Quality of life and sexual health in women with PCOS

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Existing reviews

- **Quality of life**
  - *Jones et al. 2008, Hum Reprod Update*
- **Psychological disorders**
  - *Himelein & Thatcher, 2006, Obstet Gynecol Survey*
- **Interventions**
  - *Moran et al. 2006, Reprod Biomed Online*
  - *Lim et al. 2007 Curr Opin Endocrinol Diabetes Obes*
  - *PCOS Consensus, 2008, Hum Reprod*

Quality of life

- ‘Quality of life’ (QoL) encompasses all impacts of disease and reflects an appraisal of disease that is affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (WHO, 1997)
- Generic versus PCOS-specific QoL
- Overall QoL versus specific problems

Quality of life (Jones et al. 2008)

- PCOS has a significant detrimental effect on quality of life
  - compared to controls
- Rank order to associations between symptoms & QoL
  - weight issues most prominent;
- Studies do not include a PCOS-specific instrument
- Intervention studies do not investigate QoL

Update qualitative

- 2 studies (Synder et al. *JOGNN*, 2006; Kitzinger & Willmott, *SS&M*, 2002)

- Qualitative
  - ‘freakish’, ‘abnormal’ periods
  - ‘upsetting’, ‘embarrassing excess body hair
  - ‘crushing’ fertility problems
  - ‘feel different’ re: femininity

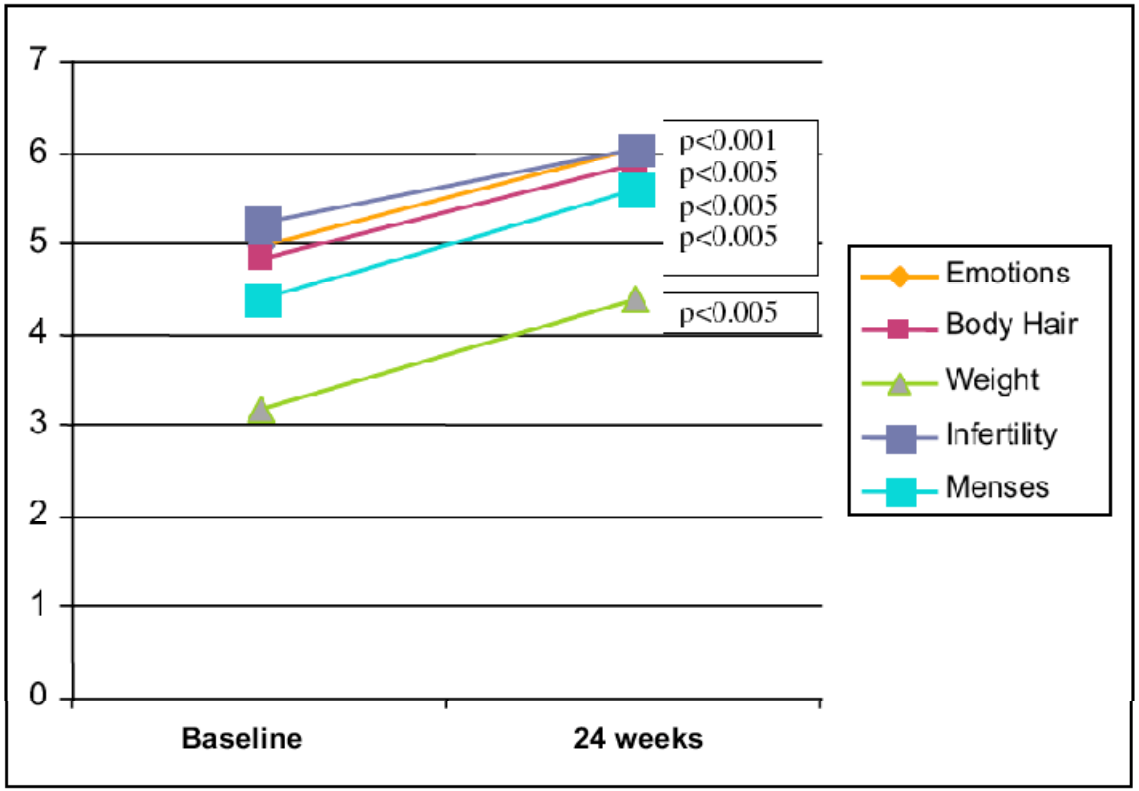
Update quantitative

- 6 studies

- Generic QoL studies (SF-36)
  - PCOS < community controls[Drosdzol, 2007], healthy controls matched for BMI[Benson, 2008], population reference groups[Tan, 2008]
- Online studies
  - PCOS (self-reported) < non-PCOS (self-reported)[Barnard, 2007; Benson, 2009]
- Intervention studies
  - Lifestyle management improves PCOS-specific QoL[Karmizadeh, 2010]
  - Effects also in adolescent girls[Harris-Glocker, 2010]

