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Illness Perceptions of Polycystic Ovary Syndrome

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Illness Perceptions of Polycystic Ovary Syndrome

by

Elizabeth A. Baker

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Community and Family Health
College of Public Health
University of South Florida

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Dedication

To all women living with polycystic ovary syndrome

Acknowledgments

I would like to extend sincere appreciation to those who not only have supported me in my program, but also who have encouraged me throughout my journey. Without them, my accomplishments would not be possible.

First and foremost, I would like to thank my mother, Joan Baker, for always giving me her endless love and unwavering support. Thank you for never allowing me to give up on my goals. By example, you have shown me what can be accomplished with hard work and perseverance. Although I will never be able to fully express my appreciation for everything you have done for me, for us, know that I am forever grateful to have had such a strong, independent woman in my life, supporting me every step of the way. You will always be my first role model, first friend, and first love.

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encouraged me to push through, and I cannot wait to meet you! It's an interesting time in my life. I have spent eleven year in college working towards what I thought would be my greatest accomplishment, a doctoral degree. While I am still very proud of myself for reaching my academic goals, I already know that, as your mother, even the smallest of your accomplishments will give me the greatest joy of anything life has to offer.

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Abbreviations
(Alphabetical order)

AACE	American Association of Clinical Endocrinologists
ACOG	American College of Obstetrics and Gynecology
ART	assisted reproductive technologies
ASRM	American Society for Reproductive Medicine
CSM	Common-Sense Model of Self-Regulation of Health and Illness
CVD	cardiovascular disease
ESHRE	European Society of Human Reproduction and Endocrinology
GAO	General Accounting Office
GDM	gestational diabetes mellitus
HIPPA	Health Insurance Portability and Accountability Act
HRQoL	health-related quality of life
ICD-9	International Classification of Diseases -Ninth Revision
IGT	impaired glucose tolerance
IPQ	Illness Perceptions Questionnaire
IPQ-R	Illness Perceptions Questionnaire - Revised
IR	insulin resistance
IVF	in-vitro fertilization
MeSH	medical subject headings
MetS	metabolic syndrome
NIH	National Institutes of Health
OBOS	<i>Our Bodies, Ourselves</i>
OCPs	oral contraceptive pills
OSA	obstructive sleep apnea
ORWH	Office of Research on Women's Health
PCOS	polycystic ovary syndrome
PCOSQ	PCOS Questionnaire
SF-36	36-Item Short Form Survey
SGA	small for gestational age
SNS	social networking site
T2D	type 2 diabetes mellitus

Abstract

Polycystic ovary syndrome (PCOS) is a chronic illness that affects approximately five million premenopausal women in the United States and is associated with significant cosmetic, reproductive, metabolic, and psychological consequences. Despite its prevalence, few studies have explored the lived experiences and illness perceptions of women living with PCOS. Identifying illness perceptions of women living with (WLW) PCOS is important, because mounting research suggests that a person's perceptions of their chronic illness and its management determine that person's coping behaviors (e.g., adherence, self-management) and, consequently, illness outcomes.

In this dissertation, the Common Sense Model (CSM) is used as a framework to identify the illness perceptions of PCOS held by WLW the syndrome. As such, this dissertation is the first to test the *ecological validity* of the CSM in a population of women diagnosed with PCOS. In addition, the relationship between illness perceptions and (1) infertility, a common symptom of the syndrome, and (2) health-related quality of life (HRQoL) is explored. Lastly, this study makes a novel contribution to the literature by describing one of the first samples of WLW PCOS recruited through a social networking site. This includes a discussion of the participant's demographic information, fertility experiences, and HRQoL.

This is a two-phase mixed methods study. Phase one consisted of an online quantitative survey capturing data on 376 participants' demographic information and medical history. Data were also collected on each participant's HRQoL using the SF-36, a generic, well-validated measure of the phenomenon. Of the 376 survey participants, 34 were interviewed via phone or

video chat in the fall 2013 and spring 2014 semesters. Quantitative data were downloaded from Qualtrics® and analyzed using SAS statistical software version 9.3. In this analysis, descriptive statistics were generated to describe sample characteristics and SF-36 domain scores were calculated for each participant. In the qualitative analysis, data were analyzed through a series of sorting techniques and transcripts were imported into NVivo 10 and subjected to content analysis.

The mean age of survey participants was 31.8 years (SD=5.8). Respondents were primarily non-Hispanic (92.5%), white (88.3%), straight (94.4%), and married (73.4%) with a college education (64.1%). On average, participants reported living with PCOS for 7.6 years (SD=6.1). Approximately half of the sample reported having biological children (47.9%) and currently trying to conceive (42.1%), and most participants reported a history of infertility (70.7%). In addition, almost half of the total sample reported heights and weights that placed them in the morbidly obese category ($BMI \geq 35$). Lastly, a history of depression (63.6%) and anxiety (68.6%) was common among participants.

Few survey participants reported their general health as being excellent (2.6%) or very good (27.4%). Similarly, women reported the lowest levels of functioning on the dimension of vitality, meaning that, in general, women reported feeling tired and being low in energy. Conversely, women reported the highest scores on the dimensions of physical functioning and role limitations due to physical health, meaning that, in general, women did not report that their health limited their physical abilities or caused problems with work or other daily activities.

Interview findings suggest that WLW PCOS generally have illness perceptions of the syndrome that are consistent with the domains identified in the CSM. In addition, it was found that, in relation to their illness cognitions, WLW PCOS described the extent to which they felt

they had a comprehensive understanding of the syndrome, a phenomenon labeled *illness coherence*. Similarly, participants identified PCOS as a common condition (i.e. labeled *perceived prevalence*). Lastly, a number of relationships were identified between illness perceptions and (1) infertility status and (2) HRQoL scores.

Overall, this dissertation identifies a number of implications for patient education, provider education, clinical practice, and policy improvements. Examples include addressing (1) unmet information needs, (2) significant psychological morbidity and unmet mental health needs, (3) breastfeeding challenges and need for breastfeeding support, (4) poor quality of care and low patient satisfaction, and (5) limited access to care – all among women living with PCOS.

Chapter 1: Introduction

Polycystic ovary syndrome (PCOS) is a common hormone disorder that affects approximately five million premenopausal women in the United States (Leventhal, Brisette, & Leventhal, 2003; National Institutes of Health, 2012). It is a chronic condition characterized by clinical and/or biochemical signs of androgen excess, ovulatory dysfunction, and polycystic ovaries (Azziz et al., 2006). As such, common manifestations of PCOS include hirsutism, acne, and alopecia, due to androgen excess, and signs of ovulatory dysfunction, including menstrual irregularities and infertility (Teede et al., 2010). These symptoms can be a major source of psychological morbidity and are associated with a significant reduction in health-related quality of life (HRQoL) (Barry, Kuczmierczyk, & Hardiman, 2011; Jones, Hall, Balen, & Ledger, 2007). Moreover, women living with (WLW) PCOS are typically insulin resistant, and, consequently, the syndrome is a risk factor for the metabolic syndrome (MetS) and associated sequelae, including cardiovascular disease (CVD) and type 2 diabetes mellitus (T2D) (Tomlinson, Millward, Stenhouse, & Pinkney, 2010). Because HRQoL is identified as a national health standard and because T2D and CVD are national health priority areas (U.S. Department of Health and Human Services), PCOS is identified as a “major public health issue for women” (National Institutes of Health, 2012).

Like other syndromes,^a the clinical spectrum of PCOS varies widely (Balen et al., 1995). At one end of the spectrum are women who are largely asymptomatic, and, at the other are

Defined as a group of symptoms that together are characteristic of a specific disorder, disease, or the like.

women who present with most manifestations of the syndrome. While the presence of a woman on the spectrum is likely predetermined by genetic factors (Givens, 1988; Govind, Obhrai, & Clayton, 1999; Kashar-Miller, Nixon, Boots, Go, & Azziz, 2001; Prapas et al., 2009; Wilroy et al., 1975), her position on the spectrum is likely related to lifestyle factors, particularly degree of obesity (Gambineri, Pelusi, Vicennati, Pagotto, & Pasquail, 2002; Glueck et al., 2005; Lord & Norman, 2006; McCook, 2002; Nestler, Clore, & Blackard, 1989; Pasquail, Gambineri, & Pagotto, 2006). That is, obese WLW PCOS typically present with more manifestations of the syndrome (Acién et al., 1999; Balen et al., 1995; Kiddy et al., 1990; Rachon & Teede, 2010).

Because there is no cure for PCOS and because body weight has an important bearing on the phenotype of the syndrome, a woman's ability to achieve and maintain a normal body weight is critical to improving her health, including her HRQoL, and preventing long-term complications of PCOS (Panidis et al., 2013; R. Thomson et al., 2010). As such, lifestyle changes, including diet modifications and increased physical activity, are advocated as the first-line therapeutic approach (Teede et al., 2010). Also, pharmacological interventions may be appropriate and are dependent on the presenting symptoms of the woman and her preferences (Benjamins & Barratt, 2009). In these cases, successful PCOS management is not only determined by a woman's ability to achieve and maintain a healthy body weight but also by her adherence to a medical regimen. In short, the management of PCOS, like other chronic conditions, requires considerable self-care efforts by WLW the syndrome.

Statement of Need

Although self-care is emphasized in PCOS management, little attention has been paid to why some women readily engage in PCOS self-care behaviors while others do not. At the same time, there is an abundance of literature on self-care among other illness populations, including

those living with PCOS-related conditions such as T2D and CVD. In this literature, many factors that influence self-care behaviors have been identified, and much attention has been given to the perceptual and cognitive factors that underlie individuals' motivations or intentions to adopt self-care behaviors (Ory & DeFries, 1998). In this field of inquiry, illness perceptions have emerged as a significant factor influencing self-care behaviors and, consequently, illness outcomes (Leventhal, Leventhal, & Robitaille, 1998).

Theoretical Framework

Illness perceptions are an individual's beliefs and expectations about an illness and have predominantly been described as part of the common-sense model (CSM) of self-regulation of health and illness developed by Leventhal and colleagues (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984). They maintain that individuals are active problem solvers who construct complex cognitive and emotional representations of illness, termed *illness perceptions*, when confronted with threats to their health. According to the model, illness perceptions give rise to self-regulation efforts or *coping strategies*, which are evaluated in terms of their success in reaching a desired goal. The result of the evaluation may be a change in perceptions about the illness and/or a change in the coping strategy. In short, the CSM presents a mediational model in which coping mediates the effects of illness perceptions on health outcomes.

Although cognitions and emotions are equally emphasized in the CSM, cognitions receive more attention in the literature. Leventhal et al. (2003) identifies five related, but conceptually and empirically distinct, core dimensions of cognitive representations of illness: *identity* (perceptions of symptoms and illness labels), *consequences* (beliefs about illness outcomes: physical, social, and behavioral), *timeline* (expectations about the duration of illness

and persistence of symptoms), *cause* (beliefs about the cause of the illness: biological, emotional, environmental, or psychological), and *cure/control* (beliefs about controllability and curability of illness or symptoms) (see Table 1 for PCOS example). These cognitive representations are processed in parallel to emotional representations, which create feeling states such as anger, depression, and anxiety (Leventhal, Diefenbach, & Leventhal, 1992).

Table 1. Cognitive Representations of Illness: A PCOS Example	
Identity	Label/name women give to <i>PCOS</i> and the symptoms women associate with the syndrome
Consequences	Impact of <i>PCOS</i> and its symptoms on women's well being
Timeline	Women's expectations about the duration of <i>PCOS</i> and persistence of its symptoms
Cause	Perceived cause of <i>PCOS</i>
Cure/Control	Women's beliefs that <i>PCOS</i> is either curable and/or controllable

The assumptions of the CSM are supported by cross-sectional and longitudinal data from studies of individual's with a range of medical conditions, including myocardial infarction (French, Cooper, & Weinman, 2006), diabetes (Mc Sharry, Moss-Morris, & Kendrick, 2011), rheumatoid arthritis (Graves, Scott, Lempp, & Weinman, 2009), asthma (Kaptein, Klok, Moss-Morris, & Brand, 2010), chronic fatigue syndrome (Knoop, Prins, Moss-Morris, & Bleijenberg, 2010), and Crohn's disease (Knowles, Wilson, Connell, & Kamm, 2011). Studies centering on mental health conditions such as schizophrenia (Lobban, Barrowclough, & Jones, 2005) and depression (Lynch, Moore, Moss-Morris, & Kendrick, 2011) also support the assumptions of the CSM. Likewise, a number of reviews and meta-analyses report a relationship among illness perceptions, coping strategies, and health outcomes (Hagger & Orbell, 2003a; Hoving, van der Meer, Volkova, & Frings-Dresen, 2010; Kaptein et al., 2008; Kucukarslan, 2012; Petrie, Jago, & Devcich, 2007).

Purpose of the Dissertation

Because little is known about factors that influence self-care behaviors of WLW PCOS and because illness perceptions have emerged as an important antecedent of self-care, **the primary purpose of this dissertation is to identify the illness perceptions of PCOS held by WLW the syndrome.** In this investigation, the relationship between illness perceptions and infertility, a common symptom of the syndrome is also explored. Infertility is emphasized for two reasons. First, the CSM posits that emotional responses to an illness (and its symptoms) are antecedents of illness perceptions. The literature suggests that WLW PCOS have strong emotional responses to infertility (Jones et al., 2007; Y. Li et al., 2011; Shi, Zhang, Fu, & Li, 2011). Therefore, the experience of infertility may influence the illness perceptions of WLW PCOS. Second, the CSM suggests that individuals construct illness perceptions according to the concrete and abstract sources of information available to them (Leventhal et al., 2003). Because WLW PCOS who experience infertility typically require additional medical interventions (Brassard, AinMelk, & Baillargeon, 2008) and because medical interventions, by nature, require more interactions with healthcare providers (who are potential sources of information), WLW PCOS who experience infertility may have additional and unique opportunities to obtain information.

The relationship between illness perceptions and HRQoL is also explored in this study. Although the literature clearly indicates that PCOS has a significant impact on HRQoL (Jones et al., 2007; Trent, Rich, Austin, & Gordon, 2002), few factors that contribute to this have been explored (Barnard et al., 2007). All but one study has focused on clinical features of the syndrome and their management. These few studies suggest (1) that symptoms associated with the syndrome (i.e. ovulatory dysfunction, hirsutism, obesity, and infertility) contribute

significantly to the reduction of HRQoL and (2) that successful management of these symptoms improve HRQoL (Jones et al., 2007). Given these findings, an expectation may exist for a direct relationship between clinical severity of PCOS and HRQoL. However, Trent and colleagues (Trent et al., 2002) report that *perception* of PCOS severity, not actual severity, correlates directly with HRQoL. This finding emphasizes the need for further investigations into the perceptual factors related to HRQoL. Because illness perceptions of PCOS may be a promising determinant of HRQoL among WLW the syndrome, an exploration of the relationship between illness perceptions and HRQoL compliments the primary aim of this dissertation.

Like other research studies, an important task is to describe the sample of women recruited for the study. Because accessing a clinical population of WLW PCOS is not feasibly in the current study, WLW PCOS were recruited from a social networking site (SNS). This study makes a novel contribution to the literature by describing one of the first samples of WLW PCOS recruited through a SNS. This includes a discussion of the participant’s demographic information, fertility experiences, and HRQoL.

Specific Aims and Research Questions

The specific aims and research questions of the dissertation are listed in Table 2.

Table 2. Specific Aims and Research Questions of the Dissertation

Specific Aims and sub-aims	Research Questions
<ol style="list-style-type: none"> 1. To identify the illness perceptions of PCOS held by WLW the syndrome. <ol style="list-style-type: none"> a. To explore the relationship between infertility and illness perceptions of PCOS held by WLW the syndrome b. To explore the relationship between HRQoL and illness perceptions of PCOS held by WLW the syndrome 	<ol style="list-style-type: none"> 1. What illness perceptions do women hold about their PCOS? How do these relate to the CSM? How do they differ? 2. Does the experience of infertility impact the illness perceptions that women hold about their PCOS? 3. Is there a relationship between women’s HRQoL and the illness perceptions they have about PCOS?

Table 2 (Cont)

Specific Aims and sub-aims	Research Questions
2. To identify the illness perceptions of PCOS held by WLW the syndrome. c. To explore the relationship between infertility and illness perceptions of PCOS held by WLW the syndrome d. To explore the relationship between HRQoL and illness perceptions of PCOS held by WLW the syndrome	4. What illness perceptions do women hold about their PCOS? How do these relate to the CSM? How do they differ? 5. Does the experience of infertility impact the illness perceptions that women hold about their PCOS? 6. Is there a relationship between women's HRQoL and the illness perceptions they have about PCOS?

Significance of the Dissertation

The present study identifying the illness perceptions of PCOS held by WLW PCOS is novel in a number of ways. Most importantly, this study is the first to identify the illness perceptions of WLW PCOS and informs future studies exploring the mediating role of illness perceptions on PCOS outcomes. If this role is significant, addressing illness perceptions could be an effective strategy in promoting self-care behaviors among WLW PCOS and preventing PCOS-related illness.

This study also is the first to test the *ecological validity* of the CSM in a population of women diagnosed with PCOS. That is, it is the first to explore to what extent the dimensions of the CSM conform to the illness perceptions of WLW PCOS. In the field of health education and promotion, an important goal is to test health behavior theories iteratively in the real world (Rosenstock, 1990). While the CSM has been used as a guiding framework in studies of acute and chronic conditions, both physical and mental, no PCOS-related studies have adopted the CSM.

In addition, this study is the first to explore the relationship between illness perceptions of WLW PCOS and their HRQoL. If specific illness perceptions are associated with HRQoL, addressing these illness perceptions could be an effective strategy in increasing HRQoL among WLW the syndrome. This is important, because HRQoL is identified as a national health standard (U.S. Department of Health and Human Services). Lastly, this study will be the first to describe a sample of WLW PCOS recruited through a SNS.

Definition of Key Terms

1. *Health-related quality of life* (HRQoL) is a “multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact health status has on quality of life” (U.S. Department of Health and Human Services).
2. *Illness perceptions*^a are a person’s beliefs and expectations about illness. According to the CSM, cognitive and emotional representations of illness shape a person’s illness perceptions (Leventhal et al., 2003).
3. *Polycystic ovary syndrome* (PCOS)^b is a chronic condition characterized by a set of symptoms that result from a hormonal imbalance in the female body (The Rotterdam ESHRE/ASRM-Sponsored PCOS consensus workshop group, 2004b). Although the diagnostic criteria for PCOS remains debated, all proposed criteria center around the

^a Some authors use the terms *cognitive representations of illness* and *illness perceptions* interchangeably. Depending on the author and/or the purpose of the text, a discussion of emotional representations of illness may or may not be included. For this dissertation, the term *illness perceptions* is used in the context of the CSM and is distinct from *cognitive representations of illness*.

^b Polycystic ovary syndrome is also known as *polycystic ovarian syndrome*, *hyperandrogenic chronic anovulation*, *functional ovarian hyperandrogenism*, and *Stein-Leventhal syndrome*. These terms are used interchangeably typically depending on author or organization preferences and date of publication. For this dissertation, the term *polycystic ovary syndrome* is used throughout for consistency.

following key features: (1) excess androgen, (2) ovulatory dysfunction, and (3) polycystic ovaries.

4. *Self-care* is defined as the activities individuals “undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health” (World Health Organization, 1983).

Chapter 2: Review of the Literature

Using the most conservative prevalence estimates (5%) of polycystic ovary syndrome (PCOS), it can be said that at least 5 million American women of reproductive age live with the syndrome (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012). While some women living with (WLW) PCOS will remain largely asymptomatic throughout their lives, others may experience numerous dermatologic, reproductive, metabolic, and psychological issues (Teede et al., 2010). Either way, the lived experience WLW PCOS may begin with a number of seemingly unrelated health issues, continue with difficulties in obtaining services that may not be covered by health insurance, and, even if receiving treatment, result in reduced health-related quality of life (HRQoL). Each step of this journey will be characterized by interactions among (1) physical and social environments, (2) the biology and behavior of the individual, and (3) the healthcare system. “On a population scale, these interactions create patterns of disease, utilization of services, and outcomes” that have major public health implications (Macaluso et al., 2010).

For this reason, a public health approach to PCOS is adopted in this dissertation. Because PCOS is not preventable, primary prevention efforts may not be directed at the condition itself (Tweedy, 2000). However, secondary prevention efforts can be directed at identifying women with PCOS early so that prompt and appropriate management can be initiated (Stankiewicz & Norman, 2006). Also, tertiary prevention efforts targeting weight reduction in obese WLW PCOS and prevention of excess weight gain in all WLW PCOS are recommended to improve PCOS-related outcomes and is the focus of this dissertation.

The following literature review is organized into three main sections. The first section provides a brief overview of PCOS. Specifically, the definitions, prevalence estimates, and manifestations are described. The pathophysiology and therapeutic approaches to PCOS are also outlined to facilitate understanding of the syndrome. In the second section, PCOS research and clinical practices related to PCOS are summarized to illustrate the need for the dissertation. Lastly, an overview of the theoretical framework on which this study is based is provided.

Polycystic Ovary Syndrome (PCOS)

Pathophysiology. In brief, an underlying hormonal imbalance created by a combination of elevated androgen (i.e. hyperandrogenism) and insulin levels (i.e. hyperinsulinemia leading to insulin resistance) underpin PCOS (Balen et al., 1995; Kiddy et al., 1990). While it is well accepted that genetic and environmental factors contribute to this imbalance (Gambineri et al., 2002; Givens, 1988; Govind et al., 1999; Kashar-Miller et al., 2001; Nestler et al., 1989; Prapas et al., 2009; Wilroy et al., 1975), a better understanding of these pathophysiological contributors has been hampered by a lack of ideal methods to assess both hyperandrogenism and insulin resistance (IR) (Azziz, 2004; Barth, Yasmin, & Balen, 2007). It has been estimated that up to 70% of WLW the syndrome have elevated androgen levels, and the other 30% are in the high-normal range (Marx & Metha, 2003). Likewise, it has been suggested that all women with the syndrome have IR, although IR has only been described in 50-80% of populations of WLW PCOS (Dunaif, 1997, 2003). Again, methods used to measure IR have been cited for this discrepancy. Because hyperandrogenism and hyperinsulinemia coexist in PCOS, it is unclear if one causes the other. However, it has been established that they reinforce one another and disrupt ovarian follicular development (Pfeifer & Kives, 2009). The consequent follicular arrest is responsible for the polycystic ovarian morphology commonly described in WLW PCOS and is

often accompanied by oligo- and/or anovulation (defined as infrequent ovulation or absence of ovulation)(Brassard et al., 2008; Carmina & Lobo, 1999; Teede et al., 2010).

Definition. Currently, there is no international consensus on the definition of PCOS. Agreement has only been reached that PCOS is indeed a syndrome (i.e. a heterogeneous condition with unknown etiology) and is a diagnosis of exclusion^a (The Rotterdam ESHRE/ASRM-sponsored PCOS consensus workshop group, 2004a). Various diagnostic criteria have been proposed, generally centered on the features of hyperandrogenism, oligo- and/or anovulation, and polycystic ovarian morphology (see Table 3) (The Rotterdam ESHRE/ASRM-sponsored PCOS consensus workshop group, 2004a). Although four main phenotypes have been identified, many experts argue that only two are justifiable (e.g. Phenotypes A and B; see Table 3) (Azziz et al., 2006). The issue that is debated most contentiously is whether the diagnosis should require confirmation of polycystic ovaries (PCO) (Azziz, 2006; Balen & Michelmore, 2002; Franks, 2006). Thus, the term *polycystic ovary syndrome* adds to the confusion surrounding its diagnosis (Balen & Michelmore, 2002).

Inclusion of PCO in diagnostic criteria is debated for two main reasons: (1) there is no universally agreed upon PCO ultrasound criteria for the diagnosis of PCOS and (2) the long-term health risks of PCOS phenotypes including PCO are poorly understood (Balen & Michelmore, 2002). The latter is important, because syndromes are largely defined by their long-term health risks (Azziz et al., 2006). In the case of PCOS, the increased risk of developing type 2 diabetes mellitus (T2D) is most often used as the phenotypic anchor against which to measure each phenotype. This does not imply, however, that all WLW PCOS will develop T2D, but that a phenotypic group collectively will be at higher risk.

Disorders which mimic PCOS phenotypes should first be excluded before diagnosis. These may include congenital adrenal hyperplasia, Cushing's syndrome, androgen-secreting tumors, 21-hydroxylase-deficient non-classic adrenal hyperplasia, thyroid dysfunction, hyperprolactemia, and androgen/anabolic drug use or abuse.

Table 3. Phenotypes of PCOS according to the 1990 NIH criteria, 2003 Rotterdam criteria, and 2006 AES criteria^a

Features	Phenotypes			
	A	B	C	D
Oligo- and/or anovulation	X	X	X	
Clinical and/or biochemical signs of hyperandrogenism	X	X		X
Polycystic ovaries	X		X	X
1990 NIH PCOS Diagnostic Criteria	✓	✓		
2003 Rotterdam Diagnostic Criteria	✓	✓	✓	✓
2006 AES Diagnostic Criteria	✓	✓		✓

X, Features included in phenotypes; ✓, phenotype included in definition

NIH= National Institutes of Health; AES=Androgen Excess Society

^a Assuming exclusion of other androgen excess or related disorders

While it is well established that phenotypes A and B are associated with an increased risk of T2D, there is less evidence to support an association with phenotypes C (i.e. “non-hyperandrogenic PCOS”) and D (i.e. “ovulatory PCOS”) (Ehrmann, Kasza, Azziz, Legro, & Ghazzi, 2005). However, research does suggest that women with PCO have a higher prevalence of androgen excess and IR (Azziz, 2004; Polson, Adams, Wadsworth, & Franks, 1988). According to NIH criteria, these women cannot be diagnosed with PCOS unless they also present with ovulatory dysfunction. Because women are able to move between ovulatory and anovulatory cycles as a result of changes in body weight, lifestyle choices, and age; a diagnosis of “ovulatory PCOS” is less debated than a diagnosis of “non-hyperandrogenic PCOS” (Azziz, 2006; Elting, Korsen, Rekers-Mombarg, & Shoemaker, 2000). However, more research is needed to determine the long-term health consequences of phenotypes C and D.

Prevalence. Prevalence estimates of PCOS are dependent on the criteria used to define the syndrome. In U.S. populations, researchers using the narrowest definition of PCOS, the NIH criteria, have consistently estimated that 5-10% of reproductive-age women have the syndrome, making it the most common endocrinopathy in this population (Speroff & Fritz, 2005). In a few

of these studies, researchers have reported that, if the broadest definition of PCOS (i.e. the Rotterdam criteria) were used, the overall prevalence of PCOS would increase approximately 21% (Trivax & Azziz, 2007). These figures are consistent with research findings in other countries, where studies using the Rotterdam criteria suggests a PCOS prevalence of 26% in women of reproductive age (Michelmore, Balen, Dungan, & Vessey, 1999). However, more research is needed to clarify the prevalence of PCOS phenotypes in both pre-menopausal and post-menopausal American women.

Also, prevalence estimates for different ethnic groups in the U.S. are difficult to compare, because different recruitment strategies and PCOS definitions are used. A few studies, however, have compared prevalence rates between ethnic groups in a single population. In a prevalence group of 400 Alabama women receiving pre-employment physicals, statistically similar prevalence rates were reported in white (4.8%) and black (8%) women using NIH criteria (Azziz et al., 2004). In another study, Lo et al. searched an automated health plan ambulatory visit database to identify WLW PCOS (Lo et al., 2006). Only 2.6% of women age 15-45 years had received such a diagnosis [International Classification of Diseases, Ninth Revision (ICD-9) code 256.4] - the smallest prevalence ever reported. Of the 11,035 women identified, 34.2% were white, 12% were Hispanic, 10.1% were Asian, and 5% were black (Note: 38.6% of the race/ethnicity data were missing). The limitations of these studies are many, and highlight the need for additional large-scale studies to clarify the prevalence of PCOS across different ethnic/racial groups. Specifically, the proportion of PCOS phenotypes among ethnic/racial groups should be determined.

Manifestations of PCOS. Despite their limitations, prevalence studies have led to a greater understanding of PCOS, and it is now recognized that there is a continuum of clinical

presentations (Balén et al., 1995). At one end of the continuum are women who are largely asymptomatic, and, at the other, are women who present with dermatologic, reproductive, metabolic, and psychological manifestations of the syndrome. While the presence of a woman on the continuum is likely predetermined by genetic factors (Givens, 1988; Govind et al., 1999; Kashar-Miller et al., 2001; Prapas et al., 2009; Wilroy et al., 1975), her position on the continuum is likely related to lifestyle factors, particularly degree of obesity (Gambineri et al., 2002; Glueck et al., 2005; Lord & Norman, 2006; McCook, 2002; Nestler et al., 1989; Pasquail et al., 2006). Obesity plays a central role in the phenotypic expression of PCOS by increasing insulin and androgen levels, leading to greater hormonal disturbances which are associated with more severe phenotypes (Gambineri et al., 2002; Nestler et al., 1989). For this reason, obese WLW PCOS present with more clinical manifestations of the syndrome, which are described below (Acién et al., 1999; Balén et al., 1995; Kiddy et al., 1990; Rachon & Teede, 2010).

Depending on the population studied, 20-76% of WLW PCOS are obese (Rachon & Teede, 2010; The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012). However, the highest prevalence of obesity is reported in studies conducted in Australia and the U.S (61-76%) (Rachon & Teede, 2010; The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012). These prevalence studies support other research findings which suggest that American WLW PCOS have more severe clinical manifestations of the syndrome than their counterparts in other countries (Carmina, Legro, Stamets, Lowell, & Lobo, 2003). These studies also highlight the public health significance of PCOS in the United States. For a summary of the etiology, hormonal, and clinical features of PCOS, see Figure 1.

Dermatologic Manifestations. Dermatologic manifestations of PCOS result from hyperandrogenism. Clinical signs of hyperandrogenism include hirsutism, acne vulgaris,

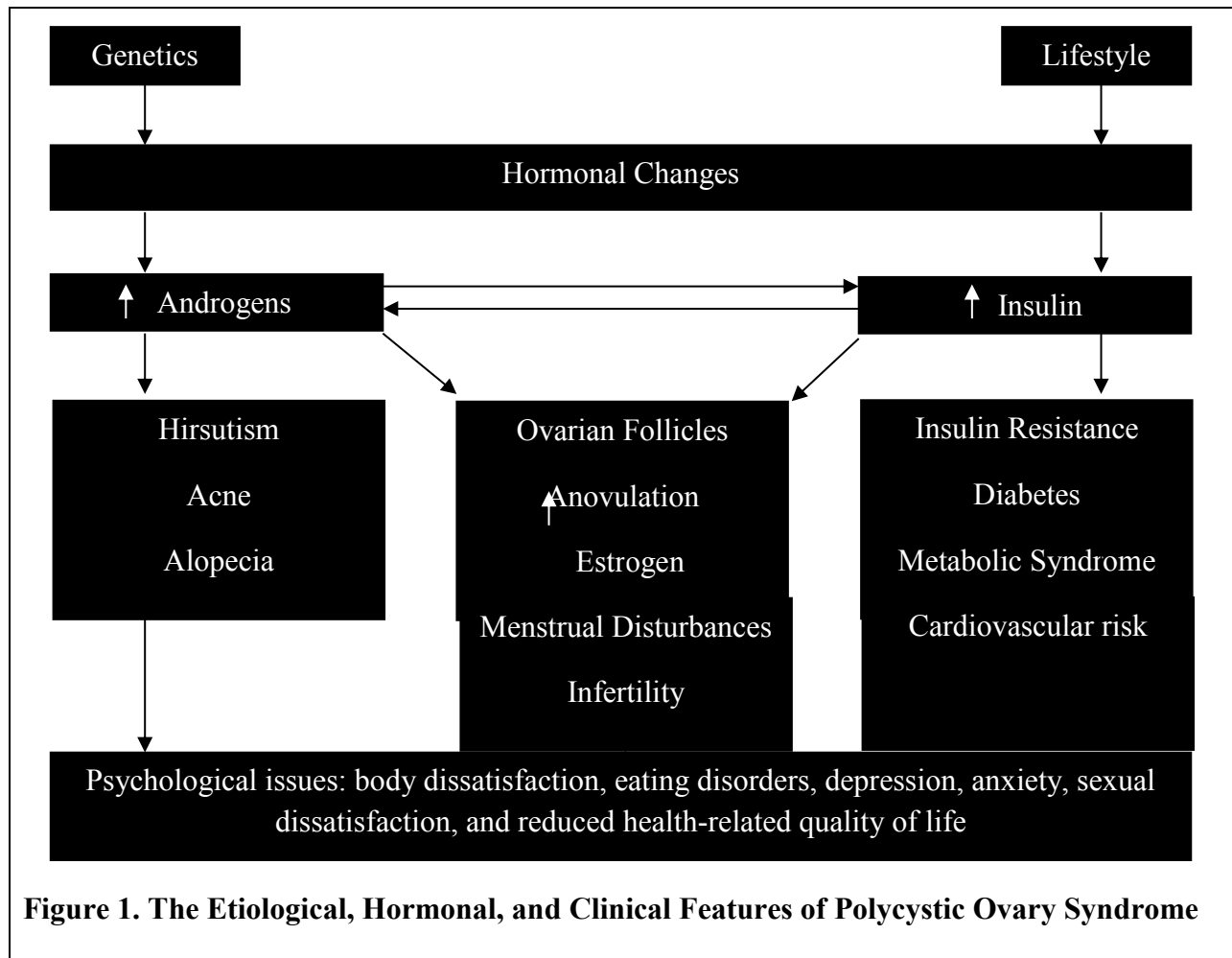


Figure 1. The Etiological, Hormonal, and Clinical Features of Polycystic Ovary Syndrome

Adapted from Teede et al. (2010)

alopecia, and/or other skin problems (i.e. oily skin and dandruff) (Teede et al., 2010). However, hirsutism is considered the best marker of hyperandrogenism (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012). Hirsutism is the excessive growth of terminal hair (defined as coarse, long, and dark hair) on androgen-sensitive areas of the body, which include the inner thighs, buttocks, abdomen, chest, back, and face (Goolsby, 2001). In general, hirsutism is present in approximately 70% of WLW PCOS(The Amsterdam

ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012). However, there is widespread variability in the prevalence of hirsutism in PCOS populations across different countries. The proportion of WLW PCOS who are hirsute ranges from 20% in Japan to 80% in the United States (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012). Ethnic differences and systemic factors, mainly obesity, are cited for these differences.

