Psycho-Social and Sexual Well-Being in Women with Polycystic Ovary Syndrome

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1. Introduction

The polycystic ovary syndrome (PCOS) is the most common endocrine disorder in women of reproductive age [1]. PCOS is not only accompanied with negative physical consequences, but this syndrome also affects psycho-social and sexual well-being. Characteristics of PCOS include enlarged ovaries with a polycystic appearance along with menstrual irregularities such as amenorrhoea or oligoamenorrhoea, excessive growth of body hair (hirsutism) or biochemical hyperandrogenism, and to a lesser extent acne. In addition, PCOS is associated with anovulatory infertility, obesity, insulin resistance, and lipid disorders [2, 3].

In clinical scenarios, the treatment of women with PCOS is mainly focused on correcting menstrual disturbances and physical consequences. Besides the physical consequences, the negative implications of PCOS in daily life such as impaired social contacts and sexual satisfaction and depression seem to be rarely discussed with PCOS women during treatment. The scientific interest in the psycho-social and sexual consequences of PCOS has grown in the past years and has increased our knowledge on these topics. For example, recent studies indicated that PCOS is associated with depression [4-6], body dissatisfaction [5, 6], decreased quality of life [7], a decreased feeling of sexual attractiveness and self-esteem as well as sexual dissatisfaction [4, 7].

First, an extensive overview is provided in this chapter on what is known about psycho-social and sexual well-being in women with PCOS (Part I). Second, we studied the association between on the one hand common physical features of PCOS (polycystic ovaries, hirsutism, acne, menstrual irregularities, and Body Mass Index) and endocrine variables (e.g. testosterone, progesterone, and estradiol) and sexual well-being on the other hand (Part II). In addition, we evaluated whether there is an association between aspects of psycho-social well-being (self-esteem, body satisfaction, and self-perceived fear of negative appearance evaluation) and sexual well-being (Part II).
2. Part I: Psycho-social well-being in women with PCOS

In some women, the appearance of PCOS might be characterized by an excess growth of body hair on various body areas such as the chin, lip, abdomen, and arms as well as by acne. It is imaginable that these outer appearances, together with non-visible characteristics (e.g. menstrual irregularities) influence psycho-social well-being. Moreover, PCOS causes infertility and involuntary childlessness. It has in fact been shown that women with PCOS report more psychological distress than controls [7, 8]. With respect to the diagnosis of PCOS itself, one study measuring patient’s perception of the diagnosis of PCOS found that the emotions associated with the diagnosis included frustration (67%), anxiety (16%), and sadness (10%) [9].

It has been shown that hirsutism, menstrual irregularities, and infertility are the PCOS symptoms experienced as most bothersome by affected women [10]. Lipton and colleagues [11] demonstrated that women with facial hair spend a considerable time on the management of their facial hair (104 min/week). Besides, two thirds reported continually checking their facial hair in mirrors and 76% by touch. In addition, more than half of the women tried at least four methods for hair removal in the past. Furthermore, it is conceivable that infertility increases a woman’s emotional distress. Indeed, many PCOS women seem to worry about remaining without children in the future and report a current wish to conceive; however, infertility does not appear to be a determinant for psychological problems [12]. Together, it is imaginable that the symptoms of PCOS might cause a woman to experience issues with their femininity and might therefore not only affect psychological well-being, but more in particular sexual well-being. Studies have indicated that women with PCOS experience more psychological problems such as depression and anxiety than non-PCOS controls with infertility problems [13], indicating that mood swings might be caused by the distressing symptoms of the syndrome. The emotional distress related to symptoms and consequences of PCOS might affect various domains of their lives, including romantic relationships, friendships, social contacts, and their working life. It could be that women find it difficult to share their experiences with other people and feel uncomfortable when conversations about motherhood are started. Also, about 50% of all women with PCOS are overweight, compared to 30% of women in the general population [2]. A higher Body Mass Index (BMI) in women with PCOS is not only related to negative physical [2, 3, 14, 15], but also to negative psychological consequences [4].

Altogether, a greater incidence of psychological problems have been found in women with PCOS [8]. In the sections below we will describe what is known about psycho-social well-being in women with PCOS as well as the association with features of PCOS. The results will not be discussed in detail as this is beyond the scope of this chapter.

2.1 Quality of Life

It is widely recognized that QoL is significantly reduced in women with PCOS [6, 16-18]. Generic QoL (focuses on domains of well-being in general) [19, 20] as well as specific QoL (focuses on domains of well-being related to a specific disease/syndrome) measurements [21] are used in research. Several studies investigated mechanisms that might be responsible for a reduced QoL in PCOS women. Being overweight has been found to be one of the most important contributors reducing QoL in women with PCOS [7, 22, 23]. In addition, there is converging evidence suggesting that hirsutism is one of the most important predictors of
impaired QoL besides obesity [4, 23, 24]. In addition, it is demonstrated that acne, diabetes mellitus [21], menstrual irregularities [7], and concerns about infertility [4, 25, 26] are related to a reduced QoL in women with PCOS. Nevertheless, Hahn et al. [23] failed to find an association between QoL and androgens and insulin resistance.

With respect to psychological mechanisms, a reduced psychological QoL in PCOS women has been indicated to be associated with a passive coping style (a maladaptive coping strategy) [16] as well as with anxiety and depression [27].

2.2 Depression

Women with PCOS report higher levels of depressive symptoms than the general population [8]. The prevalence of depressive symptoms is not only higher but also more variable (25-64%) [12, 28-31] than for women in the general population. In addition, it has been found that women with PCOS report higher depression scores than non-PCOS controls with fertility problems [13]. PCOS features, endocrine imbalance (e.g. testosterone levels), and psychological mechanisms seem to have an impact on mood in women with PCOS and have therefore been studied as mediators of depression. For example, infertility [12] and an unfulfilled wish to conceive [27] do not appear to contribute to higher depression scores; however, infertile PCOS women seem to have higher depression scores compared to infertile women in whom infertility is related to other causes than PCOS [5]. Hence, other characteristics of PCOS seem to play a mediating role. Several studies have shown that BMI is related to depressive symptoms [22, 32, 33] as well as hirsutism and acne [11, 27]. Moreover, higher depression scores have been demonstrated in PCOS women with hirsutism compared to women with newly diagnosed gynaecological cancer [34].

PCOS is associated with high testosterone levels. Lower testosterone levels seem to be related to depression in women with PCOS [35]. Also, testosterone was found to be lower in depressive PCOS women compared to PCOS women without depressive symptoms, whereas the researchers found no significant relation between BMI and hirsutism [36]. Conversely, Barry and colleagues [13] failed to find an association between testosterone and mood disturbances in women with PCOS. Accordingly, others failed to find an association between depression and hormonal and metabolic profile [36, 37].

With respect to psychological mechanisms, it has been shown that depression in PCOS women is predicted by a poorer perception of self-worth and body image [29, 38], fitness orientation, appearance evaluation, lower QoL [29], and passive coping style (a maladaptive coping strategy) [16].

2.3 Anxiety and fears

Recently, researchers showed an increased level of anxiety [27, 29] and social anxiety [8] in PCOS women compared to controls. The finding of reduced sleep in women with PCOS might be explained by a higher prevalence of sleep apnea in obese women with PCOS [39].

