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The subjective experience of Pre Menstrual Dysphoric Disorder (PMDD)

**A qualitative study exploring consequences of PMDD
symptoms in relation to occupational and private life.**

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Abstract

This qualitative essay's purpose was to relay subjective experiences of living with PMDD. The focus of the study was on experiences of: (1) impact of symptoms on the individuals with the PMDD and their workplace; (2) impact on the individual's social life and; (3) what aid is suggested and made available and how they are experienced. Nineteen people with PMDD were recruited from a Facebook page and eleven semi-structured interviews were performed and analysed thematically with a phenomenological approach. Five major themes were found: (a) The impact of PMDD on work and occupational life; (b) PMDD and social life; (c) Psychological welfare and PMDD; (d) Medical shortcomings and; (e) Participants' thoughts. Participants expressed experiencing many negative impacts from conflicting roles between work and private life. It was also found that participants with PMDD overall are negatively affected by symptoms that impinge on their productivity and sociability at work, with a possible economic burden for both themselves and the place of occupation due to, for example, absenteeism. Hope for better knowledge and engagement from the medical world was expressed. These findings could be of interest to research, employers, policymakers, health professionals, and people living with PMDD.

Keywords: PMDD, work life balance, qualitative, subjective experience, phenomenological approach, burden of illness

Abstract - Svenska

Denna kvalitativa uppsats syftar till att framföra subjektiva erfarenheter av att leva med Premenstruellt Dysforiskt Syndrom, PMDD på Engelska. Studiens fokus låg på att undersöka upplevelser av: (1) symptompåverkan på individerna med PMDS och deras arbetsplats; (2) påverkan på individens sociala liv och; (3) Vilket stöd föreslås och görs tillgängligt och hur stödet upplevs. Nitton personer med PMDD rekryterades från en Facebook-sida och elva halvstrukturerade intervjuer genomfördes och analyserades tematiskt med en fenomenologisk ansats. Fem huvudteman hittades: (a) Hur PMDS inverkar på arbete och arbetsliv; (b) PMDS och socialt liv; (c) Psykologiskt välmående och PMDS; (d) Medicinska brister och; (e) Deltagarnas tankar. Deltagarna uttryckte många negativa effekter från motstridiga roller mellan arbete och privatliv. Det visade sig också att deltagare med PMDS generellt påverkas negativt av symptom som påverkar deras produktivitet och sociala förmåga på arbetsplatsen, med en eventuell ekonomisk börda för både sig själva och arbetsplatsen till följd av till exempel frånvaro. Även hopp om bättre kunskap och engagemang från den medicinska världen uttrycktes. Dessa resultat kan vara av intresse för forskning, arbetsgivare, politiker, vårdpersonal och personer som lever med PMDD.

Nyckelord: PMDS, arbetslivsbalans, kvalitativ, fenomenologisk ansats, sjukdomsbörda, subjektiv upplevelse

At the beginning of writing this paper, the task seemed daunting. Yet, I wanted to write an honest representation of what it is like living with a diagnose as invasive as PMDD and felt that there is a true need for this kind of knowledge. All in all, the endeavor has been very intense but also, so rewarding.

My warmest thanks to all of the amazing people who participated in this study, who took time out of their lives to share on matters rarely are easy to talk about. Without you, this paper would not exist.

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Premenstrual Dysphoric Disorder (PMDD) is a severe form of Premenstrual Syndrome (PMS) where hormone-related disruptions in mood and mood regulation impair at least one aspect of a person's day to day functioning, according to The American Psychiatric Association (2013). In their review of the literature on the prevalence and burden of illness of PMDD, Rapkin and Winer (2009) estimated that approximately 3-8% of menstruating people suffer from PMDD and that this illness brings significant burdens: (a) to individuals and their family owing to impact of PMDD on their day-to-day functioning and mental health; (b) to the employer due to the cost of sick leave, absenteeism and lowered capability to perform and; (c) to society at large given the significant use of healthcare resources and lost work-time experienced by individuals with PMDD.

While much research has been done to identify the impact of PMDD on various areas of functioning and on quality of life, such research has been carried out, according to Gehlart, Chang, Brock and Hartlage (2006), using broad measures of impairment and health-related quality of life, i.e., measures that are not specific to PMDD. Also, little research has been based on the direct experience of people suffering PMDD. Subjective experiences are varied and give a wider spectrum of understanding for a phenomenon, which is extra important in the cases of such complex diagnoses as PMDD, that not only affect in one area of life, but many (i.e. psychologically, occupationally, physically, socially and more). Therefore, more qualitative studies are necessary, and more research is needed to develop and validate PMDD-specific measure of illness burden and quality of life, and this should be done with input from individuals with PMDD (Gehlart et al., 2006).

Aim of this essay

This qualitative study based on a phenomenological framework endeavors to relay the subjective experiences of private- and work life for people with PMDD. It will examine personal experiences of: (1) how having PMDD affects work efficiency, quality of work, social interaction and overall work-based well-being; (2) how having an occupation while juggling symptoms of PMDD affect the individual in private life; (3) what aids are available and how they are experienced and; (4) what could be possible solutions, according to the individuals, to help them cope with combining work/private life and PMDD in the best possible way.

This thesis should be of interest for future research, organizations, and places of occupation as well as on a societal/political level as it will touch on issues closely connected to the well being of many individuals from a population.

Clarification: In this essay use of the word “person” instead of “woman” will be preferred, as women who have transitioned into men, still can be living with PMDD and should therefore also be included as sufferers from PMDD.

Theory

Definition, Prevalence and Symptoms of PMDD

PMDD received official recognition with the publication of the Fifth Edition of the APA’s Diagnostic and Statistical Manual of Mental Disorders (DSM-V; APA, 2013), as PMDD was included in the section for affective disorders for the first time. To meet criteria for diagnosis, DSM-V (APA, 2013) states that for most of the sufferer’s menstrual cycles over the past year, the person must have, in conjunction with the luteal to remittent phase, experienced at least five of the eleven following symptoms: (1) Depressive mood; (2) Anxiety/Tension; (3) Labile mood; (4) Irritability/Aggression; (5) Social withdrawal/disinterestedness in usual activities; (6) Difficulty concentrating/confusion; (7) Fatigue/tiredness; (8) Appetite changes (cravings, overeating); (9) Hypersomnia/insomnia; (10) Feeling out of control/overwhelmed, or; (11) Physical symptoms, including: breast tenderness, bloating, acne, joint- and muscle pain, headaches and swelling (APA, 2013). In addition, one of the five symptoms must be affective in nature and the symptoms must be so severe that they impair the individual’s ability to function in at least one area of their life (e.g., work, personal care, family/social life) (APA, 2013). To give a short summary based on abovementioned theory, PMDD means that those who suffer from it can experience an array of mental and physical impairments for many days every week, and that the symptoms are so burdening that it in many ways make life difficult for the person as well as for the person’s surroundings. It is difficult to pin-point what the diagnosis is, or what it does to a person, as it is so different from individual to individual. Therefore, qualitative surveys like this should be helpful in providing different perspectives on what shapes and forms the diagnosis can take.

Moreover, the DSM-V criteria for PMDD have been criticized. Janda, Kues, Andersson, Kleinstäuber and Weise (2016) lift an ongoing discussion on the inclusiveness (or lack thereof) of the DSM-V criteria for PMDD. They argue that 10 of the 11 symptom criteria are affective in nature and so individual’s whose symptoms are mainly physical in nature might be excluded from diagnosis and the healthcare they require. Appropriately, Rapkin and Winer (2009) conclude that while epidemiological studies estimate the 12-month prevalence of PMDD as defined by DSM-V is approximately 3-8% of menstruating people, , between 13% and 18% of menstruating women are likely to suffer from both mental and physical premenstrual symptoms of sufficient severity to cause impairment and warrant treatment.

Eisenlohr-Moul et al. (2017) have also argued that the DSM-V criteria lack sufficient levels of construct validity, i.e. the criteria do not capture the heterogeneous nature of the condition. This, in turn, poses a threat for identifying PMDD sufferers and developing effective treatments (Eisenlohr-Moul et al., 2017). They developed a measure called the C-PASS (the Carolina Premenstrual Assessment Scoring System) which includes a broader range of physical symptoms. They have found that use of this measure used alongside assessments of the DSM-V criteria yields greater sensitivity (i.e., is more accurate at detecting women with clinically significant symptoms of PMDD).

Quality of Life and Burden of Illness

As PMDD is frequent and comes with heavy symptoms, this section will look into what different studies have found about the impact of PMDD, and how it affects people's lives.

Different studies have been made in an attempt to measure the impact of PMDD on people's lives. Firstly, Rapkin and Winer (2009) measured the burden (impact) of PMDD on an individual's life. They pointed out that PMDD is affected by personal factors such as age, ethnicity and overall health (mental and physical). They studied the impact of PMDD on people's lives through looking at three key points: (1) the medical cost of PMDD; (2) Impact on an occupational level due to PMDD and; (3) HRQoL of a population in USA with PMDD. HRQoL is a method of measuring the impact of a disorder on an individual's or group's mental and physical health over time. It is used by, among others, The Center for Disease Control and Prevention (CDC) in their endeavour to pre-empt poor health in populations.

It was, as mentioned, calculated by Rapkin and Winer (2009) that a person with PMDD sometimes has approximately only 7-10 days/month without symptoms. It was also calculated that on a life-spectrum, a person menstruating between ages 14-51 (normal span of fertility) who has had two children (=22 months free of symptoms), will have gone through approximately 459 cycles which amounts to 2800 days (7.67 years) of severe premenstrual symptoms. The authors reached a conclusion that PMDD has an impact economically on the individual's level due to absenteeism, decreased productivity and costs for healthcare.

They also found a significant impact on public health due to PMDD, as severity and consequences of the diagnose often are overlooked or minimized by policy makers, regulatory agencies and medical instances (Rapkin & Winer, 2009).

Psychological- and Behavioural Impact of PMDD

Rapkin and Winer (2009), as mentioned above, estimated the burden (impact) of PMDD on an individual's life and found significant impact on both behavioral and psychological aspects.

A study made by Craner, Sigmon, Martinson and McGillicuddy (2013) corroborates the findings of Rapkin and Winer (2009). The results they got showed that people experiencing moderate/severe PMS or PMDD reported on a significant health-related QOL burden, where these people also experience higher levels of health anxiety and anxiety sensitivity. Therefore one could assume that the psychological impact of PMDD is so harsh that it also affects a person somatically/physically.

Lastly, a study by Shiola, Lowin, Lindemann, Patel & Endicott (2011) draws the same conclusion as the studies mentioned above where burden of disease was proven to impact a persons activities significantly. Their analysis also suggest that significant cost burden can be associated to moderate/severe PMS and PMDD due to medical aspects, making it costly both for the individual as well as for society. This is interesting to this study as: (1) people with PMDD do in fact need medical help (for example therapy and medication to alleviate the psychological impact of the diagnose) and; (2) as economy might be yet another stressor to affect people living with PMDD and; (3) the psychological well-being of a population has an impact on a society's economy.

How PMDD Impacts on Occupational Life

Again, the complexity and severity of PMDD make for impinging on a person's adeptness at work. This section will be examining research made on how premenstrual symptoms affect work capability and work satisfaction of the individual, as well as consequences for the place of occupation due to employees with premenstrual symptoms.

Heinemann, Do Minh, Filonenko and Uhl-Hochgräber (2009) made a multinational study on work productivity and absenteeism due to PMDD and concluded that moderate-to-severe premenstrual symptoms (PMS/PMDD) seem to be associated with work impairment and therefore could be liable to a potential economic burden for the individual. They also pointed out that interference from PMDD is not only limited to work life, but also affects a person's ability to function within other settings such as school and home. These findings are supported by a recent study made in Japan by Tadekawa, Takeda, Monma, Koga and Yaegashi (2016), where 1 in 9 female students was proven to be absent from school due to premenstrual symptoms. A study of Turkish nurses by Sut and Mestogullari (2015) also found that premenstrual symptoms impacted heavily on work-related quality of life through creating anxiety, tension, and proneness to conflict.

