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How a diagnosis of Polycystic Ovarian Syndrome (PCOS) is communicated impacts well-being

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How this fits in

Women with PCOS rated their past diagnostic consultation and current well-being

Poorer communication comfort in the consultation predicted poorer current well-being

Poorer current well-being was predicted by greater use of the words 'raised' and 'irregular' and a focus on fertility and appearance

How a diagnosis of PCOS is given can have a longer-term impact

Abstract

Background: Polycystic Ovary Syndrome (PCOS) is associated with well-being. Many women report dissatisfaction with the diagnostic process. **Aim:** This study assessed the impact of aspects of the diagnostic consultation on subsequent well-being. **Design and setting:** A retrospective community survey. **Methods:** Females with PCOS (n=146) completed measures of aspects of the diagnostic consultation (consultation satisfaction, language used in terms of framing and focus) and current well-being (body esteem, quality of life). **Results:** Most diagnoses took place in Primary Care. The majority showed a medium degree of satisfaction with the consultation. Most diagnoses were framed using a neutral term 'raised' but many used the more judgemental term 'abnormal'. The majority focused on taking oral contraception and weight management. Poorer body esteem (body dissatisfaction and dieting behaviour) and poorer quality of life (self-identity, concerns about fertility, physical health, hirsutism and overall quality of life) were predicted by lower communication comfort during the diagnostic consultation and greater use of the word 'raised'. Greater use of the word 'irregular' predicted greater concerns about fertility, greater focus on fertility predicted greater concerns about physical health and greater focus on appearance predicted greater concerns about hirsutism. **Conclusion:** How a diagnosis of PCOS is delivered can impact subsequent well-being. The diagnostic consultation may take a few minutes, yet how these minutes are managed, what words are used, and how this makes the patient feel may change how the patient makes sense of their condition and influence the impact of the condition on their well-being for the longer term.

Key words: Polycystic Ovary Syndrome (PCOS); Primary Care; consultation; satisfaction; language; well-being; Quality of Life

Introduction

Polycystic ovary syndrome (PCOS) is a common disorder affecting 12-18% of women (1) resulting in a range of physical symptoms and metabolic issues (2-6). Women with PCOS are also more likely to experience depression, eating disorders, social anxiety, body satisfaction and diminished sexual satisfaction and reduced quality of life (7-13). One possible explanation for this could be the patients' experience of the diagnostic consultation in which they first have their condition explained by a Health Care Professional (HCP) as this key moment has the capacity to shape how a person makes sense of their condition. Some research has addressed the impact of having the diagnosis of PCOS and has identified both benefits and harms (14). Other research has explored the experience of the diagnostic consultation using qualitative methods and indicates that women describe a range of issues including a lack of empathy, information and advice from HCPs, difficulty in accessing specialists, unsatisfactory medication, insufficient help with fertility and a lack of knowledge about comorbidities (15, 16). Further, quantitative research indicates a lack of information giving in the consultation (17), feelings of distrust of the HCP (18), dissatisfaction with the diagnosis (19), an inability to discuss mental health issues (17) and Hoyos et al (20) found that 51.2% of participants were "not satisfied" with the recommended treatment options and 72.6% of participants described having "some" or "a lot" of negative language used in relation to symptoms.

Women with PCOS often experience poorer well-being. Many also report dissatisfaction with the diagnostic process. Research addressing a range of health conditions such as cancer, diabetes, pain, cardiovascular disease and Parkinson's disease indicates that patient satisfaction with the consultation can impact upon health outcomes in the future (eg. 21-25). Research also indicates a role for the specific words used in the consultation and the way in which a diagnosis is made (eg. 26-31). To date, however, no research has specifically explored the impact of aspects of the diagnostic consultation for PCOS on women's subsequent well-being. The present study, therefore, first aimed to describe the diagnostic consultation and second to assess the impact of aspects of the diagnostic

consultation with a focus on consultation satisfaction and language used on women's subsequent well-being in terms of body esteem and quality of life.

Method

Participants

Women aged 18 or over with a formal diagnosis of PCOS (n=146) were recruited via social media, including support groups for women with PCOS.

Design

A cross-sectional design to assess aspects of the diagnostic consultation and current well-being. Ethical approval was obtained from the University Ethics Committee.

Measures

Participants completed an online questionnaire assessing their demographics, HCP demographics, aspects of their diagnostic consultation and current well-being. Reliability was assessed using Cronbach's alpha where appropriate.

Participant demographics: Participants described their current age, age at diagnosis, delay to diagnosis, ethnicity, age of symptom onset and family history of PCOS.

