

**Psychological Distress in Women Living with Polycystic Ovary Syndrome (PCOS):
The Role of Illness Perceptions**

Rebecca S Light MSc¹, Joseph Chilcot PhD², Emily McBride CPsychol¹

¹ Department of Behavioural Science and Health, Institute of Epidemiology and Health Care,
University College London

² Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College
London

Corresponding Author: Emily McBride, Research Department of Behavioural Science and
Health, Institute of Epidemiology and Health Care, University College London, Gower Street,
London, WC1E 6BT. Email: e.mcbride@ucl.ac.uk. Twitter: @EmilyPMcBride @UCL_BSH

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¹ Research Department of Behavioural Science and Health, Institute of Epidemiology and Health Care,
University College London

² Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London

Abstract

Background: Polycystic Ovary Syndrome (PCOS) is an endocrine and metabolic condition linked to increased risk of anxiety and depression (psychological distress). This study examined the relationship between illness perceptions and psychological distress in women living with PCOS.

Methods: We used a cross-sectional survey to assess psychological distress (HADS) and illness perceptions (IPQ-R) in women living with PCOS in the United Kingdom ($N=487$). Hierarchical multiple linear regression tested the associations between illness perceptions and psychological distress, adjusting for age, years since PCOS diagnosis, education, body mass index, current depression, and current anxiety disorder.

Results: In the fully adjusted regression model, illness perceptions explained 18.6% of the variance in psychological distress ($F(7,458)=21.0, p<.001$). Reporting more symptoms ($B=.226$), higher perceived consequences ($B=.204$), lower personal control ($B=-.184$), and lower illness coherence ($B=-.127$) were significantly associated with higher psychological distress (all $p<.001$).

Conclusions: Illness perceptions may play an important role in psychological distress, even after adjusting for relevant demographics and clinical characteristics. Our findings highlight key areas where researchers and clinicians could develop targeted self-management interventions for women with PCOS, focused on altering maladaptive illness perceptions to reduce psychological burden.

Keywords: Polycystic Ovary Syndrome; PCOS; illness perceptions; psychological distress; women's health

Introduction

Polycystic Ovary Syndrome (PCOS) is an endocrine and metabolic condition estimated to affect 8-to-13% of reproductive aged women. Clinical markers of PCOS can vary and present as a range of metabolic (e.g. weight gain, cardiovascular disease, and diabetes), endocrine (e.g. unwanted facial or body hair, acne, irregular menstruation, infertility), and psychological (e.g. depression and anxiety) features and/or comorbidities. As a result of the wide-ranging symptoms associated with PCOS, diagnosis and treatment can prove challenging. It is recommended that women with PCOS are assessed and monitored within a multidisciplinary team to receive education, self-empowerment, and lifestyle interventions for prevention and self-management. Optimal self-management refers to women integrating a range of tailored interventions focussed on behaviour change (e.g. diet and exercise) and social support, with healthcare providers treating clinical features (Teede et al., 2018).

Increased rates of depression and anxiety in women with PCOS are well-documented throughout the literature (Brutocao et al., 2018; Cooney, Lee, Sammel & Dokras, 2017; Teede et al., 2018). Evidence suggests that women with PCOS display up to four-fold increased risk of exhibiting depressive symptoms, and up to six-fold increased risk of anxiety symptoms, compared with women without PCOS (Deeks, Gibson-Helm, Paul & Teede, 2011; Dokras, Clifton, Futterweit & Wild, 2011; Barry, Kuczmierczyk & Hardiman, 2011b; Cooney et al., 2017; Berni, Morgan, Berni & Rees, 2018; Brutocao et al., 2018). Longitudinal research found that although depression scores decreased over a 30-year period, scores were higher at all time points when compared with women without PCOS (Greenwood, Yaffe, Wellons, Cedars & Huddleston, 2019).

Interactions between biopsychosocial factors are thought to account for the high depression and anxiety rates associated with PCOS (Dokras et al., 2011). Higher body mass index (BMI), for example, has been shown to predict depression (Cipkala-Gaffin, Talbott, Song, Bromberger & Wilson, 2012; Brutocao et al., 2018); and has been associated with lower self-esteem and body dissatisfaction (Pastore, Patrie, Morris, Dalal & Bray, 2011; Podfigurna-Stopa et al., 2015; Stapinska-Syniec, Grabowska, Szpotanska-Sikorska & Pietrzak, 2018). Infertility and concerns about conceiving have also been linked to higher distress (Deeks, Gibson-Helm & Teede, 2010; Holton, Hammarberg & Johnson, 2018); as well as acne and unwanted hair contributing to feelings of sadness, irritability, and anxiety (Jones, Hall, Lashen, Balen & Ledger, 2011; Pastore et al., 2012; Podfigurna-Stopa et al., 2015; Asik et al., 2015; Cooney et al., 2017). Systematic review evidence found that unwanted hair and menstruation irregularities had the most significant effect on health-related quality of life (Bazarganipour et al., 2015). Linked to this, qualitative research has indicated that feelings of distress may be related to a perceived lack of control over PCOS and its impact on a woman's body (Hadjiconstantinou et al., 2017).

