human reproduction   **ORIGINAL ARTICLE** *Psychology and counselling*

Influence of the disease label 'polycystic ovary syndrome' on intention to have an ultrasound and psychosocial outcomes: a randomised online study in young women

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STUDY QUESTION: Does the disease label 'polycystic ovary syndrome' (PCOS) have an impact on desire for medical testing and psychosocial outcomes?

SUMMARY ANSWER: When given the disease label PCOS in a hypothetical scenario, participants had higher intention to have an ultrasound, perceived the condition to be more severe and had lower self-esteem than those not given the disease label.

WHAT IS KNOWN ALREADY: Widening diagnostic criteria and improved imaging sensitivity have increased the number of reproductive-aged women diagnosed with PCOS from 4% to 8% to up to 21%. The uncertain clinical benefit of knowing this diagnosis needs to be weighed against the potential for poor psychological outcomes in women labelled with PCOS.

STUDY DESIGN, SIZE, DURATION: This experimental online study randomised 181 young women to receive one of four hypothetical scenarios of a doctor's visit in a 2 (PCOS disease label versus no disease label) x 2 (information about unreliability of ultrasounds in clarifying diagnosis versus no information) design.

PARTICIPANTS/MATERIALS, SETTING, METHODS: Participants were university students (mean age: 19.4). After presenting the scenario, intention to have an ultrasound, negative affect, self-esteem, perceived severity of condition, credibility of the doctor and interest in a second opinion were measured. Participants were then presented with a second scenario, where the possibility of PCOS overdiagnosis was mentioned. Change in intention and perceived severity were then measured.

MAIN RESULTS AND THE ROLE OF CHANCE: Participants given the PCOS label had significantly higher intention to have an ultrasound (mean = 6.62 versus mean = 5.76, $P = 0.033$, 95% CI(difference) = 0.069–1.599), perceived the condition to be more severe (17.17 versus 15.82, $P = 0.019$, 95% CI(difference) = 0.229–2.479) and had lower self-esteem (25.86 versus 27.56, $P = 0.031$, 95% CI(difference) = −3.187 to −0.157). After receiving overdiagnosis information, both intention and perceived severity decreased, regardless of condition (both $P < 0.001$).

LIMITATIONS, REASONS FOR CAUTION: This study used hypothetical scenarios; it is likely that for women facing a real diagnosis of PCOS, outcomes would be more affected than in the current study. The hypothetical design, however, allowed the symptoms and risks of PCOS to be held constant across conditions, the impact on intention and psychosocial outcomes directly attributable to the effect of the disease label.

WIDER IMPLICATIONS OF THE FINDINGS: These findings demonstrate the potential negative consequences of PCOS labelling. It is crucial we consider the impact of the label before diagnosing more women with PCOS when clinical benefit of this diagnosis is uncertain.

Introduction

Polycystic ovary syndrome (PCOS) is a common, complex disorder in reproductive-aged women that has been associated with adverse reproductive, metabolic and cardiovascular outcomes (Dumesic et al., 2015). PCOS has no cure and its aetiology is poorly understood (Roe and Dokras, 2011; Dumesic et al., 2015). PCOS includes a range of symptoms, such as menstrual irregularities, polycystic ovaries and signs of androgen excess, which can vary by age, weight and ethnicity, and can cause significant symptom burden (Kitzinger and Willmott, 2002; Dumesic et al., 2015).

In 1990, the National Institute of Health (NIH) formulated diagnostic criteria to be oligo- or anovulation combined with clinical and/or biochemical signs of hyperandrogenism (Zawadzki and Dunaif, 1992). In 2003, the expert-based Rotterdam consensus expanded the initial NIH criteria by adding sonographic presence of polycystic ovaries as one of the three key diagnostic criteria, requiring 2 out of 3 to establish the diagnosis (The Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop group, 2004).

