What are women being exposed to? A review of the quality, content and ownership of websites on premenstrual dysphoric disorder (PMDD)

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Abstract

Background: An increasing number of people are now turning to the Internet for health information. Internet use is especially likely in women with the clinical condition premenstrual dysphoric disorder (PMDD), which affects approximately 8% of premenopausal women. However, to date, there has not been a review of the quality of these online resources on PMDD. The aim of the present study is to address this gap by reviewing websites containing PMDD information.

Method: A search was conducted on three commonly used search engines (Google, Yahoo, and Bing). The first 50 results were extracted and compared across each search engine results to determine unique resources. After removing inaccessible links, a total of 69 unique websites were reviewed to evaluate their general quality, condition-specific content quality, and ownership.

Results: The websites varied widely in terms of their quality and ownership. Most returned websites were from web providers, US healthcare providers and media companies. General quality (e.g. design) was modest; yet, condition-specific content quality was far poorer.

Conclusion: Women are being exposed to a varying degree of quality information about PMDD. Health professionals and website owners of this information should consider this and encourage better online resources to help this patient group. The paper presents the five highest scoring websites that may be used by those with a vested interest in PMDD, such as health professionals or women with PMDD.

Keywords: premenstrual dysphoric disorder; Internet; quality; websites

Introduction

In modern society, menstruation can occur between 400-500 times during a woman's reproductive years, and for up to 80% of women, some physical or emotional effect will be experienced during the premenstrual phase of her menstrual cycle (Hylan, Sundrell, & Judge, 1999). These premenstrual symptoms can occur up to two weeks before menses (i.e. the luteal phase of the menstrual cycle) and then cease when menses begins. These symptoms can have a significant impact on women's lives leading many to seek treatment of some form (Hylan, et al., 1999). For a sub-cohort of these women, however, extremely severe premenstrual symptoms are experienced. It is estimated that between 3-8% of women have a clinical condition known as premenstrual dysphoric disorder (PMDD) (Halbriech, Borenstein, Pearlstein, & Khan, 2003), which can have severe negative effects on their lives.

PMDD was originally referred to as the 'late luteal phase dysphoric disorder' in the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) III-R (1987) before changing to PMDD in the DSM-IV (APA, 1999). In the most recent edition (DSM-V, 2013), for women to be diagnosed with PMDD they are required to experience 5 out of 11 specific premenstrual symptoms cyclically (i.e. symptoms disappear when menstruation begins) and these symptoms must interfere with their work, school, usual activities or relationships with others. Specific symptoms include noticeable lability (e.g. moods swings), irritability or anger, anxiety and tension, depressed mood, feeling overwhelmed or out of control, difficulty in concentrating, decreased interest in usual activities, a change in appetite, sleeping patterns (e.g. insomnia or hypersomnia), and physical symptoms (e.g. headaches, breast tenderness, 'bloating') and must include the first four of these symptoms listed. Importantly, symptoms must not be related to any other disorder or underlying medical condition, other medications or drug use. They must occur in most menstrual cycles over the last year and be recorded for at least 2 months to confirm the diagnosis.

The exact cause of PMDD is still unknown but various types of treatment have been used or suggested in order to alleviate symptoms. A comprehensive review of the literature examining the evidence for PMDD treatments reveals varying efficacies but highlights the need for more research (Rapkin & Lewis, 2013). The review examines treatments including pharmacological, non-pharmacological, and other alternative self-help and therapeutic approaches. Of these, pharmacologic

treatments have received the most attention in recent years including serotonergic agents such as selective serotonin reuptake inhibitors (SSRIs), serotonin–norepinephrine reuptake inhibitors (SNRIs), atypical serotonergic antidepressants and serotonergic tricyclics. SSRIs are the most documented and have shown to be the most effective of these psychotropic treatments, easing symptoms in up to 60-80% of patients (e.g. Dimmock, Wyatt, Jones, & O'Brien, 2000; Shah, Jones, Aperi, Shemtov, Karne, & Borenstein, 2008). They are FDA (US Food and Drug Administration) approved as a treatment for PMDD and moreover, research shows that they can be taken continuously or intermittently (for example, during the luteal phase or symptom-onset) with similar results (Freeman, Sondheimer, Sammel, Ferdousi, & Lin, 2005; Ravindran, Woods, Steiner, & Ravindran, 2007; Shah, et al., 2008).