An interesting issue is determining which characteristics of PCOS are related to anxiety. It has been shown that not only visual features of PCOS such as a higher body weight and an excessive growth of bodily hair were related to an increased experience of fear of what other people thought about their appearance, but also the absence of their cycle (amenorrhea)
was negatively associated with fear of appearance evaluation [40]. The association between fear of negative appearance evaluation and non-visual characteristics might be explained by a reduced feeling of femininity [10]. The experience of women with PCOS feeling less feminine seem to be related to menstrual irregularities and hirsutism [10]. Contrasting findings have been found with respect to the relation between anxiety and hirsutism. Some studies reported women with hirsutism showing greater anxiety levels [7, 11] and social fears [41]. Moreover, one study found that higher anxiety scores were indicated in PCOS women with hirsutism than in women with newly diagnosed gynaecological cancer [34]. Furthermore, both acne and an unfulfilled wish to conceive seem to be a risk factor for clinically relevant anxiety in women with PCOS [27]; however, this study failed to find a relationship for BMI and hirsutism. This is in the same line with other study results not finding a relationship between anxiety, acne, hirsutism, and BMI [36, 42]. Contrasting findings might be explained by the use of different questionnaires.

Livadas et al. [36] studied whether anxiety was associated with hormonal and metabolic profile. PCOS women with higher anxiety scores showed significantly elevated HOMA-IR (insulin resistance) and FAI (free androgen excess) values than PCOS women with lower anxiety scores, independently of BMI; however, no relation was found with hormonal values such as testosterone, androstenedione, sex hormone-binding globulin levels, dehydroepiandrosterone sulphate, and estradiol. In the same line, the relation between greater FAI values and greater levels of anxiety was previously reported by Mansson et al. [8].

Moreover, Deeks and colleagues [29] indicated in a cross-sectional study in PCOS women and controls that poor perception of self-worth and body image as well as health evaluation predicted higher anxiety levels. It has also been found that anxiety in PCOS women is associated with having a passive coping style [16].

### 2.4 Self-esteem and body satisfaction

A recent study demonstrated a more negative body image in women with PCOS compared to healthy controls [29]. It has been indicated that women with facial hair and decreased self-esteem have higher depression and anxiety scores as well as poorer QoL [11], although poorer self-esteem compared to the general population was not confirmed. In a previous study, we showed that women with PCOS and a higher BMI in addition to hirsutism reported having poorer self-esteem and greater body dissatisfaction than women without hirsutism and lower BMI scores. In addition, amenorrhoea was associated with poorer self-esteem whereas hyperandrogenism and acne were found to be associated with body dissatisfaction. In line with our previous findings, it has been shown that women with PCOS and clinical symptoms of hirsutism and acne have greater body dissatisfaction than healthy controls with regular cycles, even after adjustment for BMI [5, 35]. Furthermore, poorer self-esteem in PCOS women has been linked to higher levels of depression and anxiety [29, 38].

### 2.5 Other domains of psycho-social well-being

#### 2.5.1 Eating disorders

A higher prevalence of eating disorders such as bulimia has been reported in women with PCOS compared to controls [8]. One study found that 12.6% of PCOS women had an eating
disorder compared to 1.6% in controls [32]. No association between PCOS characteristics (such as hirsutism and acne) and eating disorders has been found [43]. Further, Livadas and colleagues [36] failed to find an association between eating disorders and hormonal and metabolic profile in women with PCOS.

2.5.2 Suicide

Mansson et al. [8] were the first who studied suicide attempts in women with PCOS: they found that suicide attempts were seven times more common in women with PCOS compared to controls [8]. This finding might be explained by the increased risk for psychological disturbances such as depression and anxiety.

2.5.3 Neuroticism and stress responses

Furthermore, a recent study reported that women with PCOS were more neurotic, meaning that they had difficulties coping with stress, exhibited more anger symptoms, and were more likely to withhold feelings of anger compared to non-PCOS women with fertility problems [44]; however, these findings disappeared with using multiple regression analyses, indicating that they might be related to distressing symptoms of the syndrome. In addition, disturbed stress responses were indicated in PCOS women [45]. This finding might be linked to the elevated risks for depression, overweight, and the cardiovascular and diabetes risks associated with the diagnosis.

3. Sexual well-being in women with PCOS

Hormones play a major role in various aspects of sexuality. As PCOS is an endocrine disorder, it seems plausible that the endocrine changes associated with PCOS influence sexuality. Sexuality is an important aspect of an individual’s well-being, highlighting the importance of our understanding of sexuality in women with PCOS. Existing studies with respect to PCOS and sexuality have been mainly focussing on sexual satisfaction in women with PCOS, whereas for example sexual functioning has not been given much attention. Sexual satisfaction is defined as the balance between costs and rewards concerning sexuality [46], for example: A woman without problems in the domain of sexual desire but who experiences painful intercourse has lowered sexual satisfaction because the costs (pain) are too high. Sexual functioning refers to the ability to experience the phases of the sexual response cycle (desire, arousal, lubrication, orgasm), for example: A woman who is able to feel sexually aroused but who is not able to experience an orgasm has poorer sexual functioning. Sexual satisfaction is part of sexual functioning [47] given that a person without problems in the domain of sexual functioning might experience a decreased sexual satisfaction, for example caused by negative feelings such as guilt. On the contrary, not being able to function sexual fully does not necessarily mean that one has low sexual satisfaction; one might not experience this as a problem. It is imaginable that clinicians and researchers find it more comfortable talking about sexual satisfaction than sexual functioning, with the latter being more detailed and intimate. Clinicians might not be trained in discussing sexual problems with their patients or it is unknown as to where to refer patients to with sexual problems.
3.1 Sexual functioning in women in general: The role of hormones

Androgens and estrogens play an important role in female sexual functioning. The sex steroids testosterone and estradiol play a role in all structures and organs related to female sexual functioning. For example, changes in sexual desire are noticed during changes in the menstrual cycle [48]. Sexual desire refers to a subjective feeling that is triggered by both internal and external cues, which may or may not result in overt sexual behaviour [49]. Sexual arousal has physiological and subjective aspects: the physiological part is related to an increased autonomic activation that prepares the body for sexual activity and increases the amount of sexual stimulation necessary to induce orgasm. The subjective part is related to an emotional state of arousal, including sexual thoughts and fantasies [50].

3.2 Estrogens

Estrogens play an important role in making the brain susceptible for the influence of testosterone. In addition, estrogens influence mood and physical signs of sexual attractiveness (e.g. breast development). An estrogen deficiency can cause various complaints such as mood disturbances and might indirectly influence sexuality negatively [51, 52]. It has been demonstrated in healthy pre-menopausal women without PCOS that menstrual cycle changes can influence sexual behaviour by changes in psychological well-being: improved sexual activity (frequency of partner sex, masturbation and orgasm) was related to an increased well-being (mood and pre-menstrual symptoms) [48].

