“I didn’t feel normal”: Young Canadian women’s experiences with polycystic ovary syndrome

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Abstract
Polycystic ovary syndrome (PCOS), which affects 8 to 13% of reproductive-aged women, is a highly gendered disorder whose symptoms disrupt Western conceptions of femininity. This may be especially debilitating for young women, who are targeted by societal discourses governing how they “should” be. We interviewed 10 young Canadian women, aged 18 to 22, about how PCOS has influenced and/or conflated their conceptions of identity and (ab)normality within the current socio-cultural context. Using reflexive thematic analysis through a critical feminist lens, we present three themes: justifying abnormality, pathologizing the abnormal, and fear of failure in pregnancy. Young women described feeling “weird” and “not normal” as a result of their symptoms and expressed worries about their ability to adhere to gendered expectations. We argue that the blanketing of these desirable states as “normal” has pervasive

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implications for women’s lives and leaves them feeling defective and/or inadequate, which was further reinforced by implicit, gender-based power dynamics in medical institutions when women sought care. We suggest the need for engagement with discomfort and leveraging PCOS as a unique entryway into an analysis of intersectional issues to capture complexities in lived experience.

Keywords
polycystic ovary syndrome, young women, critical feminist inquiry, reflexive thematic analysis, Canada

Polycystic ovary syndrome as a deviation from Western femininity ideals

Feminist scholars have long posited that women live in a patriarchal, androcentric context in which they are viewed either as inferior or irrelevant to the understanding of human experience (hooks, 1990; Lips, 2016; Tavris, 1993). Within that context, a woman’s body is both gendered¹ and medicalized (Rosser, 1989; Young et al., 2019), and discourses about how women’s bodies “should” look and function persist in Western society (e.g., thin, hairless, fertile; Chrisler, 2011; Fahs, 2012). Women’s adherence to these rigid standards is necessary to achieve and remain within the bounds of normative femininity (Chrisler, 2013). Failure to comply creates the risk of being othered, and possibly framed as disordered and/or in need of alteration and control (e.g., Bartky, 1997; Piran, 2017; Shildrick, 1997). Often, women engage in body work to align themselves with societal expectations (Piran, 2017); however, this is difficult when living with a chronic health condition whose features contradict what is societally desired. One condition is polycystic ovary syndrome.

Polycystic ovary syndrome (PCOS) is a highly gendered endocrine disorder that mostly affects reproductive-aged women (Teede et al., 2018). The most recent estimates from a meta-analysis of studies from clinic, hospital, and community settings suggest that about 8% to 13% of reproductive-aged women have PCOS (Bozdag et al., 2016). PCOS is characterized by an imbalance of estrogen and testosterone in the body, the former of which is often associated with the female body and the latter of which is associated with the male body (though “sex hormones” preserves sex-dualistic models of hormones and ignores their social construction; Nehm & Young, 2008). Women experience debilitating symptoms, including disrupted menses (e.g., menstrual periods lasting longer than the average five to seven days); excess hair growth in undesirable places (e.g., stomach, buttocks), though what is deemed desirable regarding body hair quantity and placement is dictated by social and cultural convention (Toerien & Wilkinson, 2003); acne; hair loss; and/or higher body weight (Teede et al., 2018). Further, many
women with PCOS experience higher rates of anxiety, depression, and/or disordered eating and lower quality of life compared to women without PCOS (e.g., Deeks et al., 2010). Women with PCOS also experience impairments in sexual activity (e.g., dissatisfaction), as defined by women themselves and by scales developed to interpret what sexual (dis)satisfaction and (dys)function mean based on medical definitions of normative heterosexuality (Pastoor et al., 2018).

Thinking long-term, women who have PCOS are at risk for comorbid health concerns. These include type II diabetes, stroke, cancers (e.g., endometrial cancer; Teede et al., 2018), and possible infertility (though the evidence is inconsistent; Joham et al., 2015; Persson et al., 2019). Infertility has been noted as particularly troublesome for some young women as they report experiencing social pressures (e.g., from intimate male partners, family, popular culture, the medical system) to bear children, especially as they age and begin planning their futures (Gotlib, 2016).