Reproductive Manifestations. Menstrual irregularities are the most common reproductive manifestations of PCOS and have consistently been documented in 70-80% of WLW the syndrome (Teede et al., 2010). Usually, menstrual irregularities manifest as oligo- and/or amenorrhea (defined as infrequent menstruation or absence of menstruation) resulting from chronic oligo- and/or anovulation. Chronic anovulation can lead to infertility, and PCOS is recognized as the most common cause of anovulatory infertility in women. However, most women with the syndrome (60%) are fertile (defined as the ability to conceive within 12 months), although the time it takes to conceive is often longer (Brassard et al., 2008). Importantly, of the women diagnosed with PCOS and infertility, approximately 90% are overweight.

There is also increasing evidence suggesting a negative effect of PCOS on pregnancy outcomes. In a meta-analysis including 15 studies comparing WLW PCOS (n=720) to women living without PCOS (n=4,505), WLW the syndrome demonstrated a higher risk of developing gestational diabetes (OR 2.94; 95% CI: 1.70–5.08), pregnancy-induced hypertension (OR 3.67; 95% CI: 1.98–6.81), pre-eclampsia (OR 3.47; 95% CI: 1.95–6.17) and preterm birth (OR 1.75; 95% CI: 1.16–2.62) (Boomsma et al., 2006). In addition, babies of WLW PCOS had a significantly higher risk of admission to a neonatal intensive care unit (OR 2.31; 95% CI: 1.25–

4.26) and a higher perinatal mortality (OR 3.07; 95% CI: 1.03–9.21), unrelated to multiple births. To limit the possible confounding factor of obesity on this analysis, the authors only included studies in which BMI did not differ between study groups. However, to fully determine if PCOS is an independent risk factor for obstetrical morbidities, future studies should carefully match for BMI or analyze whether BMI is an independent predictor of outcomes. Findings from these studies will have important implications for antenatal monitoring, including earlier screening for gestational diabetes among WLW PCOS (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012).

Psychological Manifestations. Research also suggests that WLW PCOS are an at-risk group for mental illness and reduced health-related quality of life (HRQoL) (defined as a multidimensional concept that includes the physical, psychological, and social domains associated with a health condition or its treatment) (Himelein & Thatcher, 2006; Jones et al., 2007). However, studies in this area have been hampered by the existence of only one validated condition-specific questionnaire, the Polycystic Ovary Syndrome Questionnaire (PCOSQ). This measures the HRQoL in adult WLW PCOS and includes 5 domains believed to be importance to WLW the syndrome: (1) body hair, (2) emotions, (3) weight problems, (4) menstrual problems, and (5) infertility (Cronin et al., 1998). Studies applying the PCOSQ observe that the most adversely affected domain is weight, followed by infertility (Guyatt, Weaver, Cronin, Dooley, & Azziz, 2004; Jones et al., 2004; McCook, Reame, & Thatcher, 2005). Conversely, studies using validated generic measures of mental health report that hirsutism and obesity are the major sources of psychological morbidity among WLW PCOS (Himelein & Thatcher, 2006). In these studies, PCOS has been associated with several mental health issues, including anxiety and depression, body dissatisfaction and eating disorders, and diminished sexual satisfaction.

Metabolic Manifestations. Varying degrees of metabolic dysfunction are demonstrated in PCOS and may include dyslipidemia, hypertension, metabolic syndrome (MetS), and impaired glucose tolerance (IGT), – all of which are highly predictive of T2D and cardiovascular disease (CVD)(Essah, Wickham, & Nestler, 2007; Tomlinson et al., 2010). Because these features are usually present independent of obesity, lean WLW PCOS are considered a clinically significant population (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012). However, it should be emphasized that these features are magnified by obesity (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012).

A recent meta-analysis and systematic review of the literature supports a greater prevalence of T2D in WLW PCOS compared to women living without PCOS (OR 4.43; 95% CI: 4.06-4.82; BMI-matched studies OR 4.00; 95% CI: 1.97-8.10), independent of obesity (Moran, Misso, Wild, & Norman, 2010). Likewise, compared to age- and BMI-matched controls, WLW PCOS present with more subclinical atherosclerosis in multiple arterial locations including the carotid, femoral, and coronary arteries (Christian et al., 2003; Guzick et al., 1996; Talbott et al., 2000; Vural, Caliskan, Turkoz, Kilic, & Demirci, 2005). Based on this risk profile, Dahlgren et al. have predicted that WLW PCOS should have a 7-fold increased risk of myocardial infarction when compared to age-matched non-PCOS controls (Dahlgren, Janson, Johansson, Lapidus, & Odén, 1992). However, evidence for increased CVD morbidity and mortality in WLW PCOS remains inconclusive (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012; Tomlinson et al., 2010). Long-term prospective studies are needed to define metabolic outcomes and CVD risk among WLW PCOS. Specifically, outcomes based on PCOS phenotype should be clarified.

Management. There is no cure for PCOS. However, lifestyle changes, including diet modifications and increased physical activity, are advocated as the first-line therapeutic approach in PCOS management (Teede et al., 2010). Because IR and obesity play an important role in the phenotypic expression of the syndrome, prevention of weight gain is important across the lifespan for all WLW PCOS (Teede et al., 2011), and weight reduction is important for WLW the syndrome who are already overweight or obese (Thomson, Buckley, & Brinkworth, 2010). Even modest weight loss (5-14%) achieved through lifestyle changes has been shown to improve reproductive features (i.e. menstrual cyclicality, ovulation rates and fertility) (Clark et al., 1995; Clark, Thornley, Tomlinson, Galletley, & Norman, 1998; Huber-Buchholz, Carey, & Norman, 1999), metabolic features (i.e. dyslipidemia, IR, and risk factors for CVD and DM) (Holte, Bergh, Berne, Wide, & Lithell, 1995; Kiddy et al., 1992; Moran, Noakes, Clifton, Tomlinson, & Norman, 2003), and psychological features (i.e. depression, poor body image, reduced HRQoL) among overweight WLW PCOS (R. L. Thomson et al., 2010). Importantly, to promote healthy behaviors in WLW POS, it has been suggested that psychological features should be addressed to optimize self-efficacy, readiness to change, and sustainability of lifestyle interventions (Teede et al., 2011).

In addition, pharmacological interventions may be appropriate and are dependent on the presenting symptoms of the patient and the patient's preferences (Benjamins & Barratt, 2009). For example, hormonal contraceptives are beneficial to WLW PCOS who do not desire pregnancy. Not only can they establish regular menstrual cycles in WLW the syndrome, but also they can help control the physical signs of hyperandrogenism (i.e. hirsutism and acne) (Azziz, 2003). Some WLW PCOS will further benefit from a combination of a hormonal contraceptive and an antiandrogen, which reduces hirsutism at the level of the hair follicle by blocking the

androgen receptors from “seeing” the androgens (Marx & Metha, 2003). However, antiandrogens should not be prescribed for women desiring pregnancy, because these medications have teratogenic potential. Instead, women desiring pregnancy who also have unwanted hair may choose nonsystemic hair removal treatments, such as bleaching, plucking, waxing, or shaving problem areas (Marx & Metha, 2003). Women may also opt for electrolysis or laser therapy to permanently remove hair, although the latter has limited efficacy in treating dark-skinned individuals, as laser therapies are best suited for persons with light skin and dark hair (Benjamins & Barratt, 2009). In addition, insulin sensitizers, such as Metformin®, are commonly prescribed to WLW PCOS with hirsutism, IR, IGT, MetS, T2D, and/or ovulation dysfunction to improve insulin sensitivity, and, consequently, hyperandrogenism (Moll, van der Veen, & van Wely, 2007).

For infertile WLW PCOS who desire pregnancy, clomiphene citrate is the first-line medical treatment for ovulation induction (Atay, Cam, Muhcu, Cam, & Karateke, 2006; Dehbashi, Vafaei, Parsanezhad, & Alborzi, 2006). Because women with a high BMI and/or high androgen levels may be unresponsive to this medication, Metformin® is often used in conjunction with it (Radosh, 2009). If clomiphene citrate therapy is unsuccessful, gonadotropins are traditionally the next line of treatment (Wei & Pritts, 2003). Although gonadotropins are more likely to induce ovulation, they are associated with serious sequelae, including ovarian hyperstimulation syndrome and multiple gestation (Norman, Wu, & Stankiewicz, 2004). However, this approach is preferable over more invasive procedures, such as laparoscopic surgery or in-vitro fertilization (Speroff & Fritz, 2005). Laparoscopic ovarian drilling is the most common surgical procedure performed on WLW PCOS to correct anovulation (Pfeifer & Kives, 2009). In a review of the literature, Seow et al. (2008) reports that 50-100% of patients resume

ovulation after undergoing this procedure. However, if this treatment option fails, WLW PCOS may choose to utilize assisted reproductive technologies (ART), such as in-vitro fertilization (IVF). These technologies are expensive, time consuming, and usually not covered by health insurance (The Boston Women's Health Book Collective, 2005). Because infertility-related healthcare costs are often borne by individuals, significant economic and racial disparities are created (Macaluso et al., 2010). There are also many risks involved in IVF associated with egg retrieval and embryo transfer. Risks include infection, needle injury, adverse reactions to anesthesia, and reduced uterine receptivity owing to a thinner endometrium. Lastly, multiple gestation is also common, which is associated with increased risk for maternal complications (Senat, Ancel, Bouvier-Colle, & Breart, 1998; The ESHRE Capri Workshop Group, 2000). Multiple-birth infants are also at increased risk for preterm delivery, low birth weight, infant death, and disability (Dhont, De Sutter, Ruysinck, Martens, & Bekaert, 1999; Kiely, 1998; Pharoah, 2006; Senat et al., 1998; The ESHRE Capri Workshop Group, 2000). It is notable that ART-conceived singletons are also at increased risk for fetal growth restriction, preterm delivery, low birth weight, and very low birth weight (Schieve et al., 2004; Schieve et al., 2002).

For WLW infertility, adoption, surrogacy, and child-free living are also important alternatives to infertility treatments. However, “the risks, benefits, and costs associated with these alternatives are not immediately clear, and decision-making involves serious emotional responses” (Macaluso et al., 2010). Furthermore, it is difficult to find objective information on these options, and the same racial and social disparities that affect access to infertility treatments also affect access to information on alternatives to treatment. However, it should be reiterated here that most WLW PCOS (60%) are fertile and can conceive without medical intervention (Brassard et al., 2008).

Overall, management should address both the short- and long-term manifestations of the syndrome. Because the mainstay of treatment is “diet and exercise,” research programs identifying self-care behaviors among WLW PCOS are needed. However, none exists, which is the primary justification for the dissertation. In the next section of the review, PCOS research and clinical practices related to PCOS are summarized to explain the dearth of PCOS-related behavioral studies and to emphasize the need for the dissertation. To conclude this section, the economic burden of PCOS is highlighted.

Economic Burden. Because of its high prevalence and association with menstrual irregularities, infertility, hirsutism, and T2D, PCOS represents a significant financial burden to the U.S. healthcare system (Azziz, Marin, Badamgarav, & Song, 2005). In the U.S., the estimated costs of evaluating women for PCOS and its associated morbidities and treating those morbidities exceed \$4 billion annually (in 2004 US dollars). This estimate, however, is considered relatively conservative for many reasons. First, PCOS prevalence figures used in this calculation are derived using the narrowest definition of the syndrome, the NIH criteria (Azziz et al., 2005). The estimated economic burden of PCOS could significantly increase if a broader definition of PCOS was used, such as the Rotterdam criteria. Second, this estimate only includes conditions that are well established as being associated with PCOS, excluding other conditions for which data are highly suggestive but not conclusive (Azziz et al., 2005). These include obstetrical morbidities, gynecologic cancers, hypertension, and mental illness. Lastly, this estimate only accounts for the evaluation and treatment of WLW PCOS in their reproductive years (Azziz, 2007). Many of the long-term, PCOS morbidities, such as CVD and T2D, will develop in the post-reproductive years. Thus, the total economic burden of PCOS across the lifespan has yet to be estimated.

The economic burden of T2D in PCOS represents approximately 40% of the overall cost estimated (Azziz et al., 2005). The management of menstrual irregularities and hirsutism accounts for another 31% and 14% of the costs, respectively, and the provision of infertility services accounts for 12% of the costs. The cost of the diagnostic evaluation for PCOS represents only 2% of the economic burden.

PCOS: Research and Practice

Although PCOS is the most common endocrine disorder among reproductive-age women (Speroff & Fritz, 2005), much remains unknown about the syndrome and the women who experience it. Indeed, many biomedical studies have been conducted to further our understanding of the syndrome, and a few studies within the social sciences have been conducted to explore the lived experiences of WLW PCOS (Crete & Adamshick, 2011; Kitzinger & Willmont, 2002; Snyder, 2006; Weiss & Bulmer, 2011). These studies have produced substantial knowledge about PCOS. However, no behavioral studies have been conducted to identify strategies to promote health and prevent PCOS-related illness among WLW the syndrome. To better understand the existence of this gap in the literature, and, in general, the current state of PCOS research and practice in the U.S., it is important to first understand the history of women's health and the social transformation of American medicine, as this has largely impacted the way in which PCOS has been addressed.

Women's Health & American Medicine: Historical Context. Traditionally, women's health has been framed in terms of reproductive health (Mitchinson, 1998). "This focus is a legacy of the medical conception of women's health that emerged in the second half of the 19th century, when ideas about biological determinism and fundamental differences between the sexes were becoming prominent" (Weisman, 1997). During this era, the study of women's

health focused on female reproductive processes and the impact these processes were assumed to have on women's mental and overall health – processes that made women “naturally” weak (Mitchinson, 1998). At the same time, the prevailing gender ideology, which defined motherhood as women's moral function and primary social purpose, gave legitimacy to the medical focus on reproduction (Weisman, 1997). In the 1920s, the discovery of sex hormones further contributed to the medicalization of women's health (Kuh & Hardy, 2003), and, in 1930s, the American medical profession reinforced the reproductive focus in women's health by establishing a specialty board on obstetrics and gynecology (Weisman, 1997). It was within this context that PCOS was first clearly described by two American gynecologists, Drs. Stein and Leventhal, in a paper presented at the 1935 Central Association of Obstetricians and Gynecologists conference (Farquar, 2007). In their manuscript, the physicians described a small patient population of seven infertile women who presented with amenorrhea and bilateral polycystic ovaries. Drs. Stein and Leventhal found that, after undergoing ovarian wedge resection, all seven patients returned to regular menstruation and two conceived. Soon after this conference, laparotomy (i.e. abdominal surgery) and ovarian wedge biopsy – procedures primarily performed by obstetricians - became the mainstay for PCOS diagnosis and treatment.

Over the next half century, PCOS was viewed as a reproductive issue. The few PCOS research studies that were conducted at this time focused on the biology of the syndrome, and clinical management centered on fertility restoration. Consequently, women experiencing PCOS without fertility concerns remained largely undiagnosed, and WLW the syndrome remained an unrecognized segment of the population at increased risk for metabolic dysfunction.

It was also during this time that the role of OB/GYNs in the provision of well women's care expanded with the introduction of the Pap smear and first oral contraceptive and the

legalization of abortion (Weisman, 1997). As a consequence, women born after World War II (WWII) came into earlier and more continuous care by OB/GYNs than in previous generations. In terms of medical research, little attention was paid to conditions specific to women or risk factors unique to women (Baird, 2009). Moreover, women were grossly underrepresented and often excluded in clinical trials exploring non-reproductive health issues. Researchers argued that the menstrual cycle introduced a potential confounding variable, and ethicists expressed concern that experimental drug treatments would affect women's reproductive capacity and expose fetuses to unknown risks (Sen & Ostlin, 2008). It was also assumed that men and women would respond similarly to drug treatments. However, the medical profession's views of women's health and the exclusion of women in medical research would soon be challenged.

By the 1960s, the post-WWII baby-boom generation of women was college-aged, a culture of "free love" was emerging, and women were more inclined to view maternity as a peripheral component of their lives (Allyn, 2000; Weisman, 1997). Women also began to challenge the medical profession's authority to control women's reproduction lives by regulating access to contraceptives and abortion (Weisman, 1997). By the late 1960s, women were organizing for change and the Women's Health Movement (WHM) was gaining momentum. In the beginning, the WHM largely focused on reproductive rights and women's limited access to health information. Specifically, women's health advocates challenged patriarchy in medicine by educating women about their bodies and by promoting patient involvement in the decision making process. Arguably, the publication of *Our Bodies, Ourselves* in 1970 was the most iconic achievement of this period. However, editions of this text failed to mention PCOS until the mid-90s, when the Boston Women's Health Book Collaborative published the 25th anniversary edition of the text (The Boston Women's Health Book Collective, 1998).

By the 1980s, women's health advocates realized that the lack of medical research focusing on women's health issues had compromised not only the quality of health information available to women but also the health care they received (Baird, 2009). They argued for a broader definition of women's health and increased participation of women in research studies. In response, the U.S. Public Health Service commissioned a task force on women's health, which later recommended that biomedical and behavioral research be expanded to ensure emphasis on diseases or conditions that (1) are unique to, or more prevalent, in women, (2) have risk factors and adverse health outcomes specific to women, and/or (3) require interventions unique to women (Public Health Service Task Force on Women's Health Issues, 1985). Although this 1985 report received little attention and most recommendations were never addressed, the NIH did establish an advisory committee on Women's Health Issues (Baird, 2009). Also, in 1986, the NIH announced a new policy that "urged grant applicants to consider inclusion of women in study populations of all clinical research efforts" (United States General Accounting Office, 2000). However, a few years later, the U.S. General Accounting Office (GAO) found that the NIH had been slow to implement this policy. In response to criticism regarding the lack of progress in women's health research, the NIH established the Office of Research on Women's Health (ORWH) in 1990.

It is no coincidence that, also in 1990, the first international conference on PCOS was sponsored by the NIH in Bethesda, MD (The Rotterdam ESHRE/ASRM-Sponsored PCOS consensus workshop group, 2004b). Here, the first set of PCOS diagnostic criteria were recommended based on majority expert opinion, which was an important first step in standardizing diagnosis. The establishment of these criteria also led to a number of landmark randomized multi-center clinical trials in PCOS (Azziz et al., 2001; Nestler et al., 1991). Still

today, the syndrome remains one of the most poorly defined endocrinopathies and continues to produce considerable scientific debate (Farquar, 2007). Also, evidence of the increasing interest in this syndrome is not difficult to find (see Figure 2). An electronic search on PubMed using the medical subject heading (MeSH) term “polycystic ovary syndrome” (performed February 20,

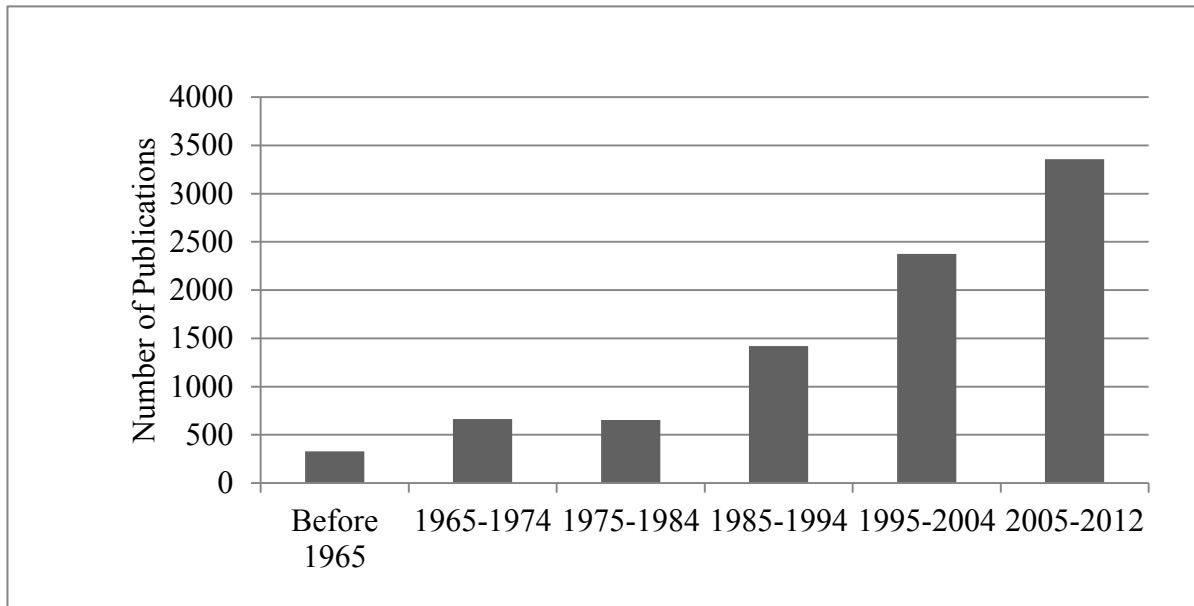


Figure 2. PCOS Publications on PubMed

2012) produced 8,786 citations; 1,589 were review articles and 971 were clinical trials; the majority (74%) of publications occurred after 1990. Arguably, the most critical issue in PCOS research and subsequent practice is the lack of uniformity in diagnostic criteria. Without a universally agreed upon definition of the syndrome, women are being diagnosed based on provider preference (of PCOS diagnostic criteria) rather than evidence-based guidelines. Furthermore, research into the genetics, etiology, clinical associations, treatment, and long-term consequences of the syndrome continues to challenge researchers (Balen & Michelmore, 2002). Likewise, comparisons of research studies on PCOS have proved difficult as different diagnostic criteria have been used for study entry (Cussons, Stuckey, Walsh, Burke, & Norman, 2005).

Contemporary Approaches to PCOS Practice in the U.S. It appears that many women experiencing PCOS continue to receive insufficient care (Weisman, 1997). One reason is the fragmentation of healthcare (defined, in terms of women's health, as the separate delivery of reproductive and non-reproductive services without provisions of coordinated care) (Weisman, 1997). Although this is not an issue unique to WLW PCOS, it does present a challenge to WLW the syndrome, because they may have dermatologic, reproductive, metabolic, and/or psychological concerns - all of which are traditionally addressed by different medical specialists. Coordination of care, however, is not the only issue. Many medical societies believe that PCOS awareness is low among physicians, and PCOS experts have expressed concern that millions of WLW T2D and CVD may be receiving inadequate treatment, because their providers do not recognize these symptoms as indications of PCOS (Christopher, 2004). Hence, more research is needed to explore the PCOS knowledge of American physicians.

For now, women's stories of their PCOS clinical experiences provide the only insight into the current state of PCOS practice. In studies exploring the lived experience of WLW the syndrome, women initially talk about the frustration they felt about delays in their diagnosis (Crete & Adamshick, 2011; Kitzinger & Willmont, 2002; Snyder, 2006; Weiss & Bulmer, 2011). Women often report seeing multiple specialists before receiving a diagnosis, and younger women in particular feel that providers are reluctant to conclude that they are observing something outside of normal pubertal development (Weiss & Bulmer, 2011). Some women even report that, after searching their symptoms online, they diagnosed themselves and later confirmed their diagnosis with their provider (Crete & Adamshick, 2011; Snyder, 2006).

During the diagnostic visit, women feel that their provider did not give them enough information about the syndrome and that the information given to them was confusing (Crete &

Adamshick, 2011; Kitzinger & Willmont, 2002; Snyder, 2006; Weiss & Bulmer, 2011). In response to feeling frustrated and confused, many women engage in information seeking activities (Crete & Adamshick, 2011; Kitzinger & Willmont, 2002; Snyder, 2006; Weiss & Bulmer, 2011). Many describe these activities as helpful and report gaining a sense of control over symptoms through self-education and treatment (Crete & Adamshick, 2011). Likewise, those who feel alienated by their diagnosis often find comfort in reading other's stories (Weiss & Bulmer, 2011). However, others say these activities heighten their anxiety, and a few report feeling overwhelmed to the point of tears (Crete & Adamshick, 2011). Interestingly, subgroups of WLW PCOS, including those who are lean and/or lesbian, report having trouble finding useable information. Their main complaints, respectively, are that PCOS information focuses on dieting and fertility (Weiss & Bulmer, 2011).

As women come to understand their diagnosis better, some develop feelings of anger and/or mistrust towards their providers for not describing the full implications of PCOS (Crete & Adamshick, 2011). Feelings of mistrust also develop for some women after different providers give them different advice and information (Crete & Adamshick, 2011). Many women also believe that they are more knowledgeable about PCOS than their provider, which often leads to a problem in the patient-provider relationship (Kitzinger & Willmont, 2002; Weiss & Bulmer, 2011). Specifically, providers make women feel like they have acted inappropriately by being assertive and asking for specific treatments.

Lastly, women express frustration over how their PCOS has been managed. Many feel that their providers are too focused on fertility and ignore other PCOS-related problems (Weiss & Bulmer, 2011). Some women even report that, after years of treatment, there have been no significant improvements in their PCOS symptoms (Crete & Adamshick, 2011). Consequently,

these women expressed a lack of confidence in their providers. Many also perceive their care as being symptom-based, rather than comprehensive, and feel that their providers are looking for a “quick fix” (Crete & Adamshick, 2011). Overall, women feel a sense of inattentiveness from their providers, and some even described their care as insensitive (Crete & Adamshick, 2011; Kitzinger & Willmont, 2002; Weiss & Bulmer, 2011). In order to gain control over the syndrome, many report visiting several doctor but rarely reported total management (Crete & Adamshick, 2011).

Contemporary Approaches to PCOS Research. As a result of the medicalization of women’s health, most PCOS research has focused on reproductive aspects of the syndrome.^a However, a few studies in the fields of public health, sociology, and nursing have explored the psychological consequences of the syndrome and the lived experiences of women with PCOS. Although the findings of these studies have already been described, it is important to note their limitations. First, almost all women included in these studies were white, straight, premenopausal women. Because PCOS affects women across the lifespan, research is needed in populations of all ages. Likewise, researchers should consider purposively sampling minority women, both in terms of race/ethnicity and sexual orientation, to explore difference among subpopulations of WLW PCOS. Second, PCOS diagnosis was defined differently in all samples. While participants in some studies were not asked to provide documented proof of their diagnosis, participants in other studies were only considered eligible after specific diagnostic criteria were confirmed. Third, all studies were retrospective and, consequently, there was potential for recall bias. For example, in one study, participants diagnosed more than 20 year

NOTE: Although certain aspects of women’s health were negatively impacted by the medicalization of women's health, others were significantly improved. For example, during this time, MCH outcomes, such as infant and maternal mortality, were reduced (Centers for Disease Control and Prevention, 1999).

ago were asked to reflect on their diagnostic visit. However, it is arguable that the data obtained still proved advantageous in achieving the overall purpose of these studies. Fourth, in regards to the qualitative studies, the data were very rich, but no findings were explored in depth. Instead of broadly exploring women's lived experiences of PCOS, future studies should explore specific findings. For example, many women report changing their lifestyles (as is recommended) after diagnosis, but no studies identify specific behaviors or the factors that promote or impede behavior change. The dissertation is the first to explore antecedents of behavior change among WLW PCOS.

Call to Action. The complexity of PCOS necessitates a multidisciplinary approach to research, practice, and policy. Currently, providers are not caring for women in a collaborative manner, and this traditional approach places women experiencing the syndrome at greater risk for PCOS-related conditions. The difficulty of receiving medical care from multiple providers who may not be in contact and/or acting collaboratively is not unique, but a paradigm shift is required to holistically care for women experiencing PCOS. In terms of clinical management, the emerging diabetes centers in the United States may provide a model for the needed collaborative approach. Likewise, the recent influx of announcements for center grants through the NIH are encouraging and may provide a funding source in which to research the best approaches to preventing, diagnosing, and managing PCOS. Specifically, research programs should be established to identify factors that impact self-care among WLW PCOS, as lifestyle changes are recommended as the first line therapeutic approach. The purpose of the dissertation is to establish such a program.

Theoretical Framework

It is well-established that health promotion efforts are most effective when they are theory-based (Crosby, Kegler, & DiClemente, 2009). For this reason, theories and models are used to guide public health research and intervention development. As a set of interrelated concepts, definitions, and propositions that present a systematic view of phenomena, theories enable researchers and practitioners to explain observed health behavior (ex. self-care among WLW PCOS) and to predict behavior change (Glanz, Rimer, & Lewis, 2002). Therefore, a well-defined theoretical approach is necessary to study self-care among WLW PCOS if the goal of the research program is to identify and test health-promotion strategies centering on this population.

Behavioral theories are organized by “levels of influence” (Crosby et al., 2009). That is, health behaviors are viewed as being affected by or affecting (1) individual, (2) interpersonal, (3) community, and (4) societal factors. Thus, health behaviors among WLW PCOS, including self-care, can (and should) be studied from a variety of perspectives including that of the women themselves, their health care providers, community-based organizations that serve WLW PCOS (ex. online PCOS support groups), as well as through the examination of social institutions (ex., U.S. healthcare system).

Importantly, the choice of a theoretical framework should begin with identifying the problem, goal, and units of practice, not with selecting a theory because it is intriguing or familiar (Glanz et al., 2002). In this dissertation, PCOS is the public health problem of interest, and, more specifically, the dissertation begins to address the dearth of information on health behaviors among WLW the syndrome. Accordingly, the unit of practice is women diagnosed with PCOS. Because the purpose of the dissertation is to identify individual factors related to self-care among WLW PCOS and because little is known about the phenomenon, it is best to

consider research in related chronic conditions, such as T2D and CVD, which have identified individual factors related to self-care (Broadbent, Donkin, & Stroh, 2011; French et al., 2006; Mc Sharry et al., 2011; Searle, Norman, Thompson, & Vedhara, 2007). In this field of inquiry, research suggests that, in response to illness, persons create their own models or representations of illness, known as illness perceptions, and that illness perceptions are antecedents of self-care behaviors (Weinmann, Petrie, Moss-Morris, & Horne, 1996). Because illness perceptions are central to Leventhal and colleagues' Common-Sense Model (CSM) of self-regulation of health and illness, it serves as the theoretical foundation of the dissertation. What follows is a discussion of the CSM and related measurements.

The Common-Sense Model (CSM). In the early 1970s, Leventhal and colleagues (1979) studied the effect of fear messages on health behaviors, demonstrating that health behaviors or *coping strategies* were related not only to fear but also to the individual's thinking related to the health threat. Over the next decade, their work led to the development of the CSM (Leventhal et al., 1980; Leventhal et al., 1984), which, posits that individuals develop complex cognitive and emotional representations of illness, termed *illness perceptions*, when confronted with an illness. These perceptions are said to affect *coping strategies* and to be affected by *appraisal* of these strategies. According to the model, this bidirectional process is an important pathway in explaining adjustment to illness and, consequently, illness outcomes.

Basic Assumptions of the CSM. Leventhal and colleagues (2003) identify three basic assumptions of the CSM:

- (1) *Individuals are active problem solvers.* Here, "problem solving" suggests that most human actions are purposeful and goal-oriented. In the context of health and illness, individuals are expected to first try to "make sense" of the illness, then to develop

coping strategies (based on their illness perceptions) in an effort to regain health and normal functioning. Here, the process of illness adaptation is similar to problem solving.

(2) *Individuals adapt to illness based on their “common sense” beliefs.* Thus, coping strategies and health outcomes are based on how the individual understands his or her illness.

(3) *Objective, medical representations of illness are distinct from subjective, individual representations of illness.* This distinction is important, because individual representations, regardless of medical accuracy, shape the responses of individuals to illness. Subjective representations may be constructed according to the abstract and concrete sources of information available to the individual, including healthcare providers, media, social networks, and previous experiences with the illness itself.

Illness Perceptions. According to the CSM, individuals develop coping strategies based on two types of illness representations: (1) cognitive representations or illness cognitions and (2) emotional representations (Leventhal et al., 2003). Importantly, illness perceptions begin to form as soon as individuals experience their first symptom of an illness and typically change with illness progression, emergent symptoms, and treatment response.

Extensive semi-structured interviews and open-ended questionnaire investigations have established that illness cognitions are multidimensional and have a common content across illnesses (Skelton & Croyle, 1991). In their original work, Leventhal and colleagues (1980; 1984) identified four related, but conceptually and empirically distinct, core dimensions of illness cognitions: (1) *identity* (i.e., illness label and perception of symptoms), (2) *consequences* (i.e., beliefs about illness outcomes: physical, social, and behavioral), (3) *timeline* (i.e., expectations

about the duration of illness and persistence of symptoms), and (4) *cause* (i.e., beliefs about the cause of the illness: biological, emotional, environmental, or psychological). Later, a fifth dimension, *cure/control* (i.e., beliefs about controllability and curability of illness or symptoms), was added based on the findings of Lau and colleagues (Lau, Bernard, & Hartman, 1989).

Emotions are also an integral component of the CSM and are processed in parallel to illness cognitions (Leventhal et al., 1992). Emotional representations develop as a more subjective experience and create feeling states such as anger, depression, and anxiety. These emotions can influence illness cognitions in a number of ways, including (1) affecting the onset and progression of illness, (2) increasing the difficulty of self-diagnosis and the decision to seek care, (3) altering attention to and interpretation of the physical state, and (4) affecting health behaviors in response to physical or somatic changes (Ory & DeFrieze, 1998). The latter is discussed more in the following section.

