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A Theoretically Grounded Exploration of Individual and Family Self-Management of Polycystic Ovary Syndrome in Adolescents

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Abstract

Polycystic ovary syndrome (PCOS) is highly prevalent and increasingly diagnosed during adolescence. This study explored the context and processes of self-management among adolescents, and parents of adolescents, who have PCOS. Adolescents with PCOS (n=7) and their parents (n=8) participated in a series of focus groups. Deductive thematic analysis was guided by the Individual and Family Self-Management Theory (IFSMT; Ryan & Sawin, 2009), and the patterns that were identified aligned with the contexts and processes described therein. A secondary inductive approach was employed as a novel contextual pattern emerged: psychological health and well-being. Study findings suggest that adolescents and their families have a desire to engage in optimal self-management, and particularly effective strategies may consider a holistic, family intervention approach that addresses psychological health and well-being in addition to behavior change. Study findings are the first to reflect the unique needs of adolescents with PCOS and their families.

Keywords

POLYCYSTIC OVARY SYNDROME; SELF-MANAGEMENT; ADOLESCENT; FAMILY; QUALITATIVE RESEARCH

Polycystic Ovary Syndrome (PCOS) is the most predominant female chronic endocrine disorder affecting 7%−18% of reproductive-aged women around the world (March et al., 2010; Tehrani, Simbar, Tohidi, Hoseinpanah, & Azizi, 2011). PCOS often manifests during the challenging developmental period of adolescence (Goodman et al., 2015). A PCOS diagnosis during adolescence has significant family-level implications as the mainstays of effective treatment (i.e., self-management) are therapeutic lifestyle changes, and an

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adolescent's ability to make these changes is heavily influenced by their family's behaviors in these areas. Despite the unique needs of adolescents and their families, current clinical practice guidelines for adolescents with PCOS are extrapolated from studies with adult women (Hoeger et al., 2004; Huber-Buchholz, Carey, & Norman, 1999; Thomson et al., 2010). There is a need for investigation into the unique self-management needs of adolescents with PCOS within the family context in order to develop more developmentally appropriate practice recommendations.

Background

PCOS is associated with significant physical morbidity and potential mortality including obesity, cardiovascular disease, metabolic syndrome, diabetes, and endometrial cancer (Bates & Legro, 2013; Boomsma et al., 2006; Chittenden, Fullerton, Maheshwari, & Bhattacharya, 2009; Wang et al., 2011). High rates of obesity among women with PCOS contribute to metabolic complications, yet after controlling for body mass index (BMI), women with PCOS are still at a 2-fold increased risk of arterial disease vs those without (De Groot, Dekkers, Romijn, Dieben, & Helmerhorst, 2011). In addition, while obese women with PCOS are 3–4 times more likely to develop diabetes than women without PCOS, women with PCOS who have normal BMIs are still 2–3 times more likely to develop diabetes than their counterparts without PCOS (Wang et al., 2011). In addition to these substantial endocrine and cardiovascular health risks, high rates of infertility, endometrial hyperplasia, and endometrial cancer disproportionately affect women with PCOS (Boosma et al., 2006; Chittenden et al., 2009).

Notwithstanding these adverse physical outcomes, women and adolescents with PCOS also display high rates of psychological dysfunction including low self-esteem, social withdrawal, poor quality of life, eating disorders, depression, and anxiety disorders (Berni, Morgan, Berni, & Rees, 2018; Pastore, Patrie, Morris, Dalal, Bray, 2011; Trent, Rich, & Austin, 2002). Prevalence of depressive and anxiety disorders in women with PCOS has been found to be as high as 34% to 40% (Dokras, Clifton, Futterweit, & Wild, 2012; Hollirake, Abreu, Maifeld, Van Voorhis, Dokras, 2007). A recent large retrospective database analysis from the United Kingdom identified a significantly increased risk of having depression, anxiety, bipolar disorder, and eating disorders among women with PCOS compared to matched controls (Berni et al., 2018).

Clinical practice guidelines for PCOS management focus on "therapeutic lifestyle changes" with weight reduction through caloric-restrictive diets, moderate-to-vigorous regular physical activity, and medication adherence (Goodman et al., 2015a; Goodman et al., 2015b). This approach to self-management with adolescents fails to consider the lifelong nature of effective PCOS self-management through sustained healthy lifestyle habits and may actually contribute to maladaptive patterns of unsustainable strategies for weight loss in adolescents (Neumark-Sztainer, Wall, Larson, Eisenberg, & Loth, 2011; Neumark-Sztainer, Wall, Story, & Standish, 2012). Moreover, these guidelines provide no guidance for nurses and other health care providers on how to address family-level contextual influences (e.g., frequent family fast food consumption, lack of physical activity in family members) that may impact an adolescent's ability to engage in optimum self-management.

