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Qualitative study of self-reported experiences of infertile women with polycystic ovary syndrome through on-line discussion forums

Vécu des femmes infertiles atteintes d'un syndrome des ovaires polykystiques : étude qualitative sur les forums de discussion en ligne

Magali Authier^{a,*}, Caroline Normand^a, Maëva Jego^a, Bénédicte Gaborit^b, Léon Boublil^c, Blandine Courbier^{c,d}

^a Département de médecine générale, faculté des sciences médicales et paramédicales – Timone, Aix-Marseille Université, 27, boulevard Jean-Moulin, 13385 Marseille, France

^b Département d'endocrinologie, diabète et maladies métaboliques, AP-HM, Aix Marseille Université, INSERM, INRA, C2VN, Marseille, France

^c Pôle femmes-parents-enfants, centre clinico-biologique d'AMP – CECOS, AP-HM Hôpital Nord/Hôpital La Conception, 147, boulevard Baille, 13005 Marseille, France

^d Aix-Marseille Université, CNRS, IRD, IMBE, Avignon Université, Marseille, France

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ABSTRACT

Objectives. – To highlight the self-reported experiences and disease perceptions of infertile women with polycystic ovary syndrome (PCOS).

Methods. – A qualitative study using an inductive method was conducted on infertile women with PCOS who shared their self-reported experiences on French-speaking on-line forums.

Results. – 785 comments by 211 women on 7 forums were analyzed. Women complained of late diagnosis and lack of information regarding PCOS. PCOS and infertility showed negative psychological impact on daily life. This impact appeared to be alleviated by the sharing of knowledge and experience enabled by these forums.

Conclusion. – The self-reported experience of infertile women with PCOS is interesting for health practitioners. The psychological impact of PCOS and perceptions of illness appear to be improved by sharing experiences between women with PCOS, suggesting a beneficial support role of online discussion forums.

RÉSUMÉ

Objectifs. – Explorer l'expérience personnelle et les perceptions de leur maladie par des femmes infertiles ayant un syndrome des ovaires polykystiques (SOPK).

Méthodes. – Étude qualitative conduite chez des femmes infertiles, ayant un syndrome des ovaires polykystiques, partageant leur expérience personnelle sur des forums Internet francophones.

Résultats. – À travers 7 forums en ligne, 785 commentaires provenant de 211 femmes ont été analysés. Les femmes se plaignaient d'un retard diagnostique et d'un manque d'informations concernant le syndrome des ovaires polykystiques. Nous avons observé un impact psychologique négatif du SOPK et de l'infertilité sur la vie quotidienne de ces femmes. Cet impact semblait être amélioré par les échanges de connaissances et le partage d'expériences permis par les forums Internet.

Conclusion. – L'expérience personnelle des femmes infertiles atteintes de SOPK est intéressante pour les professionnels de santé. L'impact psychologique du SOPK et les perceptions de la maladie semblent être améliorés par le partage d'expérience entre les femmes atteintes de SOPK, suggérant un rôle de soutien bénéfique des forums de discussion en ligne.

* Auteur correspondant.

E-mail address: magaliauthier@gmail.com (M. Authier).

1. Introduction

Polycystic ovary syndrome (PCOS) is a syndrome combining dysovulation, clinical and/or biological hyperandrogenism, and/or polycystic ovaries on ultrasound (2 out of 3 criteria affirm diagnosis, according to the Rotterdam criteria) [1–4]. PCOS is the most common endocrine disorder in women of reproductive age, affecting 5–10% [5,6]. The consequences of PCOS, such as obesity, acne, hirsutism, infertility, and metabolic syndrome, have a significant impact on the quality of life of women with PCOS [7–9]. Increased cardiovascular risk, hypertension, type 2 diabetes mellitus, dyslipidaemia and somatic complaints such as hirsutism are often given priority by physicians, while the very frequent psychological suffering is often misunderstood [10,11].

The web is a place for free, open and anonymous exchange, liberating people from psychological barriers such as inhibiting expression or emotions that might occur face-to-face [12–14]. In this context, the Internet is an accessible source of information and is commonly used for health research. Web users search for medical information in addition to that provided by their physicians [15,16].

The objective of our study was to explore the self-reported experiences and disease perceptions of infertile PCOS women through Internet discussions forums.

