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# Practitioner's Perspective on Barriers to Diagnosing Polycystic Ovarian Syndrome in Adolescents: A Descriptive Study

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PRACTITIONER'S PERSPECTIVE ON BARRIERS  
TO DIAGNOSING POLYCYSTIC OVARIAN SYNDROME IN ADOLESCENTS:  
A DESCRIPTIVE STUDY

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Science in Nursing

By

TARA LYNN WILLIAMS, RN, BSN

2014  
Cedarville University





CEDARVILLE UNIVERSITY

SCHOOL OF NURSING

August 21, 2014

WE HEREBY RECOMMEND THAT THE THESIS PREPARED  
BY

Tara Lynn Williams

ENTITLED

Practitioner's Perspective On Barriers  
To Diagnosing Polycystic Ovarian Syndrome In Adolescents:  
A Descriptive Study

BE ACCEPTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF  
MASTER OF SCIENCE IN NURSING.

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## Abstract

Polycystic Ovarian Syndrome (PCOS) is a common and reversible endocrine disorder affecting as many as 3.5-5.0 million women in the United States and has serious implications for women from adolescence to beyond menopause. PCOS is characterized by oligo-amenorrhea, anovulation, clinical, biochemical signs of hyperandrogenism, or polycystic ovaries the majority which can be identified in adolescence (ages 13-18). Although the majority of these reproductive and metabolic consequences can be identified in adolescence, diagnosis of PCOS for subsequent early intervention is still not taking place as many women are not being diagnosed until their reproductive years often after seeking the cause of their infertility. No literature could be found on barriers that contribute to the failure of early diagnosis of PCOS in adolescence. There is a gap in the literature investigating the barriers of diagnosing PCOS in adolescents. This was a descriptive study done to: (1) identify factors practitioners consider when determining the diagnosis of PCOS in adolescents (ages 13-18) and (2) identify barriers to early diagnosis of PCOS in adolescents (ages 13-18) among practitioners. Barriers to diagnose PCOS in adolescents will be explored using the *Polycystic Ovarian Syndrome in Adolescence questionnaire* which was developed by the researcher. The Qualtrics Survey Program was used to submit an electronic survey. Barriers for diagnosing PCOS in adolescents were acknowledged and identified by participants in this study. Because this data was mainly derived from a single group within the practice area, certified nurse practitioners, it is unclear whether these findings can be generalized to other



practice areas within the healthcare system. Future investigations should examine whether these barriers do exist amongst other practice areas, can yield enough results to be generalized, and focus on designing interventions to improve the diagnosis of PCOS in adolescents.

*Keywords:* barriers, Polycystic Ovarian Syndrome (PCOS), adolescents





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## Chapter 1: Introduction and Literature Review

### Introduction

Polycystic Ovarian Syndrome (PCOS) is a common and reversible endocrine disorder affecting as many as 3.5-5.0 million women in the United States and has serious implications for women from adolescence to beyond menopause (Barron, 2004). PCOS is characterized by oligo-amenorrhea or anovulation, clinical or biochemical signs of hyperandrogenism, or polycystic ovaries the majority which can be identified in adolescence ages 13-18 (Bates & Legro, 2012; Glueck, Dharashivkar, Wang, Zhu, Gartside, Tracy, & Sieve, 2005; Nicholson, Rolland, Broom, & Love, 2010). PCOS has proven long-term reproductive and metabolic consequences such as infertility, obesity, diabetes, hypertension, heart disease, and several gynecological cancers (Bates & Legro, 2012; Barron, 2004; Glueck, et al., 2005; Nicholson, et al., 2010; West, S., Lashen, H., Bloigu, A., Franks, S., Puukka, K., Ruukonen, A., Järvelin, M., Tapanainen, J., Morin-Papunen, L., (2014). Although the majority of these reproductive and metabolic consequences can be identified in adolescence, diagnosis of PCOS for subsequent early intervention is still not taking place as many women are not being diagnosed until their reproductive years often after seeking the cause of their infertility (Makarov, 2011; Meurer, Kroll, & Jamieson, 2006).

Symptoms commonly experienced by girls in their teenage years, such as irregular menses, acne, and weight gain are also part of normal physiologic pubertal changes (Hassan & Gordon, 2007). However, PCOS should not be overlooked as an underlying cause. PCOS is the source of 51% of the bleeding irregularities seen the most



common cause of hormonal disturbances triggering acne and hirsutism, and is seen in 27% of obese adolescents (Dramusic, Goh, Rajan, Wong, & Ratnam, 1997; West, et al., 2014). The diagnosis of PCOS is made by exclusion, where all other causes of symptoms are ruled out by diagnostic procedures and labs (Rosenfield, 2008). Due to the significant correlation between symptoms commonly experienced by girls in their teenage years and PCOS, it is critical healthcare providers consider an endocrine evaluation to diagnose ovulatory disorders such as PCOS (Barron, 2004; Rosenfield, 2008) when such symptoms exist in an adolescent. No literature could be found on barriers contributing to the failure of early diagnosis of PCOS in adolescence. Therefore, the purpose of this study is to identify barriers to early diagnosis of PCOS in adolescents ages 13-18 among practitioners.

### **Research Questions**

- (1) What factors do practitioners consider when determining the diagnosis of PCOS?
- (2) What are the barriers to early diagnosis of PCOS in adolescence among practitioners?

### **Literature Review**

Polycystic Ovarian Syndrome (PCOS) is the most common endocrine condition affecting young women where anovulation, hyperandrogenism, obesity, diabetes, and infertility are often seen (Barron, 2004; Bates & Legro, 2012; Glueck, et al., 2005; Nicholson, et al., 2010; West, et al., 2014 ). Typical clinical manifestations include hirsutism, acne, and alopecia (DuRant & Leslie, 2007). The diagnosis for PCOS in adolescence and women is based on the revised 2003 Rotterdam European Society of

Human Reproduction and Embryology/American Society for Reproductive Medicine (ESHRE/ASRM) consensus criteria (Rotterdam, 2004) as well as the National Institute of Health's (NIH) 1990 consensus criteria (Bates & Legro, 2012; Glueck, et al., 2005; Nicholson, et al., 2010). Studies done by Barron (2004); Glueck et al. (2005); Makarov, (2011); Meurer, Kroll, & Jamieson, (2006) conclude diagnosis and intervention in adolescent years are critical in the treatment of this reversible endocrine disorder. Although the literature review revealed symptoms of PCOS as well as metabolic consequences are seen in adolescent years, diagnosis is not taking place until women are in their reproductive years often after seeking the cause of their infertility (Makarov, 2011; Meurer, Kroll, & Jamieson, 2006).

### **Overview of Polycystic Ovary Syndrome (PCOS)**

PCOS was first diagnosed by American gynecologists Irving F. Stein and Michael L. Leventhal in 1935 after extensive research on seven women with amenorrhea, hirsutism, and bilateral polycystic ovaries, had been completed (Ehrmann, 2005; Hoe and Dokras, 2011). Although descriptions of the syndrome can be found in Italian literature dating back to 1721, it was the presentation of Stein and Levanthal's study of these seven women to the Central Association of Obstetricians and Gynecologists in 1935 gaining the syndrome a more comprehensive description. Then PCOS was described as women who had amenorrhea, hirsutism, and enlarged ovaries with multiple small cysts and thickened tunica (Farquhar, 2007). The current description of PCOS is: the most common endocrine condition with symptoms such as oligomenorrhea, anovulation, hyperandrogenism, and polycystic ovaries (Barron, 2004; Bates & Legro, 2012; Glueck, et al., 2005; Nicholson, et al., 2010).

Currently, PCOS is the most common endocrine condition affecting young women where anovulation, hyperandrogenism, obesity, diabetes, and infertility are often seen (Barron, 2004; Bates & Legro, 2012; Glueck, et al., 2005; Nicholson, et al., 2010; West, et al., 2014). Oligomenorrhea and anovulation are symptoms seen in 89% of adolescents as a normal physiological process of puberty, however 51% of these cases are due to PCOS (Makarov, 2011; Meurer, Kroll, & Jamieson, 2006; West, et al., 2014). Oligomenorrhea is defined as missing over four menstrual cycles a year after the onset of a woman's menses. Anovulation is a condition where ovaries do not release an oocyte; during a menstrual cycle. If oligomenorrhea or anovulation persists for 2 years after the onset of menses, PCOS should be considered (Hart, 2007; West, et al., 2014).

Hyperandrogenism is the most consistent diagnostic feature of PCOS; it is elevation of serum androgen levels or male hormones. Adolescents who have irregular menses have higher levels of plasma androgen than those with regular cycles (Venturoli, Porcu, Fabbri, Paradisi & Ruggeri, 1986; West, et al., 2014). Clinical manifestations of hyperandrogenism are acne, alopecia or male pattern balding, unwanted hair growth or hirsutism, and seborrhea (Azziz, Woods, Reyna, Key, Knochenhauer & Yildiz, 2004).

