

# 'Everything's from the inside out with PCOS': Exploring women's experiences of living with polycystic ovary syndrome and co-morbidities through Skype™ interviews

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## Abstract

Polycystic ovary syndrome is an endocrine disorder affecting 1 in 10 women. Women with polycystic ovary syndrome can experience co-morbidities, including depressive symptoms. This research explores the experience of living with polycystic ovary syndrome and co-morbidities. Totally, 10 participants with polycystic ovary syndrome took part in Skype™ interviews and analysed using thematic analysis. Four themes emerged from the data: change (to life plans and changing nature of condition); support (healthcare professionals, education and relationships); co-morbidities (living with other conditions and depression, self-harm and suicidal ideation) and identity (feminine identity and us and them). The findings highlight the need for screening of women with polycystic ovary syndrome for depressive disorders.

## Keywords

anxiety, depression, polycystic ovary syndrome, Skype™

## Introduction

Polycystic ovary syndrome (PCOS) is an endocrine disorder affecting 6–8 per cent of adult females (Himelein and Thatcher, 2006). Women with PCOS experience many symptoms including hirsutism (Keegan et al., 2003), obesity, acne, alopecia and menstrual irregularities (Rasgon et al., 2003). Women with PCOS can suffer from more than one condition, including type 2 diabetes, cardiovascular disease (Ong et al., 2006; Thomson et al., 2010), irritable bowel syndrome (IBS; Mathur et al., 2010) and thyroid disorders (Janssen et al., 2004; Kachuei et al., 2012; Sinha et al., 2013). Women with PCOS are also at elevated risk of developing depression (Bhattacharya and Jha, 2010) and anxiety (Laggari et al., 2009) disorders and have higher levels of depression and psychological morbidity (Coffey and Mason, 2003). Indeed, Cipkala-Gaffin et al. (2012) found that women with PCOS have a higher prevalence (31%) of mild or moderate depressive symptom levels compared to a control group (17%). Relatedly, Deeks et al. (2011) report that women with PCOS have increased

anxiety, depression and negative body image compared to women without PCOS. Furthermore, women with PCOS have an impaired quality of life and an increased prevalence of psychological morbidity (Ching et al., 2007). However, Elsenbruch et al. (2006) report that psychiatric illnesses in women with PCOS may go undetected. Thus, women with PCOS may experience co-morbidities that may have a negative impact on their quality of life; however, the majority of research in this area has been quantitative or has taken place in a clinical setting.

Qualitative research would aid our understanding of the psychological impact of PCOS, and other conditions, on quality of life. To date, few studies have explored PCOS

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from a qualitative perspective (Crete and Adamshick, 2011; Holbrey and Coulson, 2013; Williams et al., 2014). Moreover, those studies excluded women with PCOS who experienced co-morbidities; Moreira and Azevedo (2006) argue that incorporating qualitative approaches into PCOS studies could contribute to our understanding of the impact of the disease. This study, therefore, aims to explore the impact of PCOS on quality of life, through qualitative methods. It is the first such study to explicitly include women with PCOS who may have other health conditions; this is of particular importance given the high proportion of co-morbidities in women with PCOS.

## Methods

### Online research methods

Women with PCOS are frequently socially isolated (Kitzinger and Willmott, 2002); therefore, the mode of data collection needs careful consideration. Seymour (2001) suggests that online data collection methods enable the researcher to access inaccessible domains, such as hard to reach populations or socially isolated groups. Kraut et al. (2004) also argue that online research could make apparent psychological phenomena that do not exist in traditional settings. Sullivan (2012) has proposed that there is potential for data collection in social research through the use of technology such as Skype™ and Google Hangout. Accordingly, online research may enable access to a socially isolated population such as women with PCOS.