Assessing Illness Perceptions. In the 1990s, Weinman and colleagues (1996) designed a questionnaire to assess the five dimensions of illness cognitions, the Illness Perceptions Questionnaire (IPQ). Later, attempts to revise this measure highlighted the importance of additional dimensions to understanding illness (Moss-Morris et al., 2002). Today, the Illness Perceptions Questionnaire-Revised (IPQ-R) includes subscales assessing emotional representations of illness and illness coherence, the latter defined as a sense of having a comprehensive understanding of an illness. Control has also been subdivided to differentiate between two components: (1) personal control and self-efficacy beliefs and (2) outcome expectancies (i.e. belief in the treatment or recommended advice). Likewise, timeline has been subdivided to assess cyclical timeline beliefs in addition to acute/chronic timeline beliefs.

Coping Strategies. The CSM posits that illness perceptions lead to the selection and implementation of coping strategies (Leventhal et al., 2003). These are sometimes referred to as *self-regulation efforts*, as they function to manage or regulate the cognitive and/or emotional representations of illness. Overall, coping strategies are aimed at decreasing emotional distress and reducing or eliminating illness threat. If the emotional distress is overwhelming, coping will focus on emotional comfort and may include strategies such as denial and seeking emotional support. If the emotional distress is not overwhelming, the individual is focus on specific health behaviors aimed at alleviating illness threat.

Appraisal. Lastly, the CSM postulates that individuals evaluate coping strategies in terms of their success in reaching desired goals (Leventhal et al., 2003). If the strategy does not have the desired effect, individuals will modify their illness perceptions and/or coping strategies. Thus, the appraisal process functions as a feedback loop. A graphical representation is provided (see Figure 3, pg. 37). In summary, the CSM presents a mediational model in which coping mediates the effects of illness perceptions on health outcomes. The focus of this dissertation is illness perceptions only. This study lays the groundwork for future studies exploring the coping strategies and illness outcomes of WLW PCOS.

CSM Research. The assumptions of the CSM are supported by cross-sectional and longitudinal data from studies of individual's with a range of medical (French et al., 2006; Graves et al., 2009; Kaptein et al., 2010; Knoop et al., 2010; Knowles et al., 2011; Mc Sharry et al., 2011; Sullivan et al., 2010) and mental health conditions (Lobban et al., 2005; Lynch et al., 2011), both acute and chronic. Likewise, a number of reviews and meta-analyses report a relationship among illness perceptions, coping strategies, and health outcomes (Hagger & Orbell, 2003a; Hoving et al., 2010; Kaptein et al., 2008; Kucukarslan, 2012; Petrie et al., 2007).

Specifically, the literature suggests an association between illness perceptions and physical functioning, psychological distress, role functioning, social functioning, vitality, psychological well-being, and health-related quality of life. Also, there is evidence that health outcomes and quality of care can be significantly improved when illness perceptions of patients are addressed in health care settings (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009; Moss-Morris, Sharon, Tobin, & Baldi, 2005).

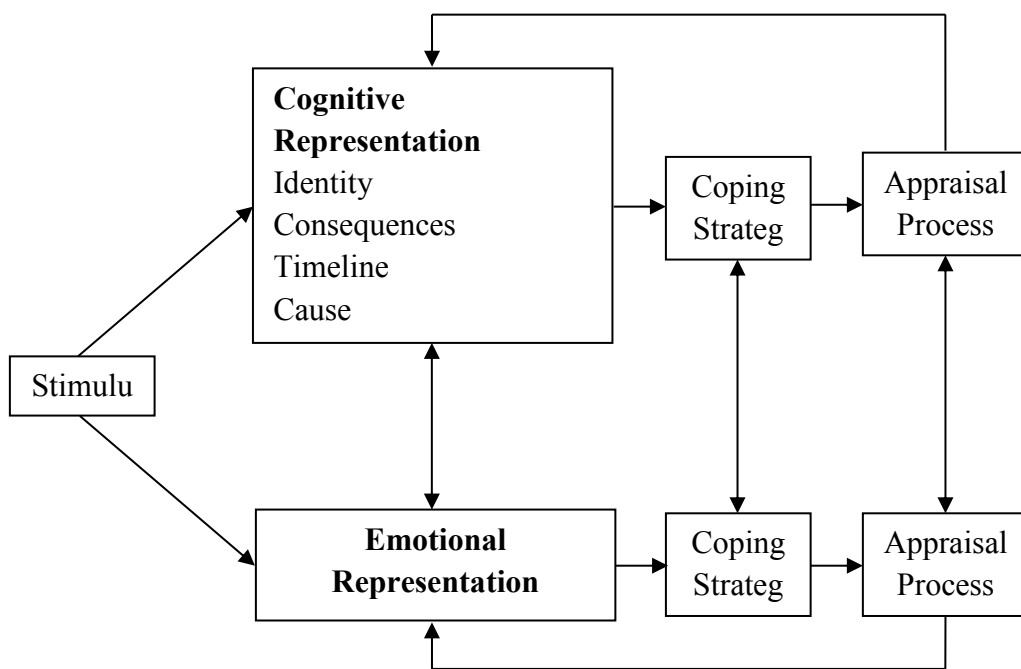


Figure 3. Graphical representation of Leventhal's Common-Sense Model

Chapter 3: Methods

The long-term goal of this research is to establish theory-driven, evidence-based interventions that will improve self-care behaviors among women living with (WLW) polycystic ovary syndrome (PCOS), resulting in increased health-related quality of life (HRQoL) and decreased PCOS-related illness. **The primary aim of this dissertation is to identify the illness perceptions of PCOS held by WLW the syndrome.** This is important, because illness perceptions research suggests that individual differences in people's perceptions of their condition influence self-care behaviors and illness outcomes, including HRQoL (French et al., 2006; Hagger & Orbell, 2003a; Kucukarslan, 2012; Mc Sharry et al., 2011).

Importantly, a sub-aim of this dissertation is to explore the relationship between illness perceptions and infertility, a common symptom of the syndrome. Infertility is emphasized for two reasons. First, the literature suggests that WLW PCOS have strong emotional responses to infertility (Jones et al., 2007; Y. Li et al., 2011; Shi et al., 2011). According to the CSM, emotional responses to an illness (and its symptoms) are antecedents of illness perceptions. Second, WLW PCOS who experience infertility typically require additional medical intervention (Brassard et al., 2008). More medical intervention, by nature, requires more interactions with healthcare providers, who are potential sources of information. According to the CSM, individuals construct illness perceptions according to the concrete and abstract sources of information available to them (Leventhal et al., 2003). Therefore, WLW PCOS who experience infertility may have additional and unique opportunities to obtain information.

A second sub-aim of the dissertation is to explore the relationship between illness perceptions and HRQoL. Although the literature clearly indicates that PCOS has a significant impact on HRQoL (Jones et al., 2007; Trent et al., 2002), few factors that contribute to this have been explored (Barnard et al., 2007). All but one study has focused on clinical features of the syndrome and their management. These few studies suggest (1) that symptoms associated with the syndrome (i.e. ovulatory dysfunction, hirsutism, obesity, and infertility) contribute significantly to the reduction of HRQoL and (2) that successful management of these symptoms improve HRQoL (Jones et al., 2007). Given these findings, there would be an expectation to observe a direct relationship between clinical severity of PCOS and HRQoL. However, Trent and colleagues (Trent et al., 2002) report that *perception* of PCOS severity, not actual severity, correlates directly with HRQoL. This finding emphasizes the need for further investigations into the perceptual factors related to HRQoL. Because illness perceptions of PCOS may be a promising determinant of HRQoL among WLW with the syndrome, an exploration of the relationship between illness perceptions and HRQoL complements the primary aim of this dissertation.

Like other research studies, it is important to describe the sample of women recruited for the study. However, because a clinical population of WLW with PCOS is not accessible for the current dissertation, women were recruited from a social networking site (SNS). As such, this dissertation makes a novel contribution to the literature by describing one of the first samples of WLW with PCOS recruited through a SNS – a secondary aim of the study.

To achieve research aims, a multi-phase, mixed-methods, cross-sectional study was conducted. In Phase 1, an online survey was disseminated (1) to collect HRQoL data on women diagnosed with PCOS and (2) to recruit participants for Phase 2. In Phase 2, qualitative

Table 4. Research Methods Utilized to Meet Research Aims

Specific Aims and sub-aims	Research Questions	Theoretical Constructs	Measure
1. To identify the illness perceptions of PCOS held by WLW the syndrome.	1. What illness perceptions do women hold about their PCOS? How do these relate to the CSM? How do they differ?	Cognitive Representations of Illness <ul style="list-style-type: none"> • Identity • Timeline • Consequences • Cure/Control • Cause AND Emotional Representations of Illness	Qualitative interviews
a. To explore the relationship between infertility and illness perceptions of PCOS held by WLW the syndrome	2. Does the experience of infertility impact the illness perceptions that women hold about their PCOS?	Cognitive Representations of Illness <ul style="list-style-type: none"> • Identity • Timeline • Consequences • Cure/Control • Cause AND Emotional Representations of Illness AND Contextual factor: Infertility	Qualitative interviews AND Online survey: Medical history, Infertility
b. To explore the relationship between HRQoL and illness perceptions of PCOS held by WLW the syndrome	3. Is there a relationship between women’s HRQoL and the illness perceptions they have about PCOS?	Cognitive Representations of Illness <ul style="list-style-type: none"> • Identity • Timeline • Consequences • Cure/Control • Cause AND Emotional Representations of Illness AND Contextual factor: HRQoL	Qualitative interviews AND Online survey: SF-36

Table 4 (Cont.)

Specific Aims and sub-aims	Research Questions	Theoretical Constructs	Measure
2. To describe one of the first samples of WLW PCOS recruited through a SNS	4. What are the demographic characteristics of one of the first samples of WLW PCOS recruited through a SNS?	Contextual Factors: <ul style="list-style-type: none"> • Age • Race/Ethnicity • Sexual Orientation • Marital Status • Education • Health insurance • Length of Diagnosis • BMI • Medical History • Childlessness • Trying To Conceive Status 	Online survey: Individual characteristics
a. To describe the HRQoL among one of the first samples of WLW PCOS recruited through a SNS	5. What is the HRQoL of one of the first samples of WLW PCOS recruited through a SNS?	HRQoL	Online survey: SF-36

interviews were conducted with WLW PCOS to investigate their illness perceptions of the syndrome. Specific aims and research questions are listed in Table 4 (pg. 40), as are the related theoretical constructs and methods used to collection data.

Population

The population for this research included women (1) who were 18 years or older, (2) who were able to read, speak, and comprehend English, (3) who were U.S. citizens, (4) who currently resided in the U.S., and (5) who had been told by a healthcare provider that they have PCOS. Citizenship and geographic criteria were set, because women’s illness perceptions may be shaped by the healthcare system itself and because healthcare systems are different in each country. Although this conceptual population may include women diagnosed with PCOS by healthcare providers using different diagnostic criteria (Azziz et al., 2009), this differentiation is not important, because, the Common Sense Model (CSM) posits that all women receiving a PCOS diagnosis will form illness perceptions of the syndrome (Leventhal et al., 2003).

Table 5. Inclusion and Exclusion Criteria of the Dissertation

Inclusion Criteria	Exclusion Criteria
Women who are: 1. 18 years or older 2. Able to read, speak, and comprehend English 3. U.S. citizens 4. Currently reside in the U.S AND 5. Women who have been told by a healthcare provider that they have PCOS	Women who are: 1. 17 years or younger 2. Unable to read, speak, and comprehend English 3. Not U.S. citizens 4. Currently reside outside the U.S 5. Currently trying to conceive (part 2 only) AND 6. Women who have NOT been told by a healthcare provider that they have PCOS

While all women meeting inclusion criteria were able to participate in Part 1 of the study, women who reported that they were currently trying to conceive were excluded in Part 2. As a

reminder, a sub-aim of this dissertation is to explore the relationship between illness perceptions and infertility. If a woman is trying to conceive, her *current* fertility status is unclear. For clarity, the inclusion and exclusion criteria are listed in Table 5.

Sampling and Recruitment Considerations. Identifying and recruiting WLW PCOS is a challenge for any U.S. study, because a comprehensive sampling frame for WLW PCOS does not exist. Therefore, a non-random sampling method is appropriate (Neuman, 2006). In extant literature, most PCOS studies have recruited participants through private clinics to ensure consistency of diagnostic criteria. However, this consideration is not important in the current study. Instead, a woman's understanding that she has received a PCOS diagnosis and, consequently, is living with PCOS is most important. Also, access to a clinical population of WLW PCOS does not exist for the current dissertation, which eliminates this option for recruitment.

Other sampling strategies for PCOS studies have included recruitment from face-to-face (Percy, Gibbs, Potter, & Boardman, 2009) and on-line (Benson et al., 2010) PCOS support groups. Face-to-face PCOS support groups, however, are not geographically near, and are not as accessible as on-line support groups. At the same time, the on-line PCOS support groups in the U.S., including PCOS Support (<http://www.pcosupport.org/>) and SoulCysters (<http://soulcysters.net/>), have not replied to numerous requests by the lead investigator to advertise the study on their websites. For this reason, WLW PCOS were recruited through online support groups created on the SNS, facebook® (www.facebook.com). This is one of the first studies to recruit WLW PCOS from SNS.

As of December 2012, facebook© had more than one billion monthly active users, and, on average, 618 million daily active users ("facebook: key facts," 2013). As a member,

individuals may create web pages for special interest groups, including social support groups, at no charge. An initial search of “polycystic ovary syndrome” yields over 100 support groups established by facebook© users. Most of these are open to the public and the largest of these has over 10,000 members. Notably, the membership in this group is active, with multiple posts per day from its members.

To assess the feasibility of recruiting WLW PCOS via facebook©, Baker (2012) conducted a study in February 2012. In this study, a survey link was posted on the largest PCOS-related group on facebook®. Those who clicked on the survey were redirected to the homepage of the survey, which included the study description and the consent form. At the bottom of the webpage, readers were instructed to click on the “I Agree” button if they gave consent and wished to participate in the survey. The first questions of the survey screened participants. Those who met the inclusion criteria, which were the same as the current study’s criteria (see Table 4), gained access to the full survey, which collected additional demographic information of the participants (ex. race, marital status, insurance status). At the end of the survey, participants were asked to provide their email addresses if they were interested in participating in future PCOS studies. Fifty-seven out of 96 persons (1) met inclusion criteria and (2) completed the survey in full. Over half of these provided their contact information. Notably, most persons who did not meet the inclusion criteria lived outside of the U.S. Also, the recruitment message was posted once and no incentives were offered. Overall, this small study demonstrated the potential of using SNS to engage WLW PCOS in public health research.

Phase 1: Quantitative Survey

Overview. The purpose of Phase 1 was to (1) collect HRQoL data on women who meet inclusion criteria (see Table 5) and (2) recruit participants for Phase 2. To accomplish these goals, data were collected using an online survey.

Sampling and Recruitment. Two strategies were used to recruit participants. First, in August 2013, a facebook® page dedicated to the study, which included a description of the study and a link to the survey, was created. This promoted the research in a number of ways. Most importantly, if a person searched for PCOS-related pages on facebook®, this page appeared in their results. Also, the lead investigator asked her facebook® “friends” to post the link to the study’s facebook® page with the message, “Please help a friend with her dissertation study on polycystic ovary syndrome (PCOS)!” As such, a snowball sample of individuals was reached through the “Share” option on facebook®. Second, a direct link to the survey was posted on the five largest PCOS-related facebook® pages with a brief message describing the study. (Note: the direct link to the survey was posted, not the link to the study’s facebook® page, on the PCOS-related pages with the purpose of reducing the number of steps the target population went through to access the survey directly.) After the initial posting, the link was reposted every two weeks until the end of December 2013, when (1) the recruitment goal was reached (see below) and (2) Phase 2 interviews were complete.

These recruitment strategies built on the aforementioned pilot study (Baker, 2012) in the following ways: (1) an additional recruitment strategy was added - a facebook® page dedicated to the study; (2) a link to the survey on the five largest PCOS-related pages was provided, compared to only the largest PCOS-related page; and (3) the link was reposted every two weeks for four months to maximize the number of participants.

Because the primary purpose of Phase 1 was to recruit participants for Phase 2, the survey was kept open until Phase 2 interviews were completed. In the pilot study, 56 women (1) met the inclusion criteria of this dissertation and (2) completed the online survey. Over half of these expressed interests in a follow-up phone interview (n=31). In this dissertation, the subset of phase 1 participants who expressed interests in a follow-up phone interview were stratified based on specific characteristics (see page 57). For these reasons, the goal was to recruit approximately twice as many participants as the pilot study for Phase I of this dissertation (1) to reach phase 2 recruitment goals and (2) to account for Phase I participants who expressed interests in participating in a phone interview and who later declined an interview. In short, the recruitment goal for Phase I of this study was 100 women.

Procedure. By clicking the link to the survey, potential participants were directed to its homepage, which acted as the consent form. This page included a description of the study, an overview of the participant's rights, and the investigator's contact information. At the bottom of the page, participants were informed that entering the survey signified their consent, after which participants had the option to click, "I agree to participate in the study" or "I do not agree to participate in the study." Those who clicked on the first option were directed to the survey that was hosted on a secure server at the University of South Florida; those who click the second option received a message thanking them for their time and encouraging them to share the study link with others who may be interested.

Instrument. The online survey was created using Qualtrics® and contained four parts. Part 1 of the survey was a screener. Only individuals who indicated that they were women (1) who were 18 years or older, (2) who were able to read, speak, and comprehend English, (3) who were U.S. citizens, (4) who currently resided in the U.S., and (5) who had been told by a

healthcare provider that they had PCOS gained access to the full instrument. Those who did not meet these criteria were informed and thanked for their time. In addition, the automated message explained that other opportunities to participate in PCOS research may become available in the future, and women were asked to provide their preferred contact information to express interests.

The next two parts of the survey captured more detailed information about the participants. Part 2 included demographic information, such as race/ethnicity, sexual orientation, marital status, education, and health insurance status. Part 3 included a brief medical history form. Women were asked if they now or if they have ever experienced infertility and a number of additional symptoms typically listed on a medical history form (e.g. anemia, diabetes, high blood pressure, and urinary tract infections). Although fertility status was the only item of interest, the additional items were included to avoid priming Phase 2 participants to discuss infertility. (Note: Infertility status is important, because a sub-aim of the dissertation is to explore the relationship between illness perceptions and infertility). Also, women were asked to enter their height and their weight, which were used to calculate BMI. Women then were asked if they were currently trying to conceive. If they were, they were excluded from Phase 2, as previously stated. Next, women were asked if they have biological children. This information was used to help stratify Phase 2 participants. Lastly, women were asked at what age they received a PCOS diagnosis. The latter is important, because the number of years a woman lives with a PCOS diagnosis may be proportionate to the amount of information she has about the diagnosis. As previously stated, the CSM posits that individual's construct illness perceptions according to the information available to them (Leventhal et al., 2003). As such, women's illness perceptions of PCOS may differ on length of diagnosis. Parts 1, 2, and 3 of the survey are available in Appendix A.

Lastly, Part 4 of the survey captured women's HRQoL. In the PCOS literature, two measures have predominately been used to capture HRQoL: (1) the Quality-of-Life Questionnaire for Women with Polycystic Ovary Syndrome (PCOSQ) and (2) the Short Form-36 (SF-36). The PCOSQ is currently the only validated PCOS-specific HRQoL measure (Guyatt et al., 2004; Jones et al., 2004). It includes 26 items that divide into five HRQoL domains: body weight (5 items), emotions (7 items), hair growth (5 items), infertility (5 items), and menstruation (4 items) (see Appendix B). Each item has a seven-point scale, in which a score of 7 denotes no problems or difficulties and a 1 indicates maximum HRQoL impairment. The mean score of all items in a domain provides a domain score for each woman.

The SF-36 is a well validated and widely used generic HRQoL measure (Ware & Sherbourne, 1992). It includes 36 items that divide into eight HRQoL domains: bodily pain (2 items), energy and vitality (4 items) general perception of health (5 items), physical functioning (10 items), mental health (5 items), role limitations due to emotional problems (3 items), role limitations due to physical problems (4 items), and social functioning (2 items). Also, there is an unscaled single item on changes in respondent's health (see Appendix C). Scoring of the SF-36 is more complex than the PCOSQ. In short, summed data from the subscales are transformed into a 0- to 100-point scale, with a score of 100 denoting no problems or difficulties and a 0 indicating maximum HRQoL impairment. Also, the subscales are combined to yield physical function and emotional health as two summary health status measures. (Note: More information on scoring the SF-36 is provided in *Data Analysis*, p. 57)

Both the PCOSQ and the SF-36 have strengths and limitations. On one hand, the PCOSQ more directly addresses the specific problems of WLW PCOS (e.g., body hair, weight, and infertility), which are not identified by the SF-36. At the same time, the findings cannot be

compared with those of samples affected by other diseases and their healthy controls, which precludes an assessment of the relative impact of the specific problems. To date, the SF-36 has been used to estimate disease burden in articles describing more than 200 diseases and conditions (Ware). Also, PCOSQ studies agree that the measure has good reliability (Guyatt et al., 2004; Jones et al., 2004; McCook et al., 2005), but some question its content validity and suggests that it is weakened by the lack of an acne scale (Jones et al., 2004). On the other hand, the SF-36 is reliable and well validated (Ware). That is, with rare exception, published reliability statistics for the eight scales and the two summary health status measures have exceeded the minimum standard of 0.70 recommended for measures used in group comparisons. Also, numerous studies have yielded content, concurrent, criterion, construct, and predictive evidence of validity.

Considering the strengths and limitations of each instrument, Jones (2008) suggests that both the PCOSQ and the SF-36 be applied in the same study to measure HRQoL among WLW PCOS. However, given (1) that the PCOSQ is an illness-specific measure that emphasizes the symptoms of PCOS, (2) that the primary aim of the dissertation is to identify the illness perception of WLW PCOS, and (3) that a domain of illness perceptions is *identify* (i.e. symptoms women associate with the syndrome), the PCOSQ was not used in this study to prevent priming of Phase 2 participants. Instead, the SF-36 was the only measure used to assess HRQoL in this study.

After completing the SF-36, participants received an automated message thanking them for their time. The automated message also explained that there was an immediate opportunity to participate in a follow-up study, where they would be interviewed via phone or online video chat. Participants were instructed to enter their desired contact information if they wished to

participate. Also, participants were given the option to provide their information if they wished to participate in future PCOS research, but not the interviews. On average, the survey took 12 minutes for participants to complete. Before the survey launched, the instrument was pilot tested with three women who live with a diagnosis of PCOS to uncover any technical or wording issues and to better estimate the time needed to complete the survey. Only minor, grammatical changes were suggested and addressed.

Data Analysis. The survey data was stored on a secure server at the University of South Florida. Data were downloaded from Qualtrics® into a text-based format and analyzed using SAS statistical software version 9.3 (SAS Institute, Cary, NC). As this study is descriptive in nature, frequencies, measures of central tendency, standard deviations, and the distribution of variables were generated to describe the overall sample on demographic variables.

Next, the average scores of the overall sample on each of the SF-36 domains were calculated: (1) bodily pain, (2) energy and vitality, (3) general perception of health, (4) physical functioning, (5) mental health, (6) role limitations due to emotional problems, (7) role limitations due to physical problems, and (8) social functioning. Scores for each SF-36 item are reported in Appendix C. To calculate domain scores, all items in a domain were summed and divided by the number of items summed. A score for each domain was obtained by taking the average of scores within that domain. Domain scores could range from zero to 100, with a score of zero representing the lowest or worst possible level of functioning and a score of 100 representing the highest or best possible level of functioning.

Data Cleaning. A total of 525 participants initiated the online Qualtrics survey. Of these participants, some did not report being 18 years old or older (n=5), being U.S. citizens (n=93), currently residing in the U.S. (n=6), or being told by a healthcare provider that they have

PCOS (n=9). Of the 412 participants remaining (i.e. the participants who met eligibility requirements), 29 participants (7%) had completely missing data or did not complete the SF-36, leaving 383 cases. Upon further review of IP addresses, it became clear that a few respondents entered the survey multiple times, changing their answers to the screening questions until they had the opportunity to enter into the full survey. To maintain the integrity of the data, all responses from these IP addresses were removed (n=7). This left a final sample of 376 responses included in the analysis reported here (Note: 276 responses more than the recruitment goal of 100 survey responses).

Phase 2: Qualitative Interviews

Overview. The purpose of Phase 2 was to investigate the illness perceptions of PCOS held by WLW the syndrome (Aim 1). Rather than starting with a generic, existing quantitative measure, such as the IPQ-R, the distinct nature of the experience of PCOS indicates the importance of adopting a qualitative method to understand what kinds of illness perceptions are developed. For this reason, this phase consisted of individual, semi-structured interviews.

Sampling and Recruitment. All women who were eligible to participate in Phase 1 of the study were eligible to participate in Phase 2, with the exception of women who report that they were currently trying to conceive. To identify participants for Phase 2, the survey data were monitored weekly and woman who expressed interest in participating in the interviews were contacted via email.

Stratification. Because exploring the relationship between infertility and illness perceptions was a sub-aim of the dissertation, Phase 2 participants were stratified into two groups: women (1) who reported and (2) who did not report current or past infertility (Note: These data were captured in Part 2 of the survey). As a reminder, one reason infertility may be

important is that WLW PCOS have strong emotional responses to infertility (Jones et al., 2007; Y. Li et al., 2011; Shi et al., 2011) and that the CSM postulates that emotional responses to an illness (and its symptoms) are antecedents of illness perceptions. To further explore the impact of infertility on illness perceptions, the two groups of women were divided into women (1) who did and (2) did not have biological children (see Table 6). It was hypothesized that, among WLW PCOS who had no history of infertility, those who did not have biological children would have different illness perceptions than those who did, because their ability to become pregnant remained unclear. Likewise, it was hypothesized that, among WLW PCOS who had a history of infertility, those who did not have biological children would have different illness perceptions than those who did, because their ability to become pregnant also remained unclear.

Table 6. Phase 2 Sample Stratification

Infertility	Biological Children	
	Yes	No
Yes	Group 1	Group 2
No	Group 3	Group 4

Given that the design focuses on qualitative description as opposed to grounded or phenomenological approaches, data from approximately 30 interviews should have been sufficient to achieve the first aim and sub-aims of the dissertation study (Guest, 2006; Mason, 2010). For this reason, the goal was to interview approximately 40 women, including 10 women in each stratum: (1) WLW PCOS with no history of infertility and no biological children, (2) WLW PCOS with no history of infertility and biological children, (3) WLW PCOS with history of infertility and no biological children, and (4) WLW PCOS with history of infertility and biological children.

Procedure. As potential participants for Phase 2 were identified, they were emailed to confirm their willingness to participate in an interview, to explain its purpose, and to answer any

questions about the study. She also confirmed that they still met inclusion criteria. If so, she sent them an additional consent form for Phase 2 via email. Based on participant preference, the interviews were conducted through telephone or video chat. Interviews lasted between 15 and 30 minutes. Each interview began with an acknowledgment that the participant understood the consent document and agreed to be recorded (i.e. audio recording for telephone interviews and video and audio recording for video chat).

Interviews. The aim of the interviews was to elicit illness perceptions of PCOS by WLW the syndrome. Although the CSM was a guiding framework, the interviews were semi-structured to allow women the opportunity to discuss their experiences from their own perspectives. Following a method originally described by Lau, Bernard, and Hartman (1989), participants were asked to describe their experience with PCOS using the standard prompt, “Tell me about your experience with polycystic ovary syndrome.” To prevent bias in the information produced by the participants, dialogue was encouraged through silence and prompts such as, “Can you tell me more about that?” After the free response task, participants were asked questions regarding each of the dimensions of illness perceptions outlined in the CSM: identity, timeline, consequences, cause, and cure/control (LEVENTHAL ET AL., 2003). These follow-up questions were modified from existing guides based on the CSM (Goodman, Morrissey, Graham, & Bossingham, 2005; Hurt, Burns, Brown, & Barrowclough, 2010; Nicholls, Glover, & Pistrang, 2004). Before data collection began, the interview guide was pilot tested with two WLW PCOS to check for content and face validity. Following these discussions, changes were made to the format and content of the interview guide (Appendix D).

Data Analysis. All interviews were transcribed by graduate students trained in transcription service, and the data were analyzed two separate ways.

Analysis 1. First, to test the ecological validity of the CSM in this population (i.e. women diagnosed with PCOS), a method of analysis described by Lau et al. (1989) and employed by a number of illness perception researchers, including Hurt (2010), Lobban (2005), and their colleagues, was used. To begin, a graduate student who was unfamiliar with the CSM was recruited to assist in the beginning stages of data analysis. This graduate student divided each transcript into distinct thoughts (usually separate sentences), which was verified by the lead investigator. Each thought was then placed on a card.

Next, the lead investigator, in addition to and independent from a second graduate student, grouped similar thoughts. For example, the statements, “Like, I know that women with PCOS are more likely to get diabetes” and “It [PCOS] can also affect your um, it can also make you more prone to diabetes,” were placed in the same group. Then, the lead investigator, together with the graduate student, settled any discrepancies in groupings, chose the most representative statement from each group, and removed the remaining statements in each group (i.e. the duplicates). This activity resulted in 172 distinct thoughts or statements.

Criterion Sorting. The same graduate student, who assisted with the above grouping activity and was familiar with the CSM, was asked to assist with a sorting activity. This student, in addition to and independent from the lead investigator, sorted the statements into the illness perception dimensions defined by Leventhal and colleagues (2003) (see Table 12). In cases where disagreement existed about statement placement, both referenced to the definitions of the dimension and reached a decision. When no consensus was possible, the statement was placed into a residual category. Statements not represented by the CSM were also placed in the residual category.

Naïve Sorting. Then, five graduate students who were unfamiliar with the CSM were recruited to sort the statements. These “naïve sorters” were all doctoral students in public health who had participated previously in qualitative research and who had been introduced to the topic of PCOS via a patient education handout printed by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (2008).

The naïve sorters were given the pile of statements (in a shuffled order) and instructed to sort the statement into categories that “made sense” to them. Before beginning the activity, naïve sorters were told that they could create as many categories as they liked and that categories did not have to be of equal sizes. Once they had completed this task, they were asked to label the categories they created. This activity was designed to test whether the dimensions were inherent in the data and if they logically emerged if a person was unaware of a model that hypothesized the existence of the dimensions. This was different from the first sorting activity, where “criterion sorters” (i.e. the lead investigator and her colleague) were only testing whether it was possible to sort the statements into the dimensions with which they were familiar. Results are reported in Tables 13 and 14.

Analysis 2 .To further explore the overall illness perceptions of WLW PCOS (Aim 1), transcripts were imported into NVivo 10. Transcripts were subjected to content analysis with respect to each of the dimensions as originally defined by Leventhal and colleagues (1984) and expanded upon by Moss-Morris and colleagues (2002) . These dimensions and their definitions are defined in Table 7. A doctoral student in Public Health, the previous “criterion sorter,” was asked to independently code a number of transcripts.

To determine inter-rater reliability, the lead investigator and the second coder first independently coded a transcript. This NVivo file was then merged and compared. Next, both

coders discussed and resolved any differences in coding, and then the coding of the transcript was revised. This process was repeated two additional times. Next, the lead investigator coded all of the remaining transcripts and the second coder coded every fifth transcript. Inter-rater reliability was calculated through NVivo and based on these remaining transcripts (n=6). Kappa results ranged between 0.71-.98, which represents substantial to almost perfect agreement (Landis & Koch, 1977).

Table 7. Definitions of Illness Perception Dimensions

Illness Perception Dimensions	Definition
Symptoms	Symptoms women identify as part of the PCOS experience
Labels	Label women give to <i>PCOS</i>
Causes	Perceived cause of PCOS
Timeline, acute/chronic	Expectations about the duration of PCOS and the persistence of its symptoms
Timeline, episodic	Beliefs about the cyclical nature of PCOS and its symptoms
Consequences	Impact of PCOS on women's everyday lives and future well being
Control, personal	Beliefs in personal control of PCOS
Control, treatment	Beliefs in treatments for PCOS
Cure	Beliefs that PCOS is curable
Illness coherence	A sense of having a comprehensive understanding of PCOS
Emotional representations	Emotional responses generated by PCOS

Next, frequencies, measures of central tendency, standard deviations, and the distribution of variables were generated to describe the demographic characteristics of the interviewees. Also, the average scores of the interviewees on each of the SF-36 domains were calculated. This allowed Phase 2 findings to be sorted by individual characteristics, including fertility status, childlessness, and HRQoL. As such, the dissertations sub-aims (i.e. sub-aims 1a and 1b) were reached: to explore the relationships between illness perceptions and (1) infertility status and (2) HRQoL.

Trustworthiness of the Data

“Qualitative and quantitative criteria of excellence are equally important but inherently different” (P. Ulin, E. Robinson, & E. Tolley, 2005). Each has their own appropriate and no less rigorous standards. To judge quantitative studies intended to describe, predict, and verify empirical relationships, criteria such as *validity*, *reliability*, and *objectivity* have been adopted. However, to judge qualitative studies intended to explore, discover, and understand phenomenon, criteria such as *credibility*, *dependability*, and *confirmability* have been adopted. When researchers evaluate the latter, they are evaluating the *trustworthiness* of the data. When researchers say that data are trustworthy, they are saying that the findings are “worth paying attention to” (P. Ulin et al., 2005).

Credibility. In quantitative studies, a measure is *valid* if it measures the concept it is intended to measure. *Credibility* is the corresponding criterion for qualitative research (Denzin, 1978). In this study, credibility was established by using an existing interview guide that has been utilized by a number of illness perceptions researchers and by pilot testing the interview guide specifically with WLW PCOS.