Polycystic ovaries are the result of a follicular arrest in which many small follicles develop in the ovaries but are not developed to an ovulatory size, and fail to ovulate. Although the term "cyst" can be an alarming term, these are not pathological cysts. They are immature follicles not developing to ovulatory size. A polycystic ovary is one in which 12 or more follicles measuring 2-9 mm in diameter or increased ovarian volumes are present, as defined by transvaginal ultrasound (Balen, 2003). Polycystic ovaries are

also a normal physiological variant of adolescents (Rosenfeld, 2011). Therefore, the use of a transvaginal ultrasound in adolescents may not confirm PCOS.

Golden & Carlson's position, "it appears to be a combination of defects in insulin resistance and ovarian and/or adrenal hypersensitivity (Golden & Carlson, 2008, p. 171). Women who have PCOS often have first generation relatives who also suffer from the disorder (Golden & Carlson, 2008). Hyperandrogenism, the main underlying problem identified in PCOS is a hormonal imbalance in which male hormones females make are higher than normal affecting the normal physiological process of ovulation; the development of follicles, and subsequent release of eggs. Hyperinsulinemia may also play a significant role in which women with PCOS have too much insulin in their bodies. Hyperinsulinemia affects the production of androgens as well. Insulin increases production of androgens, and high levels of androgens lead to acne, hirsutism, weight gain, issues with ovulation (Glueck, et al., 2005; Nicholson, et al., 2010).

### **Consequences of PCOS**

PCOS produces a negative impact on quality of life and health status. A systematic review of 18 studies on PCOS concluded there were detrimental effects of PCOS on quality of life (Jones, Hall, Ledger & Balen, 2008). Trent, Austin, Rich and Gordon (2005) examined the effect of body mass index on quality of life disturbances in adolescent girls (aged 13-22) with PCOS (demonstrated by hyperandrogenism and menstrual irregularity) in their cross-sectional study. Researchers compared disruption in health-related quality of life (HRQL) between adolescent girls with PCOS and their healthy peers. It was found adolescent girls with polycystic ovary syndrome (PCOS) have significant disruption in health-related quality of life (HRQL) compared to their

peers. Particularly, adolescent girls with PCOS had lower scores on health perception, physical functioning, and family activities. Similar findings have been reported in a qualitative study conducted by (Jones et.al., 2011). Jones and colleagues (2011) explored quality of life among adolescents (ages 17-21) with PCOS. Results from their semi-structure interviews revealed the negative impact PCOS had on their quality of life with emotional, social functioning being most affected. In addition, Trent et al. (2005) found a negative correlation between PCOS and insulin resistance. More than 50% of women with this disorder are obese, which further exacerbates difficulties with insulin resistance and increases risk for type 2 diabetes mellitus (Salehi, Bravo-Vera, Sheikh, Gouller, Poretsky, 2004).

Obesity and insulin resistance are common components of PCOS, and may trigger the onset in genetically predisposed individuals (Arslanian & Witchel, 2002). A study Warren-Ulanch and Arslanian, (2006) found the majority of adolescents are either overweight or obese. However, insulin resistance is often seen in non-obese adolescents with PCOS as well. Adolescents with PCOS generally have significant abdominal fat known as android distribution even if they are not obese, as well as signs of insulin resistance such as acanthosis nigricans (Hoe and Dokras, 2011). Abdominal obesity is also associated with greater metabolic dysfunction in adolescents with PCOS (Bruni, Dei, Nannini, Balzi & Nuvolone, 2010). Coviello, Legro, and Dunaif (2006) reported an association between PCOS and metabolic syndrome independent of body mass index (BMI); obese adolescents with PCOS had a greater prevalence of metabolic syndrome than obese adolescents without PCOS. Adolescents with PCOS have decreased insulin sensitivity compared with Body Mass Index-matched controls (Apter et al., 1995).

PCOS also produces an impact on the aspect of mental health. Major clinical manifestations of PCOS present during adolescents. Hirsutism, acne, and obesity can affect self-image, self-esteem, and quality of life of young women (Ching, Burke, & Stuckey, 2007). Depressive disorders are seen in 60% of women with PCOS (Bhattacharya & Jha, 2010). Eating disorders are seen in 35% of women with hirsutism (Morgan, Scholtz, Lacey & Conway, 2008). Androgens stimulate appetite, so high levels of these hormones can account for the inappropriate eating behaviors women with PCOS often face (Naessén, Carlström, Garoff, Glant & Hirschberg, 2006; West, et al., 2014).

Reproductive and metabolic issues are some of the major consequences of PCOS. PCOS is characterized by oligo-menorrhea, chronic anovulation, infertility, polycystic ovaries, and clinical and biochemical hyperandrogenism. Approximately 50% of women with PCOS also have obesity which exacerbates heritable insulin resistance, promoting hyperinsulinemia (Glueck et al., 2005). Obesity promotes a sequel of metabolic effects such as diabetes, cardiovascular disease, hypertension, and several cancers affecting the female reproductive system (Glueck et al., 2005; Nicholson, et al., 2010). With effective management, women may be able to conceive earlier and experience fewer adverse obstetrical outcomes, as well as lowering the risk of chronic diseases later in life (Barron, 2004).

### **Diagnosis of Polycystic Ovarian Syndrome**

Diagnostic Criteria. Diagnosis of PCOS is based on the revised 2003 Rotterdam ESHRE/ASRM consensus criteria (Rotterdam, 2004) in which two of the three criteria are required for diagnosis: oligo-amenorrhea or anovulation, clinical or biochemical signs

of hyperandrogenism, or polycystic ovaries. National Institute of Health's (NIH) consensus criteria(1990) is based on symptoms of chronic anovulation, clinical or biochemical signs of hyperandrogenism; while excluding all other etiologies (Glueck, et al., 2005; Nicholson, et al., 2010). The Rotterdam ESHRE/ASRM and NIH criteria can be used to diagnose PCOS in adults but there are no specific criteria to diagnose PCOS in adolescent girls (Drosdzol-Cop, A., Sidło-Stawowy, A., Sajdak, D., Skrzypulec-Plinta, V., 2014).

Since PCOS is a diagnosis of exclusion tools/test are often used to aid in the diagnosis of PCOS (Glueck, et al., 2005; Nicholson, et al., 2010). Diabetic screening is important due to the coorelation of and metabolic consequences of hyperinsulinemia in PCOS; insulin resistance, impaired glucose tolerance, and type 2 diabetes mellitus (Stankiewicz & Norman, 2006). Androgen analysis can help rule out other causes of hyperandrogenism ruling out an androgen-secreting tumor, congenital adrenal hyperplasia, or Cushing's stigmata (Stankiewicz & Norman, 2006). Menstrual calendars can help distinguish oligomenorrhea and anovulation (Hart, 2007; Talib & Coupey, 2012; West, et al., 2014).

Challenges of Early Diagnosis. Drosdzol-Cop et. al., (2014); Golden and Carlson (2010); Weiss and Bulmer (2010) contend there are no current diagnostic guidelines for adolescents with PCOS; therefore, the basis of diagnosis is on hyperandrogenism, oligo-amenorrhea or anovulation, and polycystic ovaries (West, et al., 2014). Due to lack of diagnostic guidelines, diagnosis is often problematic because symptoms commonly experienced by girls in their teenage years, such as irregular menses, acne, and weight gain are also part of normal physiologic pubertal changes (Hassan & Gordon, 2007). For

this age group, the most robust diagnostic criterion for PCOS is clinical or biological expression of hyperandrogenism (Drosdzol-Cop et. al., 2014; Hassan & Gordon, 2007; West, et al., 2014). The predominant manifestation of excess androgens is hirsutism, affecting 50-76% of adolescents and women (Lee & Zane, 2007; West, et al., 2014). While the use of the Rotterdam ESHRE/ASRM and NIH criteria can be used for adolescent girls, this criterion often leads to over diagnosis because of the similarity in physiological changes during puberty and common PCOS symptoms (Drosdzol-Cop et. al., 2014). Although tightening of these current criteria was proposed, it has not yet been accepted (Drosdzol-Cop et. al., 2014, Rotterdam, 2007).

Although polycystic ovaries can be defined by a transvaginal ultrasound (Balen, 2003), polycystic ovaries are also a normal physiological variant of adolescents (Rosenfeld, 2011). Furthermore, only 40% of adolescent women with PCOS have polycystic ovaries on ultrasound; therefore the use of a transvaginal ultrasound in adolescents may not confirm PCOS (Venturoli, Porcu, Fabbri, Paradisi, Ruggeri, Bolelli, 1986). A study done by Barron (2004) recommended teaching adolescents how to distinguish an anovulatory cycle from an ovulatory cycle; this differentiation could aid practitioners in their diagnosis by teaching adolescents to differentiate the two.