Despite many studies assessing the psychological burden of PCOS, few have explored the underlying psychological mechanisms with grounding in relevant psychological theory. One relevant theoretical model that helps explain variations in adaption to illness and health outcomes is Leventhal's Common-Sense Model of Self-Regulation (CSM; Leventhal, Meyer, & Nerenz, 1980; Leventhal, Brissette, & Leventhal, 2003). The CSM explores how people adapt to a health threat or diagnosis based on a dual model of cognitive and emotional processes, with 'illness representations' underpinning the cognitive pathway. Illness representations (commonly known as 'illness perceptions') refer to beliefs about an illness or somatic symptom. Leventhal's CSM emphasises six key illness perceptions: (i) illness identity (perceived symptoms related to illness); (ii) timeline (perceived chronicity and

cyclicity of illness); (iii) consequences (perceived impact of illness); (iv) control (perceived personal and treatment control over illness); (v) illness coherence (perceived understanding about illness); and (vi) emotional representations (emotional response to illness). The emotion pathway is based on how individuals emotionally regulate, cope, and appraise health threats. Adaptive illness outcomes are reliant on a consistent and stable self-regulatory system between illness perceptions (cognitive pathway), emotional response (emotion pathway), coping, and appraisal (Leventhal, Diefenbach & Leventhal, 1992). Illness perceptions can alter or worsen over time dependent on acquisition of new information (Leventhal, Leventhal & Contrada, 1998).

Associations between Leventhal's illness perceptions and psychosocial outcomes, including anxiety and depression (together termed psychological distress), have been studied across a variety of long-term conditions, including kidney disease (Chilcot et al., 2013; Chilcot et al., 2018), diabetes (Hudson, Bundy, Coventry & Dickens, 2014), coronary heart disease (Chilcot et al., 2020), and cancer (Richardson, Schüz, Sanderson, Scott & Schüz, 2017). Recent meta-analytic evidence of the CSM found that perceived control was related to a variety of outcomes including psychological distress, which was partially mediated by problem-focused coping and cognitive reappraisal (Hagger, Koch, Chatzisarantis & Orbell, 2017). Preliminary research suggests that interventions targeting illness perceptions may be key to changing behaviour and quality of life in women with PCOS (Mani et al., 2018), e.g. through tailored treatment plans to target underlying concerns and improve self-management (Teede et al., 2018).

Although there have been significant advances in understanding the aetiology of PCOS and prevalence of co-morbid psychological distress, little research has focussed on underlying psychological mechanisms which contribute to the increased risk of distress (Podfigurna-Stopa et al., 2015; Cooney et al., 2017; Teede et al., 2018). Illness perceptions

have been used to understand a wide range of chronic conditions, but to date there has been no major study formally exploring them in women living with PCOS. Exploring illness perceptions in this population should help to inform future research, as well as the treatment or support that women receive. This study aimed to examine the relationship between illness perceptions and psychological distress in women living with PCOS.

Method

Participants

Women aged ≥ 18 years old with a self-reported clinical diagnosis of PCOS living in the United Kingdom (UK) were recruited via targeted advertisements on Facebook and Twitter, and the Verity Charity online blog between 17/04/2019 and 21/05/2019. Ethical approval was granted by the University College London (UCL) Research Ethics Committee on 28/02/2019 (reference: 14981/001).

Study Procedures

Potential participants accessed an online link and were directed to a webpage (via the online survey platform, Qualtrics) which provided information about the study and eligibility criteria. To take part, women completed the online questionnaire with consent implied by submission. Debrief information and signposting to relevant support groups was provided.

