The influence of polycystic ovary syndrome on patient quality of life

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Abstract
Polycystic ovary syndrome (PCOS), as one of the most frequent endocrine disorder in adolescent and young female has an important influence on patients quality of life (QoL). We checked the literature, recent research available in the internet to systematically evaluate, what symptoms affect QoL mostly and how patients report their self esteem. We also screened, what symptoms cause mental problems, such as depression and elevated anxiety level. Comparing to a number of patients suffering from PCOS, there are little publications showing statistically important correlations between symptoms of this endocrine disorder and particular aspects of women’s QoL. Even if there is research, it commonly embraces small number of patients and is difficult to make general conclusions. The topic definitely requires further interest.

Key words: polycystic ovary syndrome (PCOS), Quality of Life (QoL)

Introduction
Polycystic ovary syndrome (PCOS) is one of the most frequent endocrine disorders which affects premenopausal women [1]. The prevalence is about 4-15%, depending on the criteria used [2, 3]. The U.S. National Institute of Health (NIH) estimates the prevalence to range from 6 to 10% [4]. Typical symptoms of PCOS are irregular menstrual cycle and anovulation resulting in subfertility or infertility. An increased serum level of androgen, which manifests itself as hirsutism, acne or androgenic alopecia, is another symptom of PCOS. Hirsutism, which can be found in 70% of patients, is the most frequent of all symptoms. Therefore, it needs to be carefully evaluated [4]. There is also a group of metabolic symptoms, all related to insulin resistance [5, 6]. Recent research shows that approximately 50% of PCOS patients are overweight or obese [14], have a higher risk of type 2 diabetes mellitus, cardiovascular diseases (including hypertension) and dyslipidemia [7-11]. There is also evidence of elevated endometrial cancer risk in these women [7, 9].

As PCOS is a chronic disease, it is very important for it to be well-classified. The Rotterdam diagnostic criteria were developed in 2003 to help the clinicians in giving a proper and accurate diagnosis of PCOS [11]. According to this criteria, a PCOS patient has to present at least two out of three of the symptoms at the diagnosis: 1) oligoovulation or anovulation; 2) clinical and/or biochemical signs of hyperandrogenism; and 3) polycystic ovaries in ultrasonography. Furthermore, presence of other endocrine disorders must be excluded (e.g. Cushing syndrome). In 2008, new criteria have been proposed by the Androgen Excess and PCOS Society [12]. These suggest that more accurate definitions are required by focusing on only two criteria: 1) hyperandrogenism (clinical hirsutism or biochemical elevated androgens levels in serum, or both); and 2) ovarian dysfunction (oligoovulation/anovulation, or polycystic ovaries, or both).

Quality of life
A proper and accurate diagnosis is now becoming more and more significant because of PCOS’s impact on patient treatment, condition and quality of life (QoL) [13]. There is no doubt that presence of a chronic disease has a great influence on one’s life, self-esteem, his or her emotions and activity. Health Related Quality of Life (HR QoL) is a multidimensional concept used to describe physical, emotional and social functioning of patients suffering from particular diseases or with specific dysfunctions [15]. There has already been a lot of research endeavoring to find a proper way of describing and measuring HR QoL. The well-known and frequently used SF36 questionnaire consists of 36 questions which, when answered, give an eight- scale profile of scores, along with summary physical and mental measures [16]. SF36 questionnaire is one of the most acknowledged and most frequently used tools to measure QoL. SF 36
is used in all types of patient and validated for many countries. Some attempts to find a more accurate and more specific questionnaire for PCOS patients have already been carried out. However, these are only employed infrequently as they are difficult to depend on. It finally shows five factors: emotional disturbances, hirsutism, weight difficulties, infertility and menstrual difficulties. Jones et al. [17] found the last factor, menstrual difficulties, consists of two aspects: menstrual predictability and menstrual symptoms. The literature studied showed an interest in PCOSQ evaluation. Cronin et al. [18] measured the QoL on a sample of 100 women in the USA using PCOSQ. The other authors, Guyatt et al. [18] in Canada and Jones et al. [18] in United Kingdom examined the psychometric properties of the questionnaire. It shows the importance of finding a proper and specific tool.