Recent recommendation by American Congress of Obstetricians and Gynecologists' (ACOG, 2010) states girls as young as age 13 to 15 should begin annual reproductive health care visits in addition to their annual well-child visits. ACOG's stance is by engaging teens early in discussions about pubertal development; obstetrician–gynecologist can supplement care given by the primary health care provider helping build a supportive physician–patient relationship as teens start learning to



negotiate the health care system on their own (ACOG, 2010). As infertility is a complication of PCOS with significant importance to adult women. A study done by Upadhyya and Trent (2007) assessed the impact infertility has on adolescents with PCOS. Although there were concerns about raising the issue with adolescents, mainly creating distress among adolescents who were not yet considering fertility. Upadhyya & Trent (2007) found there were benefit to early reproductive care and ongoing discussion with girls diagnosed with PCOS. This was due to additional finding of this study that if adolescents perceive their fertility is diminished or impaired they were less likely to use oral contraception as a treatment for PCOS.

### **Intervention and Treatment Options**

Lifestyle Modifications. Obesity in women alone should alert health care providers to consider diagnosis of PCOS (Glueck et al., 2005), because weight loss of 5-10% BMI alone shows significant reversible effects of PCOS. A structured lifestyle modification program should be first line treatment for weight loss of all overweight women with or without PCOS (Nieuwenhuis-Ruifrok, Kuchenbecker, Hoek, Middleton, & Norman, 2008). Lifestyle modification should include nutrition counseling as well as an exercise program. Nutrition counseling alone has demonstrated a decrease in weight gain and body fat as well as lowering insulin levels (Bruner, Chad, & Chzen, 2006). Decreasing body fat, especially within the abdomen may also improve metabolic and hormonal profiles even with only a minimal loss in overall body mass (Bruner et al., 2006).

Pharmacological Treatment. Traditionally oral contraceptives were used to correct menstrual irregularities, hyperandrogenism, acne, and hirsutism. Currently Metformin is the treatment of choice. Metformin not only corrects menstrual irregularities and hyperandrogenism, but restores ovulation in 3/4 of women who take it, as well as improving insulin sensitivity of cells and glucose metabolism (Vandermolen, Ratts, Evans, Stovall, Kauma & Nestler, 2001). Additionally, effects of Metformin are even more pronounced in adolescents with PCOS (Salmi, Zisser & Jovanovic, 2004).

### **Studies on PCOS in Adolescents**

Majority of studies conducted on PCOS have been quantitative with a focus on the disorder's pathophysiology, symptoms, and treatments. A literature review done by Himelein and Thatcher (2006) revealed few studies addressed psychological concerns of PCOS. Combination of physical and clinical manifestations of PCOS, as well as timing of symptoms, coincides with a time where adolescents are undergoing identity development. There is a potential for great emotional distress with this syndrome (Himilein & Thatcher, 1006; Jones et al., 2008; Jones et al., 2011). Over the past decade, PCOS research has increasingly examined the health-related quality of life (HRQL) of women with this syndrome to further understand effects PCOS has on those diagnosed (Himilein & Thatcher, 1006; Jones et al., 2008; Jones et al., 2011).

Weiss and Bulmer (2011) conducted a qualitative study to investigate emotional distress resulting from PCOS in adolescence. Data was obtained through personal, semi-structured interviews of 12 young women with PCOS from ages 18-23 at college campuses in New England. The study concluded the women faced numerous physical,

social, and emotional challenges on a daily basis. As the women came to terms with this chronic condition they realized there was a need for a more meaningful patient-provider relationship. Participants felt adolescents and young women in their early twenties could benefit from a comprehensive holistic treatment plan including useable information, psychosocial support, along with mechanisms on how to cope with symptoms.

A retrospective study done by Bruni, Dei, Nannini, Balzi and Nuvolone (2010) evaluated correlations between PCOS, obesity, and metabolic risk factors in adolescents (ages 12-19). Researchers examined clinical charts and laboratory data of 250 adolescent females in the first 8 years of gynecological age at a pediatric and gynecology unit at the University of Florence. Negative correlation between weight gain and severity of PCOS symptoms was found. In fact weight gain is probably the key factor in modifying severity of symptoms in adolescents (Bruni et al., 2010). This study concluded an intervention on lifestyle ought to be a priority in the management of these patients to prevent metabolic consequences of PCOS.

Although lifestyle modifications encouraging dietary change and physical activity are standard treatments for obesity, it is clear with the rise of obesity in adolescence, nearly triple since 1980 there is a need for effective treatment plan (Ogden, Carroll, Curtin, Lamb, & Flegal, 2010). A study done by Jakubowski, Black, Nokali, Belendiuk, Hannon, Arslanian, and Rofey (2012) looked at adolescent-parent relationships of forty adolescent females with PCOS participating in a weight management program. The stages of change model were used to assess readiness to change weight control behaviors. Participants, adolescents and parents, were given a questionnaire which assessed four

weight control domains. Their finding that parent change from baseline to treatment completion significantly predicts adolescent change in BMI from baseline to treatment completion were consistent with previous evidence for the importance of parent involvement in and commitment to child weight management interventions (Jakubowski et al. 2012).. Therefore, findings of this study supported the importance of parental involvement for youth's ability to manage their weight (Jakubowski et al. 2012).

Trent, Austin, Rich, and Gordon's (2005) cross-sectional study on 283 healthy and PCOS-affected adolescent girls evaluated effects of body mass index (BMI) on quality-of-life disturbances in adolescents with PCOS. Trent et al. (2005) found adolescent girls with PCOS have significant disruption in health related quality of life (HRQL) compared to their peers. Adolescents with PCOS scored lower on general health perceptions scale, physical functioning scale, family activities scale, and general behavior scale and scored higher on changes in health in the last year subscale. Trent et al. (2005) concluded clinical interventions effectively addressing weight issues in adolescence with PCOS may improve overall HRQL.

Laitinen, Taponen, Martikainen, Pouta, Millwood, Hartikainen, Ruukonen, Sovio, McCarthy, Franks, and Jarvelin (2003) conducted a longitudinal population-based study on a cohort of women born in 1966 to study association between body size from birth to adulthood and self-reported symptoms of PCOS, particularly hirsutism and menstrual disturbances. Out of 2007 subjects, 528 had self-reported symptoms of PCOS. An increased risk of PCOS symptoms, hirsutism and menstrual abnormalities, had been observed in 30-41% of these women who were overweight, obese, or had abdominal obesity. Study results suggested obesity in adolescence, and weight gain after

adolescence particularly in the abdomen, are associated with self –reported PCOS symptoms in adulthood.

Literature on PCOS demonstrates the negative impact of PCOS on quality of life and health status; and highlights the importance of early diagnosis for timely interventions. Adolescence is the phase where young women are undergoing identity development as well as a heightened sense of body image awareness. Cosmetic clinical manifestations of PCOS may affect social interactions and long-term emotional well-being (Weiss & Bulmer, 2011). Adolescents are at risk for reproductive, metabolic, and psychological consequences as a result of this common and reversible endocrine syndrome. However, there is a gap in the literature investigating the barriers of diagnosing PCOS in adolescents. Therefore the purposes of this study are to: (1) identify factors practitioners consider when determining the diagnosis of PCOS in adolescents (ages 13-18) and (2) identify barriers to early diagnosis of PCOS in adolescents (ages 13-18) among practitioners.

