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Transition to Self-Management among Adolescents with Polycystic Ovary Syndrome: Parent and Adolescent Perspectives[☆]

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ABSTRACT

Purpose: Polycystic ovary syndrome (PCOS) is the most common endocrine disorder among females. The foundation of PCOS self-management is engaging in healthy lifestyle habits, however, there is limited literature regarding adolescents' transition to PCOS self-management. The purpose of this study, therefore, is to explore parental and adolescent views of the transition to PCOS self-management.

Design and methods: A qualitative descriptive approach was used through focus groups ($N = 4$) with adolescents diagnosed with PCOS and their parents.

Results: A total of seven adolescents and eight parents participated in two focus groups each. The primary theme from the parent groups was *Concerns for Transition to Self-Care* with the subthemes of *facilitation versus direction* and *recognition of personal habits*. The primary theme identified from the adolescent groups was *Taking Control* with subthemes of *managing symptoms, cognitive dissonance, support, and balance*. Conclusions: Study findings provide insight into the experiences of adolescents with PCOS and their parents as they navigate both a family-level transition in health habits and anticipate the adolescent transition to self-management as an emerging adult.

Practice implications: Nurses and other health care providers can help facilitate transition to self-management among adolescents with PCOS by encouraging increased independence in health behavior decisions while they are still living at home. Middle and older adolescents who begin to take ownership of their physical activity, nutritional choices, and sleep hygiene will have a firm foundation on which to build as they transition into life beyond high school.

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Polycystic ovary syndrome (PCOS) is the most common female endocrine disorder. Prevalence rates vary depending on the diagnostic criteria used, resulting in estimates from 7 to 26% (March et al., 2010; Michelmore, Balen, Bunger, & Vessey, 2003; Tehrani, Simbar, Tohidi, Hoseinpanah, & Azizi, 2011). PCOS can manifest at a young age, and increased recognition of morbidity and potential mortality associated with suboptimal management of PCOS has resulted in a call for improved recognition early in adolescence (Bronstein et al., 2011). A PCOS diagnosis during adolescence has implications for the entire family unit, because optimal self-management can include both individual- and family-level therapeutic changes in lifestyle (e.g., healthy nutrition, increased physical activity, adequate sleep). But the adolescent and her family do not just transition to habits related to healthy lifestyle behaviors; often she must prepare for her additional transition to independent

self-management of PCOS in life after high school. To enhance patient-centered care, nurses and other healthcare providers must understand adolescents' and parents' views of this transition.

Background

Women with PCOS are at high risk for developing obesity, metabolic syndrome, diabetes, and cardiovascular disease (Bates & Legro, 2013; Chittenden, Fullerton, Maheshwari, & Bhattacharya, 2009; Ehrmann, 2005; Morgan, Jenkins-Jones, Currie, & Rees, 2012; Wang et al., 2011). After controlling for BMI, a recent meta-analysis identified a two-fold increased risk of arterial disease in patients with PCOS as opposed to those without (De Groot, Dekkers, Romijn, Dieben, & Helmerhorst, 2011). And although obese women with PCOS are three to four times more likely to develop diabetes than women without PCOS, women with PCOS and normal BMI are also two to three times more likely to develop diabetes than women without PCOS (Wang et al., 2011). In addition to these cardiometabolic complications, women with PCOS have high rates of infertility and are at three times greater risk of endometrial hyperplasia and endometrial cancer than their unaffected peers (Boomsma et al., 2006; Chittenden et al., 2009).

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Adolescents and adults with PCOS are also disproportionately affected by adverse psychological outcomes. In a large retrospective study, women diagnosed with PCOS showed a significant increased risk of depression, anxiety, bipolar disorder, and eating disorders in comparison with matched controls (Berni, Morgan, Berni, & Rees, 2018). Indeed the prevalence of depressive and anxiety disorders in women with PCOS has been found to be as high as 34–40% (Dokras, Clifton, Futterweit, & Wild, 2012; Hollinrake, Abreu, Maifeld, Van Voorhis, & Dokras, 2007). Additionally, in a cross-sectional study, Trent, Rich, Austin, and Gordon (2002) found that adolescents with PCOS experience lower health-related quality of life than did their unaffected peers.

