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# The social and the psychological impact of endometriosis on the Romanian urban population

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ABSTRACT

Objectives. Our study assesses the social and psychological impact of the symptoms of endometriosis. Materials and methods. This cross-sectional study was conducted from January 2014 to January 2016. The research involved two groups. The study instrument, the EHP-5 questionnaire, was completed by the respondents on the admission date or on the routine gynecological visit day. Results. Endometriosis has a negative social and psychological impact on women's life, the most affected areas being work, fertility and sexual activity. Moreover, pain and the negative perception of self-image are major sources of distress. Conclusion. The symptoms and effects of endometriosis, especially chronic pelvic pain, mood changes and infertility, are significant negative factors in women's life. The authors further conclude that the EHP-5 questionnaire can be more widely used to help select women who may need special attention in terms of their quality of life, thus helping gynecologists refer affected women to a health care professional.

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## Introduction

It is well acknowledged that endometriosis is a chronic inflammatory disease, which is under-diagnosed, under-reported, and under-researched. It is defined by the presence of endometrial tissue outside the uterine cavity, found in women of all ethnic and social groups [1]. Endometriosis is common during the reproductive years, which should be the most productive period in a woman's life [2]. Up to 7-15% of women have been reported with endometriosis throughout their lifetime, which causes a significant impact on public health care [3,4]. Up to 80% of the women with endometriosis suffer from painful symptoms, including chronic pain such as dysmenorrhea, dyspareunia, non-menstrual pelvic pain, and dyschezia; only 20-25% are asymptomatic [5]. Symptoms are nonspecific, and the differential diagnosis requires the exclusion of ovarian tumors or other genital causes [6]. Another fundamental problem is related to the subfertility issues associated with endometriosis [7]. About 30-35% of the women with endometriosis suffer from infertility [8].

The connection between inflammatory diseases and mood disorders is critical to understanding the impact of endometriosis on women's lives. In endometriosis, significant correlations have been found between the immunopathogenetic factors, resulting in the imbalanced production of pro-inflammatory (IL-1b, IL-2 and IFN-g) and anti-inflammatory (IL-4) cytokines, and the severity of women's shifts in mood, anxiety, and mental health in general [9,10]. Peripheral immunological changes may stimulate the central nervous system to induce the so-called "sickness response", which involves behavioural changes, depression-like behaviour, fatigue, hypophagia, irregular appetite, sleep, or sexual habits, anhedonia, sadness. All these may negatively affect social interactions and intimate relationships [11]. Some studies have emphasized the harmful effects of pelvic pain on women's mental health and quality of life, such as loss of working ability, limitations in social activities, and lack of understanding and support from the others [12-16].

Considering the increased cost of fertility treatments and the disabilities caused by endometriosis-related pelvic

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pain, it is obvious why endometriosis has become a burden for national health care services. Moreover, endometriosis is a disabling condition that may significantly affect women's everyday lives, social relationships, sexual and mental health, negatively impacting life quality [17,18].

In the majority of the cases, the quality of life (QoL) is affected by pain, the emotional impact of sub-fertility, anger about disease recurrence, and the uncertainty about the future regarding repeated treatment or long-term medical therapy [19]. Various instruments have been used to quantify this impact by measuring the effects on the QoL in patients with endometriosis. Up to this point, the only validated endometriosis-specific tools are EHP-30, and the shorter version EHP-5 [20].

No studies have systematically investigated the impact of symptomatic endometriosis on the quality of life and mental health of women with endometriosis in Romania. Therefore, we aim at assessing the social and psychological impact of endometriosis on a Romanian urban sample involving two groups of women.

## Materials and Methods

The study population. This cross-sectional study was carried out from January 2014 to January 2016. The research involved two age and sex-matched groups; a study group of women aged 27-47 years, diagnosed with endometriosis requiring surgery (n=55) and a control group composed of healthy women aged 22-37 years, recruited during a routine gynecological visit (n=36). The study instrument, the Romanian translated version of the EHP-5 questionnaire, was given to women on the admission date or on the routine gynecological visit day.

The study Instrument. The endometriosis-specific EHP-5 survey was developed and validated as a condensed QoL instrument used in a time-effective manner during a clinical consultation and encounters with the researchers. The EHP-5 comprises 11 questions (items): five items related to pain, control and powerlessness, emotional well-being, lack of social support, self-image as part of the core questionnaire; and six items from the modular questionnaire that may not apply to every woman with endometriosis, including work, intercourse, and worries about infertility, treatment, and relationship with children and medical professionals. The EHP-5 consists of questions that assess whether and how much the symptoms of endometriosis interfere with work and daily activities. Other aspects regarding the impact of endometriosis are mood and appearance changes, along with the perception that others do not understand their situation. The effects on the sexual life, childcare, relationship with the doctor, treatment efficacy, and maternity are also measured [21].