## Chapter 2: Theoretical Model

### The Theory of Planned Behavior Model

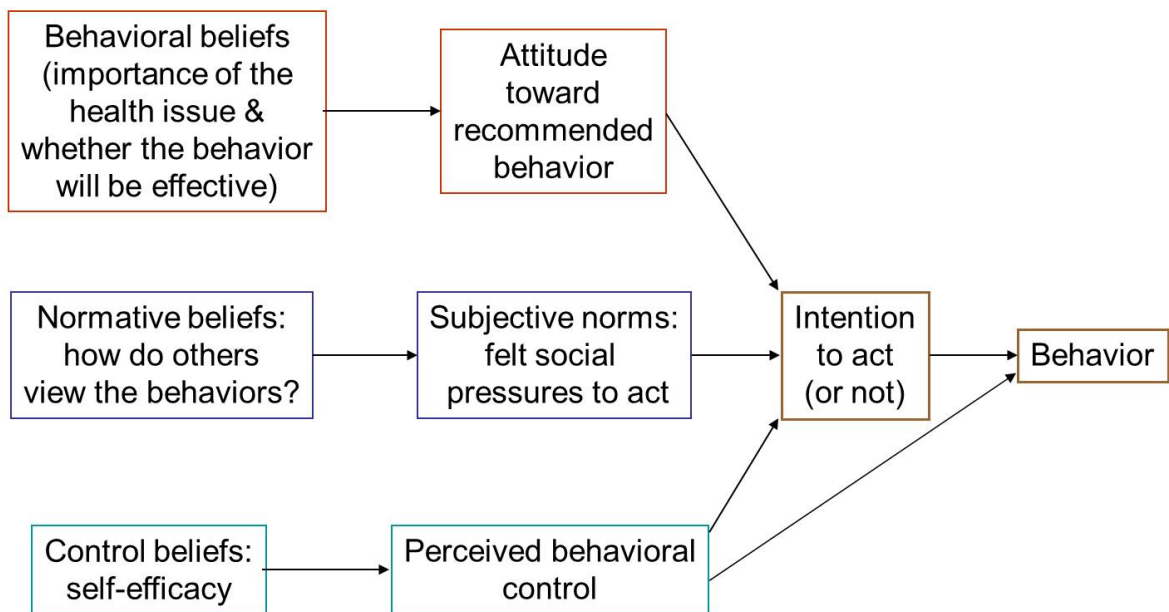
The theory of planned behavior (TPB) is a prominent reasoned action model that has been used to understand, predict, and change human social behaviors (Ajzen, 2011). TPB suggests human behaviors are not mindless or uncurious acts rather conscious awareness of thoughts leading to the decision of actions. TPB postulates human behavior is guided by three main thought processes: what are the behavioral beliefs or likely consequences of a behavior; what are the normative beliefs or beliefs of others expectations of your behavior; and what factors or control beliefs cause or stop a behavior from being performed (Ajzen, 2011). TPB proposes these three thought processes are a pathway to three concepts of this theory: attitude, subjective norm, and behavioral control (Ajzen, 2011; Cortoos, Schreurs, Peetermans, De Witte & Laekeman, 2012). These three thought processes then lead to the formation of a behavioral intention (Ajzen, 2011). Intention is the immediate antecedent of behavior, as well as a function of attitude toward the behavior, subjective norm, and perceived behavioral control (Ajzen, 2011)

In respect to the TPB (see Figure 1), behavioral beliefs produce a favorable or unfavorable *attitude toward the behavior*. Attitude of behavior links positive or negative connotation to the behaviors outcome. Therefore, according to the TPB, attitude toward a behavior is determined by accessible behavioral beliefs, linking behaviors to various outcomes and attributes. Normative beliefs are the result of *subjective norms*, referring to perceived behaviors a person thinks another individual expects from them. It is assumed

subjective norms are determined by the amount of control perceived behaviors have over a person. Control beliefs lead to *perceived behavioral control* and are determined by the amount of control a person perceives they have over any given behavior. *Intention* is an indication of a person's willingness to perform a behavior, and is based on attitude toward the behavior, subjective norm, and perceived behavioral control. Behavior, the observable response in a given situation, can then be predicted by actual behavioral control, perceived behavioral control, and intention. In the TPB, behavior is a function of compatible intentions and perceptions of behavioral control (Ajzen, 2011).

Figure 1

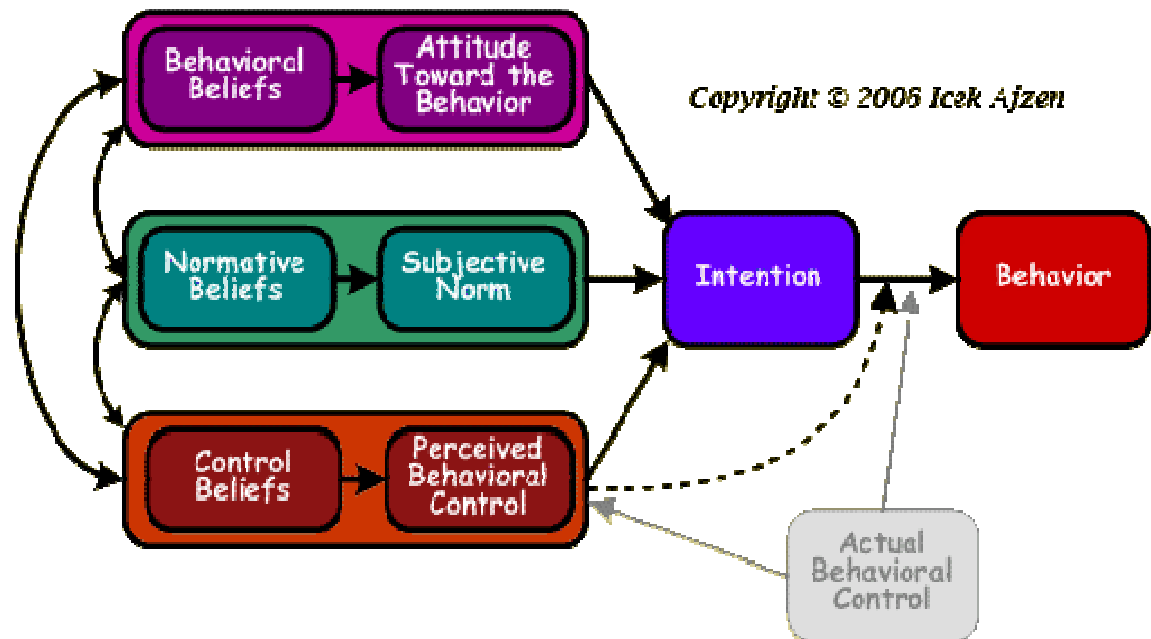
*Theory of Planned Behavior*



As a general rule, the more favorable the attitude and subjective norm, the greater the perceived control, the stronger a person's intention to perform the behavior in question should be. Implying only when a person has the perception that they have control over the behavior will a favorable intention produce a favorable behavior. TPB assumes people have a great deal of control over their behavior, and are expected to carry out their intentions when the opportunity arises. However, because many behaviors are difficult to elicit, one must also consider perceived behavioral control to help understand this in relation to intention. Perceived behavioral control can be substituted for actual control, also having the ability to predict ones behavior. A schematic representation of this theory can be seen in the diagram in Figure 2.

Figure 2

*Schematic Representation of Theory of Planned Behavior*





There are a host of correlational studies giving rise to empirical support for TPB (Ajzen, 1985, 1989, 1991, 2006, 2012; Cartoos et al., 2012; Deskins et al., 2006; Handbury, Wallace & Clark, 2010; Kelly et al., 2011; Gerend and Shepherd, 2012). These studies have repeatedly demonstrated the ability of TPB to predict intentions and behavior as well as interventions showing changes in behavioral, normative, and control beliefs can change intentions (Ajzen, 2011; Cartoos et al., 2012; Deskins et al., 2006; Handbury et al., 2010; Kelly et al., 2011; Gerend and Shepherd, 2012). The application of TPB in varied domains has allowed for identification of socially significant behavior through collection of information about behavioral, normative, and control related factors of many behaviors (Ajzen, 2011). This in turn provided the basis for effective interventions to modify social behaviors in a positive way.

Handbury et al., (2010) found the use of TPB effective in exploration of barriers health professional's had to adhering to national suicide prevention guidelines as a way to create interventions to increase their adherence. Cartoos et al. (2012) found TPB to be effective in identifying barriers physician's had in antibiotic guideline adherence to improve their prescribing practice of antibiotics. Deskins, Harris, Bradlyn, Cottrell, Coffman, Olexa, and Neal (2006) used TPB to identify barriers West Virginians faced to participating in health screening so interventions could be put in place to improve participation. Kelly, Deane, Mc Carthy, and Crowe (2011) used TPB to predict intentions of clients who have underwent alcohol and drug detoxification to undergo subsequent treatment to avoid relapse. Gerend and Shepherd (2012) used the TPB to predict decisions of patients to obtain the human papillomavirus vaccination.

Theory of planned behavior was used to guide this descriptive study for the purpose of identifying barriers in diagnosing polycystic ovarian syndrome (PCOS) in adolescence among practitioners. TPB offers a useful model for understanding the decision making process an individual goes through to perform an action such as diagnosing. Although the TPB offers three main concepts to understand an individual's intention to perform an action, only the *attitude toward the behavior* and the *intention of the behavior* will be explored in this study.

In order to promote timely diagnosis of PCOS in adolescence for subsequent intervention, it is important to identify barriers practitioners have in diagnosing PCOS in adolescence. Techniques such as developing a questionnaire to assess barriers require support of a theory such as the TPB. In this study, theoretical definition of barriers is anything preventing a practitioner from diagnosing PCOS in an adolescent who demonstrates symptoms of PCOS. Barriers will be measured by the questionnaire: *Polycystic Ovarian Syndrome in Adolescents*. TPB will aid in the assessment of barriers by thoroughly examining the habits and perceptions that exist in the diagnosis of PCOS by practitioners to address identified barriers.

## Chapter 3: Methodology

### Design

This descriptive study seeks to identify barriers preventing practitioners from diagnosing Polycystic Ovarian Syndrome (PCOS) in adolescence.

