

Help-Seeking for Premenstrual Dysphoric Disorder (PMDD) in Scotland: A Qualitative Study

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Acknowledgements

I dedicate this research project to every person who has ever felt misunderstood or isolated because of their PMDD symptoms. Please know that there are people out there that share your experiences; people who will understand and support you. May this project make them easier to come by.

*

I also dedicate this to the brave individuals that shared their experiences with me for my research; without your contributions this project never would have been possible. This work is as much yours as it is mine. Thank you.

*

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Abstract

Background: Individuals with Premenstrual Dysphoric Disorder (PMDD) are believed to experience cyclical psychological symptoms due to an abnormal response to the hormonal fluctuations within the menstrual cycle. Despite recognition that the condition results in severe distress and impairment for those affected, there is limited research on the help-seeking experiences of individuals with PMDD and the potential barriers they face. A deeper knowledge of the help-seeking process for PMDD may improve the quality of support available for the condition.

Objective: To provide an in-depth account of the help-seeking experiences of individuals with PMDD in Scotland; to explore factors and pathways within the help-seeking process, as well as ways to encourage those with the condition to access support.

Methods: Individuals (N = 9) who identified as having PMDD, or PMDD-like symptoms, were recruited to take part in online semi-structured qualitative interviews, discussing their help-seeking experiences. Inductive thematic analysis was employed to identify key themes within interview transcripts.

Results: Through the data analysis process four themes and six sub-themes were developed, each providing key insight into the participants' help-seeking experiences. A lack of awareness of the condition among health professionals and the public was reported by all participants. All participants first learned of the condition online and had conducted their own research into the condition. As a result, many reported being better informed than their doctors. Stigma, discrimination, misinformation, health system failures, and the restrictions associated with Covid-19 were all identified as barriers to help-seeking. Help-seeking facilitators included information and peer-support provided by online communities of individuals with the condition, as well as access to a health professional who had significant knowledge of PMDD.

Conclusion: Within Scotland there is a clear demand for the development of mental health promotion strategies that acknowledge the relationship between menstrual and mental health and provide tailored support for individuals with PMDD. Additionally, campaigns which increase public awareness of the condition and tackle stigma would encourage a greater number of individuals to access support for the PMDD. Disorder specific training for health professionals, improvements to menstrual health education in schools, and requiring future mental health research to account for sex-differences within the study design are among the study's recommendations.



Introduction

Women and girls face unique challenges to their mental health as a result of both their gender and biological sex (Jatchavala and Udomratn, 2019). Research shows that women experience significantly higher rates of depression and anxiety disorders in comparison to men, independent of country or culture (Bolea-Alamanac, 2017). Through the Sustainable Development Goals (SDGs), the World Health Organisation (WHO) has committed to achieving good health and well-being, as well as gender equality; both of which are considered to be basic human rights (World Health Organisation, 2020). Therefore, ensuring provision of gender sensitive mental healthcare, which reduces health inequalities on the basis of both sex and gender, is a crucial contributor to the achievement of the SDGs.

PMDD is of interest when considering the provision of gender sensitive mental healthcare, due to its association with the menstrual cycle. Recently recognised by the WHO, PMDD is considered to be a disease of the genitourinary system which is cross-listed as a depressive disorder, (Reed *et al.*, 2019). The global prevalence of PMDD is estimated at 3–8% of menstruating individuals (Weisz and Knaapen, 2009). It can result in a range of mental health symptoms, including mood swings, depression, anxiety, anger, and in some instances suicidal ideation. Individuals with PMDD typically experience these symptoms during the luteal phase of their menstrual cycle, with symptoms alleviating post-menses (Balık *et al.*, 2015). Research has found PMDD symptoms to severely impair individuals' daily functioning and to cause significant distress both for those directly affected and those closest to them (Hardy and Hardie, 2017; Siahbazi *et al.*, 2018). Furthermore, the severity and impact of PMDD has been compared to that of other major dysphoric disorders, such as chronic major depression (Halbreich *et al.*, 2003; Yamada and Kamagata, 2017).

In contrast to the majority of mental health conditions, PMDD remains significantly under-researched and under-recognised, evidence suggesting that sex differences are largely overlooked in mental health research (Bolea-Alamanac, 2017; Howard *et al.*, 2017). When PMDD was first introduced as a diagnosis, significant criticism surrounded its legitimacy which may have contributed to the limited research on the topic(Chrisler and Caplan, 2002). Available research suggests that despite the severity of PMDD, those affected will often delay or avoid seeking help entirely (Pearlstein *et al.*, 2005). When individuals do attempt to seek help for their symptoms they often access health professionals who are unaware of the condition (Hardy and Sillence, 2016). This places individuals at high risk of receiving a misdiagnosis for bipolar disorder and borderline personality disorder, given the similarities in symptomatology (Yamauchi *et al.*, 2008; Studd, 2012). Delays in access to appropriate support can lead to increased symptom severity, with consequent personal, social, and economic

losses (Andrade *et al.*, 2014). Additionally, evidence suggests that many individuals are opting for alternative, non-biomedical treatments in order to manage their PMDD, despite concerns surrounding their efficacy (Fisher *et al.*, 2016; Slavin *et al.*, 2017)

Seeking help from a health professional is seen as a crucial point in the process towards recovery in mental health, and, as such, increasing help-seeking behaviours is often prioritised in mental health policies and campaigns (Salaheddin and Mason, 2016). A common attitudinal barrier to accessing mental health support is the belief that individuals will experience stigma should speak openly of their experiences (Andrade *et al.*, 2014). Similar challenges exist when accessing support for menstrual health, with individuals often reporting high levels of shame surrounding menstruation (Ryan, Ussher and Perz, 2020). Additionally, there is a high degree of misinformation on mental health issues, which often results in individuals having no perception of the benefit of treatment (Andrade *et al.*, 2014). Many individuals with PMDD have to go online to access information on the condition, where the quality of information is often poor (Hardy and Sillence, 2016). The social stigmatisation coupled with the lack of access to appropriate information perpetuates health issues, such as PMDD (DeMaria *et al.*, 2020). Furthermore, research suggests individuals with PMDD often face significant discrimination when accessing support from health professionals (Janda *et al.*, 2019). This is of particular concern, given the evidence that previous experience of discrimination from a health professional increases one's likelihood to avoid help-seeking (Henderson *et al.*, 2017).

Nevertheless, help-seeking is complex and should not be reduced solely to attitudinal barriers. Reviews of the literature of mental health and help-seeking have found that a combination of attitudinal, structural, and demographic factors influence help-seeking behaviours (Henshaw and Freedman-Doan, 2009). Structural barriers, such as cost of treatment, limited access to services, and lack of trained health professionals can significantly reduce one's likelihood of accessing support. This is particularly relevant in low-income rural settings affected by a lack of investment in mental health services by governments and severe economic hardship (Andrade *et al.*, 2014). Therefore, access to support for PMDD will likely be partially determined by demographic variables and the help-seeking context (Henshaw and Freedman-Doan, 2009).

Importantly, there are significant limitations and biases within the literature. Existing PMDD research is predominantly conducted in the United States and typically depicts the condition through a biomedical lens, focusing on etiology, biomedical treatment, and prevalence (Ussher and Perz, 2013; Gao *et al.*, 2020). Additionally, the majority of broad population studies on help-seeking do not distinguish between mental health disorders in their samples; resulting in a lack of information on disorder specific barriers (Andrade *et al.*, 2014). In light of this, reliance on broader literature on help-

seeking to inform our understanding of PMDD, may result in key insights being overlooked and the generation of false assumptions. However, the research on the help-seeking experiences of individuals with PMDD is sparse (DeMaria *et al.*, 2020). From a mental health promotion perspective, it is crucial to better understand what factors influence an individual's decision to seek help for PMDD in order to improve health outcomes and quality of life for those with the condition (O'Connor *et al.*, 2014).

Present Study

Having identified a gap in the literature with regards to our understanding of the help-seeking process for PMDD, the research objectives of this study are as follows:

- 1. To explore individuals' experiences of help-seeking for PMDD symptoms in Scotland;
- **2.** To explore the barriers and facilitators to help-seeking for PMDD;
- **3.** To elicit individuals' views on ways to encourage help-seeking for PMDD;
- **4.** To identify formal and informal pathways to access support for PMDD.

The researcher is unaware of any existing peer-reviewed study that included a qualitative exploration on individuals' help-seeking experiences for PMDD. Scotland was chosen for reasons of greater accessibility to participants and because no previous research on PMDD has been conducted in Scotland. Of relevance to the present study is that the Scottish National Health System (NHS) recognises PMDD as a diagnosis, and has publicly committed to tackling gender-based health inequalities (NHS Health Scotland, 2017; National Health Service, 2018). Importantly, although the study is based in Scotland, it is hoped that it will increase awareness of PMDD and lead to improvements in gender sensitive mental healthcare globally.

Methods

Nine individuals, who self-identified as having PMDD symptoms, were recruited to take part in online semi-structured interviews, discussing their help-seeking experiences. An account of the methods used follows.

Design

Qualitative methods were chosen for their suitability to the study's research aims. This research allows the experiences of participants to be captured with sufficient depth, nuance, and sensitivity that would not have been possible using quantitative methods (Braun and Clarke, 2006). To ensure high levels of trustworthiness and transparency throughout the research process, the Consolidated Criteria for Reporting Qualitative Research were followed throughout (Tong, Sainsbury and Craig, 2007).