Following this widening of the diagnostic criteria, combined with increased imaging sensitivity and more testing for the disease, the diagnosis of PCOS has increased from 4% to 8% to up to 21% of reproductive-aged women (Teede et al., 2010; Boyle et al., 2012; Lizneva et al., 2016). Although it is suggested that PCOS is underdiagnosed, particularly in certain populations (March et al., 2010; Boyle et al., 2012), the rapid increase in diagnosis has raised concerns about unnecessary disease labelling and overdiagnosis (Roe and Dokras, 2011; Dumesic et al., 2015). Diagnosis may provide benefit through validation of and explanation for symptoms (Culley et al., 2013; Rowlands et al., 2016), and treatment of infertility for women actively seeking pregnancy (Fauser et al., 2012). However, it is unknown whether knowing this diagnosis encourages women to engage in recommended preventative activities for associated long-term implications, such as lifestyle management. This uncertain benefit needs to be weighed against the potential harms of disease labelling.

The presence of polycystic ovaries is also not a reliable indicator of PCOS, as numerous reports have found that ultrasound features of polycystic ovaries are common in women from the general population (Catteau-Jonard et al., 2012), particularly in younger women aged 18–27, one study finding 66–84% of healthy young women had polycystic ovaries (Duijkers and Klipping, 2010), suggesting a high percentage of young women may be overdiagnosed. Additionally, improvements in imaging technology have meant that small follicles, previously invisible using older ultrasound equipment, are now being detected, artificially increasing the number of women with polycystic ovaries (Bachanek et al., 2015; Dewailly, 2016).

The PCOS disease label may have serious psychosocial implications. Multiple studies have found that women diagnosed with PCOS have significantly higher psychological distress, anxiety and depression, and poorer self-esteem and negative body-image than women without the diagnosis (Teede et al., 2010; Dokras, 2012; Bazarganipour et al., 2013; Rowlands et al., 2016). This may be a result of labelling individuals with a condition linked to infertility, androgen excess and metabolic dysfunctions, creating concerns regarding future health and well-being (Rowlands et al., 2016). Studies in different settings have found that disease labels result in various emotional, cognitive and physical consequences, such as increased work absenteeism, increased preference for medication, even when it is ineffective, and increased desire for more aggressive cancer treatments (Pickering, 2006; Omer et al., 2013; Scherer et al., 2013; Hoyt et al., 2014).

This study tested the impact of the PCOS disease label on intention to undergo further investigation by ultrasound and psychosocial outcomes via an online study among young female university students, an age where symptoms of PCOS overlap with normal symptoms of pubertal development (Roe and Dokras, 2011). We also tested whether giving information about the unreliability of ultrasound testing in clarifying a PCOS diagnosis and overdiagnosis in this condition influenced outcomes.

Materials and Methods

Ethics approval

All study methods were approved by the University of Sydney Human Research Ethics Committee.

Participants

Participants were 181 female students from the University of Sydney who received course credit for their participation. Participants were proficient in English, with no other exclusion criteria used. Based on an initial power analysis, this sample would be sufficient to detect a medium effect size ($f = 0.30$) with power at 0.95 and significance level of 0.05.

Design

The study used a randomised $2 \times 2 \times (2)$ mixed design, where participants were randomly assigned to one of the four scenarios, where disease label (PCOS disease label versus no disease label) and information about ultrasound reliability in clarifying diagnosis (unreliability of ultrasound

effectiveness versus no information) were varied, controlling for personal and family history of PCOS (see Fig. 1). A within-subjects component was included to investigate a change in intention when informed about the possibility of overdiagnosis of PCOS.

Intervention

Hypothetical scenario of doctor's visit
Participants were asked to imagine that for the past 6 months, they have had unusually irregular periods, a few more pimples than usual and an increase of body hair in certain areas, so they visit their general practitioner (GP) to see if this is of any concern (see Supplementary Information). After describing the symptoms, each scenario depicted an appointment with the participant's doctor. The symptoms described were the same in all conditions, depicting a mild but plausible clinical presentation at one time-point.

Disease label condition
Half of participants were randomised to receive a scenario in which the doctor provided the disease label 'PCOS' for their symptoms once, and then referred to the condition as a 'hormonal imbalance' from then on. For the other half, the doctor provides the same explanation and summary of associated risks but does not give a specific disease label, instead referring to the condition as a 'hormonal imbalance' throughout the scenario.

