

Exploring the Experiential Journey of Women with PCOS Across the Lifespan: A Qualitative Inquiry

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Introduction: Peri-postmenopausal women with the chronic condition polycystic ovary syndrome (PCOS) remain at cardiometabolic risk and/or subsist with established comorbidity while continuing to manage persistent PCOS signs and symptoms, such as hirsutism. Thus, PCOS transcends the reproductive years, yet there is sparse scientific literature on the peri-postmenopausal years of women with PCOS.

Purpose: To explore how peri-postmenopausal women's perceptions about PCOS have changed over the lifespan since their PCOS diagnosis.

Methods: A cross-sectional survey with one qualitative question was conducted via Research Electronic Data Capture (REDCap) among women with PCOS aged ≥ 43 years, who were all recruited from PCOS-specific Facebook pages. Of the 107 women completing the survey, 72 substantively answered the qualitative question. The qualitative responses were analyzed using the steps of reflexive thematic analysis. Themes were interpreted and discussed through the lens of the bioecological conceptual model.

Results: Respondents were 47.6 (± 4.1) years of age, primarily White (87.5%), employed full time (65.3%), and married (75%) with children (68%). Four overall themes were identified: 1) dismissal 2) information desert, 3) PCOS experience over the lifespan, and 4) mindset.

Conclusion: The study findings illustrated the unique healthcare needs among peri-postmenopausal women with PCOS. Further research is needed to further explore their healthcare concerns and psychosocial needs followed by studies that develop and assess interventions that promote symptom and adaptive coping strategies across their lifespan.

Keywords: polycystic ovary syndrome, systems theory, life course, women's health

Introduction

Polycystic ovary syndrome (PCOS) is a complex, heterogenous collection of signs and symptoms attributed to hormonal dysregulation¹ affecting one in five women globally across all races and ethnicities.² Prevalent PCOS clinical features include visceral obesity, dyslipidemia, and insulin resistance, which each increases risk for cardiometabolic diseases^{3,4} and reproductive cancers,¹ and negatively impact health-related quality-of-life (HRQoL).⁵ PCOS is also associated with psychological morbidity, as women with PCOS are 3–8 times more likely than women without PCOS to have depressive symptoms⁶ and seven times more likely to attempt suicide.⁷

As a chronic condition, PCOS transcends the reproductive years. Peri-postmenopausal women with PCOS have a higher prevalence of visceral obesity, insulin resistance, and elevated triglycerides as compared to age-matched women without PCOS.⁸ Additionally, hyperandrogenism, a defining diagnostic criterion of PCOS, persists over the lifespan, promoting these risk factors while perpetuating undesirable signs such as hirsutism (excess male-pattern hair growth) and alopecia (male-pattern balding).⁹ Thus, peri-postmenopausal women remain at cardiometabolic risk and/or subsist with established comorbidity while continuing to manage persistent PCOS signs and symptoms.

Biological and social health determinants change across a woman's lifespan, and gender and age inequalities increase women's exposure and vulnerability to the risk of preventable illness. Health system inadequacies and limited access to relevant health information further increase health risk in women with PCOS.¹⁰ There are approximately 20 articles about peri-postmenopausal women with PCOS compared to the >2500 articles identified about premenopausal women

with PCOS. Research is needed to understand peri-postmenopausal women's perspectives about their PCOS experiences and healthcare needs as they age. This knowledge will inform both future research and patient-centered care for older women with PCOS. Thus, the purpose of this study was to explore how peri-postmenopausal women's perceptions about PCOS have changed over time since their PCOS diagnosis.

Conceptual Model

Proposed by Urie Bronfenbrenner and Stephen J. Ceci (1994), the bioecological conceptual model provides a holistic approach to assessing human development.¹¹ While early iterations of this model detailed an ecological systems theory of child development,¹² the bioecological model can be applied more broadly to human development and includes the concept of time (ie, chronosystem) as an important influence on change among people and environments. Generally, the bioecological perspective includes person, process, context, and time (PPCT) elements affecting human development. Processes involve development via progressively more complex reciprocal interactions between an active, evolving individual with unique biopsychosocial characteristics and all entities in the individual's immediate external environment. Person characteristics are categorized as force (dispositional), resource (assets and liabilities), or demand (attributes which trigger or inhibit reactions from an environment responsible for adaptive processes). Context involves five interconnected systems: microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The microsystem describes environments such as home, church, or community. Mesosystems are intersections of the relationships and settings of microsystems. The exosystem describes events that exert important, indirect influence on development (eg, social media, insurance guidelines). The macrosystem includes shared belief systems, such as cultural values, societal norms, and economic conditions. The chronosystem describes historical circumstances that affect contexts at all other levels and includes microtime (specific episodes), mesotime (frequency of those episodes), and macrotime (changes in the wider society).¹¹