Furthermore, atrophic changes (thinning of the vaginal walls) are influenced by reduced estrogen levels [53, 54]; however, sexual reactions, sexual arousal, lubrication and genital vasocongestion do not seem to be estrogen dependent. Even though estrogen levels were significantly different, studies failed to find a difference in sexual functioning between pre-menopausal and post-menopausal women [51, 52]. Likewise, no evidence has been found for a significant effect of estrogen on sexual interest, arousal, and orgasmic response [48, 53]. The best predictor for post-menopausal sexual functioning seems to pre-menopausal sexual functioning [53]. Estrogen levels are in general within the normal range in women with PCOS [55].

3.3 Androgens

Androgens have been indicated to play an important role in female sexual functioning [56] and seem to influence sexual desire and arousal (either alone or in combination with estrogen), sexual thoughts, sexual fantasies, and nocturnal genital responses [54, 57]. Androgens prepare the female sexual system to be susceptible for sexual stimuli and sexual arousal [54, 56]. Sexual arousal through non-cognitive processes (audiovisual stimulation, ‘quick and dirty’) has not been found to be androgen dependent, whereas sexual arousal through cognitive processes (thoughts, fantasies, ‘neat and slow’) has been shown to be androgen dependent [56]. Androgen levels are often increased in women with PCOS which in turn might influence sexual thoughts and desire [55]. Bancroft et al. [48] failed to find an association between testosterone levels and sexual activity with their partner; however, a positive relation was found with respect to the frequency of masturbation. Finally, testosterone and DHEAS were not found to be related with Hypoactive Sexual Desire Disorder (HSDD: a deficiency or absence of desire for sexual activity) in community based studies in women [53, 58, 59].
3.4 Hyperandrogenism and sexuality

A recent publication [60] found that not only acne and hirsutism improved by oral contraception as a result of reduced androgen levels, a positive influence on social contacts, QoL, sexual self-esteem, and feelings of sexually attractiveness has also been found. In addition, sex life in general (sexual pleasure in particular) and orgasm by intercourse improved as well as that dyspareunia (painful sexual intercourse) declined. Moreover, the frequency of intercourse increased as opposed to the frequency of masturbation. Sexual functioning seems to be improved by the mediation of improved QoL, whereas sexual self-esteem and sexual attractiveness as a result of decreasing hirsutism and acne [60]. Furthermore, Wierman and colleagues [53] found a minor influence of hyperandrogenism or its treatment on sexual functioning in women with PCOS. The researchers speculate that psycho-social factors such as decreased levels of self-esteem might have a greater impact on sexuality.

Abovementioned studies indicate that hormonal influences play a minimal role in predicting sexual functioning in women with PCOS. Lowered sexual satisfaction and sexual functioning might be mediated by psychosocial factors or by a variety in responsiveness to testosterone [61]. Finally, contextual influences (e.g. partner relationship) combined with the appropriate stimuli can cause sexual arousal resulting in sexual desire [57, 62-64].

4. Sexual functioning

4.1 Sexarche and sexual intercourse

It has been found that adolescents and women with PCOS become sexually active later in life than controls. In addition, it seems that PCOS women are less likely to have had intercourse compared to their healthy peers [7, 26, 65]. Furthermore, De Niet et al. [40] found that sexarche (the first sexual intercourse) is related to amenorrhoea; women with PCOS and amenorrhoea had an earlier sexarche than women with PCOS and oligomenorrhoea.

Although it has been indicated that PCOS women experience lower sexual satisfaction and feel less attractive than controls, the frequency of sexual intercourse [7, 66] and the number of sexual partners [66] was not found to be different compared to controls. Moreover, it has been found that the frequency of sexual intercourse increased as a result of improved QoL, sexual self-esteem, feelings of sexual attractiveness, and sexual pleasure when using oral contraceptive [60].

Pagidas et al. [67] found that intercourse compliance (2-3 times a week) was related to having an ovulatory cycle in women undergoing fertility treatment. An ovulatory cycle increased intercourse compliance, especially in women with a BMI over 35.

Painful sexual intercourse has also been studied [7, 23, 60, 66]. Two studies have found that pain during sexual intercourse is increased in women with PCOS compared to controls [23, 66]. The incidence of painful intercourse seems to be negatively influenced by BMI [23]. Painful intercourse seem to decrease with the use of oral contraceptives [60] or metformin [65], probably due to mediating factors of overall increased sexual functioning (in particular sexual pleasure).
4.2 Sexual desire

Conaglen & Conaglen [68] compared women with PCOS or idiopathic hirsutism (IH) and healthy controls on psychosocial functioning and various aspects of sexuality including sexual desire. Sexual desire was found to be significantly lower in PCOS women than in controls. After anti-androgen medication, the treatment group reported a significantly further decline in sexual desire despite a significantly increase in self-esteem and a decrease in hirsutism. This indicates that anti-androgen therapy can improve self-esteem and hirsutism, but negatively influences sexual desire. This could be due to decreasing androgen levels causing the brain to be less susceptible to sexual stimuli resulting in decreased sexual desire [54]. In line with these findings, studies failed to find a relation between sexual desire and androgen levels [57, 58, 67] in non PCOS women; however, an impaired sexual interest and desire (e.g., arousal, orgasm, pain, initiation, receptiveness, affection, relationship) was shown in with women with HSDD compared to controls [58]. In contrast, two studies indicated that women with PCOS seem to take more sexual initiative and to have greater sexual desire than controls [66, 69]. Interestingly, one study found PCOS women reporting less interest in physical contact with their partner compared to controls. These contrasting findings might be explained by psychological factors [61].

4.3 Sexual arousal, orgasm

As mentioned before, androgens influence sexual arousal; however, free or total testosterone has not been found to be related to arousal. Furthermore, it has been shown that women with PCOS are less satisfied with their sex life, had more problems with getting aroused, and showed more often no interest in physical contact with their partner compared with healthy controls [66]. In addition, insufficient lubrication was significantly higher in PCOS women [11]. This finding seems to explain the higher incidence of painful sexual intercourse.

The incidence of sexual thoughts and fantasies (part of subjective arousal) seems to be negatively correlated to BMI [23]; however, orgasm frequency was not found to differ between PCOS women and controls [66]. In addition, total serum testosterone but not FAI was positively related to higher scores in aspects of sexual functioning (such as satisfaction sex life, frequency of orgasm during intercourse, and vaginal lubrication) in PCOS women [66]. A hypothesis is that levels of testosterone above average improve sexual functioning; however, this is not in line with other findings [12, 23, 66, 68].

Using oral contraceptives seem to improve the frequency of orgasm during intercourse in women with PCOS [60], probably due to mediating factors as improved sexual pleasure, sexual self-esteem, and BMI. One study [70] failed to find a difference in sexual functioning or in genital anatomy between lean PCOS women and lean controls. Despite differences in androgen levels, no difference was found in clitoral volume and vascularisation.

4.4 Sexual satisfaction, attractiveness, and self-worth

It is widely recognized that women with PCOS report a decreased sexual satisfaction than healthy controls [7, 12, 26, 65, 66]. Sexual satisfaction seems to be influenced by both
endocrine and psycho-social factors. For example, both BMI and hirsutism seem to negatively influence sexual satisfaction, sexual attractiveness [23], and body esteem [68]. PCOS women also thought that their partners found them less sexually attractive [12]. Using an oral contraceptive improved hirsutism and acne [60, 68] which led to an improved feeling of sexual attractiveness and sexual self-esteem [60].

