RESEARCH PAPER

Quality of life and challenges in adolescent girls with PCOS

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ABSTRACT

Introduction:Polycystic ovarian syndrome (PCOS) impacts 3–8% of teenagers. It is marked by hyperandrogenism and oligoovulation or anovulation. Polycystic ovary syndrome (PCOS) adversely affects health-related quality of life (HRQoL). The degree to which various variables affect the overall HRQoL of teenagers remains unknown. Adult patients with PCOS have a greater prevalence of binge eating compared to the overall population of females of reproductive age. There is a paucity of evidence about binge eating in teenagers with PCOS. This research aims to evaluate the quality of life in teenage females diagnosed with PCOS.

Methodology:This hospital based cross-sectional study was conducted among 80 adolescent girls attending a tertiary care hospital in Chennai, India for a period of three months. The quality of life was assessed using the PCOS health-related questionnaire (PCOSQ). Data was collected and analysed to assess the factors associated with QoL.

Results:The quality of life was lower among the study participants. The highest score was seen in the infertility concern subscale with a median of 6.4 (IQR: 1.8) while the lowest result was observed for body weight concerns (Median:4, IQR; 2.7). The quality of life decreased among illiterates (p-value=0.04), hirsutism (p-value=0.001), acne (p-value <0.001) and irregular cycles (p-value=0.003).

Conclusion:The overall health-related quality of life (HRQoL) was diminished in adolescents with polycystic ovary syndrome (PCOS), with the most significantly impacted areas being body weight and hair, followed by menstruation complications. Participants exhibiting symptoms and those who are illiterate indicated worse quality of life in our study..

Keywords: Polycystic ovary syndrome, quality of life, adolescent girls, menstrual disorders; infertility; hirsutism.
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INTRODUCTION

Polycystic ovarian syndrome (PCOS) is a prevalent endocrine disorder in women of reproductive age, often presenting during adolescence. The frequency ranges from 4.8% to 16.6% in the general female population, contingent upon the examined population and the diagnostic criteria used [1]. The reported frequency among teenagers ranges from 3.34% to 8.03% [2]. Nonetheless, accurately determining the frequency among teenagers is challenging, since the illness is sometimes obscured by the typical symptoms of puberty [3].

The 2018 recommendations from the European Society of Human Reproduction and Embryology (ESHRE) stipulate that the diagnostic criteria for polycystic ovary syndrome (PCOS) in teenagers include biochemical and/or clinical hyperandrogenism and oligomenorrhea. Moreover, patients often have insulin resistance, metabolic syndrome, heightened susceptibility to type 2 diabetes, cardiovascular disease, and compromised fertility [4]. Polycystic Ovary Syndrome (PCOS) affects mental well-being. Comprehensive studies in adult populations have shown a heightened likelihood of experiencing mental disorders (depression and anxiety) and a diminished health-related quality of life. Disordered eating and eating disorders (ED) are more frequent in adult PCOS patients compared to healthy adult females [4]. Nevertheless, there is only a paucity of research about the impact of PCOS on many dimensions of health-related quality of life (HRQoL) and disordered eating in teenagers [5].

The World Health Organization (WHO) characterizes quality of life as an individual's assessment of their status within the cultural and value frameworks of their environment, relative to their aspirations, expectations, standards, and concerns. [6] Health-Related Quality of Life (HRQoL) is delineated as the aspect of a person's well-being influenced by their health. [7] The ESHRE 2018 recommendations recommend using a disease-specific questionnaire, the PCOSQ, to assess women's subjective health problems related to PCOS, notwithstanding the availability of several instruments for measuring HRQoL.