Ultrasound reliability condition
Participants were randomised to receive information that (a) ultrasounds are unreliable in clarifying a diagnosis or (b) were given no information about ultrasound reliability. This was to reflect current guidelines that recommend against using ultrasounds in adolescents due to lack of specificity of polycystic ovaries on ultrasound in this age group (Jean Hailes for Women's Health, 2015).

Overdiagnosis intervention
After completing the outcome measures at Time 1, all participants were presented with another scenario asking them to imagine they get a second opinion. In this second scenario, the new doctor says:

> I believe your symptoms are often overdiagnosed as polycystic ovary syndrome. Because of the increased sensitivity of ultrasounds, screening can lead to finding 'abnormalities' that are not harmful or unusual, resulting in unnecessary stress, anxiety and medication.

The purpose of this experimental factor was to investigate the impact of information about overdiagnosis on intention and represent the conflicting opinions regarding the diagnosis of PCOS (Dumesic et al., 2015).

Procedure

The questionnaire and randomisation process was created using Qualtrics survey software. The study was piloted to test its suitability. After giving consent, participants were randomised to one of the four hypothetical scenarios. Participants were blinded to condition prior to exposure of scenario. Participants were given instructions to keep the scenario in mind whilst completing the questionnaire. Participants were then shown the second hypothetical scenario, and answered additional measures and demographics.

Time 1 outcome measures
Primary outcome
(1) *Intention*: a single item on a 10-point scale, adapted from previous research (Fisher et al., 2012), assessed hypothetical intention to have the ultrasound: 'Which best describes your intention to have the screening test, answering as you would in the scenario above?' (1 = 'Definitely will not' to 10 = 'Definitely will').
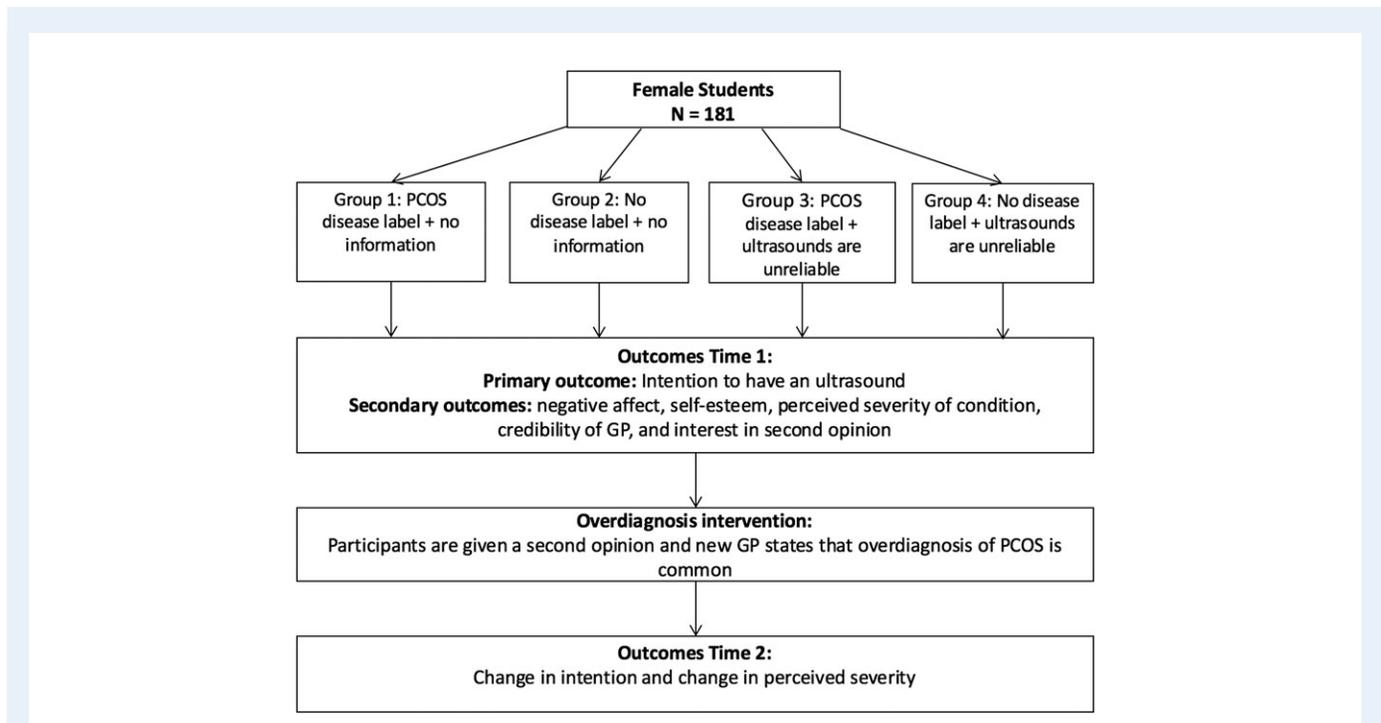
Figure 1 Study design.

