

Self-perception of the Illness Experience and Her Relation with Health Professionals in a Sample of Women Suffering Premenstrual Dysphoric Disorder

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Received date: February 12, 2017; Accepted date: February 20, 2017; Published date: February 28, 2017

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Abstract

Objective: To describe the experience of premenstrual dysphoric disorder in a sample of affected patients and to examine their experiences with health professionals.

Materials and methods: Qualitative interviews via Internet were conducted in a non-representative sample of 15 women from different countries diagnosed with the disorder. All gave informed consent prior to participation. The Atlas.ti program was used to aid the coding of the categories that emerged. The information obtained was analysed and were considered valid according to the criterion of theoretical saturation.

Results: This difficult life experience was reported to cause suicidal thoughts. In the premenstrual phase, the performance of certain daily activities is impossible. It may take a long time for patients to be diagnosed and understood; they feel a lack of comprehension both from their immediate social circle and from the health professionals who treat them. They feel they need more attention, and several individuals consider that hysterectomy maybe the definitive solution to their problems.

Conclusion: The method used yielded information that is not generally obtained via surveys. The repeated references to suffering made by the participants, evidence the need for greater collective awareness of premenstrual dysphoric disorder, particularly inside the patient's immediate environment and among health professionals. Attention should be drawn to this disorder and its serious consequences; what is more, it should be acknowledged as a chronic illness.

Keywords: Premenstrual dysphoric disorder; Qualitative interview; Health professional-patient relationship; Suicidal attempts; Hysterectomy

Introduction

This text will present part of a study which aims to contribute to the knowledge base of how non biological factors which influence the future of women affected by Premenstrual Dysphoric Disorder (PMDD).

Healthy lifestyle achievement, including relationships and a healthy workplace environment, can be considered as one of the key aspects in successfully facing PMDD. The same is considered about the doctor-patient relationship. PMDD can be compared to fibromyalgia in this aspect. The emergence of fibromyalgia, as a diagnostic entity, led to the inevitable discussion over the adequacy of health professionals practice approaching the global needs of affected patients [1]. A little known condition like PMDD is causing the same chances. Since the health professional-patient relationship is considered a key point in achieving better health [2], it is an important factor to include in this discussion. Until the point at which PMDD is completely accepted as a diagnostic entity, it will be necessary to insist on the subject.

Knowing the point of view of those affected is just a drop in the ocean regarding the work which must be done to strengthen the knowledge base on this problem. An intensive search of the

bibliography (in both English and Spanish) has yielded little information. On the other hand, no study has been found which deals with the self-perception of those affected, which reinforces the pertinence of this study.

PMDD is a condition which occurs during the premenstrual period. It is an exacerbation of Premenstrual Syndrome [3]. However, its severity is significantly worse than Premenstrual Syndrome, so much so that it can lead to it being impossible to carry out daily activities in one's social, family or work life [4]. It is so serious that, it is equal to depressive and anxiety disorders in terms of impact on quality of life [5]. It is so serious that it can lead to absence from work and suicide [6]. In fact, the DSM-V also warns of the risk of suicide in these cases [7]. Along the same vein, a recent study has concluded that the personalities of those effected by PMDD leads to suicidal tendencies [8]. The prevalence of PMDD varies according to the type of study. According to Tschudin, it is between 3% and 8% of women of reproductive age.

The inclusion of this diagnostic entity in the DSM-V could help with the lack of studies performed on this subject [7]. A few days before writing this, the National Association for Premenstrual Dysphoric Disorder (NAPMDD) held its first conference which discussed the need for more studies on the subject [9].

To obtain a basis for the data from these discourses can come from the codification of the texts produced by these patients with mediation

from the researcher, who sought to merely be the facilitator to bring out the stories of the patients [10]. The objective of the article is principally to be descriptive, with the aim of stimulating future studies which take into account the statements of those affected, according to the idea that science must be at the service of humanity, for which purpose it will be necessary to properly codify these statements without the influence of the researcher causing heavy bias. In fact, in addition to the interviews performed, documents prepared by those affected prior to the study were included (two diary extracts were evaluated), with the aim of achieving the highest level of authenticity and spontaneity in the reports. In any case, it was intended that the presence of the researcher did not influence the research.