### Subjects

The researcher contacted the Ohio Medical Board and the Ohio Board of Nursing for email access to potential study participants. The researcher was directed to the Public Information Request Tracking (PIRT) team from Ohio's Office of Information Technology Enterprise Computing which provides licensee data for the state of Ohio to the public through a computerized database. Inclusion criteria for this study were practitioners who provide women's health care for adolescents ages 13 to 18 within the state of Ohio. The inclusion criterion for this study was used to generate key terms to screen through the database for potential participants. Based on inclusion criterion, the researcher selected the potential participants: medical doctors, doctors of osteopathy who specialize in the following: endocrinology, family practice, gynecology, obstetrics and gynecology, obstetrics, pediatrics, or pediatric endocrinology within the state of Ohio. All certified nurse practitioners, certified nurse midwives, and clinical nurse specialists in the state of Ohio were included regardless of their specialty area because they were not differentiated by category in the PIRT database. Participants identified their specialty when completing the study questionnaire (see Appendix A-Polycystic Ovarian Syndrome in Adolescents Questionnaire). A total of 16,274 practitioners were selected to participate in this study.

## **Measurement Tools**

Barriers to diagnose PCOS in adolescents were explored using the *Polycystic Ovarian Syndrome in Adolescence questionnaire (PCOS questionnaire)* (see Appendix). The PCOS questionnaire was developed by the researcher to explore the process of making the diagnosis of PCOS in adolescents, and to identify associated barriers of making the diagnosis among practitioners. This eighteen-item electronic questionnaire has seventeen close-ended multiple choice questions and one open-ended question. The questionnaire consists of three categories including demographic information, diagnostic process of PCOS, and perceived barriers in diagnosing PCOS in adolescents. Estimated length of time for completing the questionnaire was 2-5 minutes.

Face validity and panel of expert validity were established. The panel consists of four experts: (1) a pediatric clinical specialist (2) a certified nurse practitioner in reproductive medicine, who has been working with women to overcome the effects of PCOS in fertility management, (3) an academic expert on PCOS, and (4) a family nurse practitioner who has done a significant amount of work in women's health and has seen firsthand the effects of PCOS in women. The questionnaire was revised based on feedback from the panel then resubmitted to the panel for final review.

## **Procedure for Data Collection**

A sample of 16,274 practitioners who met the inclusion criteria for this study were invited to participate. Participants received an informational cover sheet with the PCOS questionnaire via email. The information sheet provided study details and explained consent to participate was implied by completing the PCOS questionnaire (see

Appendix B: Information Sheet). Participants completed the PCOS questionnaire online via a link through Qualtrics Survey Program.

Internet survey methods are a convenient, cost-effective way to recruit participants. However, low response rates of less than 20% have been reported in the literature (Hunter, Corcoran, Leeder, and Phelps, 2012; Kongsved, Basnov, Holm, and Hjoullund, 2007). To increase participation for this study, the following tactics were employed. The researcher sent the email out to participants on July 29, 2014. Two email reminders were sent to the participants after the initial email; a week after the email was sent, and the 3 days prior to the completion deadline. A completion deadline of August 11, 2014 was clearly specified in the email. An extension of the survey was given from August 14, 2014 to August 17, 2014 in attempt to attain more study participants. An appreciation email was sent to the participants upon completion of the questionnaire provided via the Qualtrics Survey Program. Participants will receive the survey results via email as soon as data analysis is completed (Hunter, Corcoran, Leeder, and Phelps, 2012). Data analysis was conducted immediately following the data collection.

### **Data Analysis**

Descriptive statistics (means, standard deviations, percentages, and range) was conducted to describe the diagnostic process and barriers identified in determining the diagnosis of PCOS. Data analysis was conducted using SPSS. The alpha was set at the 0.05 level.

## **Ethical Considerations**

Study approval was attained from the Cedarville University Internal Review Board (IRB). This study was “exempt”. Completion of the questionnaire was treated as consent to participate. No harm occurred to participants of this study.

## **Strengths and Weaknesses**

There are several strengths for this study. This descriptive study addresses gaps in the literature by exploring potential barriers of the PCOS diagnosis in adolescents. Results of this study will provide a foundation for the early intervention of adolescents with PCOS by raising awareness of the need to establish early diagnosis of PCOS in adolescents when clinical manifestations appear. In addition, participants of this study were selected from a database which included all licensee data for the state of Ohio, providing a large framework to an accessible population. The comprehensive database also provided the potential to increase external validity of the study findings. Lastly, Quatric Survey Software facilitates immediacy of Internet survey results, storage and analysis of the data, and ultimately reduced errors in data entry. While low response rate from email and Internet surveys have historically been reported in the literature (Hunter et al., 2012; Kongsved, Basnov, Holm & Hjollund 2007), measures were taken to increase study participation rates. Measures included: using a shorter questionnaire, providing a clear completion deadline, sending two reminder emails, and providing survey results.

Two major weaknesses are present for this study. The PCOS questionnaire was developed by the researcher. While face validity and panel of expert validity were

established, further work is needed to establish the psychometric properties, such as validity, reliability, and sensitivity to change. In addition, recruitment bias of individuals who favor electronic surveys may exist. Therefore, under-recruitment of individuals who do not favor electronic surveys may impact generalizability of study results.

## Chapter 4: Results

There is a gap in the literature investigating the barriers of diagnosing PCOS in adolescents. Therefore the purposes of this study are to: (1) identify factors practitioners consider when determining the diagnosis of PCOS in adolescents (ages 13-18) and (2) identify barriers to early diagnosis of PCOS in adolescents (ages 13-18) among practitioners. An electronic survey was sent to 16,274 participants via the Qualtrics Survey Program in August 2014. A total of n=341 completed and returned the survey. The overall response rate was 2.09%.

### Demographic Characteristics

Demographic characteristics are presented in Table 1. Of the 341 participants, most were females (86%, n= 294), between the ages of 56- 65 (30%, n=103), white or non-Hispanic (94%, n= 317), certified nurse practitioners (62%, n=211). Practice specialties include family practice (28%, n=96), obstetric gynecologist (21%, n=72), and pediatric endocrinologists (1%, n=5) (see Table 1.2). Twenty-one percent (n=72) of the participants have been working within their practice setting for more than 20 years, while 34% (n=116) have only been working within their practice setting for 5 years or less.

### Polycystic Ovarian Syndrome Diagnosis (PCOS) in Adolescents

The majority of the participants (n=163; with a yield of 34%, n=115 for missing data) have diagnosed an adolescent (age 13-18) with PCOS in their practice setting. Pediatrics 100%, (n=26), pediatric endocrinology 100% (n=5), gynecology 93% (n=13), obstetric gynecology 80% (n=53), and family practice 60% (n=43) are among the top



practice specialties diagnosing adolescents in ranking order. Seventy-two percent (n=243) of the responses indicated the prevalence of PCOS among adolescents within participants practice setting to be less than 10%. The majority of the adolescents diagnosed were between the ages of 16-18 (73%, n=116).

The most frequently reported clinical manifestations were menstrual disruptions/irregularities (99%, n=161), acne (91%, n=149), hirsutism (90%, n=147), and obesity (83%, n=136), which were also symptoms most often used by participants to diagnose PCOS in adolescents. Sixty participants (18%) used at least three out of the four symptoms (oligo-amenorrhea, anovulation, clinical signs of hyperandrogenism, and biochemical signs of hyperandrogenism) to make their diagnosis, while forty-one participants (12%) used polycystic ovaries to make their diagnosis. The NIH diagnostic criteria guided 52% (n=152) of the participants in diagnosing adolescents. Thirty-seven participants (11%) used both NIH and Rotterdam ESHRSA/ASRM criteria to aid in the diagnosis of PCOS among adolescents (see Table 2). Other tools/testing such as diabetic screening (67%, n=212), androgen analysis (66%, n=207), and menstrual calendars (62%, n=196) were also used. Over half of the participants (52%, n=171) admit to diagnosing adult women who reported clinical manifestations in their adolescent years. Data regarding diagnosing PCOS in adolescents is presented in Table 3.

### **Barriers to diagnosing Polycystic Ovarian Syndrome Diagnosis (PCOS) in Adolescents**

More than half of the participants (56%, n=182) perceived barriers exist in diagnosing the adolescent population (see Table 5). The main barriers identified were:

adolescents were not seeking fertility counseling (44%, n=134), no definitive diagnostic criteria to diagnose adolescents (20%, n=63), lack of knowledge regarding diagnosis and treatment (18%, n=56) therefore participants were not diagnosing PCOS in the adolescent. Participants also identified PCOS manifestations as a part of the normal physiologic pubertal changes and will subside (18%, n=55), and not recognizing PCOS in adolescents (16%, n=49) as barriers.