Dependability. In quantitative studies, research is considered *reliable* if findings can be replicated in a different population (P. Ulin et al., 2005). However, this goal is meaningless to qualitative researchers, who inquire into unique constellations of phenomena and meaning. Instead, the goal for qualitative research is to be *dependable*. Research is dependable if the research process is executed with careful attention to the rules and conventions of qualitative methodology. To increase dependability in the current study, the lead investigator documented her thoughts, decisions, and methods by taking notes or memos throughout the research process (i.e. an audit trail).

Confirmability. Lastly, in quantitative research, objectivity is a traditional standard of quality. *Objectivity* generally implies that the researcher will maintain distant from participants and take measures to reduce the amount of influence their values have on the process of inquiry (P. Ulin et al., 2005). These strategies are often counterproductive in most qualitative studies. Instead, the goal of qualitative researchers is to confirm. *Confirmability* refers to a “way of knowing that, even as a coparticipant in the inquiry, the researcher has maintained the distinction between personal values and those of the study participant” (P. Ulin et al., 2005).

Applying *reflexivity* contributes to the confirmability of the results. To ensure reflexivity during research activities, the lead investigator discussed her preconceived notions about illness perceptions of PCOS with her committee members. This process of becoming aware of assumptions was done to bring the lead investigator’s beliefs into the open so that she could be aware of them and could attempt to hold them in abeyance, referred to as bracketing assumptions (Husserl, 1970). During data analysis, the committee members’ consultations provided a balanced perspective to any assumptions about the illness perceptions held by WLW PCOS. They also helped to question, refute, and clarify ideas and discussion points, reducing bias or assumptions as conclusions were made.

Protection of Human Subjects

Approval from the institutional review board (IRB) of the University of South Florida (USF) was obtained prior to the study’s initiation, and addressed a number of ethical issues including autonomy, privacy, anonymity, and confidentiality (Appendix F). For example, in Phase I, individuals indicated their willingness to participate in the study by clicking on the survey link, which directed them to the homepage containing information about the study, informed consent information, and contact information of the lead investigator. Because

individuals' survey answers were linked to their contact information, the lead investigator was the only person with access to this data.

For the interviews in Phase 2, it was important that each participant felt comfortable enough to speak openly and honestly. While the environment in which the participant chose to interview could not be controlled, participants were encouraged to select a quiet place to interview, free from distractions. As such, it was confirmed, before each interview, that the scheduled time was acceptable to the participant and that the participant was in an environment where she could speak freely. Also, before each interview, participants had the opportunity to ask questions and were asked for verbal consent. During the interview, the respondents were given an opportunity to use an alias. However, all participants chose to be referred to by their real names.

The digital recordings and word files continue to be kept on a password protected computer of the lead investigator. Transcripts and all other data are also kept on this computer. Likewise, the cognitions placed on note cards are stored in a locked cabinet in the study office. After finalizing all analysis and meeting all publication goals, all cognition cards from Phase 2 were discarded by placing them in a security container provided by the university where shred materials are placed.

The risks associated with this study were minimal. However, it was plausible that some participants would have adverse reactions to answering questions about their experiences with PCOS. For this reason, the nature of the interviews was fully described to participants prior to their participation, and participants had the option of stopping the interview at any time. However, no participants chose to stop the interview prematurely.

Other Methodological Considerations

Interview Medium. Notably, there are a number of interview techniques including face-to-face interviews, phone interviews, video chat interviews (ex., Skype), text/instant messaging, and emailing (P. Ulin et al., 2005). The advantages and disadvantages of these techniques are outlined in Appendix D. For this study, emailing and text/instant messaging were inappropriate, because they did not allow for the interview to remain fairly conversational, which is desired in a semi-structured interview (P. R. Ulin, E. T. Robinson, & E. E. Tolley, 2005). Also, for this study, face-to-face interviews were not feasible, because participants were not centrally located. Thus, phone interviews and video chat interviews were the only appropriate, feasible interview techniques for this study. The researcher, however, realizes that video chat interviews require the participants to have certain skill sets and technologies (ex., computer cameras and microphones). Consequently, the researcher let participants decide how they would like to be interviewed, by phone or by video chat. All but two participants chose phone interviews.

Disclosure. In the study, the lead investigator decided to disclose her own diagnosis of PCOS to the participants. This information was included in a short biography labeled “About the Researcher” on the facebook® study page. The lead investigator also disclosed her diagnosis to the participant during the initial contact when she described the purpose of the study to the participants and scheduled the interviews. This decision was made, in part, because the lead investigator was a member of many online support groups and realized that some participants would recognize her from those websites. She also believed that self-disclosure would create an environment of trust and facilitate authentic dialogue. In previous qualitative studies, researchers have stated that self-disclosure enhanced report, leveled the “playing field,” showed respect for the participants, and validated the participant’s stories (Dickson-Swift, James, Kippen, &

Puttong, 2007; Reinharz, 1992). Lastly, disclosure was identified as an important feature of the research given that, in previous research studies, many WLW PCOS have reported that, to their knowledge, they have never met another woman with the syndrome.

Specifically, the lead investigator's diagnosis was disclosed during the first contact to provide the participants a time to ask any questions they had of her experiences. At that time, she began by telling the participants that she was a woman living with PCOS and that she received her diagnosis at age 21 years during a routine check-up. She then asked participants if they had any additional questions for her. No participants initially asked questions, but some did after the interview was complete when the lead investigator again offered to answer any personal questions. This strategy proved effective at keeping the focus of the interview on the participant.

Chapter 4: Results

To collect health-related quality of life (HRQoL) data on women living with (WLW) polycystic ovary syndrome (PCOS), an online survey was administered. Individual phone interviews and video chats were also conducted with a subset of these women to explore their illness perceptions. This section will provide the findings related to each research question. Sample characteristics are described and expanded upon where appropriate.

What are the Demographic Characteristics of One of the First Samples of WLW PCOS Recruited Through a Social Networking Site (SNS)?

Demographic characteristics of the study sample are described in Table 8. The age of the sample ranged from 19 to 56 years with a mean age of 31.8 (SD=5.8). Respondents were primarily non-Hispanic (92.5%), white (88.3%), straight (94.4%), and married (73.4%) with a college education (64.1%).

The medical history of respondents is described in Table 9. While the number of years women had lived with the syndrome ranged from less than one year to 47 years, they, on average, reported living with PCOS for 7.6 years (SD=6.1). Approximately half of the sample reported having biological children (47.9%) and currently trying to conceive (42.1%), and most participants reported a history of infertility (70.7%). The BMI of the sample ranged from 15.2 to 65.4 with a mean of 35.1 (SD=8.9). In fact, almost half of the total sample reported heights and weights that placed them in the morbidly obese category (BMI \geq 35). Also, a history of

^a Research questions are not presented in the order in which they were previously presented.

depression (63.6%) and anxiety (68.6%) was common among participants.

Table 8. Demographic Characteristics of Study Sample (N=376)

Characteristic	No.	(%)
Age	M=31.8	SD=5.8
Hispanic		
Yes	28	(7.5)
No	348	(92.5)
Race		
White or Caucasian	332	(88.3)
Black or African American	13	(3.5)
Other	31	(8.2)
Sexual Orientation		
Straight or heterosexual	355	(94.4)
Gay, lesbian, or homosexual	2	(0.5)
Bisexual	19	(5.1)
Marital Status		
Single	89	(23.7)
Married	276	(73.4)
Separated or divorced	10	(2.7)
Widowed	1	(0.3)
Education		
High school or less	26	(6.9)
Some college	109	(29.0)
College graduate	241	(64.1)
Medical Insurance*		
Private	281	(74.7)
Public	27	(7.2)
Military	19	(5.1)
Other	15	(4.0)
None	46	(12.2)

*Numbers do not add to 100, because participants could select all that apply.

What is the HRQoL of One of the First Samples of WLW PCOS Recruited Through a SNS?

As previously described, no overall score is calculated for the SF-36. Instead, findings are reported on each of the eight domains: (1) bodily pain, (2) energy and vitality, (3) general perception of health, (4) physical functioning, (5) mental health, (6) role limitations due to

Table 9. Medical History of Study Sample (N=376)

Characteristic	No.	(%)
Years living with PCOS diagnosis (M =7.6)		
< 1 years	63	(16.8)
≥ 1 years	313	(83.2)
Biological Children		
Yes	180	(47.9)
No	196	(52.1)
Pregnant		
Yes	29	(7.7)
No	347	(92.3)
Trying to Conceive		
Yes	146	(42.1)
No	201	(57.9)
BMI (mean=35.1)		
Underweight (BMI<18.5)	4	(1.0)
Normal (18.5-24.9)	45	(12.0)
Overweight (25-29.9)	61	(16.2)
Obese (30-34.9)	95	(25.3)
Morbidly obese (BMI≥35)	171	(45.5)
History of:		
Diabetes	45	(12.0)
Hypertension	96	(25.5)
High cholesterol	101	(26.9)
Heart disease	9	(2.3)
Thyroid	63	(16.8)
Infertility	266	(70.7)
Endometriosis	31	(8.2)
Migraine	209	(55.6)
Anxiety	258	(68.6)
Depression	239	(63.6)

emotional problems, (7) role limitations due to physical problems, and (8) social functioning.

(see Table 10). Domain scores can range from zero to 100, with a score of zero representing the lowest or worst possible level of functioning and a score of 100 representing the highest or best possible level of functioning. Because the SF-36 measures HRQoL, which is personal to each individual, it is not appropriate to present normative values that define “good” or “bad” HRQoL (Sterling University, 2012). Therefore, no normative values or cut-off scores are presented.

Table 10. SF-36 Domain Scores of Study Sample

Domain	Range of Sample	Mean (SD) of Sample	Definition	
			Lowest Possible Score (0)	Highest Possible Score (100)
General Health Perceptions	0-100	50.8 (22.7)	Evaluates personal health as poor or believes it is likely to get worse	Evaluates personal health as excellent
Vitality	0-85	34.4 (18.1)	Feels tired and worn out all of the time	Feels full of pep and energy all of the time
Physical Functioning	10-100	81.2 (22.9)	Very limited in performing all physical activities, including bathing and dressing	Performs all types of physical activities including the most vigorous without limitations due to health
Role Limitations Due to Physical Health	0-100	70.6 (37.2)	Problems with work or other daily activities as a result of physical health	No problems with work or other daily activities
Bodily Pain	0-100	66.3 (24.0)	Very severe and extremely limiting pain	No pain or limitations due to pain
Social Functioning	0-100	67.4 (26.8)	Extreme and frequent interference with normal social activities due to physical and emotional problems	Performs normal social activities without interference due to physical or emotional problems
Role Limitations Due to Emotional Problems	0-100	60.3 (42.7)	Problems with work or other daily activities as a result of emotional problems	No problems with work or other daily activities resulting from emotional problems
Emotional Well Being	0-100	59.1 (20.9)	Feelings of nervousness and depression all of the time	Feels peaceful, happy, and calm all of the time

Overall, few women in the sample reported their general health as being excellent (2.6%) or very good (27.4%). Similarly, women reported the lowest levels of functioning on the dimension of vitality, meaning that, in general, women reported feeling tired and being low in energy. Conversely, women reported the highest scores on the dimensions of physical functioning and role limitations due to physical health, meaning that, in general, women did not

report that their health limited their physical abilities or caused problems with work or other daily activities. These findings are further explored by the last research question presented in this chapter: *Is there a relationship between women's HRQoL and the illness perceptions they have about PCOS?*

What Illness Perceptions do Women Hold About Their PCOS? How do These Relate to the CSM? How do They Differ?

As previously described, transcripts were analyzed two different ways. First, to test the ecological validity of the CSM in this population (e.g. women diagnosed with PCOS), a series of sorting activities were conducted (e.g. criterion and naïve sorting). Then, to answer the research question, a content analysis of all transcripts was conducted. The results of these activities are presented after a description of the interviewees' demographic characteristics and medical history.

Demographic Characteristics of Interviewees. In total, 34 survey respondents were interviewed. Of these, three chose to video chat via Skype®. All others participated in phone interviews. Demographic characteristics of interviewees were similar to the overall sample and are described in Table 11. The age of the interviewees ranged from 22 to 46 years with a mean age of 33.6 (SD=5.1). Respondents were primarily non-Hispanic (97.1%), white (94.1%), straight (85.3%), and married (64.7%) with a college education (82.4%).

The medical history of interviewees is described in Table 12. While the number of years interviewees had lived with the syndrome ranged from less than one year to 21 years, women, on average, reported living with PCOS for 10.9 years (SD=6.6). The BMI of the sample ranged from 22.3 to 65.3 with a mean of 38.4 (SD=12.8). In fact, almost half of the interviewees

reported heights and weights that placed them in the morbidly obese category ($BMI \geq 35$). Also, a history of depression (70.6%) and anxiety (64.7%) was common among this subset of women.

Table 11. Demographic Characteristics of Interviewees (n=34)

Characteristic	Total Sample (N=376) No. (%)	Interviewees (n=34) No. (%)
Age (M)	31.8	33.6
Hispanic		
Yes	28 (7.5)	1 (2.9)
No	348 (92.5)	33 (97.1)
Race		
White or Caucasian	332 (88.3)	32 (94.1)
Black or African American	13 (3.5)	2 (5.9)
Other	31 (8.2)	0 (0.0)
Sexual Orientation		
Straight or heterosexual	355 (94.4)	29 (85.3)
Gay, lesbian, or homosexual	2 (0.5)	1 (2.9)
Bisexual	19 (5.1)	4 (11.8)
Marital Status		
Single	89 (23.7)	8 (23.5)
Married	276 (73.4)	22 (64.7)
Separated or divorced	10 (2.7)	3 (8.9)
Widowed	1 (0.3)	1 (2.9)
Education		
High school or less	26 (6.9)	0 (0.0)
Some college	109 (29.0)	6 (17.6)
College graduate	241 (64.1)	28 (82.4)
Medical Insurance*		
Private	281 (74.7)	26 (76.3)
Public	27 (7.2)	3 (8.9)
Military	19 (5.1)	0 (0.0)
Other	15 (4.0)	2 (5.9)
None	46 (12.2)	3 (8.9)

*Numbers may not add to 100, because participants could select all that apply.

Criterion Sorting. Agreement between the criterion sorters was high (Kappa = 0.89).

Overall, results suggest that it is possible to categorize the statements generated by WLW PCOS into the illness perception dimensions. When there was disagreement between the criterion sorters, it was over whether the statement referred to *identity* (i.e. a symptom women identified as part of the PCOS experience) or a health *consequence*. Distinguishing between these two

Table 12. Medical History of Interviewees (n=34)

Characteristic	Total Sample (N=376) No. (%)	Interviewees (n=34) No. (%)
Years living with PCOS diagnosis	Mean =7.6	Mean=10.9
< 1 years	63 (16.8)	5 (14.7)
≥ 1 years	313 (83.2)	29 (85.3)
Biological Children*		
Yes	180 (47.9)	19 (55.9)
No	196 (52.1)	15 (44.1)
Pregnant		
Yes	29 (7.7)	3 (8.8)
No	347 (92.3)	31 (91.2)
BMI	Mean=35.1	Mean=38.4
Underweight (BMI<18.5)	4 (1.0)	0 (0.0)
Normal (18.5-24.9)	45 (12.0)	5 (14.7)
Overweight (25-29.9)	61 (16.2)	3 (8.8)
Obese (30-34.9)	95 (25.3)	8 (23.6)
Morbidly obese (BMI≥35)	171 (45.5)	18 (52.9)
History of:		
Diabetes	45 (12.0)	4 (11.8)
Hypertension	96 (25.5)	10 (29.4)
High cholesterol	101 (26.9)	11 (32.3)
Heart disease	9 (2.3)	0 (0.0)
Thyroid	63 (16.8)	3 (8.8)
Infertility*	266 (70.7)	13 (38.2)
Endometriosis	31 (8.2)	2 (5.9)
Migraine	209 (55.6)	20 (58.8)
Anxiety	258 (68.6)	22 (64.7)
Depression	239 (63.6)	24 (70.6)

*Interviewees recruited based on these characteristics.

dimensions proved to be the biggest challenge in both the sorting activities and the content analysis. For further guidance in sorting and coding, Dr. Howard Leventhal, who is credited for the development of the CSM and who has dedicated his life's work to its advancement and application, was consulted. Below is an excerpt from a personal communication with Dr. Leventhal in which he references an example the lead investigator provided, "Because I have PCOS, I have high insulin levels, and that makes me crave a lot of sugar" (2014):

I think it [cravings] is best coded as an experienced feature (a functional change) that identifies the underlying condition and not coded as a consequence...we need to recognize that the patient has an abstract concept of PCOS that subsumes elevation in insulin. The conceptual elaboration of the syndrome integrates a wide range of specific experiences; concepts provide breadth that allows multiple experience to be linked to a common source; a developmental achievement. Reasoning that way would argue to code as identity and expand the system and code both abstract and concrete features.

Based on this communication, all symptoms women (1) experienced previously or currently or (2) identified in other women as part of their PCOS experience were sorted as *identity* and coded as *symptoms* (e.g. a subscale of *identity* defined by Moss-Morris). Conversely, any references to anticipated health consequences were sorted and coded as *consequence*.

The distribution of statements resulting from the criterion sorting activity is shown in Table 13. *Symptoms* included the largest number of unique statements, followed by *cure/control*. Conversely, *timeline* contained the least number of unique statements. In addition, two unique statements were placed in the *residual* category. These statements represented a number of participants' comments related to the prevalence of PCOS and their understanding of the syndrome. These residual/other findings are expanded upon below under the heading, *Cognitive Representations*.

Naïve Sorting. Naïve sorters placed interviewees' statements into between 5 and 12 categories, with a mean of 8.8 categories. The number of times that each of the illness perception dimensions were included as a category label by the naïve sorters was recorded and is shown in Table 14, labeled *Time 1*.

After each naïve sorter completed her sorting and labeling task, they were given the labels and definitions of each illness perception dimension and asked the naïve sorter whether she could (1) re-label any of her categories or (2) collapse categories into one of the dimensions

without rearranging any of the statements. Results from this activity are reported in Table 14, labeled *Time 2*. Examples of original labels are also provided in Table 15.

Table 13. Distribution of Criterion Sorting Statements

Illness Perception Dimensions	Examples of statement	Number of statements	% of total number of statements
Identity	<ul style="list-style-type: none"> • An endocrine disorder • Polycystic ovaries • Excess hair 	56	32.5
Causes	<ul style="list-style-type: none"> • Genes • Diet • Excess weight 	11	6.5
Timeline	<ul style="list-style-type: none"> • Forever • Until menopause • Until childbearing is complete 	3	3.5
Consequences	<ul style="list-style-type: none"> • Troubles dating • Future health risks • Financial strain 	30	15.6
Cure/Control	<ul style="list-style-type: none"> • Infertility treatments • Hair removal treatments • Hormonal supplements 	44	25.6
Emotional representations	<ul style="list-style-type: none"> • Frustration • Anger • Worry 	26	15.1
Residual/Other	<ul style="list-style-type: none"> • A common condition • Lack of understanding PCOS 	2	1.2
Total		172	100

Table 14. Number of times illness perception dimensions were used as labels in sorting of statements by naïve sorters

Illness Perception Dimensions	Number of times label was used by naïve sorters:	
	Time 1	Time 2
Identity	0	5
Causes	2	2
Timeline	0	0
Consequences	0	4
Cure/Control	2	5
Emotional representations	0	3
Residual	3	3

The most commonly labeled categories by the sorters were *Identity* and *Cure/Control*. Conversely, *Timeline* was the only dimension not identified. This is unsurprising, however, because only two statements referred to this dimension. Notably, these statements were most commonly placed in the *Identity* dimension by naïve sorters under the original label *Knowledge*.

Table 15. Examples of original labels generated by naïve sorters

Illness Perception Dimensions	Examples of original labels
Identity	Symptoms Knowledge
Causes*	-
Timeline**	-
Consequences	Positive Outcomes Health Outcomes
Cure/Control	Lifestyle Management Medical Treatment
Emotional representations	Emotions Feelings

* Because *Causes* was originally used by sorters, no alternative example of original label exists.

**Because *Timeline* was not identified by naïve sorters, no example or original label exists.

After learning the labels and definitions of each illness perception dimension, all naïve sorters agreed that statements could be categorized into each dimension proposed by Leventhal and colleagues (1984). When asked why they could not (1) re-label or (2) collapse all original categories into the illness perception dimensions, naïve sorters usually replied one of the following ways:

1. Emotional representations were scattered throughout the groupings. Because they were instructed to re-label or collapse groupings without rearranging any of the statements, re-labeling and collapsing was not possible.
2. Like the criterion sorters, naïve sorters struggled over placing certain statements into *symptoms* and physical *consequences* of PCOS. After learning the definitions of each, all agreed that statements would need resorting.

Cognitive Representations of PCOS. Interviewees' responses to questions regarding the content of their cognitive illness representations highlighted areas of similarities between WLW PCOS. However, they also highlighted areas in which WLW the syndrome had developed dramatically different cognitive illness representations despite having the same diagnosis. This was expected, however, given the nature of PCOS (i.e. a spectrum disorder). These similarities and differences are described in the following paragraphs, with themes uncovered by the interview questions grouped around the illness perception domain to which it relates. The first of these domains is illness coherence, followed by identity, cause, timeline, consequences, control, and cure.

Illness coherence. Although no question on the interview guide was specifically designed to illicit participant's beliefs about the extent to which they felt they had a comprehensive understanding of their diagnosis, several discussed this topic. In fact, some seemed compelled to preface their interview with a statement regarding their lack of knowledge about the syndrome.

I guess the first thing that I need to say is that I don't really understand it, because I know that it's called polycystic ovarian syndrome, but I don't have ovarian cysts, so that's not even like an easy answer...like, "Oh, it means you have cysts on your ovaries," because it doesn't even mean that. (A.H., age 35)

Similarly, some concluded the interview by reflecting on the discussion and their overall experiences of PCOS.

Overall, I'm just a big enigma. I mean it's hard to pinpoint PCOS – who I am, what it is - it's like you spend your whole...you spend your whole life being your own mystery. (A.F., age 37)

Throughout the interviews, others focused more specifically on PCOS-related symptoms or conditions and the extent to which they understood them. These reflections often led to further discussions about the participant's clinical experiences, which most women described as

frustrating. Specifically, women expressed frustration over the information provided to them at the time of diagnosis, which they described as confusing and/or insufficient.

I mean, even the day the doctor diagnosed me, I don't think they told me anything. She printed something off for me about what it was, but I just don't remember her explaining it. Umm, and even, you know, in talking to you, I'm realizing how confused I am by all of this. (E.S., age 34)

Others made more general comments about their clinical experiences, often describing their providers as disinterested in their information needs. Several also expressed a lack of confidence in their providers and identified gaps in their provider's knowledge.

I mean, I'll be the first one to tell you that I totally don't understand terms like, "insulin resistance." All that stuff...it just goes right over my head, like, I totally don't get it, and no one I've seen has cared to help me understand it. (A.H., age 35)

I wish I had more support and that my providers knew more about it [PCOS]. I know it was a challenge for me when I knew more than, like, my provider. That's frustrating to me. It's frustrating when you go to a provider and they can't answer your questions. They're supposed to be the experts. I shouldn't be educating my doctor about the illness they're supposed to be treating (E.A., age 29)

With questions left unanswered, many women reported searching for answers. As expected from a sample recruited from a SNS, the internet was the medium of choice to obtain PCOS-related information. While some searched for answers on common search engines (ex. Google), others sought informational support from other WLW PCOS via online PCOS support groups, including the groups from which they were recruited.

I feel like I get more information, like, more good, valid information from the internet and other women with it than I have from any doctor that I've ever talked to. Maybe I'm just going to the wrong doctor...(D.T., age 37)

Identity. Identity cognitions were most common and included the name used to refer to PCOS (e.g. label), its general description, and its symptoms. Specifically, most participants responded to the initial interview prompt, "Tell me about your experience with polycystic ovary

syndrome,” by describing symptoms and spent most of their interview focused on the symptoms they had experienced, were currently experiencing, or had heard of others with the diagnosis experiencing.

Label. While all women used the label *PCOS* to refer to their diagnosis, generic descriptions of the syndrome varied. For example, many correctly identified PCOS as an endocrine disorder or a condition related to “hormone issues” or a “hormonal imbalance.” While most did not specifically name the hormones that were imbalanced or describe how they were imbalanced, those that did gave mostly accurate descriptions - a combination of elevated androgen (i.e. hyperandrogenism) and insulin levels (i.e. hyperinsulinemia leading to insulin resistance) (Balen et al., 1995; Kiddy et al., 1990).

What it is is an imbalance of hormones where your estrogen and progesterone levels are out of balance and your testosterone is higher than it should be. (J.K., age 33)

Likewise, several accurately identified PCOS as a spectrum disorder (Balen et al., 1995), although none explicitly used this label. Instead, interviewees described PCOS as “looking” different in every woman.

Well, PCOS is, as far as my understanding goes, is a very complicated condition. It can cause very few symptoms for women or it can cause many symptoms for women that have it. I recently learned that some women don't have any symptoms at all. Whereas, for myself, I have all of the lovely, I guess, signs of it. (J.S., age 33)

Some also described PCOS as a condition that affected a number of body systems and identified a number of symptoms related to the syndrome (see *Symptoms*). However, few used medical terms to describe these symptoms. For example, none made reference to *hypertension*, *anovulation*, *alopecia*, or *hirsutism*. Instead, women discussed having high blood pressure, not ovulating, balding or hair thinning, and growing excess hair, respectively.

I think it has affected every part of my body except for my ears [Laughter], and I'm just waiting for the day when it...when it does. (L.P., age 42)

Now I mean, I've hear of like the thinning of the hair and those kinds of things. As of right now, I don't have that and I really don't want that...you know, the [thinning] hair on your head. It can take all the hair off of my chin it wants [Laughter]. Leave the hair on my head alone! (D.L., age 46)

Lastly, in their general descriptions of PCOS, a few participants emphasized that PCOS was not a reproductive disorder, and one participant specifically expressed dislike of the label.

I do not like the name "polycystic ovary syndrome," because that implies that it's just exclusively a reproductive issue, and it's not! (L.P., age 42)

Notably, renaming of the syndrome recently gained national attention, when a panel of PCOS experts met to assess the available scientific evidence on the syndrome (Neilson, 2013). In this workshop, co-sponsored by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), experts agreed that the name *polycystic ovary syndrome* caused confusion and created a barrier to research progress and effective patient care. According to the panel, the name *PCOS* focuses on one of many diagnostic criterion, polycystic ovaries, which are neither necessary nor sufficient for diagnosis (see *Definition*). For this reason, in their final report, the panel recommended assigning a new name to PCOS that more accurately reflected the complex interactions that characterized the syndrome (National Institutes of Health, 2012). However, a new name was not suggested and no efforts have been made by since this workshop to address this recommendation.

Symptoms. All interviewees described symptoms related to PCOS. In large, these symptoms could be categorized as follows: (1) reproductive, (2) dermatologic, (3) metabolic, or (4) psychological manifestations of the syndrome. However, a few symptoms did not "fit" these categories and are described at the end of this section (see *Other Manifestations*). To summarize findings, all symptoms women attributed to PCOS are listed in Table 16. However, it should be noted that the relationships between PCOS and some of these symptoms are either inconsistent

with or unreported in the literature or remain unclear. These specific symptoms are highlighted in Table 16 with asterisks (*).

Table 16. PCOS symptoms identified by interviewees

Type of Manifestation	Symptom
Reproductive	<ul style="list-style-type: none"> • Ovarian cysts or polycystic ovaries • Heavy menstrual bleeding (Menorrhagia) • Infrequent menstruation (Oligomenorrhea) • Absence of menstruation (Amenorrhea) • Painful menstruation (Dysmenorrhea) • Infrequent ovulation (Oligoovulation) • Absence of ovulation (Anovulation) • “Hyper” ovulation* • Painful ovulation (Mittelschmerz) • Infertility • Pregnancy complications, including miscarriage, pre-eclampsia, and gestational diabetes** • Low breast milk supply (Hypolactation)***
Dermatologic	<ul style="list-style-type: none"> • Excess hair growth (Hirsutism) • Hair loss (Alopecia) • Oily skin • Severe, cystic acne • Discoloration of skin (Acanthosis nigricans)
Metabolic	<ul style="list-style-type: none"> • Weight gain, excess weight, or overweight • Difficulties losing weight • Insulin resistance • Diabetes • Uncontrollable food cravings • Exhaustion or feelings of tiredness • High cholesterol (Hypercholesterolemia) • High blood pressure (Hypertension)
Psychological	<ul style="list-style-type: none"> • Anxiety • Depression • Mood swings
Other	<ul style="list-style-type: none"> • Anemia • Vitamin D deficiency • Signs of virilization, including deepening of the voice and broadening of the shoulders • Insomnia*** • Hypothyroidism** • Low sex drive** • Migraines**

*The relationship between this symptom and PCOS is *inconsistent* with the literature.

**The relationship between this symptom and PCOS *remains unclear*.

***The relationship between this symptom and PCOS is *not reported* in the literature.

Reproductive Manifestations of PCOS. Of all the symptoms women described as part of the PCOS experience, reproductive manifestations were the most common. In fact, almost all reported a history of menstrual irregularity. This was expected, however, because menstrual irregularities are cited as the most common reproductive manifestations of PCOS (Teede et al., 2010).

Although menstrual irregularities were common among interviewees, their experiences varied considerably. For example, many women reported infrequent periods and/or “skipping” periods (oligomenorrhea) , which often resulted in long and/or heavy periods (i.e. menorrhagia).

I've never had regular periods in my entire life...you know, since I started menstruating...and, when I do have periods, they're really, really, really, like, extraordinarily heavy. (C.Y., age 36)

Others reported having a number of cycles per year, but reported that each cycle drastically differed in length.

Well, one [menstrual cycle] will be pretty normal, and then the next one will be 37 days, and then the next one will be 57 days, and then the one after, who knows? (B.A., age 27)

On the other hand, some women reported spotting on a daily basis and never having a “real” period. Still, others reported having all of these experiences at different times in their lives.

Also, a few reported a total absence of menstruation (i.e. amenorrhea). Lastly, one participant reported having regular periods but admitted that she had been on some form of birth control for most of her life and did not know her “natural” cycle.

For WLW PCOS, menstrual irregularities such as oligo- and/or amenorrhea result from chronic oligo- and/or anovulation (defined as infrequent ovulation or absence of ovulation). For this reason, it is not surprising that many interviewees also reported ovulatory dysfunction and described its connection to their menstrual irregularities. However, a few women also expressed the belief that PCOS may result in “hyper” ovulation, which is inconsistent with the literature.

I could go for, you know, six months without ovulating at all, or I could ovulate four times in a month. That's the way I understand it. Umm, it seems to me [that], the time I've been off the pill, I don't ovulate. I don't over-ovulate. I under-ovulate. (E.S., age 34)

Also, most women reported having polycystic ovaries (PCO), which they identified as the underlying cause of their ovulatory dysfunction and/or menstrual irregularities.

PCOS is a hormone disorder that affects your ovaries...polycystic ovaries...you have ovarian cysts, and they affect your monthly cycle. (D.T., age 37)

For about half of the women interviewed, ovulation and menstruation were a source of significant pain. While many described their pains during ovulation (i.e. Mittelschmerz) as a temporary “pinching” sensation, a few reported visiting the emergency room one or more times for pain relief.

Oh boy, I mean, I would have the pain too, because it is, it is painful sometimes. You get, like, pinching in your ovaries and you feel things bursting. (B.A., age 27)

Similarly, a few reported that chronic pelvic pain limited their ability to engage in daily activities, and one participant reported regularly going on bed rest and “not being able to move” during painful menstruation (i.e. dysmenorrhea).

From the start, my periods, they were super painful. ..to the point of laying in bed...so painful that I would say to my mom “Do I have to live with this my whole life?” (E.V., age 40)

In fact, while most women reported that menstrual irregularities prompted them to make an appointment with their provider, which later led to a PCOS diagnosis, a few identified their pain as their primary motivation to seek help.

I was diagnosed with the PCOS when I was fourteen. I went in for abdominal pain in the ER, and they did an internal ultrasound the next morning and found that my left cyst looked like a whole bunch of grapes. So, I went to my first gynecologist visit that month, in February, and they diagnosed me with PCOS. (E.C., age 22)

Infertility was also commonly discussed by interviewees, regardless if they had experienced it themselves. This was expected, however, because PCOS is recognized as the

most common cause of anovulatory infertility in women (Brassard et al., 2008) and because interviewees were partially recruited based on infertility status (see *Phase 2, Sampling and Recruitment*). For most women, it “made sense” that anovulation prevented pregnancy. However, for a few women, reasons for PCOS-related infertility remained unclear.

It causes things like...fertility issues that don't seem to necessarily have a reason.
(A.F., age 37)

Among women who reported a previous pregnancy, a few identified a number of pregnancy complications that they attributed to PCOS, including gestational diabetes and pre-eclampsia. Although emerging research supports the hypothesis that PCOS is an independent risk factor for these outcomes (Boomsma et al., 2006), most PCOS experts agree that further research is needed. Likewise, some reported having had one or more miscarriages that they attributed to PCOS. However, the association between PCOS and miscarriage remains controversial. While some investigators report an increased risk of miscarriage in WLW PCOS (Balen, Tan, MacDougall, & Jacobs, 1993; Wang, Davies, & Norman, 2001), others do not (Nejad et al., 2011). Laiu and colleagues (2014) offer a few reasons for these conflicting results: First, WLW PCOS represent a heterogeneous population with several phenotypes, each with a possibly different risk of miscarriage. Second, it remains unclear if miscarriage risk differs between WLW PCOS who have conceived spontaneously and those who have conceived following treatment. In addition, WLW PCOS who do conceive following treatment may do so using different treatment modalities, each with a different risk of miscarriage.