Interestingly, another study can be derived to suggest that the habit/prevalence of being absent from work and asking for medical help could be bound to cultural frameworks. Schiola, Lowin, Lindemann, Patel and Endicott (2011), made a study on PMDD in Latin American people where an association between disease burden on professional and social activities and severity of diagnose was found. Yet, they did not find a clear relationship between cost burden or quality of life due to illness severity. The authors regard that these findings are opposed by other studies and previous analysis, and discuss if a possible reason for the results could be that people in Latin American countries are less likely to: (1) adhere to costly medical options (e.g. treatment, therapy) and; (2) opt for absenteeism due to illness.

Another aspect of where symptoms of PMDD has an impact is at places of work. Organizational Psychology has for a long time been interested in relationships of individual's mood, environment, and emotional experiences, and international studies have been made on how premenstrual symptoms affect work proficiency and on economic levels. A general theory on work/environment/mood exists through for example Landy and Conte (2013). They present that substantial evidence has been found that indicate that moods and emotions play a major role in behaviors at work such as productivity, problem-solving, organizational citizenship and withdrawal from social interaction. Signs of withdrawal that has an impact on the organization are, for example, manifested in lateness and absence from work. Landy and Conte (2013) also discuss the importance of work-family balance, i.e. where satisfaction in one area of life (e.g. work) affects the satisfaction in another area (e.g. family) and vice versa. A balance between both different areas is the best place for wellness for the individual (Landy & Conte, 2013). Part of the theory is looking at exchanging of roles with a realization that moving from family role to work role back to a family role has an emotional impact (Landy & Conte, 2013). Work-family balance theory is of interest to this study and will be explored, as little research has been made so far on how role-balancing is impacted by PMDD, and given that the symptoms of PMDD are present at least half of the days in every month.

Medical Options and Possible Treatments

As PMDD has such an impact on individual's lives, an existence of adequate aid could be deemed imperative to help facilitate well-being on both personal and public health levels. Rapkin and Winer (2009) pinpoint the importance of medical help in their quote: "The burden of illness of the premenstrual disorders can be substantially reduced if clinicians take these symptoms seriously. Treating practitioners need to be aware that moderate-to-severe premenstrual symptoms are very prevalent and are not trivial" (p. 14). The authors report that

it was a common experience among people who asked for medical help to be told that the symptoms were “something they had to put up with” and that doctors lacked understanding.

Similarly, Lete et al. (2011) found in their study that it is not to be taken for granted that people with premenstrual symptoms seek medical help. They examined attitudes of Spanish people experiencing PMS/PMDD and found that only 18.6% of participants had asked for medical advice. A reason for this was a common conception for the people of their study to think that their symptoms were normal. Again, here a socio-cultural framework can be traced. If compared to the study of Corney and Stanton (1991) and Campbell, Peterkin, O’Grady and Sanson-Fisher (1997) who separately studied premenstrual symptoms in British and Australian people, they found that approximately 50% of all individuals in both studies had reached for medical contact. Lete et al. (2011) also described how 20% of individuals searching help from doctors did not find an adequate response to their needs due to practitioners’ attitudes. They report on indications that medical personnel seem to lack interest and/or knowledge of the severity of premenstrual symptoms, thus not recognizing PMS and then failing to diagnose or treat the symptoms.

According to Kelderhouse and Taylor (2013), the most common forms of treatment for premenstrual symptoms and PMDD are medication, followed by lifestyle management and cognitive behavioral therapies. The most frequently prescribed pharmacological agents for PMS/PMDD are selective serotonin reuptake inhibitors (SSRIs) and oral contraceptives (OC), with the latter having the best overall effect on people's well-being (Rapkin & Winer, 2009; Kelderhouse & Taylor, 2013).

Lete et al. (2011) studied the impact of oral contraceptives on people with PMS and found that a majority of sufferers experienced some benefit from the use of these medications but approximately 16.3% of participants reported a worsening premenstrual mood deterioration due to the pills. According to Lete et al. (2011), there are no regulations or uniform criteria within practitioners on when to prescribe oral contraceptives.

Other options for lessening the symptoms of PMDD are found outside of the pharmacological area, for example, lifestyle recommendations, attention to nutrition and diet, exercise, and cognitive behavioral therapies (CBT), (Kelderhouse & Taylor 2013; Shulman, 2010). But according to Lete et al. (2011), aside from medication there is no evidence for efficacy of any non-pharmacological treatment except for CBT, eating the chasteberry/castus fruit and calcium supplements. Also, the effects of treatment on HRQoL and psychological well-being are under-studied, and when studied, often used are measures developed to assess the burden of physical symptoms and not PMDD specifically

(Rapkin & Winer, 2009). This study might give some insight into possible other means of help through the experience of people who cope with the symptoms.

Author's Preunderstanding

Worth mentioning is that I myself suffer from PMDD. I was diagnosed while participating in a study in 2012, and have since then received some help from the medical arena as well as put a lot of time and effort into understanding the diagnosis better. Therefore, I do admit to having a vast foundation of knowledge when planning, preparing and executing this thesis, which is both helpful and something for me as the researcher to be mindful of. This study will in some measure be influenced from my own experience, having both lived and worked with the symptoms for a long time, but it is of utmost importance and the only interest of this study to represent what other people with PMDD are experiencing. Therefore, much of the planning of the interview guide will be based both on my experience (what areas to generally investigate) and on other empirical material combined (more targeted questions, f.ex experiences of role, monetary experiences and similar). During this work, I will be reflexive and use methods of analysis that as little as possible invite my pre-existing knowledge to influence the process.

From now on, this paper will examine, in accordance with the stated purpose (above), how individuals living with PMDD experience different aspects of life. This, to provide actual, concrete input to existing theory with the hope for effective solutions and help for people with PMDD, which in turn can contribute to the well-being and participation of an entire population in society.

Method

Phenomenological Approach

So the aim of this essay is to explore the subjective experience of people with PMDD, on how it impacts their work and social life. To achieve this goal, qualitative interviews with a phenomenological framework were carried out, that searched for themes among the responses of the participants to a set of predetermined questions. In carrying out the interviews and the thematic analysis, an article by Braun and Clarke (2006), who describe the different methods of qualitative and thematic analysis, was used as a guide. Especially their discussion of thematic analysis was useful, which is described below.

According to Bryman (2011), a phenomenological approach can help to bring clarity when exploring how an individual makes sense of one's reality and surroundings. Therefore, a phenomenological approach seemed as the most appropriate to use for this essay. To

understand the behavior and thought process of a person, the scientist has to overlook her preunderstanding (assumptions) and instead try to see the world through the participants perspective. Therefore, thematic analysis (see below) was applied to this perspective to try and deduce experiences that are specific to PMDD and yet common across PMDD sufferers, as I hoped to gain information that might be used to develop a quality of life scale that is specific to PMDD.

Following the phenomenological approach, it was my intention to try and keep my own experiences as a PMDD sufferer from influencing the answers of the participants. Still, as I had a specific aim to understand how PMDD impacted functioning in others in different areas of life, I produced an interview guide. The guide included a set of open-ended questions that would be asked of every participant and which took inspiration from: (1) studies on the functional impacts of PMDD; (2) experience gathered from people living with either PMS or PMDD from the authors own social group, and (3) knowledge gaps in the existing research on the subjective experience of living with PMDD.

Thematic Analysis

According to Braun & Clarke (2006), the purpose of thematic analysis (TA) is to find patterns ("themes") in the collected data. A 'theoretical' TA was used as a research design and tool for analyzing the data sampled through the interviews. It is a widely used, analytic method (Braun and Clarke, 2006) as it is flexible (not tied to any preexisting theoretical assumption) while being acute and detailed (doesn't impose on the complexity in the data). Also, the analysis was made on a latent level where the participant's semantics (use of words) can be assumed to have been shaped by experience (Braun and Clarke, 2006). This, in theory, means that by applying thematic analysis to the participant's responses one may obtain insight into what it is like living with PMDD, and this opens the possibility of deducing PMDD-specific "impairment themes" that might be used to create a PMDD-specific quality of life measure.

Because the essay is based on an phenomenological approach seeking to explore the subjective experience of living with PMDD in relation to being part of work life, TA was an appropriate method of analysis.

The interviews were recorded and then transcribed by hand, verbatim. The analysis process began immediately in parallel with transcribing the interviews. I would pause the recording as I made the transcriptions and put notes in the text margins that summarized what was being said. When the transcription was done for that particular interview, I went over the notes that gave a full, summarizing picture of possible themes. This was the first step of the

analysis process and it was repeated for all eleven interviews. A detailed description of the analysis process is provided below.

Participant Selection Process

Participants were eleven women who were recruited from a Swedish support group on Facebook that exists for people living with PMDD and their loved ones (<https://www.facebook.com/groups/1378241995761974/>). The group has around 950 members and was established in December of 2013 by Anna Elvira. I chose to recruit participants from this particular group as it was a good source for finding the target population, and as it was an open-minded group where people were not afraid to open up about PMDD. As for being diagnosed, nine of the eleven participants in this study had consulted medical personnel about their symptoms, and on that basis received a diagnosis of PMDD. The two remaining participants received a PMDD diagnosis after undergoing a lengthy diagnostic investigation.

The recruitment process worked as follows: first, notifications were posted on the group wall explaining the study and its purpose, and people interested in participating were asked to make contact through Facebook chat/messenger; second, from among the list of group members that indicated that they were currently employed, contact was made by private chat, asking if they'd like to participate. Altogether, nineteen people were interested in participating and selected. These individuals were then directed to a private Facebook page that I had set up for the participants, where further information about the study was posted: see (Appendix C), the questions that would be asked during the interview (Appendix A), and the consent form. These nineteen individuals signed the consent form, and returned it to me by private email. After that, a time for an interview was arranged.

No set number was decided beforehand on how many participants were needed, but an estimate was made of 10-15. Instead, as Eriksson-Zetterquist and Ahrne (2011) suggest, the goal was to reach a saturation where similar patterns in answers were detected. Such a pattern occurred after 11 interviews, and therefore no further participants were interviewed. To summarize, 11 out of a group of 19 people from different age groups (average age of participants = 27,5 years), work-areas, years with work experience and PMDD symptoms were interviewed in a semi-structured way about their experiences within the areas presented in the interview guide (Appendix A).

The differences among participants made for a relatively heterogeneous sample that still shared many similar experiences. For example, due to the way work and life around working generally is constructed (for example work hours by custom are between 8am to

5pm, expectations and duties put on the individual, switching between roles such as role at work and a family role), all participants were assumed to share some experiences..

Interviewing

According to Eriksson-Zetterquist and Ahrne (2011), interviews are a central method of gaining knowledge in societal studies and favored when students and scientists aim to gain more knowledge about conditions within certain social environments. Moreover, as this study is aspiring to define the essence of what having PMDD is like, and the argument for an phenomenological approach in combination with TA is that a relationship can be assumed between what the participant says and her experience (Braun & Clarke, 2006). Therefore, analyzation of transcripts will give direct insight, as well as the possibility to deduct meanings and theorizations around the subjective experience of living with PMDD in work life. As beforementioned, an interview guide was constructed that held the areas of interest for this study, as well as some examples of questions (see Appendix A). Some questions were formatted from previous research done on PMDD while others came from an interest in finding out more about gray areas, where little or no scientific research yet has been done. Each interview was expected to take between 20-30 minutes but an hour was always made available if the interviewee wished to consolidate or debrief.

Interviews were made one on one with open, semi-structured questions. Semi-structured interviewing was chosen as it is, according to Bryman (2011), an open and flexible method of gathering data where both participant and interviewer have the freedom to talk about related subjects and to give deeper and more descriptive answers. Apart from finding only the answers one is looking for, new perspectives can also be found. Of importance was to touch on every subject in the interview guide, but not in a specific order.

All participants had been given the interview guide in advance, to provide them with the possibility to have a think-through on the areas of questioning as well as to heighten their comfort level. This, as the subject of this essay is not something that is talked about, as well as that PMDD is a topic that comes with a stigma ("female issue," authors specification), so it was important to give the participant the option of weighing in in advance on what she felt comfortable talking about.

Overall the interview guide served as the framework during the interview from which it was easy to digress from and get back to. The areas of interest in the guide were meant to make for a holistic view on the experience of working with PMDD. The interview started in the same order where the participant was asked some basic, demographic questions, followed by an open question on her symptoms. From there, areas such as the social impact of PMDD,

hardships of PMDD, work related issues due to PMDD (both for the participant and workplace) and whether she does something to alleviate her symptoms followed, in random order. Lastly, it was of interest to gain insight in what type of work or what sort of circumstances within a job place that could be helpful, both for the woman suffering PMDD and the workplace. All participants had read through the guide and understood the questions, and no clarification was needed.