Materials and Methods

Study Design and Participants

A cross-sectional online survey was conducted among peri-postmenopausal women with PCOS aged ≥ 43 years that included one qualitative question (see *Measures*). For this study, we performed qualitative thematic analysis of the responses to the qualitative question. As most PCOS researchers define reproductive-age as 18–42 years and acknowledging that most women with PCOS experience delayed menopause, we selected 43 years as the starting point for peri-post menopause. Perimenopause was defined as deviation from normal menstrual cycle pattern and menopause was defined as one year with a menstrual cycle.¹³ The study respondents were recruited from two PCOS-specific Facebook groups: *PCOS Support Group* (21,200 members) and *PCOS Diet Support* (18,000 members). Members of each Facebook page were required to apply for membership, which helped to protect against robotic responses. To gain the privilege of posting a research link, the PI contacted the administrators of each group to explain the study and address any concerns. The administrators then posted the survey link on the message board allowing members to access the survey. If eligible, women were invited to complete an internet-based survey using Research Electronic Data Capture (REDCap).

Research Ethics and Consent

The study was conducted in accordance with the principles stated in the Declaration of Helsinki. In accordance with 45 CFR 46.104(d)(2) and 45 CFR 46.111(a)(7), the University of South Carolina Institutional Review Board provided an "exempt" status for the study (Pro00118636; 2/11/2022) because the research involved surveys in a manner that the identity of respondents could not be readily ascertained. According to federal guidelines, the IRB waived the requirement for written informed consent because the consent document would have been the only recording linking the participant and because research increasing the risk of breach of confidentiality and the research posed no harm to participants. The electronic survey link led potential participants to a webpage that provided additional details about the study and prompted the women to make an informed and voluntary decision to participate. Participants were informed that responses to the question could be anonymously publicized and selecting "begin" and completing the survey constituted

implied consent. The Completely Automated Public Turing test to tell Computers and Humans Apart (CAPTCHA) was used to minimize false respondents. Participants had the option to enter a drawing to win one of four US \$50 gift cards.

Measures

Demographics

The demographic questionnaire included age, race, geographic location, educational attainment, employment and insurance status, marital status, number of children, comorbidities, and menstrual history.

Qualitative Question

The qualitative portion of the survey involved one open-ended question: “How have your thoughts about PCOS changed since you were diagnosed to now?”. This question was created through the lens of the bioecological conceptual model, which posits that human development occurs through progressively more complex reciprocal interactions with one’s biopsychosocial characteristics, the environment, and social contexts over time. Time is crucial as evolving life stages adapt to the continuities and changes of the historical period in which a person lives. The qualitative question was posed by the primary author (PJW), a doctorally prepared female nurse scientist with several years of experience recruiting and working with women with PCOS. The question was not pilot tested. There was no follow-up with respondents, as respondents’ answers were anonymous. Thus, the respondents had no prior relationship with the research team. However, the informed consent language prior to the survey identified the research study’s principal investigator and primary author along with her credentials, vocation, and experience.

Data Collection and Management

Of the 107 respondents who completed the survey in two months, 72 provided substantive answers to the open-ended question. Substantive was defined as an answer that provided meaningful information, aside from a “yes” or “no” (n=16) or blank responses (n = 19). Written responses were collected and managed using REDCap hosted at the University of South Carolina. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources.¹³ REDCap is used by over 2.1 million researchers in 145 countries and has been cited in approximately 19,000 journal articles.¹⁴ REDCap can be used for many types of data collection, including online qualitative and/or quantitative surveys and clinical trials research.¹⁴