Among women who had successfully carried a pregnancy to term, half reported low breast milk production (i.e. hypolactation). This topic, in particular, seemed difficult for women to discuss, as this was the only time women cried during interviews.

I know one of the most frustrating thing for me is that I have low milk supply and that I feel like that was like the nail in the coffin for me. Like, I feel like PCOS has stolen so

many things from my life and that was really hard for me...[inaudible, cries]....
(E.A., age 29)

In addition, many expressed frustration that their providers did not prepare them for possible breastfeeding difficulties.

I think I had one lactation consultant tell me that PCOS could cause low milk production. But I mean, when I was pregnant, I had never heard anything about it. Before getting pregnant, I had never heard anything about it. I was, I was a wreck. You know, and it was, it was something that I felt very strongly about. Like, I knew before ever getting pregnant that I wanted to breastfeed my children. And, I was ready to work through any latch issue, or, you know, any of the other problems that come up with, with breastfeeding. But, I never considered not producing enough milk. (J.F., age 33)

However, this is not surprising, because few investigators have studied breast development and breastfeeding problems among WLW PCOS. In short, this issue has received little attention in the medical community.

Interestingly, Drs. Stein and Leventhal, the two American gynecologists that first clearly described PCOS, made reference to problems with breast development in their early studies. In their seminal article describing PCOS, they described women as having “small, pale, firm” breasts, “large, flabby breasts,” and “pendulous breasts”(1935). In a later article, Stein (1945) also mentioned “retarded breast development” and “hypoplastic breasts.” These descriptions are consistent with participants’ descriptions of their own breasts. For example, most women who reported low breast milk supply reported having tubular (or tuberous) breasts or insufficient glandular tissue (IGT) and attributed this to PCOS.

And, with the insufficient glandular tissue, which goes along with PCOS, I don't have...my breast tissue is not filled the same as somebody else's. I don't have breast tissue hardly all on top. I have very tubular, long breasts with very, very, large areolas. I have little to no breast tissue underneath - on the underneath side of my breast - and it's just caused a lot, a lot, A LOT of issues with milk production and breast feeding my child. Like, this is my biggest thing. I had no idea that it was this big of a deal until I had my baby. (E.C., age 22)

Dermatologic Manifestations of PCOS. Dermatologic manifestations were the second most commonly described PCOS-related symptoms. However, interviewees spent considerably less time discussing these symptoms compared to their reproductive issues, suggesting that the reproductive manifestations of PCOS had a greater impact on their daily lives and/or overall experience of the syndrome.

A majority of interviewees reported a history of hirsutism (i.e. the excessive growth of terminal hair). This was expected, however, because hirsutism is the best marker of hyperandrogenism, a biochemical sign of PCOS that is commonly assessed during a diagnostic visit (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012). Although hirsutism was common among interviewees, their experiences varied dramatically. For example, some described having “a little peach fuzz” and commented that other WLW PCOS had it “way worse.” On the other hand, some women reported significant hair growth, and one participant described her younger self in gym class as climbing ropes and looking like a “gorilla.” Although most women reported having hair on a number of androgen-sensitive areas, including the chest, abdomen, and back, facial hair seemed to be the most distressing symptom.

The hair is irritating. I mean, it's not fun to be 33 with a mustache. And so, that's one more thing to deal with... you know, how you get rid of it. And so, that kind of affects the way I look at myself. And, it's kind of like my body is broken...(J.K., age 33)

About a third of interviewees also described other dermatologic symptoms, including hair loss (i.e. alopecia), oily skin, and cystic acne—all of which are clinical signs of hyperandrogenism (Teede et al., 2010). While some participants only reported have one or two of the dermatologic manifestations of PCOS, some reported having all of the above.

I started noticing, like, [Sigh] my face was super-duper oily, and I was having issues with really bad acne...and also like umm my hair is thinning on top of my head, which really

sucks. Then, like, my [Sigh] ...the lady that threaded my eyebrows was like, "You want your lip done?" I'm like, "Like are you serious?" And, then my friend is like, 'Yeah you kind of do need it done.' I'm like, "Seriously, why didn't you tell me this, because that's something you're supposed to tell me" [Laughter]. Cause, I hadn't noticed, and so...and then the guy who like does my pedicures was like, "Oh you got extra hairy feet." I'm like, "Yeah, I actually just found out I have a medical condition that causes that. Thanks"(S.R., age 30)

Lastly, a few participants also described discoloration of their skin (i.e. acanthosis nigricans), a symptom commonly associated with insulin resistance. As previously stated, high insulin levels (i.e. hyperinsulinemia) underpin PCOS and lead to insulin resistance (IR) (Balen et al., 1995; Kiddy et al., 1990). Not surprisingly, the women who reported acanthosis nigricans also reported a history of IR (see *Metabolic Manifestations*). In fact, one interviewee commented that her endocrinologists, without ordering any diagnostic tests, took "one look" at her skin, and said, "Yep, your insulin resistant." (K.L., age 47)

Metabolic Manifestations of PCOS. Metabolic manifestations were also commonly described as part of the PCOS experience. Symptoms included weight issues, IR, food cravings, diabetes, high cholesterol (i.e. hypercholesterolemia), and high blood pressure (i.e. hypertension). This was not surprising, however, because the association between PCOS and these symptoms are identified in the literature (Essah et al., 2007; Tomlinson et al., 2010).

Of all the symptoms described by interviewees, weight issues, including weight gain, obesity, and difficulties losing weight, were most often identified as women's "biggest concern," followed by infertility.

Well, I think that the weight issue is the hardest to deal with, because, I mean, I know, I KNOW that it's harder for me. And, I feel like it's just something that I struggle with everyday, and I know that it's harder for me to lose weight than women that don't have PCOS. (A.H., age 35)

These results may be biased, however, given that over half of the interviewees had successfully carried to term by conceiving either spontaneously or following infertility treatment. This

consideration is exemplified by an interviewee who had experienced infertility and had children following fertility treatments:

I'm almost 39. It's, it's kinda like, for me it's...like, my weight is the biggest way it impacts me at this point. If you asked me 5 years ago - 4 years ago - I would have had to say...I would absolutely [have] told you my fertility. (J.T., age 38)

Still, it is unsurprising that interviewees described weight issues as the “hardest part” of PCOS, because, similar to the overall sample, 85.3% of the interviewees (n=29) were overweight, obese, or morbidly obese.

A majority of interviewees also reported a history of IR. This was not surprising, however, because PCOS experts suggest that all women with the syndrome have IR (DeUgarte, Bartolucci, & Azziz, 2005). Likewise, because IR is a precursor to diabetes, it is also unsurprising that a few interviewees reported a history of diabetes (n=4, 11.8%) on the Phase 1 survey and that others identified an association between PCOS and diabetes during their interview. Several interviewees also reported “uncontrollable” food cravings, which are commonly reported among persons with uncontrolled insulin levels.

I think I have different cravings than other people, because of the insulin resistance. People are like, “Oh yeah, you just have to learn to control it, you know, you have to control what your, what you want and what you do.” And it, it seems like other people have that drive...but, see, it's a never ending cycle. If I get off the bandwagon and start having cookies or brownies or something like that, then I have to get off of them for a while for the cravings to go away. (A.F., 37)

On the other hand, a number of interviewees discussed general feelings of exhaustion or tiredness that limited their daily activities or interfered with their work. Although some described these feelings as being cyclical in nature and being mostly related to their menstrual cycle, many associated these feelings with their IR.

I know there are times, specifically, say, the week where I'm supposed to be premenstrual, or if I've gone a long time in between having periods where I know I should have had one, and I'll start feeling very, very run down. I mean, to the point

where I'll be so fatigued. And, sometimes, it will be, like, difficult to even sort of drag myself up out of bed. (T.Z., age 34)

While one-third of participants also reported a history of high cholesterol (i.e. hypercholesterolemia) and high blood pressure (i.e. hypertension) on the Phase 1 survey, only a few mentioned it during their interview. Although these women all concluded that PCOS was the underlying cause of these issues, none discussed them at length, making statements in passing like, “My high cholesterol is a sign of my PCOS.” For this reason, it remains unclear if women felt like these issues were serious or if they simply found other PCOS-related symptoms more troubling.

Psychological Manifestations of PCOS. The majority of interviewees also described psychological manifestations of the syndrome, including anxiety, depression, and mood swings. This was expected, however, because the majority of interviewees reported a history of anxiety (n=22, 64.7%) and depression (n=24, 70.6%) on their Phase 1 survey. Likewise, previous studies suggest that a number of symptoms reported by interviewees, including hirsutism and obesity, are associated with anxiety and depression (Himelein & Thatcher, 2006). However, in this sample, many women attributed their moods to the hormone imbalance caused by PCOS and/or to their PCOS-related menstrual irregularities.

I know that, as far as my moods [are concerned], if my hormones are out of whack, like, [Sigh] ...when I actually would have my periods, like, I thought I had the premenstrual dysphoric disorder for the longest time, because of how much my moods swings would be so...awful. And, so, I thought that I had that, but I think it's really just the PCOS with the [Sigh] ...irregularity of my hormones, meshing with my brain chemicals that are causing me to be an emotional wreck sometimes. (S.R., age 30)

I feel like I have, I mean, I have, like, anxiety and stuff like that, but I know that it's...I feel like it's very much, like, related to my cycle and stuff like that. I have like a little bit of PMS symptoms. But then, like, also, like, in the middle of my cycle, I, I do like natural family planning, so, I, like, chart my cycles and everything. And, in the middle, I like, um...like, I can tell, like, my body's trying to ovulate, and it's, like, failing and failing and failing, and I just feel like absolute crap, like, that entire...I don't know, sometimes it

takes as long, you know, like, 20 days or something...and it just really affects my mood, and my energy, and stuff like that. And then... I just, like, cry, you know, these like mood swings, I guess. (M.W., age 25)

Other Manifestations of PCOS. As previously stated, a majority of symptoms women described as being part of the PCOS experience could be classified as either reproductive, dermatologic, metabolic, or psychological manifestations of the syndrome. However, a few did not fit neatly into these categories. Although only a couple of interviewees described each of these “residual/other” symptoms, they are important to note. For example, the association between PCOS and anemia, Vitamin D deficiency, and signs of virilization (e.g. deepening of voice and broadening of shoulders) were all described by one or two interviewees and are documented in the literature (Carmina & Lobo, 1999; Fraser & Kovacs, 2004; Li, Brerenton, Anderson, Wallace, & Ho, 2011). On the other hand, the relationships between PCOS and sex drive, hypothyroidism, and migraines remain unclear (Archer, 2006; Benetti-Pinto, Piccolo, Garmes, & Juliato, 2013; Rellini et al., 2013). Lastly, two participants also reported “suffering” from insomnia and attributed their sleep difficulties to PCOS. Although a direct relationship between these two conditions is not reported in the literature, sleep disturbances have been associated with a number of PCOS-related conditions, including IR (Cauter, 2011) and anxiety and depression (Ohayon & Roth, 2003). For this reason, it is possible that PCOS is an independent risk factor for insomnia, and future research should be conducted to explore this relationship.

Consequences. Interviewees’ responses to questions regarding the consequences of PCOS on their daily lives, the lives of significant others, and the future are reported here. Findings are organized by themes, which include the impact of PCOS on women’s self-image, work, social life, personal relationships, finances, and future health. In addition, a few “positive

consequences” of PCOS were identified by interviewees and are summarized at the end of this section.

Self-image. Many women discussed the impact of PCOS on their self-image and described themselves as different from other women due to the various signs and symptoms of the syndrome. Most commonly, women said they were “not like normal women” or discussed lack of normalcy. In fact, over two-thirds of interviewees used the term *normal* at least once during their interview.

When I finally was diagnosed with it [PCOS], it gave me a better understanding of why I wasn't quite normal. Um, that's the way I always felt. I felt not normal. (D.L., age 46)

The signs and symptoms that women most commonly identified as making them feel different included menstrual irregularities, growth of unwanted body hair, loss of head hair, breast (under)development, mood swings, and higher than normal body weight or weight gain. Hirsutism, in particular, seemed to impact women’s feelings of themselves as female and many reported daily grooming routines.

In terms of my daily life...every morning I have to shave. Like I, I, have to. If I don't, I have a five o'clock shadow. I'm just always trying to make sure I look more feminine. (K.W., age 34)

Some also specifically stated that they lacked confidence and were insecure about their body.

I guess that's the biggest thing is my, you know, confidence in myself. Sometimes, like, I get all worried that something will happen, or my acne will come back, or I'm like OCD about tracking my cycles to make sure they're all normal, and...I guess that's, you know, the way it affects me...I just wish I could, like, lose weight and, you know, stay at the same weight without getting it back in a few months. (E.B., age 29)

I'm very insecure about my body in general. I worry a lot about...I don't know why, but I have this thing where I feel like my breast never...they never developed appropriately because of this stupid thing...(K.M., age 30)

Also, one participant suggested that being different created a sense of isolation from others, while another said it created a “barrier” between her and her friends.

I guess the best way to put it is something you go through where you feel isolate, 'cause you're not developing the same like everyone else. You know, when you go through your puberty and everything like that, you're not developing the same. Then, once you start, you're getting the male characteristics. (K.W., age 34)

My friends...I think, I think, it's hard, because they don't have...they have no idea what it's like to not just have a healthy functioning, you know, reproductive system. And, and, that's just not easy to deal with. I don't think. And, I think it does create a little bit of a barrier between me and women in general, because I've always felt different, you know? And, I know it relates to this syndrome. (K.M., age 30)

Lastly, a few single participants remarked that their negative body image discouraged them from dating.

I didn't want to date...my body was, honestly, ... it was like a hearse. You know, I felt like I was stuck in this, you know, really dysfunctional and very inadequate body, and I still struggle with that at thirty. I still see that... I know that I'm a, you know, norm- I'm a woman who deserves to be loved just like any other woman...[it's just that] because of everything that's, you know, I've gone through with this syndrome and everything, I still have to remind myself [of that]. Like, if I go out on a date with a guy, and he doesn't call me, you know, it's not because I have PCOS. It's not because I'm like a freak, you know? I still have to remind myself of that. I've dated like...my serious boyfriends have made comments about the hair growth or have made comments about my breasts...and that's horrifying, you know? You, you're just horrified, and you just wanna like crawl up into a corner and you just don't wanna date! (K.M., age 30)

Work. Although problems with work were the least of the PCOS-related consequences discussed by interviewees, they are important to note. For example, a few women who reported being IR also reported difficulties fulfilling work responsibilities, mainly due to exhaustion.

I am tire a lot! I have a really hard time with memory and concentration. Like, I, it interferes with my work, because, you know, my whole job is built around listening to people, and remembering what they said, and putting it to paper, or putting it in their computer - you know, their medical record. And, I, I will find myself just spacing out and jus- and so tired...to the point where my boss will actually say to me, you know, "Go home!" 'cause she sees it! And, it's gotten worse as I, you know, as I said. It's gotten worse over the past year. So, I definitely think those [insulin resistance and feelings of tiredness] are related. (K.M., age 30)

Likewise, menstrual irregularities, particularly menstrual pain, resulted in some missing work days. Also, one participant reported that excessive bleeding particularly interfered with her work

tasks. As a trauma nurse, she described how difficult it was to fulfill her duties when she constantly had to run to the bathroom to change her feminine products.

Social life. Although most interviewees felt like PCOS had not interfered with their normal social activities, a few cited specific symptoms that discouraged them from going in public and/or being social, mainly hirsutism, alopecia, and weight.

[PCOS] alters whether I feel comfortable going in public, because I have to check my face to see if I've cleaned [the] hair well enough to feel good. If it's a beach day or a river day or something, then I have to make sure my, my, legs and arms and stuff feel, feel, socially appropriate...I think that's part of it. I feel like society has such a strong opinion about what's appropriate for a woman that, that even if I didn't care, someone cares. (E.V., age 40)

I avoid as many social gatherings as I can, so that I don't have to deal with it...deal with having to pluck this or that in time to be there on that day or this event. I have a scalp issue and I'm short, so everybody sees the top of my head. So, when there's something wrong with my scalp, I can't hide it in anyway, and I have black hair, so it just kind of stands out. I'm overweight, so I try to avoid, y'know, anything social, and I only go to the ones that I absolutely have to go to. (S.S., age 37)

However, this was not surprising, because, as previously reported, several women identified hirsutism as their greatest concern.

Personal Relationships. While most interviewees described ways in which the experience of PCOS had positively affected their relationship with friends and family (see *Positive Consequences*), a few described circumstances in which their personal relationships had been affected. For example, one interviewee, who was single, felt that her “masculine features” had interfered with her dating life.

Most guys say I'm too masculine. Usually, my features, like, just, just...some things like relations I've had...they'd be like, “Well, you just too dominant!” or “You just too manly!”... So, I mean, for some guys, it's just like a turn off cause they don't know what they're dealing with. (K.W., age 34)

Another participant, who was married and who reported problems with facial hair, described her insecurities when dating her now-husband.

When I actually first started dating my husband, it wasn't good, because I don't like my face to be touched [Laughter] ...or my neck. And, so, that was like an obstacle that we had to overcome. He was just like "Oh, you're so cute. I just want to touch your face." Then I kind of had a panic attack, because he touched my face. (S.K., age 32)

For many women, however, their biggest personal struggle when dating was deciding when to disclose their diagnosis and when to explain its possible effects on fertility – a subject that many worried would be a “deal breaker.”

When my husband and I talked about getting married, I mean, that was obviously a big topic that we needed to cover...that, you know, I don't, I've, I had never tried for children, but, according to the doctors, it would just never happen. We had gone to see a gynecologist prior to getting married to talk about other options like the IVF and the drillings and all that, and, so, we, we...I wanted to make sure that, before we got married, that it was okay with him that we might not have our own kids. (C.Y., age 36)

However, none reported that disclosing their diagnosis or possible infertility had ended their relationships.

While most women received a lot of support from their friends and family, a few felt like those closest to them did not understand their diagnosis and, consequently, made insensitive remarks and hurtful accusations.

Well, I find that the people around me don't really understand what I'm going through, because, they, they might see the symptoms, but they just...they don't understand the physical effects and how it makes you feel and why I'm gaining weight. My husband honestly sometimes thinks I'm a hypochondriac, but my doctor has flat out said that's not true, because of my lab results. But, you know, that puts a strain [on you] ...you know, feeling like people look at me like I'm fat, you know, and, and I hate using that word. I do get that a lot. I actually didn't talk to my sister for a year at one point, because, when I was really struggling with my weight...she is super thin, herself, and she does not have PCOS. She can eat, you know, pizza and beer and run and work it off, and I have to eat, you know, next to no carbs and still not lose weight. (L.P., age 42)

Lastly, of those women who reported issues with low breast milk supply, many expressed great sadness over not being able to bond with their child through breastfeeding.

It's heart breaking. I had no doubt in my mind that that was something that I wanted to do, and, then, when they said, "I can't," I'm like, "That's crazy," you know? I feel [like] this [is] something that has been taken away from me, you know. And, no one took it

away from me...you know what I mean? My body just can't do what it's supposed to just naturally do. So I'm definitely trying to do what I can, but it's still something that definitely affects the relationship with my child. That's definitely one of the tougher PCOS things I experienced. (D.T., age 30)

Finances. When asked, “What would make living with the syndrome easier?” many participants answered having better health insurance coverage. In particular, women in the study found it very troubling that a number of treatments needed to address PCOS symptoms were not covered by insurance. These treatments included gastric bypass, IVF, laser hair removal, and alternative solutions, such as acupuncture.

For a while, I did try to buy creams and things that might remove hair temporarily better than shaving or something, but, lately, I just...keep my face clean. And, I feel like I'm not in a position to spend [the] money that it would cost to, to make have a more permanent type of solution. (E.V., age 40)

One participant, in particular, reported that, because she had had a tubal ligation, her insurance would not pay for birth control pills, which she was prescribed to help regulate her hormones.

Given the complex nature of the syndrome and the need for some to see a number of specialists, a few women also reported that their health insurance limited their ability to manage the syndrome by limiting their access to certain providers. Similarly, others were troubled that they could not receive the care they needed, because they could not afford health insurance. One exchange was particularly illustrative of the complexity of the problem. This interviewee lived in Florida, a state that recently chose not to expand Medicaid (Ashtari, 2014).

Interviewee: Emotionally, it is, it's really debilitating, because, you know, I'm married. I wanna do what a lot of women my age wanna do and have a family, but I can't! I can't have children. I mean, my husband and I have tried for...I don't know, eight years. It's, it's, apparently not going to happen without, you know, healthcare, which isn't an option for me because I don't qualify for Medicaid...and I need it...It's pretty rough. It makes, it makes me feel less than a woman, I guess...to not be able to reproduce is, is, is fairly devastating to me.

PI: So, *it sounds like having better access to health care would make living with PCOS easier for you?*

Interviewee: *Well, yeah, yeah... That'd be great! Unfortunately, it doesn't look like that's gonna happen. You know, the legislature and the state has decided not to expand Medicaid, and I don't have...even though I qualify financially for Medicaid, in this state, if you do not have a child, you can't have Medicaid. That's kind of ironic, you know?* (C.K., age 32)

Lastly, some women expressed frustration with the “ups and down” of their weight, explaining that they had spent a significant amount of money to maintain a wardrobe that ranged in sizes. One participant, for example, said that she had pants that ranged from size 0 to size 16. Others could not afford the clothes they needed to accommodate these weight fluctuations.

When I was in high school, we were poor. So, when I would gain weight and then lose weight, we'd get rid of one set of clothes and wouldn't have enough money to buy more clothes...so the weight gain and the hair, that was a big issue. (E.C., age 22)

Future health. When participants were asked how they thought PCOS would affect them in the future, some projected short- and long-term complications for themselves. For example, of those who had not yet tried to conceive, the possibility of infertility was very concerning, and many worried about future pregnancy complications. In large, these concerns emerged from consultations with their provider.

I mean, it didn't really affect me until they told me that I would never have kids. Their words were, that it would be...the chance of me having a child would be slim to none, and the chance of having a healthy baby would be pretty much nil. (C.Y., age 36)

Notably, like many others in the sample who had received such “matter-of-fact” information, this participant had no trouble conceiving or complications with her pregnancy.

On the other hand, those who were older and those who had successfully carried to term were more likely to express concern over long-term complications, including diabetes and heart disease. A few of these participants also worried about developing cancers of the cervix, ovaries, and breasts. Notably, while there is insufficient data to evaluate any association between PCOS and cervical cancers (Dumesic & Lobo, 2013), small studies do suggest an association between PCOS and cancers of the ovaries and breast (Eunice Kennedy Shriver

National Institute of Child Health and Human Development, 2012). However, more research is needed to explore this relationship. Surprisingly, endometrial cancer, which WLW PCOS have a 2.7-fold increased risk for developing, was not identified as a health consequence of PCOS by any participant.

Positive consequences. As previously reported, some participants identified positive aspects of their experience with PCOS. For example, a few participants felt that receiving the diagnosis had prepared them for possible infertility and pregnancy complications.

I guess the positive is that I have not started trying to have children, and I know that I have this, so, I'm a little bit more prepared than some of the other women that find out [they have PCOS] when they're trying to have kids. Or, like, the fact that, they, they caught it at thirty, when I was not in a relationship, you know...At the time, I took it hard, but, in retrospect, it's awesome that I already know that this is, this is the case, and I don't have to waste a year wondering what's wrong with me. (E.S., age 34)

On the other hand, two women joked that having PCOS had probably prevented them from an unwanted pregnancy in their youth. In the same vein, another suggested that she had not spent as much money on “period supplies,” because she had so few periods.

Several women also discussed how receiving the diagnosis had improved their relationships with their family and friends.

I feel like talking about it with my fiancé has kind of, like, helped our relationship, I guess. Just like, as far as like, bonding [Laughter], and like, you know, seeing like, how much he cares about my health and stuff...(M.W., age 25)

I think it helped me and my mother's relationship a little bit. My mom adopted me, because my mom's never been able to have children, and I was able to call her, and be emotional with her, and let her know that it could be very hard for me to get pregnant, and all these other things, and it was nice being able to have that support system there. (B.A., age 27)

In fact, one participant expressed great happiness over helping her friend realize that her symptoms were characteristic of PCOS, which later led to her diagnosis and needed follow-up health care.

Actually, through my process, this year, a friend of mine who I go to school with...I was just kinda talking to her, and telling her, you know, about my symptoms and stuff, and she's like, "Oh, I have that same thing!" And, I gave her my doctor's number, she went to the doctor, had all the tests done, and she actually has it too. So, if anything, me having it has helped someone else, because I was able to help her get on the right path, and, you know, get herself straightened out too. (C.A., age 31)

Likewise, many reported that, by searching for answers online, they had identified and joined a number of social support groups, which they valued greatly. This was not surprising, however, given that this sample was recruited from a SNS.

Lastly, a number of women reported that, because of their diagnosis, they were "more aware of their body." For some, this meant learning about the menstrual cycle and/or charting their own cycles to become pregnant successfully. For others, it meant paying more attention to bodily cues and adopting a healthier lifestyle to improve PCOS manifestations.

I now know what's going on with my body. Like, I know if, you know, I get a pimple, like, "Ok, well..." [Laughs]. Or, you know, the gaining weight...like, I don't wanna blame it on PCOS, but at least I know it's a factor in it. So, it's like, I'm aware of it, and I know, like, I need to work twice as hard as like someone else to, you know, you know, stay healthy. Also, I eat a lot better than I probably would normally, because I'm like, "Ok, this food's not going to be great for me." (E.B., age 29)

Cause. Although all participants expressed uncertainty about the cause of PCOS, most speculated that genetics contributed significantly to the development of the syndrome. Some also believed that environmental factors contributed to its development. In particular, a few women felt like additives and hormones common in today's foods had contributed to its development, and one participant suggested that more women lived with a PCOS diagnosis today due to dietary factors.

I really think that it's a combination between genetics and my environment. I feel like there's a lot more PCOS in the population now than there was in other generations and I feel like that supports [that] there's something in the environment. ..[like] growth hormones that are in our food supply. (J.D., age 25)

Two participants also expressed the belief that BPA (e.g. bisphenol A), an industrial chemical that is used to make certain plastics and found in certain containers that store food and beverages, such as water bottles, contributed to the development of PCOS. However, this association has not been reported in the literature. Lastly, one participant expressed concern that WLW PCOS who breastfed their female children placed them at greater risk for developing PCOS.

It's something that I asked, like, lactation consultants and stuff when I had my two girls. You know? Is there something, [Sigh] that I'm going to essentially be giving to them by breastfeeding them, because I know that there's a crazy amount of hormones in breast milk. So, if my hormones are screwed up, am I therefore, like, kind of transferring that to them by breastfeeding them? And, nobody could answer that question. So I did decided to breast feed them, you know, because the other benefits kind of outweighed that risk, I guess, for me. But, it was something that I did worry about, that I do worry about, because I don't want them to be in this situation, y'know? (A.H., age 35)

This finding, in particular, not only highlights the need for better PCOS-related patient information, but also the inclusion of specific PCOS-related content in lactation consultant's training. Unfortunately, little is known, in general, about the relationship between PCOS and breastfeeding issues, and these relationships need further attention in future investigations.

Timeline. Interviewees' timeline beliefs related to their ideas about whether PCOS or its symptoms were acute, cyclical, or chronic. These beliefs were assessed not only by asking participants about how long they believed they had lived with the syndrome, but also how long they believed it would affect them.

Acute/Chronic. While many women speculated that they had lived with PCOS "forever," most believed that they experienced their first PCOS-related symptoms during puberty. This is unsurprising, however, given that most reported a history of menstrual irregularities. When asked how long they believed PCOS would affect their lives, about half of the participants, without hesitation, responded "forever" or "the rest of my life." In contrast, others questioned

whether PCOS would affect them after menopause or a hysterectomy or if these circumstances would significantly change their experience with the syndrome.

It's always felt like something was wrong, but I just...I don't know. I think it's just a life-long thing. Maybe when I go through menopause, right, then maybe it would...that, that everything would subside, you know...or maybe like a hysterectomy, maybe that would change it? (K.W., age 34)

It also seemed that a few women, particularly those with a history of infertility, had not considered the possibility that PCOS would affect them in the long-term at all. When asked, “Do you think PCOS will affect you in the future, and, if so, how?” one participant replied:

I hope not. We're done having kids, so we're not gonna have to do that again, y'know? (A. H., age 35)

This finding most likely reflects this participant's recent focus on fertility and need for infertility treatments. However, it may also suggest that, during her clinical encounters, her provider did not discuss other implications of the syndrome or that she disregarded those messages. For this reason, it is important that providers continue to discuss the larger implications of PCOS, such as diabetes and heart disease, with their patients throughout their medical treatment, emphasizing any lifestyle modifications or treatments that will help prevent any future PCOS-related conditions.

Cyclical. Lastly, when discussing symptoms, it was common for interviewees to described specific symptoms as being unpredictable or “coming and going” in cycles. These symptoms included menstrual irregularities, painful menstruation and ovulation, mood swings, and acne. This was expected, however, because these symptoms center on women's menstrual cycle. Similarly, women also described cycles of weight gain and weight loss and issues related to IR, including exhaustion and cravings. For example, one participant described the impact of her diet, which she adopted as a strategy to help manage her PCOS-related symptoms, had on her cravings:

...it's a never ending cycle. If I get off the bandwagon and start having cookies or brownies or something like that, then I have to get off of them for a while for the cravings to go away. (A.F., 37)

Control. To access beliefs about the ability to control or manage PCOS, interviewees were asked what they did to manage the syndrome and what strategies had and had not been helpful in the past. In their responses, many also discussed the extent to which they felt they had control over PCOS and/or its symptoms (i.e. personal control). These responses are summarized below.

Personal. Overall, most interviewees felt like they had little to no control over their PCOS. For many, these feelings seemed to arise from their inability to control one or more symptoms, including menstrual irregularities, alopecia, hirsutism, acne, weight issues, and mood swings.

When I pluck the hairs off of my chin, I feel like I have absolutely no control...you're never...I'm not ever allowed to forget what I have. Whether I walk by a mirror and see that I'm overweight...you know? It's very frustrating. (D.L., age 46)

Breastfeeding problems, in particular, also seemed to affect women's feelings of personal control.

[Low breast milk supply is] not in every woman with PCOS but you know...that's what hit me the most, because that's something I can't overcome, you know? I can't feed my baby and that's something I struggle with in my current pregnancy to accept, [inaudible, cries]...I'm sorry. (D.T., age 30)

For others, the length of time they had lived with the diagnosis affected their sense of control.

Understandably, those who were newly diagnosed felt less in control of their PCOS than those who had been living with the diagnosis longer.

Right now, I don't feel like I have much control over the syndrome, just for the simple fact that I'm still feeling new to the diagnosis, and they still haven't gotten my medications regulated to the point where my body is working the way it's supposed to, and I still haven't lost the weight that I have that I need to lose and that I want to lose.

I'd say it's not completely out of control, but I definitely have a lot of work ahead of me. (S.R., age 30)

In contrast, one participant reported that her physician led her to believe that there was nothing she could do to control or manage PCOS. When asked, “How much control do you feel you have over your PCOS?” she responded:

Pretty much none. Like, I... I guess I don't think that it's, you know...from what I was told by the doctors, you know, there's nothing really to do for it, you know. The only thing they were doing really for me was because I wanted to be pregnant...So, I, I guess, I just kinda felt, you know, it's something that, you know, ever since, you know, at 13, when I got my first period, I've always been irregular. So, it's been, you know, 20 years that I've dealt with this. I, I, I just, I don't think about it as...I just think about it as like part of, you know, my life...not really anything I can do anything about. (M.B., age 33)

At the same time, many interviewees reported modifying their lifestyle in order to gain control over PCOS or its symptoms. For most, their primary strategy was to lose weight through diet and/or exercise. Although no participant identified a specific exercise regimen, participants named a number of diets they had adopted – all with varying success. These included Weight Watchers™, Atkins™, Physicians' Weight Loss™, the Paleo Diet™, the low glycemic index diet, and calorie restriction (defined as 1200 calories or less). For many, slow or no weight loss discouraged them from continuing their diets and/or exercise regimens.

I started in February of last year. I was like, okay, I'm gonna make some changes, you know? I'm gonna eat better. I'm gonna start, you know, exercising. So, here, near home, we have this lake that's three miles around, and everyone walks it, runs it, rides their bike, rollerblades, whatever. That's like the spot to go to. So, I started doing that AT LEAST three or four times a week. I would go and either walk or, you know, jog, and I was eating better, and I started that in February. By October/November, like, right before the holidays, I had not lost a single pound. (C.A., age 31)

For others, uncontrollable food cravings made it difficult to follow a diet plan. However, those on Metformin® reported greater success.

After I got on Metformin, I lost weight. So, I mean, I...before, diet and exercise really didn't do a whole bunch for me, and, then, magically, I, you know, I had lost 10 pounds, and didn't do anything different, quote unquote. But I lost some of my sugar cravings, so, it made life a lot easier. (A.F., age 37)

Overall, most participants, regardless of their weight loss strategy, reported little to moderate success.

For some, receiving their PCOS diagnosis helped them gain a small sense of control.

It's good to know what it is that I have. All these weird things were happening to me, and I didn't know why, like, why I couldn't control the acne or the hair that grows on me. It's nice to have like...this is why and to use that info to be able to help myself more, I guess. (J.S., age 33)

Likewise, for one participant, finding the right healthcare provider made her feel more in control.