Secondary outcomes

(1) *Negative affect:* Positive and Negative Affect Schedule (PANAS) questionnaire, which consisted of 20 items, each of which describes a mood, measured on a 5-point scale ('Very slightly or not at all' to 'Extremely') (Watson *et al.*, 1988).
(2) *Self-esteem:* The Rosenberg self-esteem scale: 10 items on a 4-point scale ('Strongly disagree' to 'Strongly agree') (Rosenberg, 1965).
(3) *Perceived severity of diagnosis*
  (a) Perceived Severity Scale: five items on a 5-point scale ('Strongly disagree' to 'Strongly agree') (Bish *et al.*, 2000).
  (b) A single-item measure of perceived seriousness: 'I feel that being diagnosed with polycystic ovary syndrome/a hormonal imbalance is a serious condition for me to have,' on a 7-point scale ('Strongly disagree' to 'Strongly agree') (Courneya and Hellsten, 2001).
(4) *Credibility of the doctor:* The five-item Credibility Index (Meyer, 1988; Longman *et al.*, 2012) on a 5-point scale ('Fair' to 'Unfair').
(5) *Interest in a second opinion:* 'Would you be interested in getting a second opinion before making a decision about getting the ultrasound?' (7-point scale, 'Definitely not' to 'Definitely interested').

Time 2 outcome measures (after overdiagnosis scenario)
(1) Change in intention.
(2) Change in perceived severity.

Demographics and history of disease
Age, relationship status, place of birth, number of children, screening history, prior knowledge of PCOS, and whether participants themselves, a family member, and any friends their age had been diagnosed with PCOS, endometriosis, breast cancer, cervical cancer or diabetes (5-point scale, 1 = 'No one' to 5 = '4 people or more').

Analysis and covariates
Statistical Package for the Social Sciences (SPSS) version 22.0 was used, with an alpha level of 0.05 set for all statistical tests. To control for previous experience of the syndrome and its associated symptoms, a composite variable was computed by combining a personal diagnosis and/or a family history of PCOS to include as a covariate in further analyses. Prior to analyses, data were examined for missing values, outliers and accuracy, and to establish homogeneity of variance. A few outliers were identified; however, as they had no effect on results, they were retained to provide a complete report of the data.

To analyse the effect of the disease label and ultrasound reliability information on participants' intention and psychosocial outcomes, six 2 (disease label: PCOS versus no label) × 2 (ultrasound reliability: unreliable versus no information) between-participant analyses of covariance (ANCOVAS) were conducted, controlling for previous history of PCOS (personal diagnosis and/or family history). Two 2 × 2 × (2) mixed-design ANCOVAS were also conducted to investigate the impact of the two experimental factors on intention and perceived severity after overdiagnosis information was presented.

Results

Of the 204 participants recruited between June and August 2015, 21 failed to complete the study and 1 withdrew, resulting in an 89% response rate. One participant only completed one-third of the questionnaire, so was removed from the analysis, resulting in a final sample of 181 participants.

Socio-demographic characteristics

The majority of participants (96.7%) were under 25 years of age (median age = 19, IQR = 1.5), were born in Australia (77.9%), were single (64.6%), had no biological children (98.3%) and had previously heard about PCOS (58.0%; see Table 1 for demographics).