Deakin and Wakefield (2013) suggest that online synchronous interviews using, for example, Skype are a useful replacement of traditional face-to-face interviews. They describe several advantages of using Skype to conduct interviews including allowing more flexibility for the researcher and participant, and being more cost and time efficient. Janghorban et al. (2014) argue that Skype offers a useful alternative to face-to-face interviews and is suitable for conducting individual interviews. Previous research using Skype has explored online health forums (Fan et al., 2013) and online psychiatric consultations (Williams et al., 2014). Williams et al. (2014) found that there was a high acceptability of online consultations via Skype in their participants. This suggests that Skype is a viable way to conduct online research. Accordingly, this study explored how women with PCOS perceive the impact of the condition on their quality of life through online Skype interviews.

### Participants

Participants were recruited via the social networking website, Facebook. A recruitment post was posted to different PCOS support groups available on Facebook after agreement from the group moderator. The inclusion criteria for

this study were as follows: aged 18 and over, lived in the UK and suffered from symptoms of PCOS. Participants were not required to have a co-morbidity to take part in the research. Totally, 10 participants agreed to participate and were interviewed for 40–90 minutes. Of these, nine participants spontaneously discussed suffering from co-morbidities, such as depression, IBS and hyperthyroidism, and therefore just these nine were included in this analysis. Participants' ages ranged between 20 and 41 years; three participants chose not to disclose their age.

### Materials

Interviews were conducted using Skype (voice call only) over the Internet. Skype is an online method of making free video or telephone calls; it also allows for individuals to send text-based messages to one another for free of cost. The interviews were recorded using Evaer computer software (Evaer Technology, <http://www.evaer.com/index.htm>). Interview questions were developed after a review of the literature and included questions such as, 'Could you describe a typical day living with PCOS?' and 'Have you changed the way you deal with your PCOS and its symptoms over time?'

### Procedure

After participants had registered their interest in taking part in the study by email, they were sent an information sheet and a consent form by return email. They were informed that they did not need to fill anything in but were advised to read both documents before deciding whether they wished to take part in the research, thus ensuring participants had sufficient time to consider the implications of taking part in the research (The National Health Service Health Research Authority (NHS HRA), n.d.). Participants who emailed to say they would like to take part arranged an interview appointment with the researcher. At the time of the scheduled interview, participants were called through Skype (Microsoft). The participant was then sent the statements of consent from the consent form and asked to consent using the text-based service provided by Skype. They were also reminded that their information would be stored confidentially and they had a right to withdraw. The researcher then informed the participant that the Skype call was being recorded.

### Ethics

Research complied with The British Psychological Society's (BPS, 2009) ethical guidelines and their guidelines for Internet-mediated research (BPS, 2013) and ethical approval was obtained from the Psychology Research Ethics Committee at the University of Derby (Ethics Approval Number: 06012-SW).

## Analysis

The online interviews were transcribed and then analysed using an inductive thematic analysis (Braun and Clarke, 2006). Thematic analysis is a method for identifying and reporting themes within the data, which organises and describes the data in detail (Braun and Clarke). To analyse the data according to the six steps recommended by Braun and Clarke, the transcript was first read and re-read and then initial codes were generated. Next, the initial codes were sorted into potential themes. The themes were then reviewed, defined and named. Finally, the thematic analysis was written up. The final themes were reviewed by two other health psychology researchers to ensure all were in agreement, that the themes accurately represented the data and there was not too much overlap between themes (Braun and Clarke).

## Findings

Participants in this study experienced a variety of symptoms including hirsutism, obesity, acne and infertility. The participants also suffered from other conditions, both physical and psychological, in addition to their PCOS. Four major themes emerged from the data: change (to life plans and changing nature of condition); co-morbidities (living with other conditions and depression, self-harm and suicidal ideation); support (healthcare professionals, education and relationships) and identity (feminine identity and us and them). All identifying details have been removed from the quotes and participants have been referred to by pseudonyms throughout the analysis in order to ensure anonymity (BPS, 2010). Participants who chose not to disclose their age are denoted by AU.

