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Women's difficulties with endometriosis regarding the diagnosis and the impact on their lives

Dificultades de las mujeres con endometriosis en cuanto al diagnóstico y el impacto en su vida

Dificuldades de mulheres com endometriose quanto ao diagnóstico e o impacto causado em suas vidas

ABSTRACT

Purpose: To know the reality of women who had late diagnosis of endometriosis and the impact of this reality on their daily routine and self-esteem. Methods: an observational study of documentary analysis and interviews, in which data were obtained from the analysis of the answers given through a virtualized questionnaire. The data and information collected corresponded to [a] Patient characteristics [b] Diagnosis-related questions, and [c] Main difficulties to reach the diagnosis. Results: A large portion of women interviewed (83.46%) heard that their behavior in the face of menstrual cramps was exaggerated. A total of 78% of women reported that their doctors expressed that their behavior towards pain was exaggerated. In addition, "scheduling a specialist doctor's appointment in the private sector" was the least reason mentioned as a difficulty that compromised the treatment (60.70%). Conclusions: Searching for alternatives in health policies, for this clinical condition, becomes essential and urgent.

DESCRIPTORS: Delayed Diagnosis; Endometriosis; Women's Health; Women's Health Services.

RESUMEN

Objetivo: Conocer la realidad de las mujeres que tuvieron un diagnóstico tardío de endometriosis y el impacto de esta realidad en su vida diaria y autoestima. Método: Estudio observacional de análisis documental y entrevistas, en el que se obtuvieron datos del análisis de respuestas a través de un cuestionario. Los datos recolectados correspondieron a las [a] características del paciente; [b] Aspectos relacionados con el diagnóstico y [c] Principales dificultades para llegar al diagnóstico. Resultados: La mayoría de las mujeres entrevistadas (83,46%) escuchó que su comportamiento ante los cólicos menstruales era exagerado. El 78% de las mujeres informaron que sus médicos expresaron su comportamiento de dolor como exagerado. Además, "concertar cita con un especialista del sector privado" fue el motivo menos mencionado como dificultad que comprometía el tratamiento (60,70%). Conclusiones: La búsqueda de alternativas en políticas de salud, para esta condición, se torna imprescindible y urgente.

DESCRIPTORES: Diagnóstico Tardío; Endometriosis; Salud de la Mujer; Servicios de Salud para Mujeres.

RESUMO

Objetivo: Conhecer a realidade das mulheres que tiveram diagnóstico tardio de endometriose e o impacto dessa realidade na sua rotina e autoestima. Método: estudo observacional, de análise documental e entrevistas, no qual se obteve dados a partir da análise de respostas feitas a partir de um inquérito online. Os dados e informações coletadas correspondiam a: [a] Características do paciente; [b] Questões relativas ao diagnóstico; e [c] Principais dificuldades para chegar ao diagnóstico. Resultados: Grande parcela de mulheres entrevistadas (83,46%) ouviu que seu comportamento perante a dor da cólica era de maneira exagerada. Um total de 78% das mulheres relataram que seus médicos expressaram que o comportamento frente a dor era exagerado. Além disso, "marcar especialista no privado" foi o motivo menos apontado como dificuldade que comprometeu o tratamento (60,70%). Conclusões: Buscar alternativas nas políticas de saúde, para esta condição clínica, se torna essencial e urgente.

DESCRIPTORES: Diagnóstico Tardio; Endometriose; Saúde da Mulher; Serviços de Saúde da Mulher.

