

A snapshot of the lives of women with Polycystic Ovary Syndrome (PCOS): A
photovoice investigation.

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Abstract

Polycystic Ovary Syndrome (PCOS) affects 6% of women. Symptoms include hirsutism, acne and infertility. This research explores the impact of PCOS on women's lives using photovoice. Nine participants photographed objects related to their quality of life and made diary entries explaining each photograph. Three themes emerged from Thematic Analysis of the diaries: Control (of symptoms and PCOS controlling their lives), Perception (of self, others and their situation), and Support (from relationships, healthcare systems, and education). These findings illuminate positive aspects of living with PCOS and the role pets and social networking sites play in providing support for women with PCOS.

Introduction

Polycystic Ovary Syndrome (PCOS), first defined in 1935 by Stein and Leventhal, is the most common endocrine disorder amongst women of reproductive age (Franks, 1995) affecting approximately 6.5% of women (Asuncion et al., 2000; Azziz et al., 2004). PCOS is also the most prevalent cause of anovulatory infertility (Gorry, White and Franks, 2006). Women with PCOS are at increased risk of miscarriage, cardiovascular disease, type two diabetes mellitus and cancer (Balen, 2001; King, 2006; Ong, Theoduru and Ledger, 2006). Women with PCOS also report more depressive symptoms, anxiety and body dissatisfaction than women without PCOS (Himelein and Thatcher, 2006; Deeks, Gibson-Helm and Teede, 2010). Coffey, Bano and Mason (2006) have suggested that PCOS has a greater impact on women's psychological well being than illnesses such as asthma, epilepsy, diabetes, back pain, arthritis and coronary heart disease. Similarly, Lowenstein (2006) argued that patients with PCOS are often negatively affected by symptoms they experience, including acne, hirsutism, alopecia and obesity. This suggests that PCOS, and its symptoms, can have a considerable negative impact on women with the condition.

Quantitative studies have demonstrated that PCOS has a negative impact on quality of life (Ching, Burke and Stuckey, 2007; Li et al., 2011; Upadhya and Trent, 2007), even

when compared with other long-term conditions such as diabetes and coronary heart disease (Coffey et al., 2006). Qualitative studies exploring the impact of PCOS on quality of life are scarce and often limited to clinical settings (Crete and Adamshick, 2011; Percy et al., 2009; Snyder, 2006). To date only one paper has explored the experience of living with PCOS outside of a clinical setting, finding that women with the condition felt stigmatised and abnormal (Kitzinger and Willmott, 2002). Malik-Aslam, Reaney and Speight (2010) question the quality of life scale used in many of the quantitative studies and argue that it does not accurately measure quality of life. There is, therefore, a need for qualitative research that explores the impact of PCOS on quality of life and how women experience this condition. Quality of life has been described as well-being which is influenced by objective and subjective factors, across a range of life domains which are deemed as important in one's culture and time (Wallander, 2001). Testa and Simonson (2008) have defined health related quality of life as the 'physical, psychological, and social domains of health...that are influenced by a person's experiences, beliefs, expectations, and perceptions' (p.835). In order to investigate the impact of PCOS on women's quality of life, a photovoice method was employed in the present study.

Photovoice is a data collection method that is increasingly being used in health psychology research (Baker and Wang, 2006; Haaken and O'Neill, 2014; Sharma,

2010; Thompson et al., 2008; Vaughan, 2014, Wang and Burris, 1994; Wiersma, 2011).

Participants are provided with cameras and asked to take photographs to record their experiences (Wang and Burris, 1997). This gives participants great flexibility in reporting issues that are important to them and enables health researchers to gain a different perception of the world (Ruby, 1991). Wang and Burris also claim that photovoice enables participants to record things relevant to their life which health professionals and researchers may not have previously had access too. Further, Brunsden and Goatcher (2007) argue that people inhabit a visual world and experience life as visual encounters. Accordingly, photovoice engages participants in the production of new images; it puts the participant and the image they create at the centre of the research. This suggests that the process of individuals telling their story or describing meaning behind the images they create provides a glimpse into their social realities and insights into their broader community (Foster-Foshman et al., 2005).

