

A life course perspective on polycystic ovary syndrome

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Abstract: Polycystic ovary syndrome (PCOS) is a major public health problem in the US. Worldwide, the public is largely unaware of the condition and health care providers do not seem to fully understand it. Research on PCOS has primarily focused on its etiology and clinical characteristics and less on the psychosocial aspects of human development associated with PCOS. This paper posits that a life course perspective provides a framework for further understanding the psychosocial experiences of women with PCOS and the contexts in which they live. The paper discusses how life course principles of human development, constraints on agency, interdependence of lives, time and place, and timing of events and experiences are relevant to the management of PCOS and prevention of its complications.

Keywords: polycystic ovary syndrome, psychosocial, mental health, multidisciplinary, life course, adolescence

Introduction

Polycystic ovary syndrome (PCOS) is a major public health problem referred to as one of the most common endocrine disorders in women of reproductive age, yet is a condition the public is largely unaware of and that health care providers do not seem to fully understand.¹ PCOS is characterized by a spectrum of symptoms, including irregular or no menstrual periods, excess hair growth on the face and body (hirsutism), weight gain, acne, ovarian cysts, and thinning of the hair on the scalp.¹ The short- and long-term health problems associated with PCOS are significant, and include obesity, type 2 diabetes,² cardiovascular disease, obstructive sleep apnea,³ complications during pregnancy,⁴ impaired fertility, and increased risk of endometrial cancer.⁵ Just as concerning is the fact that PCOS can be a stigmatizing condition⁶ that affects a woman's identity,^{6,7} mental health,⁸ and health-related quality of life,⁹⁻¹² all these aspects associated with PCOS have received less attention than the biomedical aspects of the condition.¹³

The prevalence of PCOS in adult women aged 18–45 years in the US is estimated to be 6.6%.¹⁴ However, research in community samples from other countries such as the UK has found the prevalence of PCOS to be higher depending on the diagnostic criteria used.¹⁵ National estimates regarding the prevalence, phenotypes, and morbidities associated with PCOS are limited due to lack of large-scale, ethnically diverse epidemiological studies on PCOS in the US.¹ The annual economic cost of treating women with PCOS is estimated to be over \$4 billion. This includes the costs of evaluating PCOS and treatments for PCOS-related menstrual problems, infertility, diabetes, and hirsutism.¹⁶ Although women with PCOS also experience mental health

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problems, such as depression and anxiety,⁸ provision and utilization of mental health care for PCOS-related problems remains poorly understood.

Given the high prevalence of PCOS, its short- and long-term effects on physical and mental health, and its costs to the health care system, one might wonder why there is such a lack of awareness about PCOS. This is in part because PCOS does not have the “celebrity” status of other well known conditions and because of its misleading name.¹⁷ The term “polycystic ovary syndrome” suggests the problem lies in the ovaries, whereas the presence of polycystic ovaries alone does not indicate a woman has PCOS.¹

In the US, research on PCOS is receiving increased attention. In December 2012, the National Institutes of Health Office of Disease Prevention held its first evidence-based methodology workshop on PCOS to shed light on several aspects of the condition and promote further relevant research. The workshop panel also made recommendations for advancing research and practice with regard to PCOS. One of the recommendations was to “establish multidisciplinary programs to improve public and health care provider awareness and management for women who currently have the syndrome”.¹ The workshop report and panel recommendations are available online (http://prevention.nih.gov/workshops/2012/pcos/docs/PCOS_Final_Statement.pdf).

Life course perspective and study of PCOS

This paper posits that a life course perspective can inform the study of the psychosocial aspects of human development associated with PCOS. Life course refers to the experiences of individuals over time from birth to death that are embedded in wider society.^{18–21} As people age, they do not simply undergo biological changes, they also experience a number of life events (eg, pregnancy), new roles (eg, as partners and parents), and transitions (eg, to parenthood) through different periods of life, including childhood, adolescence, adulthood, mid life, and old age. Over time, these experiences shape the trajectories of people’s lives.

There are five core principles of the life course perspective that underscore the importance of understanding people in multiple contexts over time, ie, a biopsychosocial and longitudinal perspective of human development, constraints on agency, interdependence of lives, time and place, and timing of events and experiences.^{18–21} These principles shed light on the biopsychosocial and longitudinal nature of PCOS, constraints on women’s agency to manage their health, the influence people have on each other’s health, how women’s bodies reflect

the social conditions they live in, and how the timing of events and experiences can disrupt roles and transitions in the life course. This paper discusses each of the five principles of a life course perspective and their relevance to the management of PCOS and prevention of its complications.