Another line of pharmacological treatments is hormonal therapies, which aim primarily to supress ovulation. Oral contraceptives (OCs) containing drosperinone have shown the most efficacy in symptom alleviation across several randomised control trials and meta-analyses. According to Rapkin and Lewis (2013), other OCs following the standard dosing of 21 days on-7 days off have not been shown to be as effective for treating PMDD compared to continuous daily use (despite their wide use for treating symptoms of PMS, Rapkin & Winer, 2008). Other hormonal options include high-dose transdermal estrogen, Danazol (a synthetic partial androgen antagonist/agonist and gonadotropin inhibitor), and gonadotropin-releasing hormone (GnRH) agonists that also reduce or stop ovulation. These have shown some improvements for symptoms in women with PMS but not necessarily those who are dysphoric (e.g. Freeman, Sondheimer, & Rickels, 1997). Numerous negative side-effects, including endometriosis, hirsutism, acne, and hypoestrogensim, have been reported with use of GnRH, meaning these options are less appealing (Rapkin & Lewis, 2013). As a last resort, women can have a surgical menopause involving the removal of bilateral ovaries with or without a hysterectomy. Again, side effects may result including osteoporosis, cardiac disease, and endometrial hyperplasia unless other hormones are replaced (Mitwally, Gotleib, & Casper, 2002), which consequently may reintroduce PMS symptoms (Rapkin & Lewis, 2013). The review concluded OCs containing drosperinone are currently regarded as the most effective hormonal treatment and noted as another FDA approved treatment PMDD. Other non-pharmacological and alternative treatment options have also been explored but to a lesser degree. They are typically tested on women with PMS and also advocated as treatments for PMDD despite a lack of systematic evaluation on women with the condition. Self-help approaches include exercise (Daly, 2009), dietary modifications, and use of supplements in the luteal

phase of the menstrual cycle. Possible dietary modifications include reducing consumption of alcohol, caffeine, and sugar (Cunningham, Yonkers, O'Brien, & Eriksson, 2009; Rossignol & Bonnlander, 1990) and increasing complex carbohydrate intake (Sayegh, Schiff, Wurtman, Spiers, McDermott, & Wurtman, 1995). Supplements may include vitamin B6 (e.g., Wyatt, Dimmock, Jones, Shaughn O'Brien, 1999) and calcium (e.g., Thys-Jacobs, Starkey, Bernstein, & Tian, 1998), of which the latter has been acknowledged as showing some promise as a non-pharmacological potential treatment for PMDD (Rapkin & Lewis, 2013). Herbal remedies including hypericum perforatum (St John's wort) and agnus castus (chastebury) have also been suggested with some promise from small empirical studies, particularly for the latter (Schellenberg, 2001; Atmaca, Kumru, & Tezcan, 2003). Bright-light therapy is also showing signs as another potential alternative treatment of PMDD with some evidence of symptoms reduction from light dosing in the morning and/or evening in women with PMDD (Parry, Mahan, Mostofi, Klauber, Lew, & Gillin, 1989; Lam, Carter, Misri, Kuan, Yatham, & Zis, 1999). Finally, the psychological treatment intervention of cognitive behavioural therapy (CBT) is another non-pharmacological treatment that has some empirical evidence of its effectiveness on PMDD symptoms comparable to that of SSRIs (Hunter, Ussher, Browne, Cariss, Jelley, & Katz, 2012), whilst other relaxation-type practices, such as acupuncture and reflexology, for example, again are sometimes suggested as treatment but lack empirical evidence for PMDD.

Women can often seek medical help for premenstrual problems for several years before receiving a diagnosis of PMDD. In other cases they can receive a misdiagnosis, for example, of bipolar or borderline personality disorder (Stud, 2012; Yamauchi, Tanaka, Mukai, & Kato, 2008). An initial suggestion of a premenstrual problem can often originate from another nonmedical source leading women to feel that their physicians were inadequately informed in relation to the diagnosis and treatment of premenstrual issues (Kraemer & Kraemer 1998). Given this perception it is perhaps not surprising that women are turning to the Internet for health information and advice. In fact, this is part of a common trend towards using online resources for health.

It is estimated that 59% of US adults have looked online for health information in the past year (Pew, 2013) with a growing number searching online for health information before seeking professional medical advice (Dutton & Blank, 2011). However, the overall quality of health information online is known to be variable (Eysenbach & Köhler, 2002). Researchers have noted issues with the general quality of the website (e.g. currency of information, readability and download time

(Eysenbach & Köhler, 2002; Croft & Peterson, 2002) as well as with the specific health content provided (e.g. incomplete information; Reed & Anderson, 2002). Whilst a number of specific studies have examined the content and quality of women's health information online, such as menopause, (Reed & Anderson, 2002; Pérez-López, 2004), postmenopausal osteoporosis, (Pérez-López & Pérez Roncero, 2006), cervical cancer treatments (Selman, Prakash, & Kahn, 2006), and postnatal mental health (Moore & Ayres, 2011), to the best of our knowledge there has not been a review of PMDD information websites.

Recent evidence suggests that women with PMDD may be more likely than other women to use the Internet excessively. Ko and colleagues (Ko, Yen, Long, Chen, Huang, & Yen, 2014) found women with PMDD were five times more likely to have an Internet Use Disorder (IUD) compared to women without PMDD, and that the severity of IUD increases during the premenstrual phase. There is some suggestion that individuals who are dealing with non-curable health conditions, less well known or understood conditions or conditions that impact upon daily living often report high levels of health related Internet use (Hardy, Sillence, Briggs, & Harris, 2012). As PMDD is still a relatively unknown condition that is often misdiagnosed, these women may be looking online for help or information. It is therefore important to understand what information these women may be exposed to on the Internet. The current study provides an overview of PMDD websites available and an evaluation of the quality and content of information on the Internet relating to PMDD.