HCP demographics: The HCP at the diagnostic consultation was described in terms of gender, qualification (Nurse, GP, consultant, gynaecologist) and if the setting was private or public health care.

Aspects of the diagnostic consultation: Aspects of the diagnostic consultation were assessed as: i) **Satisfaction with the consultation** was assessed using the Medical Interview Satisfaction Scale (MISS-21; 32) consisting of 3 subscales relating to Distress Relief (5 items: e.g. "The doctor has relieved my worries about my illness"; $\alpha = 0.86$), Communication Comfort (4 items: e.g. "I felt

embarrassed while talking with the doctor"; α = 0.72) and Rapport (8 items: e.g. "I really felt understood by my doctor"; α = 0.93) rated on a 7-point Likert scale from "very strongly disagree" (1) to "very strongly agree" (7). ii) **Language during the consultation** was assessed in terms of framing of the problem and focus of the solution**.** For **framing of the problem** participants described the language used during their diagnosis for fertility problems (testosterone, periods, infertility), weight problems (weight), appearance problems (acne, hirsutism, masculine characteristics) and recorded whether the HCP used the more neutral words 'irregular', and 'raised' and the more judgemental words 'abnormal' and 'unusual' for each problem rated YES / NO. For **focus of the solution**, participants were asked whether the HCP focused on appearance problems (acne, hair management / removal), fertility problems (recommend early conception, use of coil, use of implant, take oral contraceptives, use metformin) or weight problems (lose weight, manage weight, alter diet, cut out food groups (vegan, dairy free, gluten free, keto)) rated YES/NO.

Current well-being: Current well-being for the past four weeks was assessed as follows: i) **Body esteem:** This was assessed in terms of **body dissatisfaction** using the Body Shape Questionnaire (BSQ; 33; 10 items, e.g. "Has being with thin women made you feel self-conscious about your shape?", α = 0.94). Items were rated from "Never" (1) to "Always" (6). Participants also rated their **dieting behaviour** using the restrained eating subscale of the Dutch Eating Behaviour Questionnaire (DEBQ; 34; 10 items, e.g. "Do you try to eat less at mealtimes than you would like to eat", α = 0.93). Items were rated from "Never" (1) to "Very Often" (5). ii) **Quality of life:** This was assessed using a brief version of the Health-Related Quality of Life questionnaire for Polycystic Ovary Syndrome (PCOSQ; 36) which consisted of 5 subscales: Self Identity (3 items, e.g. "Lack of satisfaction with being a woman", α = 0.80); Fertility concerns (3 items, e.g. "Felt concerned about infertility in the future", α = 0.71); Physical Health concerns (3 items, e.g. "Experienced concern about the long-term effects of PCOS medication", α = 0.61); Sexual Function concerns (3 items, e.g. "Experienced loss of libido because of PCOS", α = 0.87); Hirsutism concerns (3 items, e.g. "Embarrassed about having

excess body hair", α = 0.95). Items were rated from 'Not at all' (1) to "Very much" (5). A total QoL

score was also computed.

Procedure

Participants were recruited via social media and provided a link to complete the information sheet,

consent form and the 15 minute online survey.

Data reduction and analysis

For descriptive purposes the three subscales of consultation satisfaction were recoded into low (1-

3.5), medium (3.6-4.5) and high (4.6-7). Mean scores were also computed for the subscales of

consultation satisfaction and current well-being with higher scores reflecting greater distress relief,

greater communication comfort and greater rapport, greater body dissatisfaction and dieting

behaviour, and poorer Quality of life in terms of poorer self-identity, and greater concerns about

fertility, physical health, sexual function and hirsutism and poorer overall quality of life. For

language used in the consultation, the framing of the problem was analysed by summating the scores

for the four words 'abnormal', 'unusual', irregular' and 'raised'. For focus on the solution scores

were summated for each problem area 'appearance', 'fertility' and 'weight'. Higher scores reflected

greater frequency of these words / areas. Data was analysed to describe participant and HCP

demographics, consultation satisfaction and the language used in the consultation using descriptive

statistics. The role of participant and HCP demographics, consultation satisfaction and language used

in predicting patient current well-being (body esteem and quality of life) was assessed using multiple

regression analyses. All analyses used Jamovi version 2.2.5.

