

Experiences of PCOS diagnosis in a cohort of Polish women from the Pomeranian region: A questionnaire-based cross-sectional study

Edyta Dutkiewicz¹, Dominik Rachoń^{1*}, Helena Teede^{2,3} and Melanie Gibson-Helm²

¹Department of Clinical and Experimental Endocrinology, Medical University of Gdańsk, Dębinki 7, 80-211 Gdańsk, Poland

²Monash Centre for Health Research and Implementation, School of Public Health and Preventive Medicine, Monash University, Clayton, Victoria 3168, Australia

³Monash Partners Academic Health Research Translation Centre, Clayton, Victoria 3168, Australia

Abstract

Background: The challenges of living with PCOS may be exacerbated by a long and problematic process of diagnosis or a lack of evidence-based, personally relevant information. Therefore, the aim of our study was to evaluate the time to diagnosis, the number of health professionals seen, and patients' information needs in a cohort of women with PCOS.

Methods: A validated questionnaire was distributed via e-mail to 220 Polish women diagnosed with PCOS.

Results: In total 100 women completed the questionnaire. Among almost 40% of the respondents the process of diagnosis lasted more than 24 months and 50% of cases required seeing more than three health care professionals. Almost 65% of women pointed to the need for information on PCOS in the form of treatment standards and educational materials (16%). Only 5 % of the respondents reported the need for a web page devoted to PCOS. Women were also asked about the burden of PCOS symptoms. More than 40% of the respondents highlighted weight gain (42%) and inability to lose weight (41%) as the most problematic. Fertility problems, depression, and mood swings as well as hirsutism were noted by 36%, 34% and 33% of the respondents, respectively. Skin problems and acne were the least problematic (only for 26% of the respondents).

Conclusions: These results suggest that the process of PCOS diagnosis is prolonged, requires seeing multiple health professionals and is not supported by reliable information and resources on long-term complications and therapeutic options.

Introduction

Polycystic ovary syndrome (PCOS) in recent years has gained a lot of attention not only due to its high prevalence (8-13%) [1] and its unfavourable reproductive and metabolic consequences [2], but also due to the negative impact on psychological health [3]. Features of PCOS that may affect psychological health include the chronic nature of the condition, fertility problems, overweight or obesity, hirsutism, and acne [4]. The challenges of living with PCOS may be further exacerbated by a long and problematic process of diagnosis or a lack of evidence-based, personally relevant information [5]. A preliminary study [6] involving a sample of 210 women in Australia diagnosed with PCOS showed that the journey to obtaining a PCOS diagnosis can be lengthy, involve many health professionals and leave considerable unmet information needs. This research was then extended to over 1000 women in North America and Europe generally, with similarly concerning findings [7]. To address these needs, the international evidence-based guideline on PCOS was developed [4]. Alongside the guideline, a broad array of translation resources was developed for women and healthcare providers [8].

However, these previous studies were conducted with English-speaking women only; the experiences of non-English speaking women are vastly under-represented in the research literature. We hypothesise that the information needs of non-English speaking women may also be even greater, as most of the evidence-based information about PCOS for women has only been available in English. Thus, together with

the authors of these former studies we decided to conduct a similar study among women from the Pomeranian region of Poland. We also sought to establish the gaps that can be addressed by co- designed and translated resources.

Therefore, the main goal of this study was to investigate 'PCOS diagnosis experiences', women's concerns (including about the name of the condition) and their information needs.

Materials and methods

Study design, setting, and participants

Patients were recruited by a specialist in internal medicine and endocrinology (D.R.) from two outpatient endocrinological practices based in the Pomeranian region of Poland (one in Gdańsk and other in Gdynia). Eligibility criteria included: age 18-45 years, a prior medical diagnosis of PCOS according to the AE&PCOS criteria, which include

***Correspondence to:** Dominik Rachoń, Head of the Department of Clinical and Experimental Endocrinology, Medical University of Gdańsk, Dębinki 7, Gdańsk, Poland, Tel: +48 604 895 009; E-mail: dominik.rachon@gumed.edu.pl

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the presence of clinical or biochemical hyperandrogenism and ovarian dysfunction defined as anovulation or oligomenorrhea or/and the presence of polycystic ovary morphology (PCOM) on transvaginal ultrasound (TV USG) [9]. Exclusion criteria included current pregnancy or diagnosis of a psychiatric illness other than depression or anxiety. An e-mail with a link to a web-based questionnaire (created using the SurveyMonkey web site) was sent during the period of December 2018 and January 2019 to 220 women. Participation was voluntary and the completion of the survey was taken as consent. The study was approved by the Bioethics Committee of the Medical University of Gdańsk (permission nr NKBBN/412/2018).

Statistical analyses

The questionnaire, which was developed with input from women with PCOS and a multidisciplinary advisory group in Australia and piloted by [6] and used in a large sample of women in Europe (7), was adapted and translated into Polish language (by E.D. and D.R.). It included questions on the 'PCOS diagnosis experience', information provided at diagnosis, current concerns about PCOS features, support needs and women's perceptions related to the syndrome's name (Supporting Information Appendix S1). All the calculations were performed using the Microsoft Excel programme for Mac OS. Categorical data are presented as count and proportions and continuous data as mean \pm standard deviation (SD).

