

Socio-demographic Profile of a Sample of Women with Premenstrual Dysphoric Disorder: Exploratory Study**

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Abstract

Objective: To study the socio-demographic profile of women with Premenstrual Dysphoric Disorder to assess factors those have an impact on their pathology and to explore the consequences of the disorder.

Materials and Methods: Self-administered online survey distributed in four different internet forums around the world. The survey compiled socio-demographic data such as age, level of income, level of education, size of hometown, marital situation and employment status. Certain health-related items were also included to focus on the consequences of the illness.

Results: A non-representative sample of 102 women with Premenstrual Dysphoric Disorder has been used to create a profile of women with Premenstrual Dysphoric Disorder who use Internet forums. The women surveyed provide data that closely fitted the symptom profile in the specialized literature. Thanks to the control questions another unplanned sample emerged of 110 women not diagnosed by professionals. This sample was used to make comparisons.

Conclusions: The creation of a socio-demographic profile highlighted the consequences of Premenstrual Dysphoric Disorder. From the methodological point of view, the result emphasizes the need to use specific strategies in internet-based studies to improve participation and to check the authenticity of the responses.

Keywords: Premenstrual dysphoric disorder; Self-administered; Online survey; Self-support; Socio-demographic profile; International researches

Introduction

The conviction that social factors have a decisive impact on people's health [1] was the motivating factor behind this study. In actual fact, there are studies that identify sociological factors as key in the development of depression [2]. With this survey, we have sought to contribute knowledge that may be useful for a comprehensive understanding of PMDD. The investigation of the social aspects of it has not been addressed up to now. That is why this survey and further future research would be justified. With this approach, which is pioneering and not conclusive, we seek to complement the knowledge that we already possess on this phenomenon, a biological point of view.

First, we need to explain what is meant by this disorder. It is a symptomatic pattern that appears in the post-ovulatory/premenstrual period. After menstruation the symptoms disappear. Basic symptoms, collected by DSM-V [3], are "the expression of emotional lability, dysphoria and symptoms of anxiety." (The full list includes changes in appetite, social withdrawal, sleep disorders, decreased interest, feeling of lack of control, irritability, mood swings, decreased concentration, anxiety/ tension, depression, pain, alterations to the central nervous system, alterations to the autonomic system, hydroelectrolytic disorders, dermatological disorders). For its diagnosis, symptoms must

be recorded daily for at least two symptomatic cycles. A differential diagnosis is also necessary with, in the main, disorders such as bipolarism, PMS or dysmenorrhea.

PMDD is considered to be the exacerbation of PMS [4]. When the dominant symptoms are behavioral, one speaks of PMDD. The difference between the two categories is the greater severity of PMDD. In this case, there is interference in the performance of social, family and work functions [5]. While it is considered that PMDD has a prevalence of between 3 and 8% in women of reproductive age, the incidence of PMS is estimated to be at least 30%. This data was gathered by Tschudin et al. [6] but the authors point out that according to the methods used by the different studies, figures may vary.

The investigations are far from being definitive. In some publications, doubts even arise about the diagnosis because it may be confused with bipolar disorder. It is also noted that there is the difficulty in differentiating it from PMS [7,8] and there are even doubts raised about the very diagnostic entity [9], which considers it to be a social construct. In any case, it deserves to be studied in more depth because of its grave consequences. In an investigation about the quality of life of patients suffering from depressive and anxiety disorders [10], PMDD was considered to have seriousness comparable to other illnesses such as bipolar disorder or major depressive disorder. Even the DSM-V echoes the risk of suicide that it causes. This seriousness, which causes consequences ranging from sick leave from work to divorce [11,12], prompts the acceptance of further research. This is

what the Rappaport team believes, when they advocate a psychiatric treatment, not only dedicated to the standardised treatment of symptoms but one that also bears in mind the patients' quality of life. In that attempt to contribute to the de-medicalization of women's bodies, this study was proposed which, in some aspects, is based on the concerns of those affected.

