

# 'I drew the parts of my body in proportion to how much PCOS ruined them': Experiences of polycystic ovary syndrome through drawings

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## Abstract

Polycystic ovary syndrome is a chronic endocrine disorder associated with persistent physical symptoms and psychological and lifestyle repercussions. Eighty-nine participants (83 females, 6 non-binary) aged 19–43 years described their experiences of polycystic ovary syndrome through drawings and personal accounts. Four descriptive themes were identified: awareness of visible and invisible symptoms, misshapen self and body, limitations and barriers and resignation. Taken together, participants described a condition with all-encompassing effects: much more than symptom management alone. Findings support the use of drawings as an appropriate method with this population and suggest continuing need for supports for individuals with polycystic ovary syndrome.

## Keywords

femininity, health psychology, polycystic ovary syndrome, qualitative methods, visual method

Polycystic ovary syndrome (PCOS), a chronic endocrine disorder affecting up to 10 per cent of postpubertal individuals with ovaries, can have a broad impact on the quality of life and personal identity of those experiencing it (Azziz et al., 2004; Lindholm et al., 2008). PCOS typically involves a range of symptoms, including hirsutism, thinning hair, weight gain, irregular menstruation and infertility, and they may also be at increased risk for developing one or more related conditions, including type 2 diabetes, depression, endometrial cancer and high blood pressure (Gilbert et al., 2018; Hollinrake et al., 2007; Lindholm et al., 2008). Despite its prevalence, the diverse symptom presentation of PCOS often results in extended diagnostic processes and relative underrecognition in many medical settings, which in itself can negatively influence the quality of life and identity of those who experience PCOS (Avery and Braunack-Mayer, 2007; Crete and Adamshick, 2011; Tomlinson et al., 2017).

In recent years, literature has begun to explore what it means to live with the wide range of symptoms and medicalized experiences associated with PCOS. Commonly reported are experiences of frustration and a lack of support, including a desire for accurate knowledge about the

condition (Bazarganipour et al., 2017; Crete and Adamshick, 2011; Percy et al., 2009; Weiss and Bulmer, 2011). Participants frequently report investing considerable amounts of time into managing the effects of PCOS, from hair removal and dieting to infertility treatment and mental health management (Kitzinger and Willmott, 2002; Pfister and Rømer, 2017; Taghavi et al., 2015; Williams et al., 2016). Also, commonly expressed is a desire for normalcy (Billhult and Stener-Victorin, 2012).

Moreover, for many, PCOS is associated with losses to their sense of femininity. Changes in physicality, including body and facial hair, disrupted menstrual cycles and infertility, disrupt the traditional view of femininity and womanhood (Kitzinger and Willmott, 2002). These symptoms have been described as embarrassing shortcomings (Kitzinger and Willmott, 2002). To female-identified

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individuals with PCOS, it can feel as though their purpose in life has been diminished (Kitzinger and Willmott, 2002). Femininity may also be challenged when PCOS contributes to a non-traditional body shape and presentation (Jones et al., 2011; Pfister and Rømer, 2017; Weiss and Bulmer, 2011). Enduring feelings of loss and grief, inadequacy, and distress may result (Ekbäck et al., 2011; Taghavi et al., 2015; Williams et al., 2015).

Prior research has suggested that participant-generated images may provide unique insight into perceptions of what it means to live with a particular disease or condition, extending or re-interpreting the knowledge gained through interviews or other methods (Broadbent et al., 2006, 2009; Cross et al., 2006; Phillips et al., 2015; Reynolds et al., 2006). These approaches give each study participant the space to actively choose what they would like to focus on and how they will represent it (Woodgate et al., 2014).

Among the methods involving participant-generated images, drawings, in particular, have the potential to provide unique insight into the metaphorical understandings that individuals have about their health condition (Phillips et al., 2015). Particularly, when participants are prompted to engage in a brief time of personal reflection prior to beginning the study task, drawings hold the potential to illuminate non-literal understandings of what it means to experience a particular chronic health condition (Cross et al., 2006; Guillemin and Drew, 2010; Guillemin and Westall, 2008). More specifically, drawings provide valuable insight into the illness identity and emotions of drawing-makers, as well as potential pre-occupations and perceptions of treatment environments they may hold (Broadbent et al., 2018; Kearney and Hyle, 2004). As an easy, familiar task to most adults, drawing on paper or digitally may circumvent the technical limitations of equipment familiarity that hampers the effectiveness of other visual methods (Woodgate et al., 2014). Although participants may be unsure of their artistic abilities (Guillemin and Drew, 2010; Kearney and Hyle, 2004), they already have the skills necessary to take part.

