed with Premenstrual Dysphoric Disorder
- Are 18 years old or older
- Are comfortable understanding and communicating in English

If you choose to participate in this study, I will conduct an interview with you online at a time that is convenient for you.

If you are interested in participating in this study, or would like to know more about the study please use the information to contact me.

## **PRINCIPAL RESEARCHER**

Meghan Mosalisa  
19143451@sun.ac.za  
0835679331

This study is being conducted under the auspices of the Department of Psychology at Stellenbosch University. Ethical clearance was granted by Stellenbosch University's Health Research Ethics Committee (HREC).

**Appendix C: Healthcare Practitioner information flyer**

## Exploring the health-related quality of life of women with Premenstrual Dysphoric Disorder

### A Qualitative Study

*I am conducting research as part of my MA Research psychology degree. In this study I will explore how Premenstrual Dysphoric Disorder has impacted a woman's quality of life, assessing themes such as relationship with others and self-image.*

#### The eligibility criteria to partake in this study are:

- Have been diagnosed with PMDD
- Women 18 years or older
- Comfortable understanding and communicating in English

Data collection will be done via semi-structured interviews done on online platforms.

If you are willing to be part of the participant recruitment process and would like to know more about the study, please use the following information to contact me.

**Principle Researcher:** Meghan Mosalisa

**Email:** 19143451@sun.ac.za

**Phone:** 0835679331

## Appendix D: Ethical approval certificate



### Approval Notice

### New Application

22/07/2021

**Project ID:** 22309

**HREC Reference No:** S21/05/095

**Project Title:** Exploring the health-related quality of life of women with Premenstrual Dysphoric Disorder in South Africa

Dear Ms M Mosalisa

The **response to modifications** received on 23/06/2021 13:04 was reviewed by members of **Health Research Ethics Committee** via **expedited** review procedures on 22/07/2021 and was approved.

Please note the following information about your approved research protocol:

**Protocol Approval Date:** 22 July 2021

**Protocol Expiry Date:** 21 July 2022

Please remember to use your Project ID 22309 and Ethics Reference Number S21/05/095 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

### After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website ([www.sun.ac.za/healthresearchethics](http://www.sun.ac.za/healthresearchethics)) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

### Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/22309>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Ms Brightness Nxumalo  
HREC 2 Coordinator

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

## Appendix E: Amendment approval certificate



24/05/2022

**Project ID:** 22309

**Ethics Reference No:** S21/05/095

**Project Title:** Exploring the health-related quality of life of women with Premenstrual Dysphoric Disorder

Dear Ms M Mosalisa

Your amendment request dated 20/04/2022 14:34 refers.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendment was reviewed and approved:

**Amendment #1, 11/04/2022**

- To broaden inclusion criteria to include participants from outside South Africa

**Where to submit any documentation**

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your project ID 22309 and ethics reference number S21/05/095 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Ms Brightness Nxumalo  
Coordinator: Health Research Ethics Committee 2

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:  
IRB0005240 (HREC1)•IRB0005239 (HREC2)

*The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).*

*The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.*

## Appendix F: Information pack and consent form

# PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

Please see Section 8 of our Health Research Ethics Committee (HREC) Standard Operating Procedures (SOPs) for more detailed information about requirements for Informed Consent (IC). You will find the SOPs here: <http://www.sun.ac.za/english/faculty/healthsciences/rdsd/Pages/Ethics/SOP.aspx>.  
(Please delete this paragraph before submitting your Informed Consent Form (ICF) to the HREC)

<b>TITLE OF RESEARCH PROJECT:</b>	
Exploring the health-related quality of life of women with Premenstrual Dysphoric Disorder	
<b>DETAILS OF PRINCIPAL INVESTIGATOR (PI):</b>	
Ms Meghan Mosalisa	<b>Ethics reference number:</b> S21/05/095
	<b>PI Contact number:</b>

We would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

The Health Research Ethics Committee at Stellenbosch University has approved this study. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

### What is this research study all about?

- Premenstrual Dysphoric Disorder (PMDD) affects an estimated of 2-5% of the overall population of women and causes significant impairment on a woman's ability to function optimally in various areas of her life. There is no research on the impact of PMDD of women's quality of life and the aim of this study is to gain an in-depth understanding and description of the health-related quality of life in women diagnosed with PMDD.
- To find out more about the impact of PMDD on quality of life. I will conduct interviews with approximately 25 women online.