Polycystic Ovary Syndrome (PCOS) often emerges during a notably susceptible period of life—adolescence. This phase of significant physical, social, and emotional growth poses extra hurdles for healthcare practitioners managing

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teenage PCOS patients. Lifestyle adjustments are the primary therapy for PCOS [4]. Therefore, a healthcare professional's capacity to encourage their patient to adhere to these alterations is critically significant. The optimal approach to attain this objective is to comprehend and cater to the specific demands of a patient while simultaneously enhancing their most critical HRQoL dimensions. Diagnosing eating disorders, especially those connected to binge eating, is very important, since binge eating behavior may undermine a patient's weight loss efforts. When treating patients with disordered eating, it is important to recognize that a healthcare professional's demand on weight reduction may exacerbate disordered eating symptoms, leading to a further decline in health-related quality of life and an escalation of mental health issues [8,9]. There is little information in the literature about health-related quality of life and binge eating in teenage patients with polycystic ovary syndrome. This study plans to assess the quality of life among adolescent girls with PCOS.

Methodology

Study Design and Setting

A hospital-based cross-sectional study was conducted to assess the quality of life and challenges faced by adolescent girls diagnosed with polycystic ovary syndrome (PCOS). The study was carried out over a period of three months at a tertiary care teaching hospital in Chennai, Tamil Nadu, India. The hospital serves as a major referral center, catering to a diverse urban and semi-urban population, thereby providing access to a representative sample of adolescents seeking gynecological and endocrine care.

Study Population and Sample Size

The study included a total of 80 adolescent girls aged 12–19 years who attended the outpatient departments of obstetrics and gynecology and endocrinology during the study period. Participants were recruited using a consecutive sampling technique. Adolescent girls presenting with clinical complaints suggestive of PCOS—such as weight gain, hirsutism, acne, and menstrual irregularities—were screened for eligibility.

Inclusion and Exclusion Criteria

All adolescent girls aged between 12 and 19 years who fulfilled the diagnostic criteria for PCOS and consented to participate were included in the study. Diagnosis was made based on clinical evaluation and relevant investigations, as per standard clinical practice.

Participants were excluded if they had severe comorbid medical conditions that could independently affect quality of life, including major endocrinological disorders (such as Cushing's syndrome, congenital adrenal hyperplasia, or thyroid dysfunction) or gynecological conditions unrelated to PCOS. Adolescents with a history of early or precocious puberty, ovarian virilizing tumors, or those currently using hormonal medications (including oral contraceptive pills or hormonal therapy) were excluded. Individuals undergoing chemotherapy or radiation therapy were also excluded to avoid confounding effects on physical and psychological wellbeing.

Ethical Considerations

Prior to the initiation of the study, approval was obtained from the Institutional Ethics Committee. The study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. Eligible participants and their accompanying guardians were informed in detail about the purpose, procedures, potential risks, and benefits of the study. Written informed consent was obtained from the parents or legal guardians, and assent was obtained from the adolescent participants before enrolment. Confidentiality and anonymity of participant information were strictly maintained throughout the study.

Data Collection

Data were collected using a structured, interviewer-administered questionnaire. Information on socio-demographic variables included age, educational status, and employment or schooling details. Clinical data comprised age at menarche, menstrual history, symptoms related to PCOS, family history of PCOS or metabolic disorders, and presence of complications. Anthropometric measurements were recorded to calculate body mass index (BMI), which was classified according to age-appropriate standards.

Behavioral and lifestyle factors such as physical activity levels, dietary habits, smoking, and alcohol consumption were also documented, recognizing their potential influence on PCOS manifestations and quality of life. All interviews were conducted in a private setting to encourage honest and accurate responses.

Assessment of Health-Related Quality of Life

Health-related quality of life (HRQoL) was assessed using the Polycystic Ovary Syndrome Questionnaire (PCOSQ), a disease-specific, standardized instrument designed to evaluate the impact of PCOS on patients' wellbeing. The PCOSQ consists of 26 items grouped into five domains: emotions (8 items), body hair (5 items), weight concerns (5 items), menstrual problems (4 items), and infertility (4 items).

The questionnaire assesses symptoms experienced during the preceding two weeks. Responses are recorded on a 7-point Likert scale, where a score of 1 indicates maximum impairment or severe concern, and a score of 7 indicates no impairment or absence of concern. A score of 4 represents moderate or intermittent problems. Lower domain and total scores reflect poorer quality of life.