2. Methodology

The criterion for inclusion was to be a woman suffering from both PCOS and infertility. PCOS was a self-reported diagnosis by women on the Internet forums. Women were considered infertile according to these criteria:

- if the woman signified a failure to conceive after more than 12 months of regular unprotected sexual intercourse (WHO definition);
- if the woman, in the context of a pregnancy project, noted the use of a cyclical treatment for inducing periods or if she underwent an ovulation induction treatment;
- if the woman considered herself infertile, even in the absence of the criteria above.

This research did not require prior consent from the ethics committee, as it was conducted exclusively on the basis of public, anonymous and retrospectively collected data.

We conducted a qualitative study with an inductive thematic content analysis inspired by the grounded theory developed by Glaser and Strauss [17]. We chose to conduct qualitative research, which aims to describe in-depth phenomena in the context of everyday life, while quantitative research aims to quantify or compare elements to identify general rules [18]. Contrary to most studies, the bibliographical analysis was carried out after the data analysis to avoid predetermined ideas during the analysis.

The first stage of the study was to analyse hundreds of comments on French-speaking Internet forums concerning infertile females with PCOS. The open-access French-speaking forums were selected using the Google search engine using the following keywords: “forum” or “opinion” and “PCOS”. The forums studied were *alldocteur*, *journal des femmes santé-médecine*, *doctissimo*, *mamanpoulavie*, *magicmaman*, *pmfertilité* and *forum.fiv*. The search was deliberately large and did not contain keywords related to infertility to reduce the risk of the exclusion of discussions by the search engine, as the selection of relevant discussions and comments were made by the author. The analysis of the comments led to the emergence of a classification system of codes and categories. Simultaneously, a second physician performed a double reading

(MA and CN), which made it possible to validate the codes found in common to reduce the subjectivity of the study. Data saturation was reached after approximately 600 comments. The analysis of approximately 150 additional comments confirmed the absence of the emergence of new codes. The transcription of the data was carried out by the software N Capture®. Data analysis was performed using the qualitative research software NVivo 12 Pro (QSR International®, Victoria, Australia). The predominant themes were exploited and clarified to form the content of this article. The original quotes were in French and have been translated into English by the author.

The second stage was to carry out a literature review to compare the elements found with the bibliographical data.

3. Results

A total of 785 comments were analysed from 211 women on seven Internet forums. Important psychological suffering with anxiety and emotional distress was observed, which appears to be related to low knowledge of the disease.

3.1. Diagnostic delay and a syndrome that is hard to understand

The level of understanding of PCOS appeared to be low among infertile Internet users with PCOS. A delay in diagnosis was noted by many of the women. This is suggested to be the cause of having multiple consultations and switching doctors at the beginning of the search for an explanation of their problems.

Despite its frequency, the women were not aware of anyone who had PCOS, except for those with a family history of PCOS. As a result, a strong feeling of aloneness emerged from the women in the analysis. These elements suggested that PCOS was a disease not known by the general population.

The women requested explanations to understand their pathology. However, the quantity and complexity of information given during the medical consultation seemed difficult to integrate in the beginning, compounded by the multiple orders for additional tests on specific days of the cycle. Sometimes, in contrast, they felt like they had no information about the disease when they came out of the consultation.

A lack of understanding of mechanisms of the disease and the mode of action of the drugs prescribed, including metformin, hindered adherence and compliance to treatment. One of the patients' reflexes was to consult the Internet in search for additional information about their disease or the treatments. At first, they gave the impression of addressing worrying explanations that they did not fully understand and reported that those explanations were a source of fear and panic. Some comments even conveyed false information, such as the notion that PCOS could be due to an overly strong desire to have a child, that it could be due to stress, that it was a malformation, or that the disease was due to eggs sticking around the ovary after ovulation. However, in a second round, Internet users appreciated receiving further explanations about their particular cases on medical websites or from other women. They were very relieved to find people with similar experiences on the forums, which reduced their feelings of loneliness. Some of them expressed the wish to get together and to be able to meet other Internet users to interact face to face. The sharing experiences were highly appreciated, satisfying their desire for information and reducing apprehension and uncertainty (Table 1).

3.2. Psychological impact related to PCOS

The most constant symptomatology appeared to be an anxiety disorder and emotional distress. Internet users were initially stressed after the diagnosis of PCOS. This fear seemed to be linked

Table 1
Excerpts about diagnostic delay and a syndrome hard to understand (translated from French).

