


Analysis of the influence of endometriosis on quality of life

Análise da influência da endometriose na qualidade de vida

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Date of first submission: August 9, 2021

Last received: March 21, 2022

Accepted: May 11, 2022

Associate editor: Ana Paula Cunha Loureiro

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Abstract

Introduction: Endometriosis is a disorder that can significantly affect quality of life (QOL) and interfere in biological, psychological, social, marital and family aspects. **Objective:** To analyze the influence of endometriosis on the QOL of women diagnosed with the disease. **Methods:** The study was carried out from March to April 2018, with 10 volunteers from the Santa Casa de Misericórdia do Pará Foundation, with a clinical diagnosis of endometriosis. The Portuguese version of the endometriosis health profile questionnaire (EHP-30) was applied in order to assess QOL in women with this pathology. **Results:** The sociodemographic results revealed a predominance of women aged between 29 and 55 years, most of whom were married (6) and high school graduates (5). Seven of the ten volunteers had previous pregnancies. Of the aspects evaluated in the EHP-30, 79% of the items associated with pelvic pain in the core questionnaire were present in the participants. In other questionnaires, sexual life (82%) was the most affected index, followed by professional life (70%) and infertility (58.82%). **Conclusion:** The aspects of QOL most impacted by pelvic pain associated with endometriosis in the women evaluated were sexuality and professional life, leading to biopsychosocial trauma.

Keywords: Endometriosis. Pelvic pain. Quality of life.

Resumo

Introdução: A endometriose é um distúrbio que pode atingir amplamente a qualidade de vida (QV) e interferir no âmbito biológico, psicológico, social, marital e familiar. **Objetivo:** Analisar a influência da endometriose na QV de mulheres portadoras dessa patologia. **Métodos:** O estudo foi realizado no período de março a abril de 2018, com dez voluntárias da Fundação Santa Casa de Misericórdia do Pará, que apresentavam diagnóstico clínico de endometriose. Aplicou-se o Questionário de Qualidade de vida em Endometriose (EHP-30), versão em português, a fim de avaliar a QV em mulheres com endometriose. **Resultados:** Os resultados sociodemográficos mostra-ram uma predominância de mulheres com idade entre 29 e 55 anos, sendo a maioria casada (6) e com colegial completo (5). Sete das dez voluntárias tiveram gestações. Dentre os âmbitos avaliados pelo EHP-30, o questionário central de QV relacionado à dor pélvica teve 79% dos itens comprometendo as participantes. Nos demais questionários, a vida sexual (82%) foi o índice mais afetado, seguido da vida profissional (70%) e infertilidade (58,82%). **Conclusão:** Nas mulheres avaliadas, os aspectos da QV mais influenciados pela dor pélvica relacionada à endometriose foram a sexualidade e a vida profissional, acarretando prejuízos biopsicossociais.

Palavras-chave: Endometriose. Dor pélvica. Qualidade de vida.

Introduction

Endometriosis (EDM) is a chronic inflammatory pathology characterized by the growth of tissue histologically similar to the endometrium outside the uterine cavity, which typically affects organs in the peritoneum or pelvis, such as the ovaries and rectovaginal septum. It is one of the most frequent pelvic disorders with no defined etiology.¹ While its prevalence is still unknown, 2 to 10% of women of childbearing age may be affected by EDM and 50% of women who have chronic pelvic pain (CPP) may be diagnosed with the disorder.² It is estimated that 10% of women of reproductive age, 30 to 50% of infertile women and 3 to 5% of postmenopausal women may be diagnosed with EDM.³

Symptoms of the disease are variable and non-specific, mostly associated with dysmenorrhea, dyspareunia, CPP, infertility, and urinary or intestinal

disorders, making diagnosis difficult.⁴ The main symptoms are: pain and infertility, with some women suffering extreme pain (CPP).⁵ It is believed that, in addition to chronic disease, CPP can cause physical, psychological and social damage, negatively impacting the daily life of these women.⁶

Concerns regarding QOL have been raised in the fields of human and biological sciences, since there is a need to manage symptoms, reduce mortality and improve life expectancy.⁷ According to the World Health Organization (WHO), QOL is "the individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns".⁸ EDM is a disorder known to profoundly affect QOL and interfere in biological, psychological, social, marital and family aspects. As such, the present study seeks to analyze how EDM impacts the QOL of women and identify which areas are most affected, since there are limited scientific research carried out on this topic, despite being a widely prevalent pathology among the population.