Photovoice, therefore, may offer new insights into the impact that PCOS can have on an individual's quality of life. It may also help understanding of the condition by providing a snapshot of the day-to-day lives of women living with this condition. As such, this research is the first to explore the impact of PCOS using photovoice methodology.

Method

Participants

Participants were recruited via a PCOS charity website, Verity. The inclusion criteria for this study were: participants aged 18 and over, living in the UK and suffering from symptoms of PCOS. Participants were excluded if they reported they suffered from any other chronic or mental illness that was not related to PCOS. Thirty-four participants agreed to participate in the study and were sent a study pack; nine study packs were returned. Age ranged from 20 to 45 years old (five participants did not disclose their age).

Materials

The study pack contained a disposable 27-exposure camera, a notebook, consent form and a letter of instruction. Return postage and a pre printed return address were also included. The choice of a disposable camera was guided by the researcher's preference (Wang, 1999) as it allows for images to maintain a consistent size and format, and allows for ease of use by the participants.

Procedure

Participants were sent study packs and instructed that they had one week to take any photograph they wished. They were also asked to photograph anything that they felt impacted on their quality of life, whether negative, positive or neutral but were not

given any instruction on how to use the camera or what to take pictures of. Participants were also asked to write a diary entry for each photograph taken in the notebook provided: participants were not given any instruction on what to write in the diary. This ensured a minimum of interference from the researcher (Catalani and Minkler, 2010) and allowed participants to record their own perceptions of their quality of life. Participants were informed that they should send the consent form back with the disposable camera and the notebook. Participants were asked to return the study pack and then disposable camera films were developed and diary entries were transcribed verbatim.

Ethics

Research complied with The British Psychological Society's ethical guidelines and ethical approval was obtained from the local Psychology Research Ethics Committee at the University of Derby (Ethics Approval Number: 050-11-SW). Participants were informed that, should they wish to take any photographs of people, they were to gain fully informed verbal consent first and any photographs of people would not be published and would only be used for analysis. Participants were informed of their right to withdraw up to three weeks after participation in the research. Participants have been referred to by pseudonyms throughout the analysis in order to maintain their anonymity and identifying information has been excluded from the quotes.

Data Analysis

The diaries were analysed using Thematic Analysis (Braun and Clarke, 2006) and followed the six steps recommended by Braun and Clarke (2006): familiarisation with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes and writing the final report. The analysis was primarily undertaken by one author. The final themes were reviewed by all authors alongside diary entries and photographs to ensure that all were in agreement, that the themes were an accurate representation of the data and that there was not too much overlap between themes (Braun and Clarke, 2006).

Results

Three major themes emerged from the data: Control, (sub-themes Symptom Management and PCOS as Controlling) Perception, (sub-themes Feminine Identity and Positivity) and Support, (sub-themes The Health Care System, Education and Relationships). Quotes displayed are reproduced as written in the participant's diaries and accompanied with the participant's pseudonym and age (AU – age unavailable).

CONTROL

Symptom Management

Symptom management was discussed by all the participants in this study and was the subject of many photographs. Many participants had protocols in place to help them control their PCOS symptoms, including: hair management routines to control hirsutism, daily skin routines to control acne, specific hair washing routines to control alopecia and dietary plans and/or exercise to try and control their weight.

In the quote below Sandra describes how she spends time using hair removal methods, namely using tweezers to pluck hair, in order to stay in control of her facial hair. She further demonstrates how this takes place daily, if not more frequently, by stating that ‘Its neverending.’ Sandra also discusses how the preoccupation with her facial hair continues throughout the day, despite the situation, be it ‘at work, at home, with friends’. This is illustrated by her claim that if she were to find a hair, she ‘cannot rest until its gone’. Further demonstrating how facial hair, and the need to stay in control of it, can infiltrate and impact on every aspect of her day. Sandra accompanied the quote below with a photograph of a pair of tweezers.

I’ve now spent a good 10 minutes finding new hairs on my chin. I pluck it every single day – probably 10-15 hours a day – really thick stubborn black ones. Its neverending. I spend a lot of time feeling my chin – at work, at home, with friends.

When I feel one that needs plucked I cannot rest until its gone. I get a really

stubborn one on my shoulder too. Just the one but it bothers me SO much that if I can't pluck it myself I have to get someone else to do it. (Sandra, 31)

Participants also took photographs of food, scales and themselves to demonstrate how PCOS, and the associated weight issues, impacted on their quality of life. In their diaries, participants also referred to exercising as another means to stay in control of their PCOS.