Participants listed several “other” barriers to the diagnosis of PCOS in adolescents. Common themes included infrequent visits to healthcare providers (14%, n=19), limited access to the healthcare system (.01%, n=1), and adolescent’s reluctance to come into the office (4%, n=5). If adolescents were not sexually active they may not present for an evaluation at all (4%, n=6). In addition parent’s denial of the potential PCOS diagnosis (10%, n=12), exhaustion on behalf of the parent and the adolescent from multiple tests prior to the confirmation of the PCOS diagnosis (4%, n=6), as well as parent’s and adolescents overlooking PCOS symptoms and perceiving them as a normal part of adolescence (10%, n=15). Data regarding barriers are presented Table 6.

Table 1  
*Demographic Characteristics*

Variables	n	%
<b>Gender</b>		
Male	47	14%
Female	290	86%
<b>Age (years)</b>		
25-35	68	20%
36-45	71	21%
46-55	78	23%
56-65	101	30%
66+	18	5%

Table 1

*Demographic Characteristics (con't)*

Variables	n	%
<b>Ethnicity</b>		
White or non-Hispanic	314	94%
Black or African American	7	2%
American Indian or Alaska Native	1	0%
Asian	4	1%
Native Hawaiian, or other Pacific Islander	1	0%
Hispanic	5	1%
Other	3	1%
<b>Practitioner Type</b>		
Medical Doctor	63	19%
Doctor of Osteopath	13	4%
Certified Nurse Practitioner	210	63%
Certified Nurse Midwife	15	4%
Clinical Nurse Specialist	25	7%
Other Non-Physician Provider	8	2%
<b>Practice Specialty</b>		
Endocrinology	5	1%
Family Practice	96	28%
Gynecology	14	4%
Obstetrics and Gynecology	71	21%
Obstetrics	0	0%
Pediatrics	36	11%
Pediatric Endocrinology	5	1%
Women's health center	5	1%
Other	105	31%
<b>Years worked in practice setting</b>		
0-5	116	35%
6-10	62	18%
11-15	53	16%
16-20	34	10%
20+	71	21%

Table 2

*Diagnosis of PCOS within Specialty Practice*

	Have diagnosed an adolescent (age 13-18) with PCOS	
	n	%
Practice specialty: Endocrinology	2	1%
Family Practice	43	26%
Gynecology	13	8%
Obstetrics and Gynecology	53	33%
Pediatrics	26	16%
Pediatric Endocrinology	5	3%
Women's health center	3	2%
Other	18	11%
Total	163	

Table 3

*PCOS Diagnosis in Adolescents*

Variables	n	%
<b>Estimation of prevalence of PCOS in practice</b>		
1-5%	133	40%
5-10%	108	32%
10-20%	48	14%
20-30%	7	2%
>30%	5	2%
None	32	10%
<b>Estimation of prevalence of PCOS among adolescents (ages 13-18) in practice</b>		
1-5%	140	42%
5-10%	99	30%
10-20%	23	7%
20-30%	6	2%
>30%	2	1%
None	62	19%
<b>Have you diagnosed a patient with PCOS</b>		
Yes	222	66%
No	115	34%

Table 3

*PCOS Diagnosis in Adolescents (con't)*

Variables	n	%
<b>Have you diagnosed an adolescent (ages 13-18) with PCOS</b>		
Yes	162	73%
No	61	27%
<b>Age range of diagnosed adolescent (ages 13-18) with PCOS</b>		
<13	11	7%
13-15	33	21%
16-18	115	72%
Other <13	11	7%
<b>Clinical manifestations seen in adolescents diagnosed with PCOS</b>		
Hirsutism	146	90%
Acne	148	91%
Overweight (BMI 25.0-29.9/ 85-95 <sup>th</sup> percent.)	118	73%
Obesity (BMI 30.0+/95th percentile)	135	83%
Insulin Resistance	100	62%
Menstrual disruption/irregularities	160	99%
Other	17	10%
<b>Symptoms most often used to diagnose PCOS in adolescents</b>		
Oligo-amenorrhea	134	83%
Anovulation	85	52%
Clinical signs of hyperandrogenism	159	98%
Biochemical signs of hyperandrogenism	123	76%
Polycystic Ovaries	41	25%
Other	3	2%
<b>Diagnostic criteria used in diagnosing PCOS in adolescents</b>		
NIH	148	52%
Rotterdam EHRE/ASRM	89	31%
Other	93	33%

Table 3

*PCOS Diagnosis in Adolescents (con't)*

Variables	n	%
<b>Tool(s)/testing used to diagnose PCOS in adolescents</b>		
Menstrual Calendar	193	62%
Androgen Analysis	204	65%
Diabetic Screening	208	67%
Diagnostic Imaging	124	40%
Other	63	20%
<b>I have diagnosed adult women with PCOS who reported clinical manifestations in adolescent years (ages 13-18)</b>		
Yes	167	51%
No	160	49%

Table 4

*Barriers to Diagnosing Polycystic Ovarian Syndrome (PCOS) in Adolescents*

Variables	n	%
<b>Do you perceive barriers in diagnosing PCOS in adolescents</b>		
Yes	179	55%
No	144	45%
Missing Data	14	4%
<b>What barrier(s) do you encounter when diagnosing adolescents with PCOS</b>		
I have not seen PCOS in adolescents	49	16%
No defined diagnostic criteria	61	20%
Manifestations also part of normal physiologic pubertal changes	56	18%
Adolescents are not seeking fertility Counseling	131	43%
Lack of knowledge concerning the diagnosis and treatment of PCOS	55	18%
Other	133	44%

Table 5

*Practice specialty: Barriers to diagnosing PCOS in adolescent population*

		Do you perceive any barriers to diagnosing PCOS in the adolescent population?		Total
		Yes	No	
Practice specialty:	Endocrinology	3	2	5
	Family Practice	58	37	95
	Gynecology	6	9	15
	Obstetrics and Gynecology	35	34	69
	Pediatrics	23	11	34
	Pediatric Endocrinology	3	2	5
	Women's health center	5	0	5
	Other	49	50	99
Total	182	145	327	

## Chapter 5: Discussion

### Comparison with the Current Literature

Results of study identified factors considered and barriers experienced when practitioners diagnose PCOS in adolescents. In this study 72% of participants estimated prevalence of PCOS in the adolescent population being less than 10%. In addition diagnosis of PCOS in adolescent was made across the following practice specialties: endocrinology, family practice, gynecology, obstetrics and gynecology, pediatrics, pediatric endocrinology, women's health center. Family practice specialists (19%, n=43), and pediatricians (6%, n=26) that diagnose PCOS in adolescents (age 13-18) should also be noted. These findings demonstrate that PCOS is not exclusively being diagnosed while women are in their reproductive years, which is consistent with current literature (Makarov, 2011; Meurer, Kroll, & Jamieson, 2006).

Diagnosis of PCOS. Currently PCOS in adolescents is diagnosed using criteria for the adult population (Bates & Legro, 2012; Drosdzol-Cop et. al., 2014; Glueck, et al., 2005; Nicholson, et al., 2010). The two diagnostic criteria used are the Revised 2003 Rotterdam ESHRE/ASRM consensus criteria (Rotterdam, 2004) in which two of the three are required for diagnosis: oligo-amenorrhea or anovulation, clinical or biochemical signs of hyperandrogenism, or polycystic ovaries. National Institute of Health's (NIH) consensus criteria(1990) is based on symptoms of chronic anovulation, clinical or biochemical signs of hyperandrogenism; while excluding all other etiologies (Glueck, et al., 2005; Nicholson, et al., 2010; West, et al., 2014). Participants of this study acknowledged there were no diagnostic guidelines/criteria for adolescents with PCOS



(20%, n=63). Thirty-seven participants (11%) used both NIH and Rotterdam ESHRSA/ASRM criteria to aid in diagnosis of PCOS among adolescents.

Current there are no diagnostic guidelines for adolescents with PCOS (Drosdzol-Cop et. al., 2014; Golden and Carlson 2010; Weiss and Bulmer 2010). Therefore, basis of diagnosis is on hyperandrogenism, oligo-amenorrhea or anovulation, and polycystic ovaries (West, et al., 2014). This could account for the low number of pediatricians (6%, n=26) found in this study diagnosing PCOS in adolescents (age 13-18). Study findings show this current practice for making diagnosis of PCOS in adolescents. Sixty participants (18%) used at least three out of four symptoms (oligo-amenorrhea, anovulation, clinical signs of hyperandrogenism, and biochemical signs of hyperandrogenism) to make their diagnosis, while forty-one participants (12%) used polycystic ovaries to make their diagnosis. Due to lack of diagnostic guidelines, diagnosis is often problematic because symptoms commonly experienced by girls in their teenage years, such as irregular menses, acne, and weight gain are also part of normal physiologic pubertal changes (Hassan & Gordon, 2007; West, et al., 2014). For this age group, the most robust diagnostic criterion for PCOS is clinical or biological expression of hyperandrogenism (Drosdzol-Cop et. al., 2014; Hassan & Gordon, 2007; West, et al., 2014).