The management of PCOS in adolescents is grounded in lifestyle modification, with increased physical activity and weight loss in overweight and obese girls leading to reduction in androgen levels and improvement in menstrual regularity (Hoeger et al., 2008; Lass, Kleber, Winkel, Wunsch, & Reinehr, 2011; Ornstein, Copperman, & Jacobson, 2011). In adolescent girls, increased moderate to vigorous physical activity and weight loss also contribute to improvement in cardiovascular risk factors associated with PCOS (Harrison, Lombard, Moran, & Teede, 2011; Reinehr et al., 2016).

The complex physiology of PCOS makes medical management difficult. Multiple medications target different components of the syndrome, so that treatment is highly individualized according to each adolescent's needs. Metformin is the only medication that has been studied specifically for improving insulin sensitivity in adolescents with PCOS; in combination with lifestyle change, metformin can improve menstrual regularity and BMI (Naderpoor et al., 2015). Combination estrogen/progesterone oral contraceptives can also improve menstrual regularity and decrease effects of elevated androgen levels including excess hair growth and acne. Anti-androgen medications can be used to mitigate effects of elevated androgen production as well, with spironolactone being the most common. Pharmacologic intervention, however, is only one component of PCOS self-management; lifestyle modifications are critical. This can create challenges for both adolescent and family self-management, because changes in lifestyle often have implications for the family unit.

Self-management has been defined as the “interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition.” (Modi et al., 2012, p. e474). An understudied component of adolescent health care transitions is the shift from parent-directed disease/condition management to adolescent-directed self-management when the primary activities of optimal self-management include maintaining healthy habits. Although we have found no studies of this transition in adolescents with PCOS, a phenomenological study examining transition to self-management in adolescents with type 1 diabetes has identified the need for adolescents to develop autonomy within a framework of parental support and encouragement (Karlsson, Arman, & Wikblad, 2008). Clinical practice guidelines for management of newly diagnosed type 2 diabetes in children and adolescents speak to the importance of involving the family in making lifestyle changes to achieve therapeutic targets (Copeland et al., 2013). The guidelines fail, however, to provide practice suggestions for how clinicians can support the transition to self-management as the adolescent approaches the end of traditional adolescence (i.e., 18 years). Gaining a deeper understanding of adolescents' and parents' views regarding the adolescent's transition to independent self-management is necessary to inform the way in which nurses and other health care providers approach transition planning. The purpose of this study, therefore, is to explore parents' and adolescents' views of the transition to PCOS self-management.

Methods

Design

A qualitative descriptive approach (Sandelowski, 2000, 2010) was used to explore the phenomenon and processes of PCOS self-

management from the perspectives of adolescents with PCOS and the perspectives of their parents, obtained in focus groups.

Sample and setting

Adolescents ages 14–18 years with a diagnosis of PCOS and their parents were recruited through an adolescent medicine clinic located in a large city in the south central United States. Two medical providers (one physician and one pediatric nurse practitioner) within this clinic specialize in PCOS and other menstrual dysfunction conditions. Parents and adolescents were able to participate independently (i.e., an adolescent did not have to participate if her parent wished to participate and vice versa). Participants were recruited with study flyers and on site by research study staff.

Data collection

All study procedures were approved by The University of Texas at Austin's institutional review board and by the Ascension Seton Family of Hospitals. From December 2017 to April 2018, four focus groups (two with the adolescents, two with the parents) were conducted to explore the processes and experiences of self-management of PCOS. The Individual and Family Self-Management Theory (Ryan & Sawin, 2009) provided the theoretical framework for developing the discussion guides for the first focus group. Discussion guide prompts asked participants to describe the context (e.g., access to care, literacy, developmental stage), and processes (e.g., self-regulation skills and abilities, self-efficacy, social facilitation) related to PCOS self-management at the individual and family level. The primary prompts for the parent and adolescent discussion guides were the same with some modifications for relevance (e.g., Parent group: “What barriers or facilitators did you/do you experience in assisting your daughter manage her PCOS?”; Adolescent group: “How does/did your family help you manage your PCOS?”).