Given these unique considerations, there is a need for a theoretically grounded exploration of current self-management practices among adolescents with PCOS and their family members in order to inform the development of tailored interventions for this population. The Individual and Family Self-Management Theory (IFSMT) conceptualizes self-management of chronic conditions as consisting of three complex dynamic dimensions: context, processes, and outcomes (Ryan & Sawin, 2009). The context consists of risk and protective factors that cluster into three categories: 1) condition specific, 2) physical and social environment, and 3) individual and family. The process of self-management is also described within three defined categories: 1) knowledge and beliefs, 2) self-regulation skills and abilities, and 3) social facilitation. Outcomes are temporally differentiated with proximal outcomes such as condition specific self-management behaviors and distal outcomes such as health status and quality of life.

The consideration of both the individual with the condition and the larger family-unit within a unified framework allows for examination of the intra- and inter-dynamic processes that occur within a family system. It is important to assess to what degree the family-level factors facilitate or impede adolescents' self-management. To our knowledge no systematic evaluation of self-management of PCOS among adolescents and their families has been conducted. Therefore, this study explored the context and processes of PCOS self-management from adolescent and parent perspectives using the IFSMT as a guiding framework.

Methods

Design

This study utilized a qualitative descriptive approach (Sandelowski, 2000) to explore the phenomenon and processes of PCOS self-management from the perspectives of adolescents, and parents of adolescents, that have PCOS through focus groups. In full recognition of the philosophical underpinnings of qualitative descriptive as inductive in nature (Bradshaw et al., 2017), the IFSMT (2009) was used as the 'theoretical orientation toward the phenomenon under investigation" (Sandelowski, 2010, p. 79).

Sample and Setting

The study was carried out in an adolescent medicine clinic located in a large city in south central U. S. Adolescents, ages 14 – 18 years, with a diagnosis of PCOS (n=7) and their parents (n=8) were recruited through this clinic where the two medical providers (one physician and one pediatric nurse practitioner) specialized in PCOS and other menstrual dysfunctions. Additionally, adults who currently or previously cared for a child diagnosed with PCOS were also recruited. Parents and adolescents could participate independently of each other (i.e., parent did not have to participate if adolescent wished to participate and vice-a-versa). A multi-faceted approach to recruitment was utilized for both adolescents and parents: study flyers were handed out by clinic staff and posted in exam rooms and study staff conducted on-site recruiting person-to-person.

Data Collection

All study procedures and documents were approved by the University of Texas at Austin internal review board and by Ascension Seton Family of Hospitals. A series of five focus groups (3 adolescent groups and 2 parent groups) was conducted between December 2017 – April 2018. The findings presented in this manuscript represent analyses of the data set from the first and second adolescent and parent focus groups. The remaining adolescent focus group reviewed content of a proposed self-management intervention and is thus not included in these analyses. All groups were held in a private conference room at the clinic from which the participants were recruited.

In order to maximize convenience for participants, adolescent and parent groups were held concurrently, at the same location, but in separate, private conference rooms on a weekend morning. Each focus group had one primary facilitator [either the principal investigator or graduate research assistant (GRA)] and one additional trained study staff member (GRA or undergraduate RA) who documented field notes and distributed demographic questionnaires and gift cards at the end of the sessions. Focus group discussion guides based on the IFSMT (2009) prompted participants to explore the phenomenon of having a diagnosis of PCOS as well as the context and processes of PCOS self-management. Please see Table 1 for an abbreviated version of the discussion guide. Each focus group lasted between 50 to 75 minutes and was audio recorded and transcribed verbatim by a third party company with secure file management, secure account information, and data security measures.

Data Analysis

For this study, thematic analysis was used from an essentialist/realist perspective (Braun & Clark, 2006). Minimal interpretation was employed as the researchers were interested in the experiences, actions, and realities of the participants and sought to describe these as close to the data as possible (Sandelowski, 2010). A primary theoretical (i.e., deductive) approach was taken as the IFSTM provided a descriptive theory from which to examine self-management of PCOS at the individual and family level (Braun & Clark, 2006). The context, processes and outcomes as described in the IFSTM provided the predetermined categories, and the categories were separated into a code list that allowed the authors to organize data into coding units that fit within each category. A secondary inductive approach was utilized as a consistent pattern (theme) was identified that was distinct from the predetermined categories.