This study aims to investigate the perceptions of those diagnosed with PCOS through drawings. No previous research has explored PCOS through drawings. However, a recent photovoice study focused on PCOS suggests that visual investigation of this condition is viable (Williams et al., 2016). We propose that the non-verbal nature of the drawing task will elicit personal narratives and metaphorical understanding in a way that expands what has been learned previously, allowing a clearer picture of what it means to experience PCOS.

## Method

### Participants

Following ethical approval by the Human Research Ethics Board at Trinity Western University (#19F05), the study

was advertised on social media and on posters distributed around the Lower Mainland, British Columbia, Canada. All participants were the age of majority in their place of residence and had a history of PCOS. Written (electronic) informed consent was obtained from all participants prior to initiation of study tasks; participants also gave consent for the publication of the images and quotes used in this manuscript. Only responses containing a relevant drawing and at least a brief written response were included in the study sample. All participants who returned a drawing ( $n=117$ ) received a \$5 Amazon gift card in the currency of their country of residence.

In total, 89 participants returned both a drawing and a written reflection and formed the study sample (83 women, 6 non-binary;  $M_{\text{age}}=29.56$ , age range: 19–43 years). Most participants ( $n=82$ ) reported an existing diagnosis of PCOS, while the remainder ( $n=7$ ) were in the process of being diagnosed. Most participants lived in Canada ( $n=59$ ) or the United States ( $n=21$ ), had at least some post-secondary education ( $n=76$ ), spoke English as a first language ( $n=87$ ), and were currently in a relationship (casual or committed dating, or married,  $n=59$ ).

### Procedure

Following demographics, participants were asked to respond to one open-ended question: ‘What has been your experience of living with PCOS? Please share whatever you would like: your thoughts and feelings, bodily sensations, one or a few particular stories or experiences, challenges or uplifts’.

Instructions for the drawing task were adapted from previous drawing tasks employed with heart attack and chronic headache patients (Broadbent et al., 2004, 2006, 2009). Instructions read,

While many people have PCOS, it is often experienced in a variety of ways. As a result, people picture their PCOS in different ways. In this project, we are interested in the way you see your PCOS. We would like you to draw *your* image of *your* PCOS. We are not interested in your drawing ability – a simple sketch or line drawing is fine. We are interested in how you see your PCOS. On a blank piece of paper, please draw your PCOS as it most commonly affects you. You are welcome to use any materials available to you (e.g. pencils, pens, coloured pencils, crayons, markers, etc.).

Participants were also asked to reflect on and then describe the image they created, commenting on anything they felt might help the researchers to understand the implications of their drawing. All images were submitted to the researchers via email; hand-drawn images were scanned or photographed and saved as .jpeg format image files.

Responses were analysed using Rose’s (2007) critical visual methodology using predetermined questions to draw out overarching themes from the drawings and reflections

(per Guillemin, 2004). Thematic analysis was carried out independently by three raters, a health psychologist and two research assistants, with backgrounds in psychology and art. Ratings were compared for agreement and discrepancies discussed in a team meeting.

## Results

Drawings most commonly included self-portraits, signifiers of unwanted intrusion such as cystic ovaries or health equipment and references to infertility, including question marks placed over a womb space and large 'x's placed over drawings of infants or mother with child. Large, thickly drawn red or black 'x's were a common means of illustrating something denied to participants: children, sugary or fatty foods, a normal life. Self-portraits, typically placed as the central image, were especially likely to be included in drawings depicting sadness and disappointment, as well as to illustrate their symptoms of PCOS. These drawings suggest the self as positioned at the centre of the condition, judgements of others and external health concerns. Self-portraits were also more likely than were other images to be drawn using a single colour, typically black, except for those aspects of the self-portrait that denoted something perceived by participants as external to the self: red acne, blue tears or tear-filled eyes, red or blue medical equipment, pink cysts, blue dream or wish images, pink or yellow body fat. Unwanted features tended to be exaggerated through the use of heavier lines, standout colours (e.g. red against a black and white drawing) or exaggerated proportions compared to the rest of the image (e.g. a larger belly and thighs contrasted with tiny arms and legs). Drawings often had a dreamlike quality: daydreams about children, the nightmare of exposure to judgement from others, thoughts of a bedraggled, worn down body with too many lumps of fat and hair in unwanted places or the desired self shown in a mirror or in a before-and-after sequence.