Lifestyle management

PCOSQ Scores at baseline versus conclusion for all domains (combined data presented)



Harris-Glocker. Correspondence. Fertil Steril 2010.

All subjects were randomized to one of four 48-week interventions:
Metformin 850 mg two times per day,
lifestyle modification plus Metformin 850 mg two times per day,
lifestyle modification plus placebo, or placebo alone

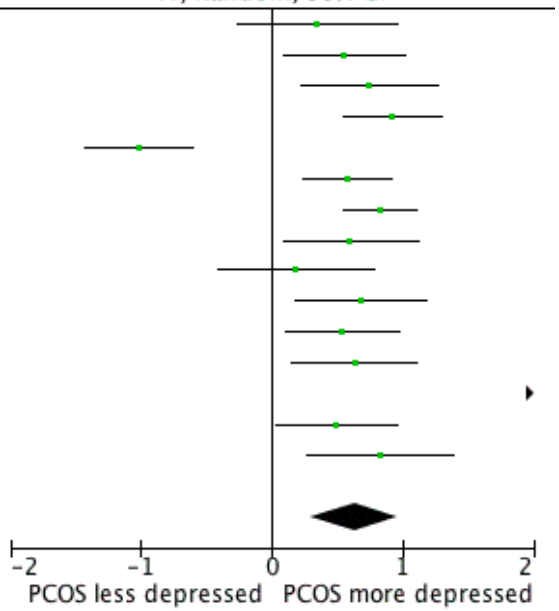
Psychological disorders

- > 20 studies
- Prevalence emotional disorders (anxiety, depression)
  - PCOS > healthy controls, normative age-matched reference value
- Results consistent
  - Measurement method (survey, interview, online)
  - Age (adolescents, younger women)
  - Cultural context (Western nations, India, Turkey)

Depression and PCOS

Study or Subgroup	PCOS Mean	PCOS SD	PCOS Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
Battaglia 2008	7.1	1.2	25	6.6	1.7	18	6.4%	0.34 [-0.27, 0.95]
Benson 2007	10.1	7.55	57	5.9	7.41	28	7.0%	0.55 [0.09, 1.01]
Benson 2009a	9.7	7.54	29	4.9	5.1	32	6.8%	0.74 [0.22, 1.26]
Bernard 2007	56	12.32	82	45	11	46	7.4%	0.92 [0.54, 1.30]
Elsenbruch 2003	0.906	0.752	50	4.897	5.435	50	7.2%	-1.02 [-1.44, -0.60]
Hahn 2005	0.88	0.72	120	0.49	0.55	50	7.5%	0.58 [0.24, 0.91]
Hollinrake 2007	11.9	11.1	103	4.5	5.9	103	7.7%	0.83 [0.54, 1.11]
Jedel 2010	10.8	7.997	30	6.5	6.004	30	6.8%	0.60 [0.08, 1.12]
Laggari 2009	12.82	7.86	22	10.32	17.19	22	6.5%	0.18 [-0.41, 0.78]
Moran 2010	6.04	3.85	35	3.59	3.21	30	6.9%	0.68 [0.18, 1.18]
Orenstein 1986b	1.54	1.67	39	0.76	1.21	45	7.1%	0.54 [0.10, 0.97]
Ozenli 2008	14.71	7.67	35	10.5	5.26	35	7.0%	0.63 [0.15, 1.11]
Rocco 1991	73	4	21	47.1	2.4	10	2.0%	7.04 [5.02, 9.07]
Soyupek 2008	9.78	8.05	37	6.42	5.03	35	7.0%	0.49 [0.02, 0.96]
Weiner 2004	12.37	5.89	27	7.89	4.77	27	6.6%	0.82 [0.27, 1.38]
Total (95% CI)			**712**			**561**	**100.0%**	**0.63 [0.29, 0.96]**

Heterogeneity: $Tau^2 = 0.36$; $Chi^2 = 105.17$, df = 14 ($P < 0.00001$); $I^2 = 87\%$
Test for overall effect: Z = 3.69 (P = 0.0002)



Verhulst et al. in prep
Case-controlled studies PCOS

Incident cases

Table III. Descriptive results based on the cut-off scores of the Greek version of BDI in all three groups.