Categories	Example of verbatim	Number of verbatim
Diagnostic delay	"In 2005, my husband and I decided to have a child...I stopped the pill and 2 years later, still nothing. We went from physician to physician and to a general practitioner, an endocrinologist, and several gynaecologists, with the answer 'Ma'am, you are too fat!!!' Therefore, [I was] in tears after each visit...until I was sent to THE gynaecologist, who looks at me and says, 'You must have PCOS'. I had an ultrasound like 2 days later, showing 20 cysts on each ovary..."	21
Isolation feeling	"I felt alone with my husband in my misadventure, but as I read all your stories, I realized that it [PCOS] affects a lot more people than I thought."	12
Lack of understanding	"What nobody's been able to explain to me is where this dystrophy comes from"; "I went to a gynaecologist to treat an infection and she told me I had PCOS with no further explanation."	72

not only to the unknown and the lack of knowledge about this disease but also to the information they gathered during the consultation of the announcement or on the Internet, in particular, the fear of not being able to have children. They were then worried about further tests, such as pain during hysterosalpingography and the side effects of ovulation induction treatments such as clomiphene citrate. Each symptom was analysed and caused anxiety about its meaning, with the women often imagining the worst: metrorrhagia as a sign of miscarriage or ectopic pregnancy and abdominal pain as a sign of ovarian hyperstimulation. The absence of symptoms also seemed to be disturbing to them and meant in their minds that the treatment had failed. For those who were able to achieve a pregnancy, anxiety continued with the fear of miscarriage or ectopic pregnancy.

The long medical history and infertility of these women, the failure of the treatments and the miscarriages were sources of discouragement, disappointment and frustration. For some, the goal of getting pregnant became a real obsession. All of this contributed to guilt and low self-esteem associated with not being able to become pregnant. Psychological distress was very frequently found, along with sadness and crying, which went as far as the expression of suicidal ideation for one woman.

In addition to the medical consultations, the women had to undergo many tests (repeated ultrasounds and blood tests), which required a significant amount of time in their everyday lives. In addition, there was a feeling of the medicalization of their private life and a loss of intimacy. Their intimacy was affected by the scheduling of sexual intercourse, which, when combined with the stress of their medical situation, led to harmful psychological pressure (Table 2).

3.3. Difficulties experienced during the medical course

3.3.1. Difficulties specific to PCOS

The issue of weight was central among the difficulties felt by PCOS infertile women. Guilt-blaming, pessimistic, and even mocking remarks were reported, implying poor involvement of women in their weight loss process. This sort of phrasing was very badly experienced by the women, who felt very stressed and even more discouraged after the medical consultations. In addition, the medical history of these women, who were given different medical opinions, often resulted in questioning the physician's assessment. Even the truthfulness of the diagnosis of PCOS was doubted because of previous diagnostic uncertainty. All these elements seemed to contribute to a real division between some physicians and women. The physician had to be supportive, reassuring, confident and optimistic. These points, normally obvious, did not seem to correspond

to the experiences of these women, pointing to possible areas for improvement in the relationships between some physicians and women with PCOS.

Additional tests must be performed at the beginning of the menstrual cycle. A major problem then appeared that was not always anticipated by the physicians: women with PCOS most often have oligo-anovulation and therefore amenorrhea or spaniomenorrhea. Several months often passed before these tests were administered if no treatment was given to induce periods.

The proposal of a care strategy explaining the different successive steps of the treatment that could be used allowed them to project themselves and to have a life plan. Active participation motivated these women. The main issues in which they could become involved were diet, lifestyle, and weight loss for those who were overweight. Empowering them on the success of treatment improved their involvement and decreased their feelings of passivity and expectation (Table 3).

3.3.2. Bad experiences of infertility not specific to women with PCOS

"Waiting" was the main burden. Infertile women began waiting for a spontaneous pregnancy. When they decided to seek help, they often faced long delays in appointments, up to several months. Once the disease was finally diagnosed, the right treatment was put in place, menstruation and ovulation resumed, and a new wait began with the hope of a positive pregnancy test. Every day was experienced as endless.

Most of the time, Internet users were deep into the feeling of uncertainty. It was impossible for them to project themselves into the years to come, or even into the next months. The interpretation of their symptoms was difficult because of the similarity of the signs of pregnancy with the side effects of ovulation induction treatments.

Women needed support and encouragement. Their partners were often less stressed, able to step back and able to be more positive and optimistic, which could have a reassuring effect. Conversely, some women suffered from their husband's lack of involvement and felt that he did not adhere to the care plan, which increased their doubts and anxiety. In addition to the feeling of misunderstanding by their relatives, the same women had great difficulty expressing themselves towards their family, most of whom were not aware of their pathology.

