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Health-related quality of life and gender roles in adolescent girls with polycystic ovary syndrome: a systematic review

Związana ze zdrowiem jakość życia oraz role płciowe u nastoletnich dziewcząt z zespołem policystycznych jajników – przegląd metodyczny

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Key words
adolescent girls, polycystic ovary syndrome, health-related quality of life, gender role, social competences

Słowa kluczowe
nastoletnie dziewczęta, zespół policystycznych jajników, związana ze zdrowiem jakość życia, role płciowe, kompetencje społeczne

Abstract

Polycystic ovary syndrome (PCOS) is the most common endocrine disorder among women in reproductive age. It affects approximately 5% to 10% females. Signs and symptoms of PCOS include anovulation, hyperandrogenism and the presence of polycystic ovarian morphology. Recent clinical studies confirm that PCOS causes a major reduction in the quality-of-life, psychosocial well-being and sexual satisfaction. The purpose of this article was to conduct a systematic review of health-related quality of life (HRQL) in adolescent girls with PCOS. The syndrome could have a significant negative influence on multiple areas of HRQL in adolescents. Girls with PCOS have lower self-image and poorer interpersonal functioning. Weight difficulties and body perceptions have been considered as the most bothering symptoms. More cross-sectional clinical studies are needed to assess properly an impact of symptoms of PCOS upon HRQL in adolescent girls. Furthermore, it is crucial to lay down a valid and reliable instrument for assessment of quality of life of adolescent with PCOS.

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Streszczenie

Zespół policystycznych jajników (PCOS) to jedna z najczęstszych endokrynopatii u kobiet w wieku rozrodczym. Dotyczy od 5% do 10% kobiet. Do objawów związanych z PCOS zalicza się brak owulacji, hiperandrogenizm oraz policystyczną strukturę jajników. Bieżące badania kliniczne potwierdzają wpływ PCOS na redukcję jakości życia, psychospołecznego dobrostanu i satysfakcji seksualnej. Celem artykułu jest systematyczny przegląd piśmiennictwa i podsumowanie danych na temat związanej ze zdrowiem jakości życia (HRQL) u nastoletnich dziewcząt z PCOS. PCOS wywiera negatywny wpływ na wiele aspektów związanej ze zdrowiem jakości życia nastolatek. Dziewczęta z PCOS mają niższą samoocenę i gorzej funkcjonują w życiu społecznym. Do kluczowych czynników ograniczających HRQL zalicza się problemy z prawidłową masą i postrzeganiem własnego ciała. Do właściwej oceny rzeczywistego wpływu PCOS na HRQL wciąż potrzeba więcej przekrojowych badań klinicznych. Ponadto ważne jest stworzenie wiarygodnego instrumentu oceniającego związaną ze zdrowiem jakość życia u nastoletnich dziewcząt.

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Introduction

Polycystic ovary syndrome (PCOS) is one of the most common endocrinopathies among women in reproductive age [1]. The prevalence of PCOS varies according to the mode of diagnosis and is estimated to be between 5% to 10% of women [2]. Furthermore, at least 90% of women suffering from infertility due to failure of ovulation suffer from PCOS [3].

The syndrome represents wide spectrum of symptoms associated with menstrual disorders and androgen excess. The symptoms of PCOS vary with age, race, weight and represent variable degrees of severity. Common clinical findings of this disorder include irregular menses, hirsutism, acne and male pattern alopecia, as a result of hyperandrogenism, as well as polycystic ovarian morphology on ultrasound. In addition, overweight and obesity, dyslipidaemia, insulin resistance, glucose intolerance and type 2 diabetes mellitus, were more pronounced in patients with PCOS [4]. Most of the symptoms and health implications are culturally defined as unfeminine and undesirable, and have negative impact on quality of life (QoL) [5–12]. Described since 1935 by Stein and Leventhal, the definition of PCOS has undergone several revisions. Most recently, in 2009, the Androgen Excess and PCOS (AE-PCOS) Society proposed revising the definition stressing hyperandrogenism (hirsutism and/or hyperandrogenemia) and ovarian dysfunction (oligo-anovulation and/or polycystic ovaries). On the basis of Rotterdam criteria, the PCOS is divided into four phenotypes [13]:

- Frank or classic polycystic ovary PCOS (menstrual irregularity, hyperandrogenism, polycystic ovaries on ultrasonography),
- Classic non-polycystic ovary PCOS (menstrual irregularity, hyperandrogenism, normal ovaries on ultrasonography),
- Non-classic ovulatory PCOS (regular menses, hyperandrogenism, polycystic ovaries on ultrasonography),
- Non-classic mild or normoandrogenic PCOS (menstrual irregularity, normal androgens, polycystic ovaries on ultrasonography).