Material and Methods

To identify relevant websites for the review, the most popular search engines used for health and medical information (Google, Yahoo, and Bing; Pew, 2013) were selected. On December 28th 2013, the phrase "premenstrual dysphoric disorder" was entered in each search engine. The first 50 results for each search engine were extracted as users typically do not go beyond this when looking at health information online (Eysenbach & Köhler, 2002; Hanif, et al., 2006). These results were compared to identify unique URLs (Uniform Resource Locator) and websites for inclusion in the review. Both researchers reviewed the websites independently within 12 weeks of the search and rated the quality of the returned results using the following scales.

Measures

Quality of information: general and condition-specific content

General quality was measured using the scale proposed by Sandvik (1999) used in other health website reviews (e.g. Pérez-López 2004; Pérez-López & Pérez Roncero 2006). Seven items were scored from 0 to 2, which included *ownership* (2=name and type of provider clearly stated, 1=all other indications of ownership, 0=no indication of ownership), *authorship* (2=author's name and qualification clearly stated, 1=all other indications of authorship, 0=no indication of authorship), *source* (2=references given to scientific literature, 1=all other indications of source, 0=no indication of source), *currency* (2=date of publication or update clearly stated on all pages, 1=all other indications of currency, 0=no indication of currency), *interactivity* (2=clear invitation to comment or ask questions by an email address or link to a form, 1=any other email address on the site, 0=no possibility for interactivity), *navigability* (2=information easily found by following links from home page, 1=information found only with difficulty by following links, search engine provided if information widely scattered on site, 0=information scattered around, no search engine), and *balance* (2=balanced information, 1=biased in favour of own products or services, 0=only promoting own products or services). Ratings were totalled and averaged across the two researchers to provide an overall score for general quality of the website content. Scores could range between 0 and 14, with 14 being the best quality score. Websites with a total score between 0-5 were regarded as poor, between 6-10 points as medium quality, and between 11-14 were excellent. This scoring method has been used in other women's health website reviews (e.g. Pérez-López & Pérez Roncero, 2006) and is based on the principles of Health On the Net (HON) and work by Silberg and others (Silberg, Lundberg, & Muacchio, 1997) that aim to provide guidance and assurance of quality health information on the web.

Condition-specific content quality criteria were devised around the diagnosis and treatment of PMDD. Four categories were rated on a 4-point scale (3=comprehensively explained, 2=briefly explained, 1=mentioned, and 0=not mentioned) including: 1) *Diagnosis*, which assessed whether the extent of information given about PMDD and its diagnostic criteria based on the DSM-V (APA, 2013); 2) *Pharmacological treatment*, which assessed the quality and depth of information provided on the various drug and hormonal treatment that is available and its effectiveness (e.g. SSRIs, SNRIs, oral contraceptives, surgical menopause); 3) *Non-pharmacological treatment*, which focused on non-drug

treatments usually requiring input from a health professional or qualified practitioner (e.g. CBT, acupuncture); and *4) Self-help*, treatments that do not require a qualified health professional (e.g. diet and exercise). However, website content should acknowledge that evidence for non-pharmacological and self-help treatment options are typically derived from evidence on PMS and not PMDD (see above and Rapkin & Lewis' (2013) review paper for more details). Ratings by each researcher were totalled and averaged to give a total condition-specific score between 0-12, with 12 indicating the best score possible. Adapting the scoring procedure for general quality, total scores for condition-specific content quality between 0-3 were considered poor; between 4-8 were considered medium quality; and 9-12 were considered excellent quality.

Website ownership

Website ownership was also recorded. Table 1 shows the 13 different categories of websites along with a description and an example of each.

INSERT TABLE 1 HERE

Results

On the day of data collection search results returned back 557,000 (Google), 156,000 (Yahoo), and 158,000 (MSN/Bing) results across the three search engines. Several sites were returned across all three search engines, with Yahoo and Bing returning identical top 50 results. Overall, 73 unique sites/URLs were found. However, 4 sites were inaccessible for either one or both researchers when reviewing. These were removed from the review providing a final sample of 69 websites.

A summary of the website categories and scores are shown in Table 2. The majority of sites came from online 'web provider' companies (n=29, 42.03%), followed by 'US healthcare providers' (n=10, 10.49%) and 'media' sites (N=9, 13.04%). Only a single website (1.45%) was returned for the 'UK healthcare provider', 'pharmaceutical', and 'educational' ownership types. The other ownership types were also found to be relatively low in prevalence.