Two investigators independently read all text data and assigned codes from the predetermined coding structure. Through an iterative, collaborative process, investigators met routinely to discuss thematic emergence within the data set and independently arrived at the inductive identification of a unique pattern that was not explicitly described within the predetermined categories. The two investigators were in agreement about final coding structure and did not require the assistance of a third analyst.

Results

The final sample consisted of seven adolescents with PCOS and eight parents. Although not a requirement, all parents who participated had a child who was participating in the adolescent focus group (a mother and father of one adolescent participated in the first parent group). The age of the adolescent participants ranged from 15 to 18 years with a median age of 15 years. The mean age at diagnosis for PCOS was 14 years, however, participants spent a significant amount of time 'searching' for a diagnosis for their child (i.e., 6 months to 2 years). The racial/ethnic background of both groups was diverse with four adolescents reporting Hispanic ethnic heritage, one non-Hispanic White, one non-Hispanic Black, and one Asian. In the parent group, five reported Hispanic ethnic heritage, one non-Hispanic White, one non-Hispanic Black, and one Asian.

The patterns that were identified mapped onto the dimensions of context and processes of self-management from the IFSTM (Ryan & Sawin, 2009), and a novel component within the context of the individual and family context was also identified: psychological health and well-being.

Context Dimension

Condition Specific—Three primary factors emerged as specific to PCOS self-management: 1) physical manifestations and symptoms, 2) variable treatment trajectory, and 3) recognition of etiology and genetics. Both adolescent and adult participants discussed uncontrolled weight gain, insulin resistance, painful/unpredictable menstrual periods, and increased facial hair as well as adverse effects of treatments such as headaches. Parents expressed recognition of the chronicity of the condition and concern for the long-term implications of sub-optimal self-management. And while the adolescents voiced recognition of potential long-term adverse outcomes (e.g., "*I had a period when I was 16 and I haven't since. And everyone's like, that's so great, but it's not, because it's not healthy…. It's increasing my risk of ovarian cancer which is terrifying, especially at 16."),* the impact of PCOS symptoms and treatments on their daily lives was the primary focus.

> "... my marching uniform. Like sometimes it'll be really nice and fit, but like there will be times it just doesn't wanna zip up or my jacket doesn't wanna zip up either." Teen 1

> "So with like the body hair with me, this was since I was little, because ever since I was little I was always like really hairy. I just might like shave it, but I get tired of it." Teen 4

> "they put me on birth control…, but I would get really bad migraines. And I mean migraines, they'll last for like three days, I'll throw up everything. And it's basically I'm just crying in bed. And so, they were like, okay, let's take you off this medication… So, they put me on this one pill that I'm on right now, and I haven't got my period since." –Teen 3

The persistence of symptoms despite multiple treatment approaches contributed to feelings of helplessness and uncertainty regarding treatment trajectories.

> "So she changed treatment… but the treatment is not working at all. She's still with some symptoms. And the doctor says, "Okay, you have one step, second step, and third step. So now we're gonna get the third step." -Parent 3

Although both adolescents and parents voiced uncertainty regarding the exact etiology, hormonal abnormalities were clearly understood, and both groups were able to identify factors that were the focus of treatment such as insulin resistance, elevated testosterone, and elevated estrogen.

> "We know that there's no cause, right? It's like a bad lottery. But also it has a lot of ramifications, right? We have this, what about insulin intolerance, right? I come from a family of diabetics, so this is a type of scary things… It's not a single symptom of – there are many, many ramifications. You have, yeah, facial hair, overweight, etc. but this is only one piece." -Parent 2

Physical and Social Environment—The primary patterns that were identified within the physical and social environment included: 1) frustrations with the current health care environment, 2) perceived discrimination, and 3) cultural influences. Difficulties in obtaining timely, quality health care were voiced by the parents, and much of this frustration came through the process of searching for a diagnosis.