Materials and Methods

Participants

The study presented was carried out based on the responses to a survey [13] of a group of 212 women who frequented online forums on PMDD. As in other studies [14], it was decided to aim the survey at a localised group with no possibility of random sampling. The women participating were mainly from four forums: three English-speaking and one Spanish-speaking. In these forums, it was mainly women from Australia, the United States, Latin America and the United Kingdom who participated. In fact the replies came from 58 women living in Spain, 50 women in the United States, 36 in the United Kingdom, 16 in Australia, 6 in Argentina and 5 in Canada. The remaining countries had no more than two respondents. In total, replies were received from 28 different countries.

The first methodological decision was taken due to the high number of female participants who had not been diagnosed by qualified specialists (in general medicine, psychiatry, gynaecology or psychology). Of the total sample, 212 women were counted, 102 diagnosed by specialists and 110 who had not been diagnosed by the above-named professionals. Of those 110 women, 66 marked the box for self-diagnosis, 32 marked the box for not diagnosed and 13 marked the option "other". The great importance of this second group deserves the attention of the researchers but due to lack of space will not be addressed on this occasion. We preferred not to distort the result of a study that was designed to learn more about a certain disorder. In all probability, including undiagnosed subjects could compromise the study's academic integrity. However, as regards learning more about women's health, all the members of the sample are worthy of attention and we have not ruled out including all of the respondents in future studies.

The group of undiagnosed women meets the criteria to be considered as a control group [15] and will help to make comparisons when discussing results.

The first step was to obtain informed consent, sending a request to the administrators of the forums, who promoted the investigation (in its different phases). It was based on logic of collaboration between all parties. That is, there was an agreement prior to the completion of the investigation. It was the administrators who were in charge of presenting the research in the forums. Specifically, in the case of the survey, the introductory text that explained the purposes of the survey (research and dissemination of results). At the same time, there was a commitment to respect confidentiality and anonymity, and in fact, no personal data was requested.

Instruments

The results obtained from the survey are the result of tools that had already been used in other surveys to achieve acceptance by the Scientific Community. The categories used [16], such as the level of studies, income, type of cohabitation, age or profession, are variables whose interest has been widely studied.

A linguistic framework was created to deal with the different situations of those surveyed, given that some were English speakers and other Spanish speakers. A bilingual survey had to be drawn up and there had to be some modification of categories to make them analogous to the situation being surveyed. No previous questionnaire existed with similar characteristics (either in English or in Spanish).

Prior to the elaboration of the survey, exploratory work was carried out, within the logic of a social research design. In the first place, a phase to familiarise the participants with the activity is initiated through qualitative techniques such as three qualitative surveys for users of the forums [17]. Secondly, the forums were analysed to determine the consistency of the study [18] regarding reliability and validity for the Scientific Community. And thirdly, the survey was designed and then administered, which this previous groundwork served to help.

The survey was administered to users of the forums for their validation. The moderators (and other users) of the forums were able to make observations which contributed towards making the questions easier to understand. After taking these considerations into account, the survey was perfected.

The type of technique used, the self-administered survey, was made possible thanks to Type form software. Of all the different programs that were examined, it was considered that this one offered some visual advantages, which were more convenient for those surveyed, that the rest did not offer.

Procedure

For approximately one month, collaboration was requested on all four Internet forums in order to complete the survey. The moderators of the forums cooperated in this respect. It was decided not to create a long questionnaire. According to the software statistics, the questionnaire could be completed in 8 minutes, as predicted in the tests. The moderators publicised the short amount of time needed, to encourage participation (Figure 1).

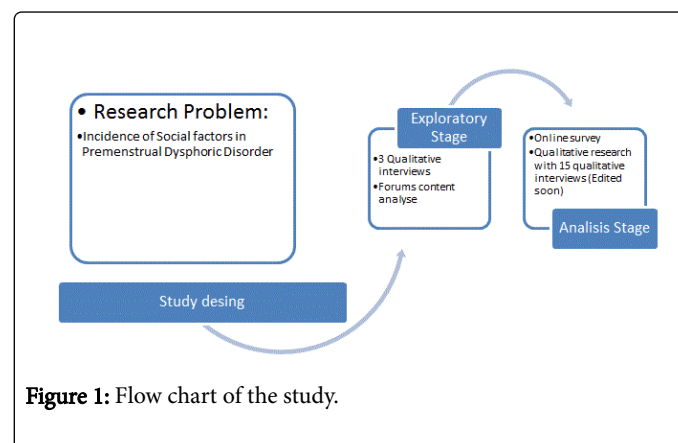


Figure 1: Flow chart of the study.