Analysis of participant drawings resulted in 13 categories that were grouped into four descriptive themes: awareness of visible and invisible symptoms, misshapen self and body, limitations and barriers and resignation. Each theme can be further understood through metaphor: PCOS as a controller, an adversary, a wall and a weight. Many drawings contained representations of multiple categories and themes. The drawings and quotations below illustrate the overarching themes in the images.

### *Awareness of visible and invisible symptoms (PCOS as a controller)*

Participant drawings reflected strong awareness of the numerous and, above all, intrusive ways in which PCOS affects their body. PCOS was presented as a controller, a force that takes control of their lives and dictates how their body is presented. Most commonly drawn were self-portraits emphasizing visible symptoms: weight gain, facial

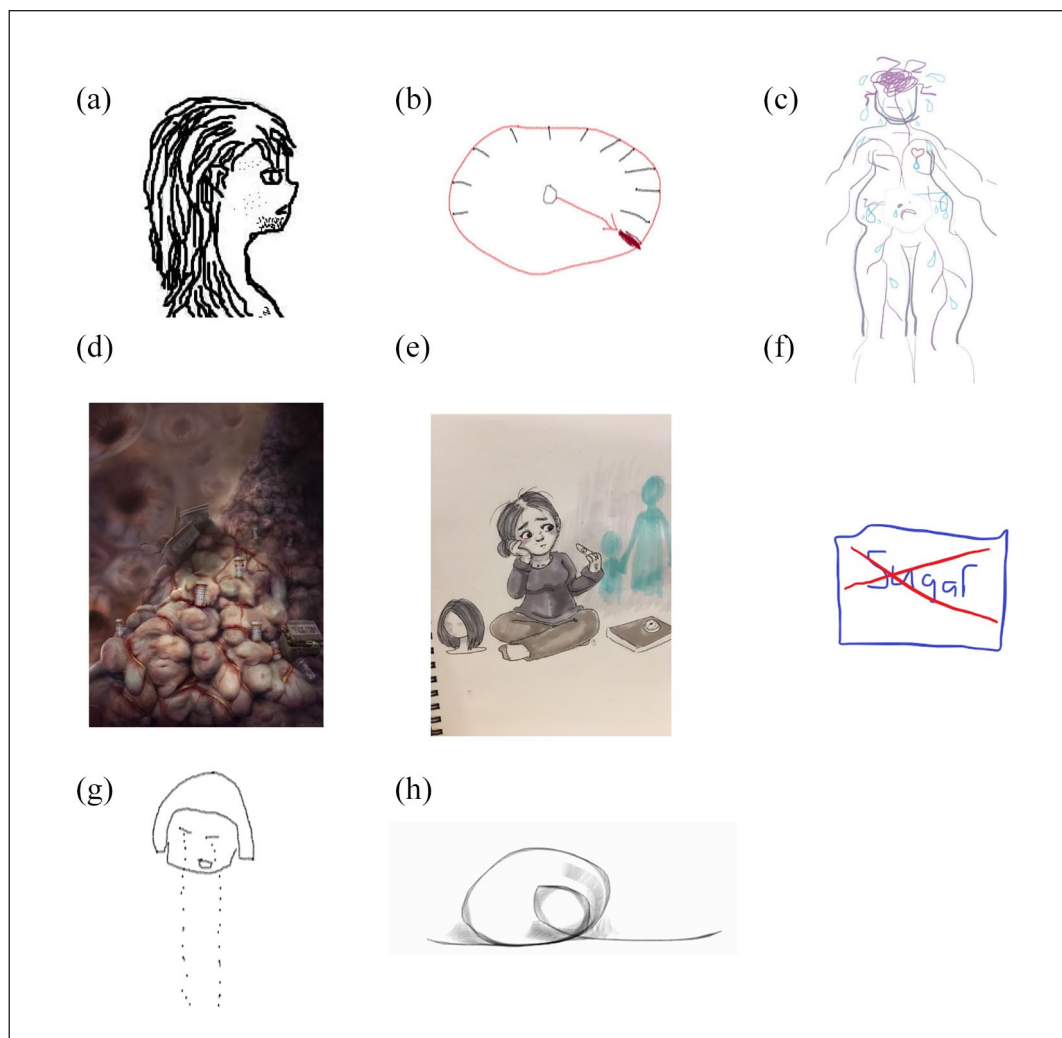
hair, body hair, oily skin, thinning hair and acne. Many noted their discomfort at seeing themselves with these unwanted features. Figure 1, image A drawn by Samantha<sup>1</sup> (26 years, female) includes several of these characteristics. She described her concerns about her appearance, stating

When I look in the mirror especially after a flare up its [sic] hard not to notice how my face feels oily and having acne. I have brown long hair but when I brush I notice how its [sic] thinning.