I don't know that I've ever trusted another doctor as much as I trust my GP now, because she was really into women's medicine, and she took the time to diagnose me with PCOS. Whereas, you know, my history with doctors before was kinda, okay, you're fat, lose weight. That's pretty much it. And the lactation consultant, we've become lifelong friends. She worked with me to use supplemental nursing systems - all sorts of fun stuff. I guess it's because it's, you meet, when you have to do things differently than other people, and you find a support system, it makes life nice. (A.F., age 37)

Unfortunately, few participants described their clinical experiences positively and most expressed frustration with their provider(s) (see *Emotional Representations, Frustration*).

Lastly, to gain control, one participant reported adopting alternative therapies, including acupuncture and herbal remedies. Although she did report great success with these alternative therapies, which she defined as spontaneous conception, she did admit that these therapies were costly.

Treatment. Almost all participants identified ways in which their PCOS had been medically managed. These experiences were largely dictated by the interviewee's symptoms and medical history and included one or more of the following: oral contraceptives, infertility treatments (see Table 19), hair removal treatments, acne treatments, Metformin®, and psychiatric drugs. Among these, oral contraceptives and Metformin® were most commonly discussed.

Because almost all interviewees reported a history of menstrual irregularities, it was not surprising that almost all reported taking oral contraceptives. Although most of these women reported that oral contraceptives had effectively treated their symptoms, by either eliminating them completely or lessening their impact, a few questioned if and how these medications “treated” PCOS.

I don't feel like doctors even understand or are willing to take the time to figure out what is really wrong - to treat what's really wrong versus just treating symptoms. Like the whole thing with, I mean, I've been to several different gynecologists who have told me that I'm "treating it" by being on birth control. Well, I'm not treating anything by being on birth control. I'm just making, you know, altering my hormones so I get my period every month. I'm not treating whatever is causing my hormones to be out of whack to begin with, y'know? (A.H., age 35)

I wish the medical community was more aware of how to deal with it besides just giving you a birth control pill, which I don't think really helps the problem. I think it just masks some of the symptoms, you know? (D.H., age 37)

While it remains unclear what type of “treatment” would be more acceptable to these women, it seems that these beliefs were based, at least partially, on a misunderstanding of PCOS and its recommended treatments. To avoid these misunderstandings and address patient concerns, providers should take time to explain the diagnosis and goals of treatments.

Many women reported medically managing their symptoms through a combination of oral contraceptives and Metformin®, an insulin sensitizer commonly prescribed to WLW PCOS with hirsutism, IR, metabolic syndrome, diabetes, and/or menstrual irregularities (Moll et al., 2007). Among those who reported taking Metformin®, quite a few reported that it “jump started” their weight loss and/or helped with their weight loss by helping control cravings.

After I got on Metformin, I lost weight. So I mean, I, before, diet and exercise really didn't do a whole bunch for me, and, then, magically, I, you know, I had lost 10 pounds and didn't "do anything different." But, I lost some of my sugar cravings, so, it made life a lot easier. (A.F., age 37)

Also, several women reported that Metformin® helped regulate their cycles. In fact, a few women, who had conceived spontaneously (i.e. without infertility treatments), credited Metformin® for their success.

Last year, they put me on Metformin, and, all of a sudden, a year later, we got pregnant...I mean, we just never thought that it was, you know, possible... I'll always give Metformin a lot of credit - that's really, that's what helped me get pregnant. (C.Y., age 36)

Similarly, one participant with low breast milk supply believed that Metformin® had significantly helped her with her breast milk production.

I know the Metformin has helped greatly with the need for sugar, and, then, it also has helped, because Metformin is, I understand a diabetic medicine, but it's also...the original form of Metformin was made from goat's rue, and Goat's Rue is a type of herbal supplement that helps grow breast tissue, and that has helped so much...especially my right breast - it's about a size and a half smaller than my left. [Taking Metformin] literally grew my right breast about a cup size from when I started taking it to the present, right now. So, that's helped me so much. I'm so grateful for Metformin and Goat's Rue. And, Metformin's free and Goat's Rue is rather expensive. (E.C., age 22)

Unfortunately, for some, the side effects of Metformin®, mainly nausea and diarrhea, were intolerable. Consequently, they stopped taking the medication.

I had really bad, like, reactions to it. Like, I'd get sick really, really bad. Like, eating, like, bland food, I'd get sick, so, I, I told my doc... I was up to two thousand milligrams and I'm like, "I cannot take this! Like, I get sooo sick," and I'm like, "It's not even worth it." (E.B., age 29)

Lastly, similar to the findings on oral contraceptives, a few participants questioned if and how Metformin® treated PCOS. When asked, "What would make living with PCOS a little easier?" one participant replied:

I would say if...if there was a medicine that was geared specifically towards PCOS patients, 'cause I feel like right now we have to kind of use diabetic medicine or use birth control, nothing that is recognized for PCOS sufferers and I would really like there to be something that could help with all the symptoms of PCOS... (L.P., age 42)

Again, this response seems to reflect, in part, a misunderstanding of PCOS treatments.

To control their hirsutism, most women in the study invested time and money in treatments. While some women bleached unwanted hairs, several reported shaving, waxing, plucking, and applying various creams. In particular, a few women used Spironolactone® and reported satisfying results with this prescription medication. Others also reported having more costly procedures, such as electrolysis and laser hair removal. Unfortunately, women reported less success with these procedures and one participant described laser hair removal as a “waste of money.”

Oh, laser hair removal...I think that's the biggest joke. I mean, they do tell you when you go and you sign the waiver, you know, for the risks and stuff, they do say it might not work for some women. I did not think it worked for me. I think it grew back.
(J.S., age 33)

Lastly, a few participants reported taking anti-depressants and/or anti-anxiety medications to address their mental health issues. All reported that these partially or completely alleviated their symptoms.

I wish I wasn't on Lexapro®, but, like, for people that do have problems with mood and stuff like that, I mean, SSRIs are really good, and, I was, I was amazed when I first started taking that. I was like, “Wow!” That worked for me, just, like, almost immediately. (M.W., age 25)

Cure. To assess beliefs about the cure of PCOS, interviewees were asked if they thought there would ever be a cure, and, if so, what that cure might be. In response, approximately half of interviewees responded that there would never be a cure, but hoped for better management solutions. Most often, these women emphasized that PCOS was a “syndrome,” not a “disease,” explaining that it could be managed, but not cured. When asked, “Do you ever think there will be a cure for PCOS?” one interviewee responded:

That would be great, but I don't, because it's pretty complicated, you know? I mean, it, it... there's so many different aspects to it that I'm just not sure that it's the kind of thing that you can necessarily cure or if it's something that, umm, you just lessen the symptoms of or try to avoid by lifestyle changes, I guess. (K.C., age 32)

In contrast, the other half expressed the belief that, one day, there would be a cure for PCOS but identified a number of barriers to its discovery. For example, a few women felt like, because PCOS was a condition specific to women, it was unimportant to the medical community. One exchange was particularly illustrative of this belief:

PI: *Do you think there will ever be a cure for PCOS?*

Interviewee: *I would hope, but I don't think so...It', a, I think small on the scale compared to a lot of things that doctors really want, to, to, you know, investigate and try to cure.*

PI: *And why do you think that is?*

Interviewee: *Because women are lesser? [Sigh] I don't know... if it was prostate cancer and, you know? They've got a nice little pill for men that can't get an erection, you know? I just, I don't know that it's, it's a...on the grander scale, for a lot of doctors to really worry about. ..I guess, maybe if it affected their daughters or their wives they would maybe care little more. But, it's where...it's not a male-focused thing. I just don't think that it quite has as much importance in our world. (D.L., age 46)*

On the other hand, a few felt that PCOS had received less attention by the medical community, because PCOS was less important than other chronic conditions, particularly cancer.

I don't know. I've never had cancer or anything like that. I would think that cancer would need a cure faster than PCOS, but, I mean, it's, it's hard to live with and sometimes it's frustrating, but, I don't think it's on the same level as cancer. (C.A., age 31)

Still, other felt PCOS had not received sufficient attention, because awareness of PCOS was low among providers and the general public. Lastly, a few felt that a cure for PCOS would be “discovered” accidentally.

Do I think there will be a cure? Yeah, if there's enough people complaining [Laughter]. Right? There's no, like, walks for PCOS or anything like that. I think if there's, like, enough funding for research into it. But, you know, there is always a chance that, like, somebody will be researching some other problem, and then they will find, you know... a solution will come up when they are looking for, you know, an answer to a different problem. (S.G., age 39)

Residual/Other. Lastly, a few interviewees described PCOS as a common condition among women. By definition, this illness cognition, coded *perceived prevalence*, does not fit into any of the illness perception domain suggested by Leventhal (1984) , Moss-Morris (2002), or their colleagues. The implications of this finding are further discussed in Chapter 5.

Emotional Representations of PCOS. The CSM posits that, when a person is confronted with an illness, he/she will develop emotional representations of illness in addition (and parallel) to cognitive representations of illness. To assess interviewees' emotional representations of PCOS, the following questions were asked: "What are your thoughts about having PCOS?" and "To what extent do you feel that your PCOS influences how you generally feel?" In response to these questions, many women expressed their feelings and/or emotions related to their symptoms or anticipated symptoms. While these responses provided invaluable information, unsolicited emotional expressions from participants were actually the most striking. For example, frustration was a dominant theme of this dissertation and was expressed most often when women described their experiences with their health care providers and clinical care – content that was also unsolicited. All responses are summarized below.

Response to PCOS and its Symptoms. When asked, "What are your thoughts about having PCOS?" most interviewees responded that having PCOS was *depressing, sad, and/or overwhelming*. Throughout the interviews, respondents also described "struggling" with one or more symptoms of PCOS and/or emphasized that PCOS was an "emotional struggle" in addition to a physical one. In particular, women were *annoyed, frustrated, and/or extremely embarrassed* by PCOS-related symptom that affected their physical appearance. These symptoms included menstrual irregularities, weight issues, acne, hirsutism, and alopecia.

I've met lots of people with PCOS, and I think, generally, people get really frustrated with the syndrome. I know, for me, it's the hair on my chin, dramatic weight gain before I was diagnosed, and my hair falling out. (E.A., age 29)

It was annoying when my face would break out for no reason...other than that...I had no idea when to expect my period. That was the most annoying, because, you know, going into school and you're in the middle of class and your period starts, and it shouldn't start for another two weeks. That was annoying. (E.C., age 22)

Likewise, among those who reported a history of infertility, women reported being *frustrated, depressed, and/or devastated* by the experience.

Well, with my son, I did have some trouble, because I wasn't ovulating, and I tried to. My doc put me on birth control to help control some of the symptoms of PCOS, but when I came off birth control, I didn't ovulate. I mean, I never did before I was on birth control, but it took me 6 months, and I didn't ovulate the entire time, and they had to try to induce my cycle with fertility drugs. So, it was obviously frustrating when you so adamantly want to conceive and can't. (D.T., age 30)

Also, women with low breast milk supply often described their experience as being *depressing, devastating, and/or heartbreaking*.

I was very, very depressed when I couldn't feed my daughter...and then I ended up using a medication to bring up my supply...so, I gained like 15 pounds on that medication. So, like, all of my baby weight that I lost, I put right back on. And, so, I really hate pictures after my daughter is 6 months old. And, that's pretty...sad for someone who works so hard to lose weight and be healthy, and, for that to be, really just out of their control...I don't know...definitely a lot of depression and really bad days during the time while I was still breastfeeding. (S.K., age 32)

One participant, in particular, expressed guilt over having to feed her baby formula.

Well, and they tell you so much, "Oh, well, you should breastfeed your baby," or, you know, "You're doing a horrible thing by feeding your baby formula." You know what I mean? It's just, like, they tell you that's the one thing you definitely want to do, but I can't. And, you get a lot of stigma, you know, in public, when your feeding your baby a bottle, when everyone else around you is breastfeeding around you. You know? So, it's just...it's definitely a challenge... [cries] (D.T., age 30)

A number of interviewees also expressed concern and worry over PCOS-related symptoms that they had not yet experienced. In particular, those with no history of infertility worried about their ability to conceive in the future.

When I was first diagnosed, I was very, very upset. I now don't see it as a, you know, as, as the end all. I know lots of women that have, you know, babies that have PCOS. I guess, it's just, it's a little bit of a rollercoaster, you know? I mean, some days I feel like I'm gonna be fine. I'm gonna have a baby no problem, and, you know, other days, it's like... I think about, on my honeymoon, I'm probably going to be on ovulation medication to make sure I ovulate. You know? That's, that's upsetting. (E.S., age 34)

On the other hand, many were thankful for not experiencing all PCOS-related symptoms, but worried that they might in the future.

I have the hair issue. I have like, the slight fuzz on my face, but it's not noticeable, at all. I wonder as I get older, if that's gonna develop into the more masculine hair. You know, darker. I don't...I know someone who had, like, a thick treasure trail, for lack of a better word, and I've never had to deal with that. I've been thankful, but I wonder, as you grow older...if I'll end up with all the, uh, crazy hair stuff goin' on. (A.F., age 37)

I, I've, I'm really lucky in that way and a lot of people have a lot of pain associated with it, but I don't, I never had that. (C.Y., age 36)

One participant, in particular, was afraid of one day losing her hair.

The hair loss, I'm really worry- that probably sounds really vain, but I'm really worried about the hair loss. The acne...I have not had an issue with that. I don't think it would be as bad as the hair loss though. That's the one [symptom] I'm most afraid of. (K.C., age 32)

Response to Providers and Clinical Care. As previously reported, frustration was a dominant theme of this dissertation, and one main area of frustration centered on interactions with health care providers, which often resulted in a lack of confidence or trust in providers. Overall, women described their care as incompetent and/or insensitive and attributed this experience to their providers (lack of) knowledge and/or training.

For some, their frustrations started with their diagnosis. For example, several participants reported reluctance from their providers to conclude that symptoms were abnormal and warranted further investigation.

I was very frustrated early on, because I was, you know, I was just told that I was perfectly fine - that some women just have problems with their periods. (D.L., age 46)

In fact, a few women interviewed felt cheated by their delayed diagnosis, questioning whether they missed an opportunity to start treatments or adopt lifestyle changes that might have altered the course of their PCOS.

I wish I would have been diagnosed earlier. I wish I would have been told earlier about it. I wish I wouldn't be 27 and just finding out about it. I really feel that there were several opportunities when I was younger to have known about it, like, when I was 15/16, going in for my birth control for the first time, because my hormo-, because my periods were out of whack, and then again when I had an ectopic pregnancy. I really think that they could have found it then and told me, and I could have made positive changes in my life back then, rather than waiting and getting heavy like I did. I got, I, I, between the ages of 18 and 22, I got really, really heavy, um, and then lost a lot of weight. So, I think I wouldn't have done those things, and I wouldn't have harmed my body in the way that I did, had I known about it before. (B.A., age 27)

Several women also voiced frustration over the (lack of) information and support they received at the time of their diagnosis and follow-up clinical encounters. When asked, “What would make living with PCOS easier for you?” one interviewee responded:

I don't know...just more support and a better knowledge base for health care professionals. I know it was a challenge for me when I knew more than, like, my lactation consultant about PCOS and milk production. I know, that, that was frustrating. It's frustrating if you go to a nutritionist and they have no idea. Just more awareness and knowledge among health care professionals. (E.A., age 29)

For others, it was the physician's delivery of PCOS information that they found most frustrating.

I feel very frustrated with the treatments that we're off-, that we have to...I mean like, I, I, I understand, I understand that there's all this information out there, and there's all these different tests you can do, and there's all these different medications you can take, but, I, I still feel very confused about all of it. And, I still struggle with finding what is wrong, you know? I, I, I just, I still wanna know, like, I wish they could say, “Okay, well, it's your estrogen,” or “You're, you're...this is why you have hair growth.” And, and, they don't ever really do that, you know? They just say, “Well, take this pill!” And, you just, you know, don't...I mean, I literally had one doctor...I was twenty-one, and I had this - I was by myself, and this doctors like, “You have to take Metformin!” and “You have polycystic...” - this was when I was officially diagnosed. He was like “You have polycystic ovarian syndrome, and you have to take this medication. If you don't, you're gonna have diabetes, stroke,” you know, “heart attack,” ...I don't know. He listed all these things, “heart disease, and this is the guide you have to follow.” And, he literally gave me a piece of paper that said nuts and cheese and water. I mean, it was a joke - the list. I mean, I'm not even ex- I'm not exaggerating! I might be exaggerating, like, just a

very small amount, but that was literally the list of foods that I could eat. And, when people give, you know, when doctors...and that's how they treat us, you know, with the syndrome. It's like, it's a joke! It's like, this is not treatment! You know? (K.M., age 30)

Also, most women interviewed were frustrated by their provider's inattentiveness to the symptoms they found most troubling. For example, one participant, who worried about having a sufficient breast milk supply (because her breast were asymmetrical), was disappointed and upset by her prenatal consultation with her provider.

Even in my current pregnancy, when I went to my doctor, and he said he'd check for asymmetry, and then he just went on through the exam, and I'm like "Really?! You didn't find the asymmetry you were looking for?" But, I just, like, I don't know. I don't think doctors care. They just say, "Oh well! You can't breastfeed. That's okay. There's formula." But, there's more to it than that. It's very upsetting, you know, not being able to do it. (D.T., age 30)

In fact, one participant reported terminating treatment and her relationship with her provider after years of hormone therapy with no improvement.

I had lots of trouble with bleeding, and they put me on birth control, and I was just told, " Oh, its hormones, its hormones, its hormones." They kept me on birth control for a year, and it was low dose, and I was fine, and then all of the sudden, it went hay-wire, and I just bled and bled and bled and bled. So, finally, they got me stopped, and I got frustrated with the doctors, and I quit going. (D.L., age 46)

At the same time, it was the perception of most women interviewed that providers were "symptom-focused." When asked, "What would make living with the syndrome easier for you?" one participants replied:

Well, I guess, if the doctors had been more helpful with explaining what it is and what could be caused from and what I can do...I don't even know. I mean...like do you just treat the symptoms of the problem? I don't even know, like, 'cause you, like, you go to the doctor complaining, like, "Oh, I don't have a regular period" and then they fix that. Or, you go and complain about, you know, some other issue, and they just fix that issue. I don't know. I feel like they're not being overly helpful. In terms of solving, sort of like, a diagnosis, of treating, like an overall problem. They just wanna go symptom by symptom. (J.B., age 33)

In particular, almost all felt that their providers were too focused on fertility. Notably, this belief was prominent even among women who were deeply concerned with their future ability to conceive.

Like I said, the concern with infertility- I worried about it, you know? 'Cause, my doctor at 17 said, you know, "We'll worry about this when you wanna have kids." So, my thought at 17 was, well, what if there was something they could be doing now to ensure that I would be able to have kids? They're seriously not gonna worry about it or do anything for me over the next 10 years? (J.F., age 33)

I was having very irregular cycles, and my mom took me to the doctor, and they did an ultrasound and saw the cysts, and said, "This is what you have." And, they put me on a birth control pill, and that was when I was 14 or 15 or something...yea, 14 or something like that. So, they just told me right off the bat and didn't really give me support for it. They just told me, "This is what you have, and you're going to have fertility problems in the future. I'm just like, "Thanks." I'm just, like, I don't want to have kids, you know, because I'm 14. I'm not really thinkin' about that. (D.T., age 30)

One interviewee, in particular, was distressed and outraged by her providers' disinterest in continued care after she successfully bore children.

I feel like...I mean, like, every doctor that I've ever talked to...I feel like has completely blown me off. You know? Like, "Oh, well, you had to do fertility treatment, but you still had your kids, so..." kinda like, "...well, what are you complainin' about? You know? You have your period, because, you know, you're on the pill. So, what are you complaining about?" Y'know? "You just need to try harder to lose weight." Like, it's just not, right... I think that, for me, the focus when I try to talk to my doctors about PCOS, like, whatever my specific complaint is... "It's not really an issue anymore, so why are you still talking to me about this?" Y'know? "Like, why are you still bringing up your PCOS when you successfully had kids, and, you know, you've gotten laser hair removal? You just need to try harder to lose weight." Not so much, like, "Let's, you know, try some things to improve your overall quality of life." (A.H., age 35)

Is There a Relationship Between Women's HRQoL and the Illness Perceptions They Have About PCOS?

As previously described, the literature suggests that PCOS has a significant negative impact on HRQoL (Jones et al., 2007; Trent et al., 2002). Yet, few factors that contribute to this reduction have been explored (Barnard et al., 2007). In one study, however, Trent and

colleagues (2002) report that *perception* of PCOS severity, not actual severity, correlates directly with HRQoL. This finding emphasizes the need for further investigations into the perceptual factors related to HRQoL.

Because illness perceptions of PCOS may be a promising determinant of HRQoL among WLW the syndrome, the relationship between illness perceptions and HRQoL was explored using the following protocol: First, each interviewee's score on each of the SF-36 domains was calculated. Then, these scores were compared to the scores of the sample mean. For each dimension, interviewees could fall either below the sample mean (i.e. Group "Below") or above the sample mean (i.e. Group "Above"). Lastly, for each domain, the responses of each group ("Above" vs. "Below") were compared. Differences among groups are summarized below by HRQoL domain.

As previously stated, it is important to note that, because the SF-36 measures HRQoL and because HRQoL is personal to each individual, it is not appropriate to label scores as "good" or "bad" (Sterling University, 2012). Instead, here, illness perceptions of those who report lower levels of functioning on each domain are compared with those who report higher levels of functioning on the same domain. This analysis plan was discussed at length with one of the lead investigator's co-major professors and was determined to be the best strategy to explore the relationships between HRQoL domains and illness perceptions.

General Health Perceptions. General Health Perception items measure each respondent's (1) evaluation of her personal health and (2) belief that her health will either improve or worsen in the future. In this study, the mean score of the total sample was 50.8 (SD=22.7). This means that, in general, about half of the sample agreed or mostly agreed with

the following statements and the other half disagreed or mostly disagreed with the following statements:

- I seem to get sick a little easier than other people.
- I am healthy as anybody I know.
- I expect my health to get worse.
- My health is excellent.

These findings may easily be explained by the nature of PCOS. As previously stated, the clinical spectrum of PCOS varies widely (Balen et al., 1995). At one end of the spectrum are women who are largely asymptomatic, and, at the other, are women who present with most manifestations of the syndrome. As such, it would be expected that, in general, some women would score higher and some women would score lower on general health perceptions, resulting in a mean score that fell roughly in the middle.

Given the above rationale, we would also expect that those who fell below the mean (n=13) and those who fell above the mean (n=21) would differ on the domain *Symptoms*, specifically on the number of symptoms reported. However, when the similarities and differences between the groups were investigated, it was found that *type* of symptom, not *number* of symptoms, related to the General Health Perceptions score. That is, those who fell above the mean spoke at length about the physical manifestations of PCOS, including weight issues, IR, hirsutism, and acne. On the other hand, those who fell below the mean emphasized the impact of PCOS on their mental health. Specifically, those who fell below the mean were more likely to report depression, feelings of worry, and constant stress. In short, these findings highlight the (1) impact of mental health issues on *General Health Perceptions* and (2) importance of providers recognizing and addressing the mental health needs of their patients with PCOS.

Those who fell above the mean also described better outcomes of PCOS treatments. For example, women who fell above the mean reported that diet, exercise, medication, and laser hair removal treatments were effective at reducing PCOS symptoms. On the other hand, women who fell below the mean were more likely to report no or little weight loss with changes in diet and increased physical activity. Likewise, they were more likely to express the belief that medications “masked” the underlying causes of PCOS and that medications commonly prescribed to address PCOS-related symptoms, such as Metformin and birth control pills, were not “real” PCOS treatments. While the reasons that lifestyle modifications and PCOS treatments failed more often in women falling below the mean remains unclear, the latter finding identifies the need for better patient information on available treatments – specifically, information that explains why certain medications are prescribed to address PCOS-related symptoms and how these medications work. Also, those who fell below the mean were more likely to express frustration with their providers for being inattentive and symptom-focused. Again, this finding may reflect providers’ own knowledge or PCOS or medical specialty. It also may reflect a greater healthcare delivery systems issue. Meaning that, in general, women’s health services are currently separated into reproductive and non-reproductive services without provisions of coordinated care (Weisman, 1997). Consequently, it is rare that women receive comprehensive care during one health care visit.

Lastly, while both groups shared the general belief that PCOS was a chronic condition, a few women who fell above the mean stated either (1) that they had not given much thought to how PCOS would affect their lives after they were done childbearing or (2) that they had stopped caring about how PCOS affected their lives once they completed childbearing. For example, when asked how she thought PCOS might affect her in the future, one interviewee who fell

above the mean and who expressed a desire for more children responded, “I guess, I really, other than fertility, I don’t know how else it would affect me” (J.B., age 33). Another woman who fell above the mean and who stated that she was “done having children” responded:

Gee, I think, I figured, as long as I am a woman I would, I would...I haven’t treated it...I treated it with, with, birth control pills initially. But, once I started having kids, I just figured, what the heck! I’m married, I can take ibuprofen when needed, and I could give a fuck about the hair on my chin [Laughs]. (E.V., age 40)

On the other hand, an interviewee who fell below the mean was the only woman who expressed anticipation that her health would continue to deteriorate. When asked how long she thought PCOS might affect her, she responded:

I think for the rest of my life...I see a gradual decline in my quality of health, and, so, I mean, I, I, think it’s gonna just keep on getting worse...(L.P., age 42)

Taken together, these data suggests that infertility or fear of infertility have important implications in PCOS. Note that the relationship between illness perceptions and fertility status is further explored under the next research question in this chapter, *Does the experience of infertility impact the illness perceptions that women hold about their PCOS?*

Vitality. This domain asks respondents to report energy levels and general feelings of tiredness during the past four weeks. In this study, the mean score of the total sample was 34.4 (SD=18.1). Among interviewees, 14 and 20 interviewees fell below and above the mean, respectively. To explore the differences between these groups, interviewees’ responses under the child code *Exhaustion* were first reviewed. Surprisingly, both groups equally described low energy levels and feelings of tiredness during their interviews. This prompted a review of the specific items that measured the sample’s *Vitality*. In general, those who fell above the mean reported that, *some of the time, they felt of pep and had lots of energy*, but at other times, they equally *felt worn out and tired*. On the other hand, those who fell below the mean generally

(1) *felt worn out and tired a good bit of the time* and (2) *felt of pep and had lots of energy a little of the time*. In summary, few in the total sample report feeling of pep or having lots of energy *a good bit of the time, most of the time, or all of the time*. In other words, both groups reported low levels of functioning on *Vitality*, explaining the similarities in interview responses. One possibility for this finding, however, may be that specific manifestations of PCOS, such as depression and IR were common among the sample and may result in low energy and feelings of tiredness.

Physical Functioning. This domain asks respondents to report current limitations on ten mobility activities, such as walking specified distances, carrying groceries, and bathing, and dressing. In this study, the mean score of the total sample was 81.2 (SD=22.9), meaning that, in general, most respondents did not feel like their mobility was limited by their physical health. For this reason, no major differences in illness perceptions between groups were expected. However, it is unsurprising that those who fell dramatically below the mean (n=3, scores ranging from 0 to 20) reported painful ovulation and/or menstruation. For example, one of these participants described the pain as “debilitating” and reported often being bedridden during menstruation. Whereas, those who fell above the mean (n=20), in general, either did not report pain or only reported minor “pinching” or cramping during ovulation and/or menstruation. Similarly, those who fell above the mean were more likely to report exercising as a strategy to alleviate PCOS-related symptoms, even though both groups equally reported weight issues. These findings highlight the importance of providers identifying and addressing any perceived or real physical limitations or WLW PCOS to promote physical activity among this population.

Role Limitations Due to Physical Health. This domain asks respondents to report problems with work or other daily activities they have experienced in the past four weeks as a

result of their physical health. In this study, the mean score of the total sample was 70.6 (SD=37.2), meaning that, in general, few respondents reported feeling like their daily activities were limited by their physical health. However, it was puzzling that no major differences were found between the illness perceptions of the two groups. To further explore these findings, each transcript was reread, with special attention paid to the six interviewees who scored a zero (0) on this domain, meaning that they answered *Yes* to all of the following questions:

- During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
 - Cut down the amount of time you spent on work or other activities.
 - Accomplished less than you would like.
 - Were limited in the kind of work or other activities.
 - Had difficulty performing the work or other activities (for example, it took extra effort).

Upon review, it was found that, among the interviewees who scored a zero (0) on this domain, all but one discussed a recent illness or medical complication that was unrelated to their experience of PCOS. These included bronchitis, stomach ulcers, blood clots, and a serious antibiotic-resistant infection. The remaining interviewee who scored a zero (0) was 6 days post-partum. In summary, domain scores reflected role limitations due to physical health issues that were not related to PCOS, highlighting a disadvantage of using a generic instrument to measure HRQoL.

As a reminder, there are two measures that have predominately been used to capture the HRQoL among WLW PCOS: (1) the Quality-of-Life Questionnaire for Women with Polycystic Ovary Syndrome (PCOSQ) and (2) the Short Form- 36 (SF-36). At first glance, it seems that it

would have been ideal to use a PCOS-specific instrument to measure the quality of life of WLW PCOS in this study. However, given (1) that the PCOSQ is an illness-specific measure that emphasizes the symptoms of PCOS, (2) that the primary aim of the dissertation was to identify the illness perception of WLW PCOS, and (3) that a domain of illness perceptions is *identity* (i.e. symptoms women associate with the syndrome), the PCOSQ was not used in this study to prevent priming of interviewees.

Bodily Pain. This domain asks respondents to report (1) the amount of bodily pain and (2) the extent to which this pain has interfered with their work inside and outside of the home in the past four weeks. In this study, the mean score of the total sample was 66.3 (SD=24.0), meaning that, in general, respondents reported that they had *mild* bodily pain in the past four weeks and that this pain had *mildly* interfered with their work and other activities. As expected, those who fell below the mean (n=16) were more likely to report painful ovulation and menstruation than those who fell above the mean (n=19). Notably, no other major differences in illness perceptions between groups were identified.

Social Functioning. This domain asks respondents to report the extent to which physical health or emotional problems have interfered with their normal social activities with family, friends, and other social groups in the past four weeks. In this study, the mean score of the total sample was 67.4 (SD=26.8), meaning that, in general, most respondents reported that their physical health or emotional problems either *moderately* or *slightly* interfered with their social activities. To first explore the differences between groups, the lead investigator searched for themes that explained how each groups' physical health interfered with their normal social activities. However, no major differences were found. On the other hand, when the lead investigator searched for themes that explained how each groups' emotional health interfered

with their normal social activities, it was found that those who fell below the mean (n=17) were more likely to report depressive symptoms and to report that these symptoms interfered with their relationships.

I think PCOS has affected, you know, every aspect of my mental health. So, for somebody who is as severely depressed as me and [who] has pulled away from people as much as I have...I mean, I sabotage relationships with friends and family members all the time - to the point where I think it's pretty much just me and my husband now. So yeah, yeah, I think it's, it affects, its affected relationships. (C.K., age 32)

Again, these findings highlight (1) the impact of PCOS on mental health and (2) the need for mental health services among women with the syndrome.

Role Limitations Due to Emotional Problems. Sample scores on this domain also highlighted the impact of PCOS on mental health. These items asked respondents to report problems with work or other daily activities they had experienced in the past four weeks as a result of their emotional health. In this study, the mean score of the total sample was 60.3 (SD=42.7). Like those who scored below the mean on *Social Functioning*, those who scored below the mean on *Role Limitations Due to Emotional Problems* (n=16) were more likely to report depression and to report that this depression was either “chronic” or “debilitating.” Interestingly, these women were also more likely to report “visible” manifestations of PCOS, including alopecia, acne, acanthosis nigricans, and weight issues, suggesting that these symptoms in particular may have a greater impact on women’s emotional health than “non-visible” symptoms.

Emotional Well Being. Lastly, this domain asks respondents to report how often they felt *nervous, down in the dumps, calm and peaceful, downhearted, and happy* in the past four weeks. In this study, the mean score of the total sample was 59.1 (SD=20.9). Like those who scored below the mean on *Social Functioning* and *Role Limitations Due to Emotional Problems*,

those who scored below the mean on *Emotional Well Being* (n=17) were more likely to report depression and “visible” manifestations of the syndrome. Also, this group was more likely to report mood swings, which they attributed to hormonal imbalances or menstrual irregularities caused by PCOS.

Does the Experience of Infertility Impact the Illness Perceptions that Women Hold About Their PCOS?

As previously described, a sub-aim of this dissertation was to explore the relationship between illness perceptions and infertility, a common symptom of the syndrome. To achieve this sub-aim, interviewees were recruited based on two criteria: (1) history of infertility and (2) reported childlessness. The latter recruitment strategy was employed to further stratify infertile and fertile WLW PCOS. This decision was made, because it was hypothesized that, among WLW PCOS who had no history of infertility, those who did not have biological children would have different illness perceptions than those who did, because their ability to become pregnant remained unclear. Likewise, it was hypothesized that, among WLW PCOS who had a history of infertility, those who did not have biological children would have different illness perceptions than those who did, because their ability to become pregnant also remained unclear. In summary, interviewees were grouped in the following way:

- Group 1: WLW PCOS with biological children and a history of infertility
- Group 2: WLW PCOS with no biological children and a history of infertility
- Group 3: WLW PCOS with biological children and no history of infertility
- Group 4: WLW PCOS with no biological children and no history of infertility

The demographic characteristics and the medical history of each group are described below. The section following highlights major differences among groups' illness perceptions. This discussion is organized by illness perception dimension.

Demographic Characteristics of Interviewees by Group. The demographic characteristics and medical history of interviewees by group are summarized in Table 17 and 18. Although many similarities existed among samples and/or groups, a number of differences were observed. For example, all groups except for Group 4 were older than the total sample. This was expected, however, given that Group 4 did not have children and, to their knowledge, were fertile, meaning that they had not yet tried to conceive. Given the older age of most of the interviewees, it was also not surprising that groups reported living with a PCOS diagnosis longer than the total sample.