To verify the authenticity of the surveys, an E-mail address was requested (although not obligatory), explaining that this data was important to confirm that the questionnaire was being answered in good faith. At the top of the survey it was stated that the data the participants were going to provide was for the sole purpose of researching and publishing their results in the academic field.

Before presenting the results section, we will discuss the precautions to be considered in self-administered surveys (in this case on the

Internet). In other studies [19] doubts were raised when the respondents were forced to ask themselves certain complex issues.

Therefore, certain limitations were assumed in terms of simplification as well as a risk, that of authenticity, since it was not a face-to-face survey. The simplification aspect was difficult since it was necessary to try to be strict, but at the same time to pose the questions simply (hence the "yes/no" questions). The lack of reliability was addressed previously. For the reasons given, a way was sought to verify possible non-conscious responses. Certain open-ended questions were introduced that forced the interviewees to write a few lines. Also, e-mail was requested for further verifications.

In other words, control methods were introduced. Some 184 E-mail addresses were obtained (n=212), which allowed verification of the authenticity of the submitted forms. In 28 cases (13%) this section was not completed (it was not mandatory). This high percentage of electronic addresses, voluntarily provided, can be related to an attitude predisposed to agreeing to an authenticity check.

To assess the intensity of symptoms and their influence on daily life, questions were asked with two possible answers.

Likewise, some Likert-scale questions were posed to gradually assess certain aspects of patients' lives. The value 0 meant that they totally disagreed. At the other end of the scale, the value 4 meant they totally agreed. The questions were all obligatory except the one referring to Religion, but it was answered by all of those surveyed.

For the analysis of the socio-demographic profile, or issues related to diagnosis, multiple response questions were used, without giving the possibility of more than one answer. For other questions we opted for open-ended questions (e.g.: opinion about the forum).

Results

One of the main concerns of those affected is the diagnosis. For this reason it was decided to look into this issue, which causes uncertainty [20]. The time that elapses until getting diagnosed became an issue to be analysed in the exploratory part of the investigation. This importance was verified since 110 people who participated in the forum responded that they had not been diagnosed by a specialist. The question was posed as follows: Since you first started reporting your symptoms of PMDD to medical staff, how long did it take for you to be diagnosed with it? Most diagnosed patients obtained a diagnosis in less than a year (50 people).

However, there was a large group that was diagnosed after years of reporting symptoms (32 cases are related of taking two years or more). Of the 102 women, 55% of the sample was diagnosed by a doctor/psychiatrist, 39% were diagnosed by their gynaecologist, and 6% by their psychologist.

Socio-demographic Profile of those Surveyed

Regarding the age of the participants, the majority is grouped, as shown in Figure 2, between the ages of 30 and 44 years, accounting for a total of 78% (Figure 2).

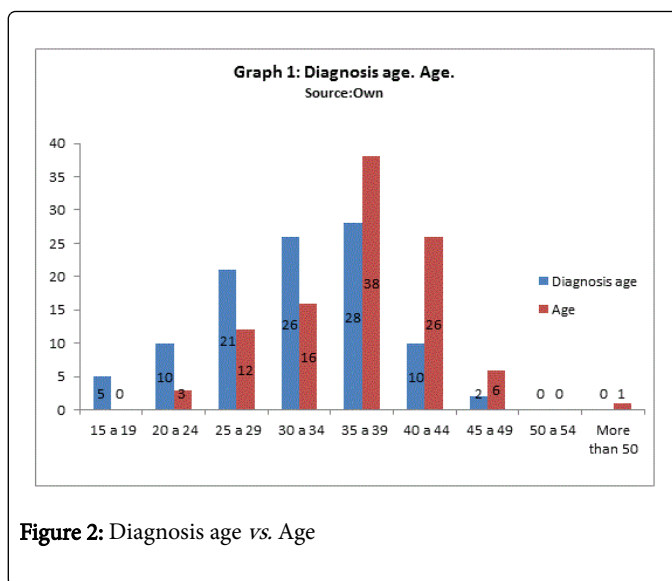


Figure 2: Diagnosis age vs. Age

The survey totalled some 75% of women with university studies. The second largest category is those with Secondary Studies, with 14%. As far as the cohabitation situation is concerned (i.e., who they live with), the most frequent type is as part of a couple with children, at 20%.

