Are Young Adult Women With Polycystic Ovary Syndrome Slipping Through the Healthcare Cracks?

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Polycystic ovary syndrome (PCOS) is a common endocrine disorder often diagnosed in adolescence or early adulthood. In adolescence, the many similarities between normal features of puberty and symptoms of PCOS make it challenging to confirm the diagnosis. Even among adult women, the changing definitions of PCOS may lead to inaccurate diagnoses. Women may present with a variety of symptoms to different healthcare providers and may be treated only for the presenting symptoms without evaluation of the syndrome and its associated morbidities. Timely evaluations, accurate diagnosis, appropriate interventions, and multidisciplinary healthcare teams can be valuable because women with PCOS have an increased risk for obesity, impaired glucose tolerance, diabetes, dyslipidemia, metabolic syndrome, infertility, endometrial cancer, and anxiety and mood disorders. Appropriate transition of care for the adolescent from pediatric to adult healthcare providers should include education of the patient and her parents regarding the chronic nature of the syndrome and the need for continued follow-up. Girls with symptoms suggestive of PCOS who fail to fulfill diagnostic criteria should undergo prolonged observation. Early identification of PCOS at different entry points in the healthcare system will require physician education and improved access. (J Clin Endocrinol Metab 99: 1583–1585, 2014)

Polycystic ovary syndrome (PCOS) is the most common endocrine disorder in reproductive-age women, and its prevalence varies from 6–15% of studied populations and depends on the diagnostic criteria used, ie, National Institutes of Health (NIH), Rotterdam, or Androgen Excess and PCOS Society (AE-PCOS) (1–3). Despite agreement that PCOS is a syndrome, much discussion continues about its precise definition in adult women; no single diagnostic test conclusively diagnoses PCOS. Geographic location, ethnic origin, genetic and environmental factors, and cultural and social practices contribute to the differing manifestations of PCOS and may influence the diagnostic accuracy.

Women with PCOS and, possibly, their sisters and daughters have an increased risk for impaired glucose tolerance, diabetes, obesity, dyslipidemia, metabolic syndrome, endometrial cancer, mood and anxiety disorders, impaired quality of life, and infertility. After the diagnosis, this high-risk group requires comprehensive care for screening and treatment of PCOS-related symptoms and associated comorbidities (4).

Confirming a diagnosis of PCOS in the adolescent and emerging young adult is often confounded by the similarities between early normal pubertal development and features of PCOS (5, 6). Adolescent girls experience acne, increased terminal hair growth, and irregular menses during the first menstrual year. On ultrasound, the typical multifollicular appearance and larger volume of the adolescent ovary typically confound the diagnosis (7). Moreover, the transabdominal ultrasound approach may provide limited assessment of the ovaries, especially in the obese adolescent. The 2013 Endocrine Society Clinical
Practice Guideline on the Diagnosis and Treatment of PCOS cautions about diagnosing PCOS in the adolescent girl (8).

Labeling an early adolescent girl with the diagnosis of PCOS implies long-term implications for gynecological, metabolic, and mental health, and possibly health insurance coverage issues. On the other hand, girls may transition from adolescence into adulthood without a clear diagnosis, thereby missing an opportunity to identify associated health problems. This diagnostic dilemma may contribute to the variability in clinical approaches toward the evaluation of PCOS as reported in a recent survey of adolescent medicine specialists (9).

It has been suggested that the diagnosis of PCOS should be deferred for at least 2 years post menarche (6). In one large series, symptoms of hyperandrogenism were apparent in late adolescent girls, but only 4.3% fulfilled diagnostic criteria for PCOS (10). Treatment of symptomatic hyperandrogenism should, however, not be delayed during this period. Adolescents with persistent hyperandrogenism and irregular menses for greater than 2 years post-menarche warrant re-evaluation for the possibility of PCOS.