Data Analysis

Substantive answers were extracted from the dataset. The research team reviewed all responses for volume of content and potential for data saturation. Using the steps of reflexive thematic analysis,¹⁵ the three researchers (PJW, RMD, CFC) independently coded the responses and then collaboratively discussed codes and emerging themes. The research team discussed data saturation and unanimously agreed that data saturation had been reached. Subsequently, an iterative categorization process was followed to draw connections between the codes. The categories were organized into sub-themes and themes. At consensus, the themes were defined and named and then viewed through the lens of bioecological conceptual model. The conceptual model was used to illustrate the connections between themes and the evolution of the PCOS journey over a woman’s lifespan. Rigor was strengthened through the reflexivity of the three researchers via regular meetings to discuss personal experiences and knowledge of PCOS and a woman’s life course.¹⁶ Continuous reassessment and reiteration of coding further strengthened rigor, as did following the Consolidated Criteria for Reporting Qualitative Research (COREQ).¹⁷ The COREQ guidelines also enabled explicit and comprehensive reporting of the findings. See [Supplementary Material](#). The data that support the findings of this study are available for view at <https://osf.io/654kr/>.

Results

The respondents were 47.6 (± 4.1) years of age, primarily White (87.5%), educated, employed full-time (65.3%), and married (75%) with children (68%). Approximately 68% of the respondents reported having one or more comorbid conditions(s) (Table 1).

Table 1 Demographic and Health-Related Characteristics of Peri-Post Menopausal Women with PCOS Aged ≥ 43 Answering the Qualitative Question (n = 72)

Characteristics	#	%
Race		
African American/Black	3	4.2
Am Indian/Native Am	3	4.2
Asian	0	0.0
Latino	1	1.3
MidEastern/N African	0	0.0
White	63	87.5
Mix of Two	2	2.8
Prefer Not to Answer	0	0.0
Educational Attainment		
Some High School	1	1.4
High School or GED	5	6.9
Some College	20	27.8
Bachelors	24	33.3
Masters	20	27.8
Doctorate	2	2.8
Prefer Not to Answer	0	0.0
Employment Status		
Not Working	10	13.9
Part-Time	15	20.8
Full-Time	47	65.3
Prefer Not to Answer	0	0.0
Medical Insurance		
Yes	66	91.7
No	5	6.9
Prefer Not to Answer	1	1.4
Marital Status		
Single	6	8.3
Married/Partnership	54	75.0
Divorced	10	13.9
Widowed	1	1.4
Prefer Not to Answer	1	1.4

(Continued)

Table 1 (Continued).

Characteristics	#	%
# Children		
0	12	16.7
1–2	42	58.3
3–4	17	23.6
≥5	1	1.4
Prefer Not to Answer	0	0.0
# Comorbid Conditions		
0	23	31.9
1–2	37	51.4
3–4	9	12.5
≥5	3	4.2

Demographic and Health-Related Characteristics of Peri-Post Menopausal Women with PCOS Aged ≥43 Answering the Qualitative Question (n = 72)

Four overall themes were identified: 1) dismissal, 2) information desert, 3) PCOS experience over the lifespan, and 4) mindset. Quotes illuminating the themes are presented as written by the survey respondents without any editorial changes.

Dismissal: “I Knew Nothing When I Was Diagnosed, Told Go Away Lose Weight Come Back When You Want to Get Pregnant”

Dismissal, the act of treating someone or something as unworthy of serious consideration,¹⁸ was reported by many of the women. The respondents described being dismissed by healthcare providers when initially seeking medical advice for PCOS symptoms such as menstrual irregularity and hirsutism.

I went to several doctors before being diagnosed, and that was later in life (late 20s). In hindsight, I had symptoms at age 10–12.

I was diagnosed in 1984. And basically was told to deal with it.

Several of the women recounted how certain PCOS symptoms were dismissed because their reported symptoms did not involve reproductive concerns.

I was told not to worry about excess hair growth until it was time to have children.

Peri-postmenopausal women described a continuation of persistent symptoms (eg, hirsutism) and the presence of comorbidity (eg, type 2 diabetes, depression), yet with even less attention from healthcare providers.

... still nothing for me.

I am disappointed I haven't been able to figure out better solutions to my health issues that seem to get more complicated as I age

More frustrated with the diagnosis as I got older

Yes. It's more than just a little infertility trouble. They were wrong.

The feeling of dismissal by healthcare providers resulted in distrust of traditional medicine.

I believe birth control caused this. I believe depo birth control is another form of population control.