They were also seeking reinsurance on the forums. Messages of encouragement and positive testimonies from other women on the web seemed to have a motivating and stimulating effect, providing hope and comfort (Table 4).

Table 2
Excerpts about psychological impact related to PCOS (translated from French).

Categories	Example of verbatim	Number of verbatim
Anxiety disorder	"It's scary I know, I was on the lookout for these pains, [...] in case of ectopic pregnancy or miscarriage[...] but it's normal, it's ligament pain. However, dear, it's only the beginning, the time seems long and frightening, you see, that's what I was talking about, that we think that once we have our+++ we will be relieved, but NOT at all! Because afterwards it's the anguish of "what if it doesn't hold". [...] I'm refraining from going to the emergency room on the pretext of pain so I can get an ultrasound"; "So I'm a little scared to gain weight with all these treatments... The life with PCOS is not fun, but you have to deal with it..."	92
Emotional distress	"For me, PCOS eats my life away"; "I always try to hope, but it's hard...I'm severely depressed"	193
Privacy implications	"It is a real obstacle course, there are still exams to be passed [...], and papers, and an unfailing availability for both of us"; "PCOS and its symptoms, weight gain, moods, then the infernal spiral of doctors, medically-assisted procreation, treatments..."	89

Table 3
Excerpts about difficulties specific to PCOS (translated from French).

Categories	Example of verbatim	Number of verbatim
Weight issue	"One day, one of the 5 gynaecologists I met told me that if I did not lose at least 30 kg (66 pounds) I would not be able to have a child" "And then they came up with this sentence that makes me so angry: Lose weight!"	29
Questioning physician's assessment	"She told me that I have PCOS despite my periods being regular, I want your opinion"	50
Menstrual cycle adjustment	"I had nothing [no period] for 9 months and they came back only because I was given Duphaston [dydrogestrone], otherwise I might still be waiting. They like to torture us"	11
Women involvement	"And in the meantime I give all I can about healthy living and sport because it is all I can do"	3

Table 4
Excerpts about difficulties about infertility not specific to PCOS (translated from French).

Categories	Example of verbatim	Number of verbatim
Expectation and uncertainty	"PCOS is a mess, you never know if it worked or not. Furthermore, with the treatments we have, the side effects cast doubt on us... In short, it is a puzzle."	170
Family support	"My wonderful husband supported me and cheered me up."	32
Difficulty to express	"My mother-in-law who would like too much to be grandmother but I do not know how to tell her it is too hard"	19
Internet forum support	"You are in the right place to come and talk about your problems, your feelings, we are all here to support each other and it feels good. For my part, I was lucky that the treatments worked but I stay on the forum to support you and to tell you the rest, because for those who know me, they have been there for me from the beginning"	115

4. Discussion

We observed a strong psychological impact among PCOS infertile women who share their experience in discussion forums. We pointed out their difficulty in understanding what PCOS is.

First, there could be a bias regarding certain inclusion criteria: the self-reported nature of the diagnosis of PCOS and the criterion of infertility reported by women, which is subjective.

The difficulty in interpreting the comments was the presence of many common features to infertile women and PCOS women. One limitation of this study is related to the specificity of the PCOS population among infertile women and to potential significant bias induced by our methodology. We relied on a qualitative approach, considering here that improved understanding of complex issues is more important than generalizability of results [18]. The women consulting the Internet forums are probably unconvinced by their management and are possibly the ones who understand the least of the medical information received by their physician regarding

PCOS. For these reasons, they may not be representative of the general population. However, we believe that these women who need to share their self-experience in Internet forums deserve to be considered.

4.1. Interest of online communities in chronic pathologies

The French population conducting health research on the web is mainly composed of middle-aged women. The majority of women who expressed themselves on the PCOS forums were the most often unsatisfied or anxious, which constitutes a selection bias. In a study of populations conducting medical research on the Internet, Renahy et al. reported that patients were not satisfied with medical consultations due to a lack of explanations for 75% of them and a lack of listening for 65% of them. Patients' recourse is therefore to obtain medical information via the Internet. However, the reliability of the information retrieved is highly variable, and patients often have difficulty selecting relevant sources [15]. Forums are a way to

gather and share experience that could increase the understanding of pathology, including women with PCOS [19]. However, the answers to the questions that Internet users ask each other were not always accurate, constituting a limitation to the improvement in knowledge. First, the Internet could be a source of anxiety regarding the information found [16]. Nevertheless, appropriation of their illness benefited from the use of the Internet, where they could learn passively, by reading information, and actively, by interacting in online communities. Knowledge and understanding of PCOS appeared to decrease women's anxiety, increase their involvement and compliance, and thus improve their quality of life [20]. On the other hand, PCOS has never been the subject of national information campaigns in France, suggesting that this disease is poorly known by the general public, even though the cardiovascular morbidity of PCOS is a real public health issue [21].