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INTRODUCTION

Known as the modern woman's disease, endometriosis is an estrogen-dependent gynecological pathology that affects women of reproductive age, which affects 6,5 million women in Brazil and 176 million in the world.^{1,2} Its pathophysiology is characterized by the growth of endometrial tissue outside the uterine cavity, which may infiltrate the external and internal genital cavity, such as the peritoneum and myometrium, or reach extragenital organs, such as the bowel and bladder.¹ Despite being a benign disease, it has no cure and is closely linked to female infertility and symptoms such as pelvic pain are debilitating factors for most carriers.³ In this way, endometriosis brings a psychological, social and economic context to contemporary women, who are part of the labor market and who put their professional training first, and then marry and have children.^{4,5,6}

Because of this, this theme is so important nowadays, and that, due to the extensive symptomatology and uncer-

tain etiology, it presents a difficult and late diagnosis, further aggravating the patient's physiological and psychological order.⁷ And it is in this scenario that the problematization of this research arises: what are the main situations experienced and difficulties encountered by women during their late diagnosis process of endometriosis?

One of the main aggravating factors in delayed diagnosis is the devaluation, by the patient, of her pain, as it is culturally silenced since it is new, while it is taught to normalize the pain, since menstrual cramps start at menarche and then the labor pains. Thus, the lack of knowledge of the main signs and symptoms can mask the disease and prevent the patient from seeking assistance;^{5,7} in addition, family and medical negligence, molded within social structures, on women's pain, and the "psychiatrization" of women's problems, which leaves these women at the mercy of medicines such as fluoxetine and affirms the social stigma that associates the woman figure to hysteria, preventing a deeper investigation of the case and, consequently, the search for the correct diagnosis.⁸

The solution is based on the dissemination of information about the disease, so that, along with self-knowledge of their bodies, women can identify problems in their health, added to the social demystification of the supposed intimate relationship that females have with pain; for family support and for the humanization of care by the health professional, valuing all the patient's complaints, so that there is a reduction in diagnosis time, anticipation of the start of treatment and reduction of complications of the disease.

Finally, this work seeks to know and expose the main situations experienced and difficulties encountered by women during their late diagnosis process of endometriosis, and propose a reflection on how it is possible to improve the condition and quality of life of these women. Even though it is a known disease, social paradigms and devaluation of symptoms mask an early diagnosis and force patients to enter into a long search for different health professionals, in order to eagerly find a solution to the problem. After all, despite being benign, endometriosis is cruel, and within its va-

riations and complications, it can take away the natural female right to consolidate her offspring and compromise her professional life, knocking out the patients' psychology.

METHOD

An observational study of document analysis and interviews was carried out, in which data were obtained from the analysis of responses made from a virtualized questionnaire. The data and information collected corresponded to: [a] Diagnosis aspects: waiting time, misdiagnosis, [b] Psychological impacts during waiting and [b] Main difficulties in obtaining the diagnosis: Examinations, access to specialists, medical management (Figure 1).

This study was carried out through an online survey of women diagnosed with endometriosis. It was developed in a virtualized way via the GoogleForms® platform due to the COVID-19 pandemic; this being made available in groups of women with endometriosis on social networks, with the consent of the group

moderators, from July to September 2020.

As it involves human beings, the current legislation in Brazil was respected, and the present project was submitted to the Research Ethics Committee (CEP) of UNIVILLE, being assessed and evaluated as approved obtaining approval protocol with registration CAAE 26897619.2.0000.5366. The TCLE was virtualized, having a first page with just the term, so that participants do not read the questions before accepting to participate in the research. To confirm acceptance, there were then two links: "I am over 18 and I accept to participate" and "I do not wish to participate".

The study population consisted of women who reported having had a diagnosis of endometriosis after 5 years, and the sample was defined based on the prevalence of women with endometriosis in Brazil (6,5 million) in which a 95% confidence level was established with 5% margin of error; being then determined the number of 385 women in the stipulated clinical conditions. Time

was defined as that counted from the date of the first disabling pain; and who were in menacme. Women who did not fit these conditions, who did not accept to participate in the research or who incompletely filled out the questionnaire were excluded from the research.

Data collection from patients took place through an interview. They were registered in a standard form developed by the researchers; present on a GoogleForms® online access platform. Then, the data were plotted in an Excel® spreadsheet and grouped according to the study variables raised above. The plotted data were expressed in graphic forms for further analysis and discussion of the results found.