An iterative process with a series of focus groups with the same participants was used as the goal of the overall project was to engage parents and adolescents in the development of a mindfulness-based healthy lifestyle intervention tailored to the needs of adolescents with PCOS. After the first focus groups discussing experiences of self-management, participants returned for a second focus group approximately one month later. Themes from the first focus group were presented to participants for discussion, and feedback was obtained on preliminary intervention materials.

To maximize participants' convenience, the adolescent and parent groups were held concurrently at the same location but in separate private conference rooms. Each focus group had one primary facilitator (either the principal investigator or a graduate research assistant [GRA]) and one additional trained study staff member (GRA or undergraduate RA) who recorded field notes and distributed demographic questionnaires and gift cards at each session's end. Each focus group lasted 50–75 min and was audio recorded; the audio recordings were transcribed verbatim by a third party company with secure file management, secure account information, and data security.

Data analysis

Analysis of themes obtained in this study was done from an essentialist/realist perspective (Braun & Clarke, 2006). Interpretation was minimal, because the researchers, who were interested in the participants' experiences, actions, and realities, sought to describe these as closely to the data as possible (Sandelowski, 2010). Two investigators independently read all text data and identified patterns (themes) in the data that addressed any component of the transition to independent self-management. The two investigators then discussed the identified

themes; finding that they were in agreement about primary themes, they did not require the assistance of a third analyst.

Results

Sample

The final sample comprised seven adolescents and eight parents. All eight parents had a child in the adolescent focus group (the mother and father of one adolescent participated in the first parent group), although this was not required. The ages of the adolescent participants ranged from 15 to 18 years, with a median age of 15. The parents' ages were not collected. The parents reported that they had attempted to obtain a diagnosis for their daughters' symptoms over a period of 6 months to 2 years, yet the mean age at diagnosis for PCOS was 14 years. Hispanic ethnic heritage was reported by four adolescents and five parents. One adolescent/parent pair reported non-Hispanic White; one, non-Hispanic Black; and one, Asian ethnic heritage.

Focus group findings

Fig. 1 presents the themes and subthemes of the transition to independent self-management that were identified in the data from the parent and adolescent focus groups. The primary theme from the parent group was *Concerns for Transition to Self-Care*. The primary theme from the adolescent group was *Taking Control*.

Parents: concerns for transition to self-care

In the parent group, the subthemes of the primary theme *Concerns for Transition to Self-Care* were *facilitation versus direction* and *recognition of personal habits*. Parents recognized that the developmental stage at which their children were diagnosed with PCOS was

challenging, and this compounded the issue of transition to independent self-management.

Facilitation versus direction

Parents were frustrated as they perceived that they had a limited amount of time to move from the role of “director” of the adolescent's self-management to a more facilitative role. They expressed a sense of urgency to instill intrinsic motivation for effective self-management before their teens began their post-high school endeavors but voiced a lack of knowledge of how best to do this:

“How we make our kids take control. My daughter is going to be off in one year, right? So at some point, she's not going to have us to remember her, ‘Okay, don't eat this.’ Or, ‘Eat that.’ Or, ‘Remember to go and exercise.’ At some point, they have to take control of their own treatment ... So, how we can help them to get ownership of their own treatment.”

(Father #1)

“We're helping her understand that, you know what, you need to take care of yourself. We won't be around ... we had to teach her that once you get to 18, you are on your own.”

(Father #2)

Further highlighting components of *facilitation versus direction*, one parent struggled with knowing the best way to intervene when seeing his daughter make unhealthy food choices:

“Sometimes when I see my daughter eating like fast food, for instance, she is not thinking about the effects it's going to take. She's just enjoying that moment. [She needs] to connect that what you are eating today is going to have an impact on the goal you have established.”