Samantha is very aware of the way her PCOS has taken control of how she appears to others, and she reported keeping constant tabs on it. This vigilance, particularly to the more visible effects of PCOS, was shared by other participants. Rene, a 29-year-old woman (not pictured), concurred, lamenting 'When I look in the mirror, all I can see is the continuous hair growth . . . its [sic] isolating'. Visible symptoms over which they feel little or no control clearly weighed heavily on participants. Robin (32 years, non-binary, not pictured) drew an image reflecting how much they 'hate how oily [their] skin is'. Samantha added, 'I find it extremely hard to live with. It affects your appearance. Your hormones. Your sense of self-worth. Your emotions. Your relationships. Your diet. How you feel, physically and emotionally'. Her symptoms are not just confined to her body. PCOS has taken away her autonomy through the constant presence of symptoms that are all-encompassing and affect her whole life.

Drawings also highlighted ongoing awareness of the control exerted by less visible symptoms. For some, the experience of PCOS is focused on cystic ovaries, internal and contained, even mysterious when they had not had an ultrasound to confirm the presence of cysts. These participants are aware of their condition, but the primary effects are on the inside, hidden.

Others drew the impact of related conditions brought on by PCOS through various meters, monitors and internal organs. Lisa (34 years, female), who takes cholesterol-lowering medication, depicted a maxed out meter emphasized with red scribbles (Image B). Lisa expressed her anxiety about having high cholesterol at such a young age, noting 'I don't want to get a heart attack . . . so it can worry me sometimes'. Notably, concern for the future was more present in drawings focused on non-visible symptoms than it was in drawings focused on visible symptoms. This is not to say that non-visible symptoms were any less intrusive in day-to-day life. The unknown influence of symptoms they could not see or control made their PCOS seem just as invasive. Sofia, aged 21 years, who was diagnosed at age 14 years (female, not pictured), described her PCOS as 'invisible on the outside yet [with pain] still visible in the eyes at times. Mental pain. Physical pain. Existential pain'. For many, PCOS and the symptoms and secondary conditions that it can lead to are widespread and seem unending. Regardless of outward visibility, the implications for the



**Figure 1.** Participant drawings. (a) Samantha's drawing. A self-portrait in profile with facial hair, acne spots, stringy hair and a numb, neutral expression (age 26 years). (b) Rene's drawing, showing her cholesterol at a dangerously high level (age 34 years). (c) Makayla's drawing. Tendrils of PCOS extend over her whole body, with tear drops on all the places it grabs hold (age 28 years). (d) Brynn's drawing, an enormous mound of fatty adipose tissue being strangled by a measuring tape and littered with pill bottles and boxes. Eyes fill the background (age 35 years). (e) Marie-Eve's drawing, showing the barriers of PCOS in her life (age 32 years). (f) Alexa's drawing, sugar that has been blocked off with a large red 'x' (age 28 years). (g) Sara's drawing, which she described as a self-portrait of how she feels (age 25 years). (h) Keira's drawing, depicting her feelings of emptiness (age 35 years).

rest of their lives can be daunting. PCOS has changed their perceptions of control and predictability.

### *Misshapen self and body (PCOS as adversary)*

Many drawings depicted an adversarial relationship with PCOS, particularly with respect to body image and other facets of their sense of self, including perceptions of jibes and barbs directed at the self from the condition, from others and sometimes from their own self-talk. Some drawings depicted PCOS as a monster, brandishing knives or pointed teeth. Full-body portrayals in this category were ballooned, disproportionate and mangled, reflecting the damage, actual and felt, caused by their adversary. Participants drew themselves as 'ugly', 'broken' and 'unattractive', describing the

hits these feelings had taken to their self-esteem and confidence. Makayla (28 years, female), who experiences PCOS-induced obesity, drew her body being overtaken by the influence of the disorder (Image C), explaining,

PCOS is always described as being seated in the reproductive system but it extends its influence across my whole body. It feels like tendrils slowly choking every part of me. Everywhere it takes hold I feel a bit more broken and sad. My body doesn't feel like it's mine any more and fighting it sometimes seems hopeless.