Family and personal history of disease

A minority of participants ($n = 44$, 24.3%) reported having a diagnosis of a condition, the most common being PCOS ($n = 8$, 4.4%), then endometriosis (2.7%), hyperthyroid (2.7%) and eczema (2.7%). Seventeen participants (9.4%) reported a family history of PCOS, four of which also reported a personal diagnosis of PCOS (2.2%).

Intention to have an ultrasound

Intention to have an ultrasound was significantly higher for those given the PCOS disease label (mean = 6.62, SD = 2.63) than those given no label (mean = 5.76, SD = 2.77), irrespective of ultrasound reliability information given ($F(1, 176) = 4.63$, $P = 0.033$, 95% CI(difference) = 0.069–1.599, see Figure 2). Intention was also significantly lower for those given information about the unreliability of ultrasound effectiveness (mean = 5.57, SD = 2.77) compared with those given no information about ultrasound unreliability (mean = 6.81, SD = 2.56), irrespective of disease label given ($F(1, 176) = 11.10$, $P = 0.001$, 95% CI(difference) = 0.527–2.061). The interaction was not significant.

Change in intention following overdiagnosis information

The main effect of overdiagnosis information on intention was significant, where intention significantly decreased for all groups after being given information suggesting PCOS can be overdiagnosed, irrespective of disease label or reliability information ($F(1, 176) = 38.37$, $P < 0.001$, 95% CI(difference) = 0.670–1.219).

There was a significant three-way interaction on intention between disease label, reliability information and overdiagnosis information ($F(1, 176) = 4.23$, $P = 0.041$, see Figures 2 and 3). Examination of pairwise comparisons using Bonferroni corrections for multiple comparisons revealed that before information about overdiagnosis was given, for those who received no disease label, intention was significantly lower for those who received information about the unreliability of ultrasounds compared with those who received no information. For participants who received the PCOS label, however, intention was high, even when told the ultrasound was unreliable. This difference between the two disease label conditions disappears after information about overdiagnosis is given by the second doctor, suggesting that the provision of overdiagnosis information alleviates this disease label effect.

Psychosocial outcomes

Self-esteem was significantly lower for those given the PCOS disease label (mean = 25.86, SD = 4.99) than those not given a disease label (mean = 27.53, SD = 5.26), irrespective of reliability information ($F(1, 176) = 4.74$, $P = 0.031$, 95% CI(difference) = −3.187 to −0.157) (see Table II for means by condition).

Severity was significantly higher for those given the PCOS disease label (mean = 17.17, SD = 3.86) than those given no disease label

Table I Demographic and disease history characteristics by condition (N = 181).

|	1. PCOS/ no info. Median (IQR)		2. No label/ no info. Median (IQR)		3. PCOS/ unreliable info. Median (IQR)		4. No label/ unreliable info. Median (IQR)	
Age (years)	19.0 (1)		19.0 (2)		18.5 (2)		18.0 (1)	
	n	%	*n*	%	*n*	%	*n*	%
Relationship								
Single	36	78.3	30	66.7	22	50.0	29	63.0
In relationship	10	21.7	15	33.3	22	50.0	17	37.0
Children								
Yes	1	2.2	0	0.0	2	2.5	0	0.0
No	45	97.8	45	100.0	42	95.5	46	100.0
Born in Australia?								
Yes	36	78.3	35	77.8	33	75.0	37	80.4
No	10	21.7	10	22.2	11	25.0	9	19.6
Diagnosis of								
PCOS	3	6.5	0	0.0	2	4.5	3	6.5
Endometriosis	1	2.2	1	2.2	2	4.5	1	2.2
Cancer	1	2.2	0	0.0	0	0.0	0	0.0
Diabetes	0	0.0	0	0.0	1	2.3	0	0.0
Other	10	21.7	6	13.3	8	18.2	11	23.9
Family history								
No history	11	24.4	9	20.0	14	31.8	12	26.1
1 condition	16	35.6	17	37.8	17	38.6	16	34.8
2 or more	18	40.0	19	42.2	13	29.5	17	39.1
PCOS history	3	6.5	4	8.9	5	11.4	5	10.9
Test history*								
Pap smear	9	19.6	10	22.2	11	25.0	7	15.2
Pelvic ultrasound	14	30.4	7	15.6	10	22.7	8	17.4
Transvaginal ultrasound	6	13.0	2	4.4	6	13.6	6	13.0
Other test	13	28.2	6	13.4	3	6.8	6	13.0
Awareness of								
PCOS	27	58.7	23	51.1	27	61.4	28	60.1
Endometriosis	23	50.0	24	53.3	28	63.6	24	52.2
Cervical cancer	42	91.3	44	97.8	41	92.2	36	78.3
Breast cancer	44	95.7	45	100.0	44	100.0	41	89.1
Diabetes	44	95.7	45	100.0	44	100.0	45	97.8
Know people same age with								
PCOS	16	34.8	9	20.0	11	25.0	18	39.1
Endometriosis	9	19.6	7	15.6	11	25.9	12	26.1
Cervical cancer	2	4.3	8	17.8	8	18.2	3	6.5
Breast cancer	7	15.2	7	15.6	11	25.0	5	90.9
Diabetes	35	76.1	30	66.7	35	79.5	32	69.6