Results

Participant and HCP demographics (see Table 1)

-Insert Table 1 about here –

Mean age was 27 years (range 18-62 years) and the majority described themselves as white. The mean age of diagnosis was 21 years, mean delay until diagnosis was 3.38 years (range 0-12 years) and most reported symptom onset between 10-15 years old. The majority had no family history of PCOS. The majority of participants had been diagnosed by a female HCP although just under half had seen a male HCP. The majority had been diagnosed by a GP although a large minority had been diagnosed by a Gynaecologist. The majority of diagnoses had taken place in a public rather than private sector setting.

Describing the consultation

The consultation was described in terms of consultation satisfaction and the language used.

Consultation satisfaction (see Table 2)

-Insert table 2 about here –

A majority of participants (>50.0%) showed a medium degree of satisfaction with their diagnostic consultation in terms of the three subscales: distress relief, communication comfort and rapport. A large minority (>25%) were not satisfied with distress relief or rapport.

Language used in the diagnostic consultation

Language used was assessed in terms of framing of the problem and focus of the solution.

Framing of the problem (see Table 3).

-Insert table 3 about here –

The more neutral term 'raised' was used the most frequently to describe all components of weight and appearance related problems and most components of fertility. The term 'irregular' however was used the most frequently to describe periods. The more judgemental term 'abnormal' was used the

next most frequently for all aspects of fertility, weight and appearance problems apart from when describing 'infertility'.

Focus of the solution (see Table 4).

-Insert table 4 about here –

The majority (ie >50%) of consultations had focused on taking oral contraception, losing weight, managing weight and altering their diet. Only a minority (<30%) had focused on acne medication, hair management / removal or using a coil or implant for contraception. The most common focus was on taking oral contraception followed by 3 weight management strategies (lose weight, manage weight, alter diet).

The role of aspects of the diagnostic consultation in predicting body esteem and quality of life (see Table 5)

The results were then analysed to explore the role of participant and HCP demographics and aspects of diagnostic consultation in predicting current well-being using Multiple Regression analysis. For this analysis HCP qualification was dichotomised into non-specialist (nurse / GP) and specialist (Gynaecologist / Consultant).

-insert Table 5 about here -

Predicting body esteem

i) Body dissatisfaction: Greater current body dissatisfaction was predicted by lower communication comfort in the diagnostic consultation, more frequent use of the word 'raised' accounting for 10% of the variance. **ii) Restrained eating:** Greater restrained eating was predicted by lower communication comfort with the diagnostic consultation accounting for 7% of the variance.

Predicting current quality of life

i)Self-identity: Poorer current self-identity was predicted by being older at diagnosis, lower communication comfort with the diagnostic consultation and lower depression and greater use of the word 'raised' accounting for 15% of the variance. **ii) Concerns about fertility**: Greater current concern about fertility was predicted by lower communication comfort during the diagnostic consultation and more frequent use of the words 'irregular' and 'raised' accounting for 12% of the variance. **iv) Concerns about sexual function:** None of the models were significant for predicting sexual function. **v) Physical health concerns:** Increased physical health concern was predicted by reduced communication comfort with the consultation, increased use of the word 'raised' and increased focus on fertility accounting for 22% of the variance. **vi) Hirsutism:** Increased concerns for hirsutism were predicted by lower communication comfort but greater rapport, more frequent use of the word 'raised' and greater focus on appearance accounting for 24% of the variance. **vii) Total QoL:** Total poorer quality of life was predicted by lower communication comfort and more frequent use of the word 'raised' in the diagnostic consultation accounting for 27% of the variance.

Discussion and conclusion

Summary

This study aimed to describe the diagnostic consultation for PCOS and to assess the impact of aspects of this consultation on well-being. Descriptive analysis indicated that the majority of diagnoses had been delivered by a female HCP in Primary Care. The majority of participants reported a medium degree of satisfaction with the consultation in terms of distress relief, communication comfort and rapport, although a large minority reported dissatisfaction with distress relief and rapport. The more neutral word 'raised' was most commonly used to frame problems relating to fertility, weight and aspects of appearance, the word 'irregular' was most commonly used to describe periods and the more judgemental word 'abnormal' was the second most commonly used word for most problems. Most consultations focused on solutions relating to oral contraception and

weight management.   In terms of predicting outcomes, communication comfort consistently predicted well-being in terms of body dissatisfaction, restrained eating, self-identity, concerns about fertility, physical health and overall quality of life with poorer communication comfort in the diagnostic consultation predicting lower well-being for all these components. In terms of specific words used, greater frequency of the word 'raised' was related to poorer well-being in terms of all components apart from restrained eating, and greater frequency of the word 'irregular' was related to greater concerns about fertility. Further, a focus on appearance related to greater concerns about hirsutism and a focus on fertility related to greater concerns about physical health.