The interviews were carried out over the internet: by skype, facetime or Facebook video chat. The reasoning behind this set up was a) participants might not be close enough for a face-to-face session, b) using the internet did not take away the possibility of visual or aural contact and c) the participant can choose her setting. According to Hedin (1996), surroundings and attributes such as clothes can have an impact on participants comfort. Therefore the last consideration was important, as the comfort of the interviewee was a priority.

The interviews were conducted in Swedish, the participants' and interviewer's mother tongue, which eliminates/lessens threats to internal or external validity through misunderstandings or inability to explain oneself the way one intends to.

As Hedin (1996) points out, interviewing takes a lot of time and focus. Therefore every day from the 20th to 31st of March (apart from Sundays), between 8 am-8 pm was made available for conducting interviews. Taken into account, was that the subjects for research all have a disorder that made half a month not optimal for an interview, and that they also are working people, it was important to make as much time available as possible so that cancellations would not pose a risk for the internal validity due to participant loss.

Data Collection

Interviews were scheduled continuously through private messaging on Facebook. Also, a Doodle-link was shared in the private Facebook group. Participants who followed the link came to a page with suggestions on available dates and times during the chosen two-week period, and they could submit their preferred option. Only three participants utilized the doodle link.

One, at a maximum two, interviews were scheduled each day during the two week period, making for approximately 7-10 interviews/week. As mentioned, all interviews were performed through either Skype, Facebook video chat or Facetime. Spoken language was Swedish. The interviews were recorded through the built-in voice recorder on an iPhone 6, and the sound file was uploaded to a private, password-protected Google Drive folder. The audio file was immediately deleted from the phone, all in accordance with Eriksson-Zetterquist and Ahrne (2011): "You could in general say that the technique used must be

readily available and trustworthy" (p.53, Authors translation). Transcription á verbatim was made immediately after an interview using Word online and Microsoft Music's sound app (directly connected to one drive) "Groove".

Each meeting was started off with a recap on the purpose of the study and the participants right to decline to answer or to participate. The participant had the opportunity to ask questions and talk about one's comfort zones concerning the study's areas of interest. None of the participants said they experienced initial discomfort or that they would decline to answer any of the questions. After that, demographic questions (age, diagnose, perceived burden of PMDD, area of work, and work-life experience in years) were asked. The participants were also asked to asses their general (most prevalent) symptoms.

Mentioned above was that pre-existing questions were to act as a framework during the interviews, as they did, but without imposing on the integrity of the participant's story. Questions touched on each area from the guide, but each conversation developed naturally with a few leading questions from the researcher. In other words, questions were presented in different orders depending on the participant's interest, and during the conversation, one topic could instinctively lead to another. Through this, as became evident during data analysis, unexpected themes had emerged which made for a deeper analysis of the data. Therefore each interview had similarities with the others while giving a unique account of one person's experience. Before ending each interview, it was made sure all areas of interest had been covered. A debriefing was offered to the participant, and performed when accepted, before ending a call.

Data Analysis

A multi-step process initiated the analysis, see D for a photographic reconstruction of the progression. First, every audio recording of each interview was listened to and transcribed verbatim. Transcription was done by hand in Microsoft word, and printed out. Immediately after printing, the transcription was read through and notes were scribbled in the margins. (Image I, appendix D.). In the third step, which Braun and Clarke (2006) refer to as "Phase 2", consisted of thoroughly reading through all data iteratively (repeatedly) from beginning to end, focused on an essentialist/phenomenological interpretation. All in all, each transcript was read through approximately 3-4 times. Further notes were made, and a picture of how to operationalize symptom descriptions emerged through deducting what was described in the data (Bremner et al., 2012).

Following Braun and Clarke (2006), a final step had the aim of collecting all sub-themes as well as all extracts of data that had been coded in relation to the themes. So, parallel

to thoroughly analyzing each transcription once more, handwritten mind-maps summarizing the codes for each transcript were made (image II, Appendix D). One page was allocated for each transcript, which easily accommodated an overview the transcript's codes. Again, following Braun and Clarke (2006), all codes from the individual mind maps were transferred into one basic mind map where themes and subthemes were fitted into principal themes (see image III, Appendix D). This was done with the purpose of gathering similar codes under one coherent theme, as this essay's purpose is to examine the experience of a specific group, not an individual.

Finally, a test of validity was made by comparing each individual transcripts to the full dataset. As a result, some new themes emerged, and others were merged together. The final product was a map of themes that accurately correlated with the full data, meaning that the essence of participant's experiences were represented and the plan gave a good summarizing overview (Braun & Clarke. 2006). Illustrative quotes representative for the various themes were translated into English by the author of this paper, printed out and sorted into easily accessible envelopes dedicated to each subject (image IV, Appendix D). The thought behind this was to allow for maximum effectiveness and overview of the data.

Ethical Aspects

The study was conducted according to the four principles of ethical science, stated by Vetenskapsrådet (n.d.): (1) informed consent; (2) the principle of information; (3) the principle of confidentiality, and; (4) the principle of privacy. No prior approval from the Swedish Research Council's Ethics Committee was asked for or required for this study. Only individuals who gave informed consent were permitted to participate. Information about the study was posted on the wall of the Facebook PMDD group, including the fact that all interviews would be confidential and no identifying information included in the study. Subsequent contacts with potential participants were done privately, and further written information was given. Just prior to the interviews, the participants were again reminded of the purpose of the study, that all information was confidential and that they could discontinue participation at any time either before, during or after the interview and all of their data would be deleted. Once the interviews were transcribed, the recordings of the interview were deleted. The transcripts themselves contained no identifying information except age. And when the transcripts were thematically analyzed and summary sheets created, the transcripts were deleted. In reporting the findings of the interviews, no identifying information was provided.

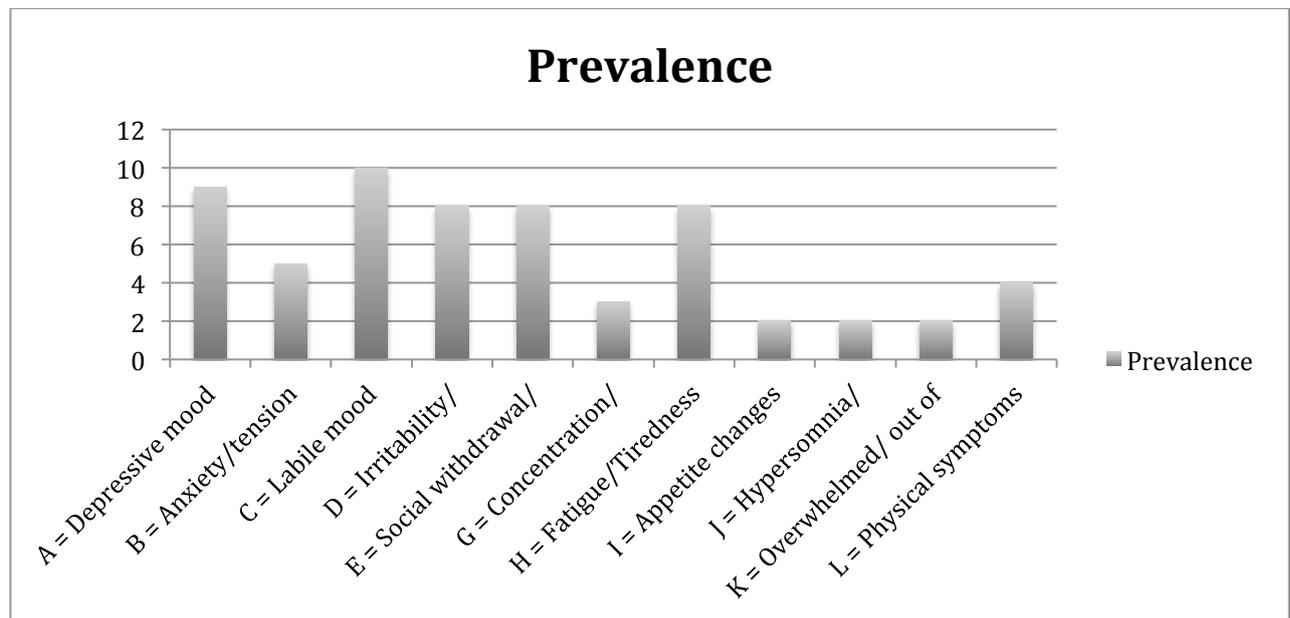
Results

Participants were asked to describe their experiences of working and what kind of work they perform (physical/psychological, full time/part time and similar). Work was defined as: (a) having a designated place to go to, (b) where expected to perform duties/work specified by another party such as an employer, buyer, customer, client or similar during, (c) by other party specified time limits and (d) receiving a monetary reward/salary. As all participants came from different work backgrounds, the spectrum of duties, workload, responsibilities, and work expectations were very broad. Tables 1 and 2 below summarize the demographic information given by this study's participants. Also, see Appendix B for participant's descriptions of how they experience the symptoms described in DSM-V.

Table 1. An overview of the study's participant's amount of work experience, workload and experienced symptoms.

Participant	Years of work experience	Workload	PMDD symptoms
1	6	Fulltime	B, C, D, E, G, H
2	16	60-100%	A, B, C, D, E, F, H
3	2	Fulltime	A, B, C, D, L (1+)*
4	1	Fulltime	A, E, F, K, H
5	13	Fulltime	C, E, H, L (1+)
6	13	Fulltime	A, B, C, D, E, L
7	20	Fulltime	A, B, C, D, E, G, J
8	18	60-100%	A, C, H, L (1+)
9	2	Freelance	A, C, D, H, I
10	17	Freelance	A, C, D, E, F, G, H, I, J, K
11	6	Freelance	A, C, D, E, H

Symptom index: **A)** Depressive mood, **B)** Anxiety/Tension, **C)** Labile mood, **D)** Irritability/Aggression, **E)** Social withdrawal, **F)** Decreased interest in usual activities, **G)** Difficulty concentrating/Confusion, **H)** Fatigue/Tiredness, **I)** Appetite changes (cravings, overeating), **J)** Hypersomnia/Insomnia, **K)** Feeling out of control/Overwhelmed, **L)** Physical symptoms
 *(1+) = More than one symptom of physical pain

Table 2. Prevalence of symptoms per participant.

Impact of PMDD on Work, Work-life and Place of Occupation

Participants were asked to describe their experiences of working and what kind of work they perform (physical/psychological, full time/part time and similar). "Work" was defined as: (a) having a designated place to go to, (b) was expected to perform duties/work specified by another party such as an employer, buyer, customer, client or similar during, (c) by other party specified time limits and (d) receiving a monetary reward/salary.

As all participants came from different work backgrounds, the spectrum of duties, workload, responsibilities and work expectations was very broad.

There was no set minimum limit for how much time spent working was required for being eligible to participate in this study, yet every participant had experienced more hours of work than when having had only one summer job. Even that amount of time was deemed to be enough for a woman with PMDD to get a good picture of what it is like holding a job when being symptomatic.

Effects on productivity, effectiveness and personal wellbeing.

When asked about their work attitude when not hormonal, all participants saw positive aspects of work. Only one said she would rather not work at all than to have a job. All participants also expressed liking their particular line of occupation and otherwise being active and enthusiastic about duties, work-related challenges, social contacts and the change of scenery from home for those specific hours.

The participants were asked to describe both how work affects them as well as reflect upon how their PMDD might affect the work they do and the workplace. A shared experience was an often noticeable decline in all abilities that otherwise would make for extraversion, engagement, productivity, and quality of work.

I have difficulties making decisions and I get caught up in myself. It's a huge difference in the social part of work. I stay to myself and can't bare bigger contexts. I'm not as good at cooperation as I am otherwise (...) I have energy to do a lot more when I don't have these hormonal fluctuations. Those days I am more engaged and able to focus. But the hormonal days... Yeah, I only do what I must do. Nothing more.

When I'm not hormonal I'd easily work all 24 hours of the day, but when I feel awful and tired like during PMDD, I'm not able to do anything else than 'extinguishing small fires'. I fidget around more, and it's really hard to focus. It really has an impact on my self-esteem.