*** INSERT TABLE 2 ABOUT HERE***

In terms of general quality, websites on PMDD ranged from poor (e.g. www.add-adhd-help-center.com) to excellent (e.g. www.healthyplace.com) with two-thirds of the sites (n=46, 66.67%, mean 7.64) were considered of medium general quality (e.g. www.postmenstrualsyndrome.com). A marginally higher proportion of websites were considered of poor quality (n=12, 17.39%) than of excellent quality (n=11, 15.94%).

When examining across the types of websites, 'government' and 'professional/academic journal' sites had the highest average general quality ratings (mean = 9.67, ranges 9.50-10.00 and 8.50-11.00, respectively). Sites rated as excellent were found in some web provider (n=6), US healthcare provider (n=1), professional body (n=1), professional/academic journal (n=1), personal (n=1), and media (n=1) types of sites. The sole pharmaceutical owned site received a "poor" general quality score (4.50). There were also 'poor' general quality sites from the retail (n=1), personal (n=1), US healthcare provider (n=2), charity (n=1), and web provider (n=6) ownership types.

A closer inspection of the results indicates that currency of information was a particular problem for websites in that it was difficult to establish when the information was last updated. References to the scientific literature or to source credentials (i.e. information about the content's author) were sometimes lacking and also, the sites often showed poor interactivity, failing to offer users a chance to add their own comments or queries.

For condition-specific content quality, the average quality was on the boundary between a low and medium score (mean = 3.94, range 0.00-12.00). More specifically, almost half of the websites (n=34, 49.28%) were considered to have 'medium' quality condition-specific content (e.g. www.thirdage.com). However, the number of sites with poor scores for content quality (n=30, 43.48%; e.g., www.depressionhelp-foryou.com) was more than double the number of sites with poor scores for general quality. The web providers category contained the most 'poor' condition-specific content quality sites (n=11), followed by media (n=4), US healthcare providers (n=4), professional body (n=2), and personal, blog-like sites (n=2). A website from each of the following types was also rated as having 'poor' condition-specific content: charity, pharmacological, educational, retail, and social media. Less than eight per cent (7.25%, n=5) of websites were considered 'excellent' (e.g. www.depression-guide.com) and came from web providers (n=3), as well one government and professional/academic

journal type. There were 6 website results that scored zero, including the two personal websites, 1 media site, 1 retail site, and 2 web provider sites.

On closer inspection, the main content specific quality issues were: a) a lack of specific diagnostic criteria required for a PMDD diagnosis according to the DSM; and b) a paucity of detailed information (and references) guiding the use and effectiveness of particular treatment options (i.e. the treatment was simply listed).

In terms of overall quality scores (general quality plus specific-content quality), the average quality across the websites was modest (mean = 11.58, range 4.00-21.00). No websites were found to have 'excellent' ratings in both quality categories. The highest overall quality sites came from government (mean = 16.33), professional/academic journals (mean = 18.33), and professional body sites (mean = 12.63). However, from the ranges of scores shown in table 2, high quality websites do occur across the ownership types. We ranked these combined quality scores and present the top 5 scoring websites in Table 3.

*** INSERT TABLE 3 ABOUT HERE***

Discussion

The present study has increased our understanding of web resources available on PMDD and their quality. The results indicate great variability in terms of general and condition-specific content quality, as well as the ownership of these websites. Specifically, the most commonly available PMDD websites came from online web providers, US healthcare providers or media sites with websites being overall of average quality. General quality was commonly rated lower in circumstances in which it was unclear when the information was published (i.e. currency), the source of information was insufficiently provided, and there was limited or no interactivity functionality. Condition-specific content on the websites was predominantly poor to medium in quality. More specifically, lists of symptoms are provided but not the specific diagnostic criteria required for a PMDD diagnosis according to the DSM. This may lead many women and/or interested readers to believe they or someone else may have PMDD when in fact they may have a less severe version of PMDD such as PMS or premenstrual tension. In addition, sometimes a treatment option was mentioned but additional information, such as information

guiding the use and effectiveness of the treatment was missing. As a result, those looking for specific information on PMDD may be engaging with inaccurate and/or out-of-date information. When compared to other website reviews, the present findings echo varying-to-poor quality for other health (e.g. Croft & Peterson, 2002; Reed & Anderson, 2002) and mental health websites (e.g. Moore & Ayres, 2011).

None of the websites reviewed here were found to be excellent in both quality criteria. This suggests that a website may be good generally (e.g. good navigability, providing authorship information, etc.), yet it may still be relatively inferior with regards to the degree of comprehensive information provided about PMDD and its treatment. Website design has improved over recent years and many people now take for granted good design. Poor design however still has the potential to lead to mistrust amongst users causing them to disengage with or exit the site early (Sillence, Briggs, Harris, & Fishwick, 2007; Sillence, Hardy, Harris, Briggs, 2014) potentially missing out on high quality information. Conversely, sites that are well designed and accessible may confer a degree of unwarranted credibility on their information content (halo effect). People engaging with well-known and often trusted sites will have expectations of the quality of the content they contain. Interestingly, the government websites achieved relatively high scores for both general and content specific quality although there was still room for improvement. Website design and content are inextricably linked and vital for producing helpful and informative websites.