As a whole, Group 1 (n=10) was older than the others (M=35.3 years). This was expected, however, given that Group 1 had a history of infertility but had biological children, meaning that they had (1) tried, unsuccessfully, to conceive spontaneously for at least 12 months, (2) pursued and been successful with follow-up infertility treatments, and (3) carried at least one pregnancy to term, which resulted in a live birth – all lengthy processes. Table 19 lists the medications and procedures that each woman in Group 1 credited for her fertility success, the most common being Clomid®. Also, Group 1 was more likely than others to report being married (90%), which was also expected, because infertility treatment-seeking is most common among married women (The Ethics Committee of the American Society of Reproductive Medicine, 2013). Lastly, Group 1 was more likely to report having private insurance (90%) and less likely to report having no insurance (0%).

Noticeably, Group 2 is much smaller than the other groups (n=3). As a reminder, this group consisted of women who had a history of infertility and who were childless. Although many survey respondents reported these characteristics, most also reported currently trying to conceive (77%), which excluded them from Phase 2 of the dissertation, the interviews. Overall, the mean age of Group 2 was highest of all groups. Women in Group 2 were also more likely than others to report a history of hypertension and high cholesterol, which was unsurprising, because all women in Group 3 met the criteria for morbid obesity ($BMI \geq 35$). Unlike the other groups, no women in Group 2 were married – two were single and one was divorced. When asked about their history of infertility, (1) all reported unsuccessfully trying to conceive spontaneously for at least 12 months (within the context of a long-term relationship or a previous marriage), and (2) none reported pursuing infertility treatments. When asked about the latter finding, one Group 2 interviewee reported having a disabled partner with significant medical needs; the second reported receiving a tubal ligation out of fear of PCOS-related pregnancy complications and post-partum depression; and the third, the divorcee, reported being single with no current desire to have children.

Lastly, Groups 3 and 4 were younger than Groups 1 and 2 and were more likely to report having no insurance. These groups were also more likely to report depression, which is further explored below. Women in Groups 4 (e.g. those who had no biological children and no history of infertility) were more likely than those in other groups to be single and to report a recent

Table 17. Demographic Characteristics of Interviewees by Group

Characteristic	Total Sample (N=376) No. (%)	Interviewees (n=34) No. (%)	Group 1** (n=10) No. (%)	Group 2** (n=3) No. (%)	Group 3** (n=9) No. (%)	Group 4** (n=12) No. (%)
Age (Mean)	31.8	33.6	35.3	39.7	32.4	31.3
Hispanic						
Yes	28 (7.5)	1 (2.9)	1 (10.0)	0 (0.0)	0 (0.0)	0 (0.0)
No	348 (92.5)	33 (97.1)	9 (90.0)	3 (100.0)	9 (100.0)	12 (100.0)
Race						
White or Caucasian	332 (88.3)	32 (94.1)	9 (90.0)	3 (100.0)	9 (100.0)	11 (91.7)
Black or African American	13 (3.5)	2 (5.9)	1 (10.0)	0 (0.0)	0 (0.0)	1 (8.3)
Other	31 (8.2)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Sexual Orientation						
Straight or heterosexual	355 (94.4)	29 (85.3)	10 (100.0)	3 (100.0)	8 (88.9)	8 (66.7)
Gay, lesbian, or homosexual	2 (0.5)	1 (2.9)	0 (0.0)	0 (0.0)	0 (0.0)	1 (8.3)
Bisexual	19 (5.1)	4 (11.8)	0 (0.0)	0 (0.0)	1 (11.1)	3 (25.0)
Marital Status						
Single	89 (23.7)	8 (23.5)	1 (10.0)	2 (66.7)	0 (0.0)	5 (41.7)
Married	276 (73.4)	22 (64.7)	9 (90.0)	0 (0.0)	7 (77.8)	6 (50.0)
Separated or divorced	10 (2.7)	3 (8.9)	0 (0.0)	1 (33.3)	1 (11.1)	1 (8.3)
Widowed	1 (0.3)	1 (2.9)	0 (0.0)	0 (0.0)	1 (11.1)	0 (0.0)
Education						
High school or less	26 (6.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Some college	109 (29.0)	6 (17.6)	2 (20.0)	1 (33.3)	2 (22.2)	1 (8.3)
College graduate	241 (64.1)	28 (82.4)	8 (80.0)	2 (66.7)	7 (77.8)	11 (91.7)
Medical Insurance*						
Private	281 (74.7)	26 (76.3)	9 (90.0)	2 (66.7)	6 (66.7)	9 (75.0)
Public	27 (7.2)	3 (8.9)	0 (0.0)	1 (33.3)	1 (11.1)	1 (8.3)
Military	19 (5.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Other	15 (4.0)	2 (5.9)	1 (10.0)	0 (0.0)	1 (11.1)	0 (0.0)
None	46 (12.2)	3 (8.9)	0 (0.0)	0 (0.0)	1 (11.1)	2 (16.7)

*Numbers may not add to 100, because participants could select all that apply.

**Group 1 (Infertile with children), Group 2 (Infertile and childless), Group 3 (Fertile with children), Group 4 (Fertile and childless)

Table 18. Medical History of Interviewees by Group

Characteristic	Total Sample (N=376) No. (%)	Interviewees (n=34) No. (%)	Group 1* (n=10) No. (%)	Group 2* (n=3) No. (%)	Group 3* (n=9) No. (%)	Group 4* (n=12) No. (%)
Years living with PCOS diagnosis	M =7.6	M=10.9	M=11.8	M=16.0	M=11.8	M=8.3
< 1 years	63 (16.8)	5 (14.7)	0 (0.0)	0 (0.0)	1 (11.1)	4 (25.0)
≥1 years	313 (83.2)	29 (85.3)	10 (100.0)	3 (100.0)	8 (88.9)	9 (75.0)
Pregnant						
Yes	29 (7.7)	3 (8.8)	2 (20.0)	0 (0.0)	1 (11.1)	0 (0.0)
No	347 (92.3)	31 (91.2)	8 (80.0)	3 (100.0)	8 (88.9)	12 (100.0)
BMI	M=35.1	M=38.4	M=	M=	M=	M=
Underweight (BMI<18.5)	4 (1.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Normal (18.5-24.9)	45 (12.0)	5 (14.7)	1 (10.)	0 (0.0)	1 (11.1)	3 (25.1)
Overweight (25-29.9)	61 (16.2)	3 (8.8)	2 (20.0)	0 (0.0)	0 (0.0)	1 (8.3)
Obese (30-34.9)	95 (25.3)	8 (23.6)	2 (20.0)	0 (0.0)	5 (55.6)	1 (8.3)
Morbidly obese (BMI≥35)	171 (45.5)	18 (52.9)	5 (50.0)	3 (100.0)	3 (33.3)	7 (58.3)
History of:						
Diabetes	45 (12.0)	4 (11.8)	2 (20.0)	0 (0.0)	1 (11.1)	1 (8.3)
Hypertension	96 (25.5)	10 (29.4)	3 (30.0)	2 (66.7)	3 (33.3)	2 (16.7)
High cholesterol	101 (26.9)	11 (32.3)	2 (20.0)	2 (66.7)	2 (22.2)	5 (41.7)
Heart disease	9 (2.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Infertility	266 (70.7)	13 (38.2)	10 (100.0)	3 (100.0)	0 (0.0)	0 (0.0)
Thyroid	63 (16.8)	3 (8.8)	1 (10.0)	0 (0.0)	1 (11.1)	1 (8.3)
Endometriosis	31 (8.2)	2 (5.9)	1 (10.0)	1 (33.3)	0 (0.0)	0 (0.0)
Migraine	209 (55.6)	20 (58.8)	7 (70.0)	2 (66.7)	5 (55.6)	6 (50.0)
Anxiety	258 (68.6)	22 (64.7)	8 (80.0)	2 (66.7)	5 (55.6)	7 (58.3)
Depression	239 (63.6)	24 (70.6)	6 (60.0)	2 (66.7)	7 (77.8)	9 (75.0)

*Group 1 (Infertile with children), Group 2 (Infertile and childless), Group 3 (Fertile with children), Group 4 (Fertile and childless)

Table 19. Group 1 Infertility Treatments

Interviewee	Treatment
A.H., age 35	<ul style="list-style-type: none"> • Ovidrel®, a prescription version of the hormone hCG • Follistim® AQ, a prescription version of the hormone FSH
A.F., age 37	<ul style="list-style-type: none"> • Clomid®, a selective estrogen receptor modulator (SERM) • Progesterone cream
C.A., age 31	<ul style="list-style-type: none"> • Clomid®, a selective estrogen receptor modulator (SERM)
D.T., age 30	<ul style="list-style-type: none"> • Fertility drugs, unspecified
D. L., age 39	<ul style="list-style-type: none"> • *Clomid®, a selective estrogen receptor modulator (SERM) • Provera®, a prescription version of the hormone progesterone • Metformin, an insulin-sensitizing agent
J.W., age 39	<ul style="list-style-type: none"> • Hormone injections, unspecified • Intrauterine insemination (IUI)
J.T., age 28	<ul style="list-style-type: none"> • Clomid®, a selective estrogen receptor modulator (SERM) • * Intrauterine insemination (IUI)
L.P., age 42	<ul style="list-style-type: none"> • Clomid®, a selective estrogen receptor modulator (SERM) • Provera®, a prescription version of the hormone progesterone • Prometrium®, a prescription version of the hormone progesterone
M. B., age 33	<ul style="list-style-type: none"> • Clomid®, a selective estrogen receptor modulator (SERM)
S.G., age 39	<ul style="list-style-type: none"> • Fertility drugs, unspecified

*Interviewee reported that this treatment “did not work.”

diagnosis. This was unsurprising, however, given their younger age. Also, Group 4 was more likely than other groups to be lesbian or bisexual and to be a college graduate.

Cognitive Representations of PCOS by Group

Illness Coherence. No differences among groups were found on this dimension. This was surprising considering the following:

- The CSM suggests that individuals construct illness perceptions according to the information available to them (Leventhal et al., 2003).
- WLW PCOS who experience infertility typically require additional medical interventions (Brassard et al., 2008).
- Medical interventions, by nature, require more interactions with healthcare providers (who are potential sources of information).

Thus, it was expected that women with a history of infertility would express a greater understanding of PCOS than those with no history of infertility, especially women belonging to Group 4, who were more likely to be recently diagnosed. Instead, all groups expressed a general lack of understanding about their diagnosis. In fact, a woman in Group 1, who had reported taking a number of prescription drugs to conceive, stated that she had experienced infertility issues that did not “seem to have a reason.” Not only do these findings again highlight the information needs of women living with PCOS, but also they bring into question whether consent to treatment of PCOS-related issues can be described as “informed.” Either way, these findings have important implications for patient-provider communication.

Identity by Group. While members of each group labeled *PCOS* and its symptoms similarly, each discussed their symptoms differently. For example, in each group, a few women identified the symptom(s) that gave them the greatest concern. Among those in Group 1, a few still worried about infertility, because they had not decided if they wanted another pregnancy, while others expressed no desire for future pregnancies but did report weight issues as their most troubling symptom. Like women in Group 1, those in Group 2 also reported weight issues as being their “greatest struggle.” Although few interviewees in Group 3 identified a “No. 1” concern, those who did were most troubled by their difficulties breastfeeding. Lastly, women in Group 4 expressed greatest concern over menstrual irregularities and dermatologic issues, such as hirsutism and acne. These findings suggest that, even though WLW PCOS may experience similar issues throughout the life course, the importance of those issues to each woman may depend on where she is in the life course. For example, while younger, single women may be more immediately troubled by symptoms that affect their appearance, those who have started but have not yet completed childbearing may be more immediately concerned with fertility and

breastfeeding. Because a major goal of PCOS management should be to improve HRQoL by alleviating symptoms women find distressing (Pfeifer & Kives, 2009), providers should pay careful attention to their patient's presenting or primary complaint in addition to addressing any other medical needs.

Surprisingly, women with children with no history of infertility (Groups 3) were more likely than women with children with a history of infertility (Groups 1) to discuss breast milk supply issues. However, reasons for this difference remain unclear and highlight the need for additional research investigating the relationship between PCOS, breast development, and breastfeeding challenges.

Lastly, women in Group 4 (e.g. women who were childless with no history of infertility) were more likely than any other group to discuss painful menstruation and/or ovulation, mood disturbances, depression, anxiety, hirsutism, alopecia, and acne during their interviews. Interestingly, these women were also more likely to report being non-compliant with their prescribed medication regime (usually birth control pills and/or Metformin®), which could easily explain their PCOS-related symptoms. The most common reasons given for this non-compliance were forgetfulness or "laziness." Likewise, those in Group 4 were also more likely than any other group to express worry and/or embarrassment over their cosmetic issues, which may have contributed to their feelings of depression or anxiety. In fact, the only interviewee who specifically reported a history of suicidal thoughts was a woman in Group 4, who expressed significant distress over PCOS-related cosmetic issues.

I really suffered with it as a teenager when I had all the side-effects...with the hormones, with the, well, hair growth. I thought I was turning into a man, and I was, pretty much, suicidal. I mean, I wanted to die. (K.M., age 30)

Again, these findings emphasize the need for providers to pay careful attention to their patient's presenting or primary concerns and to explain treatment goals.

Consequences. While women in all groups identified a number of PCOS-related consequences related to their social lives, personal relationships, finances, and future health, many differences among groups were identified. For example, women in Group 4 (e.g. women who were childless with no history of infertility) were more likely than those in other groups to report that the embarrassment, anxiety, and/or depression they felt over cosmetic symptoms discouraged them from being more social. Likewise, Group 4 members also reported avoiding the dating scene due to lack of self-confidence. In terms of personal relationships, few women reported major issues related to PCOS, but a couple of women in Group 2 (e.g. women who were childless with a history of infertility) did speak at length about the disappointment they felt over not being able to build their relationship with their babies through breastfeeding.

When discussing future health consequences, those in Group 4 (e.g. women who were childless with no history of infertility) were more likely than others to express concerns over future infertility and pregnancy complications. In fact, some women in this group worried about finding a future spouse that would accept their uncertain fertility. This was unsurprising, however, because many women in this group were single and had not yet tried to conceive. On the other hand, those in Groups 1 and 2 (e.g. women with a history of infertility), the older groups, were more likely than those in Groups 3 and 4 (e.g. women with no history of infertility) to worry about future cancer and heart disease, which may have reflected their place in the life course.

Lastly, those in Groups 3 and 4, the younger groups, were more likely to describe financial strain related to PCOS. In particular, women in these groups reported being uninsured

or underinsured, which limited their access to care and ability to medically manage their PCOS as desired. Similarly, women in these groups also reported stress over money to buy clothes as their weight fluctuated and to buy food that would allow them to stick to a healthier diet.

Cause. While most women, regardless of group, expressed uncertainty about the cause of PCOS, many believed that there was a genetic component. Interestingly, those in Group 4 (e.g. women who were childless with no history of infertility) were the only to suggest that weight “triggered” PCOS or exacerbated PCOS symptoms. While it remains unclear why women in other groups did not explicitly identify this relationship, it is important that providers emphasize the role of obesity loss in PCOS severity and weight loss in PCOS management.

Timeline. In general, all groups identified PCOS as a chronic condition and believed that the syndrome would affect them throughout their life. However, women in Group 3 (e.g. women with children with no history of infertility) were more likely to report that, because they had not struggled with fertility as expected, they were unsure of how the syndrome would affect them in the future. This finding suggests that women in Group 3 may have been so focused on in/fertility, that they did not consider other consequences of the syndrome. It also suggests that, during their clinical encounters, provider may have not discussed other implications of the syndrome or they themselves disregarded those messages. For this reason, it is important that, in addition to providers addressing immediate concern of their patients, they also remind patients of the larger implications of the syndrome and discuss any lifestyle modifications or treatments that would help prevent any future PCOS-related conditions.

Control. Although most women in each group reported feeling like they had little control over the syndrome, most expressed the belief that PCOS could be managed. Common management strategies identified by women in all groups included weight loss (through exercise

and/or diet), birth control pills, Metformin®, acne treatments, and hair removal treatments. Given group 4's concerns over PCOS-related cosmetic issues, it was unsurprising that these women were more likely than others to discuss the latter, acne treatments - especially acne creams, and hair removal treatments, which included waxing, bleaching, shaving, and plucking – all short-term solutions. On the other hand, women in Groups 1 and 2 (e.g. women with a history of infertility) were more likely than those in Groups 3 and 4 (e.g. women without a history of infertility) to report using long-term hair removal strategies, such as medications and laser hair removal. This finding may be related to the age of the groups and their financial stability. For example, a number of women in Groups 3 and 4, the two younger groups, specifically stated that laser hair removal was too expensive.

Cure. Lastly, most women in each group expressed the belief that PCOS could be managed but could not be “cured.” The most common reasons given for this belief were that PCOS was (1) a chronic condition, resulting from a number of factors, including genes and environment or (2) a spectrum disorder, which, by definition, affected women differently, and, therefore, required different treatments for different women. In contrast, there were only one or two women in each group who expressed the belief that a pill would be created, either purposively or accidentally, to cure PCOS. Interestingly, women in Group 4 (e.g. women who were childless with no history of infertility) seemed the most polarized on this domain. While some women seemed very hopeful that, given enough research, a cure would be discovered, others expressed the belief that there was little awareness of PCOS and/or that there was little interest in the medical community to address and research the needs of WLW the syndrome.

Emotional Representations of PCOS by Group. Women in all groups reported that they felt the following when thinking about PCOS and its symptoms: frustration, depression, anxiety, and embarrassment. While Group1 (e.g. women with children with a history of infertility) was more likely than any other group to express feelings of frustration, which may be expected given their additional experience with infertility and follow-up treatments, Group 4 participants were more likely to express feelings of depression. As previously stated, the latter finding may be a result of (1) less hormone regulation and, consequently, more symptoms, as a result of non-compliance issues and (2) a concern over PCOS-related cosmetic issues, which this group reported being particularly depressing.

Chapter 5: Discussion

The aim of this chapter is to discuss the implications and limitations of the exploration reported in this dissertation. The first part of this chapter will expand upon the overall findings of the dissertation in the context of current research in the field and identify implications for patient education, provider education, clinical practice, and policy improvements. Overall, this summary will illustrate how this dissertation makes a valid contribution of advancing knowledge of the CSM and of PCOS. The second part of this chapter will discuss the limitations of this dissertation along with suggestions for future research in this field.

Major Findings of the Dissertation

The Common Sense Model. In the field of health education and promotion, an important goal is to test health behavior theories iteratively in the real world (Rosenstock, 1990). While the CSM has been used as a guiding framework in studies of acute and chronic conditions, both physical and mental, no PCOS-related studies have adopted the CSM. Thus, this dissertation was the first to test the *ecological validity* of the CSM in a population of women diagnosed with PCOS. That is, this dissertation was the first to explore to what extent the dimensions of the CSM conformed to the illness perceptions of WLW PCOS.

Overall, it was found that WLW PCOS generally have illness perceptions of the syndrome that are consistent with the domains identified in the CSM (Leventhal et al., 2003). In addition, it was found that, in relation to their illness cognitions, WLW PCOS described the extent to which they felt they had a comprehensive understanding of the syndrome, a phenomenon labeled *illness coherence* and identified as an additional dimension of illness

cognitions by Moss-Morris and colleagues (2002). Similarly, participants identified PCOS as a common condition (i.e. labeled *perceived prevalence*). Although this cognition does not “fit” into any previously defined dimensions of the CSM, it is arguable that this reflects a problem with the domain definitions, rather than the framework itself. That is, it would be reasonable to include this cognition under *Identity* (defined as the label/name persons give to an illness and the symptoms they associate with that illness) if its definition were redefined or expanded (Leventhal et al., 2003).

Whether *perceived prevalence* should be added to the model as its own domain or included under an existing domain of the CSM remains debatable. However, this finding should not be ignored, because previous research (unrelated to the CSM) indicates that perceptions of illness prevalence are related to health behaviors, and, consequently, health outcomes. For example, Chang, Klein, and Gorzalka (2013) recently reported that, among women, higher perceived prevalence of male and female sexual dysfunctions was predictive of lower sexual functioning and poorer sexual satisfaction.

Unmet Information Needs. In this dissertation, the illness perceptions of WLW PCOS were identified, which included their beliefs regarding the symptoms, causes, consequences, cure/control, and timeline of the syndrome. Although some of these beliefs were consistent with medical knowledge, others were not, suggesting that the CSM may be particularly useful in identifying knowledge deficits among WLW PCOS. For example, a few participants identified “hyper” ovulation as a symptom of PCOS and/or cervical cancer as a health consequence of the syndrome, neither of which are consistent with the literature. On the other hand, endometrial cancer, which WLW PCOS have a 2.7-fold increased risk for developing (Eunice Kennedy Shriver National Institute of Child Health and Human Development, 2012) , was not identified as

a health consequence of PCOS by any participant. For this reason, PCOS informational materials, as well as providers, should make clear the risk factors for endometrial cancer, as well as cervical cancer. More specifically, WLW PCOS should be made aware of their increased risk of endometrial cancer and the protective effect of intrauterine device (IUD) use on endometrial cancer risk (Benshushan, Paltiel, Rojansky, Brzezinski, & Laufer, 2002). However, this caution should be accompanied by the disclaimer that information on endometrial cancer risk should be judged in the context of the relatively low incidence rate of endometrial cancer in the general population (National Cancer Institute, 2014). In addition, PCOS information materials should (1) highlight that no studies report an association between cervical cancer and PCOS and (2) emphasize the fact that the human papillomavirus (HPV) is a necessary but insufficient cause of cervical cancer (American Cancer Society, 2009). As a follow-up, information on HPV screening guidelines may also be provided to meet an additional information need of this population.

In addition, dissertation findings suggest that WLW PCOS do not understand the goals of clinical management of the syndrome. For example, almost all participants identified ways in which their PCOS had been medically managed. These experiences were dependent on interviewee's symptoms and medical history and included one or more of the following: oral contraceptives and Metformin®, which were the most commonly described, anti-depressants, and treatments for infertility, hair removal, and acne. When asked about the effectiveness of these medications and/or treatments, most participants reported that they effectively alleviated symptoms. However, many also expressed the belief that they were not really “treating” their *PCOS* with the medications and treatments, but, instead, were treating their *PCOS symptoms*. This thought, in particular, seemed very troubling to participants. However, given that PCOS is

a chronic condition for which there is no cure; the goals of clinical management are to (1) address reproductive health concerns, (2) prevent PCOS-related chronic illness, and (3) improve HRQoL by alleviating symptoms women find distressing (Pfeifer & Kives, 2009). As such, participants' views mostly likely reflect (1) a misunderstanding of management goals and/or (2) cure beliefs, meanings that participants believe there is a medication or treatment that cures or treats PCOS, not just its symptoms. For this reason, to minimize patient distress and to improve patient satisfaction with clinical care, providers should clarify management goals. Likewise, providers and PCOS informational materials should emphasize the chronic nature of the condition and the long-term health implications of the syndrome.

With this in mind, it is noteworthy that, in response to questions regarding the timeline of their PCOS, participants voiced drastically different views. While some responded that it was a chronic condition that would affect them the remainder of their life, others questioned whether PCOS would affect them after menopause or a hysterectomy or if these circumstances would significantly change their experience with the syndrome. Still, a few women, particularly those with a history of infertility, had not considered the possibility that PCOS would affect them after childbearing. These findings provide further evidence that WLW PCOS not only need information on the long-term health implications of PCOS, but also the underlying hormonal imbalance that is characteristic of the syndrome. That is, they need more information that will explain how menopause and/or a hysterectomy effects and does not effect this imbalance.

Lastly, perhaps the most important findings highlighting the information needs of WLW PCOS were the unsolicited admissions by most participants that they did not understand their diagnosis. Many explained that, prior to diagnosis, they had little knowledge of the syndrome, suggesting that they did not have an existing schema for this syndrome within which to make

sense of their symptoms. To complicate matters, women felt that the information given to them at the time of their diagnosis was confusing and that not enough information was made readily available to them to answer their questions, which led to feelings of frustration. In response, most participants reported searching for answers online, a behavior easily explained by the CSM and expected by a sample of women recruited through a social networking site (SNS). Although this search proved helpful to many of the women interviewed, it also left some with more questions and feelings of uncertainty. For this reason, it was suggested by a number participants that a follow-up visit soon after their diagnostic visit would have been particularly helpful. Notably, the frustration WLW PCOS felt over the information provided at diagnosis, as well as their search for answers, has been reported by other investigators over the past 12 years (Avery & Braunack-Mayer, 2007; Kitzinger & Willmont, 2002; Snyder, 2006; Weiss & Bulmer, 2011). Together with this dissertation, these studies provide overwhelming evidence that the information needs of WLW PCOS continue to be unmet. Yet, few studies have explored preferences for information provision among WLW PCOS. This knowledge gap is further addressed under *Directions for Future Research*.

Significant Psychological Morbidity & Unmet Mental Health Needs. In this dissertation, a number of findings provide additional evidence that PCOS has a negative effect on women's mental health and HRQoL, associations commonly reported in the PCOS literature (Barry et al., 2011; Jones et al., 2007). For example, the majority of survey respondents reported a history of depression and/or anxiety. Likewise, when comparing scores on health-related quality of life (HRQoL) domains, survey respondents, in general, reported lower levels of functioning on emotional well-being compared to physical functioning. Similarly, respondents

were more likely to report problems with work or other daily activities as a result of emotional problems rather than physical health problems.

Overall, few respondents reported their general health as being excellent or very good. Upon further investigation, it was found that *type* of symptom, not *number* of symptoms, related to this perception. That is, those who reported higher levels of functioning were more likely to talk at length about the *physical manifestations of PCOS*, including weight issues, insulin resistance (IR), hirsutism, and acne. On the other hand, those who reported lower levels of functioning were more likely to emphasize *the impact of PCOS symptoms on their mental health*. Specifically, those who with lower levels of functioning were more likely to report feeling depressed, worried, and /or stressed over current symptoms or the risk of PCOS-related health issues. In summary, these findings highlight (1) the impact of PCOS and its symptoms on the mental health of WLW PCOS and (2) the importance of providers identifying and addressing the symptoms WLW the syndrome find most distressing. Notably, from a clinical perspective, these symptoms may not be the most concerning. However, because improving quality of life is a main goal of PCOS management (Pfeifer & Kives, 2009) and an overarching goal outlined in *Healthy People 2020* (U.S. Department of Health and Human Services), these symptoms should not be ignored.

To improve mental health, in general, the U.S. Preventative Task Force (USPSTF) also recommends “screening adults for depression when staff-assisted depression care supports are in place to assure accurate diagnosis, effective treatment, and follow-up. (U.S. Department of Health and Human Services). At a minimum, this may include a screening nurse who screens patients for depression, reports positive findings to the resident physician, and follows a protocol to facilitate referral to mental health services. Himelein and Thatcher (2006) identify two

appropriate depression screening tools: the Patient Health Questionnaire-9 (PHQ-9), a 9-item self-report measurement tool, or a shorter version of the instrument, known as the PHQ-2 (Kroenke, Spitzer, & Williams, 2001, 2003; Löwe, Kroenke, & Gräfe, 2005; Lowe, Kroenke, Herzog, & Gräfe, 2004). While the full measurement tool is brief and has the ability to assess severity and sensitivity to change, the shorter measure may be a more efficient alternative in busier clinics. Again, if mental health issues are identified, providers should link women to appropriate, quality mental health services. On the other hand, if no staff-assisted depression care supports are in place, providers should consider referring patients to a mental health provider, who may become part of a larger multidisciplinary team of providers to support his/her patient with PCOS.

Breastfeeding Challenges and Need for Breastfeeding Support. In this dissertation, a few women interviewed reported an issue with low breast milk supply. Notably, this symptom proved to be the most difficult for participants to discuss, as these descriptions were often interrupted by tears and moments of silence during which participants took time to regain their composure. Many of these women mourned the loss of their ability to bond with their children through breastfeeding and expressed frustration that their providers had not warned them that breastfeeding may be an issue. Similarly, most reported that the lactation consultants they sought advice from had little information on the effects of PCOS on breastfeeding, and one participant expressed concern that WLW PCOS who breastfed their female children placed them at greater risk for developing PCOS, which *almost* discouraged her from breastfeeding her children. In short, breastfeeding challenges reported in this dissertation identified an unmet need not only for patient education, but also provider education and training. However, it should be noted that, although there is overwhelming evidence that breastfeeding provides substantial health benefits

for mothers and babies (Office of Women's Health, 2011), no studies have been conducted to explore the impact of PCOS on breastfeeding. This not only explains gaps in provider knowledge, but also highlights a knowledge gap in the literature, which is further addressed under *Directions for Future Research*.

Poor Quality of Care and Low Patient Satisfaction. As described in the results, frustration was a dominant theme of this dissertation, and participants' frustration largely centered on their interactions with their health care providers. In fact, some women interviewed in this dissertation became so frustrated with care that they switched providers or terminated care altogether, leaving their syndrome unmanaged and them at risk for developing PCOS-related conditions. Specific sources of frustration are discussed below.

Above all, women interviewed were most frustrated by perceived gaps in their providers' knowledge, which they believed resulted in delayed diagnosis, lack of symptom improvement, and poor conveyance of information about the syndrome, its symptoms, and treatment options. Notably, many medical societies also believe that PCOS awareness is low among physicians, and PCOS experts have expressed concern that millions of WLW type 2 diabetes (T2D) and cardiovascular disease (CVD) may be receiving inadequate treatment, because their providers do not recognize these symptoms as indications of PCOS (Christopher, 2004). It should be noted, however, that, no research provides supporting evidence for these beliefs. That is, in the United States, no studies have explored PCOS content in current medical school curriculum, nor explored the beliefs, attitudes, knowledge, or practices of providers who treat WLW PCOS. This knowledge gap is further discussed under *Directions for Future Research*.

Moreover, women interviewed in this dissertation often expressed frustration that their providers focused on fertility, regardless of their concerns, and/or did not provide a

comprehensive treatment plan. Although the reasons for these practices remain unclear, there are a few reasonable explanations for these findings. First, because PCOS was originally described as a reproductive disorder (and not an endocrine disorder) and because clinical management of the syndrome initially centered on fertility restoration, providers, especially older providers, may have learned about the syndrome in this context. Second, these practices may reflect lingering societal ideologies on gender, which define motherhood as women's primary social purpose (Weisman, 1997). Lastly, these practices may reflect a larger structural issue. That is, the fragmentation of healthcare (defined, in terms of women's health, as the separate delivery of reproductive and non-reproductive services without provisions of coordinated care) (Weisman, 1997) presents a challenge to WLW the syndrome, because they may have dermatologic, reproductive, metabolic, and/or psychological concerns - all of which are currently addressed by different medical specialists. Regardless of the reason, fertility-focused care is problematic, because women experiencing PCOS without fertility concerns remain largely undiagnosed and untreated, putting them at risk for PCOS-related conditions and subsequent reduced quality of life. Again, no studies have explored the practices of providers who treat WLW PCOS, and this knowledge gap is addressed under *Directions for Future Research*.

Lastly, some women also expressed frustration over being left out of the decision-making process, and a few who took medications admitted to not know why that medication had been prescribed or what condition it was intended to treat, suggesting that their consent to treatment was uninformed. As a consequence, some women reported stopping their medications altogether or taking their medications incorrectly, leading to little symptom reduction and greater risk for developing PCOS-related conditions. Not only do these findings highlight an unmet information need of WLW the syndrome, specifically as it related to treatment options and goals,

but also a need for research exploring provider and patient factors related to shared decision making in the context of PCOS management. This knowledge gap is also further discussed under *Directions for Future Research*.

Limited Access to Care. Lastly, women interviewed in this study faced a number of barriers to PCOS management, particularly financial strain. More specifically, participants were upset that a number of treatments needed to address PCOS symptoms, such as IVF and laser hair removal, were not covered by insurance. Consequently, many women either went into debt paying out of pocket for these treatments or reported feeling depressed by their inability to control specific symptoms, particularly infertility and excess hair growth.

At this time, it is the position of most insurance companies within the US that treatments such as IVF and laser hair removal are not medically necessary (RESOLVE, 2014). To date, this argument has made it easy for insurance companies to make a case for not covering these services. However, this argument does not take into account the impact of the diseases they are meant to treat on health-related quality of life. Because improving health-related quality of life should be a main goal of clinical treatment (U.S. Department of Health and Human Services) and because these “medically unnecessary” treatments improve health-related quality of life, health insurance systems should revisit and revise their policies on these procedures.

Study Strengths and Limitations

Study Strengths. In addition to testing the *ecological validity* of the CSM in a population of women diagnosed with PCOS, this dissertation study contributes to the literature and to the field of public health in a number of ways. This is the first qualitative study to specifically focus the investigation on the illness perceptions of PCOS held by WLW the syndrome. That is, previous qualitative research has focused primarily on the overall experience

of living with the syndrome. In these studies, researchers use phenomenological and grounded theory approaches to explore the meaning of PCOS to WLW the syndrome (Kitzinger & Willmont, 2002; Snyder, 2006; Weiss & Bulmer, 2011) and to describe the lived experience of WLW PCOS in the management of the syndrome (Crete & Adamshick, 2011). As such this is the first qualitative study to capture any experiences of WLW PCOS using the CSM as a starting point.

Unquestionably, the a priori use of a model in qualitative research can pose a threat to internal validity (Miles & Huberman, 1994). However, several points support the authenticity, plausibility, and adequacy of the data obtained in this dissertation. First, although the interview guide was framed around the constructs of the CSM, participants provided thick descriptions of their experiences of living with PCOS. They were also asked, at the end of the interview, whether there was anything else they wanted to say regarding their experience with the syndrome. No substantive information was obtained in response to this question. Second, triangulation of data from this dissertation with both quantitative and qualitative data from other populations of WLW PCOS indicates converging conclusions between the groups. Finally, the data reflect themes which emerged from previous qualitative research into the illness perceptions of those with PCOS-related illnesses, such as diabetes.