Like Samantha, Makayla feels that PCOS has taken her bodily autonomy from her, and mangled it. Reflecting on her drawing, Makayla shared, 'I definitely exaggerated [the



proportions] but I drew the parts of my body in proportion to how much PCOS ruined them'. She has been left with what she believes is a broken, uncontrollable body. Tiana (24 years, female) expressed similar feelings in her own self-portraits (not pictured), stating 'I feel like I'm slowly losing all the parts of me that make me a woman, and I have absolutely no control over it'.

Natalie (female, not pictured, age withheld) also reflected on this sentiment:

I don't feel feminine or attractive, and I have always felt that I should be grateful that any man wants to be with me – with my spots and hairs and obesity. Who wants a girlfriend with a hairier ass than he has?

Natalie's and Tiana's responses reflected the sense of inadequacy echoed by several female-identified participants. Their PCOS makes them feel unfeminine and ugly – and often there is a presumption that others see them this way, too, and treat them accordingly.

Perceptions of an antagonistic relationship with PCOS were also pictured in drawings of external crowds. Although perhaps less central to their view of their condition itself, participants felt judgement from others' views of their bodies and suppositions regarding their presumed lack of self-care. Brynn (35 years, female) filled her entire background with staring eyes (Image D) looming over 'the mounds of fatty adipose tissue being strangled by a tape measure digging in so tightly that it is, in some places, causing sores, skin tears, and bleeding'. She has been reduced to an amorphous mass literally tied up with expectations and judgement under the watchful external eyes, making her even more aware of the frustrations tied up in this condition. Kara (22 years, female) also reflected her perceptions of judgements from others in her drawing of an onlooking group of faceless people (not pictured), reflecting

It isn't considered a disorder or syndrome like it should be by the people around me. In their minds, it's fat women being too lazy to own up that they're fat and coming up with excuses. It feels devastating to see their looks.

### *Limitations and barriers (PCOS as a wall)*

The limitations and barriers reported by participants were typically couched in language that made it plain that they felt blocked from having opportunities that they perceived as related to the experience of a 'normal life'. Marie-Eve (32 years, female) shared that, 'I can still live a fulfilling life but there will always be those barriers that gets in my way and remind me that I am not the same as most people'. PCOS holds her back from wishes, goals and plans. The metaphor of a wall can be used to further conceptualize the theme of limitations and barriers. Participants experienced PCOS as a condition that blocks them from desired experiences and from achieving their dreams and goals. Most

limitations and barriers reported by participants fell into three categories: pregnancy, food and activities.

Dream bubbles of babies, families and pregnant bellies depicted experiences of the barrier of infertility and challenges with becoming pregnant. Drawings of negative pregnancy tests and question marks pointed to the long struggle of trying to have a child. Many of these drawings were annotated with phrases such as 'pipe dream', and 'no room for egg to attach!' Marie-Eve, who has been trying to become pregnant (Image E), explained 'I can't ovulate as often as others do so I can't pop out a baby like others. Everyone is pregnant but me'. Becoming pregnant is often a lengthy and difficult process for those with PCOS who undertake it. Seeing negative results again and again while others appear to succeed at becoming pregnant with little effort can be taxing; Jess, 31 years, who drew a negative pregnancy test (not pictured), stated 'It's hard when I keep trying and keep testing but still getting the same answer'. Even with the hope that things will work out one day, it was frustrating for our participants to keep running into the same walls.

Among those participants diagnosed with PCOS-related conditions such as type II diabetes, excess sugar and certain types of food represented an additional barrier to the life satisfactions they wish they could enjoy. Drawings showed crossed off restaurant logos and food items illustrating the things they could not have, many of which were crossed out with prominent red 'x's. Alexa (28 years, female), who has been diagnosed with diabetes as a result of her PCOS (Image F), explained 'I have to stay away from high sugar foods . . . One misstep and it could get worse'.

Irregular menstruation and pain also walled off participants from full participation in daily life activities. For Casey (25 years, female), irregular periods meant that, 'Especially when my flow is heavy and prolonged, [it] severely limits what kinds of activities I can do and how long I can be away from home' (not pictured). Brynn's drawing also reflected multiple barriers to desired life satisfactions (Image D). It contained three cardboard boxes stuffed with things she cannot eat, things she cannot have and things she cannot do, including sports.