4.2. Listening and acknowledging difficulties

More than one-third of women with PCOS are reported to have a depressive syndrome, with a five-fold increase in the risk of depression in obese women compared to those of normal weight [22,23]. Infertility alone is also a cause of suffering and stress for the individual and the couple, with a significant increase in the prevalence of depressive syndrome compared to fertile women [9,24]. PCOS women also suffer physically from a poor body image linked to the consequences of the disease, such as hirsutism and overweight. These two aspects have been taken into consideration, and an assessment of the psychological state is systematically recommended for women with PCOS [25–27]. Despite this, a study by Ellis et al. showed that psychological assessment was not carried out in practice, in contrast to the screening for somatic pathologies such as diabetes and high blood pressure in the follow-up [11]. Comprehensive psychological therapies have shown good results on psyche and procreation, suggesting the importance of improving psychological well-being in the success of the pregnancy project [28].

Two studies analysed the link between psychological support and Internet forums. The first study examined the social support provided by online communities to Japanese mothers for child-care. Miyata et al. showed that mothers who actively participated in forums received more support, with an increase in self-esteem and a decrease in the risk of depression with short- and long-term benefits on their social relationships in real life [12]. Sharf et al. examined an online community of women with breast cancer. They showed that the information exchanged enabled women to make more informed decisions and provided a support network that was available at any time and from any place, unlike medical consultations [13,29].

The qualitative method does not allow comparison between two populations. However, it might be interesting to explore forum users with another cause of infertility or PCOS women with or without the variable "forum user".

4.3. Diagnostic difficulties and heterogeneity of medical practices

Initial diagnostic wandering regarding PCOS is a major concern in the experience of women with PCOS. Gaps exist in this area, as we observed in the analysis of the comments. In an online survey of 1385 women with PCOS, Gibson–Helm et al. examined their satisfaction with the information received at diagnosis and their concerns at the time of the survey. They showed similar results, highlighting a diagnostic delay and an inadequacy of the information given about PCOS reported by women. In particular, more than a third of the women interviewed reported a delay of more than two years, and at least three health professionals consulted before the diagnosis of PCOS was established [30]. A retrospective study

conducted by March et al. was looking for criteria of PCOS through interrogation, clinical examination and further tests in 728 women from the general population, aged from 27 to 34 years. They showed that, according to the Rotterdam criteria, 68% of women with PCOS were undiagnosed [31]. The results of this study are probably consistent but should be interpreted with caution because of the small size and its monocentric nature. If the diagnosis of PCOS is not made despite a medical complaint attributable to the disease (hirsutism, cycle disorders, infertility), it seems legitimate to question the lack of sufficient medical training on this pathology in France, as was found in the United States by Hoyos et al. and Chemerinski et al. [32,33].

The international consensus on the diagnosis and management of PCOS, published in 2018, should be better known and widely disseminated among health professionals, particularly general practitioners, who should be the central element in the management of women with PCOS [25–27]. All health professionals should be aware of the impact of PCOS on sex life, body image and relationships. Moreover, they have the mission to inform the women that the metabolic syndrome will not disappear, resulting in difficulty losing weight despite their efforts, and prepare them for a potential delay in getting pregnant. Better knowledge of this consensus would make it possible to homogenize practices and correct the divergence factor between physicians, which is a source of anxiety and confusion for patients [34].

5. Conclusion

Infertile women with PCOS who consult Internet forums appear to suffer from low understanding of the disease, affecting their quality of life. The medical information provided to these women is perceived as inadequate or insufficient. Moreover, anxiety and psychological distress, which are very common in women with PCOS, are frequently omitted by health practitioners, despite recent recommendations for their systematic research. The use of discussion forums appears to be beneficial, representing a source of support and experiential knowledge sharing.

Disclosure of interest

The authors declare that they have no competing interest.

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