Strengths and limitations

There are some methodological limitations that need to be considered. Primarily, the data concerning the consultation was retrospective which is open to issues of bias limiting conclusions about causality. Future research should use a longitudinal design to follow patients up after their consultation or, at best, an experimental design to manipulate the content of a consultation and evaluate the later impact upon patient health outcomes.   Second, participants were recruited via social media which may alter the kinds of patients that take part. Future research could recruit via a hospital or Primary Care setting to access a more representative sample of patient receiving their diagnosis of PCOS. The present study, however, is the first to show that what occurs within this brief interaction has a long-lasting effect on the patient.

Comparison with existing literature

Previous research suggests that PCOS can impact upon women's well-being (eg. 8-11, 13) and women can be dissatisfied with the diagnostic process (eg. 15, 20). The results from the present study indicate that these two factors are related reflecting existing research illustrating a key role for consultation satisfaction on other health outcomes (eg. 21-25). Further, at a more specific level the results also highlighted the role of language supporting research across a number of health contexts

indicating that individual words can change how patients make sense of their condition (eg. 26-31). However, whereas studies indicate the use of judgemental words when diagnosing PCOS (20), the more neutral words 'raised' and 'irregular' were more predictive of poorer well-being than the more judgemental words 'abnormal' and 'unusual'.

Implications for research and practice

A diagnosis of PCOS can have a significant impact upon the lives of patients. But how this diagnosis is delivered is also key. Practitioners should therefore ensure that they take time to put their patient at ease during these diagnostic consultations and make them feel comfortable with what is being communicated. They should also be aware that both the individual words they use and what they chose to emphasise as ways to manage PCOS could have a negative and longer lasting impact on their patients.   Whilst the diagnostic consultation may only take a few minutes, the results from the present study indicate that how these minutes are managed, what words are used, what is focused on and how this makes the patient feel may change how the patients makes sense of their condition and influence the impact of the condition on their well-being for the longer term.

Ethical approval: The study was given favourable Ethical Approval by the University Ethics committee FHMS 20-21 027 EGA

Competing interests: None declared.

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Table 1: Participant and HCP Demographics

Participants' demographics	
Current Age	Mean=27 (SD=8.05)
	Range 18-71
Family History of PCOS	Yes =38 (25.9%)
	No=109 (74.1%)
Age at Diagnosis	Mean=21.2 (SD=5.28)
	Range 14-38
Years since diagnosis	Mean=5.8 (SD=7.33)
	Range=0-42
Delay to diagnosis	Mean=3.38 (3.14)
	Range=0-12
Ethnicity	White=124 (84.4%)
	Black=2 (1.4%)
	Asian=10 (6.8%)
	Other=11 (7.5%)
Age of Symptom Onset	10-15=71 (47.3%)
	16-20=51 (34.7%)
	21-25=16 (10.9%)
	26-30=4 (2.7%)
	31+=5 (3.4%)
Health Care Professional demographics at diagnostic consultation	
Gender	Male=60 (41.4%)
	Female=85 (58.6%)
Health care setting	Private=33 (22.8%)
	Public=112 (77.2%)
HCP	Nurse=5 (3.4%)
	GP=68 (46.9%)
	Gynaecologist=50 (34.5%)
	Consultant=22 (15.2%)

Table 2: Describing the consultation – consultation satisfaction

	Low (1-3.5)	Medium (3.6-4.5)	High 4.6-7.0)	Mean / SD
Distress relief	53 (36.8%)	**74 (51.4%)**	17 (11.8%)	3.3 (1.27)
Communication comfort	21 (14.6%)	**85 (59.0%)**	38 (26.4%)	4.11 (1.21)
Rapport	38 (26.4%)	**75 (51.2%)**	31 (21.5%)	3.89 (1.38)

Table 3: Describing the consultation - language used during diagnosis: framing of the problem

	Abnormal	Unusual	Irregular	Raised
Fertility				
Testosterone	36	7	16	**68**
Periods	26	6	**117**	10
Infertility	15	13	19	**33**
Weight				
Weight	19	6	14	**69**
Appearance				
Acne	24	6	11	**48**
Hirsutism	25	12	1	**33**
Masculine characteristics	12	11	2	**39**
Total frequency	157	61	180	
				300

Bold denotes most frequent use.