(Father #1)

Facilitation versus direction was also seen as parents strove to support their children through experiences related to physical manifestations of PCOS that they viewed as discriminatory or unfair. One

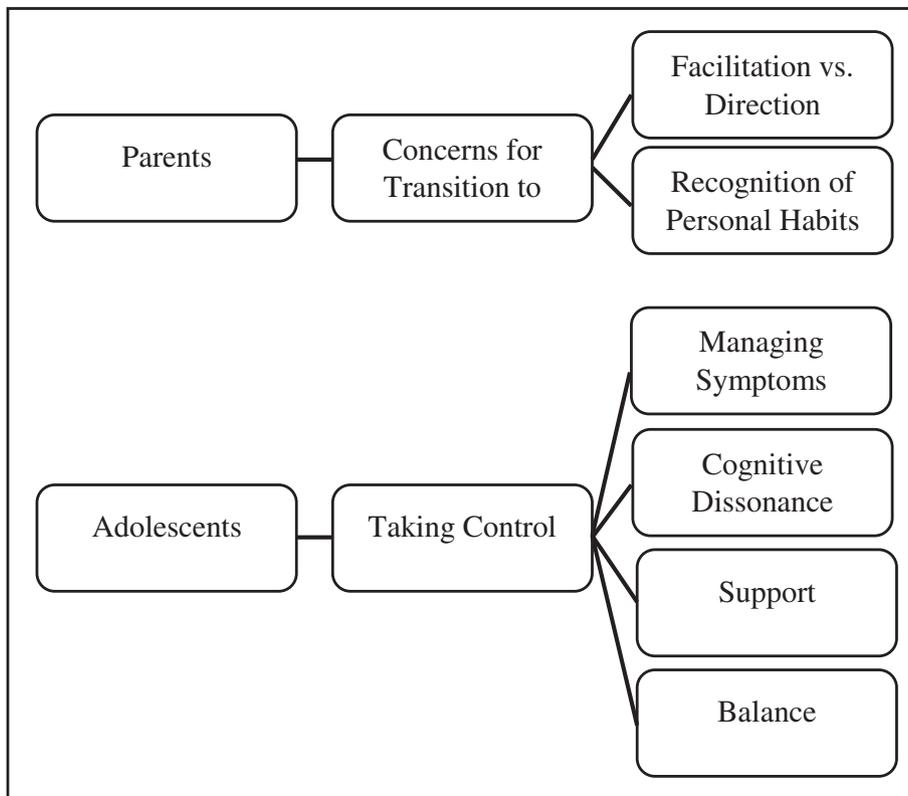


Fig. 1. Parent and adolescent primary themes and sub-themes.

parent shared his frustration about how to support his daughter after she did not make her high school's dance team for the third year in a row:

"I think there is the school system, the teachers, they don't understand it and they don't know how to cope with it. And how to deal with children with this condition, right? ... They don't know how to be fair with them. We just went through this. My daughter has danced all her life ... She has been taking private lessons, etc. for years and her technique is very good... She tried for the third time last week, and she was rejected again. We wrote a very serious letter to the teacher last year because I don't see that the reason is her dance technique."

(Father #1)

He spoke to the difficulty of trying, as a family, to support her through this disappointment yet falling short of being able to explain what he believed was the true reason for the rejection. In his view, the teams were trying to maintain a certain aesthetic that his daughter did not fit.

Recognition of personal habits

Recognition of personal habits was identified in parents' stories of adjusting to the diagnosis and management of PCOS and through acknowledgment of their need for self-reflection into their own health habits:

"I mean, I don't have control if I see sweets and all. If I don't eat, I don't eat. But, if I eat start eating like one more thing. It's okay. You live only once. And then, I can see- but, I try not to tell her, 'It's detrimental to you.' Because she is already just living through the whole thing."

(Mother #4)

"We had a routine that we would go out to eat. And, I'm talking about flip a coin, McDonald's, Burger King, Wendy's, Outback, whatever, and now it's changed the point that we eat at home. We have crockpot meals. I didn't get like this by eating salads. It's my fault too, so."