Longitudinal biopsychosocial perspective of human development

While PCOS has generally been framed as a condition affecting women of reproductive age, a growing body of research suggests that PCOS can affect development across the life span from utero to the post-reproductive years.^{22–24} Further, because PCOS is a heterogeneous condition, its symptoms and severity are variable,¹ and women’s experiences with PCOS can also vary across the life course. For example, amenorrhea (the absence of vaginal bleeding for at least 6 months) has been associated with sexarche (age of first intercourse) in youth and women with PCOS.²⁵ Additionally, stigma associated with PCOS-related hirsutism leads women to avoid activities that expose the body (eg, swimming) or involve social contact.²⁶ While there is research on the role of metabolic factors (eg, insulin resistance) in the development of the condition,²⁷ less is known about the psychosocial aspects of PCOS across the life course. A life course perspective emphasizes that a combination of biopsychosocial factors shape human development over time.^{18–21} This perspective is essential to understanding how PCOS can affect physical and mental health in each life stage, including in later life.

It is becoming increasingly clear that PCOS is associated with several aspects of mental health and psychological well-being, including mood (eg, depression and anxiety),^{28,29} eating disorders,^{28,30} self-esteem,²⁵ body dissatisfaction, and physical appearance.^{25,31} The comorbidity associated with depression is particularly alarming. For instance, depression has been associated with the metabolic (ie, insulin resistance)³² and hormonal (ie, levels of free testosterone)³³ aspects of PCOS. Women with PCOS are more likely to suffer from depression than women without PCOS,³⁴ and the severity of depressive symptoms tends to be higher in women with PCOS than in controls.²⁸ Further, anxiety is comorbid with depression^{28,29} and potentially underdiagnosed in women with PCOS.³⁵ In fact, women with PCOS tend to have higher levels of anxiety as well as higher median scores on symptoms such as poor sleep, worry about unimportant matters, phobias, and pain compared with controls (ie, women without PCOS matched for age, body weight, and body mass index).³⁶ Additionally, depression appears to be more likely among women with PCOS and infertility,³⁵ menstrual irregularities,³⁰ and binge

eating disorders.²⁸ Depression can also affect mental health in the long term, considering that women with PCOS tend to be at higher risk of a major depressive episode, recurrent depressive episodes, and suicide attempts.³⁰

Researchers also increasingly recognize the relevance of mental health and psychosocial factors in the behavioral (ie, lifestyle changes)³⁷ and therapeutic (ie, oral contraceptives, metformin) treatment of PCOS.^{38–40} However, much of the mental health and psychosocial research on PCOS has focused on women entering young adulthood (age 20–29 years) and in adulthood (age 30–40 years). As a result, less is known about the experiences of individuals with PCOS in other life stages, such as adolescence (age 13–19 years) and mid life (age 40–55 years).

A life course perspective is relevant to the management of PCOS and its complications in adolescence, ie, the time when PCOS is first diagnosable.⁴¹ Irregular periods are not uncommon in adolescence, particularly for the first 2 years after the start of menstruation, but continued irregular periods can be a sign of PCOS.^{42,43} Adolescents with PCOS are susceptible to poor mental health and additional chronic conditions (eg, type 2 diabetes) if their symptoms are untreated or poorly managed. In fact, women with PCOS express frustration at not knowing what they could have done earlier to prevent their symptoms from worsening,⁴⁴ and adolescents with PCOS express concerns about their future health: "... it kind of blew my mind that I could have all of these health problems down the line".⁴⁵ Developmentally appropriate approaches to engaging adolescents in health education and management of PCOS are especially needed given that adolescents with PCOS tend to be less physically active and knowledgeable about the benefits of exercise compared with adolescents without PCOS,⁴⁶ and affected adolescents may not have yet developed the significant psychiatric symptoms (eg, anxiety and depression) associated with PCOS.⁴⁷