Methodology

It should be noted that the present text is the third phase of an ongoing investigation. This investigation comes after the two previous stages. In the first stage, the content of internet forums for those affected by premenstrual dysphoric disorder was analysed [11]. In the second stage of the study, 213 women who had participated in these forums responded to an online survey. At this point, the third phase aims to be complementary to the two preceding ones, with new aims and using different research methods. It will attempt to contribute more to the research as a whole. It was based on the intention of interpreting and contrasting the data from both of the following perspectives: quantitative, using information from the survey and qualitative, using information from the personal interviews (Figure 1).

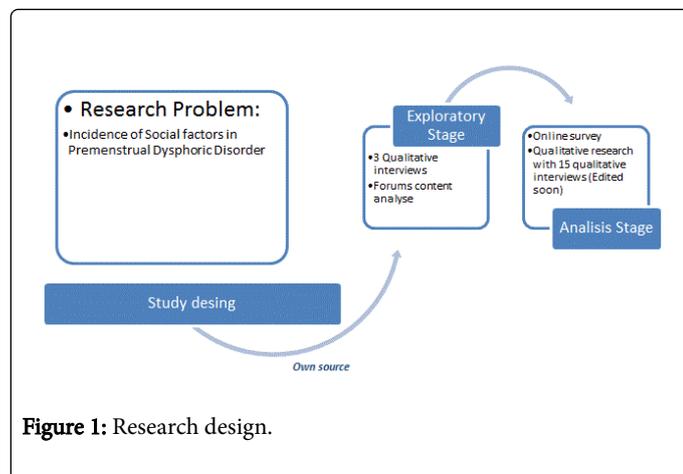


Figure 1: Research design.

Qualitative methodology has been employed, based on information from qualitative interviews and written statements from the women affected. The use of this methodological strategy attempts to give a voice to those affected, as described in classic works such as Grounded Theory [12] or the more recent work of Taylor and Bogdan [13]. Likewise, it is recommended as a methodology for the study of social inequality and emerging phenomena [14].

As for more practical issues, it is necessary to discuss the composition of the group of affected women whose testimony has formed the base of the research. They were all users of internet forums on PMDD, in English or in Spanish [15]. They were asked to report their experience for the purposes of a study, which in itself motivated them to collaborate. In fact, their interpretation was that the research would be favourable to their interests, meaning that the researcher became, to a certain extent, their ally [16]. The selection process was

motivated by heterogeneity, inspired by the technique used in *Los relatos de vida* (Life Stories) [17]. The study was limited to people diagnosed with the disorder in question or with severe premenstrual syndrome (equivalent diagnosis). Despite the precautions taken regarding the participant selection that have been diagnosed by healthcare professionals, three people who had not been diagnosed were also interviewed. Although these interviews were conducted, the information obtained does not form a part of the results of this work. Neither have I included the testimony of a woman interviewed by telephone, when the conversation was not recorded. On the other hand, the testimony of women who had been diagnosed with the disorder, but who were symptom free for various reasons, for example hysterectomy (E-2, E-6 and E-7), menopause (E-9), or effective measures taken to improve their health (E-16), were accepted.

Finding the participants was a laborious process. Participants were actively recruited through internet forums and through e-mail, since a database of email addresses had already been collected through the survey. Three interviews were possible through e-mail (written, by e-mail). 15 people were interviewed through other methods. Finding participants using the Internet forum and then becoming friends on Facebook was another method used. It is not straight forward to quantify how many contacts were needed to get the 15 interviews. Some people, having agreed to the interview in the public forum would then not allow themselves to be added on Facebook by the researcher. These rejections were not counted. 25 people initially responded positively to the original request to do an interview but then did not participate in it. If we count both of those groups then there were 40 rejections.

The interview took place online. The majority of women were interviewed using Facebook chat in sessions which lasted between one and two hours. In almost all of the cases, two or three sessions were needed to get all of the necessary data. Five interviews were self-administered thanks to the interview script which was sent to them. They are stories (some of them free coming) which, in keeping with the methodological approach taken, focus on the experience itself and the subjectivity of those talking.