The study is based within a pragmatist paradigm. Pragmatism acknowledges that while a single objective reality may exist, it will always be mediated by human experience (Kaushik and Walsh, 2019). The ontological standpoint of pragmatism neatly aligns with previous personal accounts of reproductive disorders, including PMDD, often described as both an objective reality and an experience grounded within individual circumstances (Ussher, 2004). Furthermore, pragmatist approaches provide flexibility with regards to the philosophical and methodological underpinnings of studies, stating they should be guided by the research objectives (Kaushik and Walsh, 2019). As the study aims to explore individuals' experiences of PMDD, an emic epistemological standpoint was adopted; which emphasises the importance of engaging with individuals in order to gain an in-depth understanding of the phenomena in question (Yilmaz, 2013). Similarly, inductive methodology was selected as it allows the data analysis to be driven by participants' accounts (Braun and Clarke, 2006).

Participants & Sampling

The sample-size of nine participants was deemed appropriate considering the aims and scope of the study, which were to provide rich accounts of participants' experiences. Previous research findings have shown a sample size of 6-12 to be adequate in collecting and producing sufficient quality data of appropriate depth and breadth from participants' experiences during the interview process (Guest, Namey and Mitchell, 2013). While the sample is unlikely to be generalizable to the wider population,

it can still help generate useful, contextualised, and theoretically important insights into the topic under investigation.

Participants were recruited through non-probabilistic sampling methods. Convenience and snowball sampling methods were employed given time constraints, as well as for their efficacy with regards to recruiting participants from hard-to-reach populations (Valerio *et al.*, 2016). All eligibility criteria are outlined in Table 1.

Eligibility Criterion	Description						
1.	Over the age of eighteen.						
2.	Self-identify as having PMDD or PMDD-like symptoms.						
3.	Living or had previously lived in Scotland.						

Table 1: Eligibility Criteria

A PMDD diagnosis was not included as an eligibility criterion for multiple reasons. Firstly, given the study's aims of capturing the experience of help-seeking, the sample may be potentially biased if only those that had received a diagnosis could take part. Secondly, research shows that although many individuals do not reach the threshold for a PMDD diagnosis, they still suffer significant impairment due to their menstrual cycle (Eisenlohr-Moul *et al.*, 2017). The study aimed to capture the experience from a non-clinical perspective and therefore the requirement of a diagnosis would not be in keeping with the research objectives. In contrast to previous PMDD studies, gender was not listed within the eligibility criteria as significant numbers of transgender individuals suffer from PMDD (Jatchavala and Udomratn, 2019).

Data Collection

Data were collected from participants through the interview process, as well as from their responses to a brief demographic questionnaire, providing additional context to the findings (see Table 4 for findings, Appendix IV for sample questionnaire). One interview was conducted per participant. A semi-structured interview guide (Table 2) was developed to direct the interview process. Interviews began with a brief introduction from the researcher, followed by a number of general questions for the participants, to ease into the interview process and build rapport. Participants were then asked openended questions on their help-seeking experiences. Although interview topics varied, they typically

involved discussion of participants' symptoms, how they became aware of the condition, the quality of support they received, and their views on how to improve the help-seeking process. When necessary the researcher asked probing questions to gather a more detailed account from participants. Less personal questions were grouped towards the end of the interview to reduce the risk of an abrupt ending on a sensitive topic.

Interview Topic	Sample Questions
1: Establishing Rapport	 Why did you choose to take part in this study? In your own words, how do you understand PMDD and its associated symptoms?
2: Symptoms & Support	 I am particularly interested in how individuals seek help for PMDD/PMDD symptoms, have you had experience in seeking help for similar issues? How has that been for you? How would you describe the quality of support you received?
3: Learning about the Connection	 Can you tell me how you found out that your menstrual cycle could impact your mental health? How did learning this information make you feel?
4: Symptom Severity	 Can you tell me a little about how your mental health is impacted by your menstrual cycle? Are there any symptoms that you associate with your menstrual cycle?
5: Information Quality & Support	 From your perspective do you feel there is sufficient support and information available on your condition? Do you have access to reliable information? Do you feel you have been given adequate care?

6: Improvements	What improvements, if any, would you like to see happen for persons with similar symptoms to your own?
7: Conclusion	 Is there anything else you would like to mention that you feel is relevant to your experience of seeking support that we have not discussed? Do you have any remaining questions?

Table 2: Interview Guide

Procedure

The recruitment strategy involved using gatekeepers, a common recruitment tool in qualitative health research when recruiting from hard to reach populations (Wilson, 2019). Gatekeepers, for the purpose of this study, were any professionals who promoted awareness of PMDD and had extensive connections to individuals with the condition. They advertised the study through various means, including promotion of the study on their social media sites and directly informing individuals they felt would be interested in taking part. All eligible individuals were asked to contact the researcher directly via email to secure their place in the study. Overall, 22 individuals contacted the researcher to take part. Reasons for non-participation included no response (4) and displaying interest after the target sample size had been reached (9).

All interested individuals were sent a consent form, privacy notice, participant information sheet, and information on additional support services (see Appendix IV). Participant consent was obtained through signed consent forms filled out online and emailed to the researcher, as well as their oral consent prior to beginning the interview. Obtaining a signed consent form from a participant does not of itself demonstrate that informed consent has been granted, due to the fact that the signature may be provided without the participant being fully aware of, or understanding, what their participation entails (Nusbaum *et al.*, 2017). For this reason, the researcher ensured that participants fully understood the terms of their involvement. This included provision of all relevant documentation well in advance of the interview, presented in plain English. In addition, participants were provided with the opportunity to pose any questions they may have regarding their consent, both over email and over *Zoom* with the researcher. Lastly, all participants were made aware that should they wish to withdraw their consent they could do so at any point without issue.

Consenting individuals were asked to complete a brief demographic questionnaire in advance of the interview. Additionally, prior to commencing the interview, participants were offered a £10 *Amazon* gift voucher in recognition of the commitment of their time to the study. Interviews were conducted over *Zoom*, an online video call software. The decision to use *Zoom* software to conduct the interview process was to meet all necessary safety requirements and security restrictions introduced by the Scottish government due to the Covid-19 Pandemic. Participants were advised to choose a location for their interviews where they felt they could speak freely and without interruption. All interviews were conducted in English and lasted between 36-60 minutes; the average interview length was 44.55 minutes. All interviews were audio recorded and transcribed verbatim.

Data Analysis

The aim of the data analysis process was to identify key themes among individuals' help-seeking experiences. Upon completion of transcription, transcripts were anonymized, and the researcher followed the steps of thematic analysis as outlined by Braun & Clarke (2006) (Table 3). Inductive thematic analysis was employed when analysing the data; this method was chosen for its accessibility to first-time qualitative researchers, as well as for its theoretically flexibility (Braun and Clarke, 2006). *Nvivo* software was used in the coding process, as it allowed the researcher to easily view codes within and across transcripts.

The researcher coded all sections of data that were relevant to the research question. Additionally, 30% of the transcripts, anonymized and selected at random, were co-coded by an independent researcher in order to check for discrepancies between the coders' interpretation of the data (Campbell *et al.*, 2013). Upon completion of coding, thematically similar codes were grouped together to develop preliminary themes. The total number of themes was reduced from six to four, including six sub-themes, due to ensure all themes were sufficiently distinct. Final themes were refined to properly reflect the experiences of all participants and sub-themes were added to highlight nuances within themes. To increase the transparency of the data analysis process, extracts of the coding and theme development stages have been included (Appendix II).

Thematic Analysis Stages						
Braun & Clarke (2006) Guidelines	Present Study					
1: Familiarisation with Data	Read and re-read all transcripts gaining familiarity with the data corpus.					
2: Generating Initial Codes	Used Nvivo software to break the data down into codes, (e.g. 'Lack of Awareness of PMDD' and 'Conducting Own Research').					
3: Searching for Themes	 Conceptually similar codes grouped into preliminary themes. Code prevalence across and within transcripts was noted (see table 8, Appendix II). Themes selected based on code prevalence and relevance to research questions. 					
4: Review Themes	 Preliminary themes reviewed for accuracy to overall dataset (see table 6, Appendix II). Overlapping themes collapsed. New themes/sub-themes created for data not accurately represented within preliminary themes. 					

5: Defining & Naming Themes	 Final theme refinement (see table 7, Appendix II)
	Ensured themes related significantly to research questions.
	Four overarching themes and six sub-themes developed.
6: Producing the Report	❖ Write up of findings (see Chapter Three).

Table 3: Thematic Analysis Stages

Ethical Considerations

Given the highly personal nature of the study, it was essential the researcher considered all relevant ethical considerations and made appropriate provisions to minimize potential ethical issues. The researcher ensured any identifiable information pertaining to the participants was either redacted or pseudo-anonymised, to maintain their anonymity. All personal data collected from participants, such as signed consent forms, were stored on the password-protected University server, ensuring no participant data was stored on the researcher's personal electronic equipment. All interviews were audio recorded using the integrated software provided by *Zoom* and were automatically saved to the secure server. Importantly, all participant data was pseudo-anonymised by providing each individual a unique numerical identifier. The key document which linked participants to their identifiers was only accessible to the researcher and was stored on a private server, separate to all other data.

Researchers should be cognisant of the fact that participants' backgrounds may influence their level of willingness to discuss specific topics (Jatchavala and Udomratn, 2019). Considering this, the researcher opted for a semi-structured interview format, allowing the process to be adaptable across participants whilst retaining partial structure. This was crucial in creating a sensitive study design as it allowed the interview guide questions to be broad and open-ended, ensuring that each participant could steer the interview process in whichever direction they felt most comfortable. Additionally, participants were provided with support information and resources in advance of their interviews. However, all participants thanked the researcher for taking the time to listen to them and stated their

gratitude in having their experiences acknowledged, suggesting they found the process to be rewarding, rather than upsetting.