> "… we first notice is that the healthcare system is not good…it was a doctor in Mexico telling us that, "Okay, you should look for this. Probably this is the cause." We came back with that information and then the doctor say, "Oh, yeah. Sure." I mean, come on... we missed this diagnosis for some time. We could have started earlier the treatment, right? So, it's hard because it's like error and trial, and error, trial and error until you find someone that will take, instead of ten minutes, 15 minutes. Five minutes more to understand a little bit better what is going on. And then find the right treatment… we need to find the resources here [United States], and that has proven difficult, to be honest." -Parent 2

For the parents, negative experiences and frustrations with individual healthcare providers as well as the larger healthcare system were voiced and were many times colored by perceived discrimination related to participants' Hispanic/Latino ethnic heritage.

> *"No disrespect, but I think it's the culture... If they see you as uneducated. That you're from Mexico… And they see you as, you're a Medicaid patient, you're a welfare patient. 'So come back tomorrow. We'll do another test.' This hurts… Make an appointment again.' So, it looks frustrating to me, to see that. Because I said,* [wait] *a year and a half? I cannot understand, it's an unfathomable idea that they would wait that long, when we, I mean I'm sorry, I'm saying, "we," but other people get treated almost immediately." –Parent 1*

Hispanic/Latino cultural influences also created dissonance between recognizing that something was wrong with their child but feeling that PCOS was normalized in their culture (e.g., family members living 'just fine' with PCOS for many years). An additional cultural struggle concerned the use of birth control pills as a treatment.

> "…because I was worried about my lifestyle, daughter, about the birth control in the beginning, because you know, the stereotype is, "Oh, your daughter is taking birth control." Yeah, I know. I know that, especially in my culture." –Parent 6

This same mother spoke to the challenges of traveling back to Mexico with her daughter on birth control pills and the lack of understanding or compassion from extended female family members who saw the medication as having implications for the sexual promiscuity of her daughter.

Individual and Family—Three themes were identified within the individual and family context: 1) perceived lack of knowledge, 2) adolescence as a transitional stage, and 3) psychological health and well-being. The adolescents expressed a lack of knowledge regarding the etiology of their condition but instead understood their condition through the signs and symptoms with which they had to cope (i.e., irregular periods, weight gain, and acne). Similarly, the parents had a general sense of the involvement of hormones and the symptoms their child dealt with, but there was also fear associated with learning too much about the condition. As one father stated,

> "We still don't know what it is, exactly. We haven't done research. We're too nervous [about] what we read. I just don't want to read it…." –Parent 1

This avoidance coping strategy, while perhaps cognitively and emotionally supportive in the short term, was in contrast to the identification of a pressing need to facilitate adolescent self-management as their child transitioned to young adulthood. While this viewpoint also speaks to the process of social facilitation (i.e., influence, support, collaboration), it is directly influenced by the developmental stage of the adolescent.

> "…this hits the patient like they're really specific age. And you have two worries, you have the clinical worries…But also, you have the visible effects, right? You have the overweight, you have – at that age, physical appearance is very important for them, right? They are teenagers. They are looking at other girls and comparing themselves with other girls." –Parent 1

For the adolescents, developmental stage was characterized by concerns of finding a balance between being a 'normal' teenager within a framework of the healthy lifestyle strategies they must engage in for effective self-management.

> "When I was going out before it was like let's go get fried chicken or something or burgers. You know you shouldn't, but everybody else is eating that so you don't want to be the one person that's not." -Teen 3

> "Yeah, you don't want to bum everyone out." -Teen 2

Pervasive throughout both adolescent and parent groups' discussions was the significant emotional impact of PCOS: from the uncertainty of outcomes to the transitional developmental stage to the significant physical manifestations of the condition, the participants' psychological health and well-being was ever-present. The older adolescents (i.e., those 17 and 18 years) spoke of journeys of self-discovery and acceptance of their diagnosis. Within these stories, the inter-connection between their psychological health as a

distinct individual contextual factor and their ability, willingness, and motivation to engage in the process of self-management was evident.

> "It just becomes a mystery and I'm like I must be doing something wrong, because, I'm eating right, I'm drinking a lot of water, I'm exercising, something must be wrong… Before my mentality changed about how I eat and everything I actually went through a deep depression, and that's what made me realize I can't be like this anymore, I have to change. So as I changed my diet, I began getting happier, and I began losing more weight." –Teen 5

Both groups consistently returned to the level of distress associated with the physical manifestations of PCOS. With the parents, their primary concern was for the discrimination they perceived against their child. For the adolescents, they were different from their peers, both physically and emotionally, and this created a significant amount of distress.