Comorbidities associated with PCOS can also affect women's health after menopause.⁴⁸ For instance, the prevalence of obesity and type 2 diabetes tends to be higher in postmenopausal women with PCOS compared with their counterparts without PCOS.⁴⁹ Moreover, symptoms such as insulin resistance, hyperandrogenism (ie, hirsutism), chronic inflammation,⁵⁰ and heart disease can increase the risk of cardiovascular disease in women with PCOS after menopause.⁴⁸ An area for potential future research is the relationship between health-related quality of life and PCOS in menopausal and postmenopausal women, given that menopause can negatively affect health-related

quality of life.⁵¹ Women's premenopausal experiences with menstrual irregularity, a hallmark symptom of PCOS, may resemble menopause (ie, the fluctuation or cessation of menses), and influence health-related quality of life in middle age. Psychosocial issues, such as women's perceptions of menopause, their role as caregivers, the meaning of work, and self-care behaviors (eg, social support, spirituality, and reflection) can also influence health in middle age,⁵² and these issues have yet to be examined in relationship to PCOS-related health following menopause.

Constraints on agency

Agency refers to the ability of individuals to construct their own lives through the choices and actions they make. A life course perspective posits that this agency can be constrained by the contexts in which individuals are embedded.^{18–21} There is some evidence in the literature of agency in women with PCOS. Some adolescents perceive PCOS as having a positive impact on their lives,⁵³ and some women maintain a positive outlook about their condition,⁶ search for information on their symptoms,⁴⁴ and succeed in making positive lifestyle changes.⁴⁵ Research on agency in relation to PCOS is limited, and is overshadowed by women's overwhelmingly negative experiences with PCOS. As a result, it is unclear how women with PCOS overcome barriers such as lack of awareness about the condition,^{6,44} lack of or inadequate educational materials on the subject,^{6,54} lack of social support at the time of diagnosis,⁴⁴ and poor patient-provider communication.^{44,45}

A significant constraint to agency and health that has received minimal attention in PCOS research is socioeconomic status. The research suggests that education and income play a role in the development of PCOS across the life course. For instance, low socioeconomic status in childhood (measured by parental education) has been found to increase the risk of PCOS in adulthood (measured by educational level), particularly among obese women with high socioeconomic status in adulthood.⁵⁵ Additionally, symptoms of PCOS such as anovulation (ie, menstrual problems) can differ according to socioeconomic status, and these differences are associated with clinical and endocrine factors. Specifically, patients with low/medium family income and/or low education tend to have a higher body mass index, increased waist circumference, higher insulin levels, and more severe insulin resistance than patients with a high family income and/or high education.⁵⁶ Of particular concern is the lack of research on PCOS in low socioeconomic and medically underserved populations. For example, research has primarily

been conducted with women seeking or receiving PCOS-related care in clinic and hospital settings, which tends to exclude women who have limited contact with the health care system due to reluctance to undergo physical examination, inability to afford medical care, and/or unawareness of treatment options.⁵⁷

Interdependence of lives

A life course perspective views lives as interdependent and linked through social networks and relationships.¹⁸⁻²¹ This principle can be applied to the study of how roles and relationships (eg, as mothers, daughters, friends, and partners) affect PCOS-related health and psychosocial well-being across the life course. For instance, in adolescence, PCOS-related symptoms such as acne can lead adolescents with PCOS to “stay home and hide”, obesity can limit involvement in sports and other activities, and perceptions of unattractiveness can affect dating and peer relationships.⁵⁸ Menstrual problems can also affect interaction with peers. For instance, a woman recalled not joining conversations about periods with other girls at school because she felt “separate” and “not normal” as a result of not having periods.⁷ Women with PCOS also report that hirsutism negatively affects their perceptions of attractiveness, sexual relationships, and ability to make social contacts.⁵⁹⁻⁶¹ As spouses and partners, women have difficulty communicating about PCOS, particularly about “having too many masculine hormones”.⁷ Lack of understanding about PCOS on the part of partners can negatively affect relationships over time.

Due to its misleading name, PCOS might be perceived solely as a woman’s issue, when in reality it affects the entire family. In addition to the genetic component of PCOS,⁶²⁻⁶⁴ perceptions and communication (or lack thereof) about PCOS can affect relationships between family members. For instance, while some family members, particularly mothers, can be a source of support for young women with PCOS,⁴⁵ some adolescents and young women with the condition do not receive the support they need from their caregivers, particularly when those caregivers perceive them as having full control of their bodies and become frustrated with their inability to lose weight.⁵⁸ “Dealing with my parents with this is really difficult [...] all the time my parents are like, ‘Don’t you think you should lose a little weight?’ I am really struggling to feel good about myself and feel comfortable in my body.”⁴⁵ Such perceptions and interactions could underlie the low levels of self-esteem, family activities, and family cohesion