Although having PCOS can be difficult, perhaps one of its clearest impacts has been on women’s body image. Quantitative and qualitative findings have illuminated its impact on women’s connection to their bodies. In Kitzinger and Willmott’s influential (2002) paper, they summarized a key issue of PCOS: “PCOS...poses a fundamental challenge to the social construction of ‘womanhood’ and notions of ‘femininity’” (p. 359). Indeed, women described looking like “freak[s],” “hairy monster[s],” and “bearded lad[ies]” as a result of their outwardly male-presenting symptomatology (pp. 353–4). Also, Deeks et al. (2011) observed that women with PCOS had a more negative body image as compared to women without PCOS, and Kogure et al. (2019) demonstrated that women who have PCOS had perceptual self-image distortions. Recently, women with PCOS in Thorpe et al.’s (2019) study depicted self-portraits of what they described as their misshapen body form and size and they used linguistic descriptors of “ugly,” “broken,” “fat,” and “judged” to reference their bodies while also expressing concerns that no one could relate to their experiences.

The unique and underrepresented experiences of young women with PCOS

While normative expectations for bodily appearance and function are culturally dictated and exist in all societies (e.g., Suleymani, 2020), our focus is on Western society to fill a notable literature gap on (young) women’s experiences with PCOS in a socio-cultural system that strongly reinforces gender-based expectations. Although the ubiquitous cultural appearance and femininity-related discourses are generally aimed at women, young women may be especially vulnerable to and feel the most pressure from those messages (e.g., Gilligan, 1982). Feminist theorists have grappled with the unique challenges of young women’s lives. For example, some have documented that a shift occurs between girlhood and adolescence/early adulthood that switches the focus from themselves to how others
perceive them (Brown & Gilligan, 1992; Collins et al., 2009). Early on, girls become aware of gender role expectations and are supposed to conform accordingly (e.g., dressing in gender-aligning clothing when engaging in play; Rice, 2014). Progressively, socio-cultural pressures to be petite, nice, quiet, sexually available, and eventually fertile emerge (Brown & Gilligan, 1992; Collins et al., 2009; Jacques & Radtke, 2012).

Adolescence also brings expectations that young women engage in body surveillance and alteration (Thompson & Stice, 2001). Young women’s bodies are seen as needing constant improvement to fit socially prescribed beauty standards (Rice, 2014). We know from limited previous research that young women differ in their experiences with PCOS. Soucie et al. (2021b) observed that emerging adult women who were concerned with the debilitating menstrual- and obesity-related symptoms felt less sexually attractive and physically fit as compared to women in midlife. Young women who do not conform to traditional gendered expectations are ostracized and otherized (Piran, 2017), but having PCOS creates additional complexity given the possible inability to achieve expectations. This is not to suggest that younger women may not have similar experiences to older women. Instead, we recognize that there are developmental and social differences between young women in their late teens/early 20s. Nevertheless, most research regarding PCOS in young women has focused on adolescent diagnostic guidelines (Peña et al., 2020; Teede et al., 2018). Thus, the unique experiences of young women with PCOS, set within a strict gendered context where the societal expectations that govern them are (re)produced, are missing from the existing scholarship.

The need for critical feminist inquiry into young women’s experiences with PCOS

de Beauvoir (2009 [1949]) argued that femininity is a threatened reality, one that is reinforced by idealized and inauthentic patriarchal ideals but that still requires alignment with expectations. Feminists (e.g., Chrisler, 2013) have identified the work that goes into attempts to achieve the nebulous idea of societally desired femininity. Feminists have questioned and opposed the societal expectations associated with other women’s health conditions, such as endometriosis, for example (Young et al., 2019, 2020). It makes sense that endometriosis would be a topic of feminist inquiry, especially given its threat to the expectations of women as sexually serving men and fertile. However, we were surprised to find scant critical feminist inquiry into PCOS experiences.