> "I was always really really skinny, and everything was like good through elementary and then middle school, until eighth grade and then suddenly I was gaining a lot of weight out of nowhere. So, I feel I was in so much distress, like I don't know what to do about it, I don't know where it's coming from or like what I'm doing wrong. And then, just feeling like I couldn't do anything, so.. okay, I'll just live with it. But, then within the last year or so, realizing you have power of your actions, and okay you can't control what your body does or what your diagnosis is, but you can do things to make it better… not everything is hopeless." –Teen 3

An additional pattern that was identified within psychological health and well-being was sense of responsibility to family. Half of the adolescents reported either having a job or searching for a job in order to provide additional resources for their family. One adolescent stated she was working to afford an apartment for herself and her mother so they could move away from her unsupportive father and brothers. One adolescent felt the burden of her family's financial state and recognized the impact this also had on her own abilities to participate in effective self-management.

> "I'm only 16, but I'm trying to get a job right now, because we're not from high society we don't have a lot of money… I don't wanna be stuck in a hole, a financial hole… I wanna be, I guess the person who supports everybody out of the whole family. I wanna be the one to uplift everybody, but at the same time I'm also uplifting myself, like health wise. I need to take care of myself so I can be there, because nobody else will." –Teen 4

Process of Self-Management

Knowledge and Beliefs—Although adolescents described going through a period of resistance and lack of acceptance regarding their PCOS diagnosis, they reported overcoming those obstacles and developing self-efficacy for both their nutrition and physical activity.

> "So, I just like gained weight, so it was kind of my fault the first three years. So it's just been in my hands for a while and I just haven't done anything until these past

two years. But, like my portions have gone down drastically and I'm drinking a lot of water." –Teen 1

For the parents, outcome expectancies manifested as a fear-based motivation to ensure optimum self-management, as they fully understood the health risks such as type 2 diabetes and cancer.

Self-Regulation Skills and Abilities—The primary strategies that emerged from the groups related to nutrition such as the use of a slow cooker/Instant Pot, reduction of fast food intake, keeping vegetables prepped for snacking in the fridge, etc. Parents spoke to the desire to assist with the 'actions' of self-management (e.g., planning for exercise, self-monitoring for healthy nutrition) but struggled to be compassionate and understanding about the realities of being an adolescent with competing academic and extracurricular demands. They also recognized their own imperfections with self-regulation.

"She's a vegan and she tries to eat healthy. But, then… I don't have control if I see sweets and all. If I don't eat, I don't eat. But, you live only once… I try not to tell her, "It's detrimental to you." Because she's already just living through that whole thing. No matter how much I empathize, I cannot be in her shoes, literally. So I know there are a lot of things that people go through but this is very tough." – Parent 7

The adolescents did not specifically discuss strategies of goal setting or planning and action. There was, however, identification of the impact emotions had on motivation and ability to make healthy choices and the need for self-monitoring to find the strategies that worked for them.

"I guess the biggest thing that's helped is like, reducing stress. Because, when I'm stressed, I tend to like eat more, more snacky… And then I've been volunteering every day, which is helpful, because like, I'm walking dogs, so it's exercise and it's stress relief, because I love animals and they love me too." –Teen 3

"For me, it's just been working out more, I used to work out like compulsively, and then it wasn't good because I wasn't eating either. But, then like learning to balance that out. –Teen 2

Social Facilitation—Influence, support, and collaboration all emerged as components of social facilitation. The process of influence was identified in the parent group through parental self-reflection of their own eating and exercise habits.

"…guess that's another way it impacted us because I was, between her third year, which was three, all the way to about six, seven, eight, nine, it was healthy eating. Fresh fruits, fresh food… All of a sudden we just got to the middle school and she just – we went to a quick five-minute lunch from McDonald's, this kind of opened up our eyes "Hey, you know what? You gotta change the way of eating as well, before it gets worse… I didn't get like this by eating salads. It's my fault, too, so.."- Parent 1

Just as the dissonance between ideal self-management and everyday life emerged within the processes of self-regulation, it was also found within social facilitation.