Conducting research interviews online involves different ethical concerns to those conducted in person. Previous research has noted that participants may be more prone to forgetting they are being recorded when the interview is conducted online, given that they cannot see a Dictaphone in front of them, as would be the case in a face-to-face interview (Deakin and Wakefield, 2014). To ensure the participant was fully aware, they were reminded of the recording prior to starting the process.

It was important to ensure that the compensation offered was not coercive, resulting in eligible individuals feeling it was 'too good an offer' to refuse, as this would have altered the nature of their consent. However, research has shown incentives to be an effective way of increasing participation rates and acknowledging participants' contributions (Head, 2009). Having reviewed the existing literature, the research concluded that a £10 *Amazon* gift voucher was a sufficiently low incentive so as not to be coercive in the context of the study (Stovel *et al.*, 2018).

Importantly, ethical considerations equally apply to the researcher. Before arriving at the decision to conduct qualitative interviews, the researcher ensured they were fully aware of the intensity of the interview process and its potential impact on their emotional well-being (Dickson-Swift *et al.*, 2007). Similarly, the researcher considered issues regarding their level of self-disclosure for the purposes of rapport building, as well as their right to privacy throughout the process. As a necessary precaution, appropriate researcher support provisions were put in place in the event they should be required (Dickson-Swift *et al.*, 2007).

Ethical approval was granted by the University of Glasgow's College of Medical, Veterinary & Life Sciences Ethics Committee (Project No. 200190137).

Reflexivity

The researcher is aware that qualitative research findings are co-constituted by the participants and the researcher; thus all data and findings of this study are inextricably linked to her values, beliefs, and biases (Finlay, 2002). She recognises that all aspects of the research may have been influenced by her age, social class, experiences of help-seeking, and identity as a white, female, heterosexual researcher who has been diagnosed with PMDD. While thematic analysis is subjective by design, the researcher made significant efforts to ensure the final themes developed were an accurate representation of participants' accounts, and to minimise potential bias from her personal experience with PMDD (Braun and Clarke, 2006). This included keeping extensive notes of the theme development process

and ensuring there were no major discrepancies between her coding and that of the co-coder (Appendix II).

Results

Participant Information

The sample's demographic characteristics were largely heterogeneous (see table 4). Participants were aged between 28-49, the average age of the sample was 39 and participants were predominantly

Questionnaire Responses										
Participant Number	1	2	3	4	5	6	7	8	9	Average
Age	35	49	41	37	44	38	45	30	28	39
Ethnicity	White	White	White	White	White	White	White	White	Asian	White
Primary Language	English	English	English	English	English	English	English	English	English	English
Area Lived In	Rural	Rural	Urban	Urban	Suburban	Rural	Urban	Suburban	Urban	Urban
Employment Status	Unemployed	Part-Time	Part- Time	Full-Time	Full-Time	Full-Time	Part-Time	Full-Time	Student	Full-Time
Symptom Severity	Severe	Moderate	Severe	Moderate	Moderate	Moderate	Moderate	Moderate	Severe	Moderate
Sought Help within Last Six Months	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes

ethnically White: Scottish (89%). Most of the sample (78%) had sought help for their symptoms within the last six months and all considered their symptoms to be moderate or severe, the majority selecting moderate symptom severity (67%).

Table 4: Questionnaire Responses

Themes

Four main themes and six sub-themes were developed through the data analysis process. Each of the themes presented highlight key aspects of the participants' help-seeking experiences for PMDD. The intention of the theme development process was not to generalise, but rather to provide the reader with a nuanced account of the participants' experiences, capturing the similarities and differences

between them. The themes are discussed in detail below, accompanied with quotes from the participants (for supporting evidence, see Appendix II). Importantly, sub-themes are not mutually exclusive; some participants experienced a combination of them, others just one.

Theme 1: 'Something is wrong'

For all participants, the help-seeking process began after the realisation that something was wrong. Help-seeking was prompted by the acknowledgement that they required external support, as they could no longer manage their symptoms on their own.

Symptom Driven

Many remarked that as the severity of their symptoms increased, so did their concerns, which ultimately drove them to access help. They explained how fearful they were of their rapid mood changes, which often left them feeling they were not behaving like themselves:

"[...] I used to keep saying to my husband, it's not, this isn't me." (P2).

Some participants were aware for many years that they were prone to mood changes because of their menstrual cycle, but had chosen not to seek external support until their symptoms became severe:

"[...] I actually never used to be like this, like this is bad [...] it is getting worse, kinda way. That's when I took it upon myself to kinda start researching it [...]." (P5)

Additionally, several participants arrived at the decision to seek help upon realizing that what they had considered to be typical premenstrual symptoms, were in fact much rarer and more severe than those experienced by others:

"[...] what I found out was that no it wasn't what everybody suffered and actually no these quite severe symptoms are not normal for most people [...]" (P8).

External Pressures

For others, the help-seeking process only began when those around them expressed concerns. They described thinking they were managing appropriately, until others raised doubts about their ability to cope with their symptoms:

"[...] one of my friends told me that they would never speak to me again if I didn't sort out my mood swings." (P4).

The participants' relationship to the individual that encouraged them to access support varied. One participant discussed how her supervisors had raised their concerns, after they noticed a deterioration in her performance at work:

"[...] cognitive impairment that started to affect my work, that worried them a little bit." (P6).

Others described how their friends and family members had grown concerned by their behaviour, which was putting significant strain on their personal relationships:

"I think my mom got really worried [...] I shouted at my daughter once and she was like, 'That's just actually not okay." (P7).

Theme 2: What is PMDD?

PMDD, as referenced by all participants, is not sufficiently understood within Scotland. The limited understanding of PMDD was often attributed to society's tendency to dismiss the role of the menstrual cycle in contributing to significant psychological distress:

"[...] having your period, it's just sort of accepted, as well, you might be grumpy, you might have these cravings, but what you don't realize is the darker side of that." (P1).

Various participants discussed how cultural norms had caused them to feel disconnected from their menstrual cycles. They considered this dismissal of menstruation to impede individuals with PMDD in recognising the connection between their psychological symptoms and their menstrual cycle:

"[...] it took a long time for me to realise that it's in sync with [...] my menstrual cycle." (P2).

All participants, bar one, first learned of the condition through the internet:

"I started kinda looking up on the internet, just like extreme..obviously PMS, and then I started seeing this PMDD" (P5).

However, some considered the quality of information online to be rather poor. They noted that the majority of information felt anecdotal rather than based on reliable scientific research:

"There needs to be more [...] accurate information [...] somebody needs to trawl it regularly and get rid of all the rubbish." (P6).

The absence of a single reliable source of information may contribute to confusion regarding PMDD. Several alluded to the confusion surrounding whether PMDD could be classified as a mental health condition:

"PMDD [...] impacts your mental health in a very negative way, but essentially, it's an endocrine condition." (P3).

Additionally, differences emerged in participants' descriptions of PMDD. Some provided biomedical accounts:

"[...] it's an abnormal, like, brain reaction to normal fluctuations in hormones. (P8).

In contrast, others defined PMDD in terms of how the symptoms they experienced impacted their quality of life:

"[...] it's very debilitating. [...] it interferes with normal, day to day life." (P2).

What remained consistent across all participants was the value they placed on learning that such a condition existed. Many discussed the relief and validation they felt upon learning of PMDD, as it provided them with the terminology needed to explain their experiences to others:

"[...] I'm not going crazy. There's actually a sound clinical reason for what I'm feeling [...]" (P3).

Theme 3: Who is the expert?

All participants discussed accessing support through the health system, however they had mixed views on the quality of support and information provided. Further, the time it took for participants to receive appropriate support for their symptoms was heavily dependent on the health professionals they had accessed.

'I know more'

Through their accounts of interacting with health professionals, it became evident that participants were typically better informed on PMDD than the experts they had sought advice from. Availing of information online, participants conducted a significant amount of their own research into the condition:

"I have done quite a bit of research on it to try and understand a bit more what it is." (P4).

This often led to an imbalance of knowledge between patient and doctor. Most participants had to inform their doctor of PMDD, its symptoms, and its associated treatment options:

"I self-diagnose myself with PMDD. I didn't have a practitioner diagnosing me because I suppose they failed to make a correlation between my mental health symptoms and my menstrual cycle." (P3).

Despite this, some participants expressed doubts and fears at the possibility of incorrectly attributing their symptoms to PMDD and wished for a doctor to validate their diagnosis:

"I don't want to be one of those, you know, hypochondriac people that goes to the doctor and says, 'I have diagnosed myself and I have this.' and maybe I am just crazy." (P4).

Many participants discussed disliking the treatment options available to them, namely SSRIs and contraceptive medication. Several mentioned a desire to use alternative, non-biomedical treatments to manage their PMDD. They reported feeling unsupported by their doctors and felt a greater sense of hope through managing their symptoms on their own terms:

"I am determined to research into it and do trial and error with various, em, natural remedies [...] I don't think blocking things out [...] which let's face it, SSRIs do. I don't think that's a solution." (P6).

Which Doctor Knows Best?

A wide variety of health professionals with varying levels of expertise were accessed by the participants. The majority began by engaging directly with their General Practitioner (GP); however, a minority believed their GP to be sufficient in providing care for PMDD:

"[...] she was very willing to, eh, look into it [...] you know I have no complaints of the support there." (P2).