that affect health-related quality of life in adolescents with PCOS.^{53,65,66}

The value of interdependence of lives is seen in approaches that involve the family and peers in the management of PCOS. These approaches include an intervention that combines cognitive behavioral therapy and physical activity with a family-based focus.⁶⁷ Rofey et al found this approach to be successful in reducing weight and depressive symptoms (eg, anhedonia and suicidal thoughts) and improving menstrual function in adolescents with PCOS.⁶⁷ There is also a growing body of evidence on the benefits of educational programs for PCOS that incorporate social support and peer-led components.^{68,69} These programs provide women with opportunities to meet other women with PCOS, minimize the feelings of social isolation associated with PCOS,⁶⁹ enhance women’s motivation to manage their health, and develop skills such as problem-solving and communication with health care providers.⁶⁸ Research on such approaches is scarce and tends to be based on small sample sizes.⁶⁷⁻⁶⁹ However, the findings of these studies support the potentially beneficial contribution of linked lives in the management of physical and mental health in women with PCOS.

Time and place

The principle of time and place posits that the cultural, historical, political, and economic climate affects development over time.¹⁸⁻²¹ This principle is relevant to understanding the contexts in which women with PCOS live and how these contexts affect health. For instance, research in Western Australia suggests that the high rate of PCOS in Aboriginal women is associated with cultural and lifestyle changes in Aboriginal communities resulting from colonization.⁷⁰ Community characteristics can inform community-based programs to increase public awareness of PCOS and its management. There are few examples in the literature of collaboration between researchers and community members, and any such collaboration tends to be limited to data collection. For instance, Kumarapeli et al partnered with a midwife from a village in the district of Gampaha, Sri Lanka, to identify women with symptoms of PCOS. The midwife took the researchers to women’s homes, and her presence helped to increase participants’ confidence in the researchers and their cooperation in the study.⁵⁷ Further, women with symptoms of PCOS were invited to participate in a clinical assessment on a mutually agreed day and location (nearby clinic or hospital).⁷¹ On the Greek island of Lesbos,

Diamanti-Kandarakis et al recruited a community sample of women via a large-scale publicity campaign inviting women to attend for a free medical examination. This involved collaboration with a local television, newspaper office, and radio station.⁷² Researchers have worked with natural helpers and influential people in the community (eg, midwives) and made use of resources and assets (eg, media outlets) to identify women with symptoms of PCOS, but additional efforts are needed to engage community members further in managing health in their communities.

Although some studies have been conducted on the prevalence of PCOS internationally,^{72–76} research on how sociocultural factors mediate women's experiences of PCOS is sparse. Support for the influence of race, ethnicity, and culture in PCOS comes from cultural differences in women's perceptions of health-related quality of life.^{57,77} Among women with PCOS in Austria, for instance, immigrant women from an Islamic background tend to experience poorer health-related quality of life compared with women from a Christian background.⁷⁸ Immigrant women's quality of life is affected not only by problems with infertility and irregular menstrual cycles, but also by family pressure to conceive as well as stress related to problems accessing culturally sensitive health care (eg, preferences for female practitioners and female interpreters).⁷⁸ This highlights a need to further understand how sociocultural factors affect the lives of women with PCOS.

Timing of events and experiences

The timing of events and experiences can also produce changes in roles and transitions across the life course.^{18–21} PCOS can affect the timing of events and experiences, including pregnancy and transition to parenthood. For instance, obesity increases the risk of infertility, miscarriage, and complications during pregnancy in women with PCOS.⁷⁹ Concerns about PCOS-related infertility tend to begin in adolescence,⁵⁸ and adolescents are about three times more likely to worry about their ability to become pregnant in the future compared with adolescents without PCOS.⁵³ Young women with PCOS in late adolescence and early adulthood share these concerns: "I'm not ready to have children just yet, but ... when it's time, I'm a little scared ... my dream is to adopt ... I just don't think it's necessary to go through all the heartache of trying to have babies, and not be successful."⁴⁵ Some young women also express concern about marital problems that might arise from PCOS-related infertility in the future.⁴⁵ What may

be particularly stressful for women is learning that they have PCOS only when they encounter problems trying to conceive.⁸⁰ They may not have been previously diagnosed with PCOS, and as a result, be unaware of the potential infertility problems associated with the condition. This can lead to fear, shame, embarrassment, and feelings of failing as a woman.⁷