Discouraged by lack of solid treatment plans. Not interested in a band-aid approach using drugs to cover symptoms. I want to learn what is really broken

In addition to feeling dismissed by healthcare providers at diagnosis and over the life course, the respondents also described feeling dismissed by society in general.

Nothing has really changed except there are more advocates.

I want PCOS on the free drug list

Information Desert: “Nothing Has Changed. Still No Answers No Help”

Many of the respondents commented on the lack of PCOS information at the time of their diagnosis and especially during the peri-postmenopausal years. As a “food desert” describes populated urban areas where residents do not have access to an affordable and healthy diet,¹⁹ the authors chose “information desert” to represent the limited access to unbiased, evidence-based healthcare and lifestyle information for women with PCOS.

I was told I had Stein-Leventhal Syndrome when I was 16. I was never given an explanation or offered any treatment. Nothing has changed.

no one knows anything about it.

... it's hard to find information because everything is about fertility.

While several articles explore the dissatisfaction with healthcare information from providers among younger women with PCOS,^{20–23} there are no studies examining the availability or satisfaction of medical information during the peri-postmenopausal years of women with PCOS.

More confused now than ever.

now closer to menopause - I feel there is even less info on how to help women at my age.

Consequently, many of the respondents reported the need to seek information through alternative sources and become more self-reliant.

I know more now, but only because of my own research.

In their self-search for answers, the women found more information about complementary medicine, prompting a switch from more traditional medicine.

At first I thought western medicine could help me and it did not. I gave up on western medicine and found a good naturopath.

Discouraged by lack of solid treatment plans. Not interested in a band-aid approach using drugs to cover symptoms. I want to learn what is really broken and explore more natural solutions.

Some other women felt that the information desert and traditional medical treatments were forms of governmental control.

The FDA pulled HCG off the market and I have since gained back 100lbs! They don't want us to know anything or to be better.

PCOS Experience Over the Lifespan: “I Often Think if Only I Knew Then What I Know Now”

As a chronic health condition, PCOS confers physical, psychological, and social sequela that may worsen with age and/or become more prioritized with age. Subfertility was a major concern during the reproductive years. As women surpassed these years, they were more concerned with risk factors for chronic comorbidities and other PCOS implications.

I'm no longer focused on the reproductive implications - realizing that this is a life-long concern.

From infertility to weight and health worries. There's no stop to it.

Physical

With age, health priorities shifted. Women discussed PCOS issues such as hyperandrogenism as evident by male patterned hair growth and obesity, as well as age-specific concerns such as menopause.

Now my main concerns are managing or preventing chronic illnesses, as well as PMDD and perimenopause symptoms.

so infertility is no longer an issue but worried about the possibility of heart disease or diabetes due to it.

I know now how hard it is to lose weight, it's even more so now that im older

Now, I want to lose weight and excess facial hair.

Psychological

Psychological issues do not stop after the reproductive years, nor the experience of living with anxiety and/or depression in those younger years.

this disease has ruined my life and made me question my sanity.

I find it very stressful

... caused horrible mental health problems in me.

Social

Societal expectations of women include having and raising children. Many of the respondents expressed this through statements of relief that they successfully conceived and produced children.

There's a lot less pressure. I had my babies.

I was one of the lucky ones. I have 5 kids.

Fortunate to have 2 children (1 with meds 1 without).

Mindset: "I Have Come to Terms with It"

Mindset can influence health behaviors and outcomes. Mindsets oriented toward health enabled individuals to have the motivation to pursue health, as they understand it in their cultural contexts.²⁴ Most of the respondents fell into two categories of mindset: resignation or positive reframing.

Resignation

Resignation is the acceptance of something undesirable but inevitable

I accept that it is something I have to live with

I have come to terms with it but wish I didn't have it.

I am accepting of PCOS; I've accepted it.

Positive Reframing

Positive reframing is an appraisal of a negative or challenging situation from a more favorable perspective.²⁵

I accept that it is something I have to live with and I can still live a full and healthy life with PCOS.

Anyhow, I live a good life,

I can still live a full and healthy life with PCOS

Optimistic state of mind important to deal with it

Discussion

PCOS is a chronic condition with impact on a woman's life course. The purpose of this study was to explore the PCOS experience among peri-postmenopausal women, elicit emerging themes, and view the themes through the lens of the bioecological conceptual model as described by Bronfenbrenner and Ceci (1994).¹¹ The data revealed four themes: 1) dismissal, 2) information desert, 3) PCOS experience across the lifespan, and 4) mindset. These themes were consistent with the bioecological conceptual model, as all five systems were represented.