Despite notable exceptions (e.g., Kitzinger & Willmott, 2002; Soucie et al., 2021a), scholars have not attempted to deconstruct what is considered “normal” regarding societal expectations of normative femininity for (young) women with PCOS. Young women have to balance gendered power dynamics, such as the physician-patient relationship (Nimmon & Stenfors-Hayes, 2016). It may be especially challenging for them to voice their concerns about disruptive symptoms
when faced with a physician in a place of power, perhaps due to their age and/or gender. Indeed, no current scholarly work has considered the intersection of identity in (young) women’s experiences of PCOS, despite the value in studying the complexity of individuals’ lives. Since women occupy various social locations, knowing the ways these identities and power differentials intersect to create systems of oppression is important, and has been echoed in feminist urgings to engage in intersectional analyses (e.g., Purdie-Vaughns & Eibach, 2008). It may also be challenging because young women feel they are directly contradicting societal expectations through their experiences (e.g., Soucie et al., 2021a). Balancing gendered expectations and power differentials is a reality for young women with PCOS and a critical feminist inquiry is essential, especially as a way to consider the unique combination of identity-related aspects to experience. To fill this research gap and to bring a more critical understanding of a women’s health condition that, in some ways, violates societal expectations of femininity, we explored the following research question: How does having PCOS influence and/or conflate young women’s conceptions of (ab)normality in the current socio-cultural context?

Method

Participants

We received ethics clearance from the University of Windsor’s research ethics board (REB#34212) and conducted this study from November 2017 to April 2018. We sought young women for a larger study about Canadian women’s diagnostic experiences with PCOS. Canadian women diagnosed with PCOS by a medical professional in Canada were eligible to participate. We used several recruitment strategies, including a call in the local newspaper, flyers around campus, and offering course credit through the participant pool at our Southwestern Ontario university. Here, we chose to focus our analysis on the youngest women in our sample (n = 10), adopting Levinson’s (1986) description of this age range (i.e., 17–22; in our case, 18–22) as the developmental bridge between late adolescence/early adulthood. These women were uniquely positioned to describe experiences that accompanied having undergone adolescence and beginning to grapple with adulthood. Their ages ranged from 18 to 22 years, with a mean age of 20. Six of the women self-identified their ethnicity as White, two as Middle Eastern, and two as Middle Eastern and Mediterranean.

Interview

This study involved the construction of a diagnostic timeline as a guide for participants to recall significant details (e.g., tests completed, doctors’ appointments and the associated interactions, medications prescribed) while seeking a diagnosis that then informed the semi-structured interviews that followed ("using the timeline
you just created, please walk me through your diagnosis experience”). The interviews (on Skype™ or in-person) were approximately 60 minutes long and were conducted by the third and fourth authors. There was also a brief online component where we asked for demographic information to situate our sample. Participants provided their consent in written form (in-person) or electronically by clicking “I agree to participate” (online). The interview questions focused on the women’s diagnostic journeys, including their experiences seeking and receiving care in Canada before, during, and after diagnosis, as well as their navigation of balancing societal and cultural expectations with PCOS. Participants also discussed their experiences with PCOS and where they are now, after diagnosis, and what long-term concerns they have about their futures (see Soucie et al., 2021a, for the entire interview protocol). Participants were compensated with $20 for their time.

Analytic strategy

Our analytic strategy was reflexive thematic analysis (RTA; Braun & Clarke, 2019; Terry et al., 2017), which is a rethinking of the popularized thematic analysis approach (Braun & Clarke, 2006). RTA accounts for the researcher’s position and allows the researcher to construct and guide readers through a particular story within the data. What drew us to this approach was that it urges researchers to be thoughtful and deliberate, grapple with various research assumptions, and locate participants within the larger socio-political/cultural context. Generally, RTA is an iterative process that involves a continual bending back on itself. The data analysis process involves familiarization with the data, development of codes/labels of interest, generation of initial themes, and naming of themes (Clarke et al., 2019). This process is not formulaic or linear, but rather iterative and involves revising themes to capture the “best” way of presenting arguments.