The variation in the symptomatology might lead to under- or over-diagnosing of this disease. The proper diagnosis in adolescents is challenging owing to the fact that physiological pubertal events can mimic the signs and symptoms of PCOS. First of all the diagnosis of PCOS in adolescent girls poses additional difficulties, so a complete evaluation is indicated. Up to date, adolescents are diagnosed with PCOS using the modified criteria for adults. Menstrual irregularity is the most common feature of PCOS and it is often the earliest clinical manifestation in the adolescent. However, this menstrual pattern can be difficult to distinguish from anovulation associated with immaturity of the hypothalamic-pituitary-ovarian axis to menstrual irregularity due to PCOS. Owing to this fact it has been suggested to postpone diagnosis at least 2 years after menarche. Besides of that some of the features of PCOS (ex. increased androgen levels and metabolic changes, insulin resistance or hyperinsulinemia) are physiological during puberty [14,15]. Furthermore, ovarian appearance and volume may be changing during adolescence and transabdominal ultrasound may be technically restricted in overweight and obese patients [16].

Recent studies [9–11] showed that adolescent girls experienced lower health related quality of life (HRQL) in comparison with their healthy peers, so accurate and early diagnosis of PCOS is necessary to prevent future health consequences, and elaborate appropriate interventions and medical therapies. The purpose of this article was to conduct a systematic review of HRQL as well as psychological morbidity in adolescent girls with PCOS. The clinical features (hirsutism, acne, androgenic alopecia, overweight/obesity) and long-term health implications of PCOS (cardiovascular disease; type 2 diabetes mellitus, infertility) may lead to decreased HRQL and psychological morbidity. Additionally, assessment of PCOS has been found to be connected with feelings of psychological distress and anxiety. Up to date, all clinical studies concluded that PCOS has a negative effect on HRQL. However, the determinant of the HRQL of women and adolescents is not fully understood.

Recently only few research studies have evaluated the relationship of PCOS to HRQL in adolescent girls. Trent et al. [9] conducted a cross-sectional study of female adolescents and compared the HRQL of 97 American girls with PCOS with 186 healthy adolescents. The study was conducted at an urban, hospital-based adolescent medicine clinical practice. The diagnosis of PCOS was based on hyperandrogenism (biochemical or clinical) and menstrual irregularity; ovarian morphology was not assessed. Participants complied the Child Health Questionnaire Version CF87 (CHQ-CF87) and a general health history questionnaire which elicited information regarding sexual activity, contraception and fertility concerns. This study

demonstrated that adolescents with PCOS have lower HRQL compared to their healthy peers. The results of the CHQ-CF87 pointed to negative influence upon HRQL in the domain of general health perceptions, physical functioning, general behaviour and family activities. Additionally, the study found significantly higher points on the change in health in the last year subscale. Most patients assessed their illness as mild, despite the finding that 69% had moderate to severe clinical severity scores. Interestingly, patient's perception of illness severity rather than clinician's assessment of PCOS corresponded more directly with HRQL.

Later analyses on the same cohorts [10] focused on fertility concerns and sexual behaviour of adolescent girls with PCOS as compared with healthy peers, and the effect of these concerns on HRQL. Adolescents with PCOS were less likely to have sexual intercourse than healthy subjects, but the mean age of sexual initiation was not significantly different between the two groups. In addition, this study demonstrated that girls with PCOS were more concerned about fertility than their peers, that caused a significant reductions in their quality of life. In comparison, a research conducted on 50 adolescents with PCOS in Singapore showed that affected girls were significantly concerned about sexual attractiveness and possible fertility disorders. Additionally, none of the participants was sexual active [17]. Trent at al. [10] study indicated that one-third of respondents did not understand the idea of PCOS and 48% "understood somewhat". Half of the participants considered a negative impact of PCOS on their lives.

Obesity affects the social assessment of human. Obese people are treated as being lazy, neglected or deprived of self-control [18]. However in the literature there are conflicting results regarding the impact of obesity on self-esteem and psychosocial functioning. Not objective obesity but a subjective evaluation of own body plays an important role. Not only weight loss, but for example the notion of psychological therapy improves self-acceptance and body image [19]. Trent et al. [11] also conducted study testing body mass index (BMI) as a mediator of HRQL in adolescent girls (using bivariate analyses and multivariate linear regression models). The results showed that elevated BMI redounded to lower QoL between PCOS adolescents and control group, particularly on the domains of general health perceptions, physical functioning and family activities. Additionally, the mean BMI of adolescent girls with PCOS was significantly, 8.2 points, higher than of their healthy age-matched controls. Furthermore, when BMI was added to the multivariate linear regression models, the regression coefficients were reduced on average by 3 points and became non-significant, thus, demonstrating that BMI can be a primary mediator in the relationship between PCOS and HRQL reduction. Nonetheless, the results of the studies conducted on adult females do not suggest such relation.