Materials

Psychological Distress (Anxiety and Depression)

The Hospital Anxiety and Depression Scale (HADS) was used to measure psychological distress. This questionnaire uses a four item Likert scale ranging from “strongly disagree” to “strongly agree”. The anxiety and depression domains each generate scores between 0-21, categorised as: normal (0-7); borderline (8-10); and abnormal (11-21) (Zigmond & Snaith, 1983). This widely used and validated scale excludes somatic symptoms and focuses on states of anxiety and depression. Total HADS score which combines anxiety and depression subscale scores together was used to measure psychological distress, as it has been shown to be sufficiently unidimensional to justify the use of total score, rather than subscales (Norton, Cosco, Doyle, Done & Sacker, 2013). The maximum total HADS score for psychological distress was 42 and demonstrated high internal reliability in this study (Cronbach's $\alpha = .88$).

Illness Perceptions

The Illness Perception Questionnaire-Revised (IPQ-R) measures how individuals perceive their illness, and links directly to Leventhal's Self-Regulation Model (SRM). The IPQ-R measures eight subscales: illness identity, chronic timeline, consequences, personal control, treatment control, cyclical timeline, illness coherence, and emotional representations. Each IPQ-R subscale uses a five-item Likert scale ranging from “strongly agree” to “strongly disagree”. Illness identity was the only subscale which differed, where individuals endorsed ‘yes’ or ‘no’ for each symptom they attributed to their PCOS. Illness identity was summed to generate a total number of attributed symptoms. Individuals could score a maximum of 30 for chronic timeline, consequences, personal control, and emotional representations; 25 for treatment control and illness coherence; and 20 for cyclical timeline and illness identity (Moss-Morris et al., 2002). Higher scores indicated higher chronicity, consequences, personal

control, treatment control, cyclicity, illness coherence, and emotional representations; and more symptoms.

We included five additional symptoms in the illness identity subscale based on the Modified Polycystic Ovarian Syndrome Questionnaire (MPCOSQ) (Bazarganipour, Ziaei, Montazeri, Faghihzadeh, & Frozanfard, 2012; Luo, Xu & Li, 2020): unwanted hair, thinning hair, acne, irregular periods, and weight gain. The illness identity subscale retained all the original IPQ-R symptoms to capture attributions across a range of common and less common symptoms. Each of the IPQ-R subscales demonstrated high internal reliability in this study (Cronbach's α ranged between .760 and .928 for each illness dimension; see Supplementary File 2). A confirmatory factor analysis was conducted on the IPQ-R, details of which are described in the statistical analysis section. See Supplementary File 1 for IPQ-R wording and list of symptoms included.

Demographics and Characteristics

Demographics included self-reported age (years), menopause status, ethnicity, education, country of residence, number of years since diagnosis, and age participants were diagnosed with PCOS (years). Self-reported weight and height were also measured to calculate body mass index (BMI), using the standardised formula weight divided by height squared (NHS, 2019). Participants also indicated 'yes' or 'no' to whether they had a current diagnosis of clinical depression or anxiety, as well as indicated which recruitment channel they accessed the survey through (Charity website, Facebook, or Twitter). See Supplementary File 1 for the wording used in the demographic questionnaire.

Sample size

A power calculation to estimate sample size was conducted using G-power 3.1 (Faul, Erdfelder, Buchner & Lang, 2009). The study was powered to detect a small to medium

effect ($f = 0.06$) between psychological distress (HADS) and one of the illness perceptions constructs 'consequences' (IPQ-R), which was chosen based on where we expected the strongest association in the model may lie from meta-analytic evidence across other chronic conditions ($r=0.24$) (Broadbent et al. 2015). With an α of 0.05 and 12 predictor variables, we calculated that a sample size of 295 would give us 80% power to detect a relationship.

Statistical Methods

Statistical analyses were performed using IBM SPSS v22 and MPlus v7.3. Given few studies have used the IPQ-R in women with PCOS, a confirmatory factor analysis (CFA) was conducted to evaluate structural validity. CFA of the IPQ-R was conducted using Weighted Least-Squares with Mean and Variance adjustment (WLSMV) estimation. Assessment of goodness-of-fit was based upon standard chi-square criterion and the following fit indices, a confirmatory fit index (CFI) $>.95$, root mean squared error of approximation (RMSEA) $<.08$, and the Tucker-Lewis index (TLI) $>.95$ (Hu & Bentler, 1999). The CFA revealed that the fit of the IPQ-R was good, as determined by the model fit indices (CFI=0.94, TLI=0.94 and RMSEA=0.047), albeit the chi-square statistic was significant (chi-square=3024, $p<0.01$). All items loaded significantly on their respective factors (standardised loadings ranging between 0.30 to 0.96) except for two illness identity items (weight loss [0.11, $p=0.18$] and acne [0.15, $p=0.052$]). Removing these items made no distinct difference to the model fit. It was therefore decided to compute illness identity with these items removed in all the subsequent analysis. The factor model accompanied by standardised factor loadings is presented in Figure 1.