### *Resignation (PCOS as a weight)*

PCOS weighed heavily on our participants, both in actuality and metaphorically. Nearly every drawing portrayed some form of negative affect, from sadness to frustration. Faces marked with upturned eyebrows, frowns and tears, alongside scribbles denoting frustration over the often drawn-out diagnostic process and at trying to convey their situation to others, were notated with emotional reflections. Sara (25 years, female), who is in the process of being diagnosed (Image G), stated 'What's most challenging about PCOS is being depressed for no reason. Sometimes I feel sad, and sometimes I just can't help but cry'. Sara describes

depression as an ingrained, even inevitable, part of her experience of PCOS that she experienced as weighing her down and in particular, holding her spirits down. This sense of being resigned to suffering under the weight of negative affect was shared by many other participants.

Some participants, like Keira (35 years, female), found that abstract shapes and lines conveyed their feelings and experience of being held down by the weight of PCOS better than did literal imagery (Image H). Keira noted her sense of emptiness in her written description, commenting 'It just fucking sucks man. I feel really shitty all the time, I have mood swings and its [sic] overall just a bad dream'. Like her image, Keira's feelings are amorphous and abstract, but clearly negative. It is consistent, but not straightforward. Similarly Emma (age unspecified, female), who has been through two surgeries for her PCOS, drew 'straight and straight-ish' lines representing her perceptions of the life trajectories of others; in contrast, she drew her own trajectory as a scribbled out spiral (not pictured). Emma explained that 'it feels so hard to make PCOS make sense to others . . . it's really frustrating to be misunderstood, misdiagnosed, called crazy, or [told] that I'm faking'. Paz (22 years, non-binary) also felt this added weight from perceptions of others' lack of understanding, saying, 'its [sic] really hard cause no one understands or knows what it is'. Paz's drawing was a self-portrait with tears running down their face (not pictured).

Many participants noted a resolve to keep moving forward and to not give up, despite the challenges. This resolve appeared to make the weight of PCOS easier to bear, though it did not seem to remove it entirely. Dina (24 years, female), who also drew a self-portrait communicating sadness (not pictured), explained,

I try not to think about having PCOS because it's sad to know I will have it for the rest of my life. I am committed to live my life better, [it] helps to know that I am not alone.

PCOS may touch many aspects of her life, but she is determined to live a good life, despite those weighty challenges.

## Discussion

The findings of the present study both replicate and extend past research, providing evidence for convergent validity across methods. The presence of symptoms that they simply cannot ignore left participants feeling uncomfortable and frustrated with their own bodies (Jones et al., 2011; Pfister and Rømer, 2017; Weiss and Bulmer, 2011). Likewise, participants emphasized that their experience of PCOS is one of living with a condition with all-encompassing effects – much more than mere symptom management (Williams et al., 2015, 2016). The experience of PCOS weighed heavily on each aspect of participants' lives: their

self-worth, their emotions, their life goals, their sense of femininity.

Unique to the present study is the finding that the perception of being different from others, expressed by our participants and evident in past research, may be rooted in a wider range of PCOS-related limitations and barriers than has been found previously. Although concerns about femininity and becoming pregnant have been well documented (e.g. Kitzinger and Willmott, 2002; Taghavi et al., 2015), in the present study, participants also identified food choices and activities, including sports and social gatherings, as limitations and barriers to feeling 'normal'. Some participant drawings and descriptions emphasized that they could not participate in enjoyable activities or that they would have to leave early because of, for example, pain or heavy menstrual flow. Other drawings focused on the dietary limitations introduced by secondary conditions including obesity. Although PCOS is not typically described as a condition that introduces limitations to living a full life, experiencing the condition as a controlling, weighty adversary that sets up walls can make achieving and maintaining that full life more challenging. Pregnancy is often primary among these concerns, but it is not the only area of concern for those living with PCOS. Healthcare providers may benefit from ongoing awareness that some patients regard their condition as one that is severe and limiting. Informed careful attention in hearing and addressing patient concerns about the effects of PCOS in their lives may help alleviate some of the expressed frustrations that have been documented in past research (Bazarganipour et al., 2017; Crete and Adamshick, 2011; Weiss and Bulmer, 2011). Accordingly, it might be useful to routinely screen for distress and to refer patients to appropriate resources, such as counselling therapy aimed at restoring a general sense of agency. Given the frustrations associated with extended diagnostic processes, healthcare providers may additionally consider developing focused diagnostic processes, which could well reduce total costs to the healthcare system as well as to the patient. In the case of the patient, the cost is not only emotional: it can also be financial, given that most individuals go through diagnosis in early adulthood, during which time they are typically working or studying. The diagnostic process requires time away from both, with an added cost for travel to appointments.