Methods

Ethical guidelines

This study complied with the Declaration of Helsinki and the Nuremberg Code guidelines, in line with ethical standards for research with human beings, as stipulated in resolution 466/2012 of Brazil's National Health Council,⁹ and was approved by the Plataforma Brasil Ethics Committee of the Santa Casa de Misericórdia do Pará Foundation (protocol no. 2.517.800) and Outpatient Complex Management (GAMB) under protocol no. 018/2018 - GPES/DEPE.

Study area, period and design

This descriptive observational cross-sectional quantitative study was conducted at the women's outpatient clinic of the Santa Casa de Misericórdia do Pará Foundation, from March to April 2018.

Sample

The sample consisted of ten volunteers from the women's outpatient clinic of the Santa Casa de

Misericórdia do Pará Foundation, according to the following inclusion criteria: age between 18 and 60 years, one year or more after endometriosis diagnosis, and symptoms of pelvic pain. All participants gave written informed consent. Pregnant women, women with other urogynecological disorders and/or some type of psychological or physical disorder that did not allow the questionnaire to be applied because it interfered with data analysis were excluded from the research.

Data collection instrument and procedure

Between March and April 2018, at a set time in the morning or afternoon according to the availability of the volunteers and the chosen institution, an interview was carried out to evaluate pelvic pain, and QOL was assessed through the Endometriosis Health Profile Questionnaire (EHP-30).¹⁰

Developed by Jones et al. in 2001 at Oxford University,¹¹ and translated and validated into Brazilian Portuguese by Mengarda in 2008,¹⁰ the EHP-30 was the first method used to assess QOL specifically related to endometriosis. With a view to determining and measuring which aspects of QOL are influenced by this pathology, the EHP-30 is a self-administered core questionnaire containing thirty items and five dimensions (pain, control and powerlessness, emotional well-being, social support and self-image), and a modular questionnaire, with 23 items divided into six scales: sexual relationships, work, doctor-patient relationship, infertility, relationship with child/children and treatment. Each scale corresponds to sections marked by the letters A to F, respectively, and is transformed into a score ranging from 0 to 100, where zero represents the best QOL and 100 the worst. A score ranging from 0 to 4 is attributed to each item, where: 0 = never, 1 = rarely, 2 = sometimes, 3 = often and 4 = always. According to Marqui,¹² only three studies applied this questionnaire, but compared to the SF-36, which is the most widely used questionnaire to assess quality of life in endometriosis and measure QOL in general, the EHP-30 proved to be more precise and adequate, since it is specific to the pathology in question.^{10,13-15}

In addition, the present study differs from other investigations by evaluating QOL in women with a proven clinical diagnosis of endometriosis for one year or more, using a specific tool to assess the disease.

Statistical analysis

After research was carried out, data from the questionnaires, extracted from the assessments and tabulated in an Excel spreadsheet, were compared. Next, for data analysis, the IBM SPSS program (Statistical Package for the Social Sciences) was used, where test selection for statistical analysis depended on the types of distributions found and data homogeneity of the respective variances. The Kolmogorov-Smirnov test was used to assess normality, and the Spearman's nonparametric statistical test for data comparison. The level of rejection of the null hypothesis was set at 0.05 or 5%.

Results

Ten volunteers aged between 29 and 55 years were selected, most of whom were in a committed relationship. Two criteria were used for demographic data analysis: schooling level and marital status. Five of the women have a high school diploma, six are married and seven had previous pregnancies.

The data exhibited in Table 1, obtained from the EHP-30 questionnaire, show that the daily tasks of approximately 39% of the women were compromised due to pelvic pain, over 40% had to give up some of their daily activities at some point and only 20% never had to stop performing their tasks due to pain.

The interview (Table 2) revealed that eight participants reported a pain level of 10 (worst pain possible), one of 8 and one of 6, as measured by the visual analogue scale (VAS). It can be concluded that their lives were affected by pain and that they experienced some level of discomfort during sexual relations.

Table 3 shows that seven women had previous pregnancies, three had a miscarriage and six had live children. In regards to childbirth complications, most suffered episiotomy and postpartum hemorrhage. With respect to infertility concerns, it was concluded that this was not an issue for most participants, as they already had children.

Considering $\alpha = 0.05$ and $n = 10$, there is no evidence to reject the data normality hypothesis for all variables; that is, pelvic pain directly affects the sexual life of the study participants, causing a feeling of frustration in some women because they did not enjoy sexual intercourse.

Table 1 - Results of the Endometriosis Quality of Life Questionnaire (EHP-30)

Interval	Frequency				Mean	Standard deviation
	0-25	25 - 50	50 -75	75-100		
Section A	3	1	1	5	35.0	35.4
Section B	5	2	1	2	37.5	53.0
Section C	2	1	1	6	67.5	46.0
Section D	6	3	0	1	12.5	17.7
Section E	3	0	3	4	41.7	59.0
Section F	5	1	2	2	43.8	44.2
Core	0	2	7	1	49.1	15.3

Note: Interval 0 = best quality, 100 = worst quality of life; Section A = sexual relationship, B = work, C = doctor/patient relationship, D = infertility, E = relationship with child/children, F = treatment.