Amy discusses, in the quote below, how she attempted to manage her symptoms through diet and exercise. She describes how she has improved her diet and exercises regularly in order to maintain control over her weight.

This has led me to take on a fruit and veg diet and very few carbohydrate type foods. Unfortunately my diet still consists of rather a lot of carbohydrate because that is my staple food. But, I manage to outweigh the amount I eat through exercising at least 3 times a week.... Thanks to exercising and a better diet, I have managed to lose weight. (Amy, AU)

[Insert Figure 1]

Crete and Adamshick (2011) similarly suggest that the primary importance for participants with PCOS was to gain control of their symptoms, through self-treatment of symptoms such as hirsutism, acne and through weight control.

PCOS as controlling

Another subtheme that emerged from the diary entries was 'PCOS as controlling'. In the quote below Lucy describes how she is unable to eat readymade food in order to prevent her symptoms worsening and pain developing. She also explains that she no longer gets to take part in activities she enjoys, in this case baking, because she cannot eat anything she bakes.

Ready made stuff is nono, I can literally feel my ovaries stinging in the hours after I have ready made stuff. It sucks. For the record, I was epic at baking before I was diagnosed. Don't get to anymore, really. (Lucy, AU)

Castillo (2008) also found that women with PCOS felt a lack of control of their PCOS and its symptoms.

PERCEPTION

Feminine Identity

Throughout the diaries the participants referred to their femininity and their roles as a woman. In the quote below Linda describes how having symptoms of PCOS such as irregular periods, hirsutism and carrying excess weight make her feel like she is 'not a woman'. She extends this by referring to her weight, and in particular her stomach, as being like a 'man's beer belly'. Linda uses male terminology to describe how she feels about her excess weight. Masculine language or references are also used throughout the participant's diaries either through referring to themselves or to their symptoms, for example 'shaving of the moustache', 'I'm rocking the 5 O'Clock shadow tonight' and 'Got a nice bit of stubble going on now'.

Makes me feel im not a woman *scribble* – no periods – which makes me wonder what is happening inside of me – hairy – *scribble* fat around the middle like a man's beer belly even though I go gym or swimming every week. (Linda, 45)

The theme of feminine identity has previously been discussed in the published literature, most notably by Kitzinger and Willmott (2002) who explored the experience of PCOS. One of their main conclusions was that women with PCOS felt challenged in their perception of self as feminine. Participants in a study by Keegan, Liao and Boyle (2003) also reported feeling unfeminine or unwomanly. This mirrors the findings of this study which show how women with PCOS perceive themselves as unfeminine.

Positive Outlook

The theme Positive Outlook featured in four of the nine participant's photographs or diary entries. Many participants perceived their situation in a positive way; they described how certain situations or behaviours helped them to develop a more positive outlook. Snyder (2006) briefly discussed how a positive outlook was important to some of their participants with PCOS, but this theme of a Positive Outlook has not been discussed in depth by any previous qualitative or quantitative research in women with PCOS. Amy writes in the quote below that swimming helps her to feel that she is 'combating' her PCOS and in turn this helps her to feel more positive.

Swimming, somehow, makes me feel as though I am combating my PCOS slightly and this makes me feel quite positive on my outlook. (Amy, AU)

Hefferon and Boniwell (2011) argue that individuals who develop optimism may engage constructive coping such as acceptance and positive reframing. Positive reframing has been reported to be a frequently used coping strategy for people with diabetes (Tuncay et al., 2008). Additionally, Lutgendorf et al. (2002) found that women with gynaecological cancer, who coped using positive reframing, reported better quality of life at one year follow-up than those who did not.

Positivity was also discussed by Denise who had recently suffered a miscarriage. In the quote below she explains how a story in a newspaper about miscarriage had been upsetting for her at first, but it had then given her hope that she would conceive despite having PCOS (photograph below).