Sexual self-worth seems to be lower in PCOS women [12, 17]. This finding might be related to infertility; however, this association could not be established. No other studies were found using the term self-worth. Self-esteem was reported [60, 68] and seem to be related to hirsutism and acne [68, 71].

Furthermore, it seems that BMI, hirsutism, and acne negatively influence making social contacts [12, 23] in women with PCOS. This finding might be explained by lower levels of self-esteem and other psychosocial factors [70].

Finally, poorer body-image has been found to be associated with sexual avoidance [38] in women with PCOS compared to controls. Likewise, depression as a consequence of BMI was also found to have a negative association with sexual functioning in pre-menopausal women [72]. A similar relation might be expected in women with PCOS. In the same line, psychosocial aspects seem to negatively influence sexuality in women with PCOS: impaired psychological well-being [7, 60, 68], partner relationship [47], general health [65], social influences [59], and quality of the sexual stimuli [47].

4.5 Sex-typed behaviour and sexual orientation in PCOS women

Last, there is evidence that sex typed behaviour and sexual orientations are related to hormonal levels. One study measured sex-typed behaviour online as well as self-reported PCOS diagnosis [73]. The results indicated that PCOS women reported significantly less typical feminine behaviour as a child (e.g., experimenting with make-up). In addition, PCOS women reported to have lower rates of dating boys and being part of a sports team.

The results of studies examining the prevalence of PCOS in lesbian women and heterosexual women are contrasting. For example, Smith et al. [74] did not find a difference in the prevalence of PCOS and associated factors (e.g. hirsutism and testosterone level) in a general population of lesbian and heterosexual women. In contrast, another study conducted in a clinical population found a significant higher prevalence of PCOS and associated factors in lesbian than in heterosexual women [75].

Finally, one study found that higher testosterone levels and a higher incidence of hirsutism, acne, menstrual irregularities as well as a higher prevalence of PCOS in female-to-male transsexuals (FMT) [76].

5. Part II

The objective of Part II was to evaluate the association between PCOS characteristics (polycystic ovaries, hirsutism, acne, menstrual irregularities (amenorrhea and oligomenorrhea), and BMI) and endocrine variables (e.g., testosterone and estradiol) on the one hand and sexual well-being on the other hand. In addition, we studied whether there is an association between aspects of psycho-social well-being (self-esteem, body satisfaction, and self-perceived fear of negative appearance evaluation) and sexual well-being.
6. Methods

6.1 Participants and procedure

Women with normogonadotropic anovulation (WHO II) who attended our fertility clinic at the Erasmus MC University Medical Centre between 1991 and 2006 were included in this cross-sectional study. In this group of WHO II women, we determined if the diagnosis of PCOS could be established on the basis of the revised Rotterdam criteria [77]. To establish the diagnosis of PCOS, all patients underwent a standardized evaluation including: assessing cycle history, the presence or absence of acne, transvaginal ultrasonography (to assess ovarian volume and follicle count for both ovaries), and anthropomorphometric measurements (height and weight, Ferriman-Gallwey score). Exclusion criteria included the presence of related disorders with similar clinical presentation, such as congenital adrenal hyperplasia and Cushing’s syndrome. The study protocol was approved by the Medical Ethics Committee of the Erasmus MC University Medical Centre, Rotterdam the Netherlands. All patients gave informed consent prior to their inclusion in the present study. In 2007, all women with WHO II received a letter with information about the current study and a seventy-two item questionnaire. Two months after mailing this questionnaire, non-respondents were sent a reminder together with a copy of the questionnaire.

6.2 Study outcomes

6.2.1 Independent variables: PCOS characteristics and endocrine variables

In the period of 1991 to 2006, all women who were referred to the fertility clinic underwent a standard fertility test including evaluation of the following aspects:

1. Menstrual irregularities: oligomenorrhoea was defined as an interval between menstrual periods ≥35 days and amenorrhoea as the absence of vaginal bleeding for at least 6 months, i.e. >199 days;
2. Biochemical and clinical hyperandrogenism: in accordance with the revised Rotterdam criteria, hyperandrogenism was defined as having either biochemical or clinical signs of androgen excess. Biochemical hyperandrogenism was defined by a free androgen index (FAI)>4.5. Clinical hyperandrogenism (hirsutism) was assessed by the Ferriman-Gallwey score where patients estimated their hair growth on nine different body parts from 0 (no terminal hair) to 4 (maximal growth) with a maximum score of 36. A score of 8 or more indicates the presence of hirsutism [78];
3. Acne: the presence or absence of acne was evaluated by the physician;
4. Polycystic ovaries (PCO): the presence of PCO was examined by vaginal ultrasound examination. PCO were defined as the presence of 12 follicles or more in one or both ovaries and/or increased ovarian volume (>10 ml); and
5. Endocrine evaluation: blood samples were obtained by venipuncture. Serum levels of gonadotropin hormones (luteinizing hormone (LH) and follicle-stimulating hormone (FSH)), estradiol (E₂), androgens (testosterone (T), androstenedione (AD), dehydroepiandrosterone (DHEA), and dehydroepiandrosterone sulphate (DHEAS)), progesterone, sex hormone-binding globulin levels (SHBG), fasting glucose and insulin, thyroid-stimulating hormone (TSH), and prolactin were obtained. Serum was isolated after centrifugation at 3000 rpm for 10 min at 20°C and subsequently stored at -20°C.
Immunofluorometric assays were used for the LH, FSH, TSH, prolactin and insulin, whereas serum $E_2$, T, AD, and SHBG were measured by RIA provided by Diagnostic Products Corp. (Los Angeles, CA). Intraassay and interassay coefficients of variation were $<5\%$ and $<15\%$ for LH, $<3\%$ and $<5\%$ for T, $<8\%$ and $<11\%$ for AD, $<5\%$ and $<7\%$ for $E_2$, $<4\%$ and $<5\%$ for SHBG, respectively [3].

6.2.2 Independent variables: Psycho-social well-being

6.2.2.1 Rosenberg Self-Esteem Scale (RSES)

The RSES was administered to measure the level of self-esteem. On a 4-point-Likert scale from ‘strongly disagree’ to ‘strongly agree’, responses on 5 positively worded and 5 negatively worded questions were assessed. Higher scores reflect a higher level of self-esteem. The Dutch version of the RSES was shown to have good internal reliability (Chronbach’s alpha = .87) [79].

6.2.2.2 Body Cathexis Scale (BCS)

The BCS is a self-report questionnaire assessing body satisfaction [80]. The questionnaire consists of 52 items about a person’s satisfaction with their body parts and body functions, such as hips and respiration. Body satisfaction is measured on a 5-point Likert scale from the most negative attitude towards a body part or function to the most positive attitude towards the body part or function. The Dutch version of the questionnaire was shown to have good test-retest reliability (Pearson product-moment correlation coefficient = .91) [81].