The PCOSQ has been validated across different populations and languages and has demonstrated excellent internal consistency, with a reported Cronbach's alpha of 0.912 [10]. The questionnaire was administered in a language understood by the participants, with explanations provided when required to ensure comprehension.

Statistical Analysis

All collected data were entered into Microsoft Excel 2019 and subsequently analyzed using Statistical Package for the Social Sciences (SPSS) software, version 26.0 (IBM Corp., Armonk, NY, USA). Continuous variables were summarized using mean and standard deviation when normally distributed, while categorical variables were expressed as frequencies and percentages.

Health-related quality of life scores, being non-normally distributed, were summarized using median and interquartile range (IQR). Associations between selected

socio-demographic, clinical, and behavioral variables and quality of life domains were assessed using the chi-square test. A p-value of less than 0.05 was considered statistically significant.

Results

A total of 80 adolescent girls aged between 12-19 years of age who came with complaints of weight gain, hirsutism and irregular cycles were included in this study.

The mean of the study participants was 16.12 ± 4.5 years. The majority of the participants were ≥15 years (57.5%) while 42.5% were <15 years. 80 % of the study participants were literates and 20% were illiterates. 40% oof the study participants had a BMI level of > 25 Kg/m^2 while 37.5% had BMI with in normal range.

Table 1: Socio-demographic factors

Variables		Frequency	Percentage
Age	<15	34	42.5
	≥15	46	57.5
Education	Literate	64	80
	Illiterate	16	20
BMI	<18.5	18	22.5
	18.5-24.9	30	37.5
	>25	32	40

The majority of the participants had menarche within 15 years (86.2%). Irregular menstrual cycles were present in 60.3% of the participants. 42.5% and 48% participants respectively had symptoms of hirsutism and acanthosis nigricans. 51.3% of the participants had frequent complaint of acne. 31.2% of the participants were regularly engaged in physical activities while 68.8% were not. Family history of PCOS was reported by 60% of the study participants.

Table 2: Menstrual details, symptoms and personal details

Variables		Frequency	Percentage
Age of menarche	<15	69	86.2
	≥15	11	13.8
Irregular Cycles	Yes	49	60.3
	No	31	38.7
Acanthosis nigricans	Yes	48	40
	No	32	60
Hirsutism	Yes	34	42.5
	No	46	57.5
Acne	Yes	41	51.3
	No	39	48.7
Family history of PCOS	Yes	48	60
	No	32	40
Exercise	Yes	25	31.2
	No	55	68.8
Smoking history	Yes	10	8
	No	90	72

The total PCOSQ scores and the subscale scores among the adolescent girls were generally lower in the current study. The highest score was seen in the infertility concern subscale with a median of 6.4 (IQR: 1.8) while the lowest result was observed for body weight concerns (Median:4, IQR; 2.7).

Table 3: Quality of life among adolescent girls with PCOS

Quality of life domains	Median	IQR
Emotion	5.2	1.4
Body hair	4.3	2.4
Weight concern	4	2.7
Infertility concerns	6.4	1.8
Menstrual problems	4.6	1.3
Total score	4.8	1.5

On assessing the factors associated with the quality of life among adolescent girls with PCOS, participants who literates, not having any symptoms of hirsutism, acne or irregular complaints were found to have a statistically significant association with good quality of life.

Table 4: Factors associated with QoL

Variables		QoL		Chi-square value	p-value
		Good	Poor		
Age	<15	14	20	0.478	0.574
	≥15	16	30		
Education	Literate	23	41	3.157	**0.04***
	Illiterate	7	9		
BMI	<18.5	5	13	1.023	0.102
	15.5-24.9	14	16		
	>25	11	21		
Hirsutism	Yes	8	26	4.217	**0.001***
	No	22	24		
Acne	Yes	15	26	6.147	**<0.001***
	No	15	24		
Irregular Cycles	Yes	10	39	3.879	**0.003***
	No	20	11		

DISCUSSION

The diminished HRQoL in adolescents with PCOS is linked to the PCOS diagnostic score, underscoring the need of customizing therapeutic treatments and counseling to target the specific domains (i.e., hirsutism symptoms and weight issues) that contribute to discomfort and reduce HRQoL. Infertility exhibited elevated HRQOL levels, suggesting that this issue is of lesser concern to teenage females.