> "I think I find that it's a vicious cycle in the sense that there is that lack of energy. She's also a high schooler. She doesn't have the energy so she's sleeping through [exercise]. –And I'm big on rest and all, even if homework suffers, you have to take care of your body. And then, I think she is cognizant that she needs to exercise… I said, "It's okay. If you don't have energy, how can you exercise vigorously either. So we try to do it one step at a time because you don't want to be stressed about that, I guess. Okay, we'll do it tomorrow. Like, what can you do?" –Parent 7

All of the adolescents reported at least one supportive parent. In fact, only two adolescents relayed stories of unsupportive family members (i.e., father and brother), but they were able to minimize the negative impact of these relationships by attributing their lack of support to ignorance and focused their efforts, instead, on valuing their relationship with their mother and/or other siblings. Three adolescents reported participating in the grocery shopping on a regular basis, and one participant was grateful that her parents would purchase more expensive grocery items so that she had healthy foods in their home. No one exercised regularly with their family. Instead, adolescents either went to a gym (where the membership fees were paid by parents) or participated in extracurricular activities like marching band, the dance team, etc.

Discussion

The context and processes of adolescent and family self-management of PCOS aligned with constructs in the Individual and Family Self-Management Theory (Ryan & Sawin, 2009). Participants spoke to the context of PCOS self-management through condition specific factors, the health care environment, and the adolescent and family context. The processes of self-management emerged primarily within the domains of self-regulation and social facilitation. Findings also indicate the presence of a novel contextual factor: psychological health and well-being. Inclusion of psychological health as a contextual factor provides explicit recognition of both adolescent and family members' mental health status as distinct from the emotional control processes related to PCOS self-management. This distinction is important as the participants clearly discussed their mental health status independent of PCOS self-management, but also spoke to the impact of their psychological health on their health behaviors.

Although there are studies documenting the increased risk of mental health disorders among women with PCOS (Berni et al., 2018), we are aware of no studies that specifically examine the impact of mental health status on PCOS self-management. Consistent within the literature of chronic health conditions for which adolescents with PCOS are at high risk (e.g., diabetes, cardiovascular disease) are findings that mental health disorders, such as depression and anxiety, and stress contribute to poor physical health outcomes (Chauvet-Gelinier & Bonin, 2017). Adverse outcomes are partly explained through sub-optimal self-management strategies (i.e., non-adherence to medications, physical inactivity, poor nutrition, and smoking; Lin et al., 2006). Considering our findings within this larger literature regarding impact of mental health on self-management behaviors, it appears that

comprehensive interventions that address both strategies for self-management of psychological health (i.e., mental health promotion) and the cornerstones of PCOS self-management (i.e., therapeutic lifestyle changes) may be particularly efficacious.

Moreover, developmentally-sensitive interventions that take a health promotion/wellness approach to both physical and psychological health could have a broad impact for adolescents and their families through supporting them to establish habits in healthy nutrition, regular physical activity, medication adherence, and stress management. As our findings indicate, there was recognition at both the parent and adolescent level that the adolescents were in a transitional phase where they were increasingly taking responsibility for their own self-management. This suggests that nurses working with adolescents with PCOS and their families should remain cognizant of this transitional phase and ensure adolescents are increasingly taking ownership of their self-management.

Limitations

Several limitations to the current study should be noted. First, the older adolescents in each focus group dominated the conversation. The younger adolescents would answer questions when directly asked by the facilitator, but they were not as expressive with their experiences of self-management. Future work in this area may benefit from grouping younger adolescents together (i.e., 13–15 years vs. 16–18 years). Another limitation is that all participants were recruited from a single clinic. Although there was a diverse representation of race/ethnicities, all participants were from a single geographic region. The findings particularly related to culture and its impact on context of PCOS self-management may not be generalizable to other populations. Finally, proximal and distal outcomes of PCOS self-management were not discussed within the groups and a formal assessment of level of PCOS knowledge was not obtained. Conjecture regarding potential adverse health outcomes was discussed among both parents and adolescents, but this was presented as a possible outcome of poor self-management as opposed to discussion/evaluation of actual health outcomes. Moreover, level of knowledge regarding PCOS etiology and potential health outcomes may certainly impact self-management behaviors, and future studies would benefit from an assessment of level of knowledge and self-management behaviors to explore this further.

Conclusion

In conclusion, the Individual and Family Self-Management Theory (Ryan & Sawin, 2009) provided a useful framework to explore the context and processes of PCOS self-management with adolescents and their families. Study findings provide support for this descriptive theory and also suggest the usefulness of including psychological health and well-being as a contextual risk/protective factor. Particularly effective strategies for optimizing self-management may consider a holistic, family intervention approach that addresses psychological health and well-being in addition to behavior change.