Hierarchical multiple linear regression explored the explanatory contributions of illness perceptions and relevant demographic and clinical variables for psychological distress.

Multivariate analyses used stepwise multiple regression, where demographic variables (age,

years since diagnosis, and education) were in model one, followed by sample characteristics (BMI, current depression, and current anxiety) in model two, and illness perceptions in model three. The parametric assumptions for the regression multicollinearity (psychological distress, Tolerance = .010-.904, VIF = 1.102-101.466), independence (psychological distress, Durbin-Watson value = 1.804), homoscedasticity, and linearity were met. Emotional representations were not included in the regressions given the very high correlation with psychological distress.

There were some missing data for weight, height, years since diagnosis, and age at diagnosis which amounted to less than 4%; therefore, missing data points were imputed using mean substitution (Little, Jorgensen, Lang & Moore, 2013). A sensitivity analysis was conducted comparing the dataset using completer data vs. mean imputed data, and no differences were found.

Results

Five-hundred-and-twenty-seven women completed the online survey; 40 did not meet the inclusion criteria (n=2 were aged under 18 years old; n=38 were resident outside the UK). Four-hundred-and-eighty-seven women were included in analyses.

Demographics and Sample Characteristics

On average, women were aged 30.8 years (SD=7.7), had a BMI of 34.5 (SD=8.2), were 22.2 years when diagnosed with PCOS (SD=5.8), and had been diagnosed for 8.7 years (SD=7.3). Also, the majority were White (94.5%) and educated to degree level or higher (58.5%). Mean scores for the anxiety and depression on the HADS subscales were 12.0 (SD=4.2) and 7.7 (SD=4.3), respectively. The mean score for psychological distress (anxiety and depression subscales totalled) was 19.7 (SD=7.7), which was the response variable used in analyses.

Illness perception (IPQ-R) scores ranged from lowest score for 'cyclical timeline' (M=13.2, SD=3.6) to highest score for 'chronic timeline' (M=27.3, SD=2.9). Table one provides a summary of the demographic and sample characteristics. A large proportion of women (>65%) reported symptoms (known as 'illness identity' in the illness perceptions subscale) such as pain, unwanted hair, fatigue, irregular periods, and weight gain as related to their PCOS (see supplementary file 3). Women who were younger, had a higher BMI, had been diagnosed for longer, had lower education, and had a current diagnosis of depression and anxiety displayed higher psychological distress scores (all $p < .05$, see table two). These demographic variables were adjusted for in the subsequent regression model for psychological distress.

Table 1. Demographic variables and sample characteristics

| Outcome | | Statistic |
|---|----------------------------|------------------|
| Age (years) (<i>M, SD</i>) | | 30.81 (7.65) |
| BMI (<i>M, SD</i>) | | 34.48 (8.15) |
| Weight (pounds) (<i>M, SD</i>) | | 209.44 (52.36) |
| Height (feet) (<i>M, SD</i>) | | 5.46 (0.29) |
| Years since PCOS diagnosis (<i>M, SD</i>) | | 8.69 (7.33) |
| Age at PCOS diagnosis (<i>M, SD</i>) | | 22.21 (5.81) |
| Current clinical depression diagnosis (<i>N, %</i>) | | |
| | Yes | 116 (23.8) |
| | No | 358 (73.5) |
| | Prefer not to say | 13 (2.7) |
| Current clinical anxiety diagnosis (<i>N, %</i>) | | |
| | Yes | 139 (28.5) |
| | No | 342 (70.2) |
| | Prefer not to say | 6 (1.2) |
| Menopause (<i>N, %</i>) | | |
| | Yes | 5 (1.0) |
| | No | 482 (99.0) |
| Ethnicity (<i>N, %</i>) | | |
| | White | 460 (94.5) |
| | Other | 27 (5.5) |
| Education (<i>N, %</i>) | | |
| | Qualification below degree | 202 (41.5) |
| | Degree level or higher | 285 (58.5) |
| Marital Status (<i>N, %</i>) | | |
| | Current partner | 341 (70.0) |