	Beck Depression Inventory (BDI)	
Groups	Mild Depression (BDI scores: 20–29)	Moderate Depression (BDI scores: 30–39)
PCOS	27.3%	0%
MRKHS	20.0%	20.0%
Controls	9.1%	0%

Laggari et al. 2009: *J Psychom Obstet Gynecol* (Mean age 17 years)

Controls: Convenience sample of 22 eumenorrheic females

PCOS: seeking medical help for menstrual disorders

MRKHS: Mayer-Rokitansky-Kuster-Hauser:

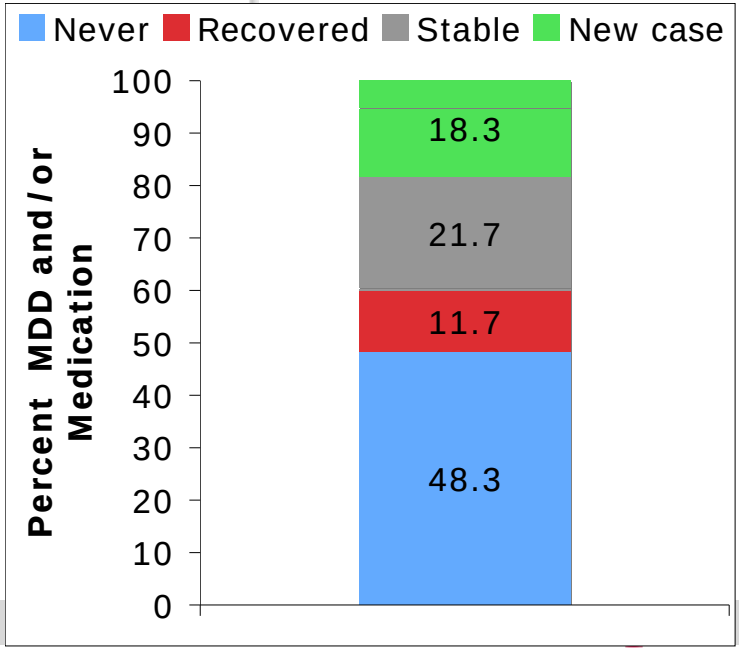
Patients will not experience menses and pregnancy due to the absence of a functional uterus and vagina

Developmental trajectory

FIGURE 1

Schematic representation of longitudinal risk of depression in women with PCOS over a 1- to 2-year time period.

Kerchner. Prevalence of mood disorders in PCOS. Fertil Steril 2009.



Mean 22 months (12-26 months) time lapse

MDD= Major depressive disorder

PRIME-MD PHQ = Primary Care Evaluation of Mental Disorders Patient Health Questionnaire

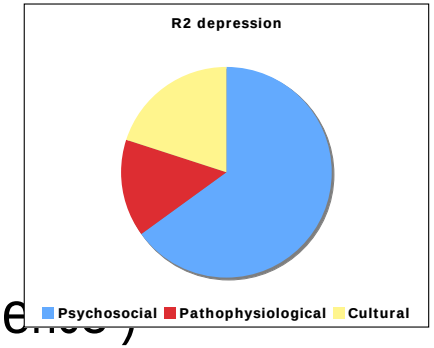
Other dysfunctions

- 4 studies sexuality
  - PCOS = healthy, age and BMI matched (sexual dysfunction, ~7%)[Battaglia, 2008]
  - PCOS > reference values (sexual distress ~64%)[Anger, 2007]
  - PCOS > controls presenting with other sexual problems (sexual dissatisfaction, 28 vs 10%)[Drosdzol, 2003]
  - PCOS ?? reference population/healthy controls (timing of sexarche)[deNiet, 2010; Trent, 2003]
- 1 study eating/social disorders (ED, SD)
  - PCOS > community controls ED (12 vs 4%) and SD (27 vs 2%)[Mansson, 2008]