6.2.2.3 Fear of Negative Appearance Evaluation Scale (FNAES)

The brief version of the FNAES was used to assess apprehension related to a negative appearance evaluative experience. The items are answered on 5-point Likert scales from ‘not at all’ to ‘enormously’. The higher the score, the more fear of negative appearance evaluation by others is experienced. This six-item questionnaire was shown to be valid and reliable with a high internal consistency (Chronbach’s $\alpha=0.87$) [82].

6.2.3 Dependent variables: Sexual well-being

6.2.3.1 Sexual well-being

Subjects completed questions that were part of a Dutch questionnaire measuring sexual health in youth and young adults between the age of 12 and 25 years [83]. The questions that we used in the current study included the following: (1) ‘How old were you when you had your first intercourse?’; (2) ‘Have you ever had a romantic relationship?’; (3) ‘How old were you when you had your first romantic relationship?’; (4) ‘Have you ever been in love?’; and (5) ‘Are you in a romantic relationship at this moment?’

6.2.3.2 Confounders: Demographics

Information on women’s demographic characteristics such as age and ethnicity were collected. Ethnicity was divided into two categories: (0) non-Caucasian (another ethnicity than Dutch) and (1) Caucasian (Dutch).
7. Statistical analyses

Data are presented for women with PCOS only. As measures for central tendency the means (for continuous data) and medians (for ordinal data) were estimated, while as measure for dispersion standard deviation was used. The observed score range was also presented. To explore the association between sexual well-being variables (dependent variables) on the one hand and the PCOS characteristics and endocrine variables or psycho-social well-being (independent variables) on the other hand, multiple linear regression analysis was applied on continuous dependent variables. The PCOS characteristics and endocrine variables were entered into the regression analysis together with confounding variables (age and ethnicity). Psychological variables were analyzed separately. For dichotomous dependent variables, adjusted odds ratios (Odds) and 99% confidence intervals (CI) were derived from logistic regression analyses. PCOS characteristics were entered as dichotomous variables: oligoamenorrhea (0) versus amenorrhea (1); no or doubtful hirsutism (0) versus hirsutism (1); few or no acne (0) versus acne (1); no PCO (0) versus PCO (1). In analyzing the relationship between sexuality and PCOS characteristics, we adjusted for the time interval between the date of the clinical evaluation and the sexuality measures, age of the participant, and ethnicity. As sexarche was prior to the clinical investigation for most women, we entered years between sexarche and the clinical evaluation as a confounding variable in the analyses. Ethnicity was entered as a confounding variable because non-Caucasian women appeared to have sexarche later in life and higher clinical scores such as hirsutism than Caucasian women. Statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS version 15.0) and testing took place at a 0.05 level of significance (two tailed).

8. Imputation

Multiple imputation was performed using the SPSS software in the Missing Value Analysis module in SPSS (version 17.0) to impute missing values under missing-at-random assumptions and the reasons for the missing data are unrelated to the outcome [84]. Multiple imputed data sets of the data were created and replaced by imputed values based on estimated underlying distributions using the Expectation Maximization method [85]. Eight variables were imputed, of which six variables had ≤ than 1.5% imputed data. The variable acne (68%) and hirsutism (35%) had a high percentage of imputed data, numbers of missings that are controversy to impute.

9. Results

9.1 Participants

In the period between 1991 and 2006, 1148 WHO II patients attended the fertility clinic of the Erasmus MC University Medical Centre and underwent standard clinical and endocrine evaluation. Of the 1148 women with WHO II, 480 women with PCOS returned the questionnaire. The overall participation rate was 51% of whom 42% had PCOS. Table I shows the demographical, clinical, endocrine, psychological, and sexual characteristics of the responders with PCOS in our study. It has been indicated that a higher percentage of non-responders with PCOS were overweight or obese and had hyperandrogenism compared to the responders [40]. In addition, we showed that PCOS women had lower self-esteem and poorer body satisfaction compared to norm scores. Of the women that completed the sexuality questions, 2.1% responded that they had their first sexual
intercourse when they were of the age of 13 years or younger and 4.0% had their first relationship when they were 13 years or younger.

<table>
<thead>
<tr>
<th>Demographical characteristics</th>
<th>PCOS responders (n=480)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years at date of clinical evaluation</strong></td>
<td>28.8 (4.3), 14.2-40.0 (480)</td>
</tr>
<tr>
<td><strong>Caucasian</strong></td>
<td>72.1% (346/480)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oligoamenorrhoea</strong></td>
<td>71.7% (344/480)</td>
</tr>
<tr>
<td><strong>Amenorrea</strong></td>
<td>28.3% (136/480)</td>
</tr>
<tr>
<td><strong>Presence of hirsutism</strong></td>
<td>31.9% (99/310)</td>
</tr>
<tr>
<td><strong>Acne</strong></td>
<td>11.1% (17/154)</td>
</tr>
<tr>
<td><strong>PCO</strong></td>
<td>92.5% (444/480)</td>
</tr>
<tr>
<td><strong>Body Mass Index (BMI kg/m²)</strong></td>
<td>26.4 (6.0) [16.8-50.6] (479)</td>
</tr>
<tr>
<td><strong>BMI ≥ 25 (kg/m²)</strong></td>
<td>48.6% (233/479)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Endocrine characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hyperandrogenism (FAI&gt;4.5)</strong></td>
<td>53.1% (255/480)</td>
</tr>
<tr>
<td><strong>LH</strong></td>
<td>7.2 (5.6) [1.0-37.9] (480)</td>
</tr>
<tr>
<td><strong>FSH</strong></td>
<td>4.9 (1.9) [1.1-10.5] (480)</td>
</tr>
<tr>
<td><strong>Progesterone</strong></td>
<td>5.1 (10.1) [0.1 - 73.0] (479)</td>
</tr>
<tr>
<td><strong>SHBG</strong></td>
<td>49.2 (33.3) [7.7 - 342] (480)</td>
</tr>
<tr>
<td><strong>T</strong></td>
<td>2.2 (1.0) [0.3 - 6.7] (480)</td>
</tr>
<tr>
<td><strong>E₂</strong></td>
<td>275.8 (159.9) [51.0 - 1141.0]</td>
</tr>
<tr>
<td><strong>AD</strong></td>
<td>13.0 (5.7) [2.6 - 40.7]</td>
</tr>
<tr>
<td><strong>DHEAS</strong></td>
<td>6.0 (3.2) [0.2 - 21.3]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Psycho-social well-being</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RSES</strong></td>
<td>31.0 (5.4) [14.0-40.0] (477)</td>
</tr>
<tr>
<td><strong>BCS</strong></td>
<td>188.6 (30.3) [72.0 – 260.0] (435)</td>
</tr>
<tr>
<td><strong>FNAES</strong></td>
<td>13.8 (5.9) [6.0 – 30.0] (473)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sexual well-being</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Are you in a romantic relationship at this moment?’ %yes</td>
<td>92.7% (443/478)</td>
</tr>
<tr>
<td>% Never or 1 time</td>
<td>14.4% (69/473)</td>
</tr>
<tr>
<td>% More than 1 time</td>
<td>84.2% (404/473)</td>
</tr>
<tr>
<td>‘Have you ever had a romantic relationship?’</td>
<td></td>
</tr>
<tr>
<td>% Never or 1 time</td>
<td>41.6% (198/478)</td>
</tr>
<tr>
<td>% More than 1 time</td>
<td>58.3% (280/478)</td>
</tr>
<tr>
<td>‘How old were you when you had your first intercourse?’</td>
<td>18.4 (3.3) [5.0 – 30.0] (467)</td>
</tr>
<tr>
<td>‘How old were you when you had your first romantic relationship?’</td>
<td>17.7 (3.2) [10.0 – 30.0] (471)</td>
</tr>
</tbody>
</table>

PCO= Polycystic ovaries; LH= luteinizing hormone; FSH= follicle-stimulating hormone; SHBG= sex hormone-binding globulin levels; DHEAS= dehydroepiandrosterone sulphate; T= Testosterone; E₂= Estradiol; AD= Androstenedione; RSES= Rosenberg Self-esteem Scale; BCS= Body Cathexis Scale; FNAES= Fear of Negative Appearance Evaluation Scale.