Though most participants (9 of 11) expressed still being able to somehow pull through a work day, albeit often at a significant cost of personal well-being, it wasn't unusual behavior to sometimes cancel or make up a reason for absence. See narratives below:

I don't know exactly when the PMDD is going to happen. But I have cancelled things because I've been so out of it.

Question (Q): Would you say any of these symptoms have affected your work life?
Yes absolutely, in every way, but especially with the fever as I really do get sick once a month.

I can probably say that 8 out of 12 months there's always a few days I've called in sick. And sometimes I've kept the children at home instead and VAB:ed. So that no one can question why I stayed at home. (VAB = Vård av sjukt barn, is the Swedish equivalent for paid absenteeism for care of sick child, author's note.)

Because I have a severe form of PMDD, even my doctor said so... It lasts between 2-3 weeks a month, so I really don't know how I'd manage working the way one is

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

It was not unusual for participants to note that their symptoms might affect their career and career progress:

I believe it takes more steps for me to succeed than for someone who don't have these hormonal issues... Just the fact that I want to kill myself because I feel so bad and worthless, It's a hinder that I need to overcome every month.

Mainly two participants particularly expressed a constant worry of severe negative repercussions because of having symptoms at work. One gave an account that proves this is a likely scenario:

I suppose I've been released from a position a few times, and such because I like... I throw fits on patients and such...

Social functioning in the workplace. Most participants described a decline in social capacity. When asked to explain how this might be expressed at work a variety of scenarios were presented. Commonly decline in social function was experienced in having less energy or interest in fellow humans/colleagues/people:

I do a good job when demonstrating products for example. Meaning, when I'm not hormonal. Then it's a different story. Then I don't want to talk to people, I'm just cold and empty.

I can definitely say that it (PMDD) has affected me in my occupational life. We have customer contact, and during PMDD I do *not* want to take on jobs around people. I simply don't have the energy to be nice! And then I have to tell my colleague that 'now you deal with the customer and I go over here and do this'.

Another aspect of a social burden when hormonal, was experienced in being irritated, aggressive and paranoid to the extent that it affected choice of work-shifts, relationships between colleagues and self-esteem while hormonal:

I do mostly point efforts and that might have to do with PMDD, that I feel I've, when I'm hormonal, gotten angry at people that I feel are not doing enough. And that...That doesn't work out too well.

Nowadays I work nights. And that's because I didn't get along with my colleagues, I felt. Especially those hormonal days.

I react to my colleagues, I become paranoid. Start thinking that they're talking behind my back and such.

Economic burden of PMDD. When talking about the difficulties that occurred due to PMDD at work, the question of staying home or avoiding work came up with most participants. It was debated from many aspects, and those who chose to go to work even though feeling they shouldn't, often brought up the issue of economic repercussions:

I wish I could be able to work 75%, but I never would as it is now. I'd lose too much money on that. (...) I feel that if I could strike up a deal with the boss, that I could take two days a month or such from home, like sick days without economic sanctions, that would enable me to take it easy and be without pressure. Because those only create more anxiety. That's good for no one.

Calling in sick isn't good either because I need that money. The more you're absent sick, the less you make. No, it's completely hopeless, I feel. I mean, you can't live without money, and money you get from either working or winning the lottery. But you need money to buy those tickets. So yeah, I get that I must work. But I'm terrified to do so.

Summary. Within the area of *'The impact of PMDD on working, work life and the place of occupation'*, three major themes were identified: (1) *Negative effects on productivity, effectiveness and personal wellbeing*; (2) *Social functioning in the workplace* and; (3)

Economic burden of PMDD. Participants' accounts framed such difficulties as productivity, quality of work, effectiveness, absenteeism, social difficulties and economic worries.

PMDD and Social Life

Work life vs. Family life. Work-family balance, as mentioned above, has an influence on a person's overall well-being and satisfaction. Participants were asked whether the switching between work- and family role invoked extra stress in their lives considering the symptoms of PMDD. It was found that the participants of this study had similar accounts of work-life imbalance due to the extra burden of PMDD:

I become really tired and blue. I just want to lock myself in a room and hide under a duvet and not talk to or see anyone. And I'm completely disengaged and don't take initiatives. (...) I usually go straight into the bedroom and hide in bed, just to collect myself. Some days I say nothing at all during the whole day. Maybe only 'yes' or 'no' to my partner... And he gets annoyed with me then. It's probably pretty awful living with me when I'm hormonal.

I sleep very, very much during PMDD, I always go to bed at 8 pm with the kids. So yeah, there's no room for anything social apart from the kids.

Another participant narrated the bias of work- vs. family roles and the toll it took on her personally and family wise:

I've always been socially oriented in my job. And that's something that to me became, unfortunately, something that took too much from me and I had no energy left after work, when I got home. (...) There's always been that feeling of never being enough as a mother, you come home tired and annoyed. And I've always said that I'd never prioritize work before my kids, but in reality that is what has happened. (...) Especially when I was hormonal and went to work though feverish or such... There was nothing left of me when I got home in the evening.

Talking about PMDD. Talking about PMDD. An area of interest from the interview guide was whether the participants felt they could choose to open up about PMDD at work and among people. The most common answer was that it would not be spoken about at work

unless a very friendly and familiar atmosphere reigned and the colleagues were more like friends. This, as many (7/11) of the participants expressed, would often be because of fear of stigma and scepticism, as these three accounts will illustrate:

I remember one occasion when we were discussing PMS generally with a male colleague and he.. His stance was that he snorted and thought it was all “made up”. Because he was of the mind that you could “man up” at work if you were one of those who don’t cry or create scenes all the time. I should add that the same colleague shared a student with me who had a form of Tourette’s syndrome but never tic:ed (spasm) in class, he/she was somehow able to control it. But when he/she got home, he/she just collapsed and felt completely under the weather. And this colleague would never dream of saying “man up” to that student, like he did about PMS-issues!

Q: Would you talk about having PMDD at your work?
 No. Because.. You know, people joke. ‘Oh, PMS. F*cking PMS-bitch’, Like that. And we all have PMS, but nobody understands. Because I have always laughed at PMS, I remember being 20 and asking my mum ‘what, you have PMS or what?’. It was one of those things, you didn't understand what it even meant. But.. Now I do.

I’m pretty used to how you can be met, and like.. judged in some way when you have a diagnosis that indicates you have a mental-something. So I am very careful with telling in general.

Subsequently, being able to communicate on PMDD with partners and family members was expressed to be very helpful by the people who openly discussed her symptoms, emotions and their consequences at home:

So when I'm hormonal I am very angry and frustrated and easily provoked and very irritated, all of it. And I go looking for fights with everyone. Then it's good that I can say to my partner that "aw, I'm really hormonal, it's not you, it's me, please don't take offence.

Another question posed to the participants was would an open discourse on a societal level could be helpful or even preferred? How would that be accomplished? Two quotes will

illustrate two perspectives. Both participants were asked whether people with PMDD should be more vocal, and if they thought that knowledge on a societal level could lead to a better inclusiveness of people with PMDD on a political, occupational and social level. Again, the issue of stigma and prejudice was raised by the participants, and how they wish it would not be so:

I feel I don't have the will or energy to take on to educate everyone, at the same time as it maybe is what we all with PMDD have to do... But I don't know, do we? Or should... You know.. Because it's a little.. Partly because it's connected to the stigma of all kinds of psychological disease. (...) I believe PMDD still is closely related to a stigma that other diseases or ailments are not. Like my husband, he hurt his hand and couldn't do his job-duties fully, and it was like 'no problem X! That's okay, you rest, you don't have to worry about it!'. I can't say I'd be met by the same, straightforward acceptance if I'd to complain about my hormones...

I don't want there to be a difference, that women with strange hormones would be a special group. On the contrary, PMDD should only be seen as any other illness. You're ill when you have a fever, are in pain or are depressed, and PMDD could be like that too. That, instead of creating more stigma for women and girls. (...) It's a difficult thing to discuss, you'd want to avoid this whole 'it's a female issue'-thing, and as much as it is just that, it's the last thing us women need to hear. We need to hear 'holy cow, you're so awesome for pulling your weight **THOUGH** you have PMDD!' We need to be recognized for our awesomeness.

The importance of social support. While most participants (8/11) felt they would not talk about PMDD at work, most of them expressed that having some form of social support/social backing was tremendously helpful.

Two accounts of actually being able to discuss PMDD with colleagues give the insight that it would be beneficial, both for work enthusiasm and psychological well-being to be open about the experience is illustrated below:

Q: Can you think of anything positive at work? Though PMDD?
Mainly my colleagues. That some have been so very understanding. It has made it so

much easier than if no one had understood, or if I'd felt that I can't tell anyone. Then I wouldn't have wanted to go to work.

It was really good there cuz there I could also talk to my boss about it. The environment there was unbelievable. We were friends, we took care of each other. And they knew I had PMDD, so they accepted if I one day ate lunch on my own. Nobody questioned it or hassled me about it.

Four participants felt they did not want to discuss their PMDD directly, but still experienced benefits from being in the social environment at work:

I talk a lot with my colleagues, and that helps. They can sit there and talk about anything, and I just sit there quietly but am there physically. At breaks, lunch and such. Otherwise, I'd just be alone with my thoughts.

Nothing positive has come out of PMDD. The only thing I can think of is working with people, you know, the social contact therefrom.

Others (5/11) experienced social backing rather from the family circle than their colleagues. One participant expressed that having a family where all her female family members also suffer from some form of premenstrual symptoms was helpful. She also expressed having an understanding and non-pressuring partner:

(...) At the same time I think about women who might not have the same understanding people around them as I have, or understanding partners... And I've always had a female collective to lean on, and others.. might not have had the same possibility.

Summary.

Within the topic area of *PMDD's impact on social aspects of life*, three major themes were identified as follows: (1) *Work life vs. Family life*; (2) *Talking about PMDD* and; (3) *The importance of social support*. Participants experienced shifting between work and private as taking a toll on them mentally and socially. Fear of stigma and social repercussions due to the association between PMDD and mental illness was described, as well as an importance of social acceptance both in professional and private arenas.

The Impact of PMDD on Psychological Welfare

The impact on one's self-image. All participants experienced a bearing from affective symptoms of PMDD. They all expressed having issues with self-esteem, doubt in one's abilities or an overall lack of self-liking. One account showed how the participant experienced feelings of hopelessness and self-disgust due to strong cravings:

And then of course comes anxiety, 'why did eat all that candy?' and then it starts getting at your mood. Like, I don't know. Feeling hopeless, sad and everything is shitty. Nothing is good. And then, have another binge of sugar.

Negative self-image in relation to PMDD seemed to be a common experience. Another participant expressed how her symptoms made for such a self-derogatory state, that it also affected her approach to life:

It's two weeks of your month when you doubt your relationships and feel extremely unattractive, you feel stupid and like you're never going to learn anything new. It feels like life is completely meaningless.

Another issue expressed by many was the impact on work. The first account describes the impact of not being able to “be as good” as other days, and how that takes a toll on her self-esteem and well-being:

Some days it's really, really hard. Some days I'd be crying in bed at home before leaving for work because it's so hard going there that day. (...) It's also so very, very hard when you're happy one day and everything runs smoothly and then you come into work the next day and are like chaos. And people don't understand why I'm not as good as the day before. That's a tough one to take at work. And it really gets to you mentally.

A second, similar account illuminates how self-doubt makes the participant question herself even though medications help take out the worst of the emotional swings:

I take premaxex which dampens it a bit, you don't get those violent swings... But the feeling of, like... It's like it automatically sneaks up on you, that you feel like you're rubbish and, like 'why can't I do this? It's not a very long work day today?

The struggle of being yourself and finding a place to belong. The participants all accounted for having heightened self-consciousness when hormonal and for periods after menstruation. One participant described that she avoids talking about her PMDD at work, as to not become "that person with PMDD":

I didn't feel like I want to tell the boss or my colleagues at the new place just yet, like 'this is my story and I have PMDD'. Because that would make me 'that' person. Instead I want to come in and define myself in a way that I feel comfortable with.