Article on miscarriage in today's metro – upset me this morning on first sight but on reflection it is a positive story not to give up hope. (Denise, 30)

[Insert Figure 2]

Snyder, Lopez and Pedrotti (2011) suggest that for an individual to continue hoping to achieve a goal, then there must be sufficient value attached to the goal. They add that hope is thought to strengthen goal striving, especially when the goal is at least somewhat in doubt and viewed as very important, such as Denise's desire to conceive with PCOS.

SUPPORT

The Health Care System

Frustration with the health care system was mentioned in the diaries by several participants. A number of qualitative studies have previously demonstrated that women

with PCOS felt frustrated by, and angry about, the lack of information and support provided by health care professionals (Castillo, 2008; Kitzinger and Willmott, 2002).

The first reaction and advice I got from doctors was that it was probably puberty, the spots were puberty, the migraines and so on. I was also told to go on a diet. I had to push and visit the doctor regularly before even getting referred, and even then it took over 2 years to get any tests other than bloods and iron done. (Jessica,

20)

Snyder (2006) also found that women with PCOS felt frustrated during the diagnosis process. Many of the women in their study of lived experience felt that the information given by health professionals was inadequate and that they did not have enough time allocated to them at the time of diagnosis. Similarly, in the quote above Jessica describes her communication with health care professionals when she first approached them about her symptoms. She stresses that she had to ‘push’ to get a diagnosis and regularly ‘visit the doctor’.

Doctor only really offers to address 1 symptom at a time – it’s like “You can either not look like a monkey under your clothes, or have a greater chance of starting a family later. Pick one. (Lucy, AU)

Crete and Adamshick (2011) also reported that women with PCOS were often frustrated with their interactions with health care providers; this then resulted in a lack of confidence in the health care system. Additionally, participants commented on the lack of attention to them and their symptoms by health care providers and many were exasperated that their treatment was symptom based. This aggravation with symptom based treatment was also expressed by Lucy in the quote above.

Education

The lack of support from health care professionals lead many of the participants to self educate. Several women commented on the ways that they had educated themselves about their condition and ways in which they can manage it, through the use of books and the internet. They accompanied these diary entries with pictures of books about PCOS and of websites on computer screens.

Some books I got to try help. I learned a lot through these, especially the GI diet book – it was recommended I look into it, but it's kind of tricky to find informations that's consistent sometimes. Doctors were asked about it, and they referred me to Waterstones. Thank you, NHS. At a bit of a loss for what to do with

my diet. I'm underweight, and looking both online and in book like these. (Lucy, AU)

Lucy explains that she has learnt a lot through using the books she photographed. However, she writes that the information available is not consistent and that this means gaining information or an insight into her condition, is difficult. Even the 'doctors' she approached about the condition referred her to books available through a national book store. This further demonstrates how difficult it is for women with PCOS to find information about the condition. Jessica describes the importance of an educational book to her. She claims it is the 'bible for PCOS', indicating how useful and important this book has been for her.

PCOS Diet book. Do I really need to say much about this. This is the bible for PCOS sufferers. Good book with positive information I would definitely recommend it. I made my mum read this to try and get her to understand me, my moods and my eating habits a little better. (Jessica, 20)

These findings mirror Crete and Adamshick's (2011) who found that many of their participants with PCOS used online resources or printed materials in order to educate

themselves about their condition; more than one participant in their study discussed how they had used the internet to gain information.

Another way participants educated themselves, which has also not previously been reported in the published literature, was through attending 'PCOS conferences', as discussed by Jessica below. She refers to an annual conference run by the PCOS charity, Verity, where women with PCOS are given the opportunity to attend a conference featuring several talks about their condition using social media.

I have learnt by attending PCOS conferences that eating is very important, especially eating the right things. (Jessica, 20)

Lucy discusses in the quote below how she gained information and educated herself about her medication through online social networking sites, in this case referring specifically to Tumblr, an internet blogging site. The use of online blogs and social networking websites has not previously been reported in the published literature for PCOS but the use of dedicated online support groups is becoming more popular for a variety of conditions, including PCOS and infertility (Holbrey and Coulson, 2013; Malik and Coulson, 2010). Lucy also demonstrates how women with PCOS can act as educators for other women with the condition.