The predominance of drawings indicating resignation, frustration and other forms of negative affect, in combination with drawings and descriptions emphasizing a sense of being 'ugly', 'broken' and 'misshapen' or 'fat', demonstrates the detrimental effects that PCOS has had on the self-concept of the participants in the present study. Negative self-concept may especially be of concern among female-identified participants, such as Natalie, who noted feeling unfeminine and like she should show gratitude to anyone who might want to have a romantic relationship with her. Moreover, participants were

concerned that others also see them this way. Participants indicated that they felt misunderstood, judged for things that are largely outside of their control, and that they do not receive enough support from people in their lives. They described the difficulties they have had getting others to understand and accept the validity of their experiences. Percy et al. (2009) have suggested that nurse-led patient support groups may be useful in helping to attenuate some of the negative emotional consequences that accompany PCOS. Support from others has been shown to positively influence persistence in symptom management in individuals with PCOS; accordingly, educational supports for family and friends who indicate a desire to be supportive may also be beneficial in countering misconceptions and reducing perceived judgement (Bazarganipour et al., 2017; Williams et al., 2016).

The consistency between our findings and those of previous research supports the validity of drawing tasks as a research technique for chronic conditions such as PCOS. Of note, a number of participants found that the drawing task facilitated a fuller, more accurate description of their experiences. One participant commented that ‘there are no words to describe this feeling. Drawing it was better’. The drawing task used in the present study reaches into a personal and metaphorical understanding of participants’ PCOS (Phillips et al., 2015). Drawings appear to be effective tools for capturing the ineffable, reaching into experiences and providing a succinct representation of their truth (Kearney and Hyle, 2004). Drawing tasks give participants an opportunity to pause, to reflect on the visuals that they are using to convey their experience and to consider the meaning of each decision that they make when completing the task, which can facilitate going more deeply into their emotions and their experiences. Importantly, this aspect of the task, the participant’s own interpretation of drawings, is integral to image analysis (Guillemin, 2004; Kearney and Hyle, 2004). Participant explanations, particularly with more abstract drawings, clarified images which might otherwise have been considered unrelated to the study task or difficult to interpret. In this way, the analysis of image approach keeps its focus on the data as provided by the participant, giving words, as best as possible, to the ineffable. In addition, the drawing task seems to offer a lower cost and lower attrition alternative to the insights offered by photovoice, a related and innovative participatory action research method (Williams et al., 2016).

The present study is among the first PCOS-related studies to take steps towards being more gender inclusive. Although most persons who experience PCOS are women, the present study recognized the diversity of gender presentation and experiences by recruiting participants of all genders who indicated having PCOS. In total, six non-binary individuals participated in the study. Being inclusive of gender identity may help to broaden our understanding of conditions that have been traditionally

considered ‘women’s diseases’. For example, some symptoms of PCOS can challenge women’s perceptions of their own femininity, but these symptoms may be experienced differently by a non-binary or male-identifying individual. Our results support the increasingly diverse patient focuses suggested by other scholars (Williams et al., 2016).

Findings in the present study may be limited by the manner in which data were collected. To maintain anonymity and to reach a broader sample, the drawing task and related questions were facilitated online in a text-based format. As such, the researchers were unable to ask for specific clarification and follow-up information regarding individual drawings. Participants were encouraged to explain and expand on their drawings with a reflection statement. However, a real-time drawing task followed by a one-on-one interview may have stimulated deeper reflections and expanded responses. Future research should strive to incorporate the anonymity and accessibility of online participation in drawing tasks while including a more detailed interview process. Moreover, the sample used in the present study was primarily North American, English speaking and educated. Although this background echoes that of the researchers, which facilitated interpretation of the images, the findings may not be relevant to people from other cultures, locations and backgrounds and should be applied cautiously. In particular, PCOS may be experienced differently in places with different gender role expectations, or in those who are lower income and less educated. Future research should continue to examine the ways in which PCOS affects individuals across cultures and social standings.

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1. Participant names have been changed to maintain anonymity

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