RESULTS

The questionnaire was answered by 678 women from the 5 regions of the country. Of these, 623 met the inclusion and exclusion criteria, and 405 responded that it took 5 years or more to have the diagnosis and were within the established sample.

In the approach on "Aspects of diagnosis", it was noted that the vast majority waited for more than 6 years to have the diagnosis, corresponding to about 55.83% of the sample, which are subject to the difficulties that women present when do not present the adequate treatment for endometriosis (Figure 2).

A large portion of women interviewed – who took more than 5 years to diagnose (83,46%) – frequently heard, either from their friends or family members, that their behavior towards the pain of colic was exaggerated (figure 3).

When asked about the medical attitude towards pain complaints during consultations, the vast majority (78%) reported that their physicians often referred to their behavior as "exaggerated behavior" (Figure 4). This condition generated a certain negative psychological impact on women, as they began to doubt what they felt and how they dealt with pain, in which many (about 50%

Figure 1: Research process included a virtualized questionnaire made available to groups of women with endometriosis in digital media. Of the total answered, those with a diagnosis of more than 5 years were separated for data analysis on the impacts of this delay, as well as the difficulties in having the diagnosis.

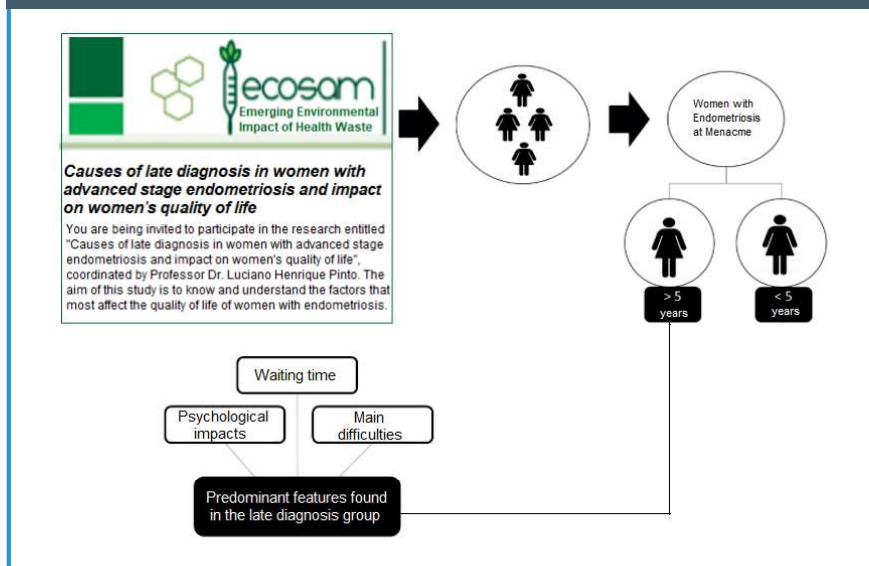


Figure 2: Time interval between the first symptoms and the definitive diagnosis, in years. Predominance of the sample evaluated over six years