I've learned so much on tumblr- way more than through doctors. I'm afraid to take Metformin (though I know it's coming) because it can make you feel so sick, and it was only through tumblr that I was able to hear about alternatives. Talking to other women with it is INVALUABLE. (Lucy, AU)

The quotes and photographs displayed demonstrate how women with PCOS seek to educate themselves through the use of books, social networking and media sites and through attending conferences in order to improve how they live with their condition, understand it and manage their symptoms: all of which aid in improving their quality of life.

Relationships

This use of websites and other media sources also helped one of the women in this study to communicate with other women with PCOS. Stephanie took a photograph (below) of her computer screen and the Verity website accompanied with a diary entry which describes how she feels 'less isolated' when using websites and when watching television shows that may feature other women with PCOS.

Finding out about other people's experiences through media like the verity website & channel 4's food hospital, helps me feel less isolated and to realise that there are people who suffer more than I do. I also like how the discusso boards and local groups (verity) mean I can talk to other people who actually 'get it'. Although you do get a few strange looks when you're sat in a coffee shop talking openly about menstruation and hair removal. (Stephanie, AU)

[Insert Figure 3]

Previous research exploring the impact of online support for women with PCOS similarly found that women with PCOS derive benefit from using dedicated online support groups and realising that they are not alone (Holbrey and Coulson, 2013). Additionally, Holbrey and Coulson also suggest that using online support groups can benefit women access information and advice that may not be forthcoming from health care professionals.

Some of the women in this study took photographs of their partners, and some of their pets, to demonstrate how they these relationships influence their quality of life whilst living with PCOS.

my husband is a wonderful support to me and bears all this PCOS stuff with patience and calmness. He remains optimistic about our chances of having a child together. He always says he loves me no matter what. I am immensely grateful to him. As for the cat, he is our “furry baby” and provides comfort and cuddles!

(Denise, 30)

Denise refers to their cat as their ‘furry baby’, suggesting that although Denise may have trouble conceiving due to her PCOS symptoms, her pet acts as a potential surrogate child who ‘provides comfort and cuddles’. The notion of pets acting as a support system for women with PCOS is an original finding not previously reported in the literature.

Linda also took a photograph of their pet dog (below) suggesting that having a pet may have a positive impact on her quality of life.

Research suggests that having a pet may be beneficial to an individual’s health (Antonacopoulos and Pychyl, 2010; Bonas, McNicholas and Collis, 2000). This is also supported by Allen, Blascovich and Mendes (2002) who proposed that individuals perceive their pets as important, supportive parts of their lives.

[Insert Figure 4]

The quotes and photographs displayed demonstrate how women with PCOS can feel about their relationships and their impact on their quality of life. Many aspects of this theme have not previously been reported in the published literature and need to be further explored in order to gain a better understanding of how women with PCOS experience their relationships.

Discussion

This research explored the impact of PCOS on quality of life from the participant's perspective and produced three super ordinate themes: Control, (sub-themes Symptom Management and PCOS as Controlling) Perception, (sub-themes Feminine Identity and Positivity) and Support, (sub-themes The Health Care System, Education and Relationships), which reflect how PCOS impacts on physical (control), psychological (perception) and social (support) quality of life. These findings also shed new light on the perceived positive aspects of living with PCOS and the supporting role that pets, and social networking websites play for women with PCOS.

Through the use of photovoice methodology, participants were able to record aspects that positively affected their quality of life, which included things that helped them to cope with the condition. The use of online support groups to access information, advice and to connect with other women with PCOS corroborates findings from other research,

such as that of Holbrey and Coulson (2013). The present study also highlights how lack of support from health care professionals, as discussed in previous literature, (Crete and Adamshick, 2011; Kitzinger and Willmott, 2002; Snyder, 2006) can lead individuals to educate themselves using books and the internet. Even so, this research is the first to report women with PCOS using online blogging websites such as Tumblr to gain information and form relationships with other women rather than dedicated PCOS online support groups (Holbrey & Coulson).

This research revealed how participants used online media and social networking as a way to self-educate and gain support. This could be problematic for individuals who may receive wrong or inadequate information either from blogging websites such as Tumblr (used by a participant in this study) or from other people on social networking sites (such as Facebook). It would be sensible, therefore, to suggest that health care practices and professionals introduce websites which would allow their patients to access correct information about their PCOS and allow them an area in which they could discuss their condition with other patients. Moreover, input from a health care professional to this environment would enable women with PCOS to feel supported by their health care professional; something which the participants in this study felt was inadequate.