A downside of self-awareness that two participants discussed were feelings of not being good enough to be suitable for any kind of work. The question asked was what kind of occupation or work place would be accepting to a person with significant symptoms that impact on every aspect (e.g. social, time-related aspects or efficiency/quality) of work:

I know what I can do and can't do, and I know for a fact that I am severely fatigued most of the time, that I become angry and volatile, that life isn't worth living and I lose all social capability... All feelings go away too. How the hell are you supposed to work with that? And with what? I feel like there is no place for me, like I don't fit in anywhere.

Summary.

Within the topic area of '*PMDD's impact on psychological welfare*' two major themes were found: (1) *The impact of PMDD on self-image* and; (2) *The struggle of being your own person and finding a place to belong*. Participants reported complex psychological impact from PMDD, where the diagnosis prevented a person from feeling good about oneself, negative self-image was prevalent and also feeling like one is redundant.

Shortcomings in Medical care

Response from the medical world. All participants of this study had contacted Swedish health care due to PMDD. They shared similar experiences from those encounters where all but one participant said to have experienced feeling neglected from a medical point of view. One issue was often being questioned or not being heard by the professional, while at the same time not knowing where else to go for help:

It's horrifying that so many doctors deny that PMDD exists. I mean, it's difficult enough to call a doctor or gynecologist. First of all, it's difficult to know where to turn for help and secondly, to make contact and meet with disbelief or denial.. Really, it's so humiliating!

I remember when I had moved to a new city and had to go to a new gynaecologist to get my prescription written. And I explained to her that I need Qlaira because I have PMDD, and I had to tell her Qlaira specifically because she wanted to give me something else... And she looked at me with a little smile and said in a very, you know, a know-it-all manner 'oh, you DO mean PMS, right?'. And I exploded. 'No. You do know about PMDD, don't you? Because that's what I have, and you're the one supposed to help me'. I've never felt so angry towards a medical person ever before. She should know this, not me.

Accounts from when asking for help from medical instances was experienced in the form of lack of knowledge or disinterestedness:

The thing is, I have a paper from a doctor that says I take my medicines due to PMDD. But I think he gave me that paper because I was briefed. And because I had been logging my days and knew stuff when I came to him/her. Soo.. Unfortunately.. I don't think they have much knowledge about PMDD, really.

I have this gynecologist that I've been in touch with, but she's this effective type that 'yes, well okay, here, have some Premalex, try that it usually helps', and.. but. It was like it wasn't interesting to her to sit down and actually investigate possible PMDD-diagnosis.

Well I brought it up at the hospital. I felt like there wasn't much knowledge about PMDD there, which makes what you do so much more important.

Another experience shared by every participant was that the only, and always prompted upon a solution for help from a medical point of view, was that of medication through SSRI or oral contraceptives. This, even when the woman felt aversion or insecurity towards it:

I felt so awful, I went to the gyn and like 'Take out the f----ng coil', I don't know. And he did. And the only thing he cared about was how I was going to protect myself. I said 'I don't need to f----ng have sex, I just need to get rid of this! He said "alright, but then we need to up your anti-depressant dose.' 'Um, say what?'. And I said 'I am not depressed, I don't need them'. But he wrote a prescription anyway. I still haven't collected the medicine.

I feel I want to completely avoid antidepressants. Because I'm not depressed! I don't have a psychological illness!

Medication is really good if you really are depressed. You wouldn't want anyone to take their own life because of PMDD, but you also want to be able to live.

Confusion around the PMDD criteria. The subject of unclear diagnosis was lifted when interacting with the participants. It was commonly expressed that there doesn't seem to be any spectrum of severity within the PMDD diagnosis. Many expressed how, when they compare to other women within the Facebook group for women with PMDD, they felt like they either had an easier or heavier form. Below are two excerpts from conversations about the subject:

Question posed: *Would you say that you have a milder or more severe form of PMDD?*
That's such a difficult question! Like, when you read what the other girls say in the Facebook group... It's hard to know where on the spectrum you are if there is one, and this is hardly ever talked about. Even medically.

The PMS-concept is very wide as in what you can feel and think or say. I think it has to do with the fact that we don't have many terms to use overall.

The consequences of SSRI as medication for PMDD. Though medication in the shape of antidepressants were prescribed for the participants of this study as a form of alleviation from the symptoms, some (7/11) instead experienced the side effects of the medication. Side effects from the medicine also had an impact on the individual's lives, which some described as being equally impairing as the symptoms of their PMDD. Three of the participant's accounts illustrate this:

It (symptoms) starts around ovulation, and some months it can be about 2 weeks when I get more or less affected. And since I started with Premalex, I've had very, very rough emotional reactions. It hasn't been like this easy-to-cry thing or being easily annoyed, but very heavy dips.

I take Premalex. I only take it that day. But it makes me exhausted, I get all the possible side effects from the medication. So instead of being suicidal I become exhausted, can't move and am constantly hungry. So I have to choose between, like, is it bad enough that I might kill myself, then I take the medication.

I was prescribed Citalopram to be taken in cycles. But that instead made me completely blunted as a person. I became a machine instead. We've talked about it, it's really difficult for my partner to see that there's only a shell left of me. I'm not there, like. No.. It's not worth it.

Longing for a non-chemical alternative and feeling scepticism towards SSRI was often (8/11) expressed:

Before I tried B6 I ate SSRI for the PMDD. But it didn't work at all. And I have a little... If I can do something non-chemical I prefer to do that.

I had some prescribed for me, but I don't take them. I suck it up and breathe through it instead. I'm scared of the meds because I think it might affect me in so many other ways.

The few participants (3/11) who seemed the most accepting of having antidepressants as an aid and took the medicine either cyclically or continuously expressed heavy side effects from the medication:

And now I've been prescribed Premalex for the bad days, and it works very well, I think. I take it the days I feel like 'OK, I've had enough, I have to do something about how I am and feel!'. The medicine takes away the deepest dips and makes me at least OK to be around. It might not be the real me, but at least it's better than not taking them.

Summary.

Within topic area '*Shortcomings in Medical care*' the following subthemes themes were identified: (1) *subjective experiences from encounters with medical institutions/workers* and; (2) *Consequences of SSRI as medication for PMDD*. The participants of this study expressed having overall negative encounters within medical areas where they felt exposed to disinterestedness, lack of knowledge and scepticism. A reluctance towards medication, especially SSRI, was relayed. This due to (a) fear of stigma/discomfort associating with psychiatric drugs and (b) in fear of possible side effects. 3 out of 11 participants still medicated with SSRI against their PMDD, and preferred the heavy side-effects.

Participants' thoughts on what could be done to alleviate the negative effects of PMDD

A need for an explicit diagnosis and work place compliance. When asked further on the subject of having PMDD, participants voiced issues from the diagnosis being so inexplicit and fairly unknown.

I experience it like it's one of those diagnosis when if you don't have a doctor who validates with some sort of form that this is actually real and serious... I really don't think people are going to realize the impact of what PMDD is or the consequences of it.

One participant shared how she had experienced consequences to her disadvantage when returning to work after a lengthier sick leave due to a comorbidity of PMDD and fatigue syndrome from workplace-stress:

I experienced we couldn't communicate. I feel I couldn't talk to him (the boss). And he didn't help me make a smooth come back to work after having been on sick leave. He opposed both what doctors and Försäkringskassan had ordained about the extent of my duties.

Though authoritarian agencies had made a clear statement of her issues and what was expected to be done to enable positive comeback, according to the participant this was not adhered to by the workplace. It is possible this was due to some systematic set back at the particular place where it was not feasible to accommodate for the individual worker, but the participant expressed a sureness in that it was ignorance of the burden of illness that was accountable.

The benefits of adopting a professional role. Even if going to- and performing at work is difficult for women during PMDD, many participants experienced having and adapting to a professional role as helpful. Five participants experienced adhering to a work role as definitely helpful, three other participants saw it as somewhat useful. One participant explained that having a routine-driven job and focusing on her duties helps her overlook her affective symptoms:

The worst thing is that I become so emotional and completely lose my self esteem. And the feeling of being so unstable... (...) But it doesn't really affect my productivity, as I have such a strong work role.

Other participants didn't find as much relief from leaning on the framework of a role. The quote below comes from a participant who works with much administrative- and social tasks. According to her, she knew her duties and what was expected, but did not experience a certain role more than what the labor directives had prescribed in her proof of employment:

Sure it helps to have a role at work, but... No, it's hard like hell. I don't think I manage well at all at anything when having PMDD.

Wishes for the future – what might make work life easier for a person with PMDD. When participants were asked on what they believe could have a positive effect on their ability to work and therefore diminish the burden of illness, overwhelmingly many expressed a wish for a) flexibility in time, duties and absenteeism:

To have flex-time. When PMDD hits it's so f***ing hard to work 9-5, especially when you work around other people. So to have my own car those days, drive around and work in my own pace, in the order that I want to and having no one around that's nagging on me.

It would be if they were very flexible. When I have these periods, so that I can.. Not.. That I maybe don't have to come to work every day, or have to do so much, because I can't do very much when I'm hormonal. And not to judge me based on the hormonal periods.

Flexibility in the shape of sick leave in Sweden would have an economical impact that certainly would affect the women's quality of life. Sick leave and absenteeism in Sweden has repercussions (Försäkringskassan, n.d.) in the shape of qualifying periods (first day of sick leave is unpaid), and a lessened sickness compensation of only 80% of original salary during 14 first days of sick leave if working fulltime. (Though never more than 714 SEK per diem). This was recognized by many participants. The possibility of striking up agreements with a work place were of interest to many participants and the quote below illustrates the urgency for such solutions:

You know.. The worst thing about work is that you physically have to be there. It's rough starting to thinking at work, like, 'oh no, now my boss is going to fire me'. I'd like to be able to go home if I needed to. Or that I could go out for a walk or just do something else, or make a call. Because I can be so submerged in how I am feeling, and just need to get out of it." But (...) I feel I wouldn't be able to work fulltime. That if one could strike up a deal with the boss that I could take 2 days a month off, like two sick days or so. It would enable me to take it easy and exist without pressure. Because that only creates more anxiety.

Another participant expressed the same urgency, and added that it would be possible with such agreements as PMDD is cyclical and easy to keep track of:

To have the possibility of being home the days you have PMDD, without those qualifying periods or your salary going down to 80% those days that you're home.

Because if you have a lot of sick days you might lose your job or be reprimanded or such. And sure, one can't always blame PMDD, but you could give your boss a schedule like 'these days I'll most likely have to stay home', because you know it and what is going to happen!

Some personal solutions by women with PMDD. Some participants had found ways of making life easier for themselves. This was not without consequences for the individual though. For example, going down in work hours and avoiding taking on full-time employment meant less economic profit for one participant, but instead gave the potential for better well-being on a personal level:

I chose not to take a full time employment, and I lose money on that. But I'd rather feel that I can handle working at a place where I also can ask for more or less work-time later on. So I don't work fulltime anymore and am at a much calmer work place than before, so that helps a great deal, it's a lot easier for me to leave for work even if it feels heavy. Because I know that it's partly a less demanding job, and partly because I'll be working less hours.

Physical activity played a big part for the participants who were able to do so while hormonal. This on the cost of other activities, such as hobbies or being social outside of home:

When I have my PMDD it's basically all about work, working out and rest. That's what I have to prioritize.

Another participant was able to avoid antidepressants altogether due to working out and minding her food habits. This, according to her, even though the effect of hardcore training was not long lasting:

No medication. I try to work out, or I DO work out every day. I am out and really try to care for myself. I eat absolutely no sugar, not in any shape or form. It makes everything worse. When I'm hormonal I might have to do really heavy work out, or a lot of cardio. And it helps for a while, like maybe an hour. But then it (symptoms) come back.

Another coping mechanism that participants experienced as helpful was minimising stress. This is also relevant from an occupational point of view, as work can be a cause of stress on many levels (e.g. social, performance, time management, role conflicts):

Handling stress, I'd say, to keep stress levels down is really important. That I like don't. You know, if I notice that I'm hormonal, I cancel everything. Everything that might be stressful in some way.

Summary.