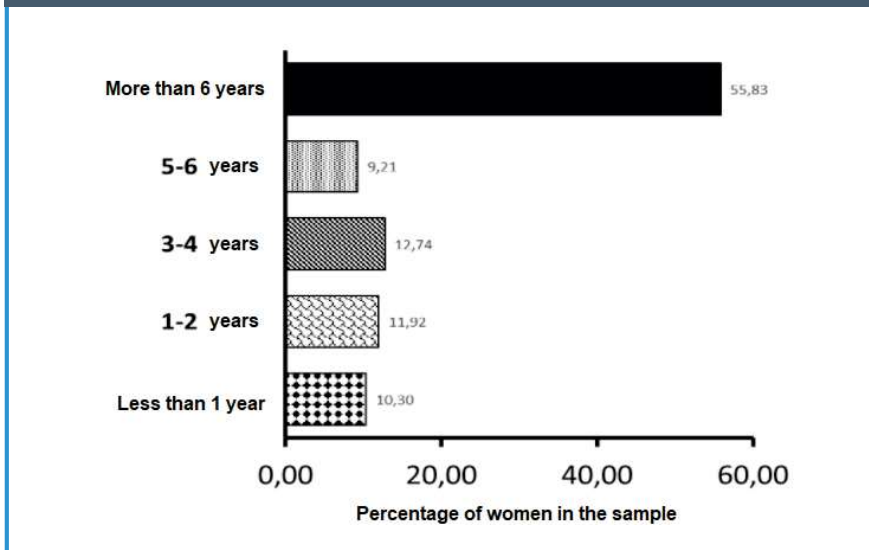


Figure 3: Percentage of women who heard from friends and family about the exaggeration in their behavior regarding the pain they reported

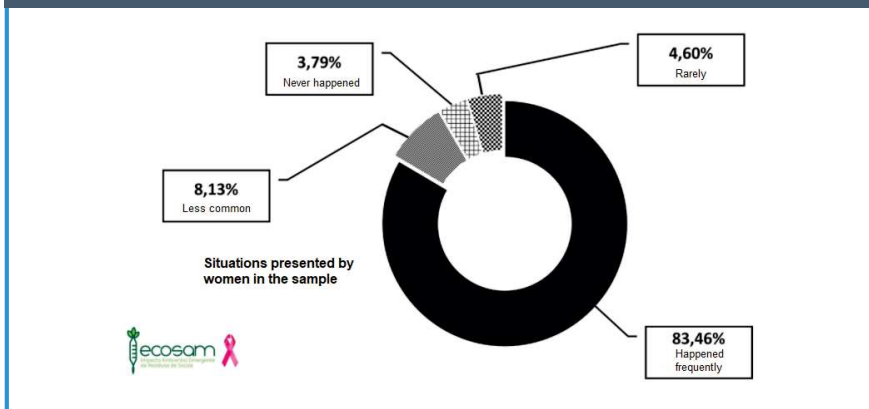
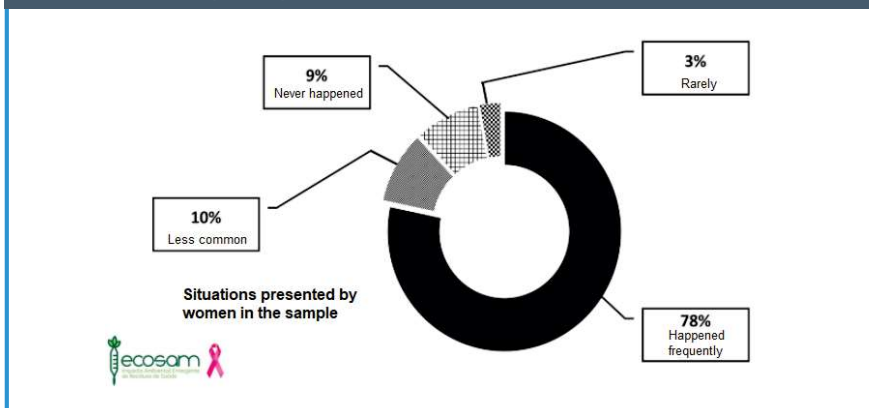


Figure 4: Percentage of women who heard from doctors about the exaggeration in the behavior regarding the pain they reported



of this group after 5 years of diagnosis) sought some psychiatric treatment.

Regarding the approach "main difficulties until diagnosis", the items "consultation with specialists in private", "performing exams in private" and "doctor not suspecting the diagnosis" were pointed out by the vast majority as difficulties in delaying the diagnosis of the treatment. Few reported being able to overcome this condition of delay with the help of friends and family, the most frequent condition being delay in accessing what could advance the diagnosis (Figure 5).