Results

Overall, 105 women responded to the questionnaire (response rate 48 %), however 5 responses were incomplete leaving 100 responses for evaluation. Mean age of the respondents was 27 ± 5 years (min-max: 18 – 42 years) and mean BMI 25.4 (min-max: 15.8 – 45.4). Eighteen per cent of the respondents were overweight (BMI 25-29.9) and 24% were obese (BMI >30). Fifty-five per cent had a healthy body weight (BMI 18.5-24.9). Thirty-nine per cent of the respondents reported that the process of obtaining the final PCOS diagnosis lasted more than 24 months. In only 36% of the cases, it lasted less than 6 months. More than one-third (34%) of the respondents also reported that before obtaining the final PCOS diagnosis they had visited three or four health care professionals and 16% had visited more than five. Overall, only 50% of PCOS cases were diagnosed after seeing one or two specialists. Only 46% of the respondents were satisfied with the diagnosis experience and only 42% were satisfied with the information obtained on the possible therapeutic options such as lifestyle change (diet and physical activity) and pharmacotherapy. Only one-fourth (26%) of the respondents were satisfied with the information related to the long-term consequences of PCOS and only 29% were satisfied with the emotional support provided by the diagnosing physician. The characteristics of the "PCOS diagnosis experience" in our cohort are presented in table 1.

When asked about how women with PCOS could be better supported, almost 65 % of women pointed to the need for more information on PCOS and its consequences in the form of treatment standards and educational materials (16%). Only 5% of the respondents reported the need for a web page devoted to PCOS.

Women were also asked about the burden of PCOS symptoms. More than 40% of the respondents highlighted weight gain (42%) and difficulty losing weight (41%) as the most problematic symptoms. Fertility problems, depression, and mood swings as well as hirsutism were noted by 36%, 34% and 33% of the respondents, respectively. Skin problems and acne were the least problematic (only for 26 % of the respondents) (Figure 1).

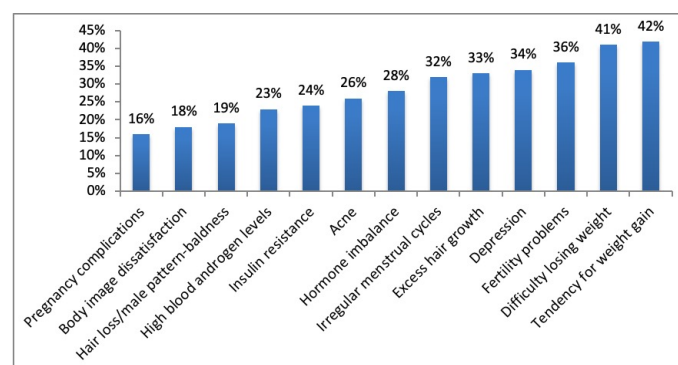


Figure 1. The most problematic clinical features of PCOS in the study cohort (n=100)

Table 1. "PCOS diagnosis experience" among women from the Pomeranian region of Poland (n=100)

	N=100
Time until diagnosis	
Within 6 months	36%
Between 6 and 12 months	14%
Between 12 and 24 months	11%
More than 24 months	39%
Number of health professionals seen before diagnosis	
1–2	44%
3–4	34%
≥ 5	16%
Satisfaction with manner of diagnosis	
Dissatisfied	38%
Neither satisfied nor dissatisfied	16%
Satisfied	46%
Satisfaction with information given about medical therapy	
Dissatisfied or indifferent	58%
Satisfied	42%
Satisfaction with information given about lifestyle management	
Dissatisfied or indifferent	58%
Satisfied	42%
Satisfaction with information about long-term complication	
Dissatisfied or indifferent	74%
Satisfied	26%
Satisfaction with emotional support and counselling after diagnosis	
Dissatisfied or indifferent	71%
Satisfied	29%
Satisfaction with information given about lifestyle management	
Dissatisfied or indifferent	58%
Satisfied	42%
Satisfaction with information about long-term complication	
Dissatisfied or indifferent	74%
Satisfied	26%
Satisfaction with emotional support and counselling after diagnosis	
Dissatisfied or indifferent	71%
Satisfied	29%

Discussion and conclusion

This study evaluated PCOS diagnosis experiences in a cohort of Polish women from the Pomeranian region. In a study conducted by Deeks et al. [10], a prolonged process of PCOS diagnosis was associated

with poor psychological functioning and depression. This has the potential to negatively impact the motivation to life-style change, which is an important aspect of non-pharmacological treatment of women with this syndrome [4]. Both our and the data from Australia, confirm the need to provide women with PCOS with information on current treatment standards and educational materials at the time of diagnosis [11]. To our knowledge this is the first study conducted among Polish women, which evaluated diagnosis experiences in women with PCOS and contributes important knowledge about the needs of non-English speaking women.