## Change

### To life plans

Several participants described how PCOS had caused them to change their life plans, particularly their plans to start a family. In the quote below, Dawn discusses how having a large family was the 'planned thing to do' and what they (her and her husband) 'had planned to do' before they got married:

when me and my husband first got together it was you know, my husband's one of six, I'm one of five, it was the planned thing to do and that's what we had planned to do before we got married erm but it, it, did bother me for a long time, a very long time actually, erm but I think the older I've gotten and the older we've gotten the more, I think since I turned 30, it's become less of an issue, if you like because we've just, we've got used to it. You know, when I turned 30 we'd been dealing with it for nearly ten years. So I don't know if it's erm, it might have impacted to start off with, but it's not, I don't, I used to look at children and think yeah I'd love one. (Dawn, 36 years)

Similarly, Julie (below) states that she had been 'dreaming' about having a family for almost '30 years'. She discusses, in the quote below, how the impact of PCOS on her fertility was 'very hard to grasp' as it was something she had 'always wanted' from a young age. The quote illustrates how women with PCOS who plan or want a family may have to change the plans they had for their life:

I really found it very hard to grasp that the one thing that I'd always wanted right from, well from being a little girl and playing with, playing with dollies and that sort of thing. I always knew I wanted children, even before I wanted a boyfriend. I knew that malarkey and always knew that I wanted a family and so this thing that I've been sort of looking forward to and dreaming about for nearly the whole of my 30 years was kind of like the, the rug pulled out from under my feet kind of thing a little bit and it was erm pretty horrible really. (Julie, 36 years)

In contrast to Dawn and Julie, in the quote below Holly describes how she planned to have kids later in life after she had established a career. Holly stresses that due to having PCOS she felt pressured by healthcare professionals to have children 'sooner, rather than later' and change the 'plan' she had for her life:

every doctors tells me that I need to start thinking about having children sooner rather than later, that's quite a change erm 'cause I'm an army wife so I travel around a lot which makes it hard to get jobs and kind of puts your career on the back foot so I was hoping to establish a career, a, a settled base and then have children but I'm not sure how that's going to work out for me now. So yeah, I think I probably will have to change my plan slightly. (Holly, 25 years)

The impact of PCOS on the ability to conceive for women with PCOS has been highlighted previously by Snyder (2006) who found that women with PCOS felt uncertain about their ability to become pregnant. Similarly, all the participants (n=10) in Washington's (2008) study expressed their concerns on their ability to get pregnant and the impact of their PCOS on conception. This study, however, is the first to discuss the pressure women with PCOS feel to have children earlier in life than they may have originally planned due to pressure from healthcare professionals.

Research exploring the fertility intentions following testing for a BRCA1 gene mutation found that predictive genetic testing for late-onset cancer susceptibility affects family planning decision-making (Smith et al., 2004). Fortuny et al. (2009) have also stated that BRCA1/2 genetic results could influence an individual's decisions regarding reproduction. As such, testing positive for a BRCA1 or BRCA2 gene mutation may be similar to that of PCOS when considering the impact a diagnosis could have on the individual's life plans concerning children.

However, further similarities cannot be assumed due to the differences in the two conditions, specifically, while women with BRCA1/2 are faced with a choice that will impact their life plans, women with PCOS experiencing fertility issues have this choice removed and as such, have no control about how their condition will impact their life plans.

### *Changing nature of the condition*

Several participants describe the changing nature of their PCOS symptoms and their inability to predict how their condition will change over their lifetime. Crete and Adamshick (2011) reported that women with PCOS were frustrated due to dealing with the uncertainties of symptoms and diagnosis. Dawn states in the quote below that her PCOS symptoms have ‘got worse over the years’ demonstrating how the symptoms of PCOS are unstable:

It’s definitely just got worse over the years. A lot worse erm I think, I think from the age of 25 its suddenly started kicking off erm with you know having to start taking care of you know, the hair issue and it just, as I said, it just seems to be getting worse. (Dawn, 36 years)

Similarly, Holly discusses the changing nature of her moods as a result of PCOS in the quote below. She describes how she feels she has ‘no control ... whatsoever’ and how she has taken medication to try and control the symptoms:

I think it’s because it’s, everything’s from the inside out with PCOS. It’s really hard to control anything that happens unless, unless you want to go on a contraceptive pill, which I don’t. I think that’s probably the only way that you control it ... I have no control over it whatsoever. I can be feeling really good and really happy and brilliant and then just get a whole load of spots and think and what is that about? It’s really upsetting and I can feel really low and really depressed about it and my skin’s looking great and I just don’t understand it at all. It’s horrible. (Holly, 25 years)

Holly was not alone in describing changes she had made to try and control her PCOS. Each participant reported trying different medications or symptom management techniques to try and control or deal with their symptoms, including hair removal and skin care routines. This has been reported by several other studies (Crete and Adamshick, 2011; Kitzinger and Willmott, 2002; Snyder, 2006). Hsu (2013) suggests that women with PCOS may experience changes in their PCOS symptoms with age, particularly in adolescence and later life. Healthcare professionals should be considerate of these changes in presenting symptoms in women with PCOS and offer appropriate support and guidance.

## **Co-morbidities**

### *Living with other conditions*

Six of the participants (Holly, Tanya, Kay, Sharon, Emma and Dawn) discussed how they lived with other physical conditions as well as their PCOS. These conditions were varied and include migraines, IBS, hypermobility syndrome, hypothyroidism, adrenal fatigue and fallopian tube obstruction.

In the quote below, Tanya describes how she has IBS as well as PCOS. Interestingly, despite suffering from two chronic health conditions, Tanya states that she and her family ‘don’t really suffer from anything’. The quotes below suggest that for Tanya, she identifies as being well, rather than ‘poorly’ even with her PCOS and IBS symptoms:

We’ve never really, we’re not really like a poorly family. We don’t really suffer from anything. Mmm I do get a lot of colds, I always pick everything up. Oh and I do have a, I’ve actually just realised, a touch of IBS. (Tanya, AU)

To date, only one study has explored the prevalence of IBS in women with PCOS. Mathur et al. (2010) found that not only were women with PCOS more likely to have IBS than healthy controls, but that women with PCOS and IBS symptoms were more likely to have a higher body mass index (BMI) and body fat percentage compared to women with PCOS but who did not suffer from IBS. In this study, only Tanya reported experiencing symptoms of IBS; however, this finding does demonstrate a need for further research exploring the prevalence, and experience of IBS in women with PCOS.

Tanya’s experience contrasts with Kay who had several other conditions in addition to PCOS. In the quote below, Kay discusses how she has asthma, eczema and hypermobility (hypermobility is a condition where people experience loose or supple joints that can often result in pain). She explains that she has ‘quite a bad time with them’, suggesting she finds it difficult living with multiple morbidities:

I have erm asthma, erm I have eczema and I also have hypermobility erm which is basically from the double jointedness [sic] erm and I have a lot of problems with my joints, especially my knees erm and I have quite a bad time with them. (Kay, AU)

The quotes above demonstrate how women with PCOS may struggle to live with other debilitating conditions in addition to PCOS. Dawn describes that it was a ‘hell of a shock’ and ‘devastating’ to learn that she had an additional health issue to PCOS, suggesting that this was a traumatic experience for her. This suggests that women with PCOS and a co-morbid condition may find it difficult to cope, particularly at the time of diagnosis of the additional condition:

it was quite a shock because it looks like one of my fallopian tubes stopped working as well. So I went in to perhaps go and have erm IVF and I went and had a scan with a, well they inject a dye into my tubes and erm one of them wouldn't even go up and it was a hell of a shock just to find out well one of your tubes is now not working at all and you're not producing erm the eggs you need and erm all this all down to this, this polycystic ovary syndrome ... it was very devastating at the time. (Dawn, 36 years)

### *Depression, self-harm and suicidal ideation*

Six participants (Dawn, Kay, Julie, Marie, Debbie and Tanya) in this study reported suffering from depressive symptoms including self-harm and suicidal ideation. This has not previously been reported in any published qualitative research. Quantitative research has shown that women with PCOS report more depressive symptoms (Himelein and Thatcher, 2006) and a higher prevalence of depression (Cipkala-Gaffin et al., 2012; Hollinrake et al., 2007) than controls even after accounting for BMI and age (Deeks et al., 2011), but findings from this study show that for some women this may be particularly severe.