| | | |
|---|---------------------------|--------------|
| | No current partner | 146 (30.0) |
| Recruitment channel (<i>N</i> , %) | | |
| | Facebook/Twitter | 398 (81.7) |
| | Verity Charity blog | 89 (18.3) |
| Illness perceptions (<i>M</i> , <i>SD</i>) | | |
| | Illness identity | 7.10 (3.29) |
| | Chronic timeline | 27.31 (2.88) |
| | Consequences | 23.15 (3.95) |
| | Personal control | 19.36 (4.55) |
| | Treatment control | 13.98 (3.8) |
| | Cyclical timeline | 13.16 (3.62) |
| | Illness coherence | 14.68 (5.25) |
| | Emotional representations | 24.27 (4.55) |
| Psychological distress (<i>M</i> , <i>SD</i>) | | |
| Depression (<i>M</i> , <i>SD</i>) | | |
| Anxiety (<i>M</i> , <i>SD</i>) | | |
| Depression (<i>N</i> , %) | | |
| | Normal | 243 (49.9) |
| | Borderline | 120 (24.6) |
| | Abnormal | 124 (25.5) |
| Anxiety (<i>N</i> , %) | | |
| | Normal | 75 (15.4) |
| | Borderline | 107 (22.0) |
| | Abnormal | 305 (62.6) |

Note. *M* = mean, *SD* = standard deviation, *N* = number of participants, % = percentage.

Education was dichotomised to represent A-Level and below (no formal qualification; General Certificate of Secondary Education; O-Level; Certificate of Secondary Education; Ordinary National

Certificate; Business and Technology Education Council; and A-Level) vs. degree level and above (degree or equivalent and postgraduate or equivalent). Ethnicity was dichotomised as White vs. other (Black, Asian, and Arab). Marital status was dichotomised as partner (married and cohabiting with a partner) vs. no partner (single, divorced, separated, and widowed).

Table 2. One-way ANOVAs and correlations exploring psychological distress and demographic variables

| Demographic variable | Psychological distress | | | | | |
|-----------------------|----------------------------|----------|-----------|----------|----------|----------|
| | | <i>r</i> | <i>p</i> | | | |
| Age (in years) | | -.108 | .017** | | | |
| BMI | | .262 | <.001*** | | | |
| Years since diagnosis | | -.098 | .030* | | | |
| | | <i>M</i> | <i>SD</i> | <i>F</i> | <i>p</i> | η^2 |
| Current depression | | | | 37.702 | <.001*** | 0.27 |
| | Yes | 23.36 | 6.9 | | | |
| | No | 18.49 | 7.59 | | | |
| Current anxiety | | | | 72.250 | <.001*** | 0.36 |
| | Yes | 23.97 | 6.33 | | | |
| | No | 17.84 | 7.48 | | | |
| Education | | | | 42.431 | <.001*** | 0.28 |
| | Qualification below Degree | 22.28 | 7.45 | | | |
| | Degree or higher | 17.85 | 7.35 | | | |

Note. Age at diagnosis, marital status, ethnicity and recruitment channel were non-significant. *:0.05, **:0.01, ***:0.001. *r* = correlation, *M* = mean, *SD* = standard deviation, *F* = f-value, *p* = p-value and η^2 = partial eta squared.

Psychological distress

Table 3 displays the standardised regression coefficients (β), R, adjusted R^2 and change in R^2 after entering all variables into the hierarchal multiple linear regression model. Model one (demographic variables) significantly explained 9.7% of the variance (adjusted R^2) in psychological distress scores. Subsequent entry of Model two (clinical characteristics) explained an additional 13.8% of the variance in psychological distress. Finally, entry of Model three (illness perceptions) explained an additional 18.6% of the variance. The overall model explained 40.4% of the variance in psychological distress, $F(13,471)=25.574$, $p<.001$. Psychological distress was significantly associated with the following demographics and clinical characteristics: education ($B=-.177$, $t(458)=-4.723$, $p<.001$), BMI ($B=.100$, $t(458)=2.594$, $p=.001$), and current diagnosis of an anxiety disorder ($B=.227$, $t(458)=4.818$, $p<.001$). For illness perceptions, psychological distress was significantly associated with: illness identity ($B=.226$, $t(458)=5.628$, $p<.001$), consequences ($B=.204$, $t(458)=4.870$, $p<.001$), personal control ($B=-.184$, $t(458)=-4.350$, $p<.001$), and illness coherence ($B=-.127$, $t(458)=-3.214$, $p=.001$). Overall, the model suggests that lower education; having a current diagnosis of anxiety; perceiving more symptoms, higher consequences, lower personal control, and lower illness coherence are significantly associated with higher psychological distress.