¹Values are mean (SD), range, N or (N/total N), or number (%) of participants.

Table 1. Demographical and (bio)clinical characteristics of PCOS responders¹
9.2 PCOS characteristics and endocrine variables and the association with sexual well-being

Table II shows the regression coefficients (B’s) and corresponding P-values derived by the logistic and linear multivariate regression analyses studying the association between the dependent sexual well-being variables and independent PCOS symptoms and endocrine variables.

Relationship at the moment

Results indicated that oligomenorrhoea was positively associated with having a relationship at the moment. In addition, the confounder ethnicity was also significant. These results indicated that PCOS women with oligomenorrhoea were more likely than women with amenorrhea to have a relationship at the moment. In addition, Caucasian PCOS women were more likely to have a relationship at the time of questionnaire completion than non-Caucasian PCOS women.

In love

Older PCOS women, Caucasian women, and women without or doubtful hirsutism were more likely to have been in love multiple times as compared to younger PCOS women.

Relationship in the past

The results showed that the confounders ethnicity, age, and the years between measuring the clinical/endocrine variables and sexuality variables were significant in logistic analysis: Caucasian women and older women were more likely to have had more than one relationship in the past.

Age at first intercourse

Non-Caucasian women and older women have had their first intercourse at an older age than younger and Caucasian PCOS women.

Age at first relationship

With respect to the age of the first relationship, we found women with PCOS and hirsutism and older women with PCOS were comparatively older when they had their first relationship. In addition, non-Caucasian women had their first relationship at an older age compared to Caucasian women.

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>DEPENDENT</th>
<th>Age first intercourse</th>
<th>Age first relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Relationship at the moment</td>
<td>In love</td>
<td>Relationship in the past</td>
</tr>
<tr>
<td>Logistic regression</td>
<td>B; P-value; odds</td>
<td>B; P-value; odds</td>
<td>B; P-value; odds</td>
</tr>
<tr>
<td>PCO</td>
<td>-1.33; 0.44</td>
<td>0.26</td>
<td>0.85; 0.55; 2.33</td>
</tr>
<tr>
<td>Cycle disturbances</td>
<td>-0.99; 0.04*; 0.37</td>
<td>-0.24; 0.49; 0.79</td>
<td>-0.24; 0.30; 0.79</td>
</tr>
<tr>
<td>Acné</td>
<td>2.01; 1.00; 7.48</td>
<td>4.69; 1.00; 108.83</td>
<td>-0.52; 0.42; 0.59</td>
</tr>
</tbody>
</table>
### Table 2. The association between the dependent sexual well-being variables and independent PCOS symptoms and endocrine variables

<table>
<thead>
<tr>
<th></th>
<th>DEPENDENT VARIABLES</th>
<th></th>
<th></th>
<th></th>
<th>Age first intercourse</th>
<th>Age first relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hirsutism</td>
<td>-0.94; 0.10; 0.39</td>
<td>-1.17; <strong>0.009</strong>; 0.31</td>
<td>-0.43; 0.14; 0.65</td>
<td>0.79; 0.07</td>
<td>1.29; <strong>0.002</strong>*</td>
<td></td>
</tr>
<tr>
<td>BMI</td>
<td>0.07; 0.16; 1.07</td>
<td>0.01; 0.79; 1.01</td>
<td>0.00; 0.82; 1.00</td>
<td>-0.04; 0.12</td>
<td>-0.04; 0.17</td>
<td></td>
</tr>
<tr>
<td>T</td>
<td>0.30; 0.40; 1.35</td>
<td>0.20; 0.38; 1.22</td>
<td>0.22; 0.15; 1.25</td>
<td>0.02; 0.94</td>
<td>-0.16; 0.44</td>
<td></td>
</tr>
<tr>
<td>E₂</td>
<td>0.00; 0.59; 1.00</td>
<td>0.00; 0.81; 1.00</td>
<td>0.00; 0.19; 1.00</td>
<td>0.00; 0.38</td>
<td>-0.00; 0.13</td>
<td></td>
</tr>
<tr>
<td>Progesterone</td>
<td>-0.02; 0.43; 0.98</td>
<td>-0.01; 0.45; 0.99</td>
<td>-0.01; 0.32; 0.99</td>
<td>0.02; 0.33</td>
<td>0.02; 0.14</td>
<td></td>
</tr>
<tr>
<td>AD</td>
<td>0.08; 0.24; 1.09</td>
<td>0.03; 0.48; 1.03</td>
<td>0.04; 0.13; 1.04</td>
<td>0.00; 0.97</td>
<td>-0.02; 0.61</td>
<td></td>
</tr>
<tr>
<td>SHBG</td>
<td>0.01; 0.26; 1.01</td>
<td>-0.00; 0.77; 1.00</td>
<td>0.00; 0.92; 1.00</td>
<td>0.00; 0.68</td>
<td>0.01; 0.13</td>
<td></td>
</tr>
<tr>
<td>DHEAS</td>
<td>-0.07; 0.39; 0.93</td>
<td>0.02; 0.73; 1.02</td>
<td>0.01; 0.79; 1.01</td>
<td>0.03; 0.64</td>
<td>0.04; 0.48</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.08; 0.12; 1.08</td>
<td>0.10; <strong>0.01</strong>*; 1.10</td>
<td>0.08; <strong>0.003</strong>*; 1.08</td>
<td>0.17; <strong>0.000</strong>*</td>
<td>0.12; <strong>0.001</strong>*</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-0.12; 0.07</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.73; <strong>0.000</strong>*</td>
<td>1.56; <strong>0.000</strong>*</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>-1.35; <strong>0.008</strong>*; 0.23</td>
<td>-1.13; <strong>0.001</strong>*; 0.32</td>
<td>-0.56; <strong>0.02</strong>*; 0.57</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-0.14; <strong>0.027</strong>*</td>
<td></td>
</tr>
</tbody>
</table>

PCO= Polycystic ovaries; BMI= Body Mass Index; T= Testosterone; E₂= Estradiol; AD= Androstenedione; SHBG= sex hormone-binding globulin levels; DHEAS= dehydroepiandrosterone sulphate.