Data analysis strategy. Data were manually entered into Excel (Microsoft) program. We used a SPSS 20 program to make a descriptive analysis of the data. Thus, absolute and percentage frequencies were calculated for the qualitative variables such as previous births and infertility diagnosis, central tendency measures (mean and median) and dispersion (standard deviation) for continuous quantitative variables such as age, height and total score. Kolmogorov Smirnov tests were used to verify the distribution of the variables. For variables recorded on Likert scales (each question of the EHP-5), we calculated the frequency of each answer's percentage. The z test was conducted to compare the proportion between the two groups and Mann-Whitney test to compare the quantitative variables between the two groups (n=91), taking into account the non-parametric distribution of the values.

## Results

The EHP-5 questionnaire was completed by 91 women aged between 22-47 years. Age was determined by subtracting the date of birth from the date of completion of the questionnaire. The design split the study population into two groups: the study group, composed of 55 women with endometriosis with a mean age (± SD) of 33.38 (±4.67) and a median of 31 years; and a control group formed by 36 healthy women. The mean age (± SD) in the control group was 31.47 (±2.90) and the median, 32. The Mann-Whitney test demonstrated that the two groups were age-matched, more accurately said, there was no significantly statistical difference between the two groups (U=803.50; p=0.13).

Table 1. The demographic characteristics of the respondents

| | Study group | Control group |
|---|---|---|
| **Age (y)-Mean** (SD) (U=803.50; p=0.13) | 33.38 +/- 4.67 | 31.47+/-2.90 |
| **BMI** | 20.31 | 20.44 |
| **Fertility status** | | |
| Fertile | 25 | 28 |
| Infertile | 23 | 5 |
| **Nulliparity** | 30 | 19 |

The majority of the women diagnosed with infertility were in the study group (Figure 1). The proportion of the subjects with infertility was significantly higher in the study group than in the control group (0.14; z=2.82; p=0.0).

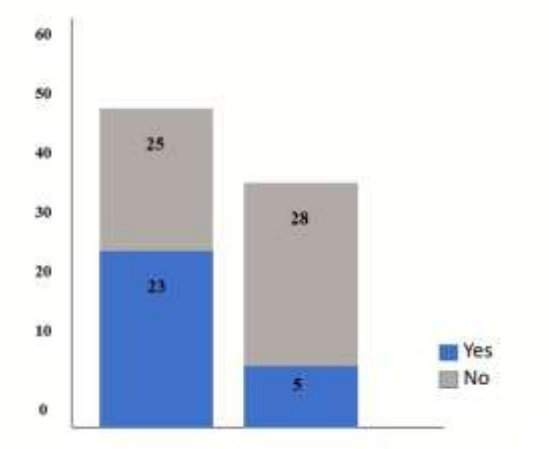


**Figure 1**. Infertility distribution in the two groups

In the study group, 65.45% of the patients experienced difficulty in daily activities because of the pain, of which 9.09% experienced lasting pain. Another 38% felt that the symptoms controlled their lives, 63.63% having mood swings, and the same percent feeling depressed due to infertility worries. A comparison test (Z) showed that the proportion of the subjects in the study group who answered "rarely" was significantly lower compared to women in the control group. Moreover, the proportion of the subjects in the study group who answered "always" was significantly higher than in the control group. The most powerful impact in terms of worries about fertility was among the nulliparous women. Two-thirds of them worried that endometriosis might have caused irreversible damage to their reproductive organs.

Around 45.5% of the respondents in the study group were frustrated about the treatment. Only 9.09% thought the medical profession did not meet nor address their concerns, but 27.27% reported that others did not understand their plight. Regarding the work domain, the majority of women (52.72%) felt the symptoms interfered with their career. An essential part of a woman's identity is her self-image, which may in turn affect their confidence, trust, and productivity. 27.27% of women believed their self-image had been affected, and 9.09% of them felt that it was would be ongoing. Another 54.54% of the respondents in the study group noticed that endometriosis had a negative impact on their sexual activity, of which 9.09% were fearful of the intercourse due to possible pain. A comparison test (Z) indicated that the proportion of the subjects in the study group who answered "often" to the question was significantly higher than that of the subjects in the control group ($z = 2.2$, $p = 0.03$). The results for the control group greatly differed, highlighting the high scores in the study group. 30.56% of women experienced difficulty in daily activities because of the pain, 11% felt that the symptoms take control of their lives, 22.22% had mood swings, and 33.33% were worried about future pregnancies. Another 22.22% felt frustrated about the treatment, 2.78% did not find support in the doctor or in other individuals. 27.27% of participants had problems at work and 8.28% in childcare. Around 13.83% of the women were not pleased with the way they looked, and 30.55% experienced difficulties in their sexual life. From another point of view, the proportion of women who answered "always", "often" and "sometimes" was, in all cases, higher in the study group. Tables 2 and 3 provide details of our results.