Dismissal

Perceptions of dismissal from healthcare providers is a well-established sentiment among women of reproductive age with PCOS and documented in several research studies. For example, in a large, international cross sectional study of 1550 respondents with PCOS, nearly 50% of the respondents visited three or more health care providers over five years before a PCOS diagnosis was established and for one-third, this took >2 years.²¹ In a similar study conducted in Canada, the mean length of time to diagnosis was 4.5 years after at least four consultations with various health care providers.²⁶ In these two studies and others, provider interactions were described as dismissive,^{21,23,26,27} curt, inattentive, rushed,²⁸ and disparaging due to lack of empathy and poor temperament²⁹ creating a sense of frustration and dissatisfaction.³⁰

All studies to date about perceived dismissal from health care providers involved women with PCOS of reproductive age (18–43 years). However, this study included peri-postmenopausal (≥ 43 years) women with PCOS and found perpetuation of perceived dismissal. Most of the women reported dismissal of their PCOS symptoms (eg, hirsutism, weight gain) and PCOS-related comorbidities before and after their reproductive years, and even more so during the menopausal years. Women felt seen and heard only during the reproductive years, which reinforced the ideology of a pronatalist society among women with a high prevalence of infertility, subfertility, and miscarriages. After the reproductive period, women report a sense of invisibility as a woman, especially as they age and enter the menopausal transition.³¹ Females feel less seen starting during the teen years with stigma-related stress due to appearance (eg, hirsutism, weight gain),^{23,30,32} which continues as women age into gendered ageism born within a sociocultural context valuing youth, beauty, and vitality.^{31,33} As such, women with PCOS face self-, public-, and institutional stigma, which all have independent and interacting negative impact on mental health at all ages.³⁴ This is consistent with a cross-sectional comparative study between women with PCOS aged 18–42 years ($n = 935$) and women with PCOS aged ≥ 43 years ($n = 109$) that found moderate to high depressive symptomology among older women with PCOS undeterred by increased resources and coping strategies.³⁵

Information Desert

Along with perceived dismissal, many women in this study reported limited or outdated information from their health care providers. This is consistent with the literature in which younger women with PCOS described either a lack of education about PCOS and its long-term complications²¹ or conflicting information about treatments and future expectations.²⁰ In fact, gaps in knowledge in physicians regarding the diagnosis and management of PCOS have been reported.^{36,37} An international survey of obstetricians and gynecologists and reproductive endocrinologists ($n=630$) revealed that 27.7% did not know which diagnostic criteria to use, 68.3% were confused about PCOS clinical features and comorbidities, and approximately 46.5% did not recommend lifestyle modification.³⁸ In a similar study about knowledge of menopause among gynecologists and primary care physicians ($n=145$), only 66% self-reported a moderate level of knowledge.³⁹ In a survey involving senior residents ($n=510$) in US obstetrics and gynecology residency programs, only 20.8% of the residents reported a formal menopause learning module.⁴⁰ Consequently, it can be assumed that even less is understood about the menopausal transition among women with PCOS.

In the absence of health information about PCOS, women with PCOS have reported mistrust in healthcare.^{28,29} Many respondents to the current survey described searching the internet for answers, only to find information about PCOS and fertility with very little to no resources for the peri-postmenopausal woman with persistent PCOS symptoms and

comorbidity. Whereas the self-directed quest for information demonstrates a strong sense of agency and self-efficacy, it can produce both positive and negative outcomes. In general, the quality of online health information has been considered suspect given unreliable sites, simplified information, and limited digital and health literacy of the user.⁴⁰ However, as found in this study, many women learn about naturopathy, an alternative style of medicine with a long list of complementary therapies ranging from vitamin and mineral supplementation to yoga to lifestyle behaviors such as physical activity. While the preliminary data for the potential utility of complementary therapies to provide PCOS symptom management is promising, uncertainty remains due to study limitations and heterogeneity among sociodemographic characteristics within and across study populations.⁴¹ Lastly, in a few people, exposure to social media along with certain psychological, social, and political predispositions can lead to non-normative conspiracy beliefs,⁴² such as population-control mentioned in this study.