Since PCOS is a diagnosis of exclusion tools/test are often used to aid in diagnosis of PCOS (Glueck, et al., 2005; Nicholson, et al., 2010). Diabetic screening is important due to the correlation of and metabolic consequences of hyperinsulinemia in PCOS; insulin resistance, impaired glucose tolerance, and type 2 diabetes mellitus (Stankiewicz & Norman, 2006). Androgen analysis can help rule out other causes of hyperandrogenism

ruling out an androgen-secreting tumor, congenital adrenal hyperplasia, or Cushing's stigmata (Stankiewicz & Norman, 2006). Menstrual calendars can help distinguish oligomenorrhea and anovulation (Hart, 2007; Makarov, 2011; Meurer, Kroll, & Jamieson, 2006; West, et al., 2014). This study shows participants are using tools/testing such as diabetic screening (67%, n=212), androgen analysis (66%, n=207), and menstrual calendars (62%, n=196) to further aid in diagnosis.

Barriers. Over half of participants (52%, n=171) report diagnosing adult women who reported clinical manifestations in their adolescent years. Potential reasons may include: (1) parent's denial of potential PCOS diagnosis (10%, n=12), (2) exhaustion on behalf of the parent and adolescent from multiple tests were prior to confirmation of PCOS diagnosis (4%, n=6), and (3) parents and adolescents overlooking symptoms of PCOS perceiving them as a normal part of adolescence (10%, n=15). Jakubowski, et al., (2012) investigated adolescent-parent relationships of forty adolescent females with PCOS who were participating in a weight management program. Their finding that parent change from baseline to treatment completion significantly predicts adolescent change in BMI from baseline to treatment completion were consistent with previous evidence for importance of parent involvement in and commitment to child weight management interventions (Jakubowski et al. 2012).. Therefore, findings of this study support importance of parental involvement for youth's ability to manage their weight (Jakubowski et al. 2012).

Study participants recognized several "other" barriers to diagnosis of PCOS in adolescents worth mentioning. Common themes included infrequent visits to healthcare providers (14%, n=19), limited access to healthcare system (.01%, n=1), and adolescent's

reluctance to come into the office (4%, n=5). This study found if adolescents were not sexually active they may not present for an evaluation at all (4%, n=6). This further supports American Congress of Obstetricians and Gynecologists' (ACOG, 2010) stance for adolescent girls to have reproductive health care visits in addition to annual well-child visits, as many of those suffering from PCOS are not being seen by a healthcare provider. As infertility is a complication of PCOS with significant importance to adult women. A study done by Upadhyya and Trent (2007) assessed impact infertility has on adolescents with PCOS. Although there were concerns about raising the issues of infertility with adolescents, mainly creating distress among adolescents who were not yet considering fertility. Upadhyya & Trent (2007) also found that there were benefits to early reproductive care and ongoing discussion with girls diagnosed with PCOS. Additionally Upadhyya & Trent (2007) found if adolescents perceive their fertility is diminished or impaired they were less likely to use oral contraception as a treatment for PCOS.

### **Strengths**

There are several strengths for this study. This descriptive study addresses gaps in the literature by exploring potential barriers of PCOS diagnosis in adolescents. Results will raise awareness of a need to establish an early diagnosis of PCOS in adolescents when clinical manifestations appear. In addition, potential participants of this study were identified from a comprehensive database for the State of Ohio, which provided a large framework of accessible population. These potential participants were medical doctors, doctors of osteopath, certified nurse practitioners, certified nurse midwives, and clinical nurse specialists. However, due to the nature of a convenience sample, electronic survey and low response rate, participants in this study may not represent the target population.

Lastly, Quatric Survey Software facilitates immediacy of Internet survey results, storage and analysis of data, and ultimately reduced errors in data entry.

### **Limitations**

Several threats to internal and external validity in this study were identified. The PCOS questionnaire was developed by the researcher and need further study to establish validity and reliability. Some items on the survey may need to be revised in order to collect the highest level of data possible (e.g. ages, years of work experience). Low response rate (2.09%, n=341) threatened external validity and limited the generalizability of the findings. While low response rate from electronic mail and Internet surveys have historically been reported in the literature (Hunter et al., 2012; Kongsved, Basnov, Holm & Hjollund 2007), measures were taken to increase study participation rates. These measures include: using a shorter questionnaire, providing a clear completion deadline, sending two reminder emails, and providing survey results. Findings of this study should not be generalized to all primary care providers as most of participants were certified nurse practitioners.

### **Conclusion**

This study identified factors considered and barriers experienced when practitioners diagnose PCOS in adolescents. Practitioners are strongly encouraged to evaluate adolescents when clinical manifestations of PCOS occur. While some symptoms may appear to be a normal physiological part of puberty, diagnosis of PCOS should be considered. In addition, PCOS is a diagnosis of exclusion. Therefore parents should be encouraged to be patient and understanding with the diagnostic process of PCOS in their

adolescent since it can be time consuming. Future studies should focus on evaluating currently used diagnostic criteria in the adolescent population, and explore developing a specific diagnostic criterion for adolescents to increase diagnostic rates.

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## APPENDICES

## Appendix A

### Questionnaire: Polycystic Ovarian Syndrome (PCOS) in Adolescence

**Purpose:** The purposes of this survey are to: (1) identify factors practitioners consider when determining the diagnosis of PCOS in adolescents (**ages 13-18**) and (2) identify barriers to early diagnosis of PCOS in adolescents (**ages 13-18**) among practitioners.

**Instructions:** Please choose the most appropriate response to the question. If more than one choice applies then choose all that apply. For the questions which require a written response, please provide a response to the best of your knowledge.

#### Demographics

1. Gender:
  - a. Male
  - b. Female
2. Age:
  - a. 25-35
  - b. 36-45
  - c. 46-55
  - d. 56-65
  - e. 66+
3. Ethnicity:
  - a. White or non Hispanic
  - b. Black or African American
  - c. American Indian or Alaska Native
  - d. Asian
  - e. Native Hawaiian or Other Pacific Islander
  - f. Hispanic
  - g. Other \_\_\_\_\_
4. Practice Area:
  - a. Medical Doctors
  - b. Doctors of Osteopath
  - c. Certified Nurse Practitioners
  - d. Certified Nurse Midwives
  - e. Clinical Nurse Specialist

- f. Other non-physician provider \_\_\_\_\_
5. Practice specialty:
- a. Endocrinology
  - b. Family Practice
  - c. Gynecology
  - d. Obstetrics and Gynecology
  - e. Obstetrics
  - f. Pediatrics
  - g. Pediatric Endocrinology
  - h. Women's health center
  - i. Other \_\_\_\_\_
6. How many years have you been working in your practice setting?
- a. 0-5
  - b. 6-10
  - c. 11-15
  - d. 16-20
  - e. 20+

### **Polycystic Ovarian Syndrome Diagnosis (PCOS) in Adolescents**

7. Have you ever diagnosed a patient with PCOS?
- a. Yes
  - b. No (if no, stop now and return survey)
8. What is your estimation of the prevalence of PCOS in your practice.
- a. 1-5%
  - b. 5-10%
  - c. 10-20%
  - d. 20-30%
  - e. > 30%
9. What is your estimation of the prevalence of PCOS **among adolescents** (ages 13-18) in your practice.
- a. 1-5%
  - b. 5-10%



- c. 10-20%
  - d. 20-30%
  - e. > 30%
10. I have diagnosed an adolescent (age 13-18) with PCOS.
- a. Yes
  - b. No (if not skip question 11 and 13)
11. I have diagnosed PCOS in an adolescent within the following age ranges:
- a. <13; if so at what age \_\_\_\_\_
  - b. 13-15
  - c. 16-18
12. The clinical manifestation(s) I have seen in adolescents I have diagnosed with PCOS:  
(select all that apply)
- a. Hirsutism
  - b. Acne
  - c. Overweight (BMI 25.0-29.9/ 85<sup>th</sup> -95<sup>th</sup> percentile)
  - d. Obesity (BMI 30.0+/95<sup>th</sup> percentile +)
  - e. Insulin Resistance
  - f. Menstrual disruption/irregularities
  - g. Other \_\_\_\_\_
13. The symptoms I most often use to diagnose PCOS in adolescents: (select all that apply)
- a. Oligo-amenorrhea
  - b. Anovulation
  - c. Clinical signs of hyperandrogenism (excess hair growth, acne, alopecia, rapid weight gain/ difficulty losing weight)
  - d. Biochemical signs of hyperandrogenism (hyperinsulinemia, hyperglycemia, hyperandrogenemia, dyslipidemia, elevated FSH:LH ratio)
  - e. Polycystic Ovaries (ovarian volume > 10 ml "string of pearls"/ hyperthecotic appearance)
  - f. Other \_\_\_\_\_
14. Diagnostic Criteria I use to guide my diagnosis of PCOS in adolescents (select all that apply)
- a. NIH
  - b. Rotterdam ESHRE/ASRM
  - c. Other \_\_\_\_\_