The second author created transcription agreements that were signed by the first author and the research assistants and the first author and an undergraduate student transcribed the interviews verbatim. We identified women only by participant numbers and pseudonyms assigned by the first author and we removed identifying information that would compromise participants’ confidentiality from the typed transcripts. Once complete, the first author printed the transcripts and read through them many times, making notes in the margins in various colors to differentiate thoughts, impressions, and patterns in experiences. The other team members also familiarized themselves with the data and kept detailed notes. We stayed as close to the data as possible, and once everyone had compiled their notes, we bracketed similar segments of meaning units into chunks. From these chunked meaning units (either words or short sentences), we generated initial codes that captured the essence of what was said. We then integrated the codes, developed based on conceptual similarity, and generated themes, organizing concepts that defined similar, sometimes overlapping codes. Theme generation was iterative and required discussion of important issues (e.g., power).
Approach and reflexive process

We approached this research from a feminist social constructionist viewpoint, which recognizes that science and knowledge production create rather than reflect reality, and that researchers, located in a specific time and context, are part of the knowledge construction process (Wigginton & Lafrance, 2019). We also adopted a critical feminist lens in our exploration. Critical feminist psychology brings forth the problems with psychology’s narrow idea of the social, as well as its failure to critically reflect on the ways that knowledge is generated and is situated in a specific culture, time, and place (Lafrance & Wigginton, 2019). Critical feminist scholarship recognizes that language is anything but neutral and instead has meaning-making and power. Importantly, there is an acknowledgment of systemic oppression and a shared dedication among feminist scholars, ourselves included, to achieve equality and social justice (Braun, 2011).

Reflexivity involves awareness of one’s role in the research process and recognition that researchers are embedded in the social worlds they study (Dowling, 2006). Given the importance of reflexivity in RTA and critical feminist work (Lafrance & Wigginton, 2019), we wanted to position ourselves. We are all White women (though the first author identifies as Serbian-Canadian, having immigrated to Canada as a child). Two of us are Ph.D. Candidates in Applied Social Psychology and two of us are in Child Clinical Psychology (an M.A. student and a faculty member). Three of us reside in Southwestern Ontario, Canada, where healthcare is universal and publicly funded, while the fourth author resides in the USA. We recognize the privilege we have, given our academic affiliation. The first two authors are PCOS-diagnosed, which created a dual role for us. We are insiders who share the participants’ diagnoses, so we could relate to many of their experiences. We have questioned ourselves in comparison to societal expectations, and we recognize we are not exempt from these experiences. Alternatively, we acknowledge the power we have in drawing conclusions based on the participants’ experiences. Balancing these dual roles was important, and our team made sure to discuss them often. Social positions can influence the research process, so it was important to foster open discussions, which aided in our analytic process.

Findings and discussion

We present three themes that summarize participants’ experiences. Justifying abnormality explores the young women’s experiences of navigating bodily changes and struggling with the process of justification. Pathologizing the abnormal captures the young women’s pathologizing of PCOS features that they felt transgressed socially defined boundaries of femininity and normality. Finally, fear of failure in pregnancy describes the young women’s worries about possible infertility as a result of having PCOS and their concerns regarding future (largely heterosexual) relationships.
**Justifying abnormality: “You’re young, don’t worry about it”**

For most of the young women, the beginning of menstruation was when they first began noticing that something may not be “right” (e.g., skipping menstrual periods some months; Teede et al., 2018). Darci was told by her physician, “you’re still a teenager so things are changing.” Rayna experienced an unfamiliar symptom of PCOS: dark patches under her arms. She said, “[me and my family] just assumed, like, I might have burnt myself when waxing... it’ll be less when [I’m] older.” The unfamiliar changes were met by many participants with caution rather than concern. Regarding menstruation, for instance, there was a sense of preparedness where they knew that their first few menstrual periods would likely be irregular. This largely came from what they had heard from close others, such as Stacey, who had heard this was “very common... just, like, lack of periods completely almost.” Tina heard “from friends, a lot of people told me within the first year, it’s probably not going to be very regular. Expect that, so I just thought nothing of it, whatever.” Willa’s experience was similar: “when you first get your period, that’s, like, kind of, like, the standard, I guess. Where you never get it constantly.” We interpreted Willa drawing on “the standard” as an abstract yet also obvious and familiar reference point from which she could determine what is expected or normal for young women such as herself at that developmental stage. Doing so may have demonstrated how her experience aligned with the expected menstrual inconsistency for all young women within this new territory of female development. Some participants engaged in self-rationalization, where they worked to convince themselves that because they were young and undergoing life changes at a pivotal developmental time, their bodies just needed time to adjust. This aligns with findings from Copp et al. (2019), where one of the younger women doubted herself, thinking her symptoms (e.g., irregular menstruation) were not that serious. We also know from previous feminist scholarship that menstruation is sometimes viewed as taboo and should be “dealt with” quietly (e.g., Jackson & Falmagne, 2013). Thus, it came as no surprise when the young women, at first, did brush off these irregularities.