Adding up the different categories, we confirmed that two-parent households account for 51%, while households composed of single women or single women with children account for 34% (Figure 3).

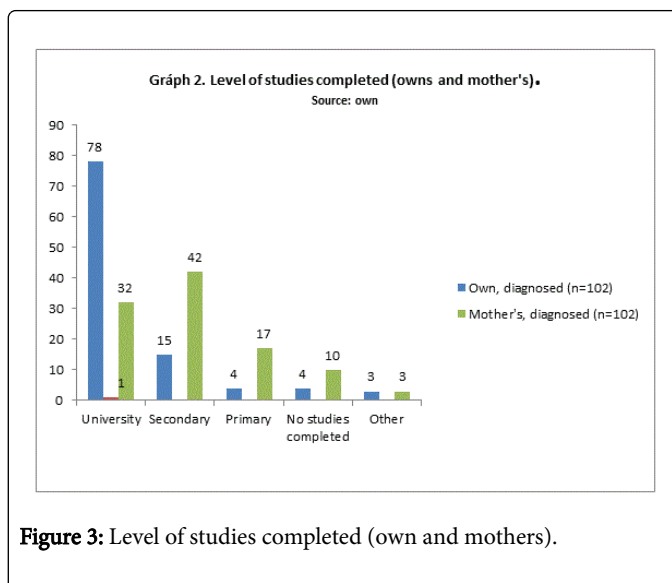


Figure 3: Level of studies completed (own and mothers).

As for the income levels, the mid-to low-values predominate, at 56% (those closest to the national minimum wage) as shown in Figure 4. The survey totalled 75% of women with university studies. The second largest category is those with secondary school education, at 14%. With regard to the cohabitation situation (i.e. who they live with), the most frequent type is as part of a couple with children, at 40%.

The second largest category is that of single women with children, at 20%. Adding up the different categories shows that two-parent households' account for 51% while households composed of single women or single women with children account for 34% (Figures 4 and 5).

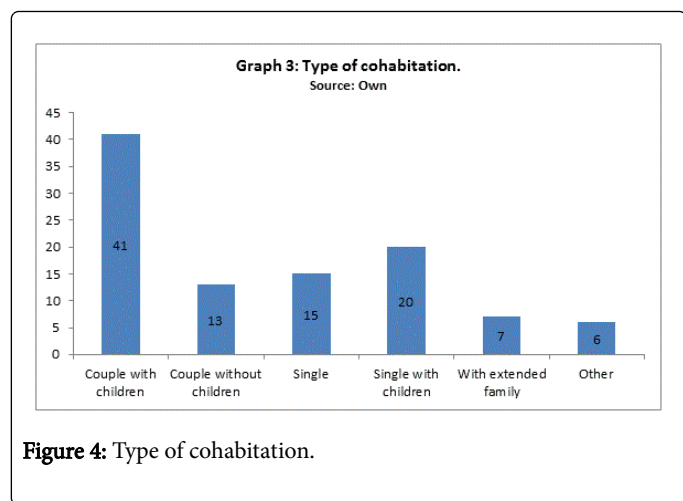


Figure 4: Type of cohabitation.

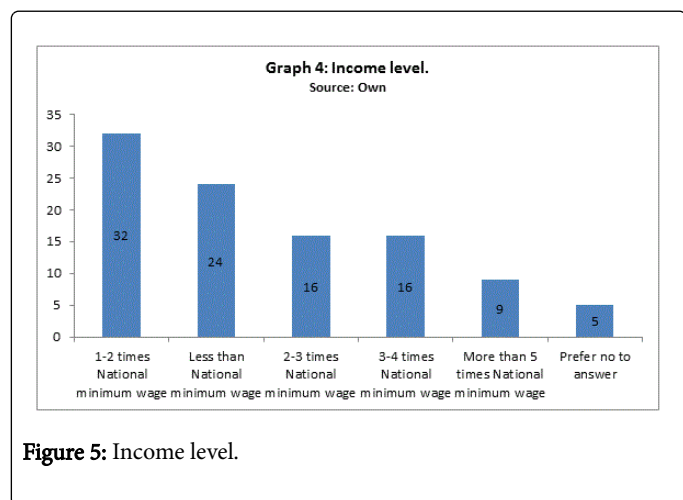


Figure 5: Income level.