**Table 2**. The distribution of the responses in the two groups

| | **Never** | | | | **Rarely** | | | | **Sometimes** | | | | **Often** | | | | **Always** | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Study | Control | Z | P | Study | Control | Z | p | Study | Control | Z | p | Study | Control | Z | p | Study | Control | Z | p |
| Pain | 15 | 11 | -0.34 | 0.73 | 4 | 14 | -3.70 | 0 | 26 | 10 | 1.86 | 0.06 | 5 | 0 | 1.86 | 0.06 | 5 | 1 | 1.19 | 0.23 |
| Control and powerlessness | 10 | 6 | 0.18 | 0.85 | 24 | 26 | 2.68 | 0.01 | 6 | 3 | 0.4 | 0.69 | 5 | 0 | 1.86 | 0.06 | 10 | 1 | 2.2 | 0.03 |
| Emotional well being | 4 | 8 | -2.06 | 0.04 | 16 | 20 | -2.52 | 0.01 | 15 | 5 | 1.51 | 0.13 | 15 | 2 | 1.51 | 0.13 | 5 | 1 | 1.19 | 0.23 |
| Lack of social support | 15 | 16 | -1.69 | 0.09 | 25 | 17 | -0.16 | 0.86 | 10 | 2 | 1.74 | 0.08 | 5 | 1 | 1.19 | 0.23 | 0 | 0 | - | - |
| Self-image | 23 | 18 | -0.76 | 0.44 | 17 | 13 | -051 | 0.6 | 0 | 3 | 2.18 | 0.03 | 10 | 2 | 1.74 | 0.08 | 5 | 0 | 1.86 | 0.06 |
| Work task | 10 | 8 | -0.47 | 0.64 | 16 | 18 | -2.08 | 0.04 | 15 | 7 | 0.85 | 0.39 | 14 | 3 | 2.05 | 0.04 | 0 | 0 | - | - |
| Child care | 40 | 26 | 0.05 | 0.96 | 0 | 7 | -3.4 | 0 | 10 | 2 | 1.17 | 0.08 | 5 | 1 | 1.19 | 0.23 | 0 | 0 | - | - |
| Intercourse | 10 | 10 | -1.08 | 0.28 | 15 | 15 | -1.4 | 0.15 | 15 | 10 | 0.05 | 0.96 | 10 | 1 | 2.2 | 0.03 | 5 | 0 | 1.86 | 0.06 |
| Relationship with medical professionals | 45 | 30 | -0.18 | 0.85 | 5 | 5 | -0.71 | 0.47 | 0 | 0 | - | - | 5 | 1 | 1.19 | 0.23 | 0 | 0 | - | - |
| Lack of confidence in the treatment | 15 | 11 | -0.34 | 0.73 | 15 | 17 | -1.95 | 0.05 | 5 | 4 | 0.32 | 0.75 | 10 | 0 | 2.71 | 0.01 | 10 | 4 | 0.91 | 0.36 |
| Worries about infertility | 10 | 9 | -0.78 | 0.43 | 10 | 15 | -2.45 | 0.01 | 15 | 9 | 0.24 | 0.81 | 5 | 0 | 1.86 | 0.06 | 15 | 3 | 2.22 | 0.03 |

Table 3. **Response frequencies in the two groups**

| | Response frequencies (%) | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Never | | Rarely | | Sometimes | | Often | | Always | |
| | Study | Control | Study | Control | Study | Control | Study | Control | Study | Control |
| Pain | 27.27 | 30.55 | *7.27* | *38.89* | 47.27 | 27.78 | 9.09 | 0 | 9.09 | 2.78 |
| Control and powerlessness | 18.18 | 16.67 | 43.64 | 72.22 | 10.90 | 8.33 | 9.09 | 0 | 18.18 | 2.78 |
| Emotional well-being | 7.27 | 22.22 | 29.09 | 55.55 | 27.27 | 13.89 | 27.27 | 5.55 | 9.09 | 2.78 |
| Lack of social support | 27.27 | 44.44 | 45.45 | 47.22 | 18.18 | 5.55 | 9.09 | 2.78 | 0 | 0 |
| Self-image | 41.82 | 50 | 30.91 | 36.11 | 0 | 8.33 | 18.18 | 5.55 | 9.09 | 0 |
| Work task | 8.18 | 22.22 | 29.29 | 50 | 27.27 | 19.44 | 24.45 | 8.33 | 0 | 0 |
| Child care | 72.23 | 72.22 | 0 | 19.44 | 18.18 | 5.55 | 9.09 | 2.78 | 0 | 0 |
| Intercourse | 18.18 | 27.77 | 27.27 | 41.67 | 27.27 | 27.27 | 18.18 | 2.78 | 9.09 | 0 |
| Relationship with medical professionals | 81.82 | 83.33 | 9.09 | 13.89 | 9.09 | 0 | 0 | 2.78 | 0 | 0 |
| Lack of confidence in the treatment | 27.27 | 30.55 | 27.27 | 47.22 | 9.09 | 11.11 | 18.18 | 0 | 18.18 | 11.11 |
| Worries about infertility | 18.18 | 25 | 18.18 | 41.67 | 27.27 | 25 | 9.09 | 0 | 27.27 | 8.33 |