Explanatory mechanism

Association between PCOS and emotional disorders due to:

- **Psychosocial mechanisms** (social exclusion)
  - visibility of disorder (acne, hirsutism)
  - Socially limiting disorders (obesity, infertility)
- **Pathophysiological mechanisms**
  - insulin-resistance
  - hyper-androgenism
  - inflammation
- **Cultural mechanisms**
  - Ethnicity
  - Socio-cultural risk (context for 'lived experience')



Correlates of poor QoL

- Weight/BMI[Barnard, 2007;Tan, 2008;Thomson, 2009; Harris-Glocker, 2010]
- Concurrent psychological problems
  - MDD, social phobia[Mansson, 2008]
- Physiological impairment
  - Immune dysregulation[Benson, 2008]
- Fertility
  - Variable[Benson, 2009; Deeks, 2010 vs Tan, 2008]
- Other
  - Sleep disturbance, phobias, pain[Jedel, 2010]
  - Hirsutism[Ching, 2007]

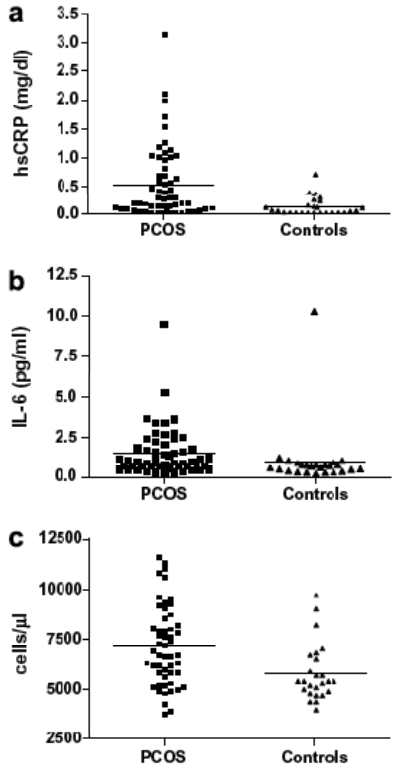


Fig. 1. Scatterplot showing raw values for PCOS and controls of (a) serum hsCRP levels, (b) serum IL-6 concentrations, and (c) leukocyte numbers. PCOS women had significantly increased levels of hsCRP ($p < .001$), higher IL-6 concentrations ($p < .01$), and increased leukocyte numbers ($p < .01$), but the group effects for IL-6 and leukocytes disappeared after covarying for BMI

Benson et al. 2008: Brain Behav Immun

Lifestyle intervention* in PCOS

Study	*N*	*Design*	*Intervention*	*Weight*	*Reproductive*	*QoL*
Aubuchon 2009	**37**	**Chart review**	**D, E**	*	*	-
Pelletier 2010	**117**	**Chart review**	**D, E**	*	n/a	-
Harris ĞGlocker 2010 (Hoeger 2004)	**36**	**RCT**	**D, E, M**	*	n/a (ns)	* PCOSQ
Karmizadeh 2010	**343**	**RCT**	**D, E, M**	*	ns	-
Tang et al. 2006	**67**	**RCT**	**D, E, M**	ns	ns	-
Thomson et al. 2008; 2009	**59**	**RCT**	**D and/or E**	*	*	* depression, PCOSQ
Palomba et al. 2007	**52**	**RCT**	**D or E**	ns	*	ns-sex activity

Note. N=Diet, E=exercise, M=Metformin. Weight indicator=loss in kg, % fat, BMI, waist circumference / hip:waist ratio. Reproductive = ovulation, cyclicity. Mainly PCOS patients. [-] = Variable not assessed

*Since Moran et al. 2006 & Lim et al. 2007 reviews

Motivation a problem

- The percent of people who take up offers (mainly in context of research), when documented, is about 75% (e.g., Clark 1998; Katcher et al. 2009; Hoeger et al. 2004) and even lower if referred to external clinics (about 5% Hughes et al. 2000).
- From those who start typically a further 25-30% dropout (e.g., Stamets et al. 2004; Thomson et al. 2009) or more depending on intervention (40% in highly restricted diets Tsgareli et al. 2006)
- Of stay in programs, compliance (e.g., attendance at classes, adherence to diet) is only between 75-85% (Thomson et al. 2009; Palomba et al. 2007; Harris-Glocker, 2010).