As many of the research haven’t shown the significant correlations on big groups of patients, scientists tried to show the correlation between an universal Body Mass Index (BMI) and QoL [19]. VAS (Visual Analogue Scale) was also used by some of the scientist, but it’s known as an not standardized with no psychometric properties, so difficult to compare between research.

PCOS patient’s specific problems

As it has been alluded above, a PCOS patient manifests a very specific set of symptoms. The disorder is usually diagnosed in young females whose personality is not fully developed [20]. Knowing the structure of one’s personality, its development and abnormalities lets clinicians treat not only biological symptoms (by prescribing hormone therapy or performing ovarian surgery), but also psychological ones. In order to better understand what can lower the QoL in PCOS women, we find it useful to divide their problems into two groups. While the first group of problems is related to current health issues, the other is linked to fear of potential deterioration in the future [19].

Factors affecting present QoL

There is a group of symptoms related to a woman’s body image and sense of femininity [21]. Just like obesity does, hirsutism, acne and alopecia have a great influence on patient body image and body satisfaction. We find a correlation between PCOS diagnosis (especially in patients with high hirsutism level and obesity), engaging in sexual activity and achieving sexual satisfaction very interesting and worth investigating in the future. One study showed the existence of statistically significantly more sexual dissatisfaction in PCOS women in comparison with the controls who suffered from other gynecological or obstetric complaints [25].

Jones et al. [22], in one of the studies on fifteen young women from two of Yorkshire out-patients clinics assumed, how female described themselves while asked about hirsutism. So they used the words “horrible”, “annoying”, “irritating” to describe the fact of having excessive hair and the word “monkey” to name themselves. McCook et al. [23] used Ferriman-Gallwey (F/G) scale to measure hirsutism. The same scale has been used by Kitzinger and Wilmott [5]. The research showed a correlation between unwanted facial hair (in patients with suspected PCOS) and elevated level of depression and anxiety [24]. Kitzinger and Wilmott showed a negative correlation between HR-QoL and F/G [5]. Surprisingly, women with isolated, not severe hirsutism (F/G around 8) presented worse QoL in some of the research) [17] than those with higher level of hirsutism in F/G, acne and BMI > 30 kg/m². It may suggest, that there is a difference in perception and body image between these two groups. Psychological deduction may also lead to hypothesis about different defense mechanism used by Ego.

Acne is one of the least developed problem affecting QoL [22].Only four out of fifteen patients named acne as a problem affecting body image and self-esteem [23].

Sense of femininity is a crucial aspect of a young woman’s developing personality. Extensive research proves the existence of an elevated level of general anxiety in PCOS patients [25]. It also specifies these as fears of loss of sexuality, loss of fertility and anxiety of not being able to have children in the future [25]. Mansson et al. [22] checked 49 women meeting the Rotterdam criteria for sexual and psychological wellbeing. 43% of the patients declared that the illness had a negative impact on their sex life. They found a correlation between sexual dissatisfaction and BMI. This group of women had BMI $31.6 \pm 7.7 \text{ kg/m}^2$, compared to $26.5 \pm 6.4 \text{ kg/m}^2$ of the other group, which hadn’t report PCOS to affect their sexual life [28].

Many scientists confirm the great meaning of obesity in PCOS patients which may trigger self-esteem problems [21]. Jones et al. (2011) found weight problems as one of the most negatively affecting HRQoL. It mostly influences social and emotional wellbeing [23]. In western culture, obesity is treated as something abnormal and negative. In adolescent communities, overweight people are often marginalized. This may cause isolation and intensify mood disorders, such as depression and
general anxiety (as listed above). What is particularly alarming, these disorders are mainly found in adolescents (i.e. 12 to 18 years) [27, 29] and young women (i.e. 18 to 25 years) [25], who are more likely to suffer from them than the control group. When isolated, PCOS patients more often present a statistically significant social phobia when compared with community controls [30].