*Significant at a 0.05 level of significance

9.3 Psycho-social well-being and the association with sexual well-being

Table III shows the regression coefficients (B’s) with corresponding P-values derived by the logistic and linear multivariate regression analyses analyzing the association between the dependent sexual well-being variables and independent psycho-social well-being variables.

**Relationship at the moment**

In logistic regression analysis studying the association between having a relationship at the moment and psycho-social variables, we found that older PCOS women and Caucasian women were more likely to have a relationship at the moment than younger and non-Caucasian PCOS women.
**In love**

PCOS women with higher self-esteem and Caucasian women were more likely to have been in love multiple times.

**Relationship in the past**

Being Caucasian, having higher self-esteem and lower body satisfaction scores were associated with having had multiples relationship in the past.

**Age at first intercourse**

Being older and non-Caucasian were both associated with having experienced the first intercourse at an older age.

**Age at first relationship**

Finally, PCOS women with lower levels of self-esteem as well as women with greater body satisfaction had their first relationship at an older age. Also, both older women with PCOS and non-Caucasian PCOS women were more likely to be comparatively older when they had their first relationship.

<table>
<thead>
<tr>
<th></th>
<th>DEPENDENT VARIABLES</th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Relationship at the moment</td>
<td>Relationship in the past</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Logistic regression</td>
<td>B; P-value; odds</td>
<td>B; P-value; odds</td>
<td>B; P-value; odds</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RSES</td>
<td>0.08; 0.07; 1.08</td>
<td>0.10; <strong>0.003</strong>; 1.01</td>
<td>0.06; <strong>0.02</strong>; 1.01</td>
<td>-0.06; 0.15</td>
<td>-0.09; <strong>0.02</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BCS</td>
<td>-0.01; 0.30; 0.99</td>
<td>-0.01; 0.11; 0.99</td>
<td>-0.01; <strong>0.04</strong>; 1.00</td>
<td>0.01; 0.17</td>
<td>0.02; <strong>0.01</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FNAES</td>
<td>-0.01; 0.84; 0.99</td>
<td>0.05; 0.09; 1.05</td>
<td>0.03; 0.22; 1.03</td>
<td>-0.02; 0.60</td>
<td>0.00; 0.97</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.08; <strong>0.02</strong>; 1.08</td>
<td>0.01; 0.76; 1.01</td>
<td>0.01; 0.51; 1.01</td>
<td>0.12; <strong>0.000</strong></td>
<td>0.08; <strong>0.004</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>-1.13; <strong>0.002</strong>; 0.32</td>
<td>-1.21; <strong>0.000</strong>; 0.30</td>
<td>-0.53; <strong>0.01</strong>; 0.59</td>
<td>1.75; <strong>0.000</strong></td>
<td>1.57; <strong>0.000</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

RSES= Rosenberg Self-esteem Scale; BCS= Body Cathexis Scale; FNAES= Fear of Negative Appearance Evaluation Scale.  
*Significant at a 0.05 level of significance

Table 3. The association between the dependent sexual well-being variables and independent psycho-social well-being variables

**10. Discussion**

A higher incidence of psycho-social disturbances [8] and impaired sexual well-being [7, 26, 65] in women with PCOS highlight the clinical relevance of these topics. To improve overall well-being in women with PCOS, we need to have a better understanding to what extent the features of the syndrome affect psycho-social and sexual well-being.
The current study examined the association of PCOS characteristics and endocrine variables with sexual well-being. In addition, we studied whether psycho-social well-being was associated with sexual health. First, we found that several PCOS characteristics and endocrine parameters predicted sexual well-being. PCOS women with amenorrhea seem to be less likely to have had a relationship at the time of completing the questionnaire. It is imaginable that an irregular cycle causes distress in women, which might have withheld them from starting a romantic relationship. In the same line, it has been found that menstrual irregularities decrease QoL [7] and are linked to fear of negative appearance evaluation [40]. An association between menstrual irregularities and any aspect of sexual health has not been confirmed previously [7].

Furthermore, we found that women with PCOS and hirsutism were less likely to have been in love more than once and were older when they had their first relationship. It is widely recognized that hirsutism is one of the many factors that has a considerable negative impact on QoL [21], self-esteem, body satisfaction [5, 35, 40], and sexual health [23]. Hirsutism is considered as one of the most stressful characteristics of PCOS [10]. As women with PCOS and hirsutism also experience greater fear of negative appearance evaluation [40] and excessive body hair seem to withhold PCOS women from making social contacts [7], it seems plausible to assume that this negatively affects starting a romantic relationship.

With respect to the studied endocrine variables, we did not find that hormonal and endocrine variables are associated with sexual health. In contrast, other studies showed that higher levels of T and androgens are associated with higher levels of sexual arousal and sexual desire [54, 66, 86], although an association with DHEAS was not confirmed in a previous study [58]. However, we measured different aspects of sexual well-being. Other studies showed decreased lubrication [66], lower levels of arousal, and improvement of orgasm frequency by using oral contraceptives [60]. Furthermore, lower levels of T seem to be associated with depression [42], which might also have indirectly influenced sexual well-being. Contrasting results have been found with respect to sexual desire in PCOS women [66, 69, 87]. Anti-androgen therapy seems to further lower sexual desire, even though it improved psychological well-being [68]. Contrasting results with respect to the association between androgens and sexual desire [66, 69, 87] indicate that androgen levels are as yet unreliable predictors of sexual functioning, specifically for sexual desire. It is hypothesized that contradicting findings concerning the role of androgens in female sexual functioning may be due to, among other factors, a greater variety in responsiveness to testosterone in women and mediation of psychological mechanisms [61].

With respect to the significant result of the confounder age, it is imaginable that older women have different norms and values concerning sexuality and romantic relationships. For example, it is not inconceivable that the age of having first sexual intercourse or a relationship is younger in the present time than in previous generations. In addition, the confounder ethnicity is also associated with sexual well-being. Possible differences in sexual morality and cultural backgrounds might have caused non-Caucasian women to have their first intercourse at an older age.

Surprisingly, BMI and acne were not found to predict any of our measured sexual well-being variables. We might have failed to find an effect for acne since this variable had much missing data. Imputing high percentages of missing data is controversial; however, when we analyzed the data again on non-imputed data. The results still indicated a non-
significant effect of acne. Also, Progesterone, SHBG, and E2 were not related to sexual health in the current study.