Table 3. Multiple hierarchical linear regression exploring how illness perceptions and relevant demographic variables are associated with psychological distress

| Parameter | Standardised coefficients | | | <i>R</i> | Adjusted <i>R</i> ² | Change in <i>R</i> ² |
|------------------------|---------------------------|------------|------------|----------|--------------------------------|---------------------------------|
| 1. Demographics | Model 1 | Model 2 | Model 3 | .311 | .097 | .097*** |
| Age (in years) | -.026 n.s. | .003 n.s. | .093 n.s. | | | |
| Years since diagnosis | -.075 n.s. | -.086 n.s. | -.083 n.s. | | | |
| Education | -.296*** | -.233*** | -.177*** | | | |
| 2. Characteristics | | | | .484 | .225 | .138*** |
| BMI | | .183*** | .100** | | | |
| Current depression | | .034 n.s. | .071n.s. | | | |
| Current anxiety | | .280*** | .227*** | | | |
| 3. Illness perceptions | | | | .649 | .404 | .186*** |
| Illness identity | | | .226*** | | | |
| Chronic timeline | | | -.047 n.s. | | | |
| Consequences | | | .204*** | | | |
| Personal control | | | -.184*** | | | |
| Treatment control | | | .056 n.s. | | | |
| Cyclical timeline | | | .025 n.s. | | | |
| Illness coherence | | | -.127*** | | | |

Note. *:0.05, **:0.01, ***0.001. *R* = correlation coefficient. Demographic and characteristic variables coded as follows education (1= Below Degree-Level, 2= Degree or Higher), current depression (1= yes, 2=no) and current anxiety (1=yes, no=2).

Discussion

Illness perceptions may play an important role in psychological distress in women with PCOS, accounting for 18.6% of the explained variance after adjusting for relevant demographics and clinical characteristics. Reporting more symptoms (known as illness identity), higher perceived consequences, less personal control, and lower understanding of illness (known as illness coherence) were significantly associated with higher distress. In addition to advancing the scientific field, our findings highlight target areas for clinicians developing or delivering self-management interventions, and patient advice and communication materials.

Given that PCOS is known to carry a burdensome symptomatic profile, it is unsurprising that both higher attribution of symptoms (illness identity) and higher perceived consequences showed the strongest associations with psychological distress. Over 65% of women in our study reported at least one common symptom of PCOS (e.g. unwanted hair, weight gain, irregular periods) and/or fatigue and pain. Whilst fatigue and pain are not usually direct symptoms of PCOS, they have been found to be symptoms of high psychological distress in PCOS and could also be side effects of pharmacological treatment (Teede et al., 2018; Dokras, 2012; Abdollahi, Mirghafourvand, Babapour & Mohammadi, 2019). Similarly, fatigue and pain have been shown to be general markers of distress across various other chronic conditions, where they are not always listed as symptoms characteristic of the physical health condition (Cook et al., 2016). Further, the association between high perceived consequences and distress may be partially explained by PCOS carrying an increased risk of other health conditions (e.g. diabetes, hypertension, endometrial cancer, infertility), which would support previous PCOS research (Moran et al., 2010; Deeks et al., 2010; Pogfigurna-Stopa et al., 2015).

Interestingly in our study, both perceptions about symptoms (illness identity) and consequences produced very similar standardised coefficients for psychological distress as was observed for reporting a current anxiety disorder ($B=.226$ for identity; $B=.204$ for consequences; $B=.227$ for an anxiety disorder). This is important as it implies that the psychological burden of living with PCOS may be attributed to specific illness beliefs, commensurate to the level of burden explained by a clinical diagnosis of anxiety (a well-established predictor of psychological distress). Psychological support beyond the psychology domain may therefore prove a viable strategy for improving mental health outcomes in this population. Primary care clinicians (e.g. general practitioners) and other secondary healthcare professionals (e.g. gynaecologists, endocrinologists, dermatologists, psychologists, dieticians) may help to prevent or mitigate patient distress by holding targeted conversations around these consequences and symptoms. Such an approach would complement the International Guidelines for PCOS, which recommend healthcare professionals discuss self-management strategies with women whilst assessing both mental health and physical outcomes (Teede et al., 2018).