PCOS Experience Over the Lifespan

As women transitioned from the reproductive years, their priorities shifted from concerns about fertility to concerns about the menopausal transition and comorbidities (eg, diabetes). This is consistent with the tenet of agency described in the feminist poststructuralist framework, a tenet that posits women in midlife focus on personal needs and desires, thus exertion of agency.⁴³ However, PCOS maintained an unwelcome and persistent presence of physical reminders such as visceral obesity, hirsutism, and alopecia.⁹ Although studies about the natural history of peri-postmenopausal PCOS phenotypes are limited, it is known that androgen levels remain either above normal range or on the upper end of normal, while estrogen levels plummet.⁸ Also, women with PCOS have a higher ovarian follicle count and volume than women without PCOS, which prolongs menopause for women with PCOS by one to two years.⁴⁴ Implied is that women with PCOS also struggle longer with the physiological symptoms of menopause including vasomotor symptoms (eg, hot flashes, night sweats), sexual dysfunction, and mood changes.⁸

There is no data examining the prevalence of mood disorders among peri-postmenopausal women with PCOS. However, Helvaci and Yildiz (2020) hypothesized that based on the general population of women, the risk of depression and anxiety may decrease during the menopausal transition for women with PCOS.⁴⁵ Data from one of our studies is contrary to this assumption, as many of the women indicated worsened symptoms of depression.³⁵ We compared HRQoL and depressive symptoms among peri-postmenopausal women with PCOS aged ≥ 43 years relative to premenopausal women with PCOS aged 18–42 years. The main finding of this study was that HRQoL among women with PCOS seems to improve with age, yet depressive symptoms remained high. Older women with PCOS may have developed coping strategies over time, however new concerns, such as aging and menopause, further disrupted psychological homeostasis.²⁴ Also not known is the prevalence of women with PCOS and a mood disorder who seek treatment and the prevalence of women with PCOS dealing with loss via one or more miscarriages.

Study findings however also indicate that peri- postmenopausal women with PCOS expressed relief from socio-cultural expectations, especially when they successfully achieved motherhood. According to Kitzinger and Willmott (2002), many women with PCOS earnestly strive to prove womanhood, especially if they defied the conventional societal standard of femininity.³² This is consistent with the literature, as motherhood is central to contemporary gendered expectations for women,⁴⁶ such that that childlessness appears aberrant.⁴⁷ Consequently, infertility has been experienced as guilt, inadequacy, and failure as a woman.⁴⁸

Mindset

Research about coping strategies among women with PCOS is limited, especially among peri-postmenopausal women with PCOS. However, sociological literature has richly described two basic coping strategies for living with a chronic health condition: active and passive.⁴⁸ Active coping is characterized by positive agency for self-management, whereas passive coping is typified as disengagement from self-management by relinquishing control to external forces.⁴⁹ Our findings were consistent with active and passive coping, as our respondents expressed either a mindset of positivity or one of resignation. Women with active coping strategies described consciously adopting a positive outlook through cognitive reframing.

In a cross-sectional study, women with PCOS aged 16–45 years from Germany (n=466) were surveyed to discern associations between active and passive coping, HRQoL, and emotional health.⁵⁰ Consistent with the literature at-large,⁵¹ mindset was significantly and linearly associated with HRQoL and emotional health, such that passive coping or resignation can predict the presence of compromised HRQoL, depressive symptoms, and anxiety.⁵⁰ In another cross-sectional study involving 183 women with PCOS aged 25–45 years, Simon and colleagues (2021) found significant levels of maladaptive coping surfaced attributed to social withdrawal due to intense body-image concerns about obesity and hirsutism (male-patterned hair growth).⁵² However, there is evidence that effective coping strategies are more likely when social patterns, such as education, employment, economic status, and resources improve as life course evolves.⁴⁹

PCOS Perception Changes Through the Lens of the Bioecological Conceptual Model

Microsystem

At the microsystem level, primary and specialty healthcare were emphasized by the respondents as a significant influence on early PCOS recognition, acceptance, and treatment. Perceived dismissal by healthcare practitioners evoked medical dissatisfaction and frustration. However, perceived dismissal also prompted some respondents to be self-reliant by examining PCOS causes, however, it persisted in affecting their mindset later in life. Unfortunately, the respondents reported that perceived dismissal by healthcare providers reoccurred during the menopausal transition.