Others engaged in rationalization by drawing on other elements of their identity for justification. Mia spoke of experiencing a host of PCOS symptoms, including an abundance of hair growth, and for her, this was attributed, in part, to her ethnicity: “I would always shrug it off as like, oh, it’s ‘cuz I’m of Mediterranean and Middle Eastern descent, right? This is what goes on with the females in these countries, so it’s probably normal, right? So, genetic, right?” Unlike Willa, Mia compared her experiences to what is normal more directly by contrasting what she perceived as normal in her current context versus that of her ethnic descent (Mihailidis et al., 2015). We interpreted this as Mia’s attempts to distinguish herself as someone who should not be expected to conform to the same standards of appearance. This contrast is based on originating from an area where hair growth in women may be more prominent but currently living in a country where hairlessness is a desirable normative trait for women (Fahs, 2012, 2014).
Mia was not alone in seeking justification. Karleen, too, experienced rationalization of her symptoms from her parents, who said “you’re Italian, you have dark hair.” The reference to these young women’s ethnic descent was meant as an explanation for the onset of disruptive, confusing, and scary symptoms.

Not all of the women justified abnormal experiences to themselves. Most described justifications and/or dismissals from their family physicians or specialists, with their reasoning including age, stress, and/or ethnicity. Stephanie’s doctor brushed her symptoms off, citing stress:

He kept telling me ‘oh, it could just be an irregular period, don’t worry about it, it’s stress-related’ and I just knew it wasn’t. And I basically just said ‘trust me, it’s not’ and he said, ‘well, I’ve dealt with cases before.’

Karleen’s family doctor explained away her symptoms via age: “you’re young, don’t worry about it yet.’ Because I was so young, it was just kind of like brushed, and don’t worry about it ‘til later.” Darci’s physician went so far as to say, “it’s just a female problem,” attempting to diminish the seriousness of her concerns and suggesting that women’s concerns are less worrisome and require less attention. Stacey’s physician blamed her for her weight gain, saying “you’re really fat and you need to fix yourself.” Ample evidence of physicians discounting women’s symptoms in gendered ways exists, with many struggling to be believed (e.g., Young et al., 2019). Women often must justify themselves and establish credibility while not being “too much” to not be seen as whiney and dramatic (e.g., Sallinen et al., 2011). Our participants, in addition to experiences of expected development, also had to navigate the onset of upsetting symptoms while both justifying to themselves and having their symptoms justified by important others.

Pathologizing the abnormal: “I didn’t feel I was normal, I didn’t feel very womanly”