Informed consent was obtained, with written proof, since the contact was through e-messenger or through Facebook, requesting collaboration for this research and assuring the anonymity of their statements. In many cases, their Facebook profile was added to that of the researcher (which facilitated subsequent access to certain information from the principal interview which may not have been collected in the initial interview).

A computer programme was used to analyse the data in order to maintain accuracy in how the data was used. The programme Atlas.ti was used with the aim of ensuring reliability, reproducibility, falsification and, ultimately, validating the analysis, trying to minimise any researcher bias.

An attempt to have different profiles represented was made. The variables of age, country of residence (in two cases this was different to country of origin), domestic situation, occupation and incidence of the symptoms were considered in an attempt to have a heterogeneous sample [17] and thus, it was ensured that the sample was representative (Table 1). The incidence of symptoms was also considered as a selection criteria for the women to be interviewed looking for a proportional number of cases with the aim of obtaining relevant testimony (Table 1).

Interview	Country	Age	Convivencia	Job	Symptoms Incidence
E1	USA	37	Couple, 3 children	P time*	yes
E2	USA	32	Couple, 2 children	Unemp**	No (Hysterectomy)
E3	Ghana	37	Couple, 2 children	Self-***	yes
E4	USA	32	Couple, 1 children	Unemp	yes
E5	UK	37	Alone, 2 children	Full T****	yes
E6	UK	41	Couple, 4 children	Full T	No (His)
E7	USA	37	Couple, 2 children	Unemp	No (His)
E8	México	28	Couple	Unemp	yes
E9	USA	52	Alone	Full T	No (Menopause)
E10	Canadá	41	Couple	Full T	yes
E11	Argentina	36	Couple	Full T	yes
E12	USA	44	Couple, 2 children	Full T	yes
E13	Argentina	37	Couple	Full T	yes
E14	USA	24	With parents	Student	yes
E15	Australia	40	Alone	Unemp	yes

Table 1: Composition of the simple of interviewed women (*Part time job; **Unemployed; ***Self-employed ****Full time job).

The interview script was the same for all participants, but it was just meant as a prompt to be used to make the story flow [18]. Basically, the questions were about the milestones of their life (childhood and family life, adolescence, their first period, friendships, dating and starting relationships, leaving home, work...). They were given a large amount of freedom to talk about what they wanted to, with the aim that the information would come out in a spontaneous way, which frequently happened, without the interviewer having to ask too many direct questions. If the wanted information was not forthcoming then different strategies were employed. In some cases, the participants were contacted again after the end of the main interview in order to find out specific information for the purposes of the study which did not come out in the transcriptions of the original (particularly this was about getting the diagnosis). The ease with which the interviewees could be contacted made it possible to find this information in all cases.

Results

The information gathered through these interviews was extensive and cannot be expounded upon in an exhaustive manner. An attempt at synthesis has been carried out bearing in mind the original objectives of the research. The collected texts used a code, represented by the abbreviation PMDD and its equivalent in Spanish; this was configured into the principal category which could be the representation of the suffering of the participants. Other codes, such as those for medication, also provided a large amount of information, but this was not strictly relevant to the current research. Therefore, other subcategories were taken into account, which were more focused on the original objectives, that is to say more focused on the experience of the participants. In this way it was decided to collect information on areas of their daily life, such as work and relationships. Allusions to

attempted suicide and thoughts about suicide are included as are hysterectomies, as emerging categories which were not present in the interview script, this is the case as they were recurrent themes and they have wide reaching social repercussions. Finally, the relationship between the participants and the healthcare providers in general and healthcare professionals specifically will be discussed because of its propositional nature.

The classification of themes to be discussed has taken into account the findings of a study by the Sociedad Española de Ginecología y Obstetricia [6], which links divorce and absence from work with this disorder.

The term PMDD and its equivalent in Spanish caused a large amount of encodings in the software used. In these cases stories about which they lived with this condition arose. In general, the participants referred to their experience of the disorder in negative and very serious terms using words such as intoxication, demon or monster.

E-2 The demon which has taken over my life for five years, the demon with my voice and (who knows) all of my secrets...