Note: PCOS = polycystic ovary syndrome.
*n = 180, as one participant did not give a response so was classified as missing data for test history.

(mean = 15.82, SD = 3.78), irrespective of reliability information ($F_{(1, 176)}$ = 5.646, *P* = 0.019, 95% CI(difference) = 0.229–2.479). Similarly, perceived seriousness scores were significantly higher for those given the PCOS disease label ($F_{(1, 176)}$ = 19.00, *P* < 0.001, 95% CI(difference) = 0.538–1.403). After being presented with information suggesting PCOS may be overdiagnosed, there was a significant decrease in perceived seriousness at Time 2 (Time 1 mean = 4.96, SD = 1.55, to Time 2 mean = 4.30, SD = 1.52), irrespective of disease
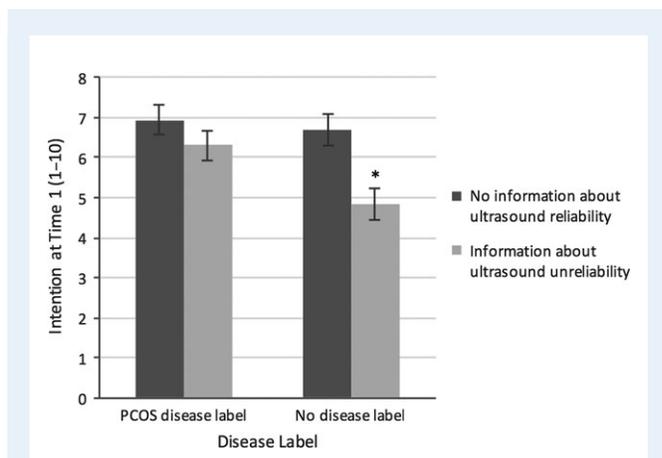
Figure 2 Mean intention to have an ultrasound at Time 1 (+SD) by disease label and information type ($n = 181$, range = 1–10).
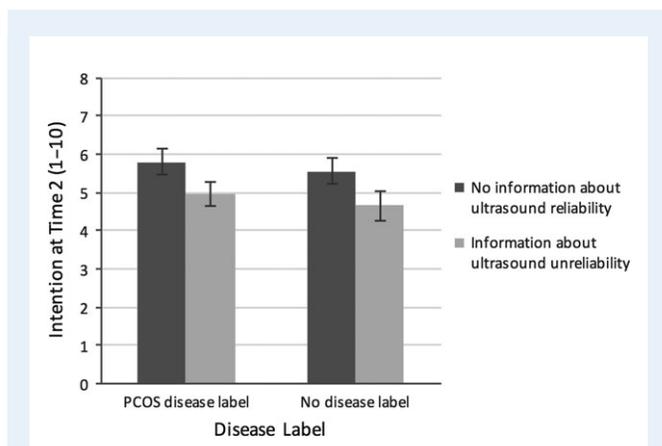
Figure 3 Mean intention to have an ultrasound at Time 2 after overdiagnosis Information is given (+SD), by disease label and information type ($n = 181$, range = 1–10).

label and reliability information ($F(1, 176) = 33.44$, $P \leq 0.001$, 95% CI (difference)=0.437–0.880).