15. The diagnosis of PCOS is typically made by exclusion. The tool(s)/testing that I use to diagnose PCOS in adolescents is/are: (select all that apply)

- a. Menstrual Calendar
- b. Androgen Analysis
- c. Diabetic Screening
- d. Diagnostic Imaging
- e. Other \_\_\_\_\_

16. I have diagnosed adult women with PCOS who have reported clinical manifestations in adolescent years (ages 13-18)

- a. Yes
- b. No

### Barriers

17. Do you perceive any barriers to diagnosing PCOS in the adolescent population?

- a. Yes
- b. No

18. What barrier(s) do you feel you encounter when diagnosing adolescents with PCOS: (select all that apply)

- a. I have not seen PCOS in adolescents
- b. There is no defined diagnostic criteria to diagnose adolescents with PCOS
- c. The manifestations most often used to diagnose PCOS are also part of normal physiologic pubertal changes and will subside
- d. Adolescents are not seeking fertility counseling
- e. My lack of knowledge concerning the diagnosis and treatment of PCOS
- f. Other barriers \_\_\_\_\_

19. Please feel free to add any comments or suggestions to diagnostic barriers of PCOS in adolescence:

## Appendix B

### Participants Information Sheet

Dear Potential Participant's,

My name is Tara Williams I am a Registered Nurse currently working on my Masters Degree to become a Family Nurse Practitioner at Cedarville University. As a part of my capstone experience I am working on a research project titled "A Practitioner's Perspective on the Barriers to Diagnosing Polycystic Ovarian Syndrome in Adolescents: A Descriptive Study".

Although the majority of reproductive and metabolic consequences can be identified in adolescence, diagnosis of PCOS for subsequent early intervention is still not taking place as many women are not being diagnosed until their reproductive years often after seeking the cause of their infertility. No literature could be found on barriers that contribute to the failure of early diagnosis of PCOS in adolescence. There is a gap in the literature investigating the barriers of diagnosing PCOS in adolescents.

I have selected you to help better understand the (1) factors practitioners consider when determining the diagnosis of PCOS in adolescents (ages 13-18) and (2) barriers to early diagnosis of PCOS in adolescents (ages 13-18) among practitioners. This descriptive study is being conducted with the hope of addressing gaps in the literature by exploring the potential barriers of the PCOS diagnosis in adolescents. Results of this study will provide a foundation for the early intervention of adolescents with PCOS through raising awareness of the need to establish an early diagnosis of PCOS in adolescents when the clinical manifestations appear.

I ask that you complete a short multiple choice questionnaire that can be accessed via the link provided at the bottom of this email. This questionnaire is based on the research findings in the literature. This eighteen-item electronic questionnaire consists of three categories: demographics, diagnostic process of PCOS and the perceived barriers in diagnosing PCOS in adolescents. The typical length of time for completing the questionnaire is 5-10 minutes. Completion of the questionnaire is treated as the consent to participate in this descriptive study. The survey results will be provided via email to participants.

Thank you for your time and consideration,

Tara Williams

Please follow the link provided below to the attached questionnaire- *Polycystic Ovarian Syndrome in Adolescent Questionnaire* and provide your feedback via email by **August 11, 2014**.  
Your assistance is greatly appreciated.

## Appendix C

### Participants Information Sheet

Please consider completing the PCOS Survey. Your time and knowledge in this matter will be greatly appreciated! Deadline for completion is a week away, August 11, 2014.

Dear Potential Participants,

My name is Tara Williams I am a Registered Nurse currently working on my Masters Degree to become a Family Nurse Practitioner at Cedarville University. As a part of my capstone experience I am working on a research project titled “A Practitioner’s Perspective on the Barriers to Diagnosing Polycystic Ovarian Syndrome in Adolescents: A Descriptive Study”. Although the majority of reproductive and metabolic consequences can be identified in adolescence, diagnosis of PCOS for subsequent early intervention is still not taking place as many women are not being diagnosed until their reproductive years often after seeking the cause of their infertility. No literature could be found on barriers that contribute to the failure of early diagnosis of PCOS in adolescence. There is a gap in the literature investigating the barriers of diagnosing PCOS in adolescents.

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Completion of the questionnaire is treated as the consent to participate in this descriptive study. The survey results will be provided via email to participants.

Thank you for your time and consideration,

Tara Williams

Please follow the link provided below to the attached questionnaire- *Polycystic Ovarian Syndrome in Adolescent Questionnaire* and provide your feedback via email by **August 11, 2014**.

Your assistance is greatly appreciated.

## Appendix D

### Participants Information Sheet

Please consider completing the PCOS Survey. Your time and knowledge in this matter will be greatly appreciated! Deadline for completion is only 3 days away, August 11, 2014.

Dear Potential Participants,

My name is Tara Williams I am a Registered Nurse currently working on my Masters Degree to become a Family Nurse Practitioner at Cedarville University. As a part of my capstone experience I am working on a research project titled “A Practitioner’s Perspective on the Barriers to Diagnosing Polycystic Ovarian Syndrome in Adolescents: A Descriptive Study”.

Although the majority of reproductive and metabolic consequences can be identified in adolescence, diagnosis of PCOS for subsequent early intervention is still not taking place as many women are not being diagnosed until their reproductive years often after seeking the cause of their infertility. No literature could be found on barriers that contribute to the failure of early diagnosis of PCOS in adolescence. There is a gap in the literature investigating the barriers of diagnosing PCOS in adolescents.

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I ask that you complete a short multiple choice questionnaire that can be accessed via the link provided at the bottom of this email. This questionnaire is based on the research findings in the literature. This eighteen-item electronic questionnaire consists of three categories: demographics, diagnostic process of PCOS and the perceived barriers in diagnosing PCOS in adolescents. The typical length of time for completing the questionnaire is 5-10 minutes.

Completion of the questionnaire is treated as the consent to participate in this descriptive study. The survey results will be provided via email to participants.

Thank you for your time and consideration,

Tara Williams

Please follow the link provided below to the attached questionnaire- *Polycystic Ovarian Syndrome in Adolescent Questionnaire* and provide your feedback via email by **August 11, 2014**.

Your assistance is greatly appreciated.



## Appendix E

### Participants Information Sheet

I had a very low response and am resending in hopes of gaining more participation for the sake of my research. Please reconsider responding to my survey by August 17,2014. If you have already responded please disregard and thank you for your input.

If you have any questions or concerns please feel free to contact me at [██████████@cedarville.edu](mailto:██████████@cedarville.edu)

Dear Potential Participant's,

My name is Tara Williams I am a Registered Nurse currently working on my Masters Degree to become a Family Nurse Practitioner at Cedarville University. As a part of my capstone experience I am working on a research project titled "A Practitioner's Perspective on the Barriers to Diagnosing Polycystic Ovarian Syndrome in Adolescents: A Descriptive Study". Although the majority of reproductive and metabolic consequences can be identified in adolescence, diagnosis of PCOS for subsequent early intervention is still not taking place as many women are not being diagnosed until their reproductive years often after seeking the cause of their infertility. No literature could be found on barriers that contribute to the failure of early diagnosis of PCOS in adolescence. There is a gap in the literature investigating the barriers of diagnosing PCOS in adolescents.

I have selected you to help better understand the (1) factors practitioners consider when determining the diagnosis of PCOS in adolescents (ages 13-18) and (2) barriers to early diagnosis of PCOS in adolescents (ages 13-18) among practitioners. This descriptive study is being conducted with the hope of addressing gaps in the literature by exploring the potential barriers of the PCOS diagnosis in adolescents. Results of this study will provide a foundation for the early intervention of adolescents with PCOS through raising awareness of the need to establish an early diagnosis of PCOS in adolescents when the clinical manifestations appear.

I ask that you complete a short multiple choice questionnaire that can be accessed via the link provided at the bottom of this email. This questionnaire is based on the research findings

in the literature. This eighteen-item electronic questionnaire consists of three categories: demographics, diagnostic process of PCOS and the perceived barriers in diagnosing PCOS in adolescents. The typical length of time for completing the questionnaire is 5-10 minutes. Completion of the questionnaire is treated as the consent to participate in this descriptive study. The survey results will be provided via email to participants.

Thank you for your time and consideration,

Tara Williams

Please follow the link provided below to the attached questionnaire- *Polycystic Ovarian Syndrome in Adolescent Questionnaire* and provide your feedback via email by **August 17, 2014**. Your assistance is greatly appreciated.