In the topic area of '*What could be helpful - hope for ease to women with PMDD*', four sub themes were identified: (1) *Need for clearer medical guidance and compliance on a professional level*; (2) *The benefits of adopting a professional role*; (3) *Wishes for the future – what might make work life easier for a person with PMDD and*; (4) *Some personal solutions by women with PMDD*. Participants expressed a desire for flexibility in their occupation as well as autonomy. Having a strong occupational role was experienced as somewhat- to very helpful in managing one's symptoms at work. Some participants had found ways to more or less cope with the symptoms of PMDD at work without the help of medication through making economical, social and commitment-related sacrifices. Other experiences of ease were found through physical activity, mindfulness, therapy and lifestyle changes.

Discussion

This study aimed to gain insight into what it is like living and working with PMDD. The focus was explored by eventually comprising four separate areas of interest from interviews: (1) how having PMDD affects work efficiency, quality of work, social interactions and overall work-based well-being; (2) how having an occupation while juggling symptoms of PMDD affect the individual in private life; (3) what kind of medical help is made available for people with PMDD; and (4) what could be possible solutions, according to the individuals, to help them cope with combining work/private life and PMDD in the best possible way? After studying other literature on PMDD (e.g., Rapkin & Winer, 2009; Lete et al, 2011), general parameters for successful occupational lives (Landy & Conte, 2013), and consultation with my supervisor, interview questions were formed that aimed to elicit the participant's experiences of the above areas of functioning. However, the interviews were conducted so that the participants could expand in any direction in their responses. I now

discuss the themes raised in the interviews.

The Impact of PMDD on Occupational and Social Aspects - and What Could Help

In this section, we look at both our themes from the result section and assumptions from the introduction. The assumptions were that: (a) PMDD offers significant burdens to a person's social-/family life and their day-to-day functioning, and; (b) PMDD causes burden for the employer due to cost of sick-leave. I will also ponder what parameters that could have an influence on making for better or worse.

That PMDD is a heavy burden on any person living with it, as well as for their surroundings, has been shown by these interviews. The symptoms envelop every aspect of a person, from one's inner feelings of self and surroundings, to one's behaviours and the consequences of behavior. This, in turn, impacts on the individual's life. Therefore, PMDD can be established, following conclusions made by Rapkin and Winer (2009), to be a very complex and invasive condition. PMDD affects how individuals cope with different social situations when hormonal, and this study's participants attested to consequences on social relations. Creating and maintaining social relationships at work or outside of family was expressed to be challenging for most participants, as they experienced having behaviors that are not always socially acceptable or easy to understand.

It was also experienced that interacting with family could be difficult due to for example lack of energy, anti-social behaviour (isolation) or lack of feelings. Concerning family, participants who had children expressed feeling like poor parents, pointing at a lack of self-esteem. Paradoxically, at the same time as being social was experienced as hardship by most participants, individual well-being was closely intertwined with social factors when hormonal. All participants expressed that social contact in some form was of utmost importance, from partners, family members, friends or just being around people who behave normally. That social intercourse is helpful for a person with PMDD, even though that person is not socially adept when hormonal, is supported by scientific findings in other parts of the world, see for example Arbat et al. (2011).

It is the author of this essay's understanding that a general comprehension of PMDD could be helpful, both for the person suffering the symptoms as well as others associated, as understanding (knowing more about) a phenomenon opens for acceptance and dialogue, which in turn opens for individuals to ask for help. As much as dialogue could be helpful, speaking up or educating others are, as shown in this study, not obvious choices to make for individuals with PMDD. A risk for being categorized by stigma or prejudice is all too real when it comes to "female issues" (authors denomination) or psychological illness. Therefore,

only some trust was given work environments to understand and empathize if the person wanted to open up about the diagnosis.

As for an employee's wellbeing being related to his/her performance at work, according to Landy and Conte (2013), no significant linkage between an employee's wellbeing/satisfaction and work performance can be found, though other and more recent studies, such as Weiss and Cropanzano (1996) have shown relationships between day-to-day emotions and how people behave. If translated to fit this study better, it is fair to say that the symptoms of PMDD, which include physical pain and affective disturbances, can be derived to pose a risk for having behavioral effects on occupational proficiency. Accordingly to Weiss' and Cropanzano's (1996) findings, this study found that PMDD makes for a significant effect on work-related aspects, such as productivity/effectiveness, social capability, career, quality of work and absenteeism for the individual. This information should be of interest for most levels of society, medical, political and organizational, and possibly open for providing a solution to prevent both negative impacts on psychological well-being for the individual and occupational ability.

One participant lifted that PMDD can be foreseen and therefore also taken into consideration when making schedules: "And sure, one can't always blame PMDD, but you could give your boss a schedule like 'these days I'll most likely have to stay home', because you know it and what is going to happen!" (p.35). Oral Contraceptives can be described as replacing one's natural menstrual cycle, therefore controlling when ovulation and menstruation happens, and by this, PMDD can be monitored. A solution to assumption (b) is that an agreement where the employee submits the acute dates and one gets the freedom to take work home or flextime the particular days could be a possible solution. The question is whether it is of interest for the workplace or on a greater, socio-economical-political level. But, as mentioned in the theory section, 3-8% of menstruating people suffer from PMDD. Translated into numbers, SVT Vetenskap (2015) has approximated that every 20th menstruating person in Sweden has PMDD. One could assume that action would be taken to prevent and alleviate a diagnosis that incapacitates such a large portion of a country's potential work force.

Another discussion would be on whether a stern and clear work role with well-formulated directives on work ethics, duties and expectations could be beneficial in facilitating for women with PMDD, to better cope with their symptoms at work. This is of interest, as participant's have testified to feeling helped by having such a role.

To summarize and relate back to the purpose stated in the beginning of this section, it is easy to establish that people suffering PMDD have an impairment that prevents normal social- and professional proficiency. Both assumption (a) and (b) in the introduction of this paper have been given subjective testimony. Some counter-measures towards the negative impact of PMDD at work and socially have been discussed above.

The Psychological Impact of PMDD and the Medical Area

In this section, we will discuss the subjective experiences related to medical and psychological aspects that were expressed in the result section. We will also relate back to assumption (c) in the introduction, that; "PMDD poses a burden to society at large due to significant use of health care and lost work-time.", as well as the statement of Gehlart, Chang, Brock and Hartlage (2006), that "measures that are not specific to PMDD" are used when researching the diagnosis which in turn makes for a need of a better foundation of understanding and diagnostics.

Apart from PMDD directly impinging on one's behaviour, it also affects one's self-image, self-esteem and general psychological well-being. The participants of this study had much to say about their encounters with medical professionals, where most opinions were negative (see above, Results section). To summarize the narratives, a common experience of reaching out for help was to be met with skepticism or lack of knowledge. This in turn, lead to many participants experiencing they did not receive appropriate medical aid. Also, most participants expressed suspicion and unwillingness towards SSRI medication. Those who took SSRI reported on side-effects that matched the symptoms of PMDD in impairment level. This should open for discussion on how to treat PMDD, and the possibility that it should maybe not be up to only one arena (the medical). Research should look into other arenas of aid, for example Chinese medicine, acupuncture, diets (low carb/high carb, paleo), self help methods/coaching, therapy or teaching people with PMDD self knowledge and techniques to handle oneself. Especially as PMDD is complex and can be connected to other ailments.

According to Rapkin and Winer (2009) people with PMDD have a 50-75% incidence of added psychological disorders (comorbidities) which, in the long run, could pose a threat on a grand socio-economic level. Försäkringskassan (2014) has estimated psychological illness (e.g. anxiety, stress and depression) to be the largest cause of sick leave in Sweden, especially for menstruating people/women. All participants in this study experienced affective symptoms, some in comorbidity with f.ex. depression or exhaustion diagnosis, and attested for it to affect their work. Based on this information, it can be assumed that psychological issues can and will have an impact on the person as well as his/her work- and other

environments.

The institution for economic aid in Sweden (Försäkringskassan, 2014) has declared that declining and/or impaired mental- and psychological health is the largest cause of long-term sick leave with an economic impact on a societal level. The study by Endicott et al. (2011) corroborates such consequences for people with PMDD. The psychological consequences can also be severe, where e.g. the study of Courtet et al. (2016) stresses the correlation between premenstrual symptoms and proneness to self-harm. In this study 3/11 of participants expressed suicidal tendencies or attitudes in one or another form, where two confided to having attempted taking their lives. In conclusion, the psychological aspect of PMDD should not be taken lightly.

Mental health and general health have for a long time been recognized as important parameters for maintaining a functioning society by the Swedish government. Laws and legislations exist in the shape of Hälso- och sjukvårdslagen (HSL, SFS 1982:763) and by law, it is stated that aid: (1) shall be given to the one who needs it (§2); (2) must be readily available (§2a.2) and; (3) must heed the integrity and decision-making of the patient. An addition to the law (SFS 2014:822) states that every patient that seeks aid from departments of health are to be given a thorough medical evaluation as soon as possible.

In contrast to the law, the participants in this study had had an overall negative encounter with medical instances and had experienced skepticism, ignorance, lack of knowledge or help, and only two out of eleven had been put through a diagnostic procedure. The attitude and adeptness of medical instances can have many reasons. However, when analyzing the results and theory of this study, some apparent reasons could be: (1) lack of general knowledge on premenstrual symptoms and even less on the newer diagnosis PMDD; (2) not knowing where to even begin, due to the difficulty of making a thorough and streamlined diagnose (spectrum-sensitive) from the current diagnostic framework and: (3) a negative and long-lived and perception of premenstrual symptoms as being something natural and not a legitimate disability, see e.g. Lete et al. (2011), can have an effect on the individual professional.

Lastly, on the matter of diagnosing: out of the 11 participants, some could be construed to experience a heavier or lighter burden of PMDD. This was a topic that became of interest to this study as participants expressed significant disorientation within their own diagnosis, see the Result section. This is another argument for creating a diagnostic tool that heeds the complexity of PMDD. Fortunately, recent research has begun examining how to assess a PMDD diagnosis best. Eisenlohr-Moul et al. (2017) for example, suggest that using

another diagnostic tool called C-PASS as a companion protocol to DSM-5 would open for making a more standardized and efficient tool when assessing a person's symptoms.

Participants' thoughts on what could be done to alleviate the negative effects of PMDD

As the participants already were active in finding different ways to ease the effect of their symptoms, their methods and thoughts on what could be helpful are of interest to this study. A question in the interview guide was specifically concerned with what the participants do to alleviate their symptoms, and what they feel they are wishing for. The thought is that the experience of the participants can help guide future research, workplaces, people with PMDD and actions in society aimed at people living with the diagnosis.

The importance of medical directive and guidance was deemed crucial in giving aid. Three trails of thought were prominent: Firstly, medical directives would be helpful in how workplaces can and should relate to a person with PMDD. This, as to give guidance on possible solutions, alternatives or options on how to prepare for the return from sick leave or to preempt possible sick-leaves. As PMDD is a complex diagnosis in that it stems from biological functions but affects both physically and psychologically, it would make sense if instances for aid would be spread between professionals. For example psychologists, gynaecologists and obstetricians could cooperate when needed.

Secondly, argument for further clarification on the PMDD-diagnose is that it needs to be studied further to pinpoint what kinds of aid would be helpful in different cases of PMDD, so that the individual can be referred to the right place from the beginning. To further argue this stand-point: attested in this study is that individuals enduring PMDD were open to help in any shape or form. They had all found different ways of coping, from simply accepting one's condition, heeding the symptoms or finding someone to talk to (social support) to actively making lifestyle changes, working out and being mindful of both small and big choices. Therefore it would be presumptuous to say that people with PMDD are completely responsible for their well-being and that help from one's surroundings would be beneficial.

Thridly, as the symptoms of PMDD are so volatile and difficult to control, it can be hard to "find a solution" that would suit every individual and workplace. Alas, something that became apparent during the interviews and makes for a possible solution, was that participants who could be deemed to have well-developed knowledge and acceptance of one's self (e.g. through therapy, mindfulness, introspection) all seemed to be able to have better control of the impact of their symptoms, as well as more ability to cope.

One idea inspired by a) these results and b) Landy and Conte (2013), would be for places of occupation to offer support through therapy, constructive talks at the workplace or

possibility for self-development (p. 379). Alternatively, in other ways make available functions that would help both the individual and the workplace (e.g. gym-pass, flexible work hours).