Similarly, Zachurzok et al. [20] carried out a pilot study assessing social abilities and gender roles in a group of 28 Polish adolescent girls with PCOS. They were compared with 12 healthy peers to evaluate the correlation between clinical and hormonal features of PCOS with psychological development and general wellbeing. Participants were recruited from the Department of Paediatrics and Paediatric Endocrinology of the Medical University of Silesia. Psychological measures included two questionnaires: social competence inventory (SCI) and psychological gender inventory (PGI). The SCI is a self-report questionnaire developed by Matczak [21] to measure competences in three aspects: Intimacy, Self Presentation and Assertiveness. The PGI is also a self-report questionnaire developed by Kuczynska [22] and consist of 35 attributes assessing sex-typical behaviour. The results suggested that social abilities and sex-typical behaviours did not seem to be disturbed in the study group. Additionally, there was no significant correlation between the clinical severity of symptoms and SCI or PGI scores. Interestingly, the authors observed a negative correlation between SCI and Assertiveness Score and testosterone level.

Jones et al. [23] also conducted a research to assess the various effects of the PCOS on the physical, social, and psychological/emotional aspects of the lives on a group of 15 adolescents. The study concluded that PCOS has a negative influence on QoL. Weight concerns, acne, hirsutism, infertility, and menstrual disorders have been identified as the major causes of emotional and social functioning. The symptomatic profile of PCOS negatively affected self-perception and confidence in social situations. On the other hand, in the same study, the majority of participants revealed that PCOS has not affected their personal relationships and their sexual intercourse. Additionally, most participants had a very basic cognisance of the illness.

Guidi et al. [24] provided a cross-sectional study to evaluate the psychosocial correlation of PCOS and other hyperandrogenic states in adoles-

cents and young females. The psychosocial implications of PCOS were assessed in a group of high school female students, aged 16–19 years. Psychological distress, level of stress, well-being, illness behaviour and QoL were examined. Sociopsychological condition was measured by the Symptoms Questionnaire, the Psychosocial Index and the Psychological Well-Being scales. The results of this research indicated that adolescents and young women with isolated clinical hyperandrogenism had significantly higher levels of psychological distress and reduced well-being and QoL in comparison to their healthy counterparts. Furthermore, a significantly higher level of hostility/irritability in a group of PCOS adolescents was noted.

The most of PCOS studies concentrated on biomedical aspects, overlooking psychosocial and emotional aspects of this disease. The impact of hyperandrogenism on female psychosocial and psychosexual behaviour is still poorly understood. The pilot study conducted by Manlove et al. [25] assessed differences in sex-typed behaviour and gender conformity in PCOS women. Based on potential perinatal androgen influence on programming a PCOS phenotype and sex differentiation, authors evaluated a variety of sex-typed outcomes (including choices in child play, gender identity, gender role and sexual orientation) among PCOS women in comparison with controls. PCOS group retrospectively recalled less feminine childhood behaviour compared with non-PCOS women. Unexpectedly adolescent behaviour did not significantly differ between PCOS group and controls. However PCOS women had higher prevalence of bisexuality and changes in sexual orientation and also lower happiness. The PCOS adolescent reported also lower self-esteem and less social interactions with their peers. These results aroused from combination of psychosocial concerns and perceiving oneself as "different", rather than, as might have been expected, of behavioural masculinisation. Interestingly, among adults, the scores on Bem's androgeny scale did not differentiate PCOS women from controls. This lack of distinctiveness in masculinity and feminity in adolescents and adult women with PCOS came from several factors. Inter alia some biochemical and endocrine disruptions may manifested after puberty and can be connected with the duration of the disease that is why not present at adolescence. On the other hand, adults can be more prone to cultural and societal norms of acceptable feminine behaviour not presenting masculine type of behaviour.