Our results are consistent with previous research suggesting that a considerable number of women with PCOS experience delays in obtaining a diagnosis and visit multiple healthcare providers of different specialities [7]. Similar to our cohort, approximately one-third of women with PCOS in North America and Europe reported the time to diagnosis to be more than 24 months and more than 10% of women reported seeing more than 5 health professionals before the final diagnosis was made. Nevertheless, the proportion of women satisfied with their diagnosis experience or with the information received is higher in our study than in previous research [7]. A possible explanation for this is that women were recruited from two outpatient endocrinological practices by the same specialist (D.R.) for this study, whereas the previous international study recruited women from the community. Even so, considerable unmet need is still indicated as less than half the women in this study were satisfied with their diagnosis experience, and satisfaction with information was as low as 26 %. Specifically, we hypothesise that these findings indicate a need for improved resources for healthcare providers in order to accelerate the diagnosis of PCOS. Also, in our study more than 60 % of the respondents reported the need for more information on the current treatment recommendations in the form of educational materials (leaflets 15 %) but surprisingly only 5 % wanted a specific website. This contrasts with data from other studies, which report that women with PCOS obtain a great deal of their information from the internet [11]. Nevertheless, women recognise and can be overwhelmed by the varying quality of information available on the internet [12-15]. Although there is freely available, reliable and evidence based online information prepared by professional Australian, North American and European societies, a recent assessment found that some such information may only be appropriate for women with high levels of English and/or health literacy [16]. The authors concluded there is a lack of easy-to-read evidence-based information online about PCOS for women. Online information specifically about lifestyle management for PCOS has also found to be limited, and of suboptimal accuracy, specificity, and applicability [16,17]. We hypothesise that women in our study may anticipate that web-based information may not be accessible enough to meet their needs. In this context, a translation and dissemination program accompanying the international evidence-based guidelines co-designed an extensive range of resources with and for women and health professionals including the “AskPCOS” mobile application and the PCOS Question Prompt List [8,18,19]. These resources are now used in over 170 countries and efforts are underway to make them available in languages other than English. Availability of such material in a wide range of languages and formats could accelerate the diagnosis and treatment of women with this syndrome, improve quality of life, and support engagement with lifestyle management [4,20,21].

Our questionnaire also asked about the emotional support given by the health care providers during the process of diagnosis. Our results showed that only one third of the respondents were satisfied with this

kind of support at the time of the PCOS diagnosis, although this is considerably greater than previous reports (29% vs. 3%, $p < 0.001$) [7]. Previous studies reported that a perceived lack of empathy from PCOS healthcare providers can lead to a lack of trust in the information, treatment or recommendations subsequently provided [13,14,22,23]. There is some evidence that support groups can meet some of the socio-emotional needs of women [22,23]. Another reason not to underestimate the importance of support for emotional wellbeing is that women with PCOS are at an increased risk of experiencing anxiety and depression. For all these reasons, assessment of emotional wellbeing and provision of appropriate referral or treatment is recommended.

The survey also evaluated the burden of PCOS symptoms [4] and the findings provide guidance for healthcare providers about topics to discuss with their patients. The respondents were asked to point out the four most bothersome symptoms related to the PCOS. Although only one quarter of our respondents were obese (BMI > 30), 40% of them noted obesity and weight gain as of great concern, indicating that women want to discuss weight gain prevention strategies with their healthcare providers. Data from other studies show that obesity and weight loss problems are a strong negative correlate of quality of life [21,24,25]. These results also align with the international Guideline recommendations and underline the need for comprehensive life-style change counselling by health care professionals in this patient's setting [4]. One third of the respondents pointed to fertility problems, lowered mood or depression, and hirsutism as the most bothersome symptoms. Previous research has also identified infertility as an important concern for women [7] and is one the most well recognised features of the condition. Depression was also nominated as a key concern and past research has identified it as a topic that women find difficult to talk to healthcare providers about [18]. PCOS is also characterised by clinical signs of hyperandrogenism such as hirsutism, acne and androgenic alopecia [26] and approximately one quarter to one third of surveyed women identified them as key concerns. Data from several studies show that these symptoms also have a negative impact on mood and quality of life [21]. In a meta-analysis conducted by [27] hirsutism and menstrual disturbances were also the strongest correlates of low quality of life in women with PCOS. Information is available to support both women and their health professionals in these areas (<https://www.monash.edu/medicine/sphpm/mchri/pcos/resources>) but detailed information for women from non-English speaking countries may still be lacking. Limitations of our study include potential selection bias as all respondents were from two outpatient endocrinological practices based in the Pomeranian region of Poland, and therefore might not represent the general Polish population of women with PCOS. Despite this limitation, to our knowledge, this is a first study to evaluate PCOS diagnosis experiences among Polish women.

In conclusion, the results of our study confirm that the process of PCOS diagnosis is prolonged, involves several different specialists and involves limited reliable information provision on long term complications and therapeutic options. This points to the necessity to translate and disseminate the already available evidence-based resources on PCOS in non-English speaking countries.

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