**Why do we invite you to participate?**

- You are invited to participate in this study because you are a woman diagnosed with PMDD.

**What will your responsibilities be?**

- If you agree to participate in the study, you will be invited to an online interview with me, Meghan Mosalisa. This interview will take approximately 45 minutes to an hour and I will ask you about the impact of PMDD on different areas of your life such as your work, interpersonal relationship, romantic relationships and more.
- Agreeing to be a participant in this study will mean that you are responsible for being honest during the interviewing process. However, if you may refuse to answer any questions that you are uncomfortable with. You may also terminate the interview at any point during the interview without providing a reason.
- I ask that you consent to having the interview audio-recorded.

**Will you benefit from taking part in this research?**

- You will not benefit directly from taking part in this research but the information that you share can allow us to gain a better understanding of PMDD.

**Are there any risks involved in your taking part in this research?**

- There are no physical risks associated with partaking in this study. However, because this study focuses on lived experiences and discussing of these experiences could potentially be triggering, details of registered counselling services will be made available for you.

**If you do not agree to take part, what alternatives do you have?**

- If you would not like to participate you may decline the offer to participate.

**Who will have access to your medical records?**

- We will not have access to your medical records.
- All information collected will be treated as confidential and protected. If it is used in a publication or thesis, the identity of the participant will remain anonymous. Individuals who will access the data will be the primary investigator, Meghan Mosalisa as well as the research supervisor, Dr. Rizwana Roomaney.
- The interviews and transcriptions will be kept for 5 years after completion of the study and then destroyed.

**Will you be paid to take part in this study and are there any costs involved?**

- You will be compensated with a R100 Takealot voucher as a token of appreciation and to compensate you for your time and inconvenience. You will also be compensated for your data with a R50 data voucher from your service provider. You will not have to pay for anything, if you do take part.

**Is there anything else that you should know or do?**

- You can phone Ms Meghan Mosalisa at 0835679331 if you have any further queries or encounter any problems.
- You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study doctor has not explained to you, or if you have a complaint.
- You will receive a copy of this information and consent form for you to keep safe.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled Exploring the health-related quality of life of women with Premenstrual Dysphoric Disorder.

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary**, and I have not been pressurised to take part.
- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (*place*) ..... on (*date*) .....

.....

**Signature of participant**

.....

**Signature of witness**

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document in a simple and clear manner to .....
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) ..... 2021.

.....

**Signature of investigator**

.....

**Signature of witness**

**Permission to have all anonymous data shared with journals:**



*Please carefully read the statements below (or have them read to you) and think about your choice. No matter what you decide, it will not affect whether you can be in the research study, or your routine health care*

When this study is finished, we would like to publish results of the study in journals. Most journals require us to share your anonymous data with them before they publish the results. Therefore, we would like to obtain your permission to have your anonymous data shared with journals.

**Permission for sharing samples and/or information with other investigators:**

*Please carefully read the statements below (or have them read to you) and think about your choice. No matter what you decide, it will not affect whether you can be in the research study, or your routine health care.*

In order to do the research we have discussed, we must collect and store interview footage and data and health information from people like you with PMDD. We will do some of the tests right away. Other tests may be done in the future. Once we have done the research that we are planning for this research project, we would like to store your sample and/or information. Other investigators from all over the world can ask to use these samples in future research [*please indicate if the samples will be shipped from South Africa, where the samples will be stored and who will have access to these samples*]. To protect your privacy, we will replace your name with a unique study number. We will only use this code for your sample and information about you. We will do our best to keep the code private. It is however always possible that someone could find out about your name but this is very unlikely to happen. Therefore, we would like to ask for your permission to share your samples and information with other investigators.