Attention to the timing of events and experiences such as menstrual problems in adolescence is particularly important. Adolescents with PCOS describe their periods as "crazy" and fear "bleeding to death".⁵⁸ In addition to health problems such as fatigue and anemia, menstrual problems can also limit activities during adolescence.⁵⁸ Similarly, women with PCOS express frustration at not knowing if or when they will get their period and the planning of activities around menstruation.⁶ The absence of menstruation, in particular, tends to be an upsetting experience that women perceive as "unfeminine".⁷ Interestingly, women recall how menstrual problems in adolescence raised a red flag about their health: "I knew all along something was wrong. I started menstruating for the first time at age 15. I didn't have another one [period] until I was like 18. And so I knew then that there was a problem."⁶ Indeed, PCOS-related menstrual problems pose significant health risks, including that of endometrial cancer.⁸¹ While lifestyle changes, medication, and hormone treatment (eg, oral contraceptives) can aid in regulating menstruation,⁴⁰ psychosocial issues that pose challenges to health should also be considered. These issues include embarrassment discussing menstrual problems during adolescence, fear of weight gain associated with contraceptives, a parental perception that adolescent sexual behavior is permissible while taking the pill,⁵⁸ and women's perceptions that contraceptives produce "artificial" periods and "fake" femininity.⁶

Conclusion

This paper discusses a life course perspective on human development associated with PCOS. To understand this, it is not enough to study the pathophysiology of the condition alone, it is also essential to examine how PCOS influences the trajectories of people's lives. A major contribution of the life course perspective is that it underscores the importance of the person in context over time. In other words, the contexts in which people are embedded are important. These contexts include periods of life, social conditions, and relationships with other people, all of which influence health, both positively and negatively.

A biopsychosocial perspective of PCOS is also central to developing multidisciplinary programs that assess both the physical and mental health outcomes associated with PCOS. A practical application of this would be for practitioners to consider how PCOS symptoms and related medical conditions affect or underlie mental health symptoms in women with PCOS. For example, type 2 diabetes,² obstructive sleep apnea,³ and vitamin D deficiency^{82,83} associated with PCOS can result in fatigue and tiredness, symptoms which are also consistent with depression. General awareness of PCOS can guide the use of diagnostic tools and inform mental health assessments and diagnoses.

A longitudinal perspective also stresses that health in one stage of life can affect health later in life. This view, in addition to the principle of timing of events and experiences, can provide a clearer understanding of how and when to intervene. Adolescence warrants further attention because PCOS can worsen over time if untreated or poorly managed during this time, with increased risk of poor health in adulthood. This requires sensitivity to developmental needs (eg, development of identity and body image) and experiences (eg, roles and transitions) in adolescence and later life, because these issues can facilitate or disrupt continuity of care.

Moreover, consistent with the principle of time and place, women's health reflects the social conditions they live in, creating a need to understand the role of social conditions in the development of PCOS. In particular, research on community conditions can inform public awareness of PCOS and management programs at the community level, and perhaps on a larger scale than clinic-based and hospital-based programs alone. These programs also have the potential to reach women unaware of PCOS or who have limited contact with traditional systems of care. Considering that community health workers have been successful in engaging community members to improve several aspects of health, including management of chronic disease,⁸⁴ programs based on community health models might be future directions in PCOS research. Consistent with the principle of constraints on agency, community health worker models value assets and resources at the individual and community level, as well as advocacy and action to overcome constraints to health promotion and disease prevention. Additionally, in line with the principle of interdependence of lives, these models also value the influence community members have on each other's development, and have the potential to engage community members in the management of PCOS and prevention of its complications.

In conclusion, although narratives found in ancient texts suggest that women have been living with symptoms of PCOS as far back as 460 BC,⁸⁵ the psychosocial aspects of PCOS and the lives of women with the condition remain poorly understood. What is clear is that PCOS is more than a spectrum of symptoms. Women with PCOS have identities, experiences, and narratives that continue to be largely hidden because of lack of awareness about PCOS. Research priorities such as those outlined in the 2012 evidence-based methodology workshop on PCOS¹ signal that PCOS is becoming a national priority. The increased attention that PCOS is receiving creates an opportunity to bring the largely hidden health and mental health issues of women with the condition to the forefront of research, practice, and health policy. Greater efforts are needed to further understand PCOS, a complex condition, from diverse multidisciplinary perspectives that can inform the development, delivery, and evaluation of programs to manage PCOS and prevent its complications across the life course.

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