There were no differences in scores of negative affect, GP credibility and interest in a second opinion across conditions (all $P > 0.05$).

Discussion

In this study, using hypothetical clinical scenarios, the PCOS disease label significantly increased women's intention to have an ultrasound, increased perceptions of severity and negatively affected women's self-esteem. Furthermore, information about the unreliability of ultrasound effectiveness in clarifying a diagnosis significantly reduced intention to have the ultrasound. When participants were provided with information about overdiagnosis, desire for ultrasound testing and perceived seriousness decreased in all conditions. The interaction analyses also suggest that participants who received the label were

influenced to a lesser extent by the information about ultrasound unreliability than those given no label.

Strengths and limitations

This is the first study to test the effect of the PCOS label on desire for further testing and psychological outcomes, using hypothetical scenarios to control for the experience of the symptoms. A strength of the study is the randomised hypothetical design, which enabled the symptoms and risks of PCOS to be held constant across conditions, allowing the impact on intention and psychosocial outcomes to be directly attributed to the effect of the disease label. The findings suggest that the label PCOS exerts a significant influence on judgements, over and above the PCOS symptoms described. Moreover, the design also allowed reactions to the PCOS label to be unbiased by previous experience of a PCOS diagnosis.

A limitation of the current study is that the sample consisted of university students, who are more educated and of higher socioeconomic status than the general population, limiting the generalisability of results. The women in the study are young (97% under 25 years) and the results may not reflect the impact of the diagnostic label in older women who may have greater concerns about the potential problem of infertility. However, this sample is specifically the age group most challenging to diagnose and at higher risk of overdiagnosis, due to the overlap of PCOS symptoms with normal symptoms of development and the unreliability of ultrasound imaging in this cohort (Roe and Dokras, 2011; Morris et al., 2016). Although rigorous Type 1 error rate control was conducted for multiple comparisons, the rate may still have been inflated due to testing multiple outcomes. However, since the majority of the outcomes are independent, it is unlikely that this has affected the results. Further limitations are that the study was conducted online, reducing control of extraneous variables and that intention was measured, not actual behaviour. It is likely that women facing a real diagnosis of PCOS or presenting with the symptoms described would be more anxious than the participants in the current study, and therefore intention and psychosocial outcomes may be more affected. Even though the scenarios were hypothetical, a significant difference was found from being more ambivalent about having the ultrasound (for those who did not receive the PCOS label) to showing more interest in having the ultrasound (for those who received the PCOS label). In our opinion, this is a clinically relevant difference that warrants further empirical investigation through randomised trials to test how different labels influence decision-making and psychosocial outcomes, both initially and over time, with a clinical sample of women presenting with real-life symptoms of PCOS and in women over 25 years of age when concerns about subfertility may be more salient.

Comparison with existing literature

Studies have found that disease labels result in various emotional, cognitive and physical consequences, and can influence medical decision-making by making a condition appear more severe and beyond one's control, portraying benign issues as serious diseases (Ogedegbe, 2010; Omer et al., 2013; Scherer et al., 2013; Dar-Nimrod et al., 2014). Hypertension labelling has been found to result in increased absenteeism from work, reduced quality or satisfaction with marital life and increased self-reported illness (Pickering, 2006; Ogedegbe, 2010;

Table II Mean score (+SD) of negative affect, self-esteem, perceived severity, perceived seriousness, credibility of the doctor and interest in a second opinion by condition.