The results show that insufficient information is often provided in terms of PMDD diagnosis criteria and the various forms of possible treatment, with some websites providing no information at all. This finding may be due in part to PMDD still being a somewhat relatively new condition, with a smaller evidence base and less accepted information available than more established mental health conditions.

For example, debates still continue around elements of the DSM criteria for PMDD, which are described by some as potentially arbitrary (e.g. too many symptoms necessary) and may lead to undercounting (Halbreich, et al., 2003)." Such arguments coupled with an emerging understanding of the cause of the condition may explain why many of the websites do not provide comprehensive information for the website user. Nevertheless, what is known about PMDD currently does not always appear on websites and maintaining current, up-to-date information is important for women seeking help and guidance.

The five highest rated websites (Table 3) provide a starting point for health professionals and researchers considering online information provision for PMDD. For health professionals, these sites may be useful for signposting women to relevant resources. For researchers, these findings prompt questions about the evolving nature of online PMDD information. None of the top five sites is from a pharmaceutical company, even though pharmaceutical sites for other women's health conditions have received high scores (e.g., Reed and Anderson, 2002). In fact, only one pharmaceutical owned site featured in the search results. This low key presence is perhaps surprising given the role of pharmaceuticals in the effective treatment of PMDD. Whilst other traditional information providers, for example charities, were also poorly represented, personal websites and social media sites were both present in the search results. We know that experiential information online can be appealing to people suffering from less well-known or understood conditions (Hardy, et al. 2012; Locock & Brown, 2010) and can influence people's health through a number of different domains, including finding information, feeling supported and using health services (Ziebland & Wyke, 2012). Although it is worth noting that both personal sites scored zero in relation to content specific quality perhaps reflecting the very narrow experiential focus of such sites. From the review, it is clear that PMDD has a presence online and whilst this study has focused on information-based web resources, it may prove fruitful moving forward to examine PMDD within a social media context.

Despite the study's insights, these findings should also be considered with its limitations. For example, like all website reviews, the Internet is constantly changing and so search results are likely to change over time. The results returned from a search engine are also determined largely by how well a site is optimized. Search Engine Optimization (SEO) is a process by which websites and their content are designed and developed in order in get the most traffic and be high on the list of results in search engines. It may be the case that there are some excellent quality websites that did not appear in our list of results because they were not optimized efficiently enough at the time of the search. Other factors that influence search engine results include the user's search history, the location and language of the search. In the present study, both researchers were based in UK so it may be of interest that future research conducts a similar review from different locations or languages. Finally, the authors occasionally found websites difficult to classify with some appearing to overlap in terms of ownership types. US healthcare provider sites, for example, were often healthcare centres associated with a medical school at a university and thus could have also been classified under the educational ownership

type. A review of similar studies noted a lack of detail surrounding classification strategies and as such the authors classified websites based on the website's primary function. These issues around ownership may present difficulties for women looking for information about PMDD online as they try to make sense of who is providing the information and their motives. However, a well-designed website that is easy to use and contains quality content, including information about the owners, would reduce negative perceptions by these women consumers. Notwithstanding these limitations, this review presents a current snapshot of the online PMDD landscape. It provides a useful baseline from which to carry out follow-up studies allowing trends in quality and content to be noted.

Implications for Practice and/or Policy

It is recommended that owners of existing websites and new websites on PMDD examine the design and content on their site, making changes where appropriate. Using recognized standards, such as the HON principles, are a useful way of achieving this, as well as using up-to-date scientific literature for their content. With increasing research on PMDD, information available on the condition is constantly changing. Websites, especially those in government or healthcare ownership, need to ensure they continually adapt and adjust their content to reflect growing understanding of this condition.
Health professionals should be aware that patients may be accessing information on PMDD from a variety of websites, some of which may have poor-quality content. The five websites identified in this review (Table 3) may prove useful as a way of signposting women to higher quality resources on PMDD.

Conclusion

This paper has presented the first review of websites on PMDD. Overall, the review concludes that whilst women are exposed to a wide range of providers of this health information, the web materials themselves are largely of medium or poor quality, particularly in terms of the specific condition information, which may be misinforming women about PMDD.

References

American Psychiatric Association (1987). *Diagnostic and Statistical Manual of Mental Disorders, Revised, Third Edition*. Washington D.C., USA: American Psychiatric Press Inc.

American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. Washington D.C., USA: American Psychiatric Press Inc.

American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. Washington D.C., USA: American Psychiatric Press Inc.

Atmaca, M., Kumru, S., & Tezcan, E. (2003). Fluoxetine versus Vitex agnus castus extract in the treatment of premenstrual dysphoric disorder. *Human Psychopharmacology*, 18(3), 191–195.