The majority considered their GPs to be an additional obstacle to overcome in the help-seeking process due to their limited knowledge of PMDD and their tendency to dismiss their concerns:

"I've never been taken seriously enough with all the doctors to be honest." (P5).

Although participants reported severe psychological distress, only three spoke of accessing psychological therapy. By and large, they did not consider professional mental health services to be particularly useful with regards to managing their symptoms, as they believed it failed to address the root cause of their distress:

"I've had, eh, various different counselling treatments [...] but it didn't really help." (P4).

Participants typically displayed a preference for health professionals with significant gynaecological and reproductive health knowledge:

"I think just going to this woman and she was specialised and just amazing [...] I really didn't want to go to the GP." (P7).

However, many reported significant challenges accessing a professional with such expertise.

All the participants that had received a formal PMDD diagnosis, expressed the immense relief they felt when encountering a health professional that was aware of the condition and validated their experiences:

"[...] she just said, "You have textbook PMDD." [...] I was like, "So, I'm not going crazy!" and then I started to cry." (P4).

It was evident from their accounts, that acknowledgement from a professional plays a pivotal role in the recovery process for PMDD.

Interestingly, while many participants considered the gender of a health professional to play a role in the quality of help they received, there was no consensus with regards to which gender provided better support:

"I actually think female GPs might be less likely to do anything than male GPs. [...] because maybe they've not experienced it so it can't be fathomed." (P7).

Theme 4: Accessing Support

Accessing support for PMDD, as described by the participants, is a challenging process with significant obstacles, namely stigma, discrimination, and limited access to appropriate support. Despite the severity of their symptoms and the challenges faced, several participants stated that in comparison to others, they felt lucky with regards to their help-seeking experiences. Many displayed a high level of awareness of potential barriers faced by those with PMDD in different circumstances to themselves and suggested means of improving help-seeking for all individuals with PMDD:

"I know there's a lot of women that struggle [...] I have to say I've been lucky." (P2).

Barriers

Stigma and discrimination, were frequently encountered by participants when help-seeking:

"I hid it for years [...] if that stigma wasn't there the same, and, em, you could be more open about it." (P2).

Of concern is the fact that they reported stigmatizing beliefs of PMDD to be grounded in negative attitudes about both mental and menstrual health; suggesting that individuals with PMDD may encounter greater stigma and discrimination than those with other mental health conditions. The majority of participants maintained individuals with PMDD are subject to greater discrimination as a result of sexism:

"I feel as if they are saying [...] women should deal with it, that's just the way it is with your hormones every month." (P5)

Despite the reported influence of stigma, few participants displayed self-stigma, the internalization of stigmatizing beliefs, and of those who did, they reported this solely as a barrier with regards to accessing informal support, rather than when engaging with health professionals:

"It definitely plays a role in me seeking [...] non-medical help." (P8).

However, the majority of participants experienced disrespectful and stigmatising attitudes from their health professionals, with many left feeling dismissed and unsupported:

"[...] I went in and I was emotional because it was just before my period [...] he asked me and this is when I stopped going to him, "Did I think I cried every month because my period was a reminder that I didn't have children and I was single?" (P4).

Furthermore, many felt the healthcare system to be inaccessible due to structural barriers, such as its disjointed design, extended waiting times, and restrictions imposed by the referral system:

"If our health systems were better linked up, we might see the connections between things a lot earlier [...]" (P4)

The interviews took place during the restrictions associated with the Covid-19 pandemic, and various participants discussed how this had aggravated the existing structural barriers to help-seeking. They

spoke of limited access to services and already brief appointments becoming even shorter phone appointments:

"She is having an awful, awful time at the moment with you know [...] obviously the global pandemic and accessing surgical management." (P3).

One participant received her PMDD diagnosis over the phone during the pandemic and felt that she was not provided with the opportunity to discuss the diagnosis in detail with her doctor:

"It would have been better to actually speak to her and get a chance to think [...] I think maybe it was a bit rushed." (P6).

Alarmingly, some participants despite reporting significant symptom severity had chosen to delay help-seeking due to concerns regarding accessing support during a pandemic, with one participant opting for alternative treatment while waiting to meet their doctor:

"I couldn't put up with the symptoms again this month [...] agnus castus [...] I just started taking that last week to see if that's going to help." (P5).

Facilitators

Importantly, not all help-seeking experiences were negative, and many participants provided suggestions of simple, yet effective ways to improve the help-seeking process for individuals with PMDD. Every participant discussed how beneficial the internet and online communities of individuals with the condition had been with regards to accessing support. Many of them relied on the accounts of others online to decipher whether they had PMDD themselves:

"[...] it has been then just from [...] social media, that's kind of flagged this up." (P1)

However, while participants were grateful to the online community for their support, the majority did not consider it an appropriate substitute for professional help:

"[...] things like support groups on Instagram [...] they are more just like, oh! We are all in the same boat." (P8).

Several discussed how they had learned of the value of symptom tracking online and how many apps aided the process. Virtually all participants encouraged anyone who suspects they are experiencing PMDD to begin tracking their symptoms in accordance with their menstrual cycle, as they considered it the best means of convincing a doctor to take their concerns seriously:

"[...] have a menstrual tracker, em, keep a note of it [...] take that along to your GP so you've got, eh, evidence [...] " (P2).

Every participant believed help-seeking for PMDD would become easier as awareness of the condition increased, and stigmatising beliefs declined. They discussed the need to ensure health professionals were appropriately informed and that young people were provided with mental and menstrual health education:

"[...] start teaching young children [...] how to recognise when it's not normal [...]" (P4).

Additionally, all thought greater research into PMDD would improve access to support for the condition:

"Any research that can be done to [...] support that area, or even just women's mental health in general [...] I think it's awesome." (P8).



Discussion

The aim of the study was to capture the help-seeking experiences of individuals with PMDD in the Scottish context; identifying factors and pathways to accessing support, as well as ways to encourage help-seeking. Through the interviews it was uncovered that, in Scotland, the process of help-seeking for PMDD is challenging, requiring those affected to direct the process. The inductive thematic analysis led to the creation of four main themes and six sub-themes: each one providing a unique insight into the help-seeking experiences participants. The findings are discussed below with regards to the research objectives of this study and their relationship with the existing literature on help-seeking for PMDD.

In line with existing research, all participants discussed how dismissive and often sexist beliefs towards menstruation are pervasive within society (DeMaria *et al.*, 2020). This was shown to negatively impact the help-seeking process in numerous ways. Firstly, participants explained that as a result of living in a society that stigmatises menstruation, it took many of them a long time to connect their symptoms with their menstrual cycle. Over the period of time it took participants to recognise the connection, they reported severe deterioration in their well-being, relationship strains, and often self-blame, as they considered themselves to be personally responsible for their symptoms. Secondly, various participants discussed how the persistent trivialisation of menstruation within society left them feeling isolated and decreased their willingness to access external support. In line with previous menstrual health research, participants discussed how family, friends, and health professionals had dismissed the severity of their symptoms, claiming that these were normal and to be expected in anyone who menstruates (Wong, 2011; Janda *et al.*, 2019). This often left participants struggling to distinguish between the signs of a normal menstruation and the symptoms of something more severe.

A novel finding of the study is that increasing public knowledge of the relationship between menstrual and mental health will significantly reduce the help-seeking barriers faced by individuals with PMDD. These findings echo the broader literature which highlights the role of menstrual and mental health literacy in driving help-seeking behaviours (Andrade *et al.*, 2014; DeMaria *et al.*, 2020). As several participants explained, their decision to access external support was predicated on their ability to recognise their symptoms as atypical. The findings partially support previous research that has shown that individuals typically underestimate their premenstrual symptom severity; suggesting that increasing awareness of PMDD symptoms should result in a higher proportion of individuals accessing support for the condition (Robinson and Swindle, 2000). However, a major contribution of the study was identifying that the greatest barrier to help-seeking for PMDD was not an unwillingness

among participants to seek help but rather the failure of health professionals to identify that their patients were experiencing PMDD.

Participants' experiences of help-seeking were heavily shaped by their health professional's knowledge of PMDD and its associated symptoms, which often was extremely limited. These findings provide further legitimacy to the research which suggests the condition to be significantly under-recognised within the medical field (Hardy and Sillence, 2016). This study has expanded on the existing evidence by highlighting how lack of awareness of PMDD heavily impacts the help-seeking process for the condition. These findings convey the detrimental impact of accessing support from a health professional who is unaware of PMDD. This experience often left participants feeling dismissed and misunderstood, which significantly deterred their help-seeking efforts; similar to previous research findings (Janda *et al.*, 2019). This is of concern as several participants reported experiencing severe psychological distress and suicidal ideation.

In accordance with previous research findings, participants often accessed support for PMDD through informal means, such as the internet (Hardy and Sillence, 2016). All participants conducted their own research online to learn about PMDD, the available treatment options, and in some cases to access peer support. The majority of participants described social media as an invaluable resource with regards to accessing information and help for the condition, in line with broader mental health research (Naslund *et al.*, 2016). The present study has shown that due to the lack of awareness, the responsibility to inform others of PMDD often falls on those with the condition. All the participants felt they needed to help raise awareness and many believed their health professionals never would have considered PMDD as a potential diagnosis had they not personally raised the issue. These findings suggest individuals with PMDD are having to fill a treatment gap caused by a general lack of awareness of the connection between the menstrual cycle and mental health.

