

Bianka Lewandowska¹
University of Wrocław

Selected conditions for endometrial acceptance and preferred forms of psychological assistance

Abstract:

A study of 41 patients was conducted in order to provide an empirical basis for cooperation between a psychologist and a support group of patients with endometriosis. Our aim was to identify psychological variables which have a connection with the disease's acceptance. The patients' ages and duration of their illness were taken into account. We demonstrated that there is a positive relationship in accepting the illness through: perceived control and the ability to reduce pain, a declared ability to cope, a sense of harmony with one's body, and disclosure of negative emotions - mostly anger and sadness. A significantly negative association was shown for: the disease's duration, coping style with stress concentrating on the emotions, alienation from the body, and "catastrophizing". Preference for the form of psychological support was also studied. Most preferred were: physician communication training, and individual consultations with a psychologist.

Keywords:

endometriosis, acceptance of the disease, chronic illness, coping, body experience

Streszczenie:

W celu dostarczenia empirycznych podstaw dla programu współpracy psychologa z grupą wsparcia chorych z endometriozą przeprowadzono badanie z udziałem 41 pacjentek. Celem było zidentyfikowanie zmiennych psychologicznych wykazujących związek z poziomem akceptacji tej choroby. Uwzględniono wiek pacjentek i czas trwania choroby. Istotnie pozytywny związek z akceptacją choroby wykazano dla: postrzeganej kontroli i zdolności zmniejszania bólu, deklarowania zdolności do poradzenia sobie, ujawniania emocji negatywnych, w tym głównie gniewu i smutku oraz dla poczucia harmonii z własnym ciałem. Istotnie negatywny związek wykazano dla czasu trwania choroby, stylu radzenia sobie ze stresem skoncentrowanego na emocjach, alienacji wobec ciała i katastrofizowania. Badano także preferencję form wsparcia psychologicznego. Najwyżej preferowanymi okazały się: trening komunikacji z lekarzem i konsultacje indywidualne z psychologiem.

Słowa kluczowe:

endometrioza, akceptacja choroby, chroniczna choroba, radzenie sobie z chorobą

¹ Bianka Lewandowska, Institute of Psychology, Faculty of Pedagogical and Historical Sciences, University of Wrocław, ul. Dawida 1, 50-527 Wrocław, Poland; b.lewandowska@psychologia.uni.wroc.pl.

Introduction

A program was designed from the review of literature and our research results for cooperating with a currently created patient group diagnosed with endometriosis. Constructing a program for the cooperation of a psychologist with the patient group, required recognizing a specific need for psychological training and education. The purpose of assistance is to raise the level of disease acceptance, for this variable is considered an important predictor for adapting to chronic illness (Juczyński, 2001, p. 171). The study measured these variables, which maybe the subject of psychological training, and searched for an answer to the question whether they are, and to what extent, related to the acceptance level. We also studied preferences for various forms of psychological support.

Endometriosis as a chronic disease and a source of psychological problems

Endometriosis is a serious women's disease of a chronic and progressive character with numerous consequences for affecting the quality of a patient's life. Its direct cause is the occurrence of endometrial tissue outside the uterine cavity in such parts of the body as the ovaries, fallopian tubes, vagina, bladder, colon, and even respiratory system. The "misplaced" tissues react to hormonal signals associated with the menstrual cycle, resulting in peeling and bleeding in those areas from which blood cannot be drained and, consequently, the formation of adhesions and cysts. It is clear from patients' stories that the disease often goes unrecognized for a long period (Denny, 2004), and therefore is not treated - because the accompanying abdominal pain and bleeding are often interpreted as very severe symptoms associated with the last days of the menstrual cycle - and treated as an aspect "of a woman's fate" by patients themselves, their immediate surroundings, and even doctors. Endometriosis currently affects more than 10-20% of women in the reproductive age (Szpak et al., 2009), although it can occur earlier or later and accompany both menstrual cycles menopause. The etiology of this disease is complex and not fully understood. It is known that it develops on a hormonal and immunological basis - it is passed on to people who are particularly sensitivity to sex hormones, but inadequate immunological surveillance can also support the illness. The main symptom is pain (often described as intense, overwhelming or dull, accompanied by contractions) which in some forms of endometriosis accompanies not only menstruation, but also ovulation or almost the entire monthly cycle (Huntington et al., 2005). The pain often accompanies intercourse (dyspareunia), urination and bowel movements, and may take the form of severe back pain (Denny, 2009). This situation often involves administering very strong painkillers, hinders work or social functioning, and influences intimate

relationships. Other symptoms include heavy and abnormal bleeding, chronic fatigue, persistent diarrhea or constipation. However, this is only the first level of suffering. The next step is the stress and uncertainty associated with difficulties in the diagnosis and localization of all sources of endometriosis - it is not only connected with the gynecologists' lack of preparation for diagnosis and treatment (Shuang-zheng et al., 2012; Hirsch, 2001), but also the invasive nature of some tests, such as use of laparoscopy. As stated by Mastro - despite its seriousness and numerous consequences, endometriosis is described by patients as "the avoidable (by medicine) disease" (by: Denny, 2004). It is common for a doctor, not having the appropriate level of knowledge about the disease, to fail to recognize its severity and to treat the intensity of experienced pain as a patient's over-sensitivity to signs of feminine physiology.

The next stage of difficulties are the consequences of medical treatment. Surgical treatment, based on cutting cysts and adhesions, has limited effectiveness - 40-50% of patients develop a recurrence. Effective hormonal therapies enjoy increasingly more recognition - but their side effects in many cases resemble sharpened menopausal symptoms: weight gain, nausea, vomiting, headache, loss of libido, hot flashes and sleep disturbances (Bergquist et al., 2001). Finally, other aspects of the disease are reproductive system abnormalities - in many cases making it difficult to become pregnant and contributing to a high rate (over 60%) of infertility (Siedentopf et al., 2008). Reported problems associated with intercourse, and the consequences of hormone therapy may enhance these difficulties, because - as has been shown in studies (Szpak et al., op.cit.) - they have a negative impact on a patient's sexual activity. This may in turn reduce the quality of partnerships and as a result limit support from the loved one.

To sum up - potential psychological problems include: difficulty and delay (average being several years) in obtaining a diagnosis, overpowering and chronic pain, limiting professional and social contacts, and creating dyspareunia and reproductive problems - which sometimes strengthen the relationship, but in many cases lead to its dissolution (Denny, 2007; Fernandez et al., 2006; Harrison, 2005). Other factors include: uncertainty about a treatment's effectiveness and a laborious search for an effective form, a need for the acceptance of the disease's chronic mode, and concerns about the future related to its progressive nature. This situation risks reducing life's quality and indicates a need for supplementing further medical treatment with properly selected psychological support.

The psychological problems of patients suffering from endometriosis – research overview

So far, the disease and its treatment, as they reflect on the patients' quality of life and mental health, were based on both qualitative and quantitative methods and the quantitative measurement of variables. The results, however, are difficult to generalize because the variables and methods used were so various, as were the number of treatment groups and the differences in the populations' cultural contexts. The Polish studies (Łuczak - Wawrzyński et al., 2007), conducted in a group of 30 diagnosed and hospitalized patients, demonstrated a high acceptance level and perceived satisfaction with life, and a relatively low disorder intensity. This is a result contrary to a number of comparable international studies carried out with numerically larger groups; they revealed on average a low level of perceived life quality and showed a significant association with the physical limitations and negative emotions (Shuang-zheng et al., op. cit., Kumar et al., 2010; De Sepulcri et al., 2009; Petta, 2004). The study also showed severe symptoms of depression and anxiety in the majority of respondents and revealed that the patient's mental health correlated positively with the intensity of current pain and a woman's young age, and that the perceived quality of life was inversely proportional to the treatment's length (De Sepulcri et al., op. cit.). Many studies showed a high or medium level of perceived emotional stress: irritability, tension, anxiety and sadness, mood swings, depression and dysthymia (Szapak et al., op. cit.; Kumar et al., op. cit.; Hawkins et al., 2003).

Forms of psychological support for women suffering from endometriosis

In Polish health service literature, there are no psychological support programs for patients with endometriosis. The psychological support described in foreign literature, offered to those patients, is aimed at modifying factors significant for the disease's development and for the process of dealing with it. Patients' experiences show the effectiveness of training in coping with stress and strong negative emotions (Zhao et al., 2012; Wright et al., 2003), with such training increasing the effectiveness to deal with pain (Hawkins et al., op. cit.), exercising self-performed, simple medical procedures, communicating with health services, and using a variety of healthy behaviors to enhance the overall psychophysical condition (Falconer, 2005; Wang, 2004). Psychological support is primarily based on group or individual impacts found in cognitive-behavioral and humanistic-existential models, in educating and supporting changing habits, and in using a wide range of relaxing and imaginative techniques (Zhao et al., op. cit.; Fernandez et al., op. cit.).

More widely used somatic supports for the patients are interventions aimed at deepening the experience of their own corporeality (Seidler et al., 2004; Corbin, 2003; Charmaz,

1995). Experiencing the body - mainly its awareness and acceptance levels- is considered to be a relatively stable aspect of personality, yet to some extent is correctable psychologically - such as selected psychotherapeutic and group training forms that use the so-called "Techniques of the body" (Aspenson, 2010; Gyllensten et al., 2010). Corporeality, one such aspect, usually remains "in the shadows" where it works relatively well, but when beginning to be highlighted and negatively perceived it hinders normal functioning. In cases of both healthy and ill patients, experiencing one's body varies individually - its continuum extends from one's own sense of self and one's sense of psychosomatic competence ("understanding" of body's needs and their adequate recognition) to a sense of bodily alienation, to a confusion in its needs, responses and sensations (Charmaz, op. cit.). Many studies indicate a relationship between one's own flesh experience and adapting to chronic disease (Emad, 2006; Plach et al., 2004; Christensen et al., 1996). The person accepting the physical nature, and sensitive to the needs and signals of the body, is better able to cope with endometriosis at its different stages. The result not only more quickly diagnoses the first symptoms and enables one to search sooner for medical help, but also creates an acceptance level of one's body so stable and well-established that it will not be degraded by the disease and will provide a high level of self-care. On the other hand, people with a low sense of bodily harmony, may have a problem with the diagnosis. Its symptoms can be wrongly interpreted and as a result, they no longer are able to cope with the stress and uncertainty created by their problem. Poor bodily acceptance may also hinder perceiving the somatic disease as a part of one's own destiny, create defensive reactions such as displacement, problem denial, and unrealistic treatment expectations, - thus making it difficult for effective adaptation. Bode, van der Heij, Taal and van de Laar developed a tool for quantitatively measuring bodily experience (Bode et al., 2010). Their study showed that the degree of body-self split is the most important predictor of self-esteem for patients with chronic rheumatic diseases.

Particular sources of information and emotional support for patients with endometriosis are online forums and blogs dedicated to this disease, allowing for the exchange of experiences; they are also places to express feelings and describe experiences with persons, and their relatives, who share the same fate (Neal et al., 2011; Emad, op. cit.). Such support is also available in Poland. Analysing patient comments posted on the Internet concerning life problems and the need to share them - also during real, non-virtual meetings, inspired the concept to create a support group for patients, within which it would be possible to conduct psychological counseling and education.

Introduction to research: examined variables

Studies show (Juczyński, op. cit., p.172) that the level of adaptation to chronic illness (whose indicator can be its acceptance level) predicts significantly one's perceived quality of life, relatively independent from the severity of medical ailments. Juczyński's study aimed to verify the relationship between selected psychological variables that are possible for a psychologist to modify and the acceptance level of endometriosis.

The first independent variable was the person's style for coping with stress. Both daily life and the disease itself can mobilize physiological stress response mechanisms. Such a reaction, in particular its long-term form, suppresses the immune system so that it is potentially disadvantageous for relieving pain and inhibiting the development of endometriosis. Strategies for coping with stress are generally divided into those focused on solving a problem and improving the emotional state, and others that distract the patient from the stress source. Fully effective coping would require the appropriate use of all these strategies. However, as research shows (Strelau et al., 2005), strategies for coping with stress have a tendency to strengthen in a style characteristic for a person, which to some extent depends on temperamental factors, thus limiting one's coping ability - the stronger the stress, the more rigid the style. Individual coping styles may, however, be highlighted and expanded in the direction of greater flexibility and relevance, in the course of psychological training. The first aim of our study was to answer the question whether there is an association between a particular style for coping with stress and the level for accepting endometriosis. The second factor are the strategies, with their perceived effectiveness, for coping with pain.. People struggling with strong pain every day in many ways try to reduce the intensity of its perception. These methods may be more or less effective for pain associated with endometriosis. The next factor was to determine whether such strategies for dealing with the pain can be identified. Our research showed that endometriosis is a complaint that generates strong negative emotions. These emotions require awareness and appropriate expression; they should not be displaced and their over-expression suppressed. As Pennebaker's study indicates (Pennebaker et al., 2007), understanding and managing negative emotions and their expression are significant factors for somatic disease. Another factor controlled in our study was, therefore, the typical level for expressing these three negative emotions: anger, sadness and fear. Another aim was to answer the question whether the level of suppressed emotions is associated with the acceptance of endometriosis.

Experiencing the patient's own body is treated here as a potentially important variable and one of the more significant illness adjustment predictors. Experiencing one's own bodily unity is highly threatened by such factors as severe and recurrent pain, bothersome medical treatments, discomfort and functioning limitations, or problems with

sexuality and fertility. Hence, it can be assumed that experiencing one's own flesh may be related to endometriosis's acceptance level and as a result the quality of life level. There is one more condition to verify the connection between bodily perception and the quality of the living experience. According to research, an important predictor of disease development is low body weight (Nagle et al., 2009), and one factor supporting treatment is to keep to an antioxidant diet (Mier-Cabrera et al., 2009) and undergo moderate physical exercise (Petta, op. cit.). This study, therefore, verifies the relationship between bodily unity as perceived by the sick person and one's acceptance level of endometriosis. The aim was to answer the question whether the level of alienation from the body and harmony with the body is related to having accepted endometriosis.

Another area of investigation (in connection with the designed support program) were the the patients' preferences- as declared by themselves- or their readiness to benefit from proposed counseling and psycho-education. The subjects were presented with a list of interventions considered adequate to the above-mentioned problems generated by the disease.

Participants and procedure

The study included 41 patients diagnosed with endometriosis. These were women who had responded to an advertisement posted on the online forum for patients (www.endoendo.pl) and then were subjected to questionnaire-examination during direct meetings. This selection method does not allow for generalized research results to the overall patient population; however, it is accepted for the purpose of research, which is to design a program of psychological support. Recruiting a group covered by this program can in fact be done in a manner similar to the procedure used for a study selection. In addition to psychological variables, such variables as potential predictive value for disease acceptance, the person's age (range: 22 – 52, M=34.4), and disease duration (since the time it was diagnosed) were included (range: 1 – 18, M=4.07). Having the disease for at least one year with no psychiatric diagnoses was adopted as a necessary condition for participation in the study. Conscious consent of the patient was adopted.

Measures

Acceptance of Illness

The acceptance level of chronic illness was measured using the AIS (Acceptance of Illness Scale), by Felton et al., as adapted by Zygfryd Juczyński (Juczyński, op. cit.). It is designed to study adult patients, currently ill. It contains eight statements describing the negative consequences of ill health, such as limitations imposed by the disease, lack of

self-sufficiency, dependence on others, and reduced self-esteem. The test determines one's status with a five-point scale. "A low score indicates no acceptance or adaptation to the disease, and strong psychological discomfort. In turn, a high score indicates acceptance" (Juczyński, op. cit., s.171). The scale is standardized according to Polish conditions involving different patient groups. It has been shown that the patients with chronic pain have the lowest acceptance level.

Style for coping with stress

For measuring coping with stress the Coping Inventory for Stressful Situations by Endler and Parker (CISS) was used, in the Polish version created by J. Strelau and colleagues (Strelau et al., op. cit.). Coping style is here understood as an individual's typical behavior under stress. The questionnaire consists of 48 statements usually concerning people's behavior. Subjects estimate, ranging from 1 to 5, how often their behavior is undertaken and obtains the result in three scales, which sequentially measure the intensity of three coping styles: Task-oriented coping, Emotion-oriented coping and Avoidance-oriented coping. Subjects can get into each scale score, ranging between 16 and 80 points. The scale "Task-oriented coping" refers to a stress style that takes efforts to solve the problem (cognitive transformation) or to attempt to change the situation (planning and undertaking tasks). "Emotion-oriented coping" refers to the tendency for people to focus on themselves, on their own emotional experiences, such as anger, guilt, or tension, as well as on wishful thinking or fantasizing, mainly to reduce tension associated with the stress. "Avoiding-oriented coping" refers to coping that involves refraining from thinking, experiencing and living the situation through various forms of distraction; it focuses on two major trends: Avoidant-social coping, and Avoidant-distracted coping - engaging in such replacement activities as watching television, overeating, or thinking about pleasant matters.

Strategies for coping with pain

Measuring the sick patients' strategies coping with pain was made using The Pain Coping Strategies Questionnaire (CSQ), by Rosenstiel and Keefe in the Polish adaptation by Juczyński (op. cit.). It consists of 42 statements describing commonly used ways to cope with pain, and two questions concerning the assessment level of control over the pain and skills to reduce it. Ways for coping with pain are represented by seven strategies: six cognitive and one behavioral, comprising three factors: cognitive coping ("reevaluation of pain sensations," "ignoring sensations" and "declaration of coping"), staying focused and taking replacement action ("distraction" and "increased behavioral activity") and searching for disaster or hope ("catastrophizing", "praying and deep hope"). The subject is asked to respond on a seven-point Likert-type scale. In each scale measuring coping strategies one can get from 0 to 36 points, and also from 0 to 6 points in the two positions

which measure “the control of pain” and the “possibility of lowering pain”. The questionnaire does not have norms - for interpreting the results, studies of several patient groups with chronic pain were used.

Control of negative emotions

To measure the degree to which negative emotions were controlled (attenuation versus disclosure), the Courtauld Emotional Control Scale by Watson and Greer, in its Polish adaptation by Z. Juczyński (op. cit.), was used. It consists of three subscales that measure the disclosure/attenuation level by testing three basic emotions: anger, depression (intensified sorrow) and anxiety. Each subscale has seven self-describing statements; the test person specifies the frequency of the way she uses to control emotions ranging from 1 to 4. The higher the result is, the stronger the given emotional reactions are controlled by the subject. On the basis of points awarded to all claims one can also calculate the overall rate of emotional control, meaning the individual’s belief about their ability to control negative emotions.

Body-self unity

The level for experiencing bodily unity was tested with the questionnaire BEQ (Body Experience Questionnaire) by Bode and colleagues, used to measure the experienced unity of self and body, which consists of two separate, fixed sensations: harmony with the body and alienation between self and body (Bode, op. cit.). The questionnaire was designed for the the chronically ill and has not been standardized for Polish conditions. We obtained approval for its use in this study. The standard back-translation procedure was performed. “Experienced unity of body and Self” is understood here as sensing harmony with the body or sensing alienation between Self and body. The original questionnaire was based on qualitative research analysis on the sensed unity / separation from one’s body by the sick. As a result of the pilot studies and factor analysis, 10 claims were selected which in turn form two separate subscales: “Alienation” (6 items) and “Harmony” (4 items). The subject expresses statement compliance with their own feelings, giving themselves points in the range from 1 to 4. The higher the result obtained in the alienation subscale (6-24), the stronger the sensed separation between body and Self (body-self split). The harmony subscale score (4-16) is stronger whenever the the degree of perceived of body–Self unity is higher.

Preferences of patients: their readiness to use the proposed psychological support forms

The tool to study patient preferences was a survey, including the question “To what extent would you like to use the following psychological support forms? In your response, please use the following scale: 5 - definitely yes, 4 - rather, 3 - I do not know, 2 - probably not, 1 - definitely not” and adhere to the list of proposed forms of support. The list

was based on the disease's adaptation predictors and on pilot study results in which sufferers were asked about their opinion concerning useful assistance forms. The list included the following forms of psychological support: 1) training for coping with stress, 2) training for managing negative emotions - such as anger, fear, sadness, 3) training for pain coping 4) workshops for developing body acceptance and awareness, 5) training for patient communication with a doctor, 6) training for communication in close relationships 7) a workshop to support introducing and consolidating a healthy lifestyle (change in eating habits and physical activity levels, implementing medical prescriptions), 8) taking part in a support group for people with endometriosis, 9) individual consultations with a psychologist.

Results

Mean variable scores in the study group and their relationship to illness acceptance

Table 1. Mean values (M), standard deviation (SD) of the variables and Pearson's linear correlation coefficients (r) for each variable, versus Acceptance of the illness (AI).

Name of variable (N=41)	M	SD	r (correlation with AI)
Acceptance of illness	19.9	7.1	-
Period of illness	5.9	4.08	-0.53**
Age	34.4	7.9	-0.17
Styles of coping with stress			
Style focused on the task	57.2	10.4	0.30
Style focused on emotions	43.1	10.9	-0.51*
Style focused on avoidance	44.3	10.7	0.13
Searching for social contact	17.2	6.1	0.25
Engaging in replacement activities	18.2	5.5	-0.03
Strategies for coping with pain			
Reevaluation of the pain sensation	9.0	5.0	0.05
Ignoring sensations	10.9	5.1	0.1
Declaration of coping	17.8	6.2	0.56**
Distraction	19.0	7.5	0.09
Increased behavioral activity	21.0	6.2	0.2
Catastrophizing	16.7	7.0	-0.39*
Praying and deep hope	15.4	7.5	0.04
Coping with pain			
Pain control	2.7	0.9	0.58**
Ability to decrease pain	2.3	0.7	0.48**

Name of variable (N=41)	M	SD	r (correlation with AI)
Control over negative emotions			
Anger control	16.8	5.3	-0.56**
Depression control	17.3	3.8	-0.37*
Fear control	16.8	4.6	-0.18
The overall rate of control over negative emotions	50.9	10.8	-0.51**
Sense of unity of body and Self			
Alienation	13.3	3.93	-0.54**
Harmony	11.7	2.84	0.31*

The coefficients significant for $p < 0.05$ marked with *, significant for $p < 0.01$ marked with **.

Table 1 presents mean variables obtained in the patient group, standard deviations, and the statistical results of the relationships between examined psychological variables, the respondents' ages, disease duration, and the levels at which the illness was accepted. The average level of acceptance equaled $M=19.9$ ($s=7.1$) - lower than in most patient groups of when compared only with patients experiencing chronic pain ($M=18.46$) (Juczyński, op. cit., p. 170). The frequency and proportions of the three stress coping styles and the average control rate of negative emotions in the study group do not differ from those trends found in the Polish normalizing studies (Strelau, op. cit.; Juczyński, op. cit.). Analogous to the general population, the task-oriented style prevails in endometriosis cases. The average anxiety control level is slightly lower than in the normalizing studies. Among the strategies for coping with pain in the study group are: increasing behavioral and distraction activity from painful experiences - similar to the study groups with back pain and neuralgia (Juczyński, op. cit., s.164), and the groups' declared methods for dealing with them (painful experiences) - as in the migraine study group (ibid.). However, feeling alienated from one's own body is higher, and the perceived level of bodily harmony is lower, than the one reported by Bode (op. cit.) in patients with chronic rheumatic diseases (although the cited results have been acquired in a much larger patient group).

The illness acceptance level in the group has a number of significant relationships with the examined independent variables. It correlates strongly with the control over the level of experienced pain and the perceived ability to decrease it. A cognitive strategy referred to - "declaration of coping" with pain, shows a significant, positive association with disease acceptance. On the other hand, a significant negative association was found for "catastrophizing". Another variable, showing a significant negative relationship with endometriosis acceptance is a coping style involving concentration on the experienced emotions. At the same time, the tendency to suppress negative emotions, and especially

the lack of expressed anger and - to a lesser extent - of sadness appear to be related to a low acceptance level of of the disease. And another variable, significantly negatively associated with acceptance, is a sense of alienation in relation to the body. Harmony with one's own organism shows a moderate positive relationship when the illness is accepted. The period of illness appears to be an important variable - and here ironically, but in correlation with the cited test results - the time does not work in the patients' favor. On the contrary - the longer they suffer from the illness, the lower its acceptance level becomes.

Psychological variables as acceptance level predictors for the disease

The predictive power of the tested variables for the disease's acceptance level was also analyzed. For this purpose a regression analysis was conducted – the dependent variable for disease acceptance was adopted; and for its predictors - examined psychological variables, participants' ages and duration of the disease. The model was significant at $F(21.19) = 3.99$, $p < 0.002$ and showed a high predictive power. Researched psychological variables explained 0.61 variance of the dependent variable ($R^2 = 0.61$). However, a significant impact on the disease's acceptance level has been demonstrated for only two variables: declared coping as the main strategy for controlling pain ($\beta=0.48$; $t = 2.52$; $p < 0.02$) and the overall rate of perceived control over pain ($\beta=0.35$; $t = 2.21$; $p < 0.04$). This indicates the importance of these variables for accepting the illness, however - the results of regression analysis may also affect existing moderate correlations between the independent variables.

Patients preferences for the proposed forms of psychological support

Table 2. Proposed forms of psychological support and indicators of patient preferences (PI).

Proposed form of psychological support	PI
Individual consultations with a psychologist	4.6
Training in communication between the patient and the doctor	4.6
Training in coping with pain	4.5
Training in coping with stress	4.2
Training in communication in close relations	4.2
Training in negative emotions management (anger, fear, sadness)	4.1
Support group for people diagnosed with endometriosis.	4.1
Workshops developing acceptance and awareness of the body	3.7
Workshop supporting an introduction to and preservation of a healthy lifestyle.	3.7

Table 2 presents the average preference values. Patients mostly prefer training in communication skills and individual consultations with a psychologist and, to a large extent, are also interested in training to cope with the pain. However, the weakest factors are the

readiness to work on bodily acceptance and awareness, and for using specialist support in changing lifestyles (to more healthy ones).

Discussion and guidelines for a psychological support program

The study allows for a better understanding of an endometrial patient's specific psychological problems, and provides the theoretical basis for planning psychological support, its directions and forms. The variable most critically related to the disease's acceptance level is "control over pain" - a factor that depends primarily on effective medical treatment, and psychological support - in the form of cognitive-behavioral training or relaxation. It has also been shown that the better the patients cope with the disease, the more likely they will convince themselves of the efficiency in this area. This probably indicates the importance for developing a sense of efficiency in dealing with ailments and discomfort, although this should be reviewed with a more specific measurement tool.

Tested dependencies show a significant tendency for coping with emotions in the process of accepting endometriosis. Acceptance is lower in patients who in situations of tension and congestion tend to analyze their emotional states; they think wishfully and fantasize in order to reduce their stress - because such behavior measures items that focus (in the used scale) on emotions. This shows the need for introducing rational strategies (psychological training to cope with stress) and for developing a task-oriented approach to problem solving and the ability to find distance from them - especially in away that seeks contact with other people (these styles showed a statistically non-significant but positive relationship in accepting the disease).

At the same time the study shows that a high level of disclosed negative emotions is important for accepting the illness - that of mainly expressing anger and sadness, whereas there was no material impact for the expression of fear. As shown above, the present works showed primarily depression and anxiety as the affective states characteristic for this disease. Yet the pain (especially strong and difficult to control), and experienced limitations can be a significant source of irritation, anger, and even a proneness toward aggression. It seems clear that patients with endometriosis, often experiencing misunderstandings about the seriousness of their condition, may feel irritated or angry. Anger, however, as opposed to anxiety, may be unacceptable in their environment as being inconsistent with the stereotypical image of femininity, and consequently gets suppressed. The inability to share anger and sadness with their environment - as well as all negative emotions having an overall low level of acceptance and awareness - can significantly impair an ill person and give rise to internal conflicts and generate additional

stress. Effective support in this area will be work that allows one to realize, accept and practice constructively negative emotions – especially anger and sadness.

And finally - our study has shown that there is a negative significance in accepting the disease when a patient feels alienated towards her own body, and a less meaningful but positive significance – when the patient feels in harmony with it. Based on analysis, it is difficult to determine if this low disease acceptance level gradually alienates a sick person from her body, or if “experiencing the body as an invaluable aspect of oneself, locking up one’s goals and aspirations” (Bode, op. cit., p. 672), does not help in accepting the life-changes caused by the disease and allowing one to accept herself in the role as the patient. In the studied group, the alienation level ($p = 0.33$, insignificant) correlates with the duration of the disease, but verifying this problem requires further study. It is clear, however, that support for a satisfactory level of confidence in one’s own body has a significant relationship with the patient’s better functioning. It shows there is a need for providing such group support, which develops mindfulness and attention to bodily needs and strengthens confidence in the body’s signals.

The demonstrated, strong tendency to reduce the disease’s acceptance level over the time of its duration gives a “grim face” to this illness, especially in context of available treatments. Endometriosis is a progressive disease. In fact, there is no effective therapy, the treatment is palliative - focused on inhibiting its growth and removing its symptoms. This allows the assumption that time spent in living with the disease - rich in discomforts, limitations and uncertainty about the future - destructively affects the sense of adapting to it. This strengthens the argument for the need for various forms of psychological support, initiated as soon as possible after diagnosis.

As can be deduced from patient preferences - a major problem experienced in this disease, in which patients expect counseling, is effective communication with doctors. This is understandable in relation to the difficulty in giving a precise diagnosis, and indicates another form of group work which is practical training in patient-doctor communication. The study group also showed a high level of readiness for individual work with a psychologist - it can indicate a high level of experienced pain or anxiety about their own mental health and requires an enriched work-plan program with possibilities for personal contact with a counselor. An interesting factor found in the group is a relatively low willingness to develop corporeality competences - both in health habits and corporeal awareness. This may be due to the cultural context - the holistic picture of the human person being relatively rare in Western culture - but also a reluctance to deal with the body by patients overwhelmed with negative physical well-being and medical procedures. Since the study has demonstrated how important it is to experience the body for a successful adaptation to endometriosis, the introduction of psychological support in

this area cannot be forsaken and must be linked to the participants' initial education and motivation.

References:

- Aspenson, D. O. (2010). Mind–body skills training groups. In St. Walfish (Ed.). *Earning a living outside of managed mental health care: 50 ways to expand your practice*. Washington: American Psychological Association, 171-174.
- Bode, Ch., van der Heij, A., Taal, E., van de Laar, M.A.F.J. (2010). Body self-unity and self-esteem in patients with rheumatic diseases. *Psychology, Health & Medicine*, (6), 672-684.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *The Sociological Quarterly*, (4), 657-680.
- Christensen, A. J., Wiebe, J. S., Edwards, D. L., Michels, J. D. Lawton, W. J. (1996). Body consciousness, illness-related impairment, and patient adherence in hemodialysis. *Journal of Consulting and Clinical Psychology*, (1), 147-152.
- Corbin, J.M. (2003). The body in health and illness. *Qualitative Health Research*, (2), 256-267.
- De Sepulcri, R., do Amaral, V.F. (2009). Depressive symptoms, anxiety and quality of life in women with pelvic endometriosis. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, (1), 53-56.
- Denny, E. (2009). "I Never Know From One Day to Another How I Will Feel": Pain and Uncertainty in Women With Endometriosis. *Qualitative Health Research*, (7), 985-995.
- Denny, E., Mann, C.H. (2007). Endometriosis-associated dyspareunia: the impact on women's lives. *The Journal of Family Planning and Reproductive Health Care*, (3), 189-193.
- Denny, E. (2004). Women's experience of endometriosis. *Journal of Advanced Nursing*, (6), 641-648.
- Emad, M. C. (2006). At WITSENDO. Communal embodiment through storytelling in women's experiences with endometriosis. *Women's Studies International Forum*, (2), 184-196.
- Falconer, S. (2005). Over the pain barrier, *Community Care*, (4), 22.

- Fernandez, I., Reid, C., Dziurawiec, S.(2006). Living with endometriosis: The perspective of male partners. *Journal of Psychosomatic Research*, (4), 433-438.
- Gyllensten, L. A., Miller, M., Gard G. (2010). Embodied identity–A deeper understanding of body awareness. *Physiotherapy Theory and Practice*, (7), 439-446.
- Harrison, V.(2005). Stress reactivity and family relationships in the developmental treatment of endometriosis. *Fertility and Sterility*, (83), 857-864.
- Hawkins, R. S., Hart, D. A.(2003). The Use of Thermal Biofeedback in the Treatment of Pain Associated With Endometriosis: *Preliminary Findings, Applied Psychophysiology and Biofeedback*,(4), 279-289.
- Hirsch, K.W., Lapido, O.A., Bhal, P.S., Shaw, R.W.(2001). The management of endometriosis: a survey of patients' aspirations. *Journal of Obstetrics and Gynecology*,(5), 500-503.
- Huntington, A., Gilmour, J.A. (2005). A life shaped by pain: women and endometriosis. *Journal of Clinical Nursing*, (14),1124-1132.
- Juczyński, Z. (2001). *Narzędzia pomiaru w promocji psychologii zdrowia* [Questionnaires using in health promotion and health psychology]. Warszawa: Pracownia Testów Psychologicznych PTP.
- Kumar, A., Gupta, V., Maurya, A. (2010). Mental health and quality of life of chronic pelvic pain and endometriosis patients. *Journal of Projective Psychology & Mental Health*, (2), 153-157.
- Łuczak–Wawrzyniak, J., Szczepańska, M., Skrzypczak, J. (2007). Ocena jakości życia kobiet z rozpoznaną endometriozą oraz sposobów radzenia sobie z negatywnymi skutkami choroby. *Przegląd Menopauzalny*, (6), 329–335.
- Mier-Cabrera, J., Aburto-Soto, T., Burrola-Méndez, S., Jiménez-Zamudio, L., Tolentino, M.C., Casanueva, E., Hernández-Guerrero, C. (2009). Women with endometriosis improved their peripheral antioxidant markers after the application of a high antioxidant diet. *Reproductive Biology and Endocrinology*, (7), 1-11.
- Nagle, C.M., Bell, T.A., Purdie, D.M., Treloar, S.A.; Olsen, C.M., Grover, S., Green, A.C. (2009). Relative weight at ages 10 and 16 years and risk of endometriosis: a case-control analysis. *Human Reproduction*, (6), 1501-1501.
- Neal, D.M., McKenzie, P.J. (2011). Putting the pieces together: endometriosis blogs, cognitive authority, and collaborative information behavior. *Journal of the Medical Library Association*, (2), 127-134.

- Pennebaker, J.W., Chung, C.K. (2007). Expressive writing, emotional upheavals, and health. In H. Friedman & R. Cohen Silver (Eds.). *Foundations of health psychology*. New York: Oxford University Press, 263-284.
- Petta, C.A. (2004). Quality of Life in Brazilian Women With Endometriosis Assessed Through a Medical Outcome Questionnaire. *The Journal of Reproductive Medicine*, (49), 115-120.
- Plach, S., Stevens, P., Moss, V. (2004). Corporeality: Women's Experiences of a Body With Rheumatoid Arthritis. *Clinical Nursing Research*,(2), 137-155.
- Seidler, K.P, Schreiber-Willnow, K. (2004). Concentrative movement therapy as body-oriented psychotherapy for inpatients with different body experience. *Psychotherapy Research*, (3), 378-387.
- Shuang-zheng, J., Jin-hua, L., Jing-hua, S., Peng-ran, S., Jing-he, L. (2012). Health-related quality of life in women with endometriosis: a systematic review. *Journal of Ovarian Research*, (1), 29-37.
- Siedentopf, F., Tariverdian, N.,Rücke, M., Kentenich, H., Arck, P. C. (2008). Immune Status, Psychosocial Distress and Reduced Quality of Life in Infertile Patients with Endometriosis. *American Journal of Reproductive Immunology*, (5), 449-461.
- Strelau, J., Jaworowska, A.,Wrześniewski, K., Szczepaniak, P. (2005). *Kwestionariusz radzenia sobie w sytuacjach stresowych*. [Coping Questionnaire for Stressful Situations]. Warszawa: Pracownia Testów Psychologicznych.
- Szpak, R., Bugała – Szpak, J., Drosdzol, A., Skrzypulec, V.(2009). Jakość życia u kobiet z endometriozą. *Wiadomości Lekarskie*, (2),129-134.
- Wang, Ch. Y. (2004). Coping with endometriosis, *Lancet*, (9447), 1800.
- Wright, C. C., Barlow, J. H., Turner, A. P., Bancroft, G. V. (2003). Self-management training for people with chronic disease: An exploratory study. *British Journal of Health Psychology*, (4), 465-476.
- Zhao, L.,Wu, H.,Zhou, X., Wang, Q., Zhu, W., Chen, J. (2012). Effects of progressive muscular relaxation training on anxiety, depression and quality of life of endometriosis patients under gonadotrophin-releasing hormone agonist therapy, *European Journal of Obstetrics & Gynecology & Reproductive Biology*, (2), 211-215.