E-3 ... I wasn't able to think or reason, I lived in a state of constant intoxication... I felt obliged to be someone who I had never been and that was devastating.

E-4 I avoided my husband and tried to avoid important conversations with people during my crazy week.

E-5 PMDD has ruined my life, ruined the lives of my children. I hate the whole world when it is here. It is a monster. It is evil.

E-7 I think that many of the symptoms of PMDD appeared to be masked by my explosive lifestyle in terms of men and drink.

E-6 I am a survivor.

E-9 PMDD incapacitates me for a lot of time. During all of those years I was two different people

Other experiences which speak for themselves and show how serious PMDD is, are the suicide attempts and reported suicidal thoughts, an issue which came up spontaneously without having been part of the interview script.

E-2 I feel into a deep depression and had thoughts of hurting myself.

E-5 I was wrecked. I had suicidal thoughts. I could not get out of bed.

E-8 I wanted to cut my arms and my legs with a kitchen knife.

E-9 At 19, I slit my wrists.

E-11 I have attempted suicide five times (...) I don't want to live with this.

E-6 and E-8 Hysterectomy is suggested as a solution to the condition; in any case, by my own experience.

E-2 I am interested in life again.

E-5 I am going to ask to be referred by someone to ask for a total hysterectomy.

E-5 I had the operation on --/--/----. It has absolutely changed my life.

E-6 I have a new life after the hysterectomy.

E-8 I have read that quite a lot of women have had good results with surgery.

Effects of PMDD on working life

In Chart 1, we see that some of the people who agreed to be interviewed could do their job, whereas others could not. Difficulties in this sphere came out during the interviews and in some cases; strategies were employed to avoid having further problems or being dismissed from the workplace:

E-3 I consider myself successful on a professional level, although I have had to distance myself from work and only work as a consultant over the last three years.

E-5 I am good at my new job and got a promotion.

E-10 I am always lying at work. I say that I have allergies (...) I have told the truth on other occasions and I was fired from work.

E-11 I always paint on my smile and show as happy and my students say they leave happy.

E-12 No, I don't talk about it at work, I don't explain it...

Relationship problems

Complications in a relationship are normal, PMDD does not have to rear its head for problems to occur, but in these cases, we can see comments which definitely refer to the influence of PMDD on home life.

E-6 Divorced at 22 because my husband could not cope with my mood swings.

E-5 I blamed my mood for the separation.

E-10 He could not take my mood swings any more. He said that I had a problem.

E-11... my marriage was a disaster; I will summarize it, there at the end, divorce, the police, judges, a total drama.

E-14 I have been single since 2013. Relationships are complicated.

E-9 It was almost impossible to maintain a relationship or a friendship. But I learned that I had to keep away from people.

(...) I have had two main relationships in my life. Neither of them was good.

On the other hand there are allusions to the sympathetic attitude of husbands and boyfriends.

E-2 I tell my husband: I love you and he replies (the same)

E-6 A very co-operative husband, he has been at my side helping me at every moment.

E-8 I got married to a marvellous man two years ago but it is difficult for us both to live with this condition it is frustrating when I am depressed. I know that he understands and supports me, but it is not easy.

E-10 I have a boyfriend who is very helpful.

Relationships with health professionals

In this section we will see allusions to the lack of knowledge about this illness in some health professionals, a perception of the lack of empathy and understanding of their illness. The same participant will talk about different experiences, which has an effect on the issue. In some cases we can see that through a confidential relationship between gynaecologist and patient an interesting mutually supporting relationship can occur.

E-2 I also want the medical community to stop embarrassing women by asking about hormone replacement therapy.

E-2 He understood unexpectedly and we did the surgery.

E-3 It was a triumph for me as well as I showed great doctors that I was not wrong.

E-5 The gynaecologist laughed at me for suggesting a total hysterectomy, saying that I was far too young.

E-8 Carla (not her real name) was familiar with this condition and had had other clients who had been treated for it. We linked my untreated post-partum depression to PMDD. She explained the correlation between the two.

E-11 Can you believe it? I can't find anyone who will look after me, hehe I drive them crazy hahaha. That's how it is, if you don't fall in love, is it the psychiatrist who supports you?