Despite participants' acknowledgement that online platforms were a major facilitator in the process of help-seeking, they displayed concerns about the quality of the information online. All commented on the need for greater evidence-based research on PMDD, echoing the conclusion of previous studies on the condition (Hardy and Sillence, 2016; Siahbazi *et al.*, 2018). A novel insight of the study is that virtually all participants maintained that while informal support may serve as a major benefit to individuals with PMDD, in so far as making them feel acknowledged and less isolated, it alone was insufficient with regards to managing their symptoms.

When help-seeking for PMDD, participants faced structural barriers in addition to the attitudinal barriers. Consistent with the existing literature on the determinants of help-seeking, participants considered a variety of factors to influence their access to support (Henshaw and Freedman-Doan, 2009). For example, several reported feeling discouraged from formal help-seeking, given the

propensity of doctors to prescribe SSRIs for psychological symptoms. In contrast to the existing literature, which heavily focuses on treating PMDD with SSRIs, the majority of participants did not consider them to be a viable treatment option due to their side effects (Pearlstein, 2016). As a result, various participants discussed the use of alternative, non-biomedical treatments to manage their symptoms. These findings support previous research which found a large proportion of individuals to rely on alternative medicine to manage their PMDD (Fisher *et al.*, 2016; Slavin *et al.*, 2017). These findings raise concerns on the limited research evidence available on the safety and effectiveness of using alternative treatments to manage PMDD.

Various participants discussed how the referral system in Scotland contributed to the difficulties in accessing care for PMDD. Participants, who predominantly displayed a preference for gynaecologists and reproductive health experts, felt such health professionals were difficult to access because they typically required GP referral to meet with them. Many conveyed their frustration that their first point of care, their GPs, lacked the appropriate knowledge to recognise that their patients required referral to a specialist. Additionally, several participants discussed how the existing structural barriers within the health system had become aggravated by the Covid-19 crisis. This study provides credence to the argument that the restrictions associated with the global pandemic have led to a decrease in individuals' willingness to access healthcare (Halford, Lake and Gould, 2020). Participants discussed delaying help-seeking for PMDD as they did not believe their symptoms were a priority during a pandemic. Participants that had accessed support during Covid-19 reported a reduction in the quality of care provided and felt access to health professionals had been reduced.

Evident in all participants' accounts was the importance of learning and receiving a diagnosis for PMDD. Many of them described the immense relief that came with learning the diagnosis, of knowing that they were not alone and that others experienced similar symptoms. These findings lie in opposition to claims that PMDD, as a diagnosis, is ineffective and only serves to pathologize women's experiences of menstruation (Chrisler and Caplan, 2002). Although several participants disliked the portrayal of menstruation as a purely negative experience, they still felt a diagnosis of PMDD to be extremely valuable. This study contributes to the literature, by providing evidence that the diagnosis is viewed by individuals with PMDD as enabling them to take control over their bodies and their health, rather than limiting it. This study suggests that if health professionals and broader society continue to dismiss the psychological impact of menstrual health issues, many individuals with PMDD will be limited in their ability to access appropriate support.



Researcher's Reflections

The research methods selected, by design, involved many value judgments on behalf of the researcher (Braun and Clarke, 2006). Perhaps the greatest of these was the decision to share with participants the researcher's identity as an individual diagnosed with PMDD. As a result of sharing this information it is possible the researcher was viewed as an 'insider' to the participants, thus increasing their willingness to share their own experiences (Greene, 2014). Importantly, there are benefits and disadvantages, including ethical issues, to being considered an 'insider' (Jootun, McGhee and Marland, 2009). On balance, the researcher chose to share the information, to increase transparency and enrich the quality of discussion in the interview process. It is important to acknowledge that the data collected, and the subsequent findings have been significantly influenced by this decision. A novel contribution of the research is that not only were the data collected grounded in the experiences of individuals with PMDD, they were also analysed by a researcher with first-hand experience of help-seeking for the condition; resulting in insights that may otherwise not have been generated.

Limitations

Firstly, there is a significant risk of selection bias as a result of the chosen recruitment methods. Given the self-selection process, it is probable that those who contributed to the research were more willing to speak openly of their experiences, thus biasing the sample with individuals who are less likely to be impacted by attitudinal barriers, such as self-stigma. Additionally, it is likely the role of social media may be overstated within the findings, given that most participants learned of the study through the medium.

Secondly, the interviews were conducted online and there were various instances when the audio connection was poor, making communication difficult. The impact of technical issues damaging rapport between researcher and participant has been reported in previous research and may have limited the quality of data collected (Lo Iacono, Symonds and Brown, 2016). Thirdly, several participants mentioned that their responses would vary depending on the point within their menstrual cycle at which they are being interviewed. To properly account for variance attributable to such mood change, the study could have included one or more follow-up interviews with participants.

Additionally, the participant pool was largely heterogeneous with regards to their demographic characteristics, thus potentially failing to uncover key insights due to bias. This issue may have been

avoided by employing purposive sampling methods, to recruit a participant pool that more accurately reflected the general population (Robinson, 2014).

Lastly, it is important to recognise the influence of context on the research findings. Scotland, as a high-income country, does not face the same challenges with regards to providing mental health care for its citizens as low- and middle-income countries (LMIC) (Rathod *et al.*, 2017). It is likely that the challenges faced by the participants would have been far greater had the research been conducted in a LMIC. For example, menstrual and mental health stigma significantly affected participants' help-seeking. However, there are many countries globally with far greater societal stigma and discrimination surrounding both menstruation and mental health (Mascayano, Armijo and Yang, 2015; Hennegan *et al.*, 2019). Therefore, it is likely that individuals with PMDD living in such countries, where high levels of stigma are pervasive, will encounter greater barriers to treatment than those reported within the findings. Additionally, the study took place in Scotland, which provides free healthcare through their NHS (Steiner and Targett, 2016). As a result, the impact of cost constraints as a barrier to accessing care in this study is likely to under-represent the importance of this barrier in countries in which free healthcare and medication are not readily accessible (Andrade et al., 2014).

Recommendations

Several recommendations are made with regards to improving support for individuals with PMDD. Firstly, there is an urgent need to increase awareness of PMDD among health professionals. When a patient presents with recurrent psychological distress, it should become routine within clinical practice to rule the menstrual cycle out as a potential cause. Additionally, the health system requires better integration of physical and mental health services, allowing health professionals to more promptly recognise the interplay between physical and mental health issues, such as PMDD (Bennett *et al.*, 2009).

From a policy perspective, greater emphasis should be placed on developing public information campaigns that tackle common misconceptions surrounding PMDD. The development of such campaigns would increase the public's ability to recognise when professional support is required (Griffiths *et al.*, 2014). Furthermore, the sexual health curriculum in schools should be updated to include a greater emphasis on menstrual health, with the aim of increasing young people's awareness of the psychological symptoms associated with menstruation, as well teaching practical skills, such as symptom tracking (DeMaria *et al.*, 2020).

Future research should investigate help-seeking for PMDD in varying contexts, particularly in LMICs where there is a paucity of research (Gao *et al.*, 2020). Furthermore, researchers should allow the views and experiences of individuals with PMDD to guide research, ensuring studies conducted reflect the needs of those affected. Lastly, future research in mental health should be required to incorporate sex and gender considerations within their study design, so as to limit the risk of bias (Howard *et al.*, 2017).

Conclusion

The findings of this study depict the help-seeking process for individuals with PMDD in Scotland as fraught with challenges. Although participants encountered some positive experiences while help-seeking, they often resulted from significant effort and research on behalf of those affected or were viewed as exceptional circumstances. These findings highlight that individuals with PMDD are at a disadvantage in terms of accessing information, treatment, and support for their condition. Evidently, there exists a clear and present need to develop mental health promotion strategies for individuals with PMDD in Scotland.



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Appendices

Appendix I: Target Journal

Women & Health: https://www-tandfonline-com.ezproxy.lib.gla.ac.uk/action/authorSubmission?show=instructions&journalCode=wwah20

Appendix II: Supporting Evidence

Themes	Sub-Themes	Quotes
Theme 1: 'Something is wrong'	Symptom Driven	"[] as soon as my periods returned and eh, you know after each child, my symptoms basically just became worse. And following the birth of my first child, I, I didn't know what was going on. I thought I was clinically depressed." P3 "[] I don't know if they thought I was overreacting, or something, and emh I don't know. Eh I just, I just feel as if it was kinda like "That's normal, that's normal to feel like that" and I'm like "Is it normal to feel like God you just want to breakdown and cry" and you don'teven some days you don't even want to go out the door kinda thing, like that's, that's not normal." P5 "[] he was like "You can't blame your period all the time!". So, eh, what I did was I went online to basically prove that most people suffered with PMS and [] it was a regular reaction to PMS []" P8 "I remember sort of speaking to someone at work about it and they, they said "Oh I don't get any of that." and I thought she was not normal, because she didn't, and I was like "Well everyone else does!" [laughs]" P8
	External Pressures	"[] my line managers changes quite regularly, and I have to go and explain all these things, why I'm off sick to each line manager every time they come in." P6 "[] my husband just said, em, "You know this isn't okay." because I just used to sit and sob for hours on end and say everybody would be better off if I didn't live with them, and, em, just really horrible, you know." P7 "[] when I had symptoms, he thinks that I'm crazy." P9

