

Health-Related Quality of Life Among Adolescents with Polycystic Ovary Syndrome

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Keywords

polycystic ovary syndrome
adolescents
health-related quality of life
qualitative study
obesity

ABSTRACT

Objective: To explore health-related quality of life (HRQoL) among adolescents with polycystic ovary syndrome (PCOS).

Design: Qualitative study.

Setting: Two out-patient gynecology clinics in Yorkshire, England.

Participants: Fifteen young women diagnosed with PCOS were recruited.

Methods: Semistructured interviews were carried out, transcribed verbatim, and subjected to thematic analysis using NVivo software version 2.0.

Results: A few areas were identified where PCOS had a positive impact upon HRQoL (e.g., improved relationships). However, overall the condition had a negative impact upon HRQoL. Weight problems (in particular the difficulties associated with managing/maintaining weight) and body perceptions appeared to be the most significant contributors to a reduced HRQoL. Menstrual dysfunction, fertility issues, and hirsutism also had adverse effects on emotional well-being, self-perception (including poor body image, self-consciousness, & low self-esteem), social functioning, and sexual behavior. A number of participants described receiving insufficient information from health care professionals (HCPs) and negative experiences in relation to the diagnosis and management of their condition.

Conclusion: Overall, PCOS has a negative impact on the HR QoL of adolescent girls with the condition. Emotional and social functioning appeared to be most affected rather than areas of physical functioning. Future research is needed to identify ways to improve communication between adolescents with PCOS and their HCPs, particularly around the diagnosis and potential for infertility. Finally, HCPs need to be more aware of the emotional impact of PCOS upon adolescents' HRQoL and of the potential for poor sexual health through risk-taking behaviors that may occur due to the potential loss of fertility.

JOGNN, 40, 577-588; 2011. DOI: 10.1111/j.1552-6909.2011.01279.x

Accepted June 2011

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Polycystic ovary syndrome (PCOS) is the most common endocrine disorder (Hart et al., 2004) affecting between 4% and 25% of women (Balen & Michelmores, 2002; Homberg, 2002). The two main sets of symptoms typically associated with PCOS include disruption to fertility resulting from irregular menses (oligomenorrhoea) or absence of menstruation (anovulation) and clinical signs of hyperandrogenism (including hirsutism, acne, and alopecia). There may be secondary metabolic problems related to obesity and insulin resistance (Fratantonio, Vicari, Pafumi, & Calogero, 2005).

Health-related quality of life (HRQoL) is a multidimensional concept that encompasses the physical, emotional, and social aspects associated

with a specific disease or its treatment (Fayers & Machin, 2000). Historically, there have been a paucity of studies addressing this issue in women with PCOS (Jones, Kennedy, & Jenkinson, 2002). More recently, however, Jones, Hall, Ledger, and Balen, (2008) reviewed 18 studies and concluded that the symptoms of PCOS have a highly detrimental effect on HRQoL. Only two qualitative studies addressed the impact of PCOS upon a woman's daily well-being and functioning (Kitzinger & Willmott, 2002; Snyder, 2006), and these showed that adult women with PCOS are challenged in their perceptions of their femininity. Kitzinger and Willmott (2002) identified three core themes of hair, menstruation, and infertility as having the most significant effect on HRQoL, with women describing themselves as different, abnormal, or freaks.

The authors report no conflict of interest or relevant financial relationships.



Polycystic ovary syndrome occurs in approximately 4% to 25% of women of reproductive age and may have a negative effect on quality of life.

Although the symptoms of PCOS typically begin around menarche (Vuguin, 2010), no qualitative studies and only four quantitative studies (Harris-Glocker, Davidson, Kochman, Guzick, & Hoeger, 2010; Trent, Austin, Rich, & Gordon, 2005; Trent, Rich, Austin, & Gordon, 2002; Trent, Rich, Austin, & Gordon, 2003) have focused on the impact of PCOS on the HRQoL of adolescents with the condition. However, three of these studies present data from the same cohort (Trent et al., 2002, 2003, 2005), and Harris-Glocker et al. (2009) were narrowly focused on assessing the impact of metformin versus placebo in a lifestyle modification program combined with oral contraceptives in obese adolescents with PCOS.

The results of these quantitative studies indicate that multiple areas of HRQoL are affected by PCOS, but weight and infertility issues appear most problematic. Trent et al. (2002) carried out a cross sectional study to examine HRQoL in 97 American adolescents with PCOS compared to healthy adolescents. The results of the Child Health Questionnaire (CHQ-CF87) indicated that HRQoL in the domains of general health perception, behavior, physical function, and family activities were significantly lower in the PCOS adolescents than the healthy adolescents ($p < 0.05$).

Later analyses on the same cohorts, which focused specifically on fertility concerns and sexual behaviour (Trent et al., 2003) and weight issues (Trent et al., 2005), also found significant differences between these groups. Adolescents with PCOS were more than 3 times more likely than their healthy age matched counterparts to be concerned about their future ability to conceive. Those PCOS participants with fertility concerns scored significantly lower on 10 of the 12 domains of the generic CHQ-CF87 (the exceptions being physical functioning and change in health). They also observed that an elevated body mass index (BMI) contributed significantly to the differences in HRQoL observed between the two groups, particularly on the domains of general health perceptions, physical functioning, and family activities (Trent et al., 2005).

Despite these findings, there has previously been neither research of adolescents with PCOS in the

United Kingdom nor any qualitative research to investigate more deeply the issues reported from the quantitative studies. The gap in this knowledge base is important. The existing literature shows that the symptoms of PCOS are profoundly negative in this age group, and in fact recent research has explicitly called for qualitative work in this area (Snyder, 2006). Consequently, this study addresses that gap by qualitatively exploring the HRQoL of adolescents with PCOS. In particular, our aim was to explore the various effects PCOS has had on the physical, social, and psychological/emotional aspects of the lives of adolescents.

Methods

Ethics committee approval for this research was obtained from South Sheffield and Leeds West. Forty adolescent patients diagnosed with PCOS (as per 2003 Rotterdam consensus workshop) (The Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 2004) who attended the out-patient gynecology clinics in Sheffield and Leeds were approached by their clinician during their routine clinical consultation to participate. Adolescents who were interested in participating were given the opportunity to discuss the study in more detail with two of the researchers and given the patient information sheet and consent form to take home. Only those adolescents who returned a signed consent form were contacted by telephone to arrange a convenient time for the interview by one of the researchers.

Exclusion criteria for this study included the presence of a coexisting illness that may have a contributory effect on HRQoL; inability to read and speak English, because this study was conducted in English; and conditions similar in presentation to PCOS, such as congenital adrenal hyperplasia.

Demographic details, BMI, presenting symptoms of PCOS, concentrations of biochemical indicators of hyperandrogenaemia (testosterone, luteinizing hormone/follicle stimulating hormone, and sex hormone-binding globulin), evidence of polycystic ovaries (PCO) on ultrasound, ethnicity, and details of the general practitioner (GP) were recorded. In accordance with current practice, obesity was defined as BMI $> 29.5 \text{ kg/m}^2$ (World Health Organization [WHO], 2000). Adolescence was defined here as ages inclusive of 17 years to 21 years. Ethical constraints forbid the recruitment of anyone younger than age 17.

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