E-13 Thanks to a doctor who was human (...) I was with a psychologist, it started with her. And I met my psychiatrist, and my nutritionist, they all know each other, and can exchange info (with my permission).

E-15 I was misdiagnosed with Bipolar Disorder.

E-15 I found a great family doctor who really listens to me (...). My current doctor is really trying to find out about PMDD. She even attended an online conference of the National Association for PMDD, just to find out more.

Discussion

First of all, some conclusions regarding the methodology. The use of qualitative techniques allows for the possibility of an approach of the experience of the participants who sometimes cannot find an adequate expression. The narratives of those suffering from the condition had a certain component of emotional relief, but, in this case, the intention was only to find information and the attribution of value to this information according to technical saturation criteria. This value could be found after the analysis of fifteen different accounts. This leads to objectivity.

A comparison was made between the data provided by the statements here and the results obtained in a survey regarding the social aspects of PMDD [15], which had similar objectives (the study of the social aspects of the disorder), which could be referred to as triangulation [19].

The use of retrospective narrative and contact with some of the participants over the course of time shows (as expected) that their experience is dynamic. Through the use of triangulation, the statistical information from the survey can be enhanced.

In terms of content, the allusions to the seriousness of the disease and its destabilising nature show through in all of the interviews, although only certain citations had to be selected as examples. Notable examples to be noticed are the suicide attempts and those hoping for hysterectomy. Despite the fact that these women know the undesired effects of a hysterectomy and that it is a last resort, they were still asking for this operation, which is still far from a generalized therapeutic option [6], although there have been examples of its effectiveness [20,21].

As far as the careers of the women suffering from this condition are concerned, the testimony shows the difficulties in getting and keeping a job. One of the interviewees even stated that she had avoided talking about the condition while at work because she thought that she would have been dismissed. The information from self-assessment corresponds with the quantitative data [15]. 40% of the participants said that they had lost a job due to PMDD. This can be contrasted with the information gained through interview.

As for medical information received, the information gathered from the women's interviews shows that they were misdiagnosed or felt embarrassed by the professionals who were looking after them. Comparing this discourse with the data obtained through survey we can see that 59% of those surveyed were "at odds with or totally disagreed with" the statement that the medical attention received was "adequate" [15]. The testimony offered through the interviews confirm the statistical data, taking into account nuances and the non-representativeness of the sample. Although the feeling of misunderstanding manifests itself throughout a person's life, not all experiences with health professionals are the same. In fact, testimony has been collected which shows the importance and success of help received. These testimonies could correspond with the 31% of the respondents which remained or simply it could be deduced that the respondents chose that some experiences were positive but not all of them.

Conclusion

As far as personal relationships are concerned, the present qualitative study highlights the difficulties caused by PMDD (one of the issues which definitely affects emotional stability). It expressly

shows that partners could not deal with mood swings, which is also shown in a study by Lanchares [6]. Remember that 59% of the survey respondents stated that they had had a relationship breakdown caused by PMDD.

All of the above has strengthened the idea that psychological and social factors associated with PMDD pose additional problems that cannot be approached purely from a physical medicine point of view with drugs for the symptom. The integral approach (which was spontaneously put by interviewee E-13) is precise. However, the expectations placed on health professionals should be consistent. Chronic conditions (and PMDD is one) require answers, but miracle solutions cannot be put forward.

To deal with PMDD, a number of factors can become assets. In fact, over time, those affected have said that they could get past certain obstacles as far as work, their relationship and their relationships with health professionals are concerned. These are some of the factors which determine health. Given the complexity, severity, and chronic nature of PMDD, a holistic approach is needed to take into account all aspects of female health. A professional training led for care managers could help to promote the health. Affected of PMDD, would be prone to this kind of experiences because they are feeling misunderstood. The methodology couldn't be the same but some creativity is necessary to innovate and provide online support by these care managers [22,23].

It should be accepted some limitation coming from the online methodology. Verbal language or paralinguistic aspects have not been able to interpret when the interviews were produced. In the other hand, it should be named some advantage as the ease to keep in touch with affected women even, when the main interview had been finished. This online feature enabled frequent contacts with no special organizational issues. The online methodology gave to the research a transversal point of view.

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