

Theses of Doctoral (PhD) Dissertation

**A QUALITATIVE AND QUANTITATIVE STUDY OF FACTORS THAT
NEGATIVELY INFLUENCE THE QUALITY OF LIFE OF PATIENTS WITH
POLYCYSTIC OVARY SYNDROME**

Bernadett Mohácsi

Supervisor: Anita Szemán-Nagy, Ph.D

Co-Supervisor: János Máth, Ph.D



UNIVERSITY OF DEBRECEN

Doctoral School of Human Sciences

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The objective of the thesis, the introduction of the topic

Polycystic ovary syndrome (PCOS) is a disease affecting women at reproductive age. It is a chronic and, according to our present knowledge, an incurable disease. Prevalence studies report prevalence data in an interval ranging from 2.2% to 26% (Chen et al, 2008; Michelmores et al., 1999). Although PCOS is a disease of internal medical and endocrine origin, the affected women first perceive the following gynecological and dermatological symptoms: *irregular periods and amenorrhoea, infertility, polycystic ovaries*, and the markers of hyperandrogenism: *excess body hair, acne, hair loss (androgen alopecia), and acanthosis nigricans* (hyperpigmentation of the skin) (Sharquie, Al-Bayatti, Al-Bahar, & Al-Zaidi, 2004). *Overweight and obesity* are also often associated with this disease, however, contrary to popular belief, they affect only a part of patients with PCOS (Hart, Hickey, & Franks, 2004). The *waist-hip ratio (WHR) shift* regardless of body weight results in andorid (masculine) type of body constitution for a significant proportion of those affected (Petrányi, 2008). The symptoms of PCOS can decrease quality of life. The reason for this may be that all the symptoms can affect the two key factors in experiencing womanhood: the reproductive ability and / or attractiveness.

One of the important objectives of the psychosocial intervention is that instead of the "suffering from disease" attitude the affected person should learn to adapt to and live with the illness. Health psychology is the discipline to support this process. The major areas of health psychology to develop and to apply preventive and therapeutic activities associated with diseases.

PCOS is regarded as a risk group in terms of mental illnesses. Several symptoms and complications make it difficult to adapt to this disease, this is why health psychological research studies should focus on this topic. In the thesis the quality of life is examined through depression, anxiety, body image and eating disorders, based on the guidelines of the British Society of Psychosomatic Obstetrics, Gynaecology and Andrology (British Society of Psychosomatic Obstetrics, Gynaecology and Andrology).

The main goal of the research is to provide psychological support of interventions through disease-specific risk reduction. For certain diseases psychosocial interventions are proved to decrease subjective distress and to improve the quality of life of the patients and to support the effectiveness of interventions indirectly.

Two research strategies were applied. The quantitative strategy was aimed to provide generalizability, therefore three questionnaires were carried out. Qualitative strategy was chosen in order to obtain authentic reports of women with PCOS.

First study: Examination of certain psychological variables associated with PCOS

Frequency and severity of depression, anxiety and eating disorders were examined among women with PCOS compared to a healthy control group. In addition women with PCOS suffering from heterogeneous symptoms were characterized on the basis of their phenotypes. Special attention was paid to the identification of the psychological variable(s) that reliably predict(s) the mental state of PCOS women in advance. Finally the connection between PCOS symptoms influencing attractiveness and body dissatisfaction was studied.

The introduction of methods applied during the pilot study

In the cross-sectional questionnaire study two groups were found: the PCOS group and the healthy control group. 134 were participated in the first questionnaire-based study: 69 patients in the PCOS group, and 65 in the control group.

Self-administered questionnaires were completed by the individuals. Two types of test battery were used: the PCOS and the Control questionnaires. The first part of the questionnaires included questions referring to demographic and anthropometric data: the second part of it were mapped the symptoms of PCOS which focused on the differential diagnosis. The third part of the questionnaires contained the measurements the psychological variables. The second and the third set of questions were as follows. Two symptom lists were applied in the second part of questions. The first one focused on the symptoms necessary for the diagnosis of the PCOS (period, the morphology of the ovaries, hyperandrogenism) and other symptoms of PCOS. Other endocrine disorders listed by Rotterdam 2003 criteria were excluded (second symptom list). The third part of the questionnaires included the following psychological measurements: Beck Depression Inventory (BDI) (Perczel Forintos, Kiss & Ajtay, 2005), Spielberger's State-Trait Anxiety Inventory (STAI) (Sipos, Sipos & Spielberger, 1988), and the Eating Disorder Inventory (EDI) (Túry, Sáfrán, Wildmann & László, 1997).

The results of the pilot study

HYPOTHESIS 1

It is assumed that the members of the PCOS group achieve significantly higher scores in the indicators of depression, anxiety and eating disorders than the members of the control group.

Results: The more adverse mental state of the PCOS group compared to the control group was confirmed. The members of the PCOS group reported clinical depression, symptoms of anxiety and eating disorder more frequently than the control group. In addition to the prevalence of depression (41.76%) its severity is also significant: 24.63% suffer from moderate or severe depression, almost half of the PCOS group experience feeling of hopelessness and 21.6% of them had already have suicidal thought. 44.64% of women with PCOS struggle with anxiety above the average.

HYPOTHESIS 2

According to the expectations the members of the complete phenotype achieved significantly higher scores in the indicators of depression, anxiety and eating disorders than the members of the milder phenotype groups.

Results: It was confirmed that the (severe) complete phenotype is regarded as a risk group within the PCOS group in terms of depression and anxiety. The hypothesis was partially confirmed, as belonging to a phenotype in the incidence of eating disorder symptoms is not differentiated.

HYPOTHESIS 3

The expectation was that depression would be proved to be the most reliable predictor among the indicators of the psychological well-being.

Results: Statistical tests have confirmed the hypothesis. When the individual with PCOS suffers from at least moderate depression, the presence of symptoms of eating disorders can be justified.

HYPOTHESIS 4

Women with symptoms of hyperandrogenism have significantly greater body dissatisfaction than PCOS women with no symptoms.

Results: In connection with the two symptoms of hyperandrogenism (acne and hirsutism) a significantly higher degree of body dissatisfaction can be seen, thus the hypothesis has been confirmed.

HYPOTHESIS 5

Women with uncontrollable appetite (which reduce the feeling of the control over the own body) reported higher level of depression and anxiety than PCOS women without these symptoms.

Results: Our hypothesis was confirm, in addition the prevalence of symptoms of eating disorder is more common among them.

Second study: The prevalence of eating disorders and the appearance of body image disorder among women with PCOS

The second research has two purposes. On one hand women with PCOS were studied to examine their attitude towards their own bodies, their self-esteem and the presence of abnormal eating attitudes. Two other groups were involved into the study: a control group consisting of healthy women and a group containing women only with hyperandrogen symptoms (HA group). The effects of the triple basal therapy of PCOS on the above mentioned psychological variables was particularly studied. The other aim of the study was the description of the prevalence of the clinical and subclinical eating disorders within the PCOS group.

Introduction of methods applied during the second study

A cross-sectional questionnaire study was conducted. The Rotterdam criteria for PCOS were used to recognized individuals with PCOS symptoms: markers of hyperandrogenism were studied with the following methods: Ferriman-Gallwey Score was used for measuring hirsutism (Ferriman & Gallwey, 1961), the individuals were asked if they had the symptoms of acanthosis nigricans, Global Acne Grading Score (GAGS) was used for measuring acne

vulgaris (Adityan, Kumari, & Thappa, 2009), and the Savin Scale (Dinh & Sinclair, 2006) measured androgen alopecia. Patients were asked about the regularity of their period and the symptom of polycystic ovary: whether cyst in their ovaries had been found by transvaginal ultrasound examination or not.

The following measurements were used to screen for eating disorders and to measure body image: body weight (kg) and height (cm) for the purpose of calculating the BMI. The measurement for eating disorders was the Eating Attitudes Test (EAT) (Túry, Szabó & Szendrey, 1990), eating disorders were measured by Eating Behaviour Severity Scale (EBSS) (Túry, 2000) and the Rosenberg Self-Esteem Scale (RSES) were used to evaluate self-esteem (Sallay, Martos, Földvári, Szabó & Itzés, 2014). The individuals were asked about the triple basal therapy. 318 individuals filled in the questionnaires, 95 individuals belonged to the PCOS group, 123 to the Hyperandrogen (HA) group and 100 persons to the healthy control group.

The results of the second study

HYPOTHESIS 1

The PCOS group has significantly lower degree of self-evaluation, more negative body image and worse eating disorders's attitude than the healthy control group.

Results: The results confirmed the hypothesis, women with PCOS can be characterized by lower degree of self-esteem, a more negative body image and worse eating attitude than healthy women.

HYPOTHESIS 2

A significantly more negative body attitude is expected in the PCOS and HA groups than in the healthy control group, while no significant difference can be shown between the PCOS and the HA groups.

Results: The results only partially corresponded to the expectations if the variable of weight was controlled in a way that only non-obese women with PCOS were left in the sample in order to test the hypothesis. However, the members of the HA group reported about the body attitude similarly to the control group. Thus it can be said that the HA group is located between

the healthy control group and the PCOS group regarding the body attitude. A further result shows that those who suffer from PCOS can be characterized by lower degree of self-esteem, a more negative body image and higher level of eating disorder than healthy women. Overweight PCOS patients view their bodies in a more negative way, and are more dissatisfied with their bodies than the non-obese women. In addition they have much more frequent compulsion to binge eat.

HYPOTHESIS 3

The PCOS group has significantly lower self-esteem than the HA group.

Results: The members of the PCOS group see themselves more negatively than the members of the HA group, regardless if obese PCOS are also included in the study.

HYPOTHESIS 4

Women with PCOS who follow the triple basal therapy have significantly higher self-evaluation, more positive body image and less eating disorders than those who do not follow the triple basal therapy everyday life.

Results: Following the triple basal therapy alone does not influence the attitude to the own body, the eating attitudes or the self-evaluation in a positive way. On this basis, however, we cannot say that changes in the lifestyle would be useless to prevent and to treat eating disorders. While analyzing each elements of the triple basal therapy it could be seen that although medication has no significant impact on the examined variables, however, women with PCOS who do exercises regularly evaluate their body size less negatively, thus their subjective body experience is more favourable. Less frequency of binge eating is a tendency among women who do exercises regularly. Individuals who keep PCOS diet, however, develop a more favourable situation for themselves regarding the assessment of the body size, the indicators of the global body attitude and the frequency of binge eating than patients who are not on this diet.

HYPOTHESIS 5

Women with PCOS who have body weight and body image symptoms have worse indicators in each psychological variables than women without symptoms.

Results: A higher degree of BMI correlated with a more negative self-evaluation, a more negative body image and higher level of pathological eating attitudes. With the exception of the pathological eating attitude WHR was related to each psychological variables. A more detailed result was obtained with the fact that weight discrepancy showed the strongest relationship with the examined psychological variables. In addition to the actual weight the difference between the actual and the desired weight (this is weight discrepancy) is a prominent variable in terms of eating disorders.

HYPOTHESIS 6

Individuals with HA symptoms can be characterized with lower self-esteem and lower body satisfaction than women without HA symptoms.

Results: The assumptions were only partially confirmed. HA symptoms were not associated with self-esteem. Higher level of distress related to the own body should be expected when the patient has symptoms of acne. Among PCOS patients with androgen alopecia the symptoms of eating disorder behaviour are more frequent. Specially binge eating and using diuretics can be associated with the symptoms of male-type hair loss.

THE PREVALENCE OF CLINICAL AND SUBCLINICAL EATING DISORDERS WITHIN THE PCOS GROUP

It was confirmed that women with PCOS are regarded as a risk group in terms of eating disorders: Clinical level bulimia nervosa (BN) can be detected for 5.3%, subclinical anorexia nervosa can be observed in 1.1% and subclinical BN can be found in 10.5%. In the HA group 1.6% subclinical BN prevalence was measured.

Third survey: The assessment of suicide vulnerability of women with PCOS and its analyse from a psychological aspect in relation with women living with endometriosis and unexplained infertility

The goal was to compare the emotional state of PCOS women with a control group which members live with a chronic disease affecting the reproductive system. That was the reason why a patient group suffering from endometriosis was chosen. The endometriosis also significantly affect the quality of life. The mental state of the two groups was compared. The second aim was to survey the suicide vulnerability which presumably affected the PCOS group on the basis of the preliminary examination. The third aim was to reveal how much age and infertility influence the infertile PCOS women's depression and anxiety indicators.

Introduction of the methods applied during the third study

A cross sectional study was conducted within the frames of TÁMOP-4.2.2/B-10/1-2010-0024 project with valid ethical permission in the Department of Obstetrics and Gynecology of the University of Debrecen. Individuals were selected from the patients of the Infertility Center between January 2012 and January 2013.

The test battery had three parts: the first part of the questionnaire included questions referring to demographic and anthropometric data. Data related to age, regularity of menstrual cycle and PCO morphology and the diagnosis confirmed by transvaginal ultrasound provided by obstetrics and gynecology specialists. The second part of the questionnaire mapped the symptoms of PCOS using the method as before (see second survey).

The third part of the questionnaire included the following psychological measurements: the shortened version of Beck Depression Inventory, which contained 9 items (Rózsa, Szádóczy & Füredi, 2001) was used to measure depression. Anxiety was measured by the Spielberger's State-Trait Anxiety Inventory (see pilot study). Hopelessness was measured by Beck Hopelessness Scale (Perczel Forintos, Kiss & Ajtay, 2005; Perczel Forintos, Sallai, & Rózsa, 2001).

Individuals with the diagnosis issued by the specialists of the certain disease could get into the survey groups. Women with the diagnosis of other endocrinological and gynecological diseases or pregnant women were not included to the study. 148 individuals completed the third questionnaire, 35 persons were in the PCOS group, 69 persons belonged to Endometriosis group, while the Unexplained infertility group contained 45 individual.

The results of the third study

HYPOTHESIS 1

The PCOS group and the Endometriosis group does not show significant difference in terms of depression.

Results: The results confirmed the hypothesis. As a result women with endometriosis, similarly to women with PCOS were identified as a risk group for depression.

HYPOTHESIS 2

It is assumed that the PCOS group had significantly higher degree of anxiety, than the Endometriosis group.

Results: According to the expectations individuals with PCOS report higher degree of anxiety, than women living with endometriosis. Masculinizing symptoms typical to the disease may be in its background. The results also suggest that the anxiety of women without children is stronger than the anxiety of women with children and in addition women who try to be pregnant for less than 12 months perceive a greater degree of anxiety than women who try to get pregnant for more than 12 months.

HYPOTHESIS 3

It is assumed that the two groups suffering from chronic diseases based on the diagnosis of specialists (PCOS and Endometriosis) have higher degree of depression than the Unexplained infertility group.

Results: The PCOS group, compared to the control group, shows higher degree of depressive symptoms, however, this connection has not been confirmed for the Endometriosis group.

HYPOTHESIS 4

It is assumed that PCOS women affected by infertility, who cross the threshold of the real and symbolic age of 35 suffer from significantly higher level of depression, anxiety and hopelessness than younger women.

Results: The hypothesis was partly confirmed. According to the results the age of 35 seems to be a turning point in terms of mental well-being of women with PCOS. For women older than

35 it meant higher level of depression and a more hopeless future image, however, it did not show connection with the level of anxiety.

HYPOTHESIS 5

It is assumed that for women with PCOS the longer the time spent with unwanted childlessness the higher the level of depression, anxiety and hopelessness.

Results: The assumption has not been confirmed. On tendency level, however, it can be seen that PCOS women waiting for having children show higher level of anxiety during the first period of trying to get pregnant (<12 months), which might affect the success of fertilization negatively.

THE RESULTS OF THE SURVEY OF THE SUICIDE VULNERABILITY

Although a similar level was measured in the PCOS and the Endometriosis groups, suicide vulnerability was higher in the PCOS group. Suicide risk is the highest among them (14.28%), compared to women suffering from endometriosis (7.24%) and to women with unexplained infertility (2.22%). According to Månssons'(2008) (2%) and by Hart and Doherty (2014) (2.9%) results healthy control groups show similar rates of suicide risk to women with unexplained infertility. The survey has confirmed that signs referring to suicide vulnerability can be identified seven times more than for the healthy control group or for women with unexplained infertility.

Fourth study: Revealing factors in connection with depressive symptoms of PCOS women through individual depth interview method

The aim of the fourth study was to map the background of depression detected in the questionnaire surveys. The aim was to reveal which PCOS symptoms could be in connection with depression.

Introduction of methods applied during the fourth study

The depth interviews were taken in Budapest and Debrecen between 30th June 2012 and 30th July 2012. Individuals were recruited through the mailing list of the Mens Mentis Health Center's webpage and through the online surface of the Hajdú-bihari Napló. The implementation of the study was a part of the TÁMOP-4.2.2/B-10/1-2010-0024 project. Only

those individuals were selected to the research who had PCOS diagnosis. Interviews were made in the Andras Peto College and in the Institute of Psychology of the University of Debrecen and 5 interviews were analysed.

In the study we also used a questionnaire. The first part of questionnaire referred to demographic and anthropometric data and the second part of questionnaire included measurements that were necessary for mapping the symptoms of PCOS (see the second study). The interview was a semi-structured thematic qualitative interview (Kvale, 2005).

The interview went through a content analyse by two independent encoders. The consistency of the categories was checked by the Cohen's Kappa statistical test.

The results of the fourth study

Based on previous studies the assumption was that certain PCOS symptoms are accompanied with higher depression. The expectation is that depressive symptoms appear in connection with obesity and with the lack of control over the own body.

Results

Assumptions were confirmed: 20.74% of all the depressive symptoms connect to body weight, while 20.46% connect to childbearing. The lack of control over body function (8.55%), dissatisfaction with the medical staff (16.42%) and atypical body function (10.66%) are also in the background of depression. The most frequent depressive symptoms of women with PCOS are dissatisfaction (49.56%), feeling of failure (17.86%) and negative body image (7.49%).

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Neptun ID: OR3UQG
Doctoral School: Doctoral School of Human Sciences
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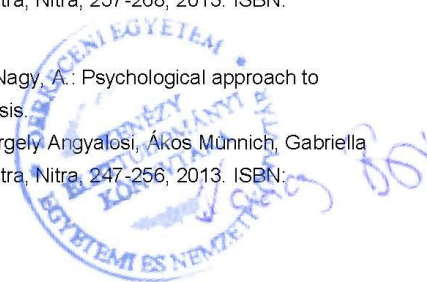
List of publications related to the dissertation

Hungarian book chapters (2)

1. Almássy, Z., **Mohácsi, B.**, Szemán-Nagy, A.: Gyermekvállalás és mentális egészség a férfiak szemszögéből.
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2. **Mohácsi, B.**: Policisztás ovárium szindróma (PCOS): Egy multikauzális betegség interdiszciplináris perspektívából. A nőiességen esett csorba: PCOS. A policisztás ovárium szindróma pszichológiai aspektusainak vizsgálata.
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4. **Mohácsi, B.**, Almássy, Z., Sápy, T., Farkas, Á., Szemán-Nagy, A.: Psychological approach to Polycystic Ovary Syndrome (PCOS) and endometriosis.
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5. **Mohácsi, B.**, Szemán-Nagy, A.: Evészavarok prevalenciája policisztás ovárium szindrómás nők körében.
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List of other publications

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8. **Mohácsi, B.**: A nőiességen esett csorba: PCOS: A policisztás ovárium szindróma pszichológiai aspektusainak vizsgálata.
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