Mesosystem

The mesosystem represents the interactions or relationships between microsystems, including integration of information, collaboration, and service.⁵³ At this level, the respondents reported medical distrust, as well as disregard as a woman, especially since information, collaboration, and service integration appeared only available if women with PCOS pursued fertility treatment.

Exosystem

The exosystem level includes external forces that affect the course of PCOS over the lifespan, such as policy and insurance. Certain medications and procedures deemed effective for PCOS symptom management, such as oral contraceptives and laser therapy, were not covered by insurance. The reason is that they are not seen as medically necessary for most women, that is, women without PCOS.

Macrosystem

At the macro-system level, cultural norms that influence a woman's development over her lifespan were implicated, especially since most respondents reported self-comparison to the conventional standard of beauty, whether younger or older, and any acknowledgement was during the younger, reproductive years if interested in having children.

Person and Process

Person and process was illustrated by the differing mindsets among peri-postmenopausal women given similar biopsychosocial factors and PCOS experiences over time. The different mindsets could be attributed to the intrinsic and available extrinsic resources.

Time

The respondents recounted the changes experienced now as peri-postmenopausal women compared to younger years when diagnosed with PCOS. The menopausal transition elicited many of the same feelings, frustrations, and concerns as did the PCOS diagnosis, given the lack of information, acknowledgement, and continuity of PCOS symptoms. Peri-postmenopausal women were also concerned about increased risk or established comorbidity, along with menopausal symptoms and long-term physiological changes. However, many respondents developed coping skills over time, and, using cognitive reframing, adopted a positive mindset.

Limitations and Strengths

One study limitation is that the respondents self-identified their age, PCOS diagnosis, and peri-postmenopausal status. Based on studies examining concordance between self-report and medical diagnoses, self-report has good concordance with electronic medical records and greater than 90% specificity for all medical diagnoses.^{54,55} Additionally, the Facebook sites used were specific to women with PCOS and required leaders' permission to join, which increased our confidence that we accessed a PCOS population.

The data analyzed, although rich and robust, was obtained from one open-ended question on an online survey, which was not pilot tested. As such, correct interpretation of the question by all respondents and response latency was unknown. The high response rate of 64% and the substantive answers increased confidence in the women's responses. Although the online, anonymous data collection method precluded an opportunity to ask follow-up questions, rigorous analytic methods were used by three experienced researchers, increasing confidence in the resultant themes.

Conclusion

PCOS is a chronic condition associated with several health risks and physical and psychological sequelae that transcend beyond the reproductive years. As the first study to explore the impact of PCOS over the life course, our findings add new knowledge to the sparse scientific literature about peri-postmenopausal women with polycystic ovary syndrome. The study findings also illustrate the unique healthcare needs among this population.

Overall, women with PCOS felt dismissed at the time of diagnosis and then again during the perimenopausal years. Women reported a lack of information from health care providers and via the internet about PCOS and menopause, and no information about menopause for women with PCOS. Women seem to relay their life experience as pre- and post-reproductive years, as childbirth was a defining moment, setting the stage for biopsychosocial adaptation in the future. In response, this sample of women adapted by adopting either a mindset of resignation or one of positivity through cognitive reframing. The identified themes aligned with the bioecological conceptual model, as the women developed over time (chronosystem) in response to the breadth of contextual systems (micro-, meso-, exo-, macro-) given the unique biopsychosocial dynamics of the PCOS experience (individual).

Further research is needed to explore the healthcare concerns and needs of peri-postmenopausal women with PCOS, including in-depth interviews that assess their psychosocial and emotional needs followed by studies that test potential interventions to promote maintenance of adaptive coping strategies across the lifespan. While not addressed in this study, additional research about biological and sociocultural influences on the health of women with PCOS are required to discover ways to reduce their risk of comorbid conditions (eg, type 2 diabetes, heart disease) and health disparities associated with such factors as healthcare access and stigma. Strategies to improve health care professionals' knowledge of PCOS and strengthen their abilities to deliver patient-centered care for women with PCOS are also necessary.

Abbreviations

CAPTCHA, The Completely Automated Public Turing test to tell Computers and Humans Apart; COREQ, Consolidated Criteria for Reporting Qualitative Research; HRQoL, Health Related Quality of Life; PCOS, Polycystic Ovary Syndrome; REDCap, Research Electronic Data Capture.

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Disclosure

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