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References

Bates GW, & Legro RS (2013). Longterm management of polycystic ovarian syndrome (PCOS). Molecular Cellular Endocrinology, 373, 91–97. 10.1016/j.mce.2012.10.029 [PubMed: 23261983]

Berni TR, Morgan CL, Berni ER, & Rees DA (2018). Polycystic ovary syndrome is associated with adverse mental health and neurodevelopmental outcomes. Journal of Clinical Endocrinology and Metabolism. [published online ahead of print April 10, 201810.1210/jc.2017-02667

Boomsma CM, Eijkemans MJ, Hughes EG, Visser GH, Fauser BC, & Macklon NS (2006). A meta-analysis of pregnancy outcomes in women with polycystic ovary syndrome. Human Reproduction Update, 12, 673–683. 10.1093/humupd/dml036 [PubMed: 16891296]

Bradshaw C, Atkinson S, & Doody O (2017). Employing a qualitative description approach in health care research. Global Qualitative Nursing Research, 4, 1–8. http://journals.sagepub.com/doi/10.1177/2333393617742282

Braun V, & Clarke V (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77–101. https://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa

Chauvet-Gelinier JC, & Bonin B (2017). Stress, anxiety and depression in heart disease patients: A major challenge for cardiac rehabilitation. Annals of Physical and Rehabilitation Medicine, 60, 6–12. [PubMed: 27771272]

Chittenden BG, Fullerton G, Maheshwari A, & Bhattacharya S (2009). Polycystic ovary syndrome and the risk of gynaecological cancer: a systematic review. Reproductive Biomedicine Online, 19, 398–405. 10.1016/S1472-6483(10)60175-7 [PubMed: 19778486]

De Groot PC, Dekkers OM, Romijn JA, Dieben SW, Helmerhorst FM (2011). PCOS, coronary heart disease, stroke and the influence of obesity: a systematic review and meta-analysis. Human Reproduction Update, 17, 495–500. 10.1093/humupd/dmr001 [PubMed: 21335359]

Dokras A, Clifton S, Futterweit W, & Wild R (2012). Increased prevalence of anxiety symptoms in women with polycystic ovary syndrome: systematic review and meta-analysis. Fertility and Sterility, 97, 225–230.e2. 10.1016/j.fertnstert.2011.10.022 [PubMed: 22127370]

Goodman NF, Cobin RH, Futterweit W, Glueck JS, Legro RS, & Carmina E. (2015a). American association of clinical endocrinologists, American college of endocrinology, and androgen excess and PCOS society disease state clinical review: guide to the best practices in the evaluation and treatment of polycystic ovary syndrome-part 1. Endocrinology Practice, 21, 1291–1300. 10.4158/EP15748.DSC

Goodman NF, Cobin RH, Futterweit W, Glueck JS, Legro RS, & Carmina E (2015b). American association of clinical endocrinologists, American college of endocrinology, and androgen excess and PCOS society disease state clinical review: guide to the best practices in the evaluation and treatment of polycystic ovary syndrome-part 2. Endocrinology Practice, 21, 1415–1426. 10.4158/EP15748.DSCPT2

Hollinrake E, Abreu A, Maifeld M, Van Voorhis BJ, Dokras A (2007). Increased risk of depressive disorders in women with polycystic ovary syndrome. Fertility and Sterility, 87, 1369–1376. 10.1016/j.fertnstert.2006.11.039 [PubMed: 17397839]

Huber-Buchholz MM, Carey DG, & Norman RJ (1999). Restoration of reproductive potential by lifestyle modification in obese polycystic ovary syndrome: role of insulin sensitivity and luteinizing hormone. Journal of Clinical Endocrinology and Metabolism, 84, 1470–1474. 10.1210/jcem.84.4.5596 [PubMed: 10199797]

Hoeger KM, Kochman L, Wixom N, Craig K, Miller RK, & Guzick DS (2004). A randomized, 48-week, placebo-controlled trial of intensive lifestyle modification and/or metformin therapy in overweight women with polycystic ovary syndrome: a pilot study. Fertility and Sterility, 82, 421–429. 10.1016/j.fertnstert.2004.02.104 [PubMed: 15302293]

Lin WHB, Katon W, Rutter C, Simon GE, Ludman EJ, Von Korff M, … Walker E (2006). Effects of enhanced depression treatement on diabetes self-care. Annals of Family Medicine, 4, 46–53. DOI: 10.1370/afm.423.375:54–64. [PubMed: 16449396]