Method Discussion

In this section, a close look at the method of making this essay will be taken, as to find strengths and limitations in the creative process. According to Willig (2008), it can be argued that interviewing never gives a perfect account of the individual's actual experience as the researcher produces the results by interpreting, and therefore creates one's conception. Therefore, this particular study was aimed at purely exploring and presenting subjective experiences, which was best achieved by adding direct quotes from the raw transcripts to the results section. Every argument made in the result section therefore was based on interpretation of verbatim quotes and the circumstances in which they were produced (the conversation). Also, all further empirical material was researched based on the data collected from interviewing, as to minimize risk for presumption in the analysis-process.

Consideration for the researcher was to be reflexive towards one's standpoints and presumptions constantly and to let the text stand on its own (Bryman, 2011). Reflection was done continuously, and this text was read through and compared to the raw transcripts to make sure it relayed and substantiated the experiences of the interviewees. A personal reflection by the author: It was interesting to hear other people's stories, and some were similar to the author's, yet it was simple to completely focus on the narratives of the participants. This essay comprises of their experiences fully, and is based on their verbatim narratives.

As criteria used in quantitative research such as reliability, generalizability and objectivity are not applicable in qualitative research, it is up to each study to tailor suitable criteria in it is research question and focus (Willig, 2008). In this essay, quality, ethical aspects and validity have been strived for from start to finish. Different ways to achieve these three goals have been described in all steps of this process. Though generalizability does not apply for this study, it is still of hope that the findings can become of use somehow, medically, scientifically, occupationally, politically or socially.

Strengths and Limitations.

Lastly, other strengths and weaknesses can be found in surrounding parameters, that can have an impact on the process. A force in the making of this study was the fact that the author herself suffers a testing form of PMDD. Many participants expressed feeling safe with talking to someone "who actually understands" and who was able to relate, which might have

made the interviews more open and fluent and lessened insecurities for the participants. It might pose a plausible explanation if future research does not reach the same conclusions. Of course, the author's objectivity can be questioned due to her own diagnosis. But as mentioned above: (1) this study was indeed planned partly from the author's experience but was equally inspired from people in her social sphere and studies done across the world, and; (2) due to the author acknowledging her diagnosis, every effort and precaution possible were made to stay objective and maintain the integrity of the essay.

Both a strength and limitation in this study concerned the selection of participants. Having more participants would have generated more stories and therefore also given depth and an even more thorough description of the experience of PMDD. On the other hand, the narratives this study is made up of make for a vast covering of what having PMDD can be like. Also, the fact that the participants all come from the same Facebook-group and later were collected in a smaller group where the 19 possible participants can see each other, can pose a risk. But as the first group comprises of over 900 people, and the smaller group of 19, and as all communication went through private messaging, the risk of breaching anonymity was deemed as small. A strength is that all the participants come from different parts of Sweden, work different jobs, are from various age-groups and experience different symptoms which make for good coverage of a population.

It would also have been optimal for all participants to have a proper, evaluated diagnosis. This was not deemed a criterion for participation though as, as above-mentioned, diagnosing is difficult to do, and this was taken into account in the planning of this essay. Every participant had done research, discussed with professionals and experienced the correct sorts- and the right amount of symptoms according to DSM-V (DSM-V, 2013). As the result part due to being qualitative, verbatim and narrative, became quite extensive, extra effort was put into sectioning and explaining each input in an attempt to make the text as fluent as possible.

Conclusions

This study attempted to identify individual experiences of living and working when having PMDD to create a more wholesome map of the shape, form, and consequences of PMDD. The goal of the essay has been achieved, and the conclusion seeks to summarize the findings from the data, as well as propose some future directions for research and action-taking. From the experiences of people living with PMDD interviewed in this essay, a few deductions can be made: (1) Severe premenstrual symptoms have negative consequences on many levels for the individuals living with it: a) economically, b) socially, c) occupationally

and d) mentally. This should make PMDD of interest for policy makers within public health, as PMDD has an impact on a significant population's well-being and ability to take part in activities on both professional and private levels;

(2) The results also lifted the direct negative consequences on professional- and family life. Discrepancies when role-shifting between work and the home was made unusually difficult for people with PMDD, with implications for everyone included. This should be of interest for further research, for example, to examine how children and spouses of people with PMDD are affected when the person's already limited functionality is further tested by shifting mentally between work and private. It should also be of interest for places of occupation to look into what sort of arrangements that could be made for people with PMDD (or employees in general). Gym-cards, dietary options, possibility to have a walk during work hours, discussing progress and well-being with the particular employee or the possibility of a working dog are all possibilities that could be of interest and make for heightened well-being and productivity at work. By assuring the well-being of a person with PMDD, the occurrence absenteeism and other negative behavioral consequences that affect the work place could possibly be reduced;

(3) The quality of medical aid for people with PMDD was experienced as below adequate, where skepticism or lack of knowledge subsequently a) made individuals hesitate to seek further help and b) hindered them receiving help at all. Therefore, knowledge of PMDD within the medical area must be deemed as paramount to make people experiencing premenstrual symptoms feel welcome and acknowledged. It is of this essay's author's belief that an effort to understand PMDD within the medical profession would also make for an interest in actually diagnosing where possible, particularly as the diagnostic system for premenstrual symptoms is looked into and further developing. A well thought out diagnose would make for an efficient and precise course of action in treatment. It would also give a person suffering the symptoms relief through acknowledgment of diagnosis, and an opportunity to learn more about what to expect from having it and how one possibly could alleviate the symptoms;

(4) It was also found that pharmacological aids was something that participants took with consequential side effects often as impairing as their premenstrual symptoms, or it was avoided. There is a need for other aid-options for people with PMDD. One possibility is for the medical area to look at non-pharmacological options used in for example natural medicine, as participants both in this and other studies have referred to using calcium, B6, Magnesium and similar. This would make for research, and in the long run possibly legitimize

the use of for example supplements, acupuncture or therapy/coaching. In turn, people suffering premenstrual symptoms could feel safe in their choice of aid, and acknowledged by the medical profession;

(5) On the matter of stigma. Goffman (1963) writes about the complexity of stigma. He describes stigma as our (often subconscious) presumptions of a person in which there is a right and wrong way for the individual to be. When he/she shows signs of inhibiting perceived "undesirable" characteristics that make him or her different from other persons, the person becomes reduced (degraded) in our minds. Women in this study have expressed concern coming forward about their diagnosis and the hardship it creates, due to the negative impact of stigmatization of both "female problems" (authors denomination) and psychological illness. This is very unfortunate, as stigma in combination with lack of knowledge make for ignorance. People with PMDD are not different from other humans in their needs, and social acceptance is paramount for human well-being. Therefore it is of utmost importance that premenstrual symptoms are well researched, explained and published.

A discourse is needed where reality is spoken about, meaning not to shy away from discussing the hardship that comes with premenstrual symptoms, but neither mystifying or magnifying. According to the perspective of this essay's author, who also suffers from PMDD, it would make a difference in feeling safe, acknowledged and accepted if it was as easy and unproblematic to talk about PMDD as a hurting back.

In accordance with the initial assumption found in the introduction, that "Subjective experiences are varied and give a wider spectrum of understanding for a phenomenon, which is extra important in the cases of such complex diagnoses as PMDD", it is of hope that this study can be of aid in guiding future research and policymaking as well as hopefully winning more understanding for this severe hormonal issue that affects not only the person suffering PMDD but everyone around.

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Appendix A - interview guide

Area 1) Demographic info - I want to know

- Age
- Diagnosed medically or self assessed?
- General symptoms - privately and at work
- Are you open about your diagnose at work?
- How long been part of working life
 - Never worked - PMDD-related?
 - Sick leave - PMDD-related?

Area 2) Work related - subjective experiences about PMDD in relation to working

- **What type of work?**
- **Time consumption:**
 - What kind of hours?
 - Every day?
 - Subjective experience of working hours/PMDD
- **Responsibilities:**
 - General duties include?
 - Much to keep track of?
 - Workload?
 - Subjective wellbeing, confidence, emotions, experience...
- **Demands (psychological experience):**
 - What is expected of you?
 - How do you cope?

Area 3) Any help? - Mitigating aspects

- **Have you yourself taken up measures to curb the effects of PMDD?** Both for work and privately. Examples: Working out, medication, therapy...
- **Has or Is your workplace a curbing effect on the symptoms of PMDD? -** Has the workplace made arrangements for you? For everyone? Is your job helping you handle the symptoms of PMDD? How?

Area 4) What would be an ultimate working place/ultimate working conditions for someone with your diagnose and symptoms?

Appendix B - Subjective experiences of symptoms

Definitions of symptoms as subjectively described by participants.

- **Depressive mood** - includes feeling blue, feeling that life is meaningless and/or pointless, suicidal thoughts and/or tendencies, profound sadness.

"When I was younger.. Umm... Yeah... I have tried taking my life. A few times. (...) But the weird thing was, I didn't want to die ALL the time. Just sometimes! I didn't know about PMDD back then, it was a long time ago, but now I understand! There was a clear pattern when you knew where to and what to look for. And I medicate, get these antidepressants. So yeah, I'm here and staying, as I should."

"It's twooo weeeeks of your month when you doubt your relationships and feel extremely unattractive, you feel stupid and like you're never going to learn anything new. It feels like life is completely meaningless."

- **Anxiety/Tension** - includes feelings of paranoia (f.ex. that people surrounding you dislike you), worry, lack of self-esteem, difficulty feeling positive towards oneself and/or surroundings, manic behaviour self-doubt.

"When it's been at it's worst it's been uuunbelievably difficult finding a reason to get out of bed at all. I feel like nobody likes me, it's hard even getting in through the door at work because it feels like nobody wants me there. My siblings don't like me, I'm a bad mom... No reason to live, like!"

- **Labile mood** - For example quick to go from happiness to anger to sadness, unstable emotionally, sudden bursts of crying/tearing up or sadness/anger/negative emotions, moodiness.

"Either I break up with my boyfriend or I start a fight or, like, do SOMETHING to create something big. Then I don't have to think about.. You know.. The chaos inside of me."

- **Irritability/Aggression** - includes constantly feeling annoyed or aggravated by something from your surroundings like smells, colours, situations or people.

"I'm constantly annoyed with everything! Touch, sounds, smells, people and the way they act or don't act, what they do... On the world and society. It's so bad that I actually get into

bad situations because.. I hate to admit it but I get into fights. (...) I know friends think it's awful going out with me when I'm hormonal because I talk loudly about what I think of random people. If I feel someone is behaving badly or is breaking some rule, like, it can be things that nobody else cares about. But I care!"

- **Social Withdrawal** - experiencing lack of feelings towards partner/family members, avoidance of social situations, isolating oneself.

"I can see I've destroyed many relationships because of PMDD. After a week, no matter how great the guy was, my feelings shut down. I feel nothing! I don't want him to touch me, to look at me, I don't want him to exist at all! And then menstruation comes and I get like "ooh, I love him so much". But by then I've already broken up with him."

"I might tell my colleagues "of course we should do something after work, I'm in!" and then when it's time for the AW and I'm hormonal it's like.. "nah. Never mind."

- **Decreased interest in usual activities** - disinterestedness in activities such as hobbies, work out, social activities. "Nothing matters", lack of care for anything.

"Last months it's gotten worse. I haven't even been able to go to yoga class. And I don't leave the house. Like... I behave like a depressed person, you know, walk around in my pyjama all day long, never see anyone or do anything."

- **Lack of concentration/confusion** - decreased ability to focus on a task for short or long periods of time. Decreased semantic- and/or memory ability, inability to detect words/memories or create context.

"I wonder if it has affected me negatively. Because a job I used to have um... My responsibilities included finishing reports and gathering information. It was... It didn't go too well. I know I often had to redo something because I had missed something or such. That was not the case when I wasn't hormonal though, I know that for a fact!"

- **Fatigue/Tiredness** - overwhelming tiredness, difficult to keep eyes open or stay awake for a period of time. Go to bed early, difficult waking up and/or getting out of bed. Such daily tiredness that it impacts social life, work productivity and most aspects of life, not to be confused with Hypersomnia/Insomnia but can be related.

"I sleep very, very much. During PMDD I always go to bed at 8 pm with my kids, like. So yeah, there's no room for anything else apart from my kids."

- **Appetite changes** - problematic cravings, inability to stop eating, inability to stay away from food, cravings for salt and/or sugar, feeling of constant

hunger.

"As soon as the time comes, I get this "ooh, I want something, oh well, yes, I can have a little.. Just a little.." And then the cravings go to absolute binging. And I just can't stop myself."