The income level of the respondents showed that 24% have a level of income below the National Minimum Wage. The rest (76%) were above that level. In the control group the percentage was 22%. The majority of the respondents were between 1 and 2 times the National Minimum Wage, which compared to the control group, gives similar results and can be related to the higher level of studies, which, at least hypothetically, gives access to higher quality jobs (Figure 6).

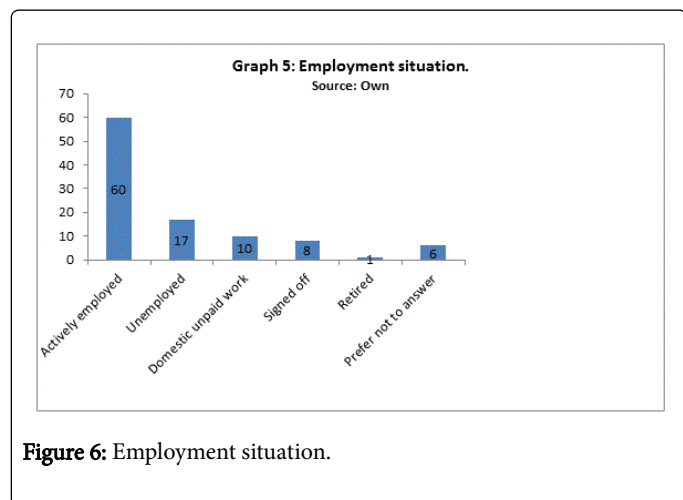


Figure 6: Employment situation.

The majority of respondents (59%) are actively employed. Some 8% are signed off, as reflected in Figure 6. Regarding where they live, a considerable proportion is urban. At least 67% of the respondents dwell in urban surroundings, according to the data obtained.

Having shown the results, these will be examined, with the proviso that this study is exploratory in nature, and should be confirmed with complementary studies. Another warning must be made: the sample is not representative due to the impossibility of performing a truly random sampling, therefore it would not be correct to generalise the results. For the discussion of same, we will use the literature on the subject and the comparison with the control group represented by the undiagnosed women who answered the survey.

The patients were found thanks to internet forums, which, evidently, tend to determine the profile of the participants. As a matter of fact, we believe that the sample does not collect data or opinions from women with a lower level of studies. The level of studies of the respondents is striking, 75% answered that they have university studies, which tallies with the control group since it totalled 80%. It must be remembered that the countries where the surveys were carried out are advanced, such as the United States, United Kingdom, Mexico or Spain. This profile is in line with people who use the latest technology and use it to search for information [21]. Presumably, people with no internet access or less inclined to read, would need other types of techniques to be surveyed. It could also be argued whether this high level of studies can be linked to the fact that people with a higher level of studies make greater use of specialists, an issue studied internationally [22] and in Spain [23]. On the other hand, the level of studies of the mothers (indication of the social class of origin) is lower. The data correlates to the control group.

Regarding their age, and the age at which they were diagnosed, their profile corresponds to the average age at which mental disorders are diagnosed. They appear later when it comes to anxiety or depression [24,25].

The level of income of the respondents showed that 24% had an income level that was below the National Minimum Wage. The rest (76%) was above that level. In the control group the percentage was 22%. The majority of the respondents were located between 1 and 2 times the National Minimum Wage, which compared to the control group, gives similar results and can be related to the high level of studies, which, at least hypothetically, gives access to higher quality jobs.

Regarding the size of the town of residence, the predominantly urban habitat is also repeated in the sample and in the control group. The urban factor is considered foreseeable: higher concentrations of people present a higher probability of diagnosis.