Previous feminist research has suggested that during the transition from girlhood to adolescence, girls switch to a focus on others, mainly concerning how others see them (Brown & Gilligan, 1992; Rice, 2014). Young women become more attuned to how they should present and behave, particularly in relational contexts (Gilligan, 1982). We saw this with our participants, who drew on their concerns for how others saw their bodies. Jenna said, “I used to be confident. I liked to wear what I wanted. Now, I’m so self-conscious. I don’t like how my body looks.” Similarly, Tina expressed vulnerability when saying, “I just felt so out of place.” Both Jenna and Tina drew on how others perceived them. Jenna expressed a dislike for her bodily appearance, which others would see, while Tina discussed how she felt in comparison to others, highlighting how she did not fit in as a result of having PCOS (Kitzinger & Willmott, 2002).
Almost all participants spoke about migrating from justification to pathologizing of their abnormal symptoms because of a coming to terms with the fact that in some ways, they were deviating from traditional conceptions of Western femininity (e.g., Kitzinger & Willmott, 2002). Irene struggled with knowing that something was wrong: “I had people telling me that there was nothing wrong with me when there was clearly something that isn’t normal and no one’s dug deeper.” Tina experienced acne and excess body hair and said, “being a 16-year-old girl, those symptoms are devastating. I didn’t feel like other girls. I didn’t feel I was normal. I didn’t feel very womanly.” She went on to question why she was getting symptoms that were “kind of male features.” Others used the language of “odd” (Rayna), “not normal” (Darci), and “[not] regular” (Stephanie) to describe changes in their menstruation, hair growth, weight, and motivation. The young women’s use of “not normal” and “unwomanly” is comparable to the language used by women in previous research (e.g., Kitzinger & Willmott, 2002). What sets this apart is the particularly devastating effect that the “abnormality” of PCOS has on young women. Tina referenced the masculine/feminine dichotomy and established rigid boundaries of femininity that she and others in our study violated because of their PCOS-related symptoms. This differentiation impacts how women think about and live in/with their bodies (Lorber & Moore, 2011). Also, invoking age in the young women’s reasoning of why PCOS is especially debilitating is important because it demonstrates the perception that they are, in some ways, violating the boundaries of what is expected and normal for their gender at that developmental time (Chiodo, 2015).

A couple of the women grappled with societal pressure more directly. Karleen discussed excess stomach hair that she noticed: “I actually had to start shaving ‘cuz, like, I just thought it was weird.” Jenna also referred to an implicit requirement regarding body hair: “I have all this facial hair that I have to get threaded, like, every few weeks.” The language of “having to” reinforces pressures to conform to expectations for fear of being othered (Fahs, 2014). Western femininity ideas are ubiquitous and resistant to change. Women receive societal messages from various sources, including loved ones and the media, about how they should present, ideally as thin and hairless (Fahs, 2012; Thompson & Stice, 2001). The current Western socio-cultural context, one where discourses governing women’s bodies are widely supported, may have made deviations from what is societally normal and acceptable especially difficult. The young women began pathologizing their experiences by attributing them to something abnormal (“weird”) and that needs fixing (Thompson & Stice, 2001). Two prominent examples that the young women in our study referenced were the pathologizing of fatness (e.g., Murray, 2008) and of body hair (e.g., Fahs, 2012). This pathologizing led to all of the young women we spoke with seeking some sort of corrective medical intervention (e.g., oral contraception for hormonal regulation, diet plans that restricted caloric intake) from a qualified professional. Their pathologizing expanded to include a host of future fears, namely around pregnancy and children.
Fear of failure in pregnancy: “If I can’t have kids, then I can’t find someone to marry”

Nine of the 10 young women expressed a desire to bear children in the future and many of them had been told by their physicians that achieving and maintaining a pregnancy in the future would likely be difficult if it is even possible. This information was conveyed despite these women being younger and family planning not being important to them at that time. Stephanie said, “I have been told already that if I do want to have children, it will be difficult but not impossible.” Willa expressed wanting children in the future but was also aware of possible difficulties: “there’s, like, a slimmer chance of me getting pregnant in the future.” Still, a fear of failure colored their explanations of a desire to achieve and maintain a successful pregnancy. Stacey had “a lot of health-related worries, um, even in the future trying to, like, have a family...if I would have difficulties.” Their worries aligned with the worries of others in previous research, such as in Amiri et al.’s (2014) study, where women worried about possible infertility with PCOS. What is striking is the unspoken language of failure, the worry of not being able to get and/or stay pregnant. This was not surprising, given that there is a language of failure used within the context of infertility, especially by medical professionals, and this framing of young women not being able to succeed in pregnancy is disempowering (Moore & Cattapan, 2020).

Many of the participants recognized that because they have PCOS, they may face challenges achieving and maintaining a successful pregnancy, though the evidence is inconclusive regarding the prevalence of infertility among women with PCOS (e.g., 23% from a large community-based cohort study, Joham et al., 2015; 19.8% in a population-based study, Persson et al., 2019). Comparatively, there is an estimated 9% infertility prevalence among couples in the general population (Boivin et al., 2007). Their description of wanting children was abstract (“in the future”), indicating that it was something that they recognized and were thinking about now, but that may not affect them until later (Segal et al., 2008).