March WA, Moore VM, Willson KJ, Phillips DI, Norman RJ, Davies MJ (2010). The prevalence of polycystic ovary syndrome in a community sample assessed under contrasting diagnostic criteria. Human Reproduction, 25(2), 544–551. 10.1093/humrep/dep399 [PubMed: 19910321]

Neumark-Sztainer D, Wall M, Larson NI, Eisenberg ME,. & Loth K (2011). Dieting and disordered eating behaviors from adolescence to young adulthood: findings from a 10-year longitudinal study. Journal of the American Dietetic Association, 111, 1004–1011. 10.1016/j.jada.2011.04.012 [PubMed: 21703378]

Neumark-Sztainer D, Wall M, Story M, & Standish AR (2012). Dieting and unhealthy weight control behaviors during adolescence: associations with 10-year changes in body mass index. Journal of Adolescent Health, 50, 80–86. 10.1016/j.jadohealth.2011.05.010

Ostlund U, & Persson C (2014). Examining family responses to family systems nursing interventions: An integrated review. Journal of Family Nursing, 20, 259–286. [PubMed: 25026964]

Pastore LM, Patrie J, Morris WL, Dalal P, & Bray MJ (2011). Depression symptoms and body dissatisfaction association among polycystic ovary syndrome women. Journal of Psychosomatic Research, 71, 270–276. 10.1016/j.jpsychores.2011.02.005 [PubMed: 21911106]

Ryan P, & Sawin KJ (2009). The individual and family self-management theory: background and perspectives on context, process, and outcomes. Nursing Outlook, 57, 217–225. 10.1016/j.outlook.2008.10.004 [PubMed: 19631064]

Sandelowski M (2010). What's in a name? Qualitative description revisited. Research in Nursing and Health, 33, 77–84. [PubMed: 20014004]

Sandelowski M, (2000). Whatever happened to qualitative description? Research in Nursing and Health, 23, 334–340. [PubMed: 10940958]

Tehrani FR, Simbar M, Tohidi M, Hoseinpanah F, & Azizi F (2011). The prevalence of polycystic ovary syndrome in a community sample of Iranian population: Iranian PCOS prevalence study. Reproductive Biology and Endocrinology, 9, 39 10.1186/1477-7827-9-39 [PubMed: 21435276]

Thomson RL, Buckley JD, Lim SS, Noakes M, Clifton PM, Norman RJ, & Brinkworth GD (2010). Lifestyle management improves quality of life and depression in overweight and obese women with polycystic ovary syndrome. Fertility and Sterility, 94, 1812–1816. 10.1016/j.fertnstert.2009.11.001 [PubMed: 20004371]

Trent ME, Rich M, Austin SB, & Gordon CM (2002). Quality of life in adolescent girls with polycystic ovary syndrome. Archives of Pediatric Adolescent Medicine, 156, 556–560. 10.1001/archpedi.156.6.556

Wang ET, Calderon-Margalit R, Cedars MI, Daviglus ML, Merkin SS, Schreiner PJ, …Bibbins-Domingo K (2011). Polycystic ovary syndrome and risk for long-term diabetes and dyslipidemia. Obstetrics and Gynecology, 117, 6–13. [PubMed: 21173640]

Table 1.

Focus Group Outline

Group	Focus Group #	Exemplar Questions
Parents	1	What is your understanding of PCOS? How did your daughter's diagnosis of PCOS impact you/your family? • Emotionally? Nutrition? Exercise? Medical Appointments? What was it like to access healthcare for your daughter? Did you (or other family members) seek information regarding PCOS? Where did you seek information? How did your daughter appear to cope with a diagnosis of PCOS? What are your primary concerns related to a diagnosis of PCOS? What barriers or facilitators did you experience in assisting your daughter manage her PCOS?
Adolescents	1	What is your understanding of PCOS? What is most distressing about PCOS? What do you do to manage your PCOS? How important is it for you to manage your PCOS? What should other women know about having PCOS? What do you wish you would have known when you were first diagnosed with PCOS? What are some of the major barriers to self-management? What types of things motivate you to eat healthy and exercise? How did your family help you manage your PCOS?
	2	Critique a variety of healthy lifestyle and disease specific self-management interventions/educational materials (including internet websites and mobile-based apps) for strengths, weaknesses, and relevance to PCOS.