The relationship between PCOS and depression was discussed by Kay and Marie (below). Kay states that her depression 'is led from' her PCOS suggesting that rather than her depression being a result of a biological cause, such as polycystic ovaries, Kay sees it as a result of living with the symptoms of PCOS. Conversely, Marie states that it is her PCOS that adds to her depression, suggesting that she perceives this as a separate phenomenon. This suggests that participants are not receiving adequate information regarding their conditions from their healthcare professional and may not get the best care for them (Percy et al., 2009):

'cause I don't, for me polycystic ovaries doesn't create my depression, my depression is led from the aspects of polycystic ovaries. (Kay, AU)

I wouldn't have thought the depression would impact the PCOS really but I suppose it could, I haven't really thought about that but definitely having the PCOS adds to the depression because of all the things you hate about yourself makes it diff, harder. (Marie, 20 years)

Marie also admits that she has a history of self-harm. She discusses how she still thinks about self-harming and the impact PCOS and her depression have on one another; she suggests it is 'a cycle' between her depression and her thoughts about her PCOS:

I don't think I deal with it very well because erm I have a history of self-harming which got quite bad at one point erm I don't do it anymore but it's always still in my mind so when I have a really bad day I always still think about doing it. Erm

and when, if I'm depressed about PCOS my thoughts can sort of go round and round and switch between all the different things that PCOS is doing and the depression is doing and it's all just a cycle really as when I do get really depressed it's hard to get back out of it. (Marie, 20 years)

Two participants reported that they had or do self-harm (Dawn and Marie). Currently, there is no published research reporting incidences of self-harm in women with PCOS. Dawn describes how she will self-harm when she gets 'hormonal surges':

I think I get an over, an overload of testosterone because my whole attitude changes and it's really unpleasant for my husband and my family when I go through this, I think, a hormonal surge ... I will self-harm when I get this. It's like I'm more reckless, erm it's, it's, I become withdrawn and then I almost become like dual personality. (Dawn, 36 years)

Research by Månsson et al. (2008) has found that suicide attempts were higher in women with PCOS than age-matched controls; lifetime suicide attempts were seven times more common for women with PCOS than controls. Suicidal ideation was briefly discussed by Tanya (below); she describes how on 'really, really blue days' she would begin to think about 'ending it' but that thinking of her family and the impact it would have on them helps prevent her from following through with these thoughts:

I had suffered some days where I was so depressed and so down I wouldn't leave the house, some days I wouldn't go out to buy food because I was just so miserable and so fed up and there are times that you, not that, you just have these really, really blue days where you just think 'Oh God, I'd love to just end, end it all as in, not, I'm finding it hard to explain it. I realise by ending it you would obviously end your life but I feel like if my body just stopped working. If I just shut my body down and it will all stop and it will stop doing this and it will stop doing that, but then obviously I just think to myself it's a selfish way of thinking. (Tanya, AU)

Suicidal ideation is considered a serious psychiatric issue in patients diagnosed with chronic illnesses (Amer and Hamdan-Mansour, 2014); however, the way in which physical illness increases the risk of suicidal behaviour is not completely understood (O'Connor and Knock, 2014). Webb et al. (2012) suggest that the link between suicidal behaviour and physical illness is attributable to depressive symptomology; however, Scott et al. (2010) report that the link remains even after controlling for mental disorders. As such, more research is needed to explore these links within a population of women with PCOS. Moreover, Carpenter et al. (2000) found that obesity was associated with an increased risk of depression and suicidal ideation among women in the United States. Similarly, Ekbäck

et al. (2009) report that women in their study, who suffered from hirsutism, had also contemplated suicide as a way of escaping their condition. As obesity and hirsutism are common symptoms of PCOS (Cipkala-Gaffin et al., 2012), it is important for healthcare professionals to be aware of this risk in women with PCOS.