Jenna and Karleen nuanced their fears by introducing societal expectations. For instance, Karleen expressed her concern for the future:

The fear of, like, not knowing what’s gonna happen in the future. So, just that fear kind of impacting relationships. Like, whenever I’ve had a relationship, and if he expresses ‘I want a big family,’ it kind of scares me. And I’m like, ‘oh, I don’t know if I can deliver that.’ So, I get kind of scared.

Jenna said, “I’m afraid that I won’t have kids [and] that if I can’t have kids, then I can’t find someone to marry, ‘cuz you know, a lot of people want kids.” Karleen and Jenna implied that partner and child(ren) go hand-in-hand and that an inability to bear children may mean that finding someone with whom to marry or have a long-term relationship is not feasible. Mia’s worries, similar to Jenna’s, brought in
Mia expressed many worries about her role as a woman within her cultural context. She drew on expectations to bear children at a young age and perceived stigma for not having children as fears for her as someone living with and attempting to navigate PCOS.

In our study, most spoke about the motherhood mandate, the socio-culturally backed expectation that women have and properly raise children (Russo, 1976). This was surprising to us given both feminist efforts to dismantle rigid gender roles (e.g., Jacques & Radtke, 2012) and changes in childbearing and childrearing practices in Canada. Far fewer women are having children before their 30s and some women choose not to have children at all (Provencher et al., 2018). Our findings reinforce that there is still an expectation that women will bear children at some point during the time in which they can; otherwise, there is a risk of being labelled “defective” (Arendell, 2004). Karleen, Mia, and Jenna highlighted the attainment of an intimate partner for marriage or long-term commitment as an important goal. Having PCOS stands as a roadblock given that, as they have described, not being able to achieve and maintain a pregnancy is a possible deterrent to marriage.

**Conclusion and implications**

In Western society, a woman’s body, which is both gendered and medicalized, is a site of tension concerning patriarchal ideals of femininity and normality (e.g., Garland-Thomson, 2002), and we saw overwhelming evidence for this. Indeed, many of the concerns noted by our participants can be summarized as fear of deviating from society’s pre-determined ideals regarding what is considered normal and feminine in the Western socio-cultural context. We know from feminist scholars (e.g., Chrisler, 2013) that young women are expected to adhere to rigid societal standards or else be framed as disordered and/or in need of correction. In our study, there was a collective disconnection from the traditional Western conceptions of femininity and a perception that many of the symptoms of PCOS were abnormal. As well, the healthcare system remains a pervasive context in which women continue to be oppressed and/or othered (Johnson et al., 2004). For instance, men have served as the medical version of the ideal normal patient, though little emphasis has been placed on men’s hormonal fluctuations despite men also experiencing them (Rosser, 1994). It would be simple to suggest
variations in body size and hair growth are due, in part, to factors like age, ethnicity, and/or stress, but the issue runs deeper. PCOS has incidence rates of up to 25% (see the retrospective birth cohort study by March et al., 2010), thus requiring a reformation of what normal means concerning young women. Blanketing of desirable experiences and states as normal has serious implications for women’s lives, such as taking up (sometimes risky) practices to adhere to these standards (e.g., Fahs, 2014; Piran, 2010; Soucie et al., 2021b). In the context of PCOS more specifically, this may result in them perceiving themselves and their experiences as defective and/or abnormal and thus pathologized (Arendell, 2004).

Our findings from the women’s narratives suggest that engagement with discomfort (Ahmed, 2017) is imperative for both (young) women with PCOS as well as their physicians. The affective experience of discomfort, particularly around their perceptions of their bodies, is similar to that of shame, anger, and embarrassment. This experience often puts us off from seeing, knowing, and further exploring certain things because of a visceral desire to escape (Chadwick, 2021). One example may be being confronted with a deviation from rigid standards of normality, such as in the case of PCOS. Shutting down and erasing feelings of discomfort can be dangerous insofar as they can work to maintain power relations and dominant forms of knowing (e.g., doctor-patient interactions where weight loss is mandated due to the conflation of thinness and health; Gard, 2010). Chadwick (2021) suggests engaging with discomfort as a “form of political labour” (Ahmed, 2017, p. 32) and presents it as a fruitful feminist praxis.