As previously stated, we observed a reduced overall HRQOL in teenage patients with PCOS. This aligns with the results of a recent comprehensive review of research investigating teenage PCOS patients [5]. Furthermore, research by Trent and colleagues similarly reported a poorer quality of life in young PCOS patients (13–22-year-olds) than healthy controls [11]. However, a later publication by the same group regarding the same research population indicated that the disparities in HRQoL between the two

groups vanished once adjusting for BMI, hence underscoring the significance of weight in overall HRQoL [12]. Two further investigations including adolescents with PCOS and healthy populations revealed no significant changes in quality of life between the groups [13,14]. Comparing these research is challenging owing to the use of varying diagnostic criteria. None of the studies used the most referenced Rotterdam criteria, and only this research utilized the latest ESHRE criteria particularly designed for teenage populations. Furthermore, other instruments were used to assess quality of life, including the Child Health Questionnaire [11,12], Psychosocial Index [13], and Paediatric Quality of Life Inventory [14], all of which are not disease-specific HRQOL questionnaires [4].

In our research group, the PCOSQ categories with the lowest scores were body weight, followed by body hair and menstruation issues. This is likely attributable to the participants' youth, during which menstruation is a novel experience that may induce anguish and anxiety. The infertility domain score was elevated among our research participants. This is likely due to the fact that reproductive concerns are not of significant relevance to females at this youthful stage. A negative body image, shown by low scores in the body hair and weight areas, is typical of the teenage demographic.

The PCOSQ domains have been variably influenced across several PCOS groups. For instance, young women with PCOS in India identified infertility as the first concern, followed by excessive body hair [15], while obese teenage PCOS patients in the USA prioritized weight issues and monthly irregularities [16]. The decreased score in the weight category aligns with our multivariate analysis, which indicates that BMI significantly impacts the reduction of overall HRQOL. The impact of BMI on overall HRQoL in adult populations has been well examined [17]. Nevertheless, there is a paucity of knowledge about this problem among teenage populations [12,16]. Trent and colleagues demonstrated that, after adjusting for BMI, the quality of life of teenage PCOS patients was comparable to that of healthy peers [16]. Conversely, Harris-Glocker et al. [12] identified that BMI was the lowest domain in the PCOSQ among adolescent PCOS patients, and that HRQoL improved with weight reduction.

We determined that BE was not more prevalent among PCOS patients compared to healthy controls. Nevertheless, BE contributed to the lower overall HRQoL in PCOS patients, even after accounting for the variation attributed to the PCOS diagnosis. This discovery underscores the significance of disordered eating for teenagers' health-related quality of life (HRQoL). Other researchers have identified problematic eating, particularly binge eating, as more prevalent among adult PCOS patients compared to their healthy counterparts [18]. Nevertheless, there is little research about BE in teenage populations with PCOS. Mizgier and colleagues found that disordered eating attitudes were five times more common in 14-17-year-old PCOS patients with elevated weight compared to those with normal weight.

The limited size of the research sample may have influenced the outcomes. Nevertheless, given that all participants adhered to rigorous diagnostic criteria and assessments, we assert that the research findings are relevant to a wider population. All individuals with PCOS were freshly diagnosed instances. Consequently, to authenticate the HRQoL outcomes (overall score and domain scores), the analysis must be conducted again after a designated interval.

CONCLUSION

The overall HRQoL was decreased in adolescents PCOS patients, with the most adversely affected domains being body weight and hair, followed by menstrual issues. Participants expressing symptoms and those who are illiterate reported lower standards of quality of life in our research. The primary factor affecting the overall HRQoL of adolescents with PCOS is the diagnosis of PCOS itself. Additional study is necessary owing to insufficient data on quality of life in teenagers with polycystic ovary syndrome..

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