DISCUSSION

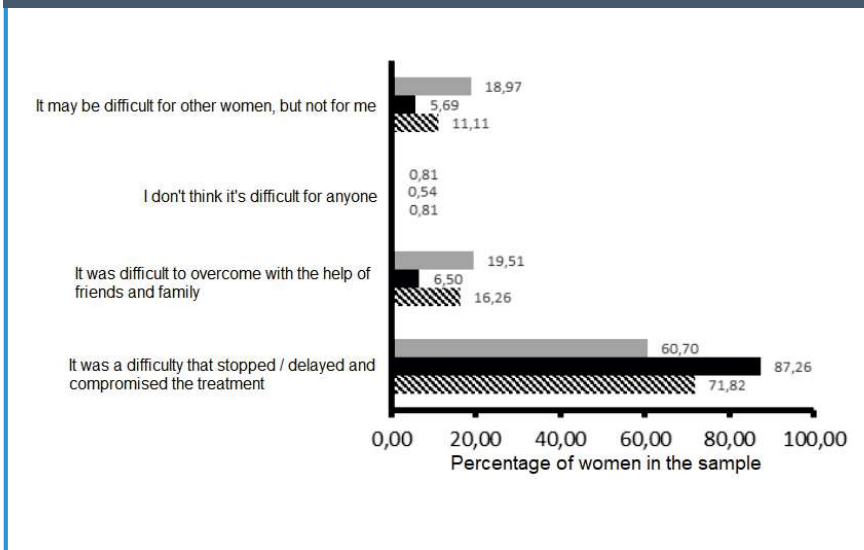
The pelvic pain present in endometriosis is the result of an inflammatory process arising from the growth of ectopic endometrial tissue, this phenomenon being hormone-dependent and also related to immunological problems.⁹

The endometrial tissue that should be eliminated by the vagina exits through the fallopian tubes, in a process known as "retrogressive menstruation", in which the endometrium adheres to other tissues, leading to an extremely painful inflammatory process. The immune system, in turn, would be responsible for the elimination of such endometrial nodules, but if it is not capable, the clinical condition is established.⁸ Since the disease and its mechanism are unknown, the pelvic pain of endometriosis is easily confused with common menstrual cramps, being wrongly treated, and socially considered an exaggeration on the part of the woman when feeling such pain.

In addition to this lack of knowledge, structural machismo is highlighted as responsible for a large part of the undervaluation of the pain felt by women. The structural neglect caused by gender issues, as well as deficiencies in the care network, reflects in the psychiatry of female suffering.⁸

By being culturally silenced, women start to normalize their pain, in a way

Figure 5: Main difficulties presented by the women in the sample to obtain the diagnosis and treatment



that even contributes to the delay in diagnosis. Still, even after being diagnosed, when analyzing the treatment provided for the disease, there is a greater risk of inadequate pain relief in relation to men, portraying, once again, the socially inserted cultural stereotype.⁹

Despite the fact that the studied group reported the passivity of medical professionals regarding complaints of intense pain, the delay cannot be restricted to professional conduct. This is

a factor to be worked on by encouraging the humanization of medical actions, but the system is also a limiting factor. Access to examinations and specialist doctors by SUS is another issue to be evaluated and considered. Laparoscopy is now the gold standard for diagnosis, however, the definitive diagnosis is still obtained through a biopsy and, therefore, it depends on an invasive surgical procedure to obtain this material. Surgery, however, is only performed in

cases where there is a strong clinical suspicion of endometriosis. Thus, the delay in diagnosis can mean the chronicity of the disease, regardless of its stage and complications.⁶

CONCLUSION

The prevalence of pain, the delay in diagnosis and infertility are outstanding features in the framework of endometriosis. The disease remains surrounded by myths, little known and understood by women themselves. This work allowed us to know and expose the main situations, in which the issue of a considerable delay until the diagnosis, the lack of family understanding, stands out; failures in the health system for quick access to exams and consultations with specialists. Issues that for most are difficult to be overcome and impact the delay for the referral of treatment.

It is necessary, then, to guarantee access to quality public service and expand the dissemination of the problem, in order to contribute to the identification of the signs and symptoms of the disease, so that the complaints of women are not devalued and there is a deconstruction of cultural myths, in addition to the recognition of this important theme. ■

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