In psychology and medicine, there is a proclivity for homogenizing and categorization of experiences (e.g., Parker, 2007). Engaging with the politics of discomfort is a way to resist claims of epistemic authority and avoid engaging with comfortable homogenizations and categorizations. In our study, the young women talked about what was expected and acceptable, and for the most part, their physicians reinforced and validated those expectations and conceptualizations of “normality” and “femininity.” Engaging with discomfort may be one way to begin dismantling Western conceptions of normality by, for instance, creating space for a variety of body shapes, sizes, and functions (e.g., Cooper, 2016) and not conflating thinness with health and womanhood with motherhood (e.g., Russo, 1976). In practice, this may involve physicians confronting their own biases about ideas of health, weight, reproduction, and social location as they pertain to women (e.g., Cho, 2019). Our data also suggest the need for education and awareness aimed at (young) women that unpacks these conceptions of normality regarding women’s health and women’s health disorders such as PCOS (e.g., Tomlinson et al., 2017). Both courses of action avoid perpetuating discourses of normality and femininity that are unrealistic and often unattainable by most women.

While our goal was to have the voices and experiences of young women represented and amplified through this work, our sample was not fully representative. Over half were self-identified White young women, all of whom had access to education (which may suggest that they are middle class, though we have no evidence for this), and resided in Southwestern Ontario. This likely afforded them a
greater probability of success when attempting to advocate for themselves than perhaps others who may be in more marginalized positions (Halwani, 2004). An additional limitation was our failure to ask the young women about their self-identified gender and sexual identity. Many women who do not identify as heterosexual and/or are gender non-conforming also have PCOS (e.g., Agrawal et al., 2004). For instance, queer women may be less concerned with performing normative femininity as compared to cisgender heterosexual women (Pfeffer, 2014) and having that information would have been valuable to extend understandings of PCOS.

An avenue through which future researchers could explore the presentation and navigation of PCOS in non-cisgender, non-heterosexual individuals is through the adoption of an intersectional lens. Despite the emergence and uptake of this framework (Crenshaw, 1989), there has been little consideration of the different ways that identities intersect to create unique challenges within the context of women’s healthcare, thus excluding diverse women’s experiences from the conversation (Cho et al., 2013). In our study, we saw evidence of the intersection between age, gender, and sometimes ethnicity (e.g., Mia) and the impacts it had on the young women. Buddhavarapu (2020), in addition to us, has suggested that PCOS acts as a unique entryway into an analysis of intersectional issues, especially given the very nature of its features and the challenges they pose to gendered medical discourses governing women’s lives. An intersectional analysis, set against the backdrop of societally and medically imposed standards for women’s bodily appearance and function, is an important line of future inquiry that can capture complexities in lived experience as well as concomitant factors of social inequity which are inherent in understanding health inequities (Hankivsky & Christoffersen, 2008).

Acknowledgements
The first author would like to thank Kieran O’Doherty, Ph.D., for his review of the first draft of this paper and his constructive feedback. We wish to thank Marissa Rakus, Chelsea Reaume, and Cheyene Shuart for their assistance with transcription and Tamara Samardzic for providing a fresh set of eyes and organizational assistance during the drafting process. We are grateful to the following members of the Health Experiences and Longevity Lab (HEAL) for their help with data recruitment: Chantal Vien, Carli Cristofari, Rachel Plowman, Amanda Bailey, Sanaya Dhabhar, Christine Elgie, Cindy Ly, Noelle Citron, and Zoha Salam. Finally, we wish to express our heartfelt and sincere gratitude to all of the women who shared their experiences with us.

Declaration of conflicting interests
The author(s) declare no potential conflicts of interest with respect to research, authorship, and/or publication of this article.
Funding
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the University of Windsor through an Internal Research Grant for Women awarded to the second author [eRSO #33937, 2015].

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Note
1. Men also face gendered social constructions of their bodies (e.g., Lorber & Martin, 2007). While they may experience some adverse consequences, these social constructions largely serve to reinforce patriarchal structures from which they benefit.

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