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EVEN SILENCE HAS AN END: INFORMATIVE STUDY ON ENDOMETRIOSIS AND ITS SIGNS/SYMPTOMS

NÃO HÁ SILÊNCIO QUE NÃO TERMINE: ESTUDO INFORMATIVO SOBRE ENDOMETRIOSE E SEUS SINAIS/SINTOMAS

NO HAY SILENCIO QUE NO TERMINE: ESTUDIO INFORMATIVO SOBRE LA ENDOMETRIOSIS Y SUS SEÑALES/SÍNTOMAS

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ABSTRACT

Objective: to inform (in the sense of *to alert*) about the signs and symptoms of endometriosis referred to in the literature, and their importance in the reduction of delay in diagnosis. **Methods:** informative study. Data were collected from specialized literature found in articles published in the databases MEDLINE, PubMed, Sociological Abstracts, as well as in textbooks. Initial findings were read, analyzed and analytically described by the authors. **Results:** signs and symptoms such as dysmenorrhea, dyspareunia, menorrhagia, among others, receive little attention from health professionals and are not sufficiently investigated by them. This strongly contributes to the delay in the diagnosis of endometriosis, leading to a prolonged interval between the onset of symptoms and the final diagnosis. **Conclusion:** gender issues contribute to a delay in the diagnosis of endometriosis. Advertising strategies may help solve this problem. **Descriptors:** Delayed Diagnosis; Endometriosis; Nursing; Women's Health; Public Health.

RESUMO

Objetivo: informar, no sentido de alertar, para os sinais e sintomas da endometriose, referidos pela literatura, e sua relação com a importância na diminuição do *delay* para o diagnóstico. **Método:** estudo informativo com dados obtidos por meio de literatura especializada, encontrados em artigos nas bases de dados MEDLINE, PubMed, Sociological Abstracts, bem como livros didáticos. Os achados passaram por leitura, análise e descrição analítica. **Resultados:** sinais e sintomas, tais como, dismenorreia, dispareunia, menorragia, entre outros, são pouco valorizados e investigados pelos profissionais de saúde, sendo um fator fortemente contribuinte para o atraso no diagnóstico da endometriose, causando uma grande distancia entre o início dos sintomas e o diagnóstico definitivo. **Conclusão:** aspectos de gênero contribuem para o *delay* para o diagnóstico da EDM e estratégias de divulgação podem ajudar para resolução do problema. **Descritores:** Diagnóstico Tardio; Endometriose; Enfermagem; Saúde da Mulher; Saúde Pública.

RESUMEN

Objetivo: informar (en el sentido de alertar) sobre las señales y los síntomas de la endometriosis referidos por la literatura, así como su relación con la importancia en la disminución del retraso diagnóstico. **Método:** estudio informativo con datos obtenidos de la literatura especializada y encontrados en artículos publicados en las bases de datos MEDLINE, PubMed, Sociological Abstracts, además de libros didáticos. Se realizó la lectura, análisis y descripción analítica de los hallazgos. **Resultados:** señales y síntomas tales como dismenorreia, dispareunia, menorragia, entre otros, son poco valorados e investigados por los profesionales de la salud, lo que resulta en un factor contribuyente al retraso en el diagnóstico de la endometriosis, generando una gran distancia entre el inicio de los síntomas y el diagnóstico definitivo. **Conclusión:** aspectos de género contribuyen al retraso en el diagnóstico de la endometriosis y estrategias de divulgación pueden ayudar en la resolución del problema. **Descriptor:** Diagnóstico Tardío; Endometriosis; Enfermería; Salud de la Mujer; Salud Pública.

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INTRODUCTION

Endometriosis (EDM) is a progressive, immune-dependent and estrogen-dependent disease, showing a chronic character. It is one of the main causes of gynecologic hospitalization in industrialized countries¹, and has been acknowledged as a recent problem, since it has only recently been noticed by scientists.¹⁻⁵ Its first reference in the literature actually appears in the book *Disputatio Inauguralis Medica de Ulceribus Ulceri*, and it is attributed to Daniel Shroen in the seventeenth century (1690). In 1860, Carl Freiherr Von Rokitansky (in his work *Uterusdrüsen-Neubildungen in Uterus und Ovarial-Sarcomen*) described the presence of the endometrium outside the uterine cavity. Thirty years later, Friedrich Von Recklinghausen postulated that the disease would be caused by persistence in the pelvis.⁶ It was only in 1921/1927, however, that EDM was described by Albert Sampson as it has been known ever since.⁶⁻⁸