Personal control refers to beliefs about one's own ability to control symptoms and has been shown to predict illness outcomes and subsequent coping strategies across a range of health conditions (Hudson et al., 2014; Broadbent et al., 2015; Richardson et al., 2017). In our study, lower personal control was significantly associated with higher distress. Consistent with this, women with PCOS have been found to report a lack of control over their emotions and body, which they have expressed as contributing to feelings of anxiety and depression (Jones et al., 2011; Hadjiconstantinou et al., 2017). More broadly across wider health domains, low levels of personal control have also been associated with poorer illness self-management; though this belief may be malleable to change from an early point in diagnosis and treatment (Leventhal, Phillips & Burns, 2016).

In contrast to personal control, the perceived effectiveness of treatment for controlling symptoms (treatment control) was not associated with distress in our study. The relevance of personal control but not treatment control may reflect the profile of a group who would benefit more from interventions aimed at activating empowerment and internal agency as part of self-management plans, rather than treatment changes. These findings, again, support International Guidelines for PCOS which recommend that treatment should be patient-centred and co-designed, promoting education, lifestyle interventions, and self-empowerment (Teede et al., 2018). It is possible that mediation or interaction effects may exist between personal control, psychological distress, and successful self-management strategies in PCOS; however, further research is needed to explore potential mechanisms.

Lower perceived understanding of PCOS (known as illness coherence) was also associated with higher distress in our study, as was lower educational attainment (though not a primary outcome). As documented in previous research, these findings may reflect women's difficulty in obtaining adequate and reliable information (Hadjiconstantinou et al., 2017; Holton et al., 2018). In the UK and other countries, the gold standard model of care promotes collaboration between multidisciplinary healthcare professionals and the use of evidence-based information for PCOS. However, few studies have evaluated PCOS resources (Gibson-Helm, Tassone, Teede, Dokras & Garad, 2018) or measured how to improve the sustainability of behaviour change (Pundir et al., 2019). It is possible that education may play a moderating role in the relationship between low illness coherence and high distress, which could be tested in future research. In particular, research across other health conditions has indicated that illness perceptions can change upon acquisition of new information (Leventhal et al., 1992), supporting the possibility that PCOS education interventions may improve illness coherence and, in turn, potentially reduce psychological distress. Integration of education into counselling-based interventions could also facilitate behaviour change and

perceived patient satisfaction of healthcare plans (Colwell, Lujan, Lawson, Pierson & Chizen, 2010). PCOS education materials should take health literacy considerations into account and adopt multiple medias (e.g. written, audio, and visual interfaces) through e-health and face-to-face delivery (Teede et al., 2018; Chiu et al., 2018).

Finally, it is worth noting that we found no associations between distress and the illness perceptions chronic timeline (perception that PCOS is a lifelong condition) and cyclicity (perception that symptoms repeat/persist in cycles). This may suggest that women with PCOS accept of the longevity of their condition and the recurring nature of their symptoms. Again, this reinforces that illness perceptions centred on self-management may be the most important target for minimising distress (Teede et al, 2018).

Limitations and Strengths

To our knowledge, this is the largest study to assess illness perceptions and their contribution to psychological distress in women with PCOS. We used widely tested, validated measures for our main outcomes, which were grounded in established theory and support the use of the CSM in this population. Although we accounted for demographic and clinical characteristics (e.g. age, BMI, clinical anxiety, and depression), these outcomes were self-reported and some may be particularly subject to bias (e.g. self-reported weight and height). Also, we did not measure infertility which is known to contribute to psychological distress and is incorporated into other PCOS questionnaires (e.g. the MPCOSQ), making this a clear limitation of our study which should be integrated into future research. Further, we relied on women self-reporting a clinical diagnosis of PCOS. Like many cross-sectional survey studies, we had a predominantly White and well-educated sample that did not reflect the racial/ethnic diversity and education levels of the UK population as a whole. We recruited

online via support groups, charities, and social media, meaning that our sample may overrepresent the most highly distressed women who were actively accessing social support; reinforced by the higher depression and anxiety scores in our study compared with other PCOS research (mean HADS score of 7.7 and 12.0 vs. ranges from 3.2-6.1 and 6.7-10.5 in other research) (Barry et al., 2011a; Brutocao et al., 2018). This possible self-selection bias, however, may increase the relevance of our findings for informing outcomes in highly distressed target groups (i.e. those most likely to contact clinical services). Lastly, as we used a cross-sectional design, causation cannot be inferred and our findings must be interpreted in this context.