Girls who fulfill the diagnostic criteria for PCOS require ongoing pediatric, gynecological, psychological, and cardiometabolic counseling and care. Those who do not fulfill the strict criteria should be treated for current symptoms and re-evaluated as adults. Both groups of girls benefit from a progressive planned transition from pediatric to adult healthcare providers; this transition considers medical, psychosocial, educational, and cognitive needs of the young woman. Most importantly, recognizing that PCOS is a chronic disorder will allow healthcare providers to better coordinate transition of medical care.

Yet, healthcare is often not a priority for the emerging adult. The young adult is usually focused on education and career choices. Hence, when a potential condition such as PCOS is undiagnosed, the adolescent has no apparent reason to transfer care in a timely manner to an adult healthcare provider. Regulation of menses and treatment of acne or hirsutism remain the mainstay of therapy during this time period in both adolescents diagnosed with PCOS and those awaiting confirmation. Suboptimal or delayed transitions to an adult healthcare provider can lead to significant interruptions in healthcare until patients are interested in fertility or when PCOS-related comorbidities become a major concern. To better address these concerns, data on the magnitude of this problem, factors associated with development of PCOS, and potential issues interfering with the transition of care are urgently needed.

undiagnosed women with PCOS may seek care from the dermatologist for hirsutism and acne; from the primary care physician for isolated dyslipidemia, obesity, or impaired glucose tolerance; and from the mental health specialist for anxiety and depression. In the absence of communication among these healthcare providers, PCOS may remain undetected, and although some symptoms are treated, the patient may not receive counseling or screening for gynecological, metabolic, or psychiatric problems. Incomplete disclosure from the patient compounded with targeted evaluation by the healthcare provider may lead to medical care similar to what the six blind men said when they touched the elephant in the poem “Blind Men and the Elephant” by John Saxe (1816–1887) (11). Will each of these providers recognize the wide-ranging features, make an accurate diagnosis of PCOS, and screen for comorbidities? Or will the situation result as in the poem? Each man was partly correct as he characterized only the aspect of the elephant he felt, but all were wrong.

Adolescent medicine providers, gynecologists, and/or pediatric/medical endocrinologists are in the best position to make an accurate diagnosis of PCOS and discuss some or all of its long-term implications. We propose that comprehensive care provided in an interdisciplinary setting will likely reduce the significant medical, social, and economic burdens associated with PCOS. In the recent NIH report, the expert panel recommended “the establishment of multidisciplinary programs to improve public and healthcare provider awareness and management for women who currently have the syndrome.” The establishment of a PCOS center emphasizes the medical and societal importance of this condition. In addition, a center can provide research and fund-raising opportunities. Other models for successful transition of care during this period of life include treatment of congenital adrenal hyperplasia (12). On the other hand, interdisciplinary approaches may not be successful if the silos are maintained across disciplines and appropriate communication is lacking. In addition to improving physician access, establishment of support groups will also help women with PCOS cope with the complexities of this syndrome.

Recently, the PCOS Australian Alliance was founded to promote education, improve health outcomes, and conduct research for Australian women with PCOS (13). Their guidelines also recommend an interdisciplinary care approach in collaboration with the patient and her care team (dietetics, psychology, endocrinology, gynecology, exercise physiology, general practice) with clear communication and a designated care coordinator.

Future strategies should include more widespread and liberal screening for PCOS, education of providers in the various disciplines to formulate an interdisciplinary approach, improved access for patients, and planned transition programs from pediatric to adult healthcare pro-
The AE-PCOS Society, the American College of Obstetrics and Gynecology, and The Endocrine Society have published screening and treatment guidelines for PCOS primarily focused on the adult (4, 8, 14). Nevertheless, there is an urgent need to establish guidelines for the diagnosis of PCOS in adolescents and for the management of girls with symptoms of PCOS who fail to meet the diagnostic guidelines. Without a clear diagnosis of PCOS, identification of PCOS-related comorbidities may be overlooked, and the opportunity for the patient, her family members, and healthcare providers to initiate appropriate interventions will be missed. Longitudinal studies of adolescents with PCOS-like features are essential to ascertain the proportion of girls who develop well-defined PCOS in young adulthood and to determine whether any specific clinical characteristics predict outcome.

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References