Similar study assessing influence of PCOS and concomitant hirsutism on psychological gender, was conducted by Kowalczyk et al. [26]. Authors did not find differences between the PCOS women and control group in terms of age, height, weight, BMI, marital status or education level. However, women with PCOS over 31 years of age were more often (however insignificantly) in the "sexually undifferentiated" group in comparison with controls, less likely to identify themselves witch a gender scheme and more likely to see themselves androgynous. Interestingly, these differences were not observed in the younger PCOS women group. The difference between the younger PCOS women and older PCOS group can arise from time of duration and severity of PCOS symptoms, which often increases with age. Another possible explanation of these results may be the incompletely formed social roles of teenagers because adults are more culturally shaped and more often undertake stereotypical roles connected with gender. Contemporary literature increasingly emphasizes the positive importance of androgenic type, which is a combination of the characteristics of male and female and facilitates social functioning. Modern women are expected to take many roles simultaneously, including roles stereotypically female and male. So reduced important of gender differences, emphasizing the adaptive function of male characteristics in woman, could be considered to be desirable nowadays [27,28]. Girls with PCOS in childhood more often than their peers behave less feminine and so are called tomboys [26].

Further study assessing identity and gender roles of women with PCOS was carried out by Fatemeh Nasiri Amiri et al. [29] on group of 23 Iranian women diagnosed with PCOS based on Rotterdam criteria. Each participant described their individual perception of PCOS and its influence on QoF and gender-related roles. The physical features of PCOS, especially obesity and hyperandrogenism leading to hirsutism, acne, androgenic alopecia, resulted in low self-esteem and low self–perceived physical attractiveness. The consecutive experience of PCOS women was sense of loss of womanhood and feeling more masculine. The majority of participants were not satisfied with their sexual life and marital relations, additionally most of them experienced fear about possible problems with fertility. Changes in the aesthetical aspects of PCOS women's bodies and imbalance in sex hormones negatively impact on HRQL and also limit their personal and social life.

All of the mentioned researches confirmed the negative association between PCOS and HRQL. Lower self-esteem and body satisfaction, psychological stress and PCOS diagnosis have been shown to be intimately related.

Conclusions

PCOS is a complex, chronic condition which has a strong impact on the physical as well as mental health of affected women. This condition has clinical implications across the lifespan including increased risk of insulin resistance, type 2 diabetes mellitus, obesity, hypertension, dyslipidaemia and cardiovascular disease. Additionally, PCOS results in the higher prevalence of depression and anxiety, sexual disabilities, marital and social maladjustment. Recent studies confirmed relationship between PCOS and sexual dissatisfaction, depression, anxiety, bodily pain, altered self-esteem and poorer interpersonal functioning [5,9,11,23,24,30]. Furthermore if the depression was present it tended to be more severe in PCOS group and was associated with testosterone level [6]. Hirsutism, irregular menses and infertility concerns were identified as the most distressing symptoms in female adults with PCOS [30]. Previous research has also indicated that weight difficulties were significant contributory factor that reduced the QoL [6,9,10,11]. Coffey et al. [12] conducted the study comparing HRQL between women with PCOS and patients with other medical disorder. PCOS women's HRQL was comparable to those of with asthma, epilepsy, diabetes mellitus and back pain [12].

The results of this systematic review showed that multiple areas of HRQoL are affected by PCOS, but weight and infertility issues appear most problematic. However, more complimentary and quantitative studies are needed to assess the HRQL of adolescents with PCOS. The most common limitations are the small number of participants in the study groups and in the controls. Additionally, it has been suggested that a generic and disease-specific instrument to measure HRQL in adolescent group should be applied. Currently only the polycystic ovary syndrome health-related QoL questionnaire (PCOSQ) is suggested to be an appropriate instrument to measure HRQL in adult females [7,31].

Other problem is the absence of clear-cut diagnostic criteria for adolescent patients. Some signs and symptoms of PCOS can overlap characteristics of normal puberty [14–16]. Therefore, some authors proposed different and stricter criteria for adolescent girls with PCOS than applied to their adult counterparts [32,33]. Over-diagnosis of PCOS among adolescent girls may result an unnecessary treatment and psychological burden.

In conclusion, more cross-sectional studies are needed for proper assessment of the impact of symptoms of PCOS upon HRQL in adolescent girls. Better understanding of HRQL in PCOS adolescents may provide a more appropriate management, effective treatment and apposite supportive intervention. The presence of clinical and biochemical disturbances of PCOS might have an influence on sociopsychological condition, social abilities and psychological development. Therefore, proper and early diagnosis of PCOS is necessary to prevent future health complications and psychological disturbances. The congruent HRQL measurement not only allows for comprehension but also for the appropriate interventions and medical therapies for the PCOS adolescents patients. The PCOS is a multi-symptomatic disorder with number of physical, social and psychological consequences. In this respect patients with PCOS should be treated for their external but also psychological symptoms.

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