Implications for Practice

To date, PCOS interventions have mostly focused on weight and diet to reduce symptoms and improve health outcomes, yielding small and short-term effects (Kataoka et al., 2017). Our findings highlight alternative target areas for clinical practitioners and researchers to develop interventions to reduce psychological burden, which may in turn improve other outcomes such as symptom self-management. For example, personal control and consequences could be tested in self-help interventions or used to guide formulations in cognitive behavioural therapy (CBT). Information about PCOS (to improve illness coherence) could be better integrated into women's self-management plans by health professionals during diagnosis and ongoing clinical reviews. Given that there is little psychological research exploring cognitive mechanisms in PCOS to date, our findings also act as a springboard for future work to develop this literature and identify causal mechanisms between illness perceptions and psychological distress. Specific symptoms (such as infertility) and other psychological factors (such as self-esteem) which are known to influence psychological distress, and were not measured in this study, should be explored in tandem.

Conclusion

Illness perceptions may play an important role in psychological distress in PCOS, even after adjusting for relevant demographic and clinical characteristics. Perceptions of low personal control, low illness coherence, high consequences, and more symptoms were significantly associated with higher psychological distress. As PCOS is predominantly a self-managed syndrome with high prevalence of comorbid anxiety and depression, these findings have important implications for progressing research and clinical management.

Contributions

RL and EM conceived the study. RL managed participant recruitment. RL, JC and EM analysed the data. EM and RL drafted the paper. All authors contributed to the final version of the manuscript.

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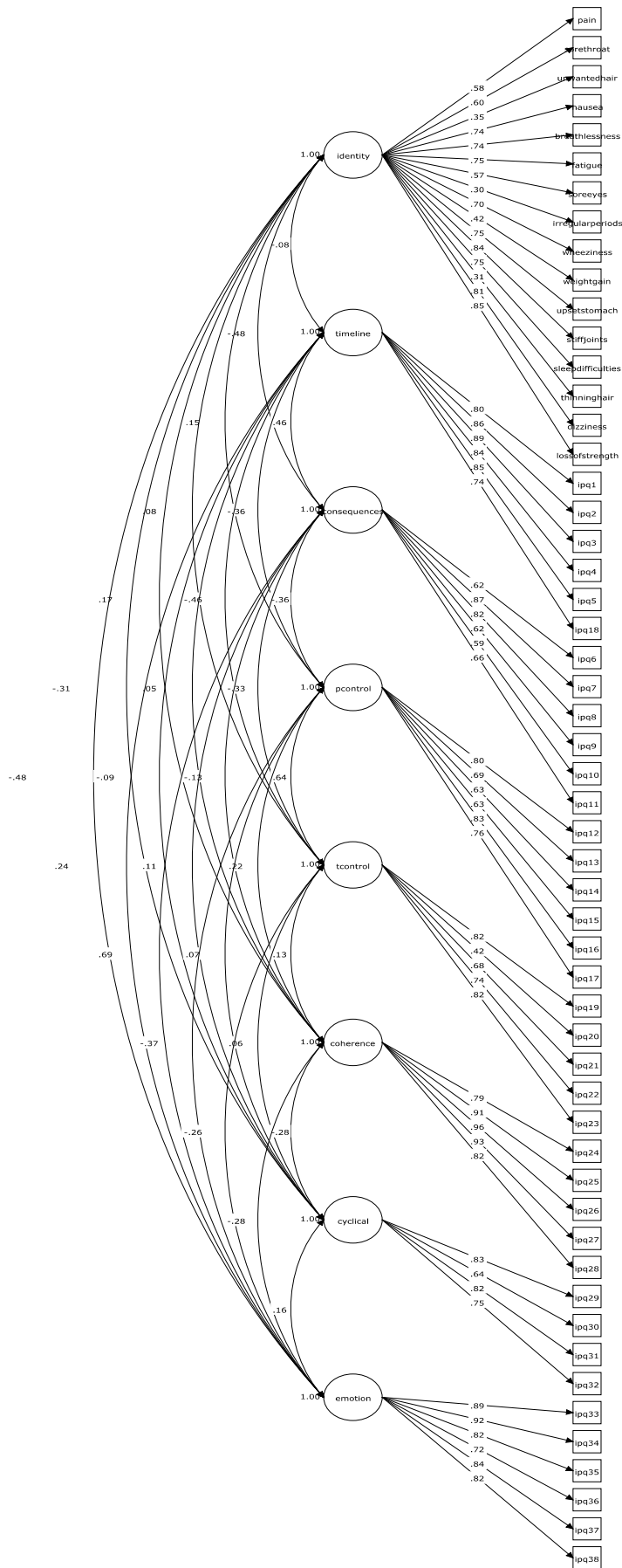


Figure 1: Confirmatory Factor Analysis of the IPQ-R (standardised estimates shown)