Second, we studied the association between psycho-social variables and sexual health. Women with PCOS seem to have poorer self-esteem and poorer body satisfaction compared to the general population [40]. In addition, it is indicated that PCOS characteristics such as hirsutism, menstrual irregularities, and BMI are related to impaired psychological functioning [40]. In the current study, we demonstrated that self-esteem plays a significant role in sexual health. We showed that PCOS women with greater self-esteem are more likely have been in love multiple times, to have had more than one relationship in the past, and to have their first relationship at a younger age compared to PCOS women with poorer self-esteem. Decreased sexual satisfaction has been reported in PCOS women [7, 26, 65, 66], which is negatively correlated to BMI and hirsutism. Improving hirsutism and acne, for instance by using an oral contraceptive, seem to improve sexual satisfaction, sexual attractiveness, and self-esteem [60, 68, 71]. Furthermore, an improvement in QoL seems to be related to an increase in the frequency of sexual intercourse and satisfaction with sex life in women with PCOS [7, 65]. Also, it has been shown that BMI, hirsutism, acne negatively influences making social contacts in women with PCOS [61], probably due to low self-esteem. Therefore, it seems conceivable that women with higher levels of self-esteem feel more confident to make social contact and specifically start romantic relationships. Surprisingly, we found that women with greater body satisfaction were older when they had their first relationship. Likewise, it is indicated that body dissatisfaction increased the probability of coitus onset in adolescent girls [88]. Future research should further investigate this relationship. Fear of negative appearance evaluation was not related to any of the sexual variables. This is surprising as it would be plausible to assume that if a person fears what others think of their appearance, they are less likely to be involved in romantic relationships. A recent study indicated that increased anxiety predicted lifelong female sexual dysfunctions in a sample of the general population [89]. Future research should focus on the relation of anxiety and sexual health in women with PCOS.

Pitfalls of studies conducting research on psycho-social and sexual well-being in women with PCOS include the use of self-reported measures. Self-reported questionnaires measure mostly mental symptoms but not clinical syndromes. Mansson et al. [8] did use clinical structured interviews to assess DSM-IV diagnoses and did show psychiatric disorders such as depression and anxiety to be more common in women with PCOS compared to controls. Other drawbacks of our study include that the PCOS women completed the questionnaires later in time than the laboratory and clinical tests were performed. Patients reasonably would have scored the psychological questionnaires different at the time when laboratory and clinical parameters were measured and reported to them. Therefore, we also adjusted for the time interval in years between the endocrine evaluation and the psychological measures. Furthermore, we did not include a matched control group. The current results therefore particularly apply to differences within the PCOS population. Finally, the non-responding rate in our study was high [40]. This might be due to a high percentage of non-Caucasian patients in the non-responding group. A possible explanation is that the Caucasian non-responders had trouble filling out the questionnaires due to insufficient command of the Dutch language. Therefore, the results could not be generalized to all women with PCOS. Furthermore, it might be that those women returning the questionnaire were those PCOS women whose psycho-social and sexual well-being were the least affected.
by their syndrome. In the latter case, the impact of PCOS on psycho-social and sexual well-being might even be underestimated. The impact of symptoms of PCOS on sexual well-being established in the current study might also be underestimated because the non-responders harboured the more pronounced phenotypes.

In conclusion, this study stresses that the treatment of women with PCOS should notably focus not only on physical but also on psycho-social and sexual well-being. Future research should study various aspects of sexuality, e.g. sexual satisfaction, sexual motivation, and sexual self-esteem in randomized control trials with validated questionnaires as well as the influence of PCOS features. To fully understand the correlation between PCOS and sexuality, future studies should take all confounders (endocrine, psychological, and interpersonal) into account.

11. Clinical management

The overview provided in this chapter demonstrates the considerable impact of PCOS and its symptoms on psycho-social and sexual health. As women with PCOS are four times more likely to have abnormal depression scores compared to controls [90] This risk was independent of BMI, therefore it seems necessary to screen all women with PCOS for depression using validated measurements. Moreover, the literature shows an impairment of a variety of psycho-social and sexual health domains in women with PCOS and associations with features of PCOS characteristics. Therefore, we recommend assessing psycho-social and sexual domains by validated measurements.

An important finding is that treatment of associated PCOS characteristics seems to improve psychological and sexual outcomes. For example, metformin or oral contraceptive pill treatment in women with PCOS seems to be related to a reduction of clinical symptoms as well as to an improved psychological and sexual well-being [65]. In addition, using an oral contraceptive [60] or metformin [65] seems to decrease the frequency of painful intercourse. A reduction in body weight and normalized menstrual cycle seems to have mediated these findings. Various oral contraceptives seem to have a different effect on sexuality and psychosocial factors [60, 68, 91]. This should be taken into account when prescribing these medications.

Furthermore, the presence of obesity in PCOS women is associated with various physical consequences and psychological impairments. Lifestyle modification should be the first step before treating PCOS women for their infertility. Various studies have investigated the effects of weight loss and weight loss interventions in women with PCOS, indicating the beneficial effects of weight loss on the clinical and biochemical manifestations of PCOS [92, 93], insulin sensitivity [94], and menstrual cyclicality and fertility outcomes during treatment [95, 96]. Moreover, self-esteem [95] and quality of life [97] have found to be improved by modest weight loss of 5% to 10% of the initial body weight. We also discussed the considerable impact of hirsutism on several psychosocial and sexual domains. It has been shown that laser treatment aimed at reducing the severity of facial hirsutism has not only a positive effect on the severity of facial hair, but also seems to improve self-esteem and QoL [98] and alleviate depression and anxiety [99]. Therefore, treatment of related PCOS symptoms should be considered.
A recent paper of Farrell and colleagues [37] demonstrated the benefits of psychological and behavioural approaches in addition to medical management of PCOS. Likewise, Rofey et al. [38] found decreased depression scores as well as weight loss after a behavioural program in adolescents with PCOS. The intervention consisted of phone calls and face to face meetings addressing coping mechanisms, scheduling behaviourally activating events, and engaging in positive thinking and cognitive restructuring. Furthermore, another study showed that a nurse-led peer support group providing socio-emotional and informational support reduced isolation and women reported feeling empowered [100].

Bitzer et al. [101] developed a tool for sexual counselling that can be used by physicians. It contains 3 dimensions (pre-existing person related factors, disease specific factors, and the individual’s and partners reaction to the disease) that can be addressed when discussing sexuality with the patient. Remembering these dimensions is fairly easy and gives a good direction in discussing sexuality aspects with patients. A treatment plan might depend on the outcome of the conversation. Another easy-to-use tool is the PLISSIT model [102]. This is a stepped care model providing guidance in counselling and treating sexual problems.

Aforementioned treatments and their positive effect on psycho-social and sexual well-being indicate that physicians should work interdisciplinary to also address consequences other than physical consequences and discuss treatment options aimed at reducing PCOS characteristics and improving psycho-social and sexual well-being.

12. References


[19] Coffey S, Bano G, Mason HD. Health-related quality of life in women with polycystic ovary syndrome: a comparison with the general population using the Polycystic Ovary Syndrome Questionnaire (PCOSQ) and the Short Form-36 (SF-36). Gynecol Endocrinol. 2006 Feb;22(2):80-6.


Psycho-Social and Sexual Well-Being in Women with Polycystic Ovary Syndrome


Brought into the limelight many decades ago, Polycystic Ovary Syndrome (PCOS) is still, to date, surrounded by controversy and mystery. Much attention has been attracted to various topics associated with PCOS research and there has been a healthy advance towards bettering the understanding of the many implications of this complex syndrome. A variety of topics have been dealt with by a panel of authors and compiled in this book. They span methods of diagnosis, reproductive anomalies, metabolic consequences, psychological mindset and ameliorative effects of various lifestyle and medical management options. These books are designed to update all associated professionals on the recent developments in this fast-growing field and to encourage further research into this thought-provoking subject.

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