**Anxiety of the future**

Already existing symptoms are not the only source of anxiety of PCOS women. Research shows that PCOS patients face an elevated risk of developing other diseases. Almost all of these are related to insulin resistance [14]. Obesity is what women fear most [25]. So it does affect present QoL and it causes fears about future. McCook et al. [28] found that PCOS women had significantly higher BMI (31.7 kg/m²) when compared to healthy controls (23.5 kg/m²). In given study 54% of PCOS patients were overweight and 22% were at risk of being overweight. The controls percentage were 14% and 17% [28]. It shows the frequency of weight problems and as it has proven impact on QoL – requires further investigation to find weather weight loosing may lead to QoL improvement.

When a given patient feels fine at a particular moment in time, she may feel much worse once she contacts the doctor or finds out more on elevated risk of developing other conditions in the future. In PCOS patients, perception of elevated risk has a negative impact on QoL [31]. On the other hand, it is crucial to instill accurate risk perception in patients suffering from a chronic disease, as it can motivate them to lifestyle changes and salutogenic behavior [30]. Many factors have an influence on risk perception – some of them are related to knowledge and are more objective, including immediacy of the risk (generally the earlier the consequence may appear, the higher the risk perception), severity of consequences, patient knowledge of the risk and her personal experience. There is also a group of psychosocial factors such as personality, patient emotional well-being, which affects influence and the social context [32].

**Treatment affecting the QoL**

As PCOS is a chronic disease affecting one of the most important functions of a woman, namely reproduction, it requires an intensive treatment. There are several group of aims we can establish to improve the QoL. The first group consists of additional hair reduction and acne reduction. In the case of hirsutism, the major goal is to reduce androgen production, which in fact means decreasing free testosterone fraction and its bioactivity [4]. There is a consensus that this therapy should last at least 6 months to be effective [4]. However, because it takes time from the beginning of the therapy to get visible results, it may lead to frustration. The second group of aims is battling obesity and insulin resistance, which automatically reduces the risk of type 2 diabetes mellitus and risk of cardiovascular diseases in the future. Obesity is the main target of intervention in PCOS patients. Based on questionnaires filled by the patients, women obtaining metformin therapy, or those following a diet and engaging in regular physical activity, experienced noticeable improvements in QoL [27]. Another group of actions to be taken is reinstating ovulatory cycles, which should allow a woman to get pregnant and have an offspring. When a treatment is effective and the aims are achieved, QoL should improve significantly. Unfortunately, there are patients whose casebook is really long and full of ineffective treatment. When prescribed a new therapy, patients may feel hope and make plans (like pregnancy). Disappointment usually escalates mood disorders and fears. Patients may participate in support groups where they can express their emotions and find the support they need. As it has been verified by one study, the benefits of joining such groups are significant and result in reduced isolation, increased knowledge and enabling change [33].

**Discussion and conclusions**

Systematic research about PCOS patient’s QoL showed a lack of studies involving big groups of patients. Commonly scientists checked around 100 women in each study.

Despite the fact of rather small samples in the studies, scientists mostly focus on adolescent or young women. We find it interesting and worth investigating how PCOS affects postmenopausal women. There was no study found investigating this group of patients.

In most studies, it was weight, which mostly affected HRQoL. It’s not surprising, but there are still investigations, whether PCOS patients have different control of satiety or metabolic rate than a healthy control [34]. It could than explain their problems with weight reduction it PCOS patients. The other domain which affected QoL was infertility. Surprisingly, patients with high BMI and high F/G level presented better QoL than those with moderate F/G only (X).
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The review indicates that PCOS has a negative impact on patients’ QoL. To explore the topic, more quantitative studies are required. As listed above, scientists should focus on bigger sample size to show statistical correlations. A research on postmenopausal women with PCOS diagnosis should be performed to show the general impact of the illness on life cycle. Longitudinal studies are required to show the QoL in untreated patients and potential changes of it during treatment and the resolution of the symptoms.

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