		''[] at the beginning I don't know what happens with me. Even my supervisor is like, eh, I was, I was behaving, mh, when I, when I was in the 'hell week' I was taking it out on my supervisor. Can you imagine?'' P9
Theme 2: What is PMDD?	N/A	"I think actually if you look at it, it is women who are disconnected from their bodies, because you are trying to [] fight against your own body. You are fighting against your own body's acts, impulses, and needs, whatever it needs []" P1 "I put in various things into Google and this came up. Em, I don't think it was recognised in the UK in 2013. "P2 "[] I started, you know, doing a significant amount of research and then self-diagnosed. And it was, it was that typical you know everyone says "That lightbulb moment." P3 "[] it's a really important topic, and it is, I mean m-menstruation in general is not talked about enough. But when it is talked about it is very much focused on physical symptoms. And my pet bugbear is that the emotional and the psychological aspects of it are very rarely discussed." P4 "[] it was actually quite a relief to see when I joined a Facebook page and actually started reading all the things that that I was in, I showed it to my partner, and he was like [] that is you." P5 "I read a little bit into it, em, I don't think it's a mental health disorder." P6 "A lot of women, as I say, just think that's just the way it is and we should just take it. So, I've got worse than her or her, maybe I just can't handle it the same way, and I don't think that's right either." P6 "I don't think I ever would have been diagnosed if I hadn't randomly Googled to prove to my partner." P8 "To be honest, first thing is I don't think people even know about what is PMDD." P9
Theme 3: Who is the expert?	'I know more'	"[] even on the lowest dose of fluoxetine, I just, I couldn't function [] I thought, well you know, I know that that's not going to be a tolerable, uhm, option for me." P2 "They were, you know, largely willing to be guided by the fact that I'd done research, that I had come in sort of armed, you know, papers and kind of, you know, my symptom tracker and everything else. So, I think, they, they were supportive, yeah. "P3 "[] I thought you're not living it, I'm living it. I'm the one that has to live with the symptoms of, you know, wanting to sort of occasionally, you might feel

		like I want to throw myself in front of a train at the height of my PMDD symptoms." P3
		"Em, so that, that was kind of the route they put me down, em, antidepressants which I didn't want. "P4
		"Yeah, I'm tracking and I'm taking it to I'm going to have three months of tracking and then I'm taking it to the doctor and I'm gonna say to them, look, this is what I'm, this is what I'm dealing with, so I am." P5
		"Of course, the first thing they tell you is diet and exercise, eh but then you research it and diet has no effect on PMDD at all." P6
		"[] I'm also not daft enough to put, to read something on the internet and go, "Omg I've got it!" There's, there's all of this in the back of my mind saying, "Be careful what you are doing, you need somebody's professional opinion on this." P6
		"Yeah, I'd say it was more me guiding the doctor." P8
		''I didn't really want to use antidepressants.'' P9
		''[]I was at that doctor [] I did mention PMDD and there was just a, eh, blank, didn't know, didn't know what that was no.'' P1
		"[] awareness of doctors, not to just brush off mental health symptoms without, you know, identifying any correlation between, you know, a menstrual cycle." P3
		"[] the doctors never ever said anything. Not once did any doctor say it, so no, no I don't think there's a great awareness in Scotland, at all." P5
	Which Doctor	"One of the doctors tried me on emh antidepressants [] it just, they just, made me feel sick to be honest [] whenever I took them. I was feeling very sickly on them []" P5
	Knows Best?	"Eh, I think there needs to be a greater understanding in the GP practice of things like PMS, PMDD, PME, em it's not very well understood []." P6
		"But to be honest I really don't think that is going to help, em, because I'm not depressed. That just teaches you how to rethink things or how you should think things through so there's nothing wrong with my thought patterns. "P6
		"No one has ever asked me "Oh are your symptoms just a week before?" and I just don't think doctors or GPs really have a, a big knowledge of PMDD." P8

		"Emh so yeah. I'd, I'd say PMDD specifically, I think, em, I used to Google things, em, to try and figure out where to go. Like, em, magnesium I think was one that I recently came across and things like that []" P8
Theme 4: Accessing Support	Barriers	"And they are basically saying, "We are going to give you a tiny, a tiny bit and it is going to take a gazillion weeks, again, to maybe, maybe not work. And you might, you may or might not know and, em give it time. But then you can try another one" and I'm like, why the hell?!" P1 "You get all the jokes about and PMS and being a bit crazy that month, then people don't joke about if you're bleeding really heavily but they joke about if you're crying all the time." P4 "So, I've got worse than her or her, maybe I just can't handle it the same way [] I link that to the stigma, em, "You are not woman enough to deal with it." Does that make sense? I know you've got the term, you are not man up, so it's like woman up." P6 "I just don't think, you know I don't think it's in society it is valued enough. I still think it is seen as hysterical women, a little bit." P7 "And that's supposed to be slightly more effective and I did think about going to the GP and asking to get that. And, eh, I don't know, eh, again I can't be bothered with a fight really. "P7 "[] it's almost like the whole mental health stems from your uterus. [] and all the stigma around mental health, men, women, being lunatic is eh yeah, you know, it's all tied in, and I just think it's, eh, you know that's fair enough in the 1600s but now."P7 "So, there's definitely a stigma there on both sides [] It's just like, em, thing about, on one hand we are impacted by the time of the month and we do, our behaviour does change, but at the same time, eh, a lot of women are like "Well you can't blame it on my period." so it's like, eh, I don't know. It's like rock in a hard place like." P8
	Facilitators	"[] they have the PMDD awareness month in April. Em, eh, I was, eh, I was at the first conference last year [] that was very helpful, and I took lots of notes and things like that." P2 "[] following, like, particular groups or, em, following particular pages or Instagram's. Eh, just because it gives you more information and a bit more understanding about what it is." P4

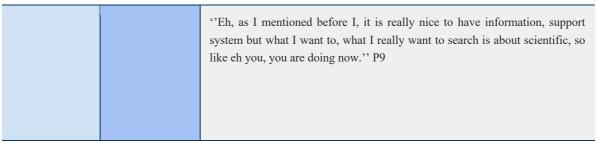


Table 5: Supporting Quotes

Thematic Map:

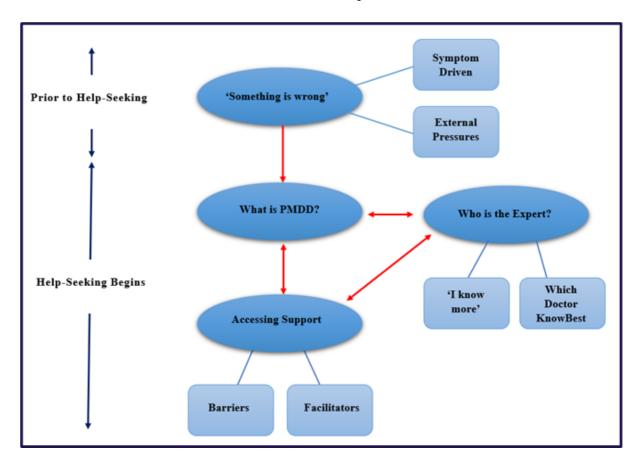


Figure 1 - Thematic Map: Ovals represent themes and rectangles represent sub-themes. The red arrows display the relationship between themes. Arrows pointing in one direction depict a hierarchical relationship. Arrows which point in two directions depict a lateral relationship. Solid blue lines connect themes to their sub-themes. Blue arrows highlight the stage of help-seeking the themes fall under.

Stages of Theme Development: Sample

Stage 1

Theme 1: Knowledge & Information	Theme 2: Interactions with Health Professionals	Theme 3: Self-Reliance	Theme 4: Not Like Everyone Else
Codes: - Accessing Information Online - Lack of Research Available - Preference for Scientific Research - Conduct Own Research	Codes: - Professional Unaware - Gender Importance - Referral System - Misdiagnosed - Long Time to Receive Correct Diagnosis	Codes: - Symptoms are their Responsibility - Self-Diagnosis - Self-Doubt - Fear of Being a Hypochondriac - Ignoring Symptoms	Codes: - Feeling Crazy - Not Themselves - Different to Others - Difficulty Understanding Symptoms - Others Don't See Every Side
Theme 5: Barriers	Theme 6: Need for Change	Theme 7: Support Systems	Remaining Codes

Codes:	Codes:	Codes:	Codes:
- Unaware of Cycle Connection	- Policy Changes	- Freedom to Express Themselves	- Experience of Pregnancy
- Lack of Information Available	- Holistic Care - ''Don't Act Like	- Someone to Open Up To	- PMDD a Mental Illness?
- Written Off as Something Else	They Know Everything''	- Social Media	- Pressure of External Factors
- Stigma	- Symptom Tracking	- Accessed Information Online	- Non-Biomedical Treatment
			110000000

Table 6: Preliminary Theme Development

Final Stage:

Theme 1: 'Something is Wrong'	Theme 2: What is PMDD	Theme 3: Who is the Expert?	Theme 4: Accessing Support
Codes:	Codes:	Codes:	Codes:
- Decision to Seek Help	- Lack of Awareness of PMDD	- Professional Unaware	- Feeling Lucky
- Impact on Those Around Them	- Accessed Information Online	- Dislike of Treatment Option	- Policy Changes - Growing Awareness
- Relationship Impacted	- Symptom Tracking - Conduct Own	- Gender Importance- Professional Awareof PMDD	- Pandemic Barrier - Health System
- Professional Life Impacted	Research	- Feeling Dismissed	Barriers
- Ignoring Symptoms	- Menstruation Stigma	- Fight to be Taken Seriously	- Lack of Access - Need to Talk More
- Different from Others		- Therapy Treatment	- Holistic Care
- Others Concerned			- Lockdown Stressor

Table 7: Final Themes

Code Prevalence Table:

Code Name	No. Transcripts	Total No. References
Professional Help	9	62
Mental Health Symptoms	9	49
Biomedical Treatment	9	49
Role of Support Systems	9	45
Physical Symptoms	9	33
Lack of Awareness of PMDD	9	29
Accessing Information Online	9	27
Conduct Own Research	8	27
Symptom Tracking	8	25
Menstruation Stigma	7	25
Dislike Treatment Option	8	24

Professional Unaware	9	23
Social Media	9	22
Stigma as a Barrier	7	22
Gender Importance	7	21

Table 8: Code Prevalence Tables

Appendix III: Research Ethics Committee Approval Letter



14th May 2020

MVLS College Ethics Committee

Project Title: A Qualitative Exploration of How Individuals with Lived Experience of Premenstrual Dysphoric Disorder (PMDD) or PMDD-like Symptoms Access Information and Support for their Symptoms in Scotland.