RCT laser surgery

Table 2 Main outcome measures (mean scores ± SD)

	Intervention		Control		
	Baseline	6 months	Baseline	6 months	P-value[a]
Self-reported severity	7·3 ± 1·8	3·6 ± 2·8	7·1 ± 1·9	6·1 ± 2·6	< 0·05
Minutes per week removing hair	112 ± 135	21 ± 19	92 ± 88	56 ± 73	≤ 0·05
HADS Depression	6·7 ± 4·5	3·6 ± 3·5	6·1 ± 3·7	5·4 ± 3·8	< 0·05
HADS Anxiety	11·1 ± 3·5	8·2 ± 3·8	9·6 ± 4·5	9·3 ± 4·9	< 0·05
WHOQOL-BREF Psychological	49·6 ± 18·8	61·2 ± 16·7	50·1 ± 20·6	51·5 ± 21·5	< 0·05
WHOQOL-BREF Social	49·5 ± 22·6	57·8 ± 24·0	49·3 ± 31·6	53·6 ± 27·2	> 0·05
WHOQOL-BREF Physical	64·3 ± 19·9	70·6 ± 18·9	68·7 ± 19·3	67·9 ± 20·5	> 0·05
WHOQOL-BREF Environmental	62·4 ± 13·7	65·6 ± 15·9	59·1 ± 16·8	60·6 ± 18·8	> 0·05
Rosenberg Self-Esteem	27·7 ± 5·4	30·9 ± 5·3	26·3 ± 5·7	28·7 ± 6·0	> 0·05

HADS, Hospital Anxiety and Depression Scale. [a]P-value from ANCOVA comparing differences between the intervention and control groups at 6 months while allowing for any differences in baseline scores.

Clayton et al. 2005

Five high-fluence (intervention) vs. five low-fluence treatments (control)

6 months in a National Health Service teaching hospital.

ORIGINAL RESEARCH

Nurse-led peer support group: experiences of women with polycystic ovary syndrome

Carol A. Percy, Tineke Gibbs, Lynne Potter & Shirine Boardman *JAN*

- Nurse led support group for PCOS
  - Emotional expression and support
- Qualitative evaluation
  - Increased knowledge, reduced isolation, enabling change

Methodological & conceptual issues

- PCOS at risk group but proportion at risk unknown
  - Inappropriate designs for prevalence studies (e.g., online, advocacy groups, advertisements appealing for sub-groups, intervention studies with high attrition)
  - Self-reported diagnosis, no blinding
- Nature of PCOS impact on prevalence
- Onset of PCOS is rarely known
  - Cannot disentangle features from reactions
- Race variation in manifestation & cultural variation in symptom acceptability
- Assessment artefacts

Methodological & conceptual issues

Review Goverde, Westerveld, Verhulst & Fauser *Expert Review Obstet Gynecol*

Birth	Childhood	Puberty	Reproductive life	Middle age and beyond	Physician
Low birthweight					Pediatrician
	Precocious pubarche				
		Obesity			General practitioner
		Acne			Dermatologist
		Hirsutism			
		Oligo-amenorrhea			Gynecologist
			Infertility		
			Pregnancy complications		
				Type 2 diabetes	Endocrinologist
				Cardiovascular events	Cardiologist

Figure 1. Presentations associated with polycystic ovary syndrome during the different life phases and medical specialties involved.
Adapted from [16].

Methodological & conceptual issues

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Methodological & conceptual issues

- PCOSQ items problematic
  - 'Emotion' subscale refers to specific concerns (infertility, weight)
  - Overestimates difference between PCOS & control
  - Overestimates importance of weight & infertility in explaining QoL effects
- Subjective versus medical evaluation
  - Symptom bother versus behavioral disorder

Recommendations

- Further efforts to establish true prevalence of psychological disorders in PCOS should be carried out using appropriate designs
- Screening of all PCOS patients for psychological disorders is not yet warranted
- Feasible and acceptable tailored interventions (lifestyle management, hirsutism, psychosocial demands) should be identified/developed and offered to patients

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