- **Hypersomnia/Insomnia** - too much or too little sleep. Abnormal sleep patterns.

"I have like five alarms consecutively on the loudest and most horrible noise. And still I get up from only 10 minutes before I have to leave. I get my clothes on, that's it. If I'm lucky I brush my teeth. (...) Yeah. It's mad. I go to bed at 8 pm and wake up 12 hours later, still as tired as when I went to bed"

- **Physical Symptoms** - include breast tenderness, fever, bloating, swelling, joint- and/or muscular pain, pain around ovulation, head ache and/or migraines, back ache, menstrual pain. Pain includes sensations such as stabbing, dullness, aching, tenderness, throbbing and pains similar to torticollis around head, neck, back and lower abdomen.

"I take heavy medications against the pain, just to be able to act normal, to be able to go to work, to... You know, otherwise I'd just be a crying pile with cramps on the floor."

"I get fever. I know many of us express that we feel like we're a bit under the weather, like the flue. But I really get a temperature. I become sick for real, and a bad month it can last for 10 days in a row"

Appendix C - Informational letter to participants

Till dig som ska delta i min kvalitativa och deskriptiva studie om hur det är att ha PMDS i relation till arbetsliv:

Jag är alltså ute efter att höra dig berätta om din personliga upplevelse, dina tankar, känslor och erfarenheter. Själva intervjun kan se ut på olika sätt, beroende på hur bekväm du känner dig, men i grund och botten siktar jag på ett samtal mellan två personer :)

Intervjuerna måste ske mellan 20-31 Mars, så hör snarast av er till mig antingen via PM eller, ännu lättare, genom att klicka i en tid om du följer Doodle.länken här nedan. Berätta också om du vill ses IRL eller via Skype. (Jag finns i Lund och har möjlighet att röra mig inom Skåne, men pga. tidspress kan det bli svårt att ta mig längre än 20 min bort åt gången.)

Själva intervjun beräknas ta mellan 30-40 minuter, men jag har avvarat en timme sammanlagt för varje samtal om det skulle vara så att du före eller efter intervjun vill ställa frågor eller helt enkelt samtala/"debriefa".

Vårt samtal kommer att spelas in på min personliga bandspelare, och materialet kommer omedelbart att raderas från den då jag har transkriberat vårt samtal. Ingen annan kommer ha kontakt med varken dina uppgifter som namn och bostadsort (som ju kan bli aktuellt för mig att veta om vi ska träffas IRL istället för via Skype), och du kommer förbli anonym genom hela fortsatta undersökningen. Även för mig, då ditt namn kommer att koda till ett deltagarnummer.

OBS! Du har all rätt att dra dig ur studien när som helst före och under intervjun.

Varför är den här studien och ditt deltagande viktigt?

PMDS är en riktig marodör för oss som har det och det inverkar på både privatliv, hälsa och människor runt omkring. Därför är det vedertaget att PMDS även påverkar på arbetslivet. Hur vi arbetar, vår sociala kontakt och förmåga med medarbetare/kunder, våra energi nivåer m.m. Just detta är det dock dåligt forskat på, vilket i sin tur leder till att PMDS ännu inte har belagts med rättigheter (ex. förkortade arbetsdagar? Flexibilitet?) så som andra diagnoser/handikapp har gjort.

Tanken med den här inledande studien är att samla in personer med PMDS subjektiva upplevelser, och genom det få en "pekpinne" på vad fortsatt forskning kan titta på. Vi ger alltså forskningen ett försprång :)

Förväntad läskrets:

Forskare, läkare, arbetsplatser som har kunskap och vetskap om PMDS och/eller att medarbetare har PMDS. Dessa är mina främsta målgrupper. Men självklart också att nå ut till kvinnor med PMDS och kanske ge dem idéer, tankar eller bara ren och skär medsyserskap.

Övrigt:

Efter avslutad intervju finns möjlighet för debriefing för din egen del. Du kan ställa frågor, vädra känslor eller vadhelst du känner för. :)

Jag kommer också att hålla er deltagare uppdaterade om fortsatt utveckling i arbetet, och slutresultatet kommer att postas här.

Jag kommer också att be min handledare att hålla oss alla uppdaterade om fortsatt arbete om PMDS och PMDS/arbetsliv, vilket han har gjort klart för mig att han är fast besluten att ta upp facklan. :) (Fantastiskt!)

Slutligen vill jag åter igen tacka för att du ställer upp och är en röst för oss Ladies som rockar fett med/trots PMDS :)

Appendix D - Photographic version of TA-procedure

Image 1 (authentic). In this image, the printed out transcript has been read through and initial notes of possible themes are scribbled in the margin.

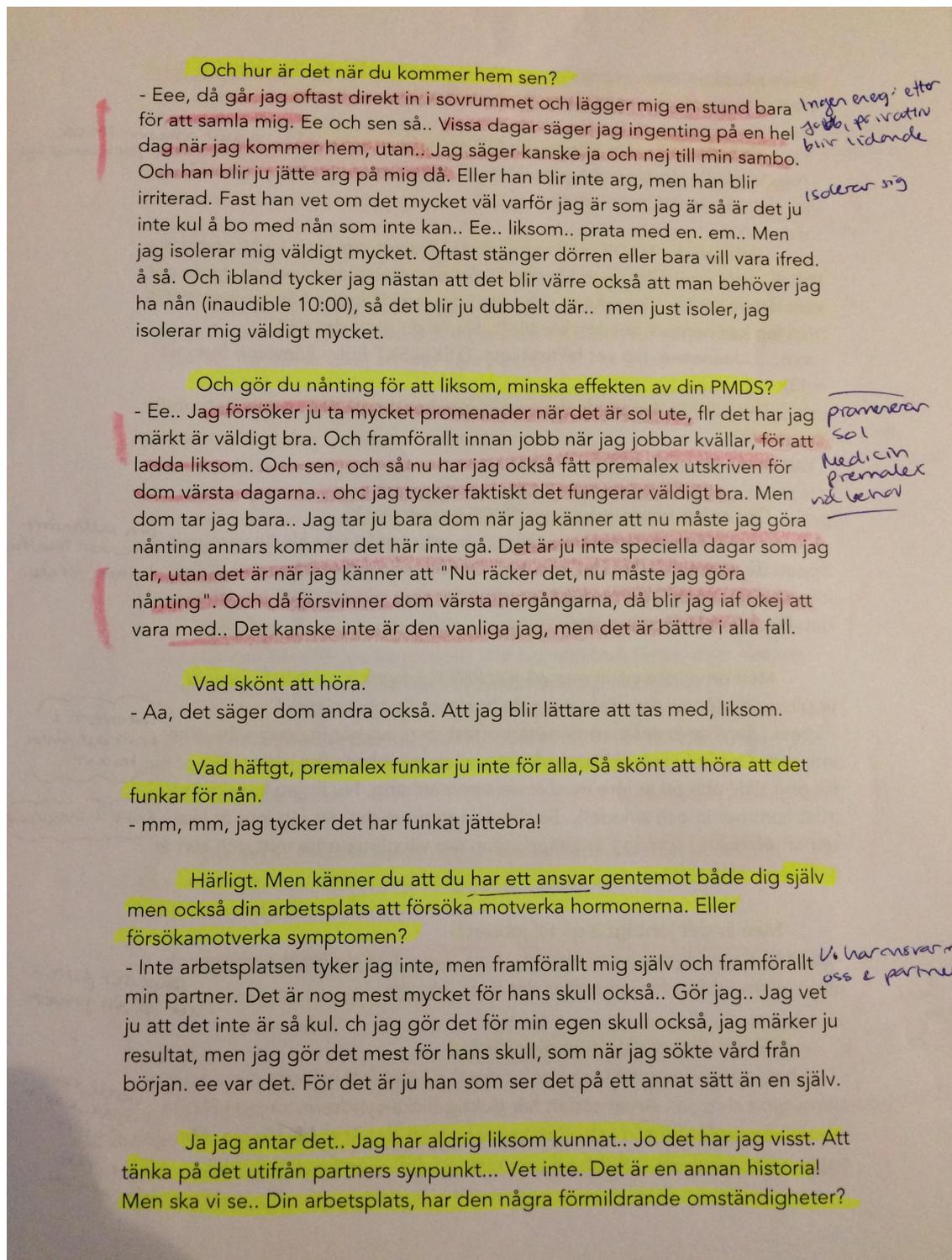


Image II. An initial mind map was made of every transcript. Major themes are circled and color-coded, sub-themes are written below. Image is not authentic but a de-personalized remake, as to protect participant's anonymity.

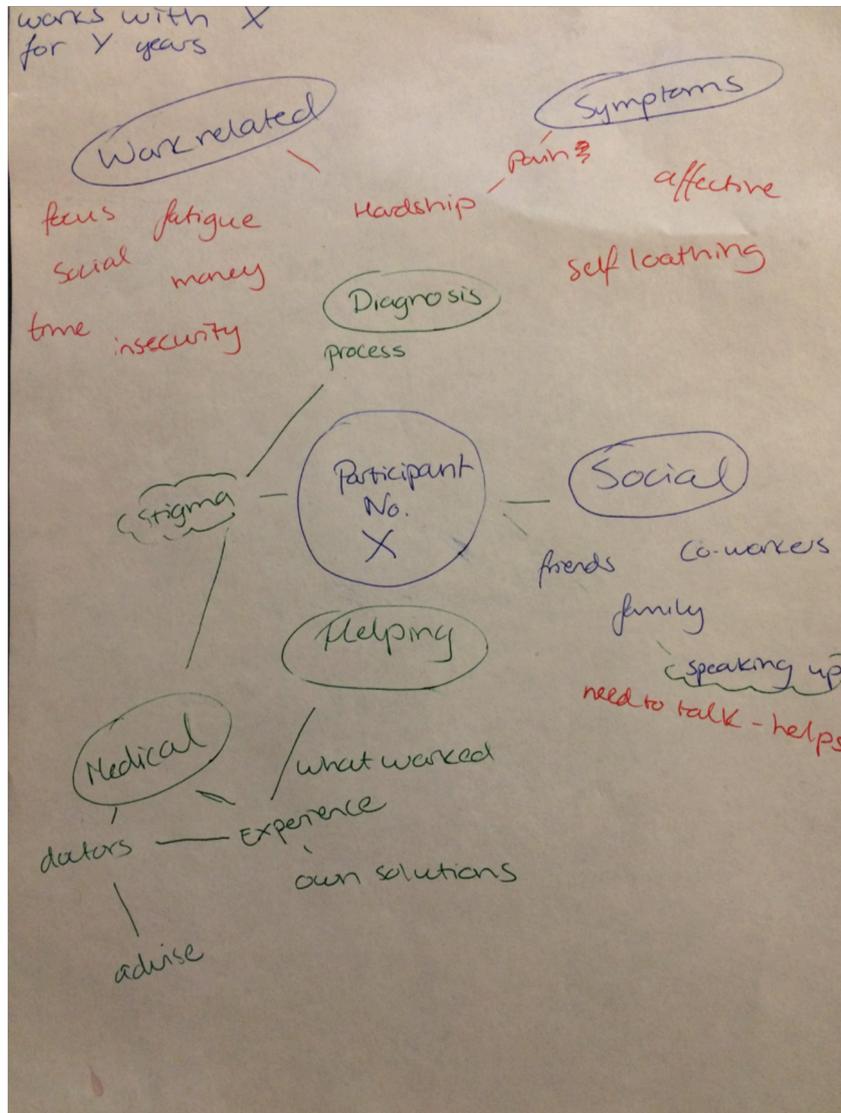


Image III. A re-made version of the final mind-map is shown below. Here, major themes are chrystalized (circled with a "cloud" and color coded) and sub-themes are written around, color coded to the main theme they belong to. Arrows show where themes both envelop more than one theme yet can stand on their own, depending on what quotes to be used. The "P" below each theme is a key for which participant/participant's have discussed within the theme, and therefore where quotes can be found.



Image IV (authentic). Here, quotes for each theme have been derived from the transcripts and printed out. The quotes were then sorted into envelopes. Each envelope was, in turn, representative of a theme, and named thereafter. The results were written according to

each envelope's theme and content. Note: not all quotes were utilized due to similarities and lack of space.