(Father #2)

"We changed our way of eating as a whole family and then we try to exercise, but we don't do so great at that now."

(Mother #1)

Adolescents: taking control

In the adolescent group, the subthemes of the primary theme *Taking Control* were *managing symptoms, cognitive dissonance, support, and balance*. The experiences described by the adolescents included an increasing recognition of the need to take an active role in self-management and a shift in perspective that allowed for a more positive outlook and decreased stress. The following quotes from the adolescents capture the process of *Taking Control*:

"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. At the beginning of this year, like the first two months, I lost a lot of weight..."

(Adolescent #2, 17 years)

"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. So, you can still eat well and exercise and do things that you like to do, and lead a happy life. And that is on you and not everything is hopeless."

(Adolescent #3, 17 years)

Managing symptoms

The adolescents spoke about experiencing symptoms of PCOS such as irregular periods, excessive hair growth, and weight gain:

"I kinda struggled the same with her, like my insulin. I was gaining a lot of weight."

(Adolescent #1, 16 years)

"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."(Adolescent #6, 15 years)

"I don't have irregular periods, but body hair and symptoms she explained."

(Adolescent #5, 15 years)

"Like for sure irregular periods even though they're getting more regular with time, and then weight gain is one of them. It's like hard to lose, hard to keep off, yeah, high testosterone."(Adolescent #2, 17 years)

These participants recognized that hormones were involved in their symptoms but felt that they lacked a true understanding of their pathophysiology. They spoke of distress associated with not knowing when their periods would arrive (particularly while in school) and the embarrassment of not fitting into uniforms/costumes associated with extra-curricular activities. Initially, managing the symptoms of PCOS created feelings of helplessness and isolation, but over time these teens felt that they improved in their ability to take control (the primary theme) of symptom management.

Cognitive dissonance

The subtheme of *cognitive dissonance* manifested as adolescents navigated how to engage in optimal self-management in a world not always conducive to or supportive of healthy decisions. Part of the normal adolescent developmental trajectory includes increasing influence and desire to be accepted by one's peers, and making consistent healthy self-management choices was complicated by feelings of not wanting to be perceived as different from peers:

"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 is not. You don't want to bum everyone out."

(Adolescent #1, 16 years)

Sometimes friends' and/or families' efforts to support adolescents' healthy decisions were not welcome:

"Okay, so there's a slice of cake. It's somebody's birthday. All right. I guess I'll eat, but then everyone will say; wait, I thought you weren't supposed to eat sugar. Are you sure about that? [But] you don't know that I haven't had sugar all week; you don't know that I've been waiting—like this is my treat, right—you don't know that."

(Adolescent # 4, 17 years)

Cognitive dissonance also emerged in stories of personal struggles with self-management in which the adolescents believed that they were doing everything "right" but they continued to gain weight. This dissonance between perceived actions and actual outcomes created personal self-doubt and self-judgement, which led to significant psychological distress:

"it's been a real big struggle this past year. There are times that I lose weight, and I'm really good and then there's time where I just gained so much weight, it's incredible, and it's like what happened and I'm doing everything right. 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."

(Adolescent #2, 17 years)

"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 just kind of, okay, I'll just live with it."

(Adolescent # 3, #17 years)

Support

The adolescents spoke of the importance of utilizing all available support systems but also expressed a desire to reciprocate their parents' support:

"For me, it's been like, I want to make sure that my parents know that I want to support them as much as they support me. So, I feel if they ever needed anything I'd be like the first person to be there. And for me, I was talking to my mom and she was like, just seeing you take charge of your life is, as a mother, is amazing to see. So, just being health and starting to—she doesn't have to be on top of me and I'm starting to do my own thing."

(Adolescent # 3, 17 years)

Although some of the adolescents reported that family members were not supportive of their efforts at self-management, they did feel supported by the clinic staff, and all had at least one parent who was supportive. They also shared "lessons learned" from their own experiences of accepting support:

"[Other adolescents] should know that there is things they can do, and I feel at the beginning I really closed off ... and I closed off to everybody that tried to talk to me about it. And then, I realized ... the people around me are trying to help me. So, if I'm honest with my doctors and honest with my mom, and just getting all the help is the best thing I couldn't done."