Table 2 - Pain assessment

Participants	Ovulation pain	Premenstrual pain	Pain other than cramps	Severe pain during sex	Groin pain when lying down	Post-sex pelvic pain lasting hours/days	Full bladder pain	Joint/muscle pain	Menstrual pain	Post menstrual pain	Post-sex burning vaginal pain	Pain when urinating	Lower back pain	Migraines	Pain when sitting
1	0	0	0	10	0	5	0	0	0	0	0	0	4	0	0
2	0	8	10	0	0	10	10	10	10	10	10	10	10	10	10
3	6	0	10	8	0	7	0	7	8	0	9	7	7	10	0
4	0	5	4	0	0	0	0	0	10	0	0	4	0	0	0
5	10	10	10	10	8	10	10	10	10	10	8	10	10	5	8
6	7	7	0	8	5	0	3	0	8	0	0	0	4	5	3
7	10	7	10	5	4	5	5	6	10	6	5	0	6	10	4
8	10	10	10	10	10	10	10	10	10	0	10	0	10	10	0
9	5	6	2	0	2	0	1	3	6	0	2	0	2	2	0
10	2	8	0	0	5	0	3	10	10	6	0	3	10	10	6

Note: 0 = no pain to 10 = worst possible pain.

The professional activities of most volunteers with endometriosis (70% according to the EHP-30 questionnaire) were compromised due to pelvic pain. Only 30% of participants reported never experiencing work problems due to endometriosis-related pelvic pain, 4% rarely suffered from this issue, 12% reported

occasional difficulties, 6% often had their work routine compromised and 48% indicated that this type of pain has always interfered with professional activity.

With regard to urinary symptoms (Table 4), four participants reported urine leakage on exertion, six experienced recurrent urinary tract infection, two

hematuria, eight complained of a full bladder feeling after urination, most reported between three and six bathroom visits during the day, eight mentioned nightly bathroom visits and seven experienced voiding urgency.

In relation to pelvic congestion syndrome (Table 5), nine women were sexually active and seven felt pain during sexual intercourse, which caused them to avoid

it. Seven women reported worsening pain in the pelvic region after physical activity, nine improvement in pelvic pain at rest, seven dyspareunia, eight pain or throbbing after sexual intercourse, three migratory pain, and four reported that pelvic pain ceased spontaneously. Only one participant underwent physical therapy to control endometriosis-related pelvic pain; the others resorted to surgeries and painkillers.

Table 3 - Obstetric history

Participants	Previous pregnancies	Miscarriages	Living children	Complications
1	4	2	2	Episiotomy; Cesarean
2	4	0	4	Episiotomy
3	0	0	0	-
4	1	1	0	-
5	3	1	2	Episiotomy and postpartum hemorrhage
6	1	0	1	Episiotomy
7	0	0	0	-
8	2	0	2	Episiotomy
9	0	0	0	-
10	1	0	1	Cesarean

Table 4 - Urinary symptoms

Participants	Urine leakage on exertion	Recurrent urinary infection	Hematuria	Feeling of a full bladder after urination	Bathroom visits	Nightly bathroom visits	Urinary urgency
1	Yes	Yes	No	Yes	3-6	3	Yes
2	Yes	No	Yes	Yes	7-10	4 or more	Yes
3	No	Yes	No	Yes	3-6	2	No
4	No	No	No	No	3-6	2	No
5	No	Yes	Yes	Yes	7-10	3	No
6	Yes	No	No	No	3-6	1	Yes
7	Yes	Yes	No	Yes	3-6	1	Yes
8	No	Yes	No	Yes	3-6	2	Yes
9	No	Yes	No	Yes	7-10	0	Yes
10	No	No	No	Yes	3-6	0	Yes

Table 5 - Pelvic congestion syndrome

Participants	Sexually active	Pain during sexual relations causes participant to avoid them	PP worse after physical activity	PP improves at rest	Deep vaginal pain or PP	Post-sex pain or throbbing	PP on alternate sides	PP ceases spontaneously
1	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
2	Yes	Yes	Yes	Yes	Yes	Yes	No	No
3	Yes	Yes	No	Yes	Yes	Yes	No	No
4	Yes	No	No	Yes	No	No	No	No
5	No	Yes	Yes	No	Yes	Yes	No	Yes
6	Yes	Yes	Yes	Yes	Yes	Yes	No	No
7	Yes	Yes	No	Yes	Yes	Yes	Yes	No
8	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
9	Yes	No	Yes	Yes	No	Yes	No	No
10	Yes	No	Yes	Yes	No	No	Yes	Yes

Note: PP = pelvic pain.