Briggs, P., Sillence, E., & Hardy, C. (2013). Advertising as a trustbuster in online peer-to-peer healthcare. Paper presented at the `*Symposium on Usable Privacy and Security: A Turn for the Worse: Trustbusters for User Interfaces workshop*', Newcastle upon Tyne UK, July 24-26 2013.

Croft, D. R., & Peterson, M. W. (2002). An evaluation of the quality and content of asthma education on the world wide web. *Chest, 121*(4), 1301-1307.

Cunningham, J., Yonkers, K. A., O'Brien, S., & Eriksson E. (2009). Update on research and treatment of premenstrual dysphoric disorder. *Harvard Review of Psychiatry*, 17(2), 120–137.

Daley A. (2009). Exercise and premenstrual symptomatology: a comprehensive review. *Journal of Womens Health (Larchmt.)*, 18(6), 895–899.

Dimmock, P. W., Wyatt, K. M., Jones, P. W., & O'Brien, P. M. (2000). Efficacy of selective serotonin-reuptake inhibitors in premenstrual syndrome: a systematic review. *Lancet*, 356(9236), 1131–1136.

Dutton, W. H., & Blank, G. (2011). *Next generation users: the Internet in Britain*. Retrieved December 15, 2013 from http://www.oii.ox.ac.uk/publications/oxis2011_report.pdf

Eysenbach, G., & Köhler, C. (2002). How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *British Medical Journal*, 324, 573-577.

Freeman, E. W., Sondheimer, S. J., & Rickels, K. (1997). Gonadotropin-releasing hormone agonist in the treatment of premenstrual symptoms with and without ongoing dysphoria: a controlled study. *Psychopharmacology*, 33(2), 303–309.

Freeman, E. W., Sondheimer, S. J., Sammel, M. D., Ferdousi, T., Lin, H. (2005). A preliminary study of luteal phase versus symptom-onset dosing with escitalopram for premenstrual dysphoric disorder. *Journal of Clinical Psychiatry*, 66(6), 769–773.

Halbreich, U., Borenstein, J., Pearlstein, T., & Khan, L. (2003). The prevalence, impact, and burden of premenstrual dysphoric disorder (PMS/PMDD). *Psychoneuroendocrinology, 28*, 1-23.

Hanif, F., Sivaprakasam, R., Butler, A., Huguet, E., Pettigrew, G. J., Michael, E. D., Praseedom, R. K., Jamieson, N. V., Bradley, J. A., & Gibbs, P. (2006). Information about liver transplantation on the World Wide Web. *Medical Informatics and the Internet in Medicine*, 31, 153-160.

Hardy, C., Sillence, E., Briggs, P., & Harris, P. (2012). Online patient experiences: exploring differences between health groups. Paper presented at The *First International Conference on Global Health Challenges*, Venice, Italy. 21-26 October, 2012.

HON Code of Conduct (HONcode) for medical and health web sites. Retrieved December 1, 2013 from http://www.hon.ch/HONcode/Conduct.html.

Hunter, M. S., Ussher, J. M., Browne, S. J., Cariss, M., Jelly, R., & Katz, M. (2002). A randomized comparison of psychological (cognitive behaviour therapy), medical (Fluoxetine) and combined treatment for women with premenstrual dysphoric disorder. *Journal of Psychosomatic Obstetrics & Gynaecology*, 23(2), 193-199.

Hylan, T. R., Sundell, K., & Judge, M. D. (1999). The impact of premenstrual symptomatology on functioning and treatment-seeking behavior: experience from the United States, United Kingdom, and France. *Journal of Women's Health & Gender-based Medicine*, 8(8), 1043-1052.

Ko, C., Yen, C., Long, C., Chen, C., Huang, T., & Yen, J. (2014). The association between premenstrual dysphoric disorder and internet use disorder. *Women & Health*, 54(3), 245-261.

Kraemer, G. R., & Kraemer, R. R. (1998). Premenstrual syndrome: diagnosis and treatment experiences. *Journal of Women's Health*, Sept 7(7), 893-907.

Lam, R. W., Carter, D., Misri, S., Kuan, A. J., Yatham, L. N., & Zis, A. P. (1999). A controlled study of light therapy in women with late luteal phase dysphoric disorder. *Psychiatry Research*, 86(3), 185–192.

Locock, L., & Brown, J. B. (2010). 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND). *Social Science & Medicine*, 71(8), 1498-1505.

Mitwally, M .F., Gotleib, L., & Casper, R. F. (2002). Prevention of bone loss and hypoestrogenic symptoms by estrogen and interrupted progestogen add-back in long-term GnRH-agonist down-regulated patients with endometriosis and premenstrual syndrome. *Menopause*, 9(4), 236–241.

Moore, D., & Ayers, S. (2011). A review of postnatal mental health websites: help for healthcare professionals and patients. *Archives of Women's Mental Health*, 14, 443-452.