## Discussions

Our results show that one of the most common symptoms of endometriosis, chronic pelvic pain, affects women's daily activities, the majority of the respondents in the study group feeling that the symptoms overtook their lives. This sense of lack of control is one of the most significant topics related to endometriosis, and is itself related other emotional or psychological problems. Chronic pelvic pain interferes with the quality of life and, as shown in our study, with women's careers. Several studies discuss the link between endometriosis and chronic pelvic pain and also the impact of chronic pain on women's lives; their findings suggest that psychological factors may be involved, which influence pain experience in women with endometriosis [22-24].

An essential domain in the life of modern women is self-image, which had been altered due to the endometriosis. More accurately, a high proportion of women in the study group did not have a favorable self-image, an effect that can greatly impact productivity, self-trust, and the ability to build healthy relationships. Clearly, further studies are needed to fully understand the impact of the symptoms of endometriosis on women's self-confidence and image; at the same time, it is important to guide them towards professional help.

In our study, 52.72% of the women perceived that the symptoms interfered with their career. Regarding the work domain, endometriosis seems to be associated with reduced working ability, especially in women with severe endometriosis. Sperschneider et al. recommend psychological support for patients to improve the quality of their working life [25].

As hypothesized, the majority of the women with endometriosis also have fertility problems, a critically important issue in most women's lives. The proportion of women who developed depressive symptoms because of fertility issues was high, especially in nulliparous women. Although we do not discuss gynecological treatment or management in this paper, we note that the Endometriosis fertility index (EFI) and biological markers such as CA-125 or IL-6 [2,26] can be useful in predicting fertility problems. Severe cases of endometriosis benefit from surgical treatment, and eventually, the majority of the

women with endometriosis are able to carry a pregnancy. Thus, there is need for these women to be referred to health care professionals so that they can understand and cope with the situation. In this respect, the EHP-5 questionnaire could be more widely used to help identify women who may need special attention in terms of mental health care.

Moreover, infertility carries a significant psychological burden for the couple, with women being significantly more vulnerable to the psychological consequences of infertility than men. This consequence affects the quality of life of couples undergoing infertility treatment. Iordachescu et al. have recently published data on emotional disorders, marital relationship, and social support associated with infertility in Romanian couples [27].

In sexually intimate relationships, endometriosis has an important impact on the quality of sex life, due to dyspareunia and painful sexual intercourse. We found a substantial impact, 54.54% of women reported that endometriosis negatively affected their sexual life, compared to the results obtained by Bernuit et al. (33.5%) and Fourquet et al. (71%) [20,28]. This in turn can negatively affect their relationships, in some cases, contributing to their breakdown [29].

We found that 45.45% of the respondents in the study group were frustrated about the treatment. This may reflect the inefficacy of the treatment or the high risk of relapse that characterizes endometriosis.

Finally, we note that the EHP-5 is a user-friendly and suitable tool that can help gynecologists identify and refer women with endometriosis to health care professionals that may use a multidisciplinary approach to the management. Psychological assessment may be recommended for women with endometriosis to reduce the impact of endometriosis on the quality of life and psychological well-being of these patients as much as possible.

## Conclusions

The present study aimed at quantifying the social and psychological impact of the symptoms of endometriosis on a Romanian urban sample. We conclude that the symptoms of endometriosis, especially chronic pelvic pain and mood swings, represented significant negative factors in women's lives, affecting daily activities and especially their careers. Furthermore, psychological support is essential for these patients in order to improve their life quality.

## Conflict of interest disclosure

There are no known conflicts of interest in the publication of this article. The manuscript was read and approved by all authors.

## Compliance with ethical standards

Any aspect of the work covered in this manuscript has been conducted with the ethical approval of all relevant bodies and that such approvals are acknowledged within the manuscript.

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