Psychosocial outcome	1. PCOS/no info. (n = 46)	2. No label/no info. (n = 45)	3. PCOS/unreliable info. (n = 44)	4. No label/unreliable info. (n = 46)
Negative affect (range 10–50, higher scores = higher negative affect)	19.3 (8.63)	20.7 (10.03)	21.9 (9.74)	18.3 (7.61)
Self-esteem (range 10–40, higher scores = higher self-esteem)	26.0 (4.46)	27.8 (5.12)	25.8 (5.53)	27.3 (5.44)
Perceived severity (range 5–25, higher scores = higher perceived severity)	17.1 (3.35)	16.0 (3.85)	17.2 (4.38)	15.7 (3.74)
Seriousness (Time 1) (range 1–7, higher scores = higher perceived seriousness)	5.6 (1.18)	4.6 (1.55)	5.3 (1.64)	4.3 (1.49)
Seriousness (Time 2 post-overdiagnosis info.) (range 1–7, higher scores = higher perceived seriousness)	4.8 (1.42)	4.0 (1.51)	4.5 (1.59)	4.0 (1.52)
Credibility of the doctor (range 1–5, higher scores = lower credibility)	2.3 (0.60)	2.2 (0.55)	2.4 (0.76)	2.4 (0.74)
Interest in second opinion (range 1–7, higher scores = higher interest)	5.4 (1.78)	5.6 (1.38)	5.7 (1.30)	5.7 (1.33)

Jorgensen et al., 2015). Disease labels have also been found to result in increased desire for medication. A hypothetical study examining the effects of the disease label 'Gastro-oesophageal Reflux Disease' (GERD) found that when children were given the disease label GERD, parents had higher interest in medicating their children, even when told the medication was ineffective (Scherer et al., 2013). Research examining the disease label 'Ductal Carcinoma in Situ' (DCIS) found that when DCIS was referred to as a 'non-invasive cancer', significantly more women chose surgical interventions compared to when it was called a 'breast lesion' or 'abnormal cells' (Omer et al., 2013; McCaffery et al., 2015). These previous findings support the results of the current study, in which the disease label PCOS resulted in significantly higher intention to have an ultrasound and higher perceived severity, suggesting that disease labels increase perceptions of disease severity and influence medical decision-making by implying that medical interventions are appropriate. Self-esteem was also lower for those given the PCOS disease label, supporting research regarding the detrimental impact of a PCOS diagnosis on women's self-esteem and confidence (Bazarganipour et al., 2013), the diagnosis causing women to feel isolated and abnormal (Kitzinger and Willmott, 2002).

The provision of information about the unreliability of ultrasounds resulted in lower intention to have the ultrasound, regardless of the presence of the disease label. This finding contrasts to the results of the GERD study (Scherer et al., 2013) where information about medication ineffectiveness lowered intention only for those who did not receive the disease label. However, the current study results highlight the importance of communicating information about both the limitations as well as the benefits of interventions to support informed decision-making (Hoffmann and Del Mar, 2015).

Information about overdiagnosis decreased intention to have an ultrasound and perceived severity in all conditions, consistent with previous research on communicating information about overdiagnosis (Hersch et al., 2015).

Implications

The results of this study suggest the potential harms of the PCOS disease label. There is increasing concern that for some women PCOS may not be a lifelong condition but a transitory condition (Zhuang et al., 2014), and given the increase in number of women being diagnosed and the uncertain clinical benefit, it is crucial that we carefully consider the effects of the disease label, as the potential advantages of the diagnosis have not been weighed against the disadvantages of labelling the disease.

Conclusion

These findings bring awareness to the costs of being labelled with PCOS, highlighting that the label independently may contribute to the reduced psychosocial well-being of women with PCOS and increase the desire for further medical tests and interventions. More awareness of the risk of overdiagnosis of PCOS is warranted to reduce the use of unhelpful labels, unnecessary tests and treatments, and prevent the detrimental effects of labelling on psychological well-being.

Supplementary data

Supplementary data are available at *Human Reproduction* online.

Acknowledgements

Authors' roles

J.J. and T.C. conceived the study. T.C., J.J., K.M., L.A., J.D. and B.M. were involved in formulating the research question and designing the study. T.C. coordinated the running of the study and recruited participants. T.C., J.J., L.A. and K.M. contributed to the analysis. All authors critically revised the manuscript and approved the final version.

Funding

Conflict of interest

None declared.

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