## Support

### *Healthcare professionals*

Every participant in this study conveyed 'frustration' over the support, or lack of support that they received from healthcare professionals (Kitzinger and Willmott, 2002). Several women expressed having to 'push' for tests to diagnose their PCOS after they are presented to their doctors with symptoms. This is illustrated by Dawn in the quote below who presented with symptoms of hirsutism and infertility:

I think I became a right pain in the butt to the, my doctors because I kept going on 'I think something's not right', you know, erm and obviously they just, they just kept fobbing (sic) me off. You know, 'you'll grow out of it', erm and I think it was, it was because I started getting erm like quite a heavy moustache on my top lip ... I couldn't fall pregnant after six months that they actually put me through for a scan. Erm so, yeah so then I reckon yeah it's when they found out that I had the little string of pearls going on. (Dawn, 36 years)

Holly also describes how her doctors made her feel like her symptoms were not real. She discusses how she saw several general practitioners (GPs) before she was able to take the tests to diagnose PCOS:

I saw a doctor and he said I'll treat you as if you have got PCOS but I'm not going to do any tests and, and this wasn't good enough. So I went to another GP and she said 'no absolutely, let's do your tests' erm and it just strikes me that doctor's, GPs especially just don't really know anything about PCOS. (Holly, 25 years)

Several participants described a similar experience of visiting several GPs before getting what they perceived was appropriate care. This appears to be a common problem for women with PCOS (Crete and Adamshick, 2011; Snyder, 2006; Washington, 2005). These findings suggest that healthcare professionals need to be more supportive of women with PCOS particularly at the time of diagnosis, and that there is a need for them to recognise the impact of this condition, and co-morbid conditions, on an individual's quality of life. Future research exploring these phenomena from a healthcare provider's perspective may help shed new light on this problem and how this may be improved.

## Education

Several participants in this research resorted to researching and educating themselves about their condition due to a lack of information and support from their healthcare professionals. Dawn describes below how she felt when she was diagnosed, and that she was left to research her condition and educate herself about PCOS:

It's just like we've got this, this label of polycystic ovaries and but there's not a lot of explanation and that was about, oh goodness me, that was about 15 years ago and it was up to me to sort of like try and research as much as I could on it. (Dawn, 36 years)

Holly also proactively researched her condition using books and the Internet (blogs) that allowed her to create her 'own action plan' in order to be better able to manager her condition. She explains that although there is 'a wealth of information out there' this is not from healthcare professionals but from women with PCOS who are 'doing it themselves':

So when I got the diagnosis it made me, you know, I could go out and read the books and read the blogs and come up with my own action plan; which I did ... So it really does, there's such a wealth of information out there, but unfortunately it's not from the medical erm industry, it's from people doing it themselves, people who want to cure it naturally. (Holly, 25 years)

Later in the interview, Holly goes on to discuss that doing her own research and trying new ways to manage her symptoms can become 'exhausting'. She also describes how, if new methods do not work it can lead her to going 'back down to that low place', suggesting that the trial and error process of research can be taxing:

I do lots of research and I think oh I'll try this. I'll try something new and you kind of rally yourself to do new things and then you realise it's not going to work, it's not working then you go back down to that low place and then you've got to rally yourself up again to try something else and it's just, it's quite exhausting just always, I don't know. (Holly, 25 years)

These findings accord with Snyder's (2006) who found that women with PCOS actively searched for answers without the help of a healthcare professional. Similarly, Crete and Adamshick (2011) found that participants in their study discussed formally searching for answers through the use of online resources and books, supporting the findings of this study that suggest that women with PCOS self-educate.

## Relationships

Several participants found support and information from other women with PCOS by using online support groups.