Parry, B. L., Mahan, A. M., Mostofi, N., Klauber, M. R., Lew, G. S., Gillin, J. C. (1989). Light therapy of late luteal phase dysphoric disorder: an extended study. *American Journal of Psychiatry*, 146(9), 1215–1217.

Pérez-López, F. (2004). An evaluation of the contents and quality of menopause information on the World Wide Web. *Maturitas*, 49(4), 276-282.

Pérez-López, F., & Pérez Roncero, G. (2006). Assessing the content and quality of information on the treatment of postmenopausal osteoporosis on the World Wide Web. *Gynaecology & Endocrinology*, 22(12), 669-675.

Pew Research Center's Internet & American Life Project (2013). *Health Online 2013*. Retrieved August 25, 2014 from http://www.pewinternet.org/files/old-media//Files/Reports/PIP_HealthOnline.pdf

Rapkin, A. J., & Lewis, E. I. (2013). Treatment of premenstrual dysphoric disorder. *Women's Health*, 9(6), 537-556.

Rapkin, A. J. & Winer, S. A. (2008). The pharmacologic management of premenstrual dysphoric disorder. *Expert Opinion on Pharmacotherapy*, 9(3), 429–445.

Ravindran, L. N., Woods, S. A., Steiner, M., & Ravindran, A. V. (2007). Symptom-onset dosing with citalopram in the treatment of premenstrual dysphoric disorder (PMDD): a case series. *Archives of Womens Mental Health*, 10(3), 125–127.

Reed, M., & Anderson, C. (2002). Evaluation of patient information Internet web sites about menopause and hormone replacement therapy. *Maturitas*, 43, 135-154.

Rossignol, A. M. & Bonnlander, H. (1990). Caffeine-containing beverages, total fluid consumption, and premenstrual syndrome. *American Journal of Public Health*, 80(9), 1106–1110.

Sandvik, H. (1999). Health information and interaction on the internet: a survey of female urinary incontinence. *British Medical Journal,* 319, 29-32.

Sayegh, R., Schiff, I., Wurtman, J., Spiers, P., McDermott, J., & Wurtman, R. (1995). The effect of carbohydrate-rich beverage on mood, appetite, and cognitive function in women with premenstrual syndrome. *Obstetrics and Gynecology*, 86(4 Pt 1), 520–528.

Schellenberg, R. (2001). Treatment for the premenstrual syndrome with agnus castus fruit extract: prospective, randomized, placebo controlled trial. *British Medical Journal*, 322(7279), 134–137.

Selman, T. J., Prakash, T., & Khan, K. S. (2006). Quality of health information for cervical cancer treatment on the internet. *BMC Women's Health* 6, 9. Retrieved August 25, 2014 from http://www.biomedcentral.com/1472-6874/6/9.

Shah, N. R., Jones, J. B., Aperi, J., Shemtov, R., Karne, A., & Borenstein, J. (2008). Selective serotonin reuptake inhibitors for premenstrual syndrome and premenstrual dysphoric disorder: a meta-analysis. *Obstetrics & Gynecology*, 111(5), 1175–1182.

Silberg, W. M., Lundberg, G. D., Musacchio, R. A. (1997). Assessing, controlling, and assuring the quality of medical information on the internet. *Journal of American Medical Association,* 277, 1244-1245.

Sillence, E., Hardy, C., Harris, P. R., & Briggs, P. (2014). *Modelling patient engagement in peer-to-peer healthcare*. In: WWW'14 Proceedings of the companion publication of the 23rd international conference on World Wide Web companion, 7-11 April 2014, International World Wide Web Conferences Steering Committee Republic and Canton of Geneva, Switzerland.

Sillence, E., Briggs, P., Harris, P. R., & Fishwick, L. (2007). How do patients evaluate and make use of online health information? *Social Science & Medicine,* 64, 1853-1862.

Studd, J. (2012). Severe premenstrual syndrome and bipolar disorder: a tragic confusion. *Menopause International, 18*, 82-86.

Thys-Jacobs, S., Starkey, P., Bernstein, D., Tian, K. (1998). Calcium carbonate and the premenstrual syndrome: effects on premenstrual and menstrual symptoms. Premenstrual Syndrome Study Group. *American Journal of Obstetrics & Gynecology*, 179(2), 444–452.

Wyatt, K. M., Dimmock, P. W., Jones, P. W., & Shaughn O'Brien, P. M. (1999). Efficacy of vitamin B-6 in the treatment of premenstrual syndrome: systematic review. *British Medical Journal,* 318(7195), 1375–1381.

Yamauchi, K., Tanaka, M., Mukai, Y., & Kato, T. (2008). The diagnosis and treatment of premenstrual dysphoric disorder in a patient who had been misdiagnosed as having either rapid cycling bipolar I disorder or borderline personality disorder. *School Health,* 4, 16-23.