(Adolescent #2, 17 years)

Balance

Balance characterized the way in which the adolescents felt that they were achieving optimal self-management. As in the quote that referred to choosing to eat a piece of birthday cake as a treat for avoiding sugar in the prior week, the adolescents shared personal stories and definitions of what finding a sustainable balance meant to them:

"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. And so, now like I go do a really good workout three times a week and I'm holding back on just binge eating like I used to, and reminding myself you have to eat healthy things, because not eating shouldn't be an option. And then, getting that all to balance out has been helpful with like regulating my periods and then just making my mood better. Because I used to be really really bad."

(Adolescent # 3, 17 years)

"I can't eat a lot, I just can't eat a lot, but then I finish my plate, I feel like I'm stuffed. Then like after an hour or two, I'll get hungry and then I'm like trying to pick at things, but I'm like I can't be doing this. I'm not gonna be losing weight if I keep doing this. So, I try to go for fruits, something better. So, my mom, always has cucumbers in the house already precut, so I can just get some, and try to like distract my hunger."

(Adolescent #1, 16 years)

Discussion

To our knowledge, this is the first report to document parents' and adolescents' concerns regarding the transition to independent self-management among adolescents with PCOS. The parental theme and subthemes *Concerns for the Transition to Self-Management*, *facilitation versus direction*, and *recognition of personal Habits* represent experiences of parenting across normative adolescent transitions along with recognition of the increased complexity of parenting an adolescent with PCOS. Among the adolescents, the primary theme of *Taking Control* was woven throughout their narratives of accepting a PCOS diagnosis, living with their PCOS diagnosis, and discovering ways to establish their own self-management practices, which were represented by the subthemes of *managing symptoms*, *cognitive dissonance*, *support*, and *balance*.

The juxtaposition of the adolescents' primary theme of *Taking Control* of their self-management and the parents' *Concerns for the Transition to Self-Management* (i.e., expressing that they were not confident about their adolescents' ability to independently self-manage) suggests a need

for family-level interventions in this population. The findings of this study align with those of *Karlsson et al. (2008)*, who identified that the transition to autonomy among adolescents with type 1 diabetes was characterized by "hovering between individual actions and support of others" (p. 566). Collaborative conversations facilitated by nurses and other health care providers can provide a therapeutic environment within which parents can better understand the attitudes and actions of their children as they take ownership of their self-management. Within the same context, adolescents can better understand the concerns of their parents, and families can explore ways to navigate self-management conversations.

The majority of the literature on adolescent health transitions has focused on structural and logistical aspects of transition from pediatric to adult care (*Bloom et al., 2012; Reiss, Gibson, & Walker, 2005; White, Cooley & Transitions Clinical Report Authoring Group, 2018*). Successful navigation is indeed essential for effective medical transition, but the specific nature of the transition from parental management to independent self-management has received very little attention. The findings of the present study, along with the work of others (*Giarelli, Bernhardt, Mack, & Pyeritz, 2008; Karlsson et al., 2008*), highlight the need to conduct theoretically grounded investigations to clearly define factors (i.e., personal, community, and society), processes, and expected outcomes involved in transition to self-management for adolescents with PCOS. An ideal framework to examine the adolescent's experience of this transition to self-management is provided by transitions theory (*Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000*), which specifically recognizes that transitions are not mutually exclusive, allowing for consideration of the transition to PCOS self-management superimposed on the normative adolescent developmental trajectory. Moreover, a thorough understanding of the "properties and conditions inherent in a transition process will lead to the development of nursing therapeutics that are congruent with the unique experiences of clients and their families" (*Meleis et al., 2000, p. 27*).