Table 4: Describing the consultation - language used during diagnosis: focus of the solution

Focus of solution		YES (n/%)	Rank
Appearance	Acne medication	37 (26.1%)	8
	Hair management / removal	35 (24.3%)	9
Fertility	Metformin	46 (31.9%)	6
	Use of implant	18 (12.7%)	11
	Use of coil	29 (20.3%)	10
	Early conception	50 (35%)	5
	Oral Contraception	102 (70.3%)	1
Weight management	Lose weight	90 (62.9%)	2
	Manage weight	86 (59.7%)	4
	Alter diet	87 (60.4%)	3
	Cut out food groups	43 (30.1%)	7

Table 5: Role of aspects of the consultation in predicting current well-being (Bold <0.05)

	Body esteem				Quality of life			
	Body diss. (β, p)	Rest. eating (β, p)	Self Identity (β, p)	Fertility concern (β, p)	Sexual function (β, p)	Physical health (β, p)	Hirsutism (β, p)	Total QoL (β, p)
Demographics								
Current age	-0.15 0.14	-0.14 0.16	-0.18 0.07	-0.08 0.44	0.009 0.92	-0.14 0.13	0.08 0.37	-0.06 0.49
Diagnosis age	0.14 0.15	0.03 0.78	**0.23 0.01**	0.17 0.07	0.15 0.11	0.13 0.13	-0.07 0.41	0.16 0.06
HCP Gender	0.17 0.06	0.02 0.85	0.14 0.11	0.10 0.23	0.03 0.75	0.03 0.71	0.12 0.13	0.11 0.16
HCP Qual	-0.06 0.5	-0.06 0.53	-0.15 0.08	-0.07 0.44	-0.001 0.99	-0.13 0.11	-0.10 0.2	-0.13 0.11
Model 1 adj R^2/F/ p	0.005/ 1.17 / 0.3	0.003/1.1 2/0.35	0.03/ 2.16/ 0.08	-0.002/ 0.94 / 0.44	-0.008/ 0.72 /0.6	0.02 / 1.89/0.12	-0.01/ 0.31/0.8	-0.003/ 0.88/ 0.48
Communication satisfaction								
Distress Relief	-0.19 0.16	-0.07 0.59	-0.09 0.43	-0.09 0.45	-0.12 0.35	-0.01 0.92	-0.14 0.22	-0.15 0.19
Comm. Comfort	**-0.26 0.03**	**-0.26 0.03**	**-0.24 0.02**	**-0.27 0.01**	-0.12 0.29	**-0.33 0.001**	**-0.29 0.004**	**-0.33 0.001**
Rapport	0.21 0.15	0.15 0.15	0.11 0.43	0.14 0.31	0.09 0.31	0.17 0.19	**0.26 0.04**	0.23 0.07
Model 2 adj R^2/F/p	**0.07/ 2.52 / 0.02**	**0.05/2.01 /0.06**	**0.09/ 3.23/ 0.003**	**0.07/ 2.48/ 0.02**	0.003/ 1.37/0.18	**0.11/3.54 /0.002**	**0.07/2.48/ 0.02**	**0.12/3. 86/ 0.001**
Framing and focus of language used								
Irregular	-0.005 0.9	-0.02 0.84	-0.01 0.87	**0.21 0.01**	0.09 0.31	0.13 0.09	-0.07 0.38	0.07 0.35
Raised	**0.28 0.007**	0.15 0.15	**0.25 0.009**	**0.16 0.08**	**0.26 0.008**	**0.26 0.004**	**0.33 0.001**	**0.37 0.001**
Abnormal	0.06 0.52	0.05 0.61	0.09 0.24	-0.02 0.79	-0.004 0.96	0.11 0.18	0.12 0.12	0.11 0.18
Unusual	-0.006 0.94	-0.11 0.22	-0.12 0.14	0.0001 0.99	-0.01 0.87	-0.05 0.51	-0.11 0.14	-0.09 0.20
Appearance	-0.08 0.38	-0.05 0.59	0.07 0.38	-0.04 0.67	0.01 0.87	-0.02 0.77	**0.17 0.03**	0.08 0.33
Fertility	0.06 0.5	0.09 0.34	0.04 0.65	0.13 0.13	0.008 0.93	**0.18 0.02**	0.04 0.61	0.09 0.23
Weight	-0.003 0.9	0.12 0.21	-0.04 0.65	0.03 0.77	**-0.21 0.03**	0.01 0.90	0.04 0.68	-0.07 0.39
Final Model adj R^2/F/ p	**0.10 / 2.06 /0.02**	**0.07/1.77 / 0.05**	**0.15 / 2.76 / 0.001**	**0.12/2. 40 / 0.005**	0.03/1.37 / 0.17	**0.22/3.92 /0.001**	**0.24/4.3/ 0.001**	**0.27/4. 73/ 0.001**