Holly found support from women with PCOS online, claiming that they have ‘more knowledge’ than her family and are ‘more understanding’. The quote below demonstrates how Holly’s family was unable to ‘understand’ her condition in a way that other women with PCOS could, even though they were supportive. Thus, using online support groups may help reduce feelings of loneliness or isolation in women with PCOS:

I think erm these women have er more knowledge than my family about it and they’re more understanding. My family are supportive but they don’t understand it at all. Even my sister whose got PCOS, she has, she hasn’t really got any symptoms other than a bit of excess hair. She’s never even researched it because she doesn’t feel she needs to but these women online, they’ve done so much research and, and they’re so supportive. (Holly, 25 years)

This concurs with Holbrey and Coulson (2013) who found that participation in an online support group for women with PCOS can help women feel empowered, as it allows them to connect with other women with PCOS and enables them to access information and advice.

## Identity

### *Feminine identity*

Six participants (Tanya, Dawn, Emma, Anna, Julie and Kay) discussed their PCOS in relation to their identity as a woman. Washington (2008) also found that for women with PCOS, the condition could have a negative impact on their self-concept including their self-image and their femininity.

In the quote below, Tanya describes how instead of feeling ‘sexy’ or ‘attractive’, because of her PCOS she feels like a ‘man’. She states that she feels ‘like a freak’ because of her PCOS and its symptoms, suggesting she thinks she is abnormal because of her condition. Kitzinger and Willmott (2002) also found that their participants described themselves as ‘freaks’ because of the symptoms of their PCOS:

I think, as a woman, you, you want to feel sexy. You want to feel attractive to the opposite sex. I think when you have these problems, you don’t. You feel like a freak. You feel like a man. (Tanya, AU years)

A number of women talked about having masculine attributes due to symptoms of PCOS, threatening their identity as a woman; women with PCOS can see themselves as unfeminine, often using male language and terminology to refer to their PCOS and its symptoms (Williams et al., 2014):

I’ve got a very good sense of humour about it because sometimes I swear I’m just like one penis away from turning into a guy. (Dawn, 36 years)

I’m waiting for the day when one of them is drunk and particularly aggressive and mentions it erm and makes some comment along the lines of bearded lady or God knows what they’d do. (Emma, 25 years)

Similarly, Washington (2008) describes how participants felt that PCOS negatively impacted on all areas they associated with being a woman because of symptoms such as hirsutism, alopecia and infertility problems. Snyder (2006) found that women with PCOS felt that their symptoms impacted on their perception of themselves as female and reported that women with PCOS wanted to be normal and look more feminine. Kitzinger and Willmott (2002) also found that women with PCOS felt challenged in their perception of themselves as women because of their symptoms.

### *Us and them*

Several participants discussed how they felt it was ‘unfair’ that they had PCOS compared to other women without PCOS. Tanya states that it is ‘really unfair’ that she suffers from PCOS and ‘not’ other ‘people’, questioning ‘why’ she has the condition:

I do wonder a lot, why me? Why, why did I have to it and not, and not people? I don’t know anybody else whose got it er and part of me does feel like my bodies let me down and, and it’s really unfair. (Tanya, AU)

Snyder (2006) found that women with PCOS identified themselves as different to women without the condition. The participants in this study made social comparisons that could have a negative impact on the quality of life and adjustment to the condition (Dibb and Yardley, 2006). This is also demonstrated in the quote below by Debbie:

I suppose you have to think more about things rather than when other people wouldn’t really give, like other women and stuff probably wouldn’t give thoughts to. (Debbie, AU years)

## Discussion

This research explored the impact of PCOS and co-morbid conditions on women who have PCOS and found four super ordinate themes: change (to life plans and changing nature of condition); co-morbidities (living with other conditions and depression, self-harm and suicide); support (healthcare professionals, education and relationships) and identity (feminine identity and us and them). The themes of support and identity have been discussed previously in the literature (Kitzinger and Willmott, 2002). However, this research is the first to explicitly explore women’s experiences of living with PCOS and co-morbid conditions. Thus, this research is the first to report how women with PCOS

and co-morbid conditions perceive its impact on their life plans and how they manage their conditions.