Ziebland, S., & Wyke, S. (2012). Health and illness in a connected world: how might sharing experiences on the Internet affect people's health? *Millbank Quarterly*, 90(2), 219-24.

Tables

Table 1. Ownership types of websites.

Ownership of websites	Definition	Example
Educational	Website belonging to a university or similar with no medical provision facilities.	http://med.monash.edu.au/sphpm/womenshealth/docs/pms-and-pmdd.pdf
Media	A communication-focused website such as online newspapers or magazines.	http://www.nytimes.com/health/guides/disease/premenstrual-dysphoric-disorder/overview.html
Professional/academic journal	A peer-reviewed or refereed periodical for disseminating scholarly information.	http://www.currentpsychiatry.com/index.php?id=22661&tx_ttnews[tt_news]=176770
Retail	A website whose activity is mainly the selling of good or commodities.	http://www.add-adhd-help-center.com/Depression/premenstrual_dysphoric_disorder.htm
Professional body	An organisation seeking to further a profession, the individuals engaged in that profession, and the public.	http://www.apa.org/monitor/oct02/pmdd.aspx
Pharmaceutical company	A company involved in the manufacturing and sale of medicinal drugs.	http://www.bayerpharma.com/en/therapeutic-areas/therapeutic-areas-a-z/premenstrual-dysphoric-disorder-pmdd.php
US healthcare provider	An organisation within the US who acts as a direct provider of healthcare services.	http://medicine.med.nyu.edu/conditions-we-treat/conditions/premenstrual-dysphoric-disorder
UK healthcare provider	An organisation within the UK who acts as a direct provider of healthcare services.	http://www.nhs.uk/Conditions/Premenstrual-

		syndrome/Pages/Symptoms.aspx
Government	A website provided by the group of people governing a country a country.	http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2440788/
Web provider	An encyclopaedic-type website containing information and resources about a wide variety of topics.	http://adam.about.net/encyclopedia/infectiousdiseases/Premenstrual-dysphoric-disorder.htm
Charity	A not-for-profit organisation, excluding any of the other ownership types such as professional body or government.	http://www.mooddisorders.ca/faq/premenstrual-dysphoric-disorder-pmdd
Personal/blog	A website written by a person(s) that include their own opinions, activities and experiences.	http://scientopia.org/blogs/scicurious/2011/02/21/the-cerebellum-and-premenstrual-dysphoric-disorder/
Social media	Websites designed to allow the public to create, share or exchange information, picture or videos virtually.	http://www.youtube.com/watch?v=zqrMg_e4VGE

Table 2. Ownership types of website (n) and their general quality score, condition-specific content quality scores, and total quality score (and range of scores in brackets, where appropriate).

Ownership type	General quality	Condition-specific	Total Quality
Educational (n=1)	6.50	1.50	16.00
Media (n=9)	8.56 (6.50-10.50)	2.89 (0.00-7.50)	11.40 (6.50-17.00)
Journal (n=3)	9.67 (8.50-11.00)	8.67 (7.00-11.50)	18.33 (16.00-21.00)
Retail (n=2)	6.25 (3.00-9.50)	2.00 (0.00-4.00)	8.25 (7.00-9.50)
UK healthcare provider (n=1)	8.50	7.00	15.50
US healthcare provider (n=10)	6.90 (4.00-11.00)	4.25 (2.00-7.50)	11.15 (6.50-15.50)
Web provider (n=29)	7.35 (4.00-12.00)	4.00 (0.00-12.00)	11.35 (4.50-21.00)

Government	9.67	6.67	16.33
(n=3)	(9.50-10.00)	(1.50-8.50)	(12.50-21.00)
Pharmaceutical (n=1)	4.50	1.00	5.50
Personal	7.50	4.00	7.50
(n=2)	(4.00-7.00)	(1.50-8.50)	(4.00-11.00)
Professional body	8.63	4.00	12.63
(n=4)	(5.50-11.50)	(1.50-8.50)	(7.00-20.00)
Charity	6.00	4.00	10.00
(n=2)	(5.00-7.00)	(3.00-5.00)	(8.00-12.00)
Social Media	8.25	2.00	10.25
(n=2)	(6.50-10.00)	(0.50-3.50)	(7.00-13.50)
Total	7.59	3.94	11.58
(N=69)	(3.00-12.00)	(0.00-12.00)	(4.00-21.00)

Table 2. Top 5 websites on PMDD

Website name	URL	Ownership type
Cleveland Clinic Journal of Medicine	http://ccjm.org/content/71/4/303.full.pdf	Professional/academic journal
Medscape	http://emedicine.medscape.com/article/293257-overview	Web provider
National Centre for Biotechnology Information	http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2440788/	Government
UpToDate	http://www.uptodate.com/contents/premenstrual-syndrome-pms-and-premenstrual-dysphoric-disorder-pmdd-beyond-the-basics	Web provider
WebMD	http://www.webmd.com/mental-health/premenstrual-dysphoric-disorder	Web provider