In addition, this dissertation was the first to explore the relationship between illness perceptions of WLW PCOS and their HRQoL. Because specific illness perceptions were associated with HRQoL, addressing these illness perceptions could be an effective strategy in increasing HRQoL among WLW the syndrome. This is important, because HRQoL is identified as a national health standard (U.S. Department of Health and Human Services). Lastly, this

study is the first to describe a sample of WLW PCOS recruited through a SNS, information that may be useful to other PCOS researchers.

Study Limitations

The dissertation has limitations related to disclosure, which was previously described, and to web-based surveys, mainly sample selection and recruitment. To date, researchers have recruited WLW PCOS primarily through healthcare settings or the internet. In extant literature, researchers in medicine and nursing have mostly recruited women through large hospital networks and large healthcare practices, (Crete & Adamshick, 2011; Ekback, Wijma, & Benzein, 2010; Jones, Hall, Lashen, Balen, & Ledger, 2011; Percy et al., 2009; Snyder, 2006) and researchers from the social sciences have mostly recruited women through online support groups (Avery & Braunack-Mayer, 2007; Kitzinger & Willmont, 2002). Unlike most studies, Weiss and Bulmer recruited women from a number of colleges by posting recruitment flyers around campuses (Weiss & Bulmer, 2011).

The advantages and disadvantages of each recruitment strategy are clear. If recruiting through clinical populations, it can be confirmed that women meet inclusion and exclusion criteria. However, this requires accessing patient's medical records, and the "Privacy Rule," a federal regulation under the Health Insurance Portability and Accountability Act (HIPAA), protects certain health information (National Institutes of Health). Thus, healthcare personnel would have to have been relied upon to identify and to make first contacts with potential participants. This process could have been time consuming and costly, and it could have been difficult to find healthcare personnel willing to assist in the study. On the other hand, it took less time to identify participants via SNS. Researchers using this recruitment strategy have gained the cooperation of groups such as Verity (<http://www.verity-pcos.org.uk/>), a United Kingdom organization, and the PCOS Association of Australia, Inc (<http://main.posaa.asn.au/>). In these

studies, researchers were not able to clinically confirm participant's PCOS diagnosis; rather, they asked women if a healthcare provider had ever told them they had PCOS (as was reported in the current dissertation study).

In addition to a PCOS diagnosis, a number of inclusion and exclusion criteria were outlined. Although participants were asked to complete a screening survey prior to their interview, it was impossible to verify that women were answering screening questions truthfully. This data collection issue, however, is not unique to this dissertation. Getting honest answers to survey questions is a limitation of any research study collecting survey data (Neumen, 2006).

Also, no data exists to determine how a number of PCOS populations differ including: (1) clinical populations and online populations, (2) populations that do and do not subscribe to facebook®, and (3) populations of facebook® subscribers who do and do not belong to PCOS-related interests groups. The difference between the women who did and did not follow the link to the survey also could not be determined. Thus, the representativeness of the sample could not be fully determined. However, sample representativeness and generalizability were not relevant to the goals of this dissertation – to produce data that were conceptually representative, not statistically representative, of women's illness perceptions of PCOS.

Lastly, when a researcher advertises to a group with a specific experience, *primary selection* of a sample is said to have occurred (Bryant & Charmaz, 2007). While those who contacted the lead investigator met “experience” criteria, it was unknown if they would be able to articulate and reflect – participant qualities important within a qualitative study (Morse, 1991). To account for this, *secondary selection* was employed (Bryant & Charmaz, 2007). That is, when it became clear during an interview that the participant could not articulate her experience, the interview was politely completed, the digital recording was kept, but then the interview was

not transcribed, and the data was not incorporated into the study. This procedure was followed for one interview.

Directions for Future Research

Despite some limitations, the findings from this dissertation have several implications for future public health research. These are summarized below.

Adapting the IPQ-R for WLW PCOS. As previously described, there is a growing interest in Leventhal's Common Sense Model (CSM) to explain the cognitive and emotional antecedents of health behaviors and illness outcomes in chronic illness (Hagger & Orbell, 2003b). This is largely credited to the development and subsequent revision of the Illness Perceptions Questionnaire (IPQ and IPQ-R), a quantitative operationalization of the CSM, which has made it easier for researchers to utilize the general framework (Moss-Morris et al., 2002; Weinmann et al., 1996). The authors of both the IPQ and IPQ-R have encouraged researchers to adapt these measures to suit different health conditions and note that the applicability of the scales and sub-scales may vary depending on the unique characteristics of such groups. Accordingly, researchers studying different health conditions have reported modifications to the instruments to improve model fit (see the IPQ website, <http://www.uib.no/ipq>), illustrating that a thorough evaluation of the instruments' psychometric properties is necessary before it can be applied in research to different illness populations.

Given the aim of the current dissertation - to identify illness perceptions of WLW PCOS – the findings reported here lay the groundwork for developing and testing a modified version of the IPQ-R to study illness perceptions of WLW PCOS. Notably, this instrument should include items assessing *perceived prevalence*. An IPQ-R measure for PCOS could be useful in clinical practice to identify whether women diagnosed with PCOS have an accurate or inaccurate

conception of the syndrome that may be contributing to inappropriate coping strategies and/or increased symptom burden. An IPQ-R measure for PCOS may also be useful for identifying cognitive and emotional predictors of PCOS outcomes and self-care behaviors. In addition, such a scale could help to capture how beliefs regarding PCOS (1) differ among women living with PCOS, based on symptoms and health status, (2) change over time as women move from child-bearing years to post-menopausal years, and relate to HRQoL. This information would be critical to tailoring health promotion messages to WLW PCOS.

Addressing the Unmet Needs of WLW PCOS. As in previous studies exploring the lived experiences of WLW PCOS (Crete & Adamshick, 2011; Kitzinger & Willmont, 2002; Snyder, 2006; Weiss & Bulmer, 2011), this dissertation reports an unmet information need in this population. However, because the primary purpose of this dissertation or these studies was not to assess the information needs of WLW PCOS, the usefulness of findings is limited.

The only study that has specifically explored the information needs of WLW PCOS was conducted in Australia in 2007. Surprisingly, the authors did not report the *types* of information women were looking for, only that women preferred using the Internet when searching for information (Avery & Braunack-Mayer, 2007). The study also had several limitations. First, because women were recruited from a PCOS intervention program, these women already had high PCOS knowledge and were aware of the implications of PCOS on their future health. These women also represented an age group (28-38 years old) where fertility was likely a concern versus other PCOS symptoms.

In the future, information needs of WLW PCOC should be assessed. Qualitative and quantitative studies are needed to further explore the (1) PCOS knowledge of women with the

syndrome, which, to some extent, was captured in this dissertation, and (2) their preferences for information provision. To date, no scales exist to measure the PCOS knowledge of women affected by the syndrome, nor their attitudes and beliefs about PCOS, such as their perceived severity and susceptibility to PCOS-sequelae. A self-administered questionnaire measuring these constructs in women with PCOS could be developed and/or tested in future studies. Different types of PCOS media could also be developed and/or tested and the quality and helpfulness of existing PCOS information could be assessed. Notably, these research activities are related to two *Healthy People 2020* objectives: (1) to “increase the proportion of health-related websites that meet three or more evaluation criteria disclosing information that can be used to assess information reliability” and (2) to “increase the proportion of health-related websites that follow established usability principles” (U.S. Department of Health and Human Services).

Because research suggests that women with the syndrome prefer using the internet to search for PCOS information (Avery & Braunack-Mayer, 2007), future studies could also explore how women access the internet to answer their PCOS questions and whether they retrieve accurate answers to their questions. Research could also include secondary data analysis, where questions posted by WLW PCOS on PCOS support group websites and/or information pages would be analyzed.

Most importantly, to advance the CSM, future studies should assess how PCOS information shapes women’s illness perceptions of PCOS and subsequent health behaviors and outcomes. Notably, the social sciences literature has generally described information interventions as necessary but insufficient drivers of health behaviors (Glanz, Rimer, & Lewis, 2002). As such, future studies exploring individual-level determinants of health, such as illness

perceptions, can determine the role of information in motivating women to adopt health-promoting behaviors such as weight reduction and management or screening behaviors. Overall, findings from studies proposed in this section could be used to improve health communication strategies in WLW PCOS and potentially improve health outcomes among WLW PCOS.

Exploring Relationships Between Breastfeeding and PCOS. As previously reported, a few women interviewed in this study reported problems with breastfeeding and expressed frustration towards their providers for not advising them that they were at risk for low breast milk production. However, this finding was not surprising, because no investigators have studied breast development and breastfeeding problems among WLW PCOS. In short, this issue has received little attention in the literature. To promote breastfeeding in the population and to improve provider training, more research is needed to explore the relationships between PCOS, breast development, and breastfeeding. Medical school curriculum, as well as educational materials for lactations consultants, should also be reviewed for PCOS-related content.

Improving Quality of Care and Patient Satisfaction. To improve quality of care and patient satisfaction among WLW PCOS, more research is first needed to assess the breadth and depth of PCOS-related content in the medical school curriculum. In addition, research is needed to assess the PCOS knowledge, diagnostic practices, and management strategies of providers. Arguably, the CSM would provide a useful framework in which to explore this phenomenon. That is, in this dissertation, the primary purpose was to identify illness perceptions of WLW PCOS to lay the groundwork for future research exploring how illness perceptions impact health behaviors, and, consequently, health outcomes. However, the same program of study could be repeated with physicians to not only identify their illness perceptions of PCOS but also to explore how their perceptions impacted their diagnostic and clinical practices (i.e. their health

behaviors), and, consequently, the health outcomes of their patients. In addition, an IPQ-R could be adapted for *providers* treating WLW PCOS, which would also require testing in future studies.

Also, as previously described, PCOS experts agree that awareness of PCOS among physicians remains low - a problem that medical associations, such as the American Association of Clinical Endocrinologists (AACE), the Androgen Excess Society (AES), and the American Society of Reproductive Endocrinologists (ARSE) have promised to address through position papers, workshops, trainings, and continuing medical education courses (CEUs) (Christopher, 2004). In future studies, researchers could partner with these organizations to develop, pilot, and evaluate these trainings and CEUs. Before developing these trainings, however, researchers would need to explore the current clinical knowledge, attitudes, and beliefs about PCOS among providers – research which is described above.

Given the clinical experiences regarding shared-decision making among those interviewed in the dissertation and the *Healthy People* objective to “increase the proportion of persons who report that their healthcare providers always involve them in decisions about their healthcare as much as they want” (U.S. Department of Health and Human Services), research is needed to explore physician and patient factors related to shared decision making. First, studies should explore to what extent WLW PCOS want to participate in medical decision making related to their condition. Previous research addressing this issue in other clinical populations has found mixed results and patient preferences appear to be condition specific (Frosch & Kaplan, 1999). This suggests that preferences may vary in different phenotypic groups of WLW PCOS, whose symptoms vary in severity. Second, it should be determined if physicians treating WLW PCOS want to engage in shared decision making as a patient’s preferences will have little impact if the

physician is not open to the process. Although studies consisting of large samples of physicians regarding their views on shared decision making have not been conducted, a number of variables are believed to impact their attitudes towards the process (Frosch & Kaplan, 1999). For example, some physicians may feel threatened by patient empowerment, may engage in limited dialogue to avoid emotionally charged situations, may be reluctant to disclose information relevant to making uncertain choices, or may lack the necessary communication skills needed to engage patients in the shared decision making process (Frosch & Kaplan, 1999). Kaplan and colleagues report that physicians who encourage shared decision making have lower patient volume in their practices, previous training in primary care or in interviewing skills, and more satisfaction with the extent of their personal autonomy (Kaplan, Greenfield, Gandek, Rogers, & Ware, 1996). Future studies should explore these factors in provider treating WLW PCOS and determine if there are other factors unique to this condition, including illness perceptions, which facilitate or prevent providers from adopting a shared decision making paradigm. Third, future studies should explore strategies to implement shared-decision making in PCOS care. Decision aids are often utilized to prepare patients to participate in healthcare decisions (Stacey et al., 2011). To date, no decision aids have been developed for PCOS, which could be developed and tested in future studies. Lastly, future studies should identify health outcomes related to shared-decision making in PCOS populations. For example, in other clinical populations, shared decision making has been associated with lowered blood pressure and improved diabetes control - positive health outcomes relevant to WLW PCOS (Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Stewart, 1995). Overall, findings from these studies could inform strategies to improve patient-provider communication and encourage shared decision making in PCOS care.

Improving Access to Care. Assurance is one of the core public health function. This function assures that services necessary to achieve agreed-upon goals (i.e. which are outlined in *Healthy People 2020*) are provided, either by encouraging actions by other entities (private or public), by requiring such action through regulation, or by providing services directly (Novick & Morrow, 2008b). One major activity related to assurance is linking persons to needed services. To date, no studies have explored how WLW PCOS identify, access, utilize, and pay for PCOS-related services. Specifically, more research is needed to understand how WLW PCOS are linked to additional services after gaining entry into the healthcare system. Given the numerous health implications of PCOS, most literature emphasizes the importance of a multidisciplinary healthcare team, consisting of medical providers, mental health providers, and dieticians, to improve PCOS treatment (Ahonen, 2010). However, no studies have explored how providers perceive a team approach to PCOS care. Research is needed to understand provider's perceptions of their role in PCOS care and to understand referral practices of providers caring for WLW PCOS. Again, future research studies could also specifically explore how referral practices (i.e. provider behaviors) are related to providers' perceptions of PCOS.

Conclusion

It is now recognized that women's health includes diseases and conditions that affect a woman's health across the lifespan. These conditions include the leading causes of death in women, such as CVD and type 2 DM – conditions which have also been identified as public health priorities by the *Healthy People* initiative (Centers for Disease Control and Prevention). The first step in reducing the disease burden of these conditions among women is recognizing the women at risk. Previous public health efforts have targeted women with behavioral risk factors such as cigarette smoking, poor nutrition, and physical inactivity; and condition-specific

risk factors such as obesity, hypertension, high cholesterol, and metabolic syndrome (Mosca et al., 1997). Although the latter are all characteristic of women with PCOS, the syndrome itself has yet to receive the same attention as other conditions (Corley, 2007). Consequently, PCOS women may represent the largest underappreciated segment of the female population at risk for diabetes and cardiovascular disease. Given the high prevalence of PCOS in the general population and the current obesity epidemic, which is an environmental risk factor for the syndrome, it is arguable that **PCOS is not only a public health issue, but also is of increasing public health importance.**

Although some women who experience PCOS will not develop CVD and/or type 2 DM, it is likely that they will experience infertility, hirsutism, and/or obesity in their lifetime. Because these conditions reduce women's HRQoL and because HRQoL has been identified as a new topic area in *Healthy People 2020* (U.S. Department of Health and Human Services), it is further arguable that **PCOS warrants increased public health attention.** Moreover, PCOS represents a huge financial burden to the U.S. healthcare system and this burden is only expected to worsen as obesity rates rise and, subsequently, more cases of PCOS are identified.

Although the specific aims of this dissertation were to explore the illness perceptions of WLW PCOS and their HRQoL, it is hoped that the findings reported here will inspire future investigations on the issues faced by WLW PCOS and spark a larger dialogue on the public health significance of PCOS. It is also hoped that the findings reported in this dissertation will not only help WLW PCOS better understand their condition and the experiences of other WLW PCOS, but also contribute to provider's understanding of how WLW PCOS experience their condition.

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Appendices

Appendix A. Parts 1-3 of the Online Survey

Part 1

1. Sex

What is your biological sex?

- a. Male (exclude)
- b. Female

2. Age

How old are you? (Enter age in years) (>18 years, exclude)

3. Citizenship

Which statement best describes you?

- a. I am a United States citizen, and I currently live in the United States.
- b. I am a United States citizen, but I do not currently live in the United States. (exclude)
- c. I am not a United States citizen. (exclude)

4. PCOS

Has a medical provider ever told you that you have polycystic ovary syndrome (PCOS)?

- a. Yes
- b. No (exclude)
- c. Unsure (exclude)

Part 2

5. Ethnicity

Are you Hispanic or Latina, or of Spanish origin?

- a. Yes
- b. No
- c. Unsure (code as No)

6. Race

Which of the following groups describes your racial background? (Check all that apply.)

- a. American Indian or Alaska Native
- b. Asian
- c. Native Hawaiian or Other Pacific Islander
- d. Black or African American
- e. White
- f. Other (fill in the blank)

7. Sexual Orientation

How would you describe your sexual orientation?

- a. Heterosexual or straight
- b. Homosexual, gay, or lesbian
- c. Bisexual
- d. Not sure/questioning

8. Marital Status

What is your current marital status?

- a. Married to a male
- b. Married to a female
- c. Not married, but living together with a male partner
- d. Not married, but living together with a female partner
- e. Widowed
- f. Divorced
- g. Separated, because you and your partner are not getting along
- h. Never been married

9. Education

What is the highest level of education you have completed?

- a. Less than high school
- b. High school/GED
- c. Some college
- d. 2-year college degree
- e. 4-year college degree
- f. Master's degree
- g. Doctoral Degree
- h. Professional Degree (JD, MD)

10. Health Insurance

Which type of health insurance do you have? (Check all that apply.)

- a. No insurance (self-pay for all healthcare costs)
- b. Private insurance (ex. Blue Cross, Aetna, United Health Care, etc.)
- c. Public insurance (ex. Medicaid, Medicare, etc.)
- d. Military or Veterans Administration
- e. Student Health Insurance
- f. Other (fill in the blank)
- g. Unsure

Part 3

11. Weight

What is your weight (in pounds)? (Enter numeric value.)

12. Height

What is your height in feet and inches? (Enter numeric value.)

13. Medical History

Below is a list of common medical conditions. Have you EVER had any of the conditions listed below? Choose yes or no.

1. Diabetes? Yes/No
2. High blood pressure or hypertension? Yes/No
3. High cholesterol? Yes/No
4. Heart disease? Yes/No
5. Thyroid problems? Yes/No
6. Infertility? Yes/No
7. Endometriosis? Yes/No
8. Migraines? Yes/No
9. Depression? Yes/No
10. Anxiety? Yes/No

14. Children

Do you have biological children?

- a. Yes
- b. No

Are you currently trying to conceive?

- a. Yes
- b. No

15. Length of PCOS Diagnosis

You previously indicated that a medical provider diagnosed you with PCOS. How old were you at the time of diagnosis? (Enter age in years)

Appendix B. The Polycystic Ovary Syndrome Questionnaire (PCOSQ)

To what extent have you felt that growth of visible hair on your chin has been a problem for you during the last two weeks:							
	A severe problem	A major problem	A moderate problem	Some Problem	A Little problem	Hardly any problem	No problem
1. Growth of visible hair on chin?							
During the past two weeks, how much of the time have you felt:							
	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	Hardly any of the time	None of the time
2. Depressed as a result of having PCOS?							
3. Concerned about being overweight?							
4. Easily tired?							
5. Concerned with infertility problems?							
6. Moody as a result of having PCOS?							
In relation to your last menstruation, how much were the following issues a problem for you:							
	A severe problem	A major problem	A moderate problem	Some Problem	A Little problem	Hardly any problem	No problem
7. Headache?							
8. Irregular menstrual periods?							
To what extent has growth of visible hair on your upper lip been a problem for you during the last two weeks?							
	A severe problem	A major problem	A moderate problem	Some Problem	A Little problem	Hardly any problem	No problem
9. Growth of visible hair on							

upper lip?							
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During the past two weeks, how much of the time have you:

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	Hardly any of the time	None of the time
10. Had trouble dealing with your weight?							
11. Had low self-esteem as a result of your having PCOS?							
12. Felt frustration in trying to lose weight?							
13. Felt afraid of not being able to have children?							
14. Felt frightened of getting cancer?							

Over the last two weeks, to what extent have the following issues been a problem for you:

	A severe problem	A major problem	A moderate problem	Some Problem	A Little problem	Hardly any problem	No problem
15. Growth of visible hair on your face?							
16. Embarrassment about excess body hair?							

During the past two weeks, how much of the time have you been:

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	Hardly any of the time	None of the time
17. Worried about having PCOS?							

18. Self-conscious as a result of having PCOS?							
In relation to your last menstruation, how much were the following issues a problem for you?							
	A severe problem	A major problem	A moderate problem	Some Problem	A Little problem	Hardly any problem	No problem
19. Abdominal pain?							
20. Late menstrual period?							
21. Menstrual cramps?							
How much of the time during the last two weeks did you:							
	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	Hardly any of the time	None of the time
22. Feel like you are not sexy because of being overweight?							
23. Feel a lack of control over the situation with PCOS?							
24. Have difficulties staying at your ideal weight?							
25. Feel sad because of infertility problems?							
To what extent has growth of visible body hair been a problem for you during the <u>last two weeks</u>:							
	A severe problem	A major problem	A moderate problem	Some Problem	A Little problem	Hardly any problem	No problem
26. Growth of visible body hair?							

(Guyatt et al., 2004)

Appendix C. The Short Form-36 (SF-36)

Survey Question	Answer Choices (Item Score)	HRQoL Domain	Summary Measure
1. In general, would you say your health is:	1. Excellent (100) 2. Very good (75) 3. Good (50) 4. Fair (25) 5. Poor (0)	General Health (GH)	Physical Health
2. Compared to one year ago , how would you rate your health in general now ?	1. Much better now than one year ago (100) 2. Somewhat better now than one year ago (75) 3. About the same (50) 4. Somewhat worse now than one year ago (25) 5. Much worse now than one year ago (0)	N/A	N/A
The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?			
3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1. Yes, limited a lot (0) 2. Yes, limited a little (50) 3. No, not limited at all (100)	Physical Functioning (FP)	Physical Health
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf			
5. Lifting or carrying groceries			
6. Climbing several flights of stairs			
7. Climbing one flight of stairs			
8. Bending, kneeling, or stopping			
9. Walking more than a mile			
10. Walking several blocks			
11. Walking one block			
12. Bathing or dressing yourself			

During the past 4 weeks , have you had any of the following problems with your work or other regular daily activities as a result of your physical health ?			
13. Cut down the amount of time you spent on work or other activities	1. Yes (0) 2. No (100)	Role-Physical (RP)	Physical Health
14. Accomplished less than you would like			
15. Were limited in the kind of work or other activities			
16. Had difficulty performing the work or other activities (for example, it took extra effort)			
During the past 4 weeks , have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?			
17. Cut down the amount of time you spent on work or other activities	1. Yes (0) 2. No (100)	Role-Emotional (RE)	Mental Health
18. Accomplished less than you would like			
19. Didn't do work or other activities as carefully as usual			
20. During the past 4 weeks , to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?	1. Not at all (100) 2. Slightly (75) 3. Moderately (50) 4. Quite a bit (25) 5. Extremely (0)	Social Functioning (SF)	Mental Health
21. How much bodily pain have you had during the past 4 weeks ?	1. None (100) 2. Very mild (80) 3. Mild (60) 4. Moderate (40) 5. Severe (20) 6. Very severe (0)	Bodily Pain (BP)	Physical Health

22. During the past 4 weeks , how much did pain interfere with your normal work (including both work outside the home and housework)?	<ol style="list-style-type: none"> 1. Not at all (100) 2. A little bit (75) 3. Moderately (50) 4. Quite a bit (25) 5. Extremely (0) 	Bodily Pain (BP)	Physical Health
<p>These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give one answer that comes closest to the way you have been feeling.</p> <p>How much of the time during the past 4 weeks...</p>			
23. Did you feel of pep?	<ol style="list-style-type: none"> 1. All of the time (100) 2. Most of the time (80) 3. A good bit of the time (60) 4. Some of the time (40) 5. A little of the time (20) 6. None of the time (0) 	Vitality (VT)	Mental Health
24. Have you been a very nervous person?	<ol style="list-style-type: none"> 1. All of the time (0) 2. Most of the time (20) 3. A good bit of the time (40) 4. Some of the time (60) 5. A little of the time (80) 6. None of the time (100) 	Mental health (MH)	Mental Health
25. Have you felt so down in the dumps that nothing could cheer you up?			
26. Have you felt calm and peaceful? (reverse score)			
27. Did you have a lot of energy?	<ol style="list-style-type: none"> 1. All of the time (100) 2. Most of the time (80) 3. A good bit of the time (60) 4. Some of the time (40) 5. A little of the time (20) 6. None of the time (0) 	Vitality (VT)	Mental Health
28. Have you felt downhearted and blue?	<ol style="list-style-type: none"> 1. All of the time (0) 2. Most of the time (20) 3. A good bit of the time (40) 4. Some of the time (60) 5. A little of the time (80) 6. None of the time (100) 	Mental health (MH)	Mental Health
29. Did you feel worn out?	<ol style="list-style-type: none"> 1. All of the time (0) 2. Most of the time (20) 3. A good bit of the time (40) 4. Some of the time (60) 	Vitality (VT)	Mental Health

	5. A little of the time (80) 6. None of the time (100)		
30. Have you been a happy person?	1. All of the time (100) 2. Most of the time (80) 3. A good bit of the time (60) 4. Some of the time (40) 5. A little of the time (20) 6. None of the time (0)	Mental health (MH)	Mental Health
31. Did you feel tired?	1. All of the time (0) 2. Most of the time (20) 3. A good bit of the time (40) 4. Some of the time (60) 5. A little of the time (80) 6. None of the time (100)	Vitality (VT)	Mental Health
32. During the past 4 weeks , how much of the time has your physical health or emotional problems interfered with your social activities (like visiting your friends, relatives, etc.)?	1. All of the time (0) 2. Most of the time (25) 3. Some of the time (50) 4. A little of the time (75) 5. None of the time (100)	Social Functioning (SF)	Mental health
How true or false is each of the following statements to you:			
33. I seem to get sick a little easier than other people	1. Definitely true (0) 2. Mostly true (25) 3. Don't know (50) 4. Mostly false (75) 5. Definitely false (100)	General Health (GH)	Physical Health
34. I am healthy as anybody I know (reverse scoring)			
35. I expect my health to get worse			
36. My health is excellent (reverse scoring)			

(Ware & Sherbourne, 1992)

Appendix D. Sample Interview Guide Based on the Common-Sense Model (CSM) of Self-Regulation of Health & Illness

Hi! Thank you for taking the time to talk to me today. My name is Elizabeth Baker, and I am a PhD student at the University of South Florida. Right now, I am conducting my dissertation research where I'm asking women who have been diagnosed with polycystic ovary syndrome or PCOS to tell me about their experience with the syndrome. Although I am a woman living with PCOS, I understand that everyone's experience is different, and I need other women like you to tell me about their experiences.

As a reminder, I will be recording this interview, but all the information you provide will be kept confidential. Is this still ok with you?

You can also skip any question you don't want to answer or stop the interview by letting me know that that's what you would like to do. I will never use your name or any identifying information when reporting the results of the interview, so no one will ever know your responses. In fact, if you'd like to use another name during the interview, we can do that. What would you like for me to call you while I am recording?

Do you have any questions before we begin?

Ok, then let's get started.

Tell me about polycystic ovary syndrome. How would you describe the syndrome to someone who had not heard of it?

Probes: Cognitive Representations

1. Identity
 - a. Could you describe any symptoms you have that are related to your PCOS?
2. Timeline
 - a. How long do you believe you have had PCOS?
 - b. How long do you think PCOS will affect you?
 - i. How do you think PCOS will affect you in the future? (Consequences)
3. Consequences
 - a. How do you think PCOS has affected your life?
 - b. What are the effects on your everyday life?
 - i. Prompts: work, socializing, everyday activities, relationships, family, friends, finances
4. Causes
 - a. What do you understand about the cause of your condition?

5. Control/Cure
 - a. How much control do you feel you have over PCOS?
 - b. What things do you do to deal with your PCOS symptoms?
 - i. What strategies have been successful?
 - ii. What strategies have failed?
 - c. What would make living with syndrome easier for you?
 - d. Do you think there will ever be a cure for PCOS? If yes, do you have any ideas what the cure might be?

Probes: Emotional Representations

6. What are your thoughts about having PCOS?
7. To what extent do you feel that your PCOS influences how you generally feel?

Probes: If woman reports history of infertility

8. On your survey, you indicated that you had a history of infertility. Tell me about that.
 - a. When were you diagnosed?
 - b. How were you diagnosed?

Probes: If woman reports history of infertility and having biological children

9. How have you addressed your fertility concerns?

Appendix E: Advantages and Disadvantages of Interview Techniques

Type of Interview	Characteristics	Strengths	Weaknesses
In-person	Interviewer and participant are in the same place at the same time (e.g. office)	Interviewer can record nonverbal cues that may indicate the importance of particular questions or topics to respondents;(Berg, 2009; Esterberg, 2002) Interviewer has more control over environment; Does not require participant to have a particular skill set which may be required for phone or internet interviewing;	Travel time and costs for participant or interviewer may be too long or too high, respectively, especially if both are not in the same geographical location; (Opdenakker, 2006) Participant may be less willing to discuss sensitive topics;(Opdenakker, 2006)
Phone			
Audio-only	Interviewer and participant communicate via phone and cannot see each other	Participant and interviewer do not accrue travel expenses; Time commitment is reduced without travel; Enables interviewer to interview populations that might be difficult to access; Does not require participant to have a particular skill set which may be required using other interview techniques; Participant may be more willing to discuss sensitive topics;(Opdenakker, 2006)	Interviewer cannot record nonverbal cues that may indicate the importance of particular questions or topics to respondents; Participant and interviewer must have phone; Phone connection may not be reliable; Participant may accrue additional costs based on their individual phone plan; Interviewer cannot control the environment in which the participant chooses to interview; Participant may be less willing to discuss sensitive topics;
Face-to-face	Interviewer and participant communicate via phone but are able to look at each other using video chat program (e.g. FaceTime or Skype)	Interviewer can record facial expression that may indicate the importance of particular questions or topics to respondents; Participant and interviewer do not accrue travel expenses; Time commitment is reduced without travel; Enables interviewer to interview populations that might be difficult to access; May allow interviewer to establish addition rapport with participants that may not be possible with traditional phone interviews;	Interviewer may not be able to observe all non-verbal cues; Participant and interviewer must have phone with video chat capabilities and both must know how to use such technologies; Technologies may not be reliable; Participant may accrue additional costs based on their individual phone plan; Interviewer cannot control the environment in which the participant chooses to interview;
Text messaging	Instantaneous transmission of text-based messages from sender to receiver	Participant and interviewer do not accrue travel expenses; Time commitment is reduced without travel; Enables interviewer to interview populations that might be difficult to access; May be appealing to younger participants who use text messaging as a primarily way of communicating;	Participant must know how to read and write; Participant must have a phone with texting capabilities and must know how to use such technologies; Technologies may not be reliable; Participant may accrue additional costs based on their individual phone plan; Interviewer cannot record nonverbal cues that may indicate the importance of particular questions or topics to respondents; Interviewer and participant cannot clue in to verbal cues such as tone which may lead to a misunderstanding between parties;

Internet	Face-to-face	Interviewer and participant communicate via internet but are able to look at each other using video chat program (e.g. FaceTime or Skype)	Interviewer can record facial expression that may indicate the importance of particular questions or topics to respondents;(Berg, 2009; Esterberg, 2002) Participant and interviewer do not accrue travel expenses; Time commitment is reduced without travel; Enables interviewer to interview populations that might be difficult to access; May allow interviewer to establish addition rapport with participants that may not be possible otherwise;	May be significant time delay between question and answer;(Opdenakker, 2006) Concentration of the interviewer and the participant may be decreased; Interviewer may not be able to observe all non-verbal cues; Participant and interviewer must have internet access and video chat capabilities and both must know how to use such technologies; Technologies may not be reliable; Interviewer cannot control the environment in which the participant chooses to interview;
Instant Messaging	Instantaneous transmission of text-based messages from sender to receiver (e.g. Facebook messenger)	Participant and interviewer do not accrue travel expenses; Time commitment is reduced without travel; Enables interviewer to interview populations that might be difficult to access;	Interviewer cannot record nonverbal cues that may indicate the importance of particular questions or topics to respondents; May be significant time delay between question and answer;(Opdenakker, 2006) Participant must know how to read and write; Participant must have internet access and instant messaging software and know how to use such software; Technologies may not be reliable; Interviewer cannot record nonverbal cues that may indicate the importance of particular questions or topics to respondents; Interviewer and participant cannot clue in to verbal cues such as tone which may lead to a misunderstanding between parties; May be significant time delay between question and answer;(Opdenakker, 2006) Concentration of the interviewer and the participant may be decreased;	

Note: Only synchronous communication activities in time and/or space are outlined above. Specifically, emailing as an interview technique has been omitted as it does not allow for the interview to remain fairly conversational, which is desired in a semi-structured interview.(P. R. Ulin et al., 2005)

Appendix F: Institutional Review Board Approval



RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

7/31/2013

Elizabeth Baker, M.P.H.
Community and Family Health
The Lawton & Rhea Chiles Center, University of South Florida
3111 E. Fletcher Avenue, MDC 100, 2nd floor
Tampa, FL 33613-4660

RE: **Expedited Approval for Initial Review**
IRB#: Pro00012873
Title: Experiences of Women Living with Polycystic Ovary Syndrome (PCOS)
Study Approval Period: 7/31/2013 to 7/31/2014

Dear Ms. Baker:

On 7/31/2013, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents outlined below.

Approved Item(s):

Protocol Document(s):

[Approved Dissertation Proposal](#)

Consent/Assent Document(s):

[Interview Consent Document](#)

[Survey Consent Document](#)

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your study qualifies for a waiver of the requirements for the documentation of informed consent as outlined in the federal regulations at 45CFR46.117(c) which states that an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in cursive script that reads "John A. Schinka, Ph.D.".

John Schinka, Ph.D., Chairperson
USF Institutional Review Board