Regarding the work situation, the presence of sick leave from work is in line with what is stated in the specialized literature [11]. On the other hand, the responses of the sample and of the control group show some divergence. Those diagnosed with PMDD had a lower percentage of work activity than the control group, which could indicate that the absence of diagnosis is a factor that affects this issue. The hypothesis of other diagnoses in the alternative sample, such as PMS, could also be considered [8]. As has been found in the literature, PMS is taken as normal.

As for other questions that were included in the questionnaire, other than the socio-demographic profile, an obvious discomfort in those affected can be deduced from the results, attributable to this disorder.

There is also a certain lack of understanding surrounding them. The number of women who are signed off work in Figure 5; Women who reported having lost a job due to PMDD (40%); Those that attributed sentimental break-ups to PMDD (56%); The ones that responded, some 40%, that the relationships with others around them was one of incomprehension; Or the 59% who "disagreed or totally disagreed" that the medical attention received was adequate, are eloquent figures of that discomfort, a discomfort that concurs with the bibliography [25].

Conclusions

The study shows how the women affected manifest unease with those around them (lack of understanding from health agencies and their own families) due to not finding an answer to their suffering. If health is defined as the absence of disease (a restricted concept) it will be difficult to achieve a global approach. To limit oneself to the medicalization of the woman's body or to describe them as disturbed, when the treatment of drugs has not worked, is far from an integral consideration of the health of these women. The symptom/drug, professional/patient binomial seems insufficient when facing such a complex phenomenon as PMDD.

Brown [9] wonders whether it is necessary to be diagnosed in order for the reports of symptom to be taken seriously. From these assumptions, it is believed that it is necessary to address women's premenstrual tension more comprehensively. Women who complain cyclically should be taken into account in medical consultations in a specific way and for this to happen, a conclusive diagnosis should not be necessary. Having said that however, the expectations that are generated around medical consultations could also be analysed. Trusting one's health solely to the doctor-patient relationship also represents a simplistic approach to achieving good health.

Good use of the internet can be considered as an asset to health. Given the low prevalence (or few diagnoses) of a particular disorder, it is difficult to group patient samples. Therefore, this type of on-line approach makes unprecedented knowledge possible. On the other hand, we have tried to illustrate how the health problems are experienced outside the clinical scope. The adoption of strategies to deal with PMDD does not exclusively refer to what is reported in clinical consultations. There are environmental factors that fall outside the range of the clinical environment. These factors include the interactions of patients within their social network (the Internet, and others). Therefore, part of the welfare of those affected depends on that environment [2]. In a social environment, where there is a weakening of informal networks, it is common to seek information and emotional support in the mutual support groups offered by the internet [18]. That these supports can become an aid to good health depends on their correct usage. This usage can be assessed by health professionals

No conclusive data has been found to suggest that any specific social factor causes a predisposition towards suffering this disorder. The average woman suffering from PMDD who answered the survey, is 35 to 39 years old, lives in a developed country in an urban environment with her partner and her children; her level of studies is high; she is in active employment; she earns more than the National Minimum Wage and was diagnosed either within six months or after several years of reporting symptoms of her illness.

The finding of the high number of women participating in these forums who remain undiagnosed, leads to a large question mark over the massive use of the Internet when information and mutual support are needed. People are concerned about wanting to improve their

health, and there is a need to find answers when they do not get them from the regular healthcare systems. Because of this concern, it is believed that the survey has received an outstanding response, because those affected want explanations.

The responses of those surveyed point to a profile that corresponds to the bibliographical references consulted [11]. The need to continue to insist on studies on PMDD is evident. The survey may continue to be used for research, since no variable cross references or correlations between the sample and its control group have yet been raised. In next stages of study it is planned to use the online survey in order to get a large sample. With the increase of the sample the data will be more valuable. In than momento multivariate analysis will be able to be employed. Anyway the use of a survey as research tool shows their limits. For this reason it will be complemented with qualitative data. This data are going to be soon published.

The self-support has been offered in forums as, very often, the only answer to these women. Project Leonardo [26] essays to empower affected people to face their own diseases. A professional training led for care managers help to promote the health. Affected of PMDD, would be prone to this kind of experiences because are wanting for help. The methodology couldn't be the same but some creativity is necessary to innovate [26,27]. An online professional support could be an interesting approach for these groups of women.

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