Although the present research focused on the experiences of transition to independent self-management, significant distress associated with the physical manifestations of PCOS (e.g., hirsutism, weight gain/difficulty losing weight, irregular periods) was apparent within both the parent and adolescent groups. This is strongly consistent with the literature that documents highly prevalent psychological issues associated with body image and self-esteem (*Emeksziz et al., 2018; Holsen, Kraft, & Røysamb, 2001; Jones, Hall, Lashen, Balen, & Ledger, 2011*). The most common health-related quality of life concern reported by adolescents and women with PCOS is associated with their weight (*Jones et al., 2011; Jones, Hall, Balen, & Ledger, 2008; McCook, Reame, & Thatcher, 2005; Trent, Austin, & Rich, 2005*). Interestingly, although concerns about fertility and romantic partners have been identified in other studies of adolescents (*Jones et al., 2011; Trent, Rich, Austin, & Gordon, 2003*) and adults with PCOS (*McCook et al., 2005; Schmid, Kirchengast, Vytiska-Binstorfer, & Huber, 2004*), these issues were not identified in the present study. This may be due to the fact that the study's theoretical framework and focus group discussion guide focused on the self-management of a chronic condition (i.e., in terms of an individual and family self-management theory; *Ryan & Sawin, 2009*). Identification of concerns about weight, irregular menses, and body hair emerged within this self-management context, and perhaps neither the adolescents nor the parents linked current self-management with potential future fertility issues.

Limitations

Several limitations to this study should be noted. First, the adolescent and parent samples were small. This small sample was offset by meeting with each focus group twice, so that participants were given the opportunity to hear themes identified in the prior groups. Participants were then able to further reflect on their experiences of living with and managing PCOS. Second, in the adolescent group, conversations were dominated

by the older adolescents, so that the perspectives of younger adolescents were not as strongly voiced. Of course the older adolescents were farther along in their transition to self-management. Future investigations specifically with younger adolescents closer to the time of diagnosis are warranted. In the parent group, two participants spoke Spanish as their primary language. Although these participants were active in the discussion, it is likely that a group conducted in their native language would have enabled a more nuanced discussion of their experiences.

Implications for future research

This study's findings point to a substantial need for theoretically grounded research examining the transition to self-management among adolescents with PCOS. Meleis et al.'s (2000) transitions theory is an excellent example of a guiding framework to systematically evaluate the experience of transitions. Gaining a deeper understanding of the components and processes of the numerous transitions navigated by adolescents with PCOS should provide crucial evidence for the development of tailored interventions for this high-risk population. Longitudinal studies that examine adolescent self-management behaviors and trajectories of health outcomes pertinent to females with PCOS (e.g., hemoglobin A1c, BMI, blood pressure) could further inform nursing interventions to support successful transitions.

Clinical implications

Nurses and other health care providers can help facilitate transition to independent self-management among adolescents with PCOS by encouraging increased independence in health behavior decisions while adolescents are still living at home. Encouraging an adolescent to participate in meal planning and grocery shopping will reinforce family-level involvement while also allowing the adolescent to make decisions regarding nutrition. For physical activity and sleep, the use of tracking behaviors and specific, measurable goals (e.g., "I will walk for 30 minutes three times per week") are helpful tools for both adolescents and providers. Such metrics allow modification based on outcomes. For example, if reached, can the goal become more ambitious? If not reached, what barriers prevented attainment and how can those barriers be overcome? Working through this process with a nurse or other health care provider can help facilitate increased autonomy over self-management behaviors and provide a firm foundation as adolescents transition into life beyond high school.

Conclusion

Adolescents diagnosed with PCOS are faced with making the transition to self-management within a much larger context of normative adolescent development and the family life cycle. This study is the first to examine parental and adolescent concerns regarding the transition to independent self-management, and the themes identified here can inform nursing practice with families coping with a PCOS diagnosis. Although additional research is clearly needed in order to achieve a fuller understanding of this complex phenomenon, it is clear that family and adolescent involvement may help both parents and adolescents develop the motivation and skills to engage in optimal self-management.

CRedit authorship contribution statement

Cara C. Young: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing. **Lynn Rew:** Funding acquisition, Investigation, Methodology, Formal analysis. **Maria Monge:** Conceptualization, Writing - original draft.

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