This study also highlighted how women with PCOS retained a positive outlook despite living with their condition and its symptoms. It demonstrated how women remained hopeful and optimistic about their future living with PCOS in the face of uncertainty; particularly with regards to future fertility. Research suggests that optimism is a significant predictor of positive health outcomes (Rasmussen, Scheier and Greenhouse, 2009). Indeed Litt et al. (1992) found that women undergoing in vitro fertilisation (IVF), a fertility procedure often undertaken by women with PCOS, who were the most optimistic were the least distressed after unsuccessful fertilisation. Bleil et al. (2012) similarly report that being pessimistic may be a risk factor for IVF treatment failure. This suggests that being optimistic may be advantageous for the psychological quality of life of women with PCOS who are suffering with infertility and implies interventions to promote hope and optimism may be beneficial. However, the longer term benefits of optimism are less clear (Cohen et al., 1999; Segerstrom and Sephton, 2010) and so the long term effects of having a positive outlook with no improvement in circumstances need to be examined.

One strength of this study is the use of diaries completed at the same time as the photographs. Several participants created entries in their dairies which referred specifically to photographs they had taken; yet, upon development of the camera there were no associated photographs. It can be assumed that the photographs either were not

taken properly or failed to develop. This issue therefore demonstrates the advantage of asking participants to complete diary entries for photographs rather than asking them at a later date about photographs which have been developed as in previous research (Frith and Harcourt, 2005). Moreover, Thompson et al. (2008) suggested that by carrying out photovoice research at two different time points (time of photograph and time of interview about photograph), many participants had forgotten why they had taken the photo. In this way diaries allow the researcher to see the photographs in an accurate context.

There were limitations with this study; primarily the attrition rate for this research was high. A large sample of participants were recruited and sent study packs (N=34) but only nine participants returned their packs, despite reminder emails. A number of participants also stated they had returned completed packs but these never arrived. Although there were a small number of participants, this replicates other photovoice research (Duffy, 2010; Thompson et al., 2008; Vaughn, Rojas-Guyler and Howell, 2008; Wiersma, 2011) and may therefore be related to a methodology which places quite a high burden on the participant.

The high attrition rate could also be due to the lack of a personal relationship between the participant and researcher as participants were only in contact with the researcher

via email. Booth and Booth (2003) suggest that many women in their photovoice study found it difficult to use the camera film so put the camera aside and then forgot to go back to it. It is possible, therefore, that the women in this study simply forgot to use the camera.

Baker and Wang (2006) similarly reported issues of high attrition in their photovoice research; they suggest that this may be due to the number of steps participants have to take in order to complete the research. Indeed, some participants in this research may have completed the study but failed to return the study pack. Consequently, the lack of responses may have limited the findings of this study and potentially biased the findings to represent those women who engaged with the research who may be more able to cope with their PCOS or, indeed, those who feel less supported.

Participants in this study were not given a definition of quality of life before taking part. Whilst this may be seen as a limitation to the study, this enabled participants to conceptualise what quality of life meant to them. This, therefore, allowed for the research to explore the perceptions of quality of life for women with PCOS, rather than data being derived according to a specified definition that may not have fully captured the quality of life of women with PCOS. As such, the data in this study represents how participants perceive their quality of life, and the impact PCOS may have on it.

Nevertheless, aspects of PCOS identified by the participants reflected the psychological, physical and social factors that are thought to make up the quality of life construct (Testa and Simonson, 2008).

Future qualitative research employing photovoice methodology would be useful to explore the impact of PCOS on quality of life. There are several ways that this study could be improved; primarily through the use of smart phones for taking photographs. The use of mobile phones with cameras has become extremely widespread (Kindberg et al., 2005). Indeed, Boulous et al. (2011) suggest that smartphone technology may be able to achieve lower attrition rates in health research due to its ease of use.

Dissemination of this study's findings to health professionals may aid understanding of the condition that participants reported in this study and enable them to not only provide better health care to women with PCOS, but also allow them to feel better supported.

Acknowledgements

We would like to thank the Verity committee for giving us permission to recruit participants through their charity and also all the women who took part in this research and allowed us to explore their experience of polycystic ovary syndrome.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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