Discussion

Chronic pathologies are considered prolonged diseases that do not resolve spontaneously.¹⁶ These pathologies interfere in people's lives, impacting daily activities, decreasing vitality, and affecting family, social and work relationships.¹⁷

As demonstrated in the present study, all areas of a woman's life are affected by endometriosis, which greatly influences QOL by impairing daily activities and affecting interpersonal relationships. Even in cases where these activities are less impacted by endometriosis, it still causes physical, psychological and social trauma. Some studies, such as that by Minson et al.,⁵ relate QOL to endometriosis, using different assessment methods; however, the EHP-30 questionnaire is currently one of the most widely used instruments to identify the main effects of this disease on women's QOL.¹⁰

Most of the women reported that their sexual relationship ($\pm 82\%$) and work life (70%) were affected by the condition, with 58.82% concerned about infertility and 79% complaining of at least one aspect in the core questionnaire. Women with endometriosis experience reduced QOL, which compromises their daily activities and especially their work. About 70% of women reported some difficulty in effectively exercising their profession,

which leads to a series of emotional consequences, such as frustration, listlessness, shame, worry, in addition to absenteeism due to pain, potentially causing financial losses. As shown in the studies by Simoens et al.,¹⁸ women with endometriosis miss between 23 and 24 hours of work per week due to reduced work capacity, absenteeism due to pain and/or hospitalization or lack of cognitive and psychological abilities to perform their work tasks.^{19,20} This loss of productivity can cause a weekly financial impact of 3.5 euros in developing countries such as Nigeria and 400 euros in developed countries such as Italy.²¹

Sexual function was the most relevant QOL aspect considered by participants in the present study, since most women reported avoiding sex due to pain and, consequently, feeling guilty and frustrated. In addition, when they still engaged in sexual intercourse, they felt no pleasure. It can be inferred that due to the fact that most were in a committed relationship, the pressure they felt to achieve sexual satisfaction for themselves and their partners led to symptoms of anxiety and depression.

In 1999, Laumann²² suggested that in order to analyze female sexual function, several related factors need to be considered, such as: anxiety, depression, income,

breastfeeding, menopause, chronic diseases, infertility, oral contraceptives, antidepressants, sexual abuse, stress, religious factors, marital relationship, surgeries, and neurological, endocrine, vascular and urogynecological disease similarities. With endometriosis, factors such as infertility, surgical procedures, anxiety and depression are the most emphasized.

As in the present study, where it was shown that endometriosis symptoms (especially pelvic pain) affects marital relationships and QOL, the study by De Graaff et al.²³ revealed similar results, where many women reported being unable to start or sustain a committed relationship due to issues related to this disease.

The decrease in sexual satisfaction may be why 34% of women diagnosed with endometriosis report that their sex life is affected and 19% claim that the disease was the cause for their divorce.²⁴ For these reasons, 50 to 70% of women report that endometriosis has greatly affected their well-being, physical condition, and marital and sexual relationships.²⁵ Due to slow and ineffective treatment, participants reported an increase in aversion to sexual intercourse and that dyspareunia affected sexual satisfaction, leading to a decrease in the frequency of sexual relations.²⁶ Based on the results of the present study, it is concluded that QOL with endometriosis is not just the absence of pelvic pain, but encompasses broad and varied aspects of a woman's life in the biopsychosocial context that need to be considered in order to prescribe treatment protocols focusing on the main complaints of the patient and providing overall well-being.

Conclusion

With respect to the results obtained from the EHP-30 questionnaire, it was found that the quality of life of women diagnosed with endometriosis was compromised by pelvic pain, which affects both their professional and sexual life, with consequent psychological, physical and social impacts. Since the present study was based on a small sample size, it is not possible to extrapolate the results obtained to the reality of all women affected by endometriosis.

In light of the above, it is suggested that further research be carried out with a larger number of endometriosis patients whose primary symptom is pelvic pain in order to better clarify the impacts of this

disease and establish treatment consistent with the main complaints, in an effort to promote quality of life and a holistic health intervention.

Authors' contribution

LAR, SAA, GNF recruited individuals and conducted interviews. LAR analyzed the data and wrote the manuscript with contributions from all co-authors. EFCN developed the study design, PESA supervised the study, and both contributed to the critical revision of the manuscript. All authors read and approved the final manuscript.

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