**Tick the Option you choose for anonymous data sharing with journals:**

I agree to have my anonymous data shared with journals during publication of results of this study

☐

Signature\_\_\_\_\_

OR

I do not agree to have my anonymous data shared with journals during publication of results of this study

☐

Signature\_\_\_\_\_



## Appendix G: Interview Questions

### Interview Questions

*I am going to ask you a few questions about the impact of PMDD on your quality of life.*

*Please take your time to answer the questions, providing as much or as little information as you feel comfortable sharing. The information that you share will be treated as confidential.*

*If at any time you would like to end this interview you are free to do so.*

1. How old are you? Do you have any children? How many people are in your household? What is your current relationship status? (demographic)
2. Are you employed at the moment? What is your occupation?
3. Can you tell me more about the process you went through in attaining your PMDD diagnosis? What was your experience of the health-care system during this process? Did you speak to friends or family about your symptoms and if you did, what was their response? Who diagnosed you?
4. How long has it been since you received your diagnosis for PMDD?
5. How did you feel when you received your diagnosis of PMDD?
6. What is your current treatment plan?
7. Can you tell me about how your life has changed since you were diagnosed with PMDD? (how life differs now from before diagnosis)
8. Did you hear the term PMDD before your diagnosis? What did you know about PMS and PMDD before you were diagnosis?
9. Tell me about the symptoms you experience as a result of your PMDD?

10. How do your relationships (Social, Familial, and Romantic) differ from before you were diagnosed with PMDD to after your diagnosis?
11. PMDD is related to menstruation, so I am going to ask you a few questions about this, if it is okay with you. How did you experience your first time getting your period? Did you have discussions with family members or friends? How did this shape your experience of menstruation up until now?
12. Would you say the experiences you have had because of your PMDD has been rooted in culture, social expectations or spirituality? Why and how? If so, please tell me more.
- Relationships: Other participants of the study so far have noticed their symptoms are more severe during romantic relationships. Has this been your experience as well? (PMDD Influence relationship or relationship influence PMDD).
  - Feminist Perspective: This perspective does not necessarily agree with a diagnosis of PMS or PMDD. (Labelling of illnesses specifically for women).
    - May allow/promote for further stigma and labelling.
    - Women have reproductive systems and hormones allowing for premenstrual disorders.

## **Appendix H: Interview schedule**

### **Interview Schedule**

#### **Interviewing Procedure**

##### **Prior to Interview**

- Before interviews take place participant will be sent the consent form and information pack.
- Upon receiving signed consent form and recognition that participant has read through information pack, a suitable interview date and time will be established.
- The interviews will be conducted via an online platform, MS Teams or Skype.
- The participant will choose their own space to reside in for the duration of the interview.
- I will advise them in the email that it should preferably be in a quiet and comfortable area for them as the interview will be long and the questions private.
- All interviews will be done from my side in the study at my home. My background will be simple with notes, organization supplies and books.

##### **On and During Interview**

- I will log onto the call on the preferred platform of the participant 10 minutes before the interview is scheduled.
- Upon participants' arrival, I will introduce myself and greet participant. I will then give them a moment to introduce themselves.
- I will briefly discuss the same points that were stipulated within the information pack.

- I will stipulate the intended time frame for the interview.
- I will also take this time to answer any questions participant has regarding interview and research.
- After formalities, I will start the interview and start recording.
- I will proceed to ask the first interview question and follow a structure as set out in the mock interviews with RR.
- The interview will be semi-structured and will be led by questions regarding participants' experiences with PMDD.
- The interview questions will be asked in the following sequence:
  - Demographic questions
  - Medical questions regarding treatment and diagnosis of disorder
  - Prior knowledge about disorder
  - Impact on intra and inter personal life
  - Menarche
  - Cultural and social influence
- Before the last question I will state to the participant that this will be the final question.

**End of interview**

- After the last question I will state that the interview is concluded.
- I will thank participant for the time and contribution to my study.

- I will then communicate all necessary steps relating to payment for participation.