Endometriosis is characterized by the presence and growth of functional endometrial tissue in atypical places, i.e. outside the uterine cavity.^{2-5,7,9-13} The name *endometriosis* originates from the word *endometrium*, the internal lining of the uterus that grows during every menstrual cycle and is eliminated during menstruation¹⁴ Thus, the formation of endometriotic lesion (also referred to as endometriotic implant/tumor/node) involves the dissemination of endometrial tissue into the peritoneal cavity during menstruation. Endometrial cells adhere to mesothelium, there is proliferation, differentiation and subsequent inflammatory response, and invasion below the tissue²

The inflammatory process mentioned above is triggered by the menstrual bleeding, since endometrial lesions respond to cyclical hormonal stimulation. The expected shedding of the endometrial tissue also occurs with the lesions (a kind of *mini-menstruation*³). The bleeding triggers an inflammatory reaction mediated by prostaglandins,^{5,14} with subsequent fibrosis and adherence to adjacent organs.^{4,14-5} The elucidation of its etiology is a complex topic and it is still under study. Several theories are being investigated (lymphatic and bloodstream dissemination; immunological, embryologic, and genetic dissemination). The most known is the transplant theory, i.e. the implantation of endometrium in other locations would be caused by retrograde menstruation (Sampson's Theory, 1927). According to this

theory, endometrial tissue is mechanically transported into peritoneal cavity.^{2-5,11,14-5} More recent researches defend the multifactoriality and the integration of several factors to generate endometriosis, since the retrograde menstruation theory (which occurs in 80% of women) does not explain the genesis of the disease.^{6,11}

Implants may be located in varied sites, being more commonly found in the ovaries, posterior and anterior cul-de-sac, uterosacral ligaments, posterior leaflet of the broad ligament, fallopian tubes, uterine serous, rectovaginal septum, bladder and intestine (rectum and sigmoid). Other sites may also have implants, such as vulva, vagina, cervix, umbilical scar, episiotomy scar, laparotomy scar, lung, intestine, appendix, heart, gall bladder, brain, etc.^{2-5,11,13-5}

The presentation of the disease is manifold, affecting women's lives for a long time: from adolescence, during the immediate post-menarche period, until the post-menopause (on hormone replacement therapy). It is a common situation that affects 6%-10% of women in their reproductive age, with variable prevalence rates (depending on the studied population). For instance, in investigating infertility in women, prevalence rates are 21%-40%.^{2,5,15} This study exposes a serious public health problem: the delay in the diagnosis of EDM. This delay remains an important issue, hindering the proper management of this disease and jeopardizing the lives of numerous women.

The present article aims at contributing to the visibility of the topic by providing a state of the art about studies related to endometriosis. A literature review was conducted with this purpose in mind. Literature coverage is limited to articles published since 2008 and textbooks/specialized texts.

In the first stage of the text analysis¹⁶, the textual exploration, we identified key elements for the elucidation of the topic *endometriosis*. Signs and symptoms that suggest the occurrence of the disease were especially identified.

Commonalities among the author's descriptions of the clinical condition emerged from a floating reading. The role of health professionals involved in healthcare and their contributions were pointed out. In the second stage, the thematic analysis, we identified ideas, actions, and theoretical perspectives that support the studies (biomedical, extended care).

In the last stage of analysis, the interpretative stage, we show some

conclusions about the issue of silence/unawareness about the disease and the disservice they represent for women’s health. To reiterate, this is an informative study. Although this study was anchored to a search in health databases in order to access scientifically validated studies on this topic, there is no intention to make a systematic or integrative review of the literature.

◆ **State of the art of researches and the invisibilization of the disease**

Because this disease causes pain (many times disabling) and infertility, many women have their lives seriously compromised by it, personally and professionally.^{10,17-9}

The invisibility of the problem - whether to the population or to health professionals-negatively contributes to it. Hence, the early diagnosis of endometriosis should be promoted in order to reduce the time elapsed between the onset of symptoms and the final diagnosis. The current time interval until diagnosis is from 7,9 to 11,7 years (women’s average age is 32,4 years). