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THESES OF THE DOCTORAL DISSERTATION

GABRIELLA MÁRKI

The health-psychological aspects of endometriosis

Doctoral School of Psychology
Head of the Doctoral School:
Prof. Dr. Zsolt Demetrovics, DSc, professor, Eötvös Loránd University

Personality and Health Psychology Program
Head of the Program: **Prof. Dr. Attila Oláh**, CSc, professor, Eötvös Loránd University

Supervisors
Dr. Adrien Pigniczkiné Rigó, PhD, habil. associate professor, Eötvös Loránd University
Dr. Attila Bokor, PhD, senior lecturer, Semmelweis University

Committee members:

President:	**Prof. Dr. Éva Bányai**, PhD, CSc, professor, Eötvös Loránd University
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	Dr. Edit Czeglédi, senior lecturer, Semmelweis University
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	Dr. Réka Brubel, assistant lecturer, Semmelweis University
	Dr. Zsuzsa Török, lecturer, University of Debrecen
	Dr. Péter Szeverényi, habil. associate professor, University of Debrecen

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1. INTRODUCTION

Endometriosis is a complex, chronic, benign, inflammatory and estrogen-dependent gynecologic disorder that affects every tenth woman of reproductive age worldwide. This gynecological disease is characterized by the presence of endometrium-like tissue outside the uterus and it is associated with chronic pelvic pain and infertility (Giudice & Kao, 2004). The early diagnosis of the disease is essential to prevent chronic pain symptoms to preserve the chances of better fertility (Brosens, Benagiano, & Brosens, 2017). Nonetheless from the onset of symptoms to the time of diagnosis, the diagnostic delay is 4-10 years (Ballard, Lowton, & Wright, 2006; Bokor et al., 2013; Hadfield, Mardon, Barlow, & Kennedy, 1996; Hudelist et al., 2012). The biomedical approach of endometriosis focuses mainly on the pathogenesis of the disease (Taylor, et al., 2012; Vercellini et al., 2014), on the examination of diagnostic and treatment options (Dunselman et al., 2014; Kennedy et al., 2005) which set a goal to improve the health quality of life in women living with endometriosis (Fritzer et al, 2012, 2014. Namely, according to the study of Simoens et al. (2012) quality of life was identified as the main predictor factor for health care costs.

Previous studies highlighted the central role of pain on quality of life (Giudice & Kao, 2004; Souza et al., 2011; Taylor et al., 2012). The presence of pain has a negative impact on the quality of sexual life, on relationship, and on daily routine and work quality (Fourquet et al., 2010; Jones, Jenkinson, & Kennedy, 2004), and mental health and emotional well-being can be negatively affected as well (Gao et al., 2006; Sepulcri & Do Amaral, 2009; Souza et al., 2011).

According to the literature, the women with endometriosis are characterized by increased psychological problems (depressive and anxiety symptoms), increased level of stress and lower coping (Eriksen et al., 2008; Kaatz et al., 2010; Lemaire, 2004; Roth, Punch, & Bachman, 2011; Sepulcri & Do Amaral, 2009). The presence of chronic pelvic pain or other comorbid pain syndrome has been identified in the background of impaired quality of life. Women with both chronic pelvic pain and endometriosis have higher level of depression and anxiety compared to healthy women (Lorençatto et al., 2006; Sepulcri & Do Amaral, 2009; Smorgick et al., 2013). In the last decade more complex and differentiated studies were highlighted that the presence or absence of pain plays a central role, as asymptomatic women reported a significantly lower degree of deterioration (Facchin et al., 2015). Studies showed the not only the presence or absence of pain symptoms make a difference, but the intensity of pain affects the women’s mood symptoms as well. A positive correlation between the level of mood change and the intensity of pain was detected (Sepulcri & do Amaral, 2009). The study results were supported by medical interventions, as patients have lower depressive symptoms after medical treatments (Van den Broeck et al., 2013; Vercellini et al., 2013).

Besides depressive and anxiety symptoms, the stress experienced by women with endometriosis is increasingly becoming in the focus of studies. Psychological stress has a negative impact on the neurohormonal system and correlates with health-related quality of life. As a result of the presence of pain symptoms, women diagnosed with endometriosis reported significantly higher level of health-related distress compared to women with chronic pelvic pain (without endometriosis) or healthy controls (Mathias et al., 1996; Petrelluzzi et al., 2008). There is a two-way process between pain and distress, leading to maladaptive processes in the neuroendocrine immune system (Tariverdian et al., 2007). The presence of a higher distress may aggravate the condition of the affected person and may hinder the improvement of the condition.

Women with endometriosis experienced a higher functional impairment in social and work-related functioning compared to other inexplicable painful illnesses that may extend to all areas of social and family life (see within relationships with family, friends, and children). The presence of chronic pelvic pain and the stage of illness have been identified as the underlying causes of social and workplace involvement (Gao et al., 2006; Jia, Leng, Shi, Sun, & Lang, 2012). Consequences include the lack of social support, loss of workplace in the case of intense pelvic pain, or incapacity to work, which may lead to uncertainty about the future. Uncertainty negatively correlates with depressive symptoms, (Choi & Jun, 2005), which impairs the daily functioning as well.

In addition to emotional and social well-being, there is an increasing focus on sexual functioning and partnering. The pain that occurs during sexual intercourse (dyspareunia) greatly leads to increased distress and decreased satisfaction of sexual life (Ferrero et al., 2005; Tripoli et al., 2011). Dyspareunia appears in nearly half of women with endometriosis, leads to a decrease in the frequency of sexual intercourse and changes the quality of the relationship. Furthermore, there is an increasing interest towards men living with women with endometriosis (Fernandez, Reid, & Dziurawiec, 2006), as they are indirectly affected, and they may also need supportive care.

Based on the results presented above, we have precise knowledge of the negative consequences of the disease, while the role of social support, emotional regulation in relation with quality of life in endometriosis has not been researched yet.

The physical and mental aspects of quality of life are positively influenced by the medication and surgical procedures used to treat the symptoms of endometriosis (Dunselman et al., 2014). The effectiveness of medical interventions is mainly researched in the improvement of sexual functioning, pain and mood symptoms, However, only a few feasibility and pilot studies are available on the effectiveness of psychosocial interventions. The effects of progressive muscle relaxation, psychotherapy and mindfulness-based methods have been shown to improve quality of life and reduce pain and mood symptoms (Hansen, Kesmodel, Kold, & Forman, 2016; Kold, Hansen, Vedsted-Hansen, & Forman, 2012; Meissner et al., 2016; Zhao et al., 2012).

2. OBJECTIVES

The objectives of this doctoral dissertation were to summarize the medical and health psychological literature of endometriosis in Hungarian language, followed by five studies (Figure 2.1.).

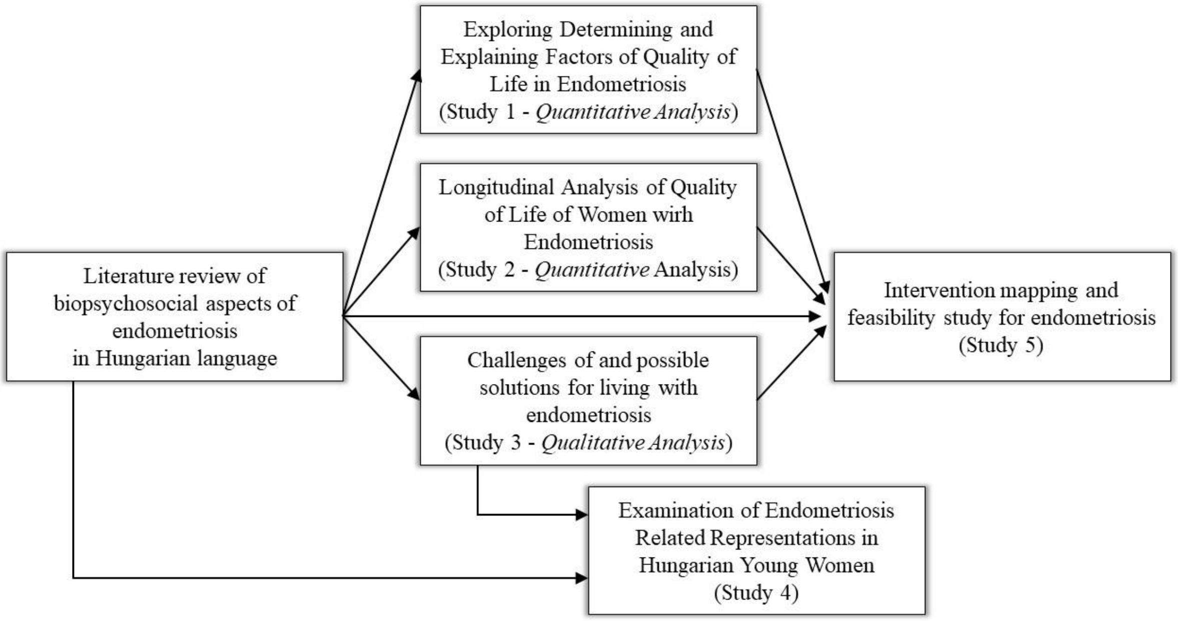
The purpose of the *first study* was to identify the predictor factors for quality of life. Correlation were hypothesized between pain, depression, anxiety, stress, sexual function, social support, and emotional regulation.

The aim of the *second, longitudinal study* was to find out how the quality of life changes and which medical and mental variables (surgery, pregnancy, childbirth, etc.) are in relation with the change in health-related quality of life.

The aim of the *third study* was to analyze the affected areas of endometriosis by qualitative approach using focus group (Cox et al., 2003; Moradi et al., 2014).

The aim of the *fourth study* was to explore endometriosis-related knowledge and illness representations among healthy and young women. Results showed that inadequate or incomplete knowledge may lead to uncertainty and patient dealy for help when symptoms of endometriosis occur (Ballard et al., 2006; Lemaire, 2004).

Figure 2.1. – Summary of the studies of the doctoral dissertation.



The aim of the *fourth study* was to explore endometriosis-related knowledge and illness representations among healthy and young women. Results showed that inadequate or incomplete knowledge may lead to uncertainty and patient delay for help when symptoms of endometriosis occur (Ballard et al., 2006; Lemaire, 2004).

In the *fifth study,* I reached the base of my applied health psychological starting point, as the review of literature and the first and third studies provided a good guide for planning a health promotion program. We expected result of the program a significant improvement in the quality of life, stress, emotional regulation difficulties and self-efficacy in the management of chronic disease.

3. EMPIRICAL STUDIES

STUDY 1 – Health-related quality of life in endometriosis

In our first cross-sectional study, we examined the correlations and predictive factors of health-related quality of life. Based on the literature, the most pronounced correlation is between deterioration of health-related quality of life and the level of pain symptoms. The role of pain in mental quality of life is also outstanding (Souza et al., 2011); the studies mention a significant relationship between pain intensity and anxiety symptoms (Sepulcri & do Amaral, 2009) as well as between stress levels and mental quality of life (Levenstein et al., 1993). In addition to the variables listed, we expected a significant relationship between quality of life and social support, sexual function, and emotional regulation.

3.1.1 Methods

3.1.1.1. Participants

A total of 220 women diagnosed with endometriosis completed the questionnaire. Participation required the diagnosis of endometriosis, the age over 18 years and lack of psychiatric diagnosis. Participants with self-reported comorbid psychiatric diagnosis (N=17) were excluded from the sample, which made the number of study participants 193.

3.1.1.2. Instruments

Demographic and endometriosis-related disease variables were collected before the main questionnaires.

Numerical analog scales were used to measure the intensity of endometriosis-related pain symptoms (1 = not at all - 10 = completely painful).

Short Form 36 (SF- 36) was used to measure health-related quality of life, which consists of 8 subscales. Each of the scales contains a score between 0 and 100, a higher score indicates better quality of life (Czimbalmos, Nagy, Varga, & Husztik, 1999; Ware & Sherbourne, 1992).

Hospital Anxiety and Depression Scale (HADS) is a 14-item, self-reported questionnaire of mood. Seven items measure the level of depression and seven other the level of anxiety symptoms. The evaluations of the anxiety and depression subscales are aggregated separately. Higher scores indicate a higher level of symptoms. (Muszbek et al., 2006; Zigmond & Snaith, 1983).

Support Dimension Scale (SDS) was used to measure how much a person can expect to receive social assistance from his/her family members, friends, colleagues and other helpers in a difficult life situation. The higher the total score received, the more the person can expect to receive social support from his/her environment (Caldwell, Pearson, & Chin, 1987; Kopp & Skrabski, 2000).

Perceived Stress Scale (PSS) measure the perceived stress by using 14 items. Higher scores indicate a higher frequency of stressful situations and a difficulty of coping with stress (Cohen, Kamarck, & Mermelstein, 1983; Stauder & Konkolÿ Thege, 2006).

Female Sexual Function Index (FSFI) examines the dimensions of female sexual (dys)function (Hevesi et al., 2017; Rosen et al., 2000).

Difficulties in Emotion Regulation Scale (DERS) consists of 36 items, a higher score shows greater difficulties in emotional regulation (Gratz & Roemer, 2004; Kökönyei, Urbán, Reinhardt, Józan, & Demetrovics, 2014). Our team followed the recommendation of Kökönyei et al. (2014), who suggested that the total DERS score be calculated independently of the awareness subscale.

3.1.1.3. Process

The sample was collected at the Endometriosis Center at the I. Department of Obstetrics and Gynecology, Semmelweis University (registration number: TUKEB 60/2014). We have asked the women visiting the outpatient care to participate in the study.

3.1.2. Results

According to the results, there was a significant correlation between the intensity of pain symptoms and the deterioration of the quality of life. Based on the SF-36, there was weaker significant relationship between the intensity of pain symptoms and mental health. Furthermore, the analysis of the relationship between psychological indicators and quality of life showed strong correlations between mental health and quality of life. Based on the correlation coefficients, strong significant relationships were found with depressive, anxiety and stress symptoms and difficulties in emotional regulation, while social support and sexual functioning showed weaker relationship with quality of life (Table 3.1.1).

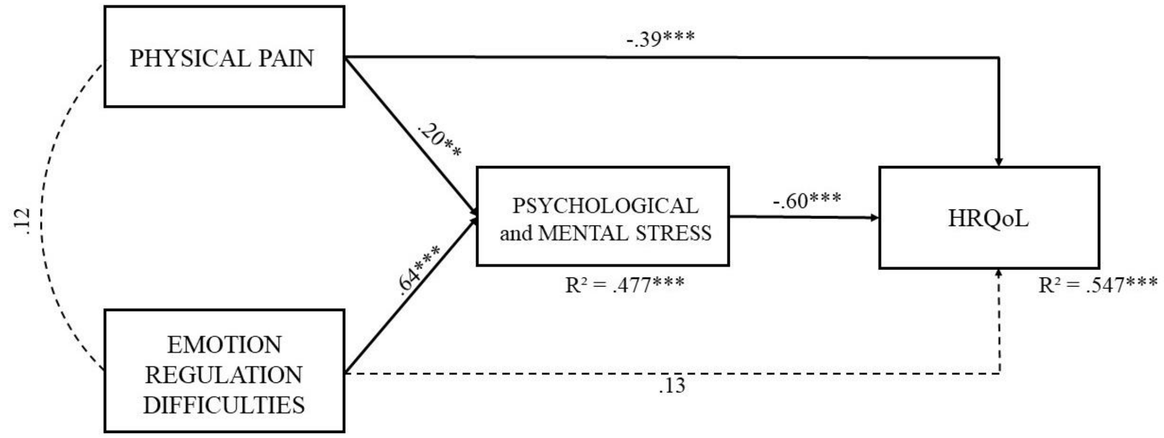
Table 3.1.1 – Correlations of quality of life in endometriosis

SCALES		SF-36 total score	SF-36 physical health	SF-36 mental health
Pain variables	first day of menstruation	-.29**	-.33**	-.17*
	additional bleeding days of the menstrual cycle	-.39**	-.57**	-.17*
	bleeding-free days	-.34**	-.44**	-.20**
	sexual intercourse (dyspareunia)	-.35**	-.40**	-.26**
	urination (dysuria)	-.18*	-.21**	-.14
	bowel movement (dyschesia)	-.40**	-.35**	-.31**
Psychological variables	HADS-D	-.56**	-.34**	-.64**
	HADS-A	-.61**	-.41**	-.70**
	PSS	-.59**	-.36**	-.68**
	SDS	.22*	.10	.22*
	FSFI	.25**	.13	.28**
	DERS	-.40**	-.17*	-.55**

Note: SF-36 = Short Form 36; HADS-D = Hospital Depression and Anxiety Scale – depression subscale; HADS- Hospital Depression and Anxiety Scale – anxiety subscale; PSS = Perceived Stress Scale; SDS = Support Dimension Scale; FSFI = Female Sexual Function Index; DERS = Difficulties in Emotion Regulation Scale; * $p < 0.05$; ** $p < 0.01$.

Structural equation modeling (SEM) was used to test three proposed mediation models, and to understand the complex relationship between the measured variables. Compared to the results of correlations, the overall quality of life model included only physical pain, emotional regulation difficulties and psychological and mental stress. In this pathway analysis the three variable explained 54.7 percent of the variance of quality of life (Figure 3.1.1).

Figure 3.1.1 – Quality of life mediation model for endometriosis (Model 1, N=193)[1]



Note: HRQoL = health-related quality of life; solid line = significant path; dashed line = nonsignificant path; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Based on the differences in correlation results, we examined health-related quality of life separately along two major (physical and mental health) scales. The results of physical and mental HRQoL were similar to those in Model 1 and to each other (see Figure 3.1.2). Physical pain, emotion regulation difficulties and psychological and mental stress explained 41% of the variance in physical quality of life and 55% in mental quality of life.

Among the predictive factors of physical quality of life, pain symptom showed a direct negative effect ($_{\text{direct}}\ \beta = -.52$; $p < 0.001$) and an indirect negative effect via psychological stress ($_{\text{indirect}}\ \beta = -.70$; $p < 0.01$). Physical health was predicted by pain symptoms and emotion regulation difficulties by direct and indirect paths as well. The negative indirect path appeared via psychological and mental stress ($_{\text{indirect}}\ \beta = -.23$; $p < 0.001$). The significant positive effect of emotion regulation difficulties on physical quality of life was explained by the statistical suppressor effect ($_{\text{direct}}\ \beta = .20$; $p < 0.05$), as this connection couldn't be explained by the literature of emotion regulation. Therefore, only physical pain had a real effect on physical quality of life.

The mental quality of life model showed two indirect paths (see Figure 3.1.2). In the case of physical pain and emotional regulation difficulties, the direct paths did not show a significant relationship with the mental quality of life, however, the indirect effect of both variables was presented through the mediating effect of psychological and mental stress. The explained variance of the psychological and mental stress mediator variable was more pronounced in the case of emotional regulation difficulties ($\beta = .65$, $p <0.001$) than with physical pain ($\beta = .20$, $p <0,01$). This difference has also appeared in the calculated value of standardized indirect effects related to mental quality of life (physical pain $\beta = -.14$, $p <0.01$; emotion regulation difficulties $\beta = -.46$, $p <0.001$), therefore emotional regulation difficulties – through the mediation of psychological and mental stress – explain mental health in a higher proportion.

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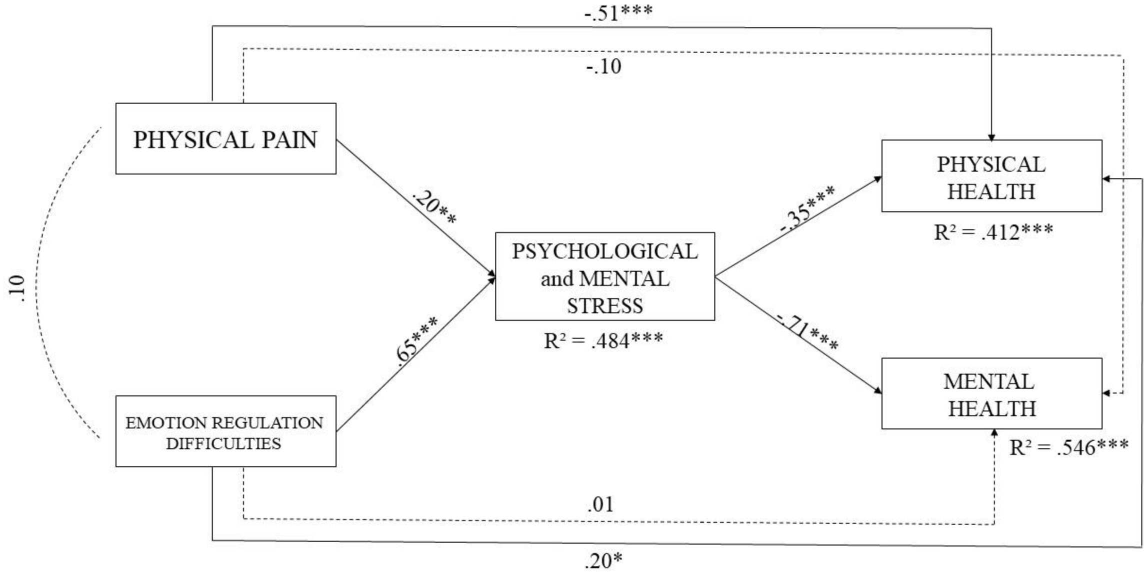
[1] Before model testing, we created two new variables – physical pain, psychological and mental stress – with main component analysis.

Figure 3.1.2 – Comparative mediation model of physical and mental quality of life in endometriosis (Model 2, N=193)



Note: HRQoL = health-related quality of life; solid line = significant path; dashed line = nonsignificant path; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

3.1.3. Discussion

Our results suggest that symptoms of physical pain and difficulties in emotion regulation are negatively associated with health-related quality of life via psychological stress (anxiety, depression and distress) in women living with endometriosis. Psychological stress is a major predictive factor of health-related quality of life, although there are differences in the mediation paths between the models of physical and mental health-related quality of life. These results supported the notion that women with a higher level of pain have a lower quality of life (Souza et al., 2011), however, clearly outlined by our models, that quality of life is not only determined by physical pain.

Based on the models presented, psychological and mental stress mediate between physical pain and quality of life, which supports the idea that perceived pain is affected by increase in negative mood symptoms. Earlier studies suggest that higher pain-intensity is associated with increased anxiety and depressive symptoms, stress levels and catastrophization (Carey et al., 2014). In connection with mental health, in our present study, emotional regulation difficulties showed significant correlation with (physical and mental) quality of life, mental health indicators and pain symptoms associated with endometriosis. The results support that negative mood may alter pain experience which is linked to pain-induced changes in the emotion regulation mechanism (Agar-Wilson & Jackson, 2012). To summarize, our findings showed, that the health care professionals need to on focus the development of emotional regulation skills and mental health as well.

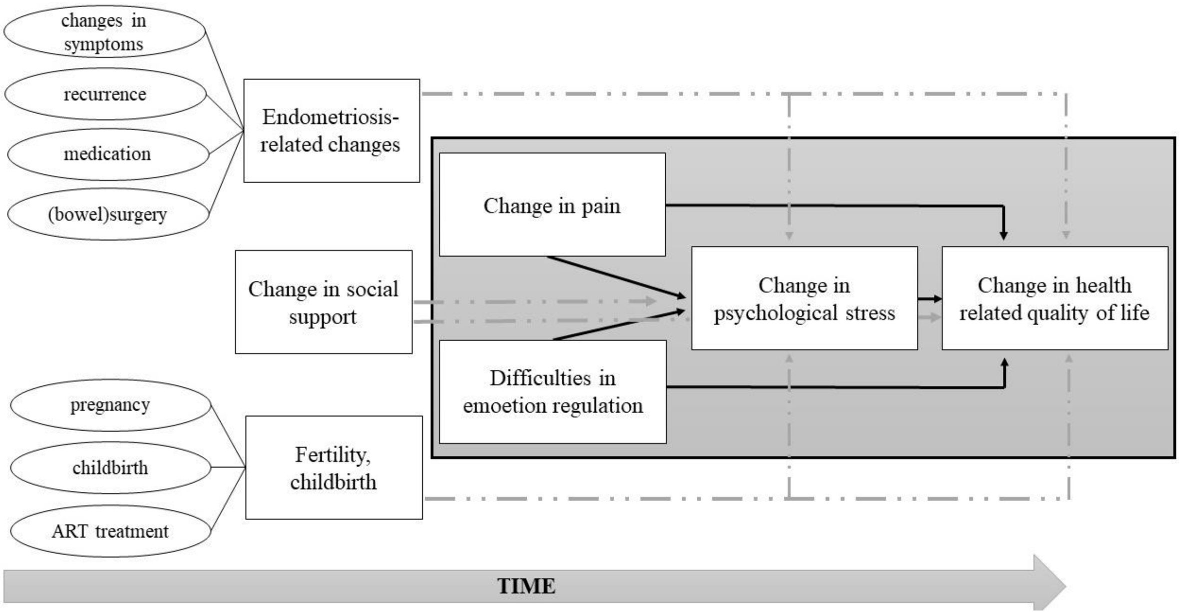
The limitations of the study are the cross-sectional method, the lack of the control group and the usage of control variables. Consequently, a longitudinal design would provide us with a more accurate picture of the exact and causal relationships. In the longitudinal study, it would be necessary to include biomedical indicators as control variables. Among the limitations we have to mention our results regarding social support and sexual activity. Social support and sexual activity, despite showing a correlation with health-related quality of life, were not included in the resulting mediation model (presumably due to low correlation coefficients. In addition to optimizing the measurement of the two variables discussed above, the validity of the presented models could be increased by increasing the number of participating health care institutions and controlling the severity of endometriosis.

Study 2 – Longitudinal Analysis of Quality of Life in Women Living with Endometriosis

Longitudinal studies on endometriosis focus mainly on identifying the effect of the medical treatment of the disease. Pharmacological and surgical interventions are measuring primarily on the change in pain intensity, secondly on the change in quality of life, and thirdly on the improvement of the quality of sexual life. There is a lack of examination about other psychological factors such as depression, anxiety, and stress, whose analysis would be relevant in the light of their correlations with health-related quality of life. In the research presented in the dissertation we could not examine the above issue due to the absence of an accessible sample.

We have not found information in the literature about how the health-related quality of life of women with endometriosis changes in the already treated group. Therefore, the purpose of our prospective study was to identify the factors determining the change in quality of life by integrating medical and psychological variables. Keeping the core of our model in the previous cross-sectional study (see Figure 3.1.1), we created a hypothetical model for analyzing longitudinal change in quality of life (Figure 3.2.1). The aim of this model was to predict the change in quality of life as the output variable. Based on the results of our previous correlation analysis, we assume that the change in pain intensity and psychological (and mental) stress will affect quality of life change. With the fourth included variable, emotion regulation, we assume that emotion regulation can explain the quality of life in the long run even under the control of biomedical and social variables (Diamond & Aspinwall, 2003; Trindade et al., 2018; van Middendorpet al., 2005).

Figure 3.2.1 – A hypothetical model of change in quality of life



Note: ART = *assisted reproductive techniques*; solid line = results supported by the literature and previous findings; dashed line = hypothetical paths.

3.2.1. Methods

3.2.1.1. Participants

In our first quantitative study, 220 people were involved, but only half of the sample, 125 people provided data that is valid for follow-up. We have asked those 125 people to participate in the longitudinal study, who has given proper contact information. We did not use filter questions to participate in the study, as the age over 18 and the diagnosis of endometriosis were already included as an input requirement in the first study.[2]

3.2.1.2. Instruments

In our study we have examined the intensity of pain symptoms (numeric analog scale), the quality of life (SF-36) and the level of stress symptoms (PSS) accordingly to the description in Study 1, with a repeated data collection, while in the case of the Difficulties in Emotion Regulation Scale, we have used the brief, 18 item-version.

3.2.1.3. Process

The study is a direct continuation of Study 1. At the end of that study, the participating women had the opportunity to give access to further research and participation. The invitation for the follow-up study was sent as an e-mail message and it was completed through Quatrics questionnaire management software in July 2017. There were no other dates for follow-up due to the high drop-out in the sample.

3.2.2. Results

Responses to the first questionnaire took place between September 2014 and September 2015 (see Study 1), and respondents for the second questionnaire arrived between July and September 2017, with an average of 2.5 years between the two measurements. In this way, we analyzed the changes that took place in two and a half years. Finally, the follow-up sample consisted of a total of 47 responses (corrected response rate was 37.6%). The low response rate did not allow testing of the hypothetical model outlined, so the dissertation does not address this analysis. At the same time, some preliminary results were found to be worth sharing, so the longitudinal study changed to a preliminary study.

According to our expectations, we have seen a significant relationship between T1 quality of life and T1 stress (Spearman's rank correlation coefficient = -.45; $p = 0.003$), but the relationship between T1 quality of life and T1 emotional regulation was not significant (Spearman's rank correlation coefficient = -.28; $p = 0.065$), while there was a significant correlation between T1 stress and T1 emotion regulation (Spearman's rank correlation coefficient = .68; $p < 0.001$).

During the second data collection we have also seen the expected correlation between T2 quality of life and T2 stress (Spearman's rank correlation coefficient = -.64; $p < 0.001$), and between T2 stress and T2 emotion regulation (Spearman's rank correlation coefficient = .82; $p < 0.001$). Furthermore, we have found a connection between quality of life and emotion regulation (Spearman's rank correlation coefficient = -.43; $p = 0.003$) that was not present at the first data.

When analyzing the correlations of T2 quality of life, we have found a significant connection only with T1 quality of life (Spearman's rank correlation coefficient = .56; $p < 0.001$). T2 quality of life did not show a relationship with T1 stress (Spearman's rank correlation

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[2] We did not ask for psychiatric disorders appearing in the past 2.5 years, so it may appear as a limitation.

coefficient = -.21; p = 0.156) or T1 emotion regulation (Spearman's rank correlation coefficient = -.11; p = 0.472).

We wanted to understand in more detail the changes in the results of follow-up, so we created three new variables for measuring change (change = T2 - T1). The analysis of the relationships between the indicators analyzed in the preliminary study and the change indicators showed additional results (see Table 3.2.1). The change in the quality of life showed a significant relationship with the indicators of stress change and pain change, while the values of emotional regulation difficulties in the first and second measurements did not. According to our preliminary analyzes, there was no detectable role of emotion regulation in the change of quality of life. The impact of emotion regulation on quality of life may be indirect, as we found a significant relationship between T1 emotion regulation and change in pain and between T2 emotion regulation and change in stress variables. The number of available data sample did not allow for more detailed, statistical model testing of these relationships.

Table 3.2.1 – Relationship between the indicators examined and the indicators of change

Correlates of change in quality of life

	T1 PSS	T2 PSS	T1 DERS-18	T2 DERS-18	change in stress	change in pain
change in quality of life	.36*	-.13	.26	-.06	-.52**	-.49*

Correlations of change in stress

	T1 SF-36	T2 SF-36	T1 DERS-18	T2 DERS-18	change in emotion regulation	change in pain
change in stress	-.07	-.57**	-.17	.37*	-.52**	.47*

Correlation of change in pain

	T1 SF-36	T2 SF-36	T1 PSS	T2 PSS	T1 DERS -18	T2 DERS -18	change in quality of life	change in stress
change in pain	.21	-.29	-.29	.13	-.39*	.06	-.49*	.47*

Note: T1 = first data collection; T2 = second data collection; SF-36 = Short Form-36 (quality of life); PSS = Perceived Stress Scale; DERS-18 = brief version of Difficulties in Emotion Regulation Scale; *= p <0.05; **= p <0.01.

Comparisons of control variables of medication treatment (N = 16), surgery (N = 21; of which bowel surgery N = 5), assisted reproduction (N = 8), childbirth (N = 4), pregnancy (N = 1) led to low number of test subgroups. We have decided to exclude the results of the examinations as the low number of data and the outnumbered control variables would have resulted decreased strength of the statistical analysis and the validity of the results would have been questionable.

3.2.3. Discussions

In our preliminary study we have repeated the measurement of the first, cross-sectional study, with an average of 2,5 years later. The change in quality of life showed a relationship with changes in pain and stress, meaning that the improvement in quality of life resulted in a significant reduction in pain and stress. Among the variables included in the study, the effect of emotional regulation on long-term quality of life was not supported by the available data and analysis, however at the same time, the preliminary analyzes revealed confirmatory results, similar to our model presented in Study 1, where emotion regulation difficulties indicate an indirect effect on quality of life.

In addition to group breakdowns, it would be worth thinking in cluster analyzes as many control variables and their changes can affect the quality of life change. The identification of different patterns would be possible with a much larger sample size, which would require the cooperation of international endometriosis centers. In addition to cluster models, we need to think in complex models that include physical, psychological and medical indicators, as we assume not only linear relationships between the variables. The identified clusters and models would make it possible to design and organize specific health promotion and intervention programs.

The limitations of the study include long-term follow-up time, low sample size, because of the low response rate.

Summarizing the results of our follow-up study, we did not have any additional knowledge of endometriosis-related quality of life, but we have found new potentially useful study questions, arrangements and aspects. The planning of the future longitudinal examination of the health psychology of endometriosis requires a multidisciplinary and multicenter collaboration, as well as the maintenance of the remaining motivation of the women participating in the study.

Study 3 – Challenges of and possible solutions for living with endometriosis – Hungarian results

According to quantitative and qualitative literature, endometriosis has a negative effect on many aspects of health-related quality of life. In qualitative studies of endometriosis, focus grouping and interview-based techniques are used to gain a deeper insight into the experiences regarding the disease of women living with endometriosis. The qualitative studies identified the following main areas: nature of endometriosis and healthcare experiences; living with endometriosis (impact of the disease on quality of life, mental health, social and sexual quality of life, studies and work); cooperation with healthcare staff and self-management (assertive behavior and control) (Cox et al., 2003; Culley et al., 2013; Moradi et al., 2014). A higher proportion of published results focuses on quality of life deterioration and medical experience, while a lower proportion of results include additional opportunities for self-management, social support, femininity, the “meaning” and role of chronic illness, and the needs expressed by patients.

The first aim of our present study was to reveal the effects of endometriosis on quality of life in the lives of women with endometriosis in Hungary, and thus to learn about their experiences and concerns with the Hungarian healthcare system. The aim of our study was to explore the possibilities and mechanisms of dealing with the negative effects of the disease on women living with endometriosis.

Previously published data demonstrated the negative impact of endometriosis on quality of life and medical experiences, but offered fewer findings about self-management, social support, femininity, meaning of life with a chronic disease and future directions and needs of patients.

Therefore, the aim of this study is to expand knowledge of (i) the difficulties women have when living with endometriosis and (ii) their opportunities and mechanisms for coping with the negative impact of the disease. It is our assumption that by exploring these main areas we can help to develop health promotion strategies in order to reduce further negative effects on women's lives.

3.3.1. Methods

3.3.1.1. Participants

We have invited 125 women with endometriosis diagnosis and over 18 years of age, whom we contacted through the contact information given in the first cross-sectional study. Of the 125 people invited, 21 people were able to participate in focus group discussions.

3.3.1.2. Instruments

In the course of the qualitative study we used a short, demographic and disease indicator questionnaire. The other part of our research was the focus group as used method. (Kitzinger, 1995; Morgan, 1997). For the purposes of later analysis, the entire content of the group conversations were audiotaped with the written consent of the participants, so we had a total of 462 minutes of audio at the end of the sample collection phase.

3.3.1.3. Process

With the usage of the contact information gathered during the cross-sectional study, a total of 125 women living with endometriosis received invitations to the focus group discussion. The focus group occasions were completed in the same way all the four times. We made a verbal transcript of a total of 462 minutes of audio. The focus group transcript is composed of a text block of 62051 words. Within the postpositivist qualitative paradigm (Ponterotto, 2005) we followed the phenomenological approach to inquiry.

3.3.1.4. Analyzes

The verbatim transcript was examined with a text-based, bottom-up content analysis approach, focusing on identifying explicit content spoken in conversations (Joffe & Yardley, 2004). Overall, there were 462 minutes of recording which were then transcribed into a 62,051–word corpus for the purpose of the analysis. The basic element of analysis was the word. After checking the transcript, the text was analyzed line by line using content analysis in ATLAS.ti by two independent coders. We discussed and compared collected codes from the data and after reaching consensus code groups, defined categories and created themes (Braun & Clarke, 2006).

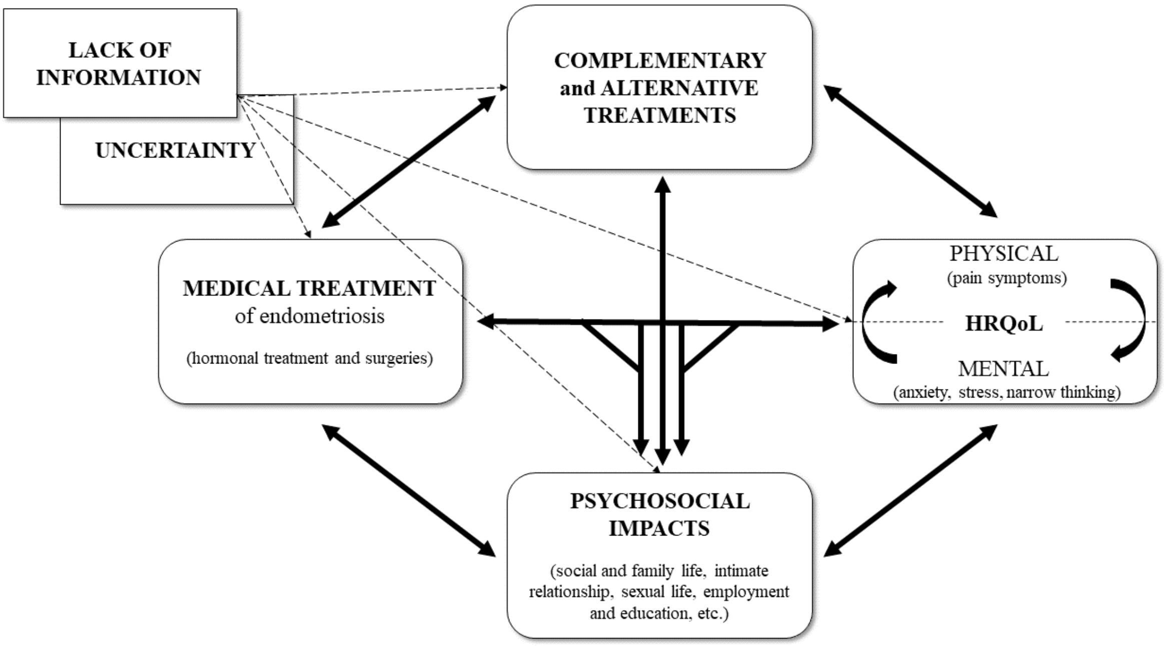
3.3.2. Results

Four main themes emerged from the analysis: (a) impact of endometriosis on quality of life, (b) medical experiences, (c) complementary and alternative treatments, (d) different coping strategies in disease-management. It is notable that all themes were highly affected by a lack of information and uncertainty as a result of endometriosis (Table 3.3.1).

In the analysis of the text corpus, besides the descriptive level analysis, we found significant relationships, overlaps and explanations between the identified topics, during which we were primarily concerned that each of the four themes identified was largely affected by the lack of information and uncertainties (see Figure 3.3.1).

In the relationship between quality of life and psychosocial effects and specialist treatments, the coping strategy of women with the disease (see Figure 3.3.2) and the attitudes of health care professionals play an important role. The doctors' negative attitude to physical symptoms and lack of knowledge to recognize endometriosis has delayed the recognition of the disease, which had a feedback effect on living with the disease, the quality of life and psychosocial characteristics of these women. The deteriorating health status has had a negative impact on the treatment-related adherence and compliance.

Figure 3.3.1 – A model of the relationship of endometriosis-related themes and the negative impact of uncertainty and lack of information.



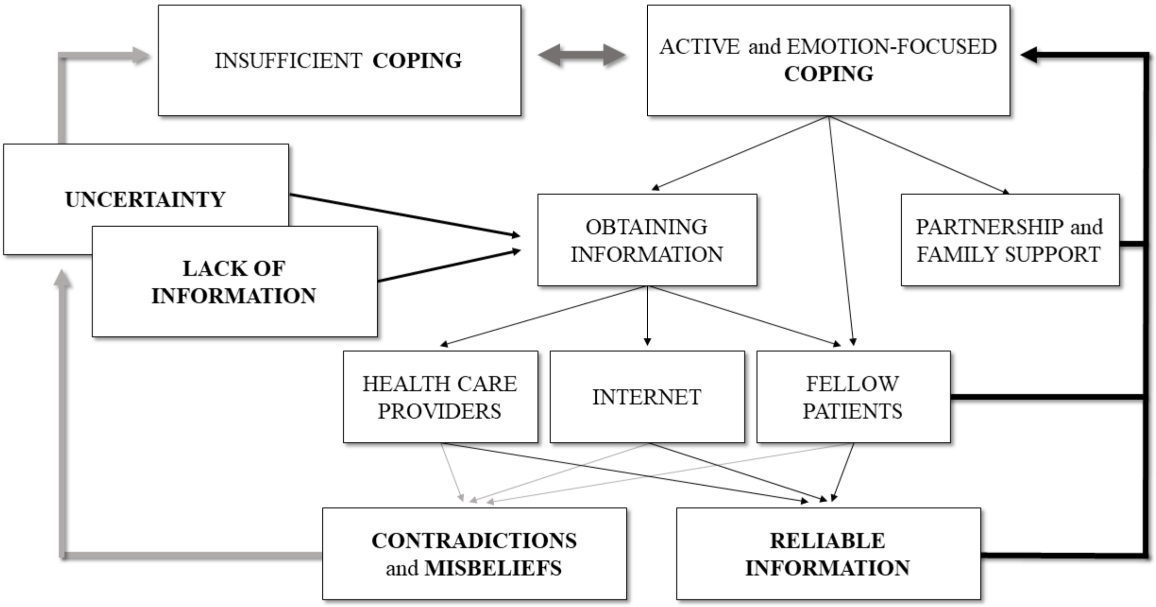
Depending on the information received there were two possible processes regarding coping strategies. The study groups were homogeneous in their coping strategy, as they were characterized by active and emotional focus coping. Activities were carried out in three areas: information retrieval, contact with fellow patients, and partnership and family support. In spite of the controversial content of information obtained from the three main sources (health, internet, and fellow patients), despite their self-care, women reported an increase in insecurity leading to inadequate coping with the disease.

The limit of our results is that in the examined groups the group of women with passive disease management did not appear, so we could not analyze the passivity.

Table 3.3.1 – Themes, categories and subcategories that emerged from the data

Themes	**Categories**	**Subcategories**
Impact on quality of life		
	Physical impacts	
	Psychological impacts	
	Psychosocial impacts	*Social and family life*
		Intimate relationship
		Sexual life
		Fertility
		Femininity
		Employment and education
		Financial impact
Medical experiences		
	Diagnostic delay	*Normalization of symptoms*
		Doctor delay
	Treatment of endometriosis	*Pharmacological treatments*
		Surgery and surgical experiences
		Childbearing as treatment option
		ART treatment
		Recurrence of endometriosis
	Doctor-patient relationship	
Complementary and alternative treatment		
	Lifestyle changes as treatment	*Diet and nutrition*
		Physical activity
	Psychology	
	Naturopathy and other methods	
Different coping strategies in disease-management		
	Obtaining information	*Information provided by doctors*
		Internet
		Fellow patients
	Active control and emotion-focused coping	*Self-care*
		Positive attitude
	Social support	*Personal relationships*
		Endometriosis community

Figure 3.3.2 – The model of different coping strategies and their effects.



3.3.3. Discussions

In our qualitative study, we have identified a dynamic relationship between topics regarding living with endometriosis – health-related quality of life, health experiences, complementary and alternative treatments and coping strategies. In addition, it is clear that the quality of life areas of endometriosis cannot be considered independent. All four areas and the relationship between them are negatively affected by lack of information and uncertainty. Identified topics are compatible with the results of previous studies (Facchin et al., 2017; Young et al., 2015). Furthermore, we have identified areas that have been barely mentioned in literature (see fertility uncertainties, femininity, financial burdens). Difficulties were most effectively addressed by women with active control and emotionally focused coping strategies, which was helped by positive health experience, accurate disease information from reliable sources, and effective social support. Despite the fact that problem-focused coping is not dominant in our focus group study, we agree with the suggestion of Roomaney és Kagee (2016), who consider both the problem-focused and the emotional-focused coping mechanism as an effective form of coping in the case of endometriosis.

Within the limits of the study, it should be noted that participants had rather homogeneous demographic characteristics and disease characteristics, which is why our results for the overall population of women affected by endometriosis cannot be generalized. Secondly, our study included women with active disease management and positive, optimistic attitudes, so we could not identify the experiences of women living passively with endometriosis.

Study 4 – Study of endometriosis-related representations among young Hungarian women

In the qualitative studies of endometriosis, the lack of information about the disease is a major problem (Moradi et al., 2014). Women with endometriosis often encounter the name endometriosis when receiving the diagnosis, and therefore do not have prior knowledge of the disease. This causes these women to lose the potential benefits of the information and the health-promoting behavior. Thus, the lack of knowledge of the symptoms of endometriosis and their possible normalization leads to an increase in diagnostic delay and deteriorating health (Ballard et al., 2006).

In this study, we examined the knowledge and behavior regarding women's health in Hungarian young women, as well as their representations related to endometriosis and their knowledge of the disease. In addition to mapping endometriosis-related knowledge, we have hypothesized that endometriosis-informed groups have a higher rate of accurate knowledge and disease representations of endometriosis compared to a group of women who do not know the disease on their own. Our suggestion may seem self-evident, but it was also important to identify inaccurate representations. In addition, we assumed that the amount of information related to endometriosis positively correlates with age. Our hypothesis is based on the fact that individuals' disease representations evolve and change from time to time. (Leventhal, Leventhal, & Contrada, 1998). The final goal of the study was to briefly inform the participants about the disease in question.

3.4.1. Methods

3.4.1.1. Participants

A total of 513 responses were received to the study questionnaire, 92 of which indicated that they were affected by endometriosis and another 61 were affected by polycystic ovarian syndrome. All together 360 completed answers were submitted to the final sample.

3.4.1.2. Instruments

Demographic variables and behavior related to women's health was also surveyed, and the knowledge of endometriosis and the related representations were measured on the basis of the questionnaire. The study questionnaire ended with a brief, psychoeducation of endometriosis.

3.4.1.3. Process

The participants were recruited from healthy (not suspected of having a gynecological disease) university students and their social network, with non-probabilistic sampling and snowball method. These women were invited to the research through university and community (online) calls. The study was approved by the Research Ethics Committee of the Faculty of Education and Psychology of Eötvös Loránd University.

3.4.2. Results

Nearly three quarters of women knew the definition and main symptoms of endometriosis (pain and infertility). Half of the women responded correctly to menstrual irregularities, while 20-25 percent of the respondents did not necessarily think of endometriosis if the menstrual cycle changed.

In addition to the characteristics of the disease, the screening, diagnosis and treatment categories showed surprising results. 59.55 percent of women thought that endometriosis was easy to diagnose. 53.28 percent of women knew correctly that endometriosis was not easy to treat, while 29.60 percent of the participants were unable to answer this question, however, 71.05 percent of the participants knew that endometriosis could be treated by surgery.

In the case of prevalence values, an interesting result was also obtained. Only 28.61 percent of the respondents knew the prevalence of endometriosis, while 49.67 percent of the participants were unable to answer the question. It is worth to mention that the estimated prevalence of endometriosis in this study was 26.32%, higher than the actual prevalence.

The enumerated value of their knowledge of endometriosis allowed us to examine the relationship with the variables examined in the study. When comparing with demographic data, the level of knowledge of endometriosis showed a low-level, significant relationship with age (Spearman’s rank correlation coefficient = .21; $p < 0.001$; $N = 304$), so the amount of knowledge about the disease increases with age.

3.4.3. Discussions

The examination of endometriosis-related representations painted a picture of young Hungarian women's knowledge of the disease. Analyzes of the study showed results that correspond to our expectations (the acquaintances of those affected by endometriosis have greater knowledge of the disease), but we also identified new assumptions about patient delay in diagnosis.

An interesting result of the research was that the participants estimated the prevalence of endometriosis to be almost 2.5 times higher than the actual prevalence, so it was perceived as a greater threat. According to this threat as described by Leventhal (1998), the disease representations were correct of the definition and symptoms of endometriosis, while the proportion of knowledge was much lower in terms of disease recognition and treatment. The (false) representations of the easy recognition and treatment of endometriosis may, in the event of symptoms appearing, cause a latency in doctor visit and may delay the participation in diagnostic laparoscopic surgery if patients think of themselves as treated, forgetting the chronic aspects of this disease.

According to our results, the level of knowledge related to endometriosis increases with age, which was confirmed by our results in education and work status. It is possible that with age, especially as the fertile age progresses, people will find more information or reports about fertility or its difficulties. These findings also point to the fact that endometriosis-related education in the group of younger women would be a niche. It was also supported by the fact that young Hungarian women have heard very little about endometriosis in their education and health care. By identifying and using an effective communication source, appropriate and accurate information could be provided to women through primary prevention.

A limitation of this study is the homogeneity of participants; therefore it would be worthwhile to repeat the study with a representative sample. The review questionnaire requires some refactoring because of the high proportion of negative claims. Based on the distribution of scores, it would make sense to make the questionnaire easier and to use items about recognition of other diseases. To study the extent of knowledge and the connections of biological-psychological aspects, it would be beneficiary to use new instruments, with which we could examine the already mentioned family, cultural and environmental factors, as well as the aspects of referral to the physician, in order to get more comprehensible responses to women's health behavior and representations.

Study 5 – Creation and feasibility study of the intervention process called „Health promotion program for women living with endometriosis”

The feasibility studies of psychology interventions in the area of women with endometriosis usually focus only on a single method. Based on the results of the pilot studies reported, psychological interventions have a positive impact on quality of life, intensity and management of pain symptoms, depressive and anxiety symptoms. (Gonçalves, Barros, & Bahamondes, 2017; Hansen et al., 2016, 2016; Meissner et al., 2016; Zhao et al., 2012).

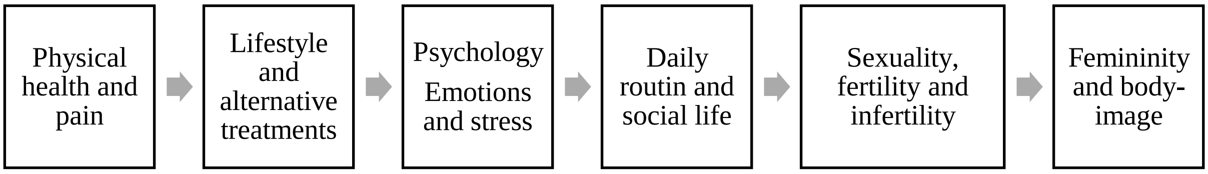
Comparing the areas affected by endometriosis and psychological intervention processes, psychological intervention processes do not provide solutions for every affected area (see social relationships and quality of life, fertility infertility, femininity and self-image, and relationships and communication with healthcare providers). The above observation led to the idea of creating a themed health promotion program, which was implemented in the framework of doctoral training. The program consists of an intervention mapping and a feasibility study.

3.5.1. Methods

3.5.1.1. Introduction to „Health promotion program for women living with endometriosis”

The program is a series of six thematic events, which follow each other in a defined order (see Figure 3.5.1), two hours each, in a group arrangement. The aim of health promotion events was to transfer knowledge from an accurate and reliable source of endometriosis, to promote psycho-education and to learn easy-to-understand psychological methods and practices that helps to reduce the uncertainties and negative consequences associated with the disease and to encourage an active role in coping with the disease.

Figure 3.5.1 – The thematic structure of „Health promotion program for women living with endometriosis”



3.5.1.2. Participants

We have invited 125 women with diagnosis of endometriosis, and above 18 years of age to participate, whom we have contacted through the information received during the first cross-sectional study. Participation in the study required endometriosis diagnosis, age over 18 and no psychiatric diagnosis. A total of 32 women were enrolled in the study, but only 25 were included in the final sample due to late joins and missing answers.

3.5.1.3. Instruments

To evaluate the efficiency of the program, we have used a shortened version of the questionnaires used in Study 1 and 2 (quality of life – SF-12, stress – PSS-10, emotion regulation – DERS-18) complemented with the **Self-Efficacy for Managing Chronic Disease 6-item Scale,** which is used to measure self-efficacy in disease management (Lorig et al., 2001). Finally, the program could be evaluated by participants using a five-point Likert scale prepared by us. (1 – lowest, 5 – highest score).

3.5.1.4. Process

The recruitment of the participants in the study was partly done on the Endometriosis Center of I. Department of Obstetrics and Gynecology, Semmelweis University and partly through online email requests between October and November of 2016. For the email inquiries, we used the contact details provided in our first questionnaire. The study was conducted with the permission of the Semmelweis University's Regional Scientific and Research Ethics Committee (registration number: TUKEB 60/2014).

Four measurements were made in the study, the first measurement (T0) was done on the application surface, while the second measurement (T1) was sent two weeks before the start of the program. Since the first group started two weeks after the invitation, their T0 and T1 data are the same. The third measurement (T3) took place one week after the end of the program and the fourth measurement (T3) three months after the end of the program.

3.5.2. Results

During the comparison of the values two weeks prior to the program and one week after the program, the average values of all variables showed an improvement, however significant results were found only in the quality of life and stress indicators as a short-term result of the program (see Table 3.5.1).

To assess the impact of the program on follow-up, we compared the data before and three months after the program. Based on the results shown in Table 3.5.2, no significant change was observed in any of the tested variables, so the long-term effect of the program could not be detected.

Table 3.5.1 – Comparison of pre- and post-program status

Scales	**T1**		**T2**		**Results of matching t-tests**					
	M	SD	M	SD	t	df	p	95% CI		Cohen-d
PAIN-6	12.56	12.90	11.34	8.98	0.59	15	0.566	-3.097	5.451	0.11
SF-12	**53.78**	**22.77**	**66.31**	**21.95**	**2.28**	**14**	**0.039**	**-24.310**	**-0.745**	**0.56**
PSS-10	**22.67**	**6.35**	**16.67**	**7.69**	**2.59**	**14**	**0.022**	**1.025**	**10.975**	**0.85**
DERS-18	43.47	12.12	38.47	12.14	1.95	14	0.072	-0.514	10.514	0.41
SEMCD-6	6.60	1.72	7.39	1.96	1.31	14	0.213	-2.085	0.507	0.43

Note: T0 = data at the time of recruitment; T1 = data two weeks prior to program; T2 = data one week after the program; T3 = data three months after the program; PAIN-6 = sum score of six pain scales; SF-12 = brief version of Short Form-36 (quality of life); PSS-10 = brief version of Perceived Stress Scale; DERS-18 = brief version of Difficulties of Emotion Regulation Scale; SEMCD-6 = Self-Efficacy for Managing Chronic Disease 6-item Scale.

Table 3.5.2 – Comparison of the status before and three months before the program

Scales	**T1**		**T3**		**Results of matching t-tests**					
	M	SD	M	SD	t	df	p	95% CI		Cohen-d
PAIN-6	10.87	10.86	7.45	7.30	1.10	9	0.300	-3.609	10.449	0.37
SF-12	63.17	14.77	64.92	16.29	-0.28	9	0.788	-16.073	12.573	0.11
PSS-10	20.20	6.18	17.50	5.44	1.25	9	0.244	-2.199	7.599	0.46
DERS-18	37.00	6.29	36.80	5.75	0.07	9	0.948	-6.551	6.951	0.03
SEMCD-6	7.38	1.33	6.79	1.69	0.70	3	0.532	-2.055	3.222	0.38

Note: T0 = data at the time of recruitment; T1 = data two weeks prior to program; T2 = data one week after the program; T3 = data three months after the program; PAIN-6 = sum score of six pain scales; SF-12 = brief version of Short Form-36 (quality of life); PSS-10 = brief version of Perceived Stress Scale; DERS-18 = brief version of Difficulties of Emotion Regulation Scale; SEMCD-6 = Self-Efficacy for Managing Chronic Disease 6-item Scale.

3.5.3. Discussions

The results of the feasibility study of the "Health promotion program for women with endometriosis" suggest that the program can effectively improve quality of life and reduce stress symptoms in the short term. In addition, we found a reduction in pain intensity – arithmetic, non-significant – three months after the end of the program. In addition to intervention, the program also created a supportive community, along with changes in lifestyle (nutrition and exercise). These variables also correlate with the prognosis of the disease (Buggio et al., 2017).

The limitations of the study were that the study group proved to be fairly homogeneous in terms of demographic and disease indicators, treatment institute and psychological care. The response rate has been reduced from measurement to measurement, and the validity of the low sample size and high standard deviation measurements should be handled with care. In addition to the statistical features, the distorting effect generated by the participants has also appeared, in which they wanted to promote the continuation of the program with their answers.

Considering the results of psychological intervention processes published so far, it may be worthwhile to incorporate the teaching of a specific (cognitive, relaxation, mindfulness-based) method into the program. It is assumed that the effect of techniques presented during the occasions, in the absence of their proper depth, did not appear during follow-up. Based on our results, we find it worthwhile in the future to combine the use of group-based psychoeduction and the teaching of the chosen methods.

4. CONCLUSION

The doctoral dissertation has provided a detailed summary of the literature on many aspects of endometriosis. The gaps and issues identified in the literature review of endometriosis were, as far as possible, answered and discussed in our dissertation. Our most important result is that we have identified a complex relationship between the intensity of endometriosis-related pain symptoms, health-related quality of life, and mental health indicators. Furthermore, the main challenges and difficulties of living with endometriosis are the pervasive uncertainty and lack of information. Thus, the results presented show that women living with endometriosis would require complex treatment.

The results of the dissertation draw attention to many areas of health promotion. The first area is the lack of knowledge regarding endometriosis in the population of young and healthy women. The lack of knowledge about endometriosis – especially in the context of the recognition and treatment of the disease – identified young women as potential risk groups. In this group, we also need to think about the adolescent population, because as the endometriosis definition includes, the disease affects women of fertile age (Janssen et al., 2013). By providing the right information, we would expect early diagnosis, which has a positive impact on the quality of life and reproductive potential of the women living with endometriosis.

In the case of endometriosis, a further important second step should be the reduction of diagnostic delays associated with chronic gynecological diseases (appearing among adolescent women as well). For example, the development of a simpler screening technique for endometriosis (vs. laparoscopic surgery). In addition to the symptoms of the disease, screening of mental states would also be important in the affected group.

As a third area, we would emphasize the need for a multidisciplinary approach, where collaboration with health care specialists, psychologists and endometriosis communities can lead to solutions at all levels of health promotion for the needs of women living with endometriosis.

It may be worthwhile to ensure the widespread availability of intervention programs that are easier to implement but still prove effective. By summarizing the results of the doctoral dissertation, health programs can play an important role in providing accurate and credible information on the disease and providing social support. At the same time, it would be necessary to train and transfer knowledge about coping strategies in order to promote prolonged change in the identified difficulties (pain, negative mood, increased stress levels, etc). If the recommendations of the doctoral dissertation are implemented, women with endometriosis may have a chance to achieve asymptomatic, fertile and harmonious life.

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[3] All co-authors have granted permission for these publications to be included in the dissertation.

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