Project No: 200190137

Dear

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- · Project end date: As stated in application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media 227599 en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is
 necessary to change the protocol to eliminate hazard to the subjects or where the change
 involves only the administrative aspects of the project. The Ethics Committee should be informed
 of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson MD, BSc (Hons), FRCP, FESO Professor of Stroke Medicine Consultant Physician

Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion

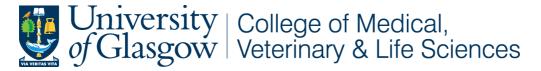
Chair MVLS Research Ethics Committee

Institute of Cardiovascular and Medical Sciences
College of Medical, Veterinary & Life Sciences
University of Glasgow
Room M0.05
Office Block
Queen Elizabeth University Hospital

jesse.dawson@glasgow.ac.uk

Appendix IV: Sample of Documents Received by Participants

Questionnaire



Questionnaire for Research Participants

Participant Number:

We ask you to complete the following survey as part of your participation in the following study:

"A Study of How Individuals with Lived Experience of Premenstrual Dysphoric Disorder (PMDD) (or PMDD-like symptoms) Access Information and Support for their Symptoms in Scotland."

These questions are asked in order to accurately capture the characteristics of the study participants, allowing the researcher to develop a better understanding of the factors which influence the access to information and support for PMDD or PMDD-like symptoms. Should you feel uncomfortable answering any of the following questions, please tick the 'Prefer Not to Say' box. As with the rest of the research study your participation in this questionnaire is entirely voluntary and anonymous.

Thank you for taking the time to fill in this questionnaire; it should only take a couple of minutes. Please return your completed questionnaire to the researcher. If you have any questions or concerns about this questionnaire, please raise them with the researcher. Please send completed questionnaire via email to:

1.	Age:	
	Prefer Not to Say	
2.	Ethnicity:	
	White Mixed/Multiple Ethnic Groups Asian	

	Black Other (Please State):	
	Prefer Not to Say	
3.	Primary Language Spoken:	
	Prefer Not to Say	
4.	Area Lived In:	
	Urban Rural Prefer Not to Say	
5.	Employment Status:	
	Full-Time Part-Time Self-Employed Unemployed Other (Please State):	
	Prefer Not to Say	
6.	Average Monthly Symptom Severity:	
	No symptoms Slight/Mild Symptoms Moderate/Considerable Symptoms	

	Severe Symptoms Prefer Not to Say		
7.	Have you sought help for these symptoms within the last 6 months?		
	Yes No Prefer Not to Say		
Ad	ditional Comments:		

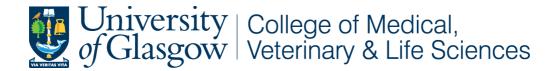
Thank you for taking the time to complete this survey.

Consent Form:

Project Number: Participant Number:		
Title of Project: Name of Researcher:	A Study of How Individuals with Lived Experience of Premens Disorder (PMDD) (or PMDD-like symptoms) Access Information their Symptoms in Scotland.	
	CONSENT FORM	Please tick box
	and understood the Participant Information Sheet version 4 y questions I raised have been answered satisfactorily.	
	and understood the Privacy Notice version 1 dated 21/02/2020 d have been answered satisfactorily.	
I understand that my part withdraw at any time, with		
I confirm that I agree to the will be stored for up to 10 relevant Data Protection		
seen only by study researchers (<i>Please note unless evidence of seriou</i>	and information I provide will be kept confidential and will be richers and regulators whose job it is to check the work of a that assurances on confidentiality will be strictly adhered to us harm, or risk of serious harm, is uncovered. In such cases, liged to contact relevant statutory bodies/agencies).	
I agree that my name, co kept for the purposes of t		
I agree to my interview be		
I wish to be informed of the researcher contacting me		
Please include email addı	ress in space provided if you consent:	
I agree to take part in the	study.	

Name of participant	Date	Signature	
Researcher	Date	Signature	

Participant Information Sheet



Participant Information Sheet:

A Study of How Individuals with Lived Experience of Premenstrual Dysphoric Disorder (PMDD) (or PMDD-like Symptoms) Access Information and Support for their Symptoms in Scotland.

Thank you for taking the time to read through the Participant Information Sheet and for taking an interest in the study. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the study about?

The purpose of this study is to capture the experiences of individuals with Premenstrual Dysphoric Disorder (PMDD) or PMDD-like symptoms with regards to accessing information and support for the condition. This research project contributes towards the Researcher's Master's qualification in Global Mental Health.

Why have I been asked to participate?

You have expressed an interest in taking part in this study. Please note, you can only be in this study if you (1) are over 18 years old; (2) have PMDD or PMDD-like symptoms; (3) live in Scotland; (4) are willing to use Zoom as part of the interview process.

What are PMDD-like symptoms?

For the purpose of this study, you are considered to have PMDD-like symptoms if you experience any of the following emotional symptoms in accordance with changes in your menstrual cycle:

- Mood swings.
- Depression or feelings of hopelessness.
- Intense anger and conflict with other people.
- Tension, anxiety, and irritability.
- Decreased interest in usual activities.

Do I have to take part in the study?

Your participation in the study is entirely voluntary. If you decide to take part, you are still free to withdraw without giving a reason up the point at which your data have been analysed.

What would taking part involve?

Participation in one 30-45 min audio-recorded interview via Zoom and a completion of a brief demographic questionnaire. Interviews will be recorded using Zoom recording software upon your consent.

What are the potential disadvantages and risks of taking part?

It is possible that the interview process may require you to reflect on memories and experiences which might be personal, uncomfortable or painful for you. There is a potential risk that you may find the interview upsetting. However, every effort will be made to ensure you feel comfortable throughout the process. You can request for the audio recording to be paused, as well as requesting the interview be paused or stopped entirely at any point throughout the process.

What are the possible benefits of taking part?

Taking part may be of no direct benefit to you. The information that is collected during this study will give us a better understanding of the information and support available to persons experiencing PMDD or PMDD-like symptoms. This information could potentially lead to raised awareness and improvements in the treatment and care of individuals with mental health issues connected to their menstrual cycle.

Will I be compensated?

You will receive a £10 Amazon gift voucher in order to thank you for your participation in the research.

Will my taking part in this study be kept confidential?

All personal information you provide throughout the study process and any personal data collected will remain strictly confidential. You will be identified by an ID number, and any information about you will have all identifiable details removed so that you cannot be recognised from it by anyone but the Researcher. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies. All data in electronic format will be stored on secure password—protected computers. No one outside of the research team or appropriate governance staff will be able to access any information which could identify you.

What will happen to my data?

We may be collecting and storing identifiable information from you in order to undertake this study. This means that the University is responsible for looking after your information and using it properly. All study data will be held in accordance with The General Data Protection Regulation (2018).

Should you wish withdraw data from the study, this can be withdrawn at any point up until the point of data analysis. To safeguard your rights, we will use the minimum personally identifiable information possible. For interviews conducted via Zoom, Zoom reserves the rights to access some of your data within their Terms of Service. Zoom data is encrypted and in accordance with data protection guidelines. For more information on Zoom privacy policy visit the following: https://zoom.us/privacy.

The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, your data will be securely destroyed in accordance with the relevant standard procedures.

What will happen to the results of the research study?

The results of the study will form part of the Researcher's research dissertation project as part of the MSc Global Mental Health Programme. Should you wish to view this dissertation and view the research findings, please confirm this on the consent form provided. Upon your consent, you will be emailed a copy of the dissertation and findings upon their completion. It is possible that the results of the study may be published in an academic journal. If this does occur, you will be updated with all relevant information on where to find the published results should you decide to provide your email address on the Consent Form provided. Please note direct quotes from your interview may appear in any resulting research publications, however, these will be anonymised and will not be traceable to you.

Who is organising or funding this research?

This study is being conducted by the University of Glasgow, as part of coursework for the MSc in Global Mental Health. No outside funding has been obtained for this research.

Who has reviewed this study?

This study has been reviewed by the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee.

Who can I contact for additional information?

Should you require any additional information or clarification with regards to participation in this study, you may contact the researcher or principal researcher at the following:

Researcher:	(University of Glasgow)
Email:	
Principal Researcher:	(University of Glasgow)
Email:	

Leaflet





VOLUNTEERS NEEDED FOR ONLINE RESEARCH STUDY ON MENSTRUAL & MENTAL HEALTH

The purpose of this study is to capture the experiences of individuals with Premenstrual Dysphoric Disorder (PMDD) or PMDD-like symptoms with regards to accessing information and support for the condition. If you experience deteriorations to your mental health in accordance with your menstrual cycle, we'd like to hear from you. All participation is anonymous.