While quantitative research has described the prevalence of depression in women with PCOS (Bhattacharya and Jha, 2010), this study is the first to report how women with PCOS experience and live with this condition and other co-morbidities such as IBS. Over half of the participants in this study discussed depression, self-harm and/or suicide; yet, there is little discussion of self-harm and suicide in the literature. Of the two studies that do exist, both explore this using quantitative methodology and a clinical sample (Hart and Doherty, 2014; Månsson et al., 2008); therefore, they do not attempt to understand how women with PCOS experience this. This suggests that the experience of living with PCOS and depression is under researched. Healthcare professionals should be aware that women with PCOS are likely to report depressive symptoms, self-harm and suicide and therefore, offer them necessary and appropriate support. Further research should explore the prevalence of self-harm in women with PCOS and aim to develop interventions to decrease depressive symptoms in this population.

This study also highlights how women with PCOS may feel under pressure to have children from healthcare professionals and the impact this can have on their life plans. The experience of being pressured to conceive by healthcare professionals appears to be a unique phenomenon for women with PCOS; women who test positively for the BRCA1 and BRCA2 gene mutation may also experience a similar impact on their plans to have children (Smith et al., 2004). However, for women with the BRCA1 and BRCA2 gene, this impact may be a choice of whether to have children or not, for women with PCOS this choice can be removed. Certainly, research suggests that infertile women report a poorer quality of life compared to controls (Monga et al., 2004) and they experience similar psychological symptoms to those associated with cancer, hypertension and cardiac rehabilitation (Domar et al., 1993). Infertility can have a large negative impact on the women who experience it, without the perceived added pressure to conceive from a healthcare professional that some women with PCOS experience. Thus, research is needed that explores the psychological impact that pressure from a healthcare professional to conceive may have on women with PCOS.

The use of Skype interviews in this study meant participants, who described themselves as socially isolated, were easily able to take part, and the costs, *including time and financial costs*, were minimal to both the researcher and the participant. The online interviews may have allowed participants to feel comfortable, as evidenced by participant's behaviours, such as answering doors or watching their children, demonstrating minimal interference in their day-to-day lives. Nevertheless, while providing an important

account of women's experiences living with PCOS and co-morbid conditions, there were a number of limitations with this study. Indeed, it is possible that the presence of children may have had a negative impact on the participant's openness and willingness to discuss their experiences with PCOS and any co-morbid conditions.

Using Skype was a viable method for data collection for this study, but there were issues with the technology itself (Saumure and Given, 2010) in the form of noise interference on calls which could have had a negative impact on the interviews and resulted in missing information. Participants in this study were self-selecting and all were recruited through PCOS support groups on the social networking website Facebook. Therefore, it could be argued that the women in this study were already seeking support for their PCOS. It is unclear what, if any, support participants received for their co-morbidities from either PCOS groups, or indeed other support groups on Facebook.

Participants were not required to have co-morbidities, nor were they asked to provide information on clinical diagnoses of any conditions to take part. However, this resulted in the participants spontaneously discussing their co-morbidities, highlighting the importance of these to the participants. While previous studies have explored the prevalence of specific co-morbidities (including diabetes, hypertension, sleep apnoea, anxiety, depression) in a population of women with PCOS (Betha and Nestler, 2008; Sirmans et al., 2014), there is a need for further research which explores the prevalence and impact of clinically diagnosed co-morbidities in women with PCOS in the United Kingdom, which is inclusive of the conditions mentioned by participants in this study. It also highlights the need for future studies with women with PCOS to be inclusive of co-morbid conditions.

In conclusion, this research has identified several new areas of importance for healthcare professionals and researchers including occurrences of self-harm and suicidal ideation in women with PCOS. Additionally, this study highlights participants' experiences of living with co-, or often multiple morbidities as well as their PCOS and its associated symptoms. It reports the apparent unique occurrence of changing life plans due to the condition and consequently, with regard to family planning, the pressure placed on individuals by healthcare professionals to conceive. Finally, it also highlights the need for appropriate support to be available for women with PCOS to help deal with the psychological and physical symptoms arising from their condition(s).

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