Version 4; 04/05/20

You Qualify for the Study If:

You are over 18 years old.

You have PMDD or PMDDlike symptoms.

You live in Scotland.



Benefit of Taking Part:

Help raise awareness and understanding of menstrual health.



Participation Involves:

A recorded interview for 30 – 45 mins. on your experiences of menstrual health & seeking help for your symptoms, via Zoom & a brief questionnaire.



Compensation:

You will receive a £10 Amazon Gift Voucher for vour participation.

For More Information Contact Researcher:

MSc

Global Mental Health Student

- -

Appendix V: Research Project Outline

Project Title:

An Exploration how of Individuals with Lived Experience of Premenstrual Dysphoric Disorder (PMDD) Access Information and Support for the Disorder.

Introduction and Summary of Existing Literature:

Premenstrual Dysphoric Disorder (PMDD) is defined in the International Classification of Disease 11th Edition (ICD-11) as "a pattern of mood symptoms, somatic symptoms, OR cognitive symptoms that begin several days before the onset of menses, start to improve within a few days after the onset of menses, and then become minimal or absent within approximately 1 week following the onset of menses." (World Health Organization, 2018). Although the etiology of PMDD remains uncertain, it is believed to result from a greater sensitivity to the regular hormonal changes within the menstrual cycle (Hantsoo & Epperson, 2015). PMDD is associated with 3 years lost using QALY measurements (Yamada & Kamagata, 2017).

PMDD has only recently been recognised by the WHO as a mental disorder (Reed et al., 2019). Research suggests that individuals with PMDD are at risk of receiving a misdiagnosis for bipolar disorder and borderline personality disorder given the similarities in symptomatology of the disorders (Yamauchi et al., 2008). Of particular concern is that misdiagnosis may lead to the prescription of medication which is ineffective at treating PMDD (Studd, 2012). A survey published in 1998 on the experiences of 220 women diagnosed with premenstrual syndrome found that it often took many years to receive such a diagnosis from a physician and the majority of which believed their physician to be insufficiently informed on the topic (Kraemer & Kraemer, 1998). Additionally, there is research to suggest that it can take many years for an individual to receive a PMDD diagnosis (Studd, 2012). It is therefore somewhat unsurprising that individuals turn to the internet as an informal means of seeking information and support for PMDD. However, even the information available online is limited in quality (Hardy & Sillence, 2016). In spite of the difficulties individuals face in seeking care, there has been no qualitative research study carried out on the issue.

The aim of this dissertation is to try and capture the experience of living with a mental health disorder for which it is often difficult to seek information and support for. I believe that by raising awareness of the issues faced by individuals with PMDD, I can help to raise awareness of the disorder and encourage the promotion of better health care for individuals suffering from it.

Aims and Research Questions:

- ❖ Highlight the experiences of those seeking support for PMDD or PMMD-like symptoms.
- ❖ Identify key factors in the process of support seeking.
- ❖ Highlight any real or perceived barriers to help-seeking in relation to PMDD.
- Explore individuals' views of ways to encourage help-seeking.

Proposed Methods:

The research methods proposed for this dissertation will be qualitative. Primary data will be collected from individuals with PMDD or PMDD-like symptoms through semi-structured interviews. The face-to-face interviews, lasting an average of 30 minutes will be recorded with a Dictaphone, assuming the participant has given their consent to do so.

The decision to choose qualitative methods over quantitative was due to the research aims of the dissertation, which are to draw light on the experiences of person's with PMDD in seeking help and support (Pope et al., 2002)[wu13]. Qualitative research will allow me to capture the voices and experiences of the participants with a depth and understanding that would not have been possible using quantitative methods. PMDD research has typically focused on quantitative measures, with little focus given to individual experience. [wu14] Furthermore, there is a lack of consensus from epidemiological studies on the true prevalence rate of PMDD (Mahfoud et al., 2019). Discrepancies in prevalence are not only found between countries but within them (Park et al., 2005), (Hong et al., 2012), suggesting there is a lack of reliable quantitative data from which to build a quantitative research dissertation upon.

In order to recruit participants to take part in the study, small incentives in the form of 10-pound gift vouchers. Incentives have long been used to increase participation rates for studies and I believe this also for the contributions and efforts of the participants to be acknowledged (Head, 2009). Although incentives have the potential to be coercive, I believe the 10-pound gift voucher is set sufficiently low so as not to be coercive. The vouchers will be given to the participants prior to starting the interview to ensure it is made clear that the incentive is solely for the participation and not for the information they share throughout the study.

Although the research aims of this dissertation are exploratory, inductive sampling will not be chosen. This is due to the potential ethical issues and time constraints that this form of exploratory sampling involves (Guest et al., 2013). As a more feasible alternative, typical case sampling will be employed. It is the hope that those who have recently sought help for PMDD will be reflective of the typical case. Additionally, I will employ convenience sampling given the time and resource constraints associated with the project.

Semi-structured face-to -face Interviews were selected over other potential alternatives, such as questionnaires or focus groups, due to the fact that they allow each individual the space and time to elaborate on their experiences (McIntosh & Morse, 2015). A questionnaire, although useful in many regards, can limit the participants ability to elaborate or clarify. It was my concern that if a questionnaire were chosen I wouldn't fully be capturing the experiences of the participants but rather an altered version of their experience mediated through the questionnaire. Similarly, my concern with a focus group is that it would not give each participant equal opportunity to discuss their experiences and ultimately the experiences of those who spoke up more would heavily bias the data collected. However, that is not to say that interviews do not have limitations. There is definitely a possibility that the data I collect from them will not be an accurate reflection of the participants' true experiences, for example there is a strong possibility that my own bias and framing as a researcher will influence the data collected. In order to try and limit this potential for bias, semi-structured interviews were selected, as they allow the research and participant to be more flexible in their discussion and gives the participant a platform to discuss the issues of most importance to them, while still following the themes central to the topic of interest (McIntosh & Morse, 2015).

Although the study's sample size will depend on the success of the recruitment process, the aim is to recruit between 6 - 9 participants. I believe this sample size to be appropriate for the scope and aims of the dissertation. Previous research findings have shown a sample size of 6 to be sufficient in collecting good quality data from the interview process (Guest et al., 2013). Furthermore, giving the restriction of the dissertation to 8,000 words, a large sample size would be beyond the scope and feasibility of the dissertation.

Once the interviews have been transcribed, the process of data analysis will begin. Thematic analysis will be employed to analyse the interview transcripts for key themes and issues raised by the participants. Thematic analysis was chosen due to its flexibility and adaptability as an analysis method (Braun & Clarke, 2006). Additionally, thematic analysis is recommended for first time qualitative researchers and is not restricted to the philosophical principles which guide other qualitative research methods (Braun & Clarke, 2006).

Eligibility Criteria:

Person's over the age of 18 with lived experience of Premenstrual Dysphoric Disorder, 'severe PMS' or similar negative mental health issues in connection with their menstrual cycle.

Must have lived experience of receiving or attempting to seek information/help/support for their symptoms, through either medical (e.g. GP, counsellor, psychiatrist) or non-medical means (e.g. online, friends).

- There is a restriction on the minimum age to participate given the ethical issues and safety concerns that arise from the participation of minors in the research study.
- ❖ There is no restriction based on gender for this study as significant numbers of transgender individuals suffer from PMDD (Jatchavala & Udomratn, 2019).

Recruitment Strategies:

Several recruitment strategies will be employed in order to reach the target sample size of 6 - 9 participants.

- Recruiting via personal and professional connections. Although I will not be interviewing persons who I know personally for my dissertation as it would damage the integrity of my data, I am also 'an insider' to the research topic. I have various professional and personal connections to individuals who are 'gatekeepers' to networks of individuals who have PMDD and may be able to give me recommendations for individuals to invite to take part in my study (Rugkåsa & Canvin, 2011).
- Recruitment may also be done by means of flyers and social media posts. I will make a professional twitter handle through which to adverstive the research study. I also hope to use the 'gatekeepers' in the field to advertise their social media platforms to recruit participants.

Potential Barriers to Success:

- Difficulty recruiting participants to take part in the research may limit the quality of the research findings.
 - ➤ In order to overcome this measure will be made to incentivise participants to take part in the study and to compensate them for their time. This will include a voucher to compensate for taking part in the survey and potentially include some additional money to cover their transportation costs.
- There is potential for the sample to be biased in terms of who is willing to take part in the research study and who has the time available to do so.
 - ➤ Although qualitative data can rarely claim to be generalisable, efforts will be made to ensure data collected is as representative and as unbiased as possible. The use of incentives (as mentioned previously) is one method of limiting the bias of the research. Additionally, sampling methods (outlined above) will be used to generate a representative sample.
- ❖ Potential issues with ethics approval could delay or heavily alter the research aims and design.
 - ➤ Although it is possible the ethics committee may request alterations be made to the research, in order to limit the number of potential changes I will provide a comprehensive overview of my research in the application process and provide them with all relevant information. Additionally, my ethics application will be reviewed by my dissertation supervisor prior to submission to ensure it is of the appropriate standard.

Obtaining Research Ethics Committee Approval:

Ethics approval will be required for this research, as it will involve collecting personal data from participants. The ethics application form is in the process of completion and the plan is for it to be submitted the last week in January. Prior to its submission it will be reviewed by my dissertation supervisor to ensure it is of the appropriate standard for submission. Any concerns or queries I have regarding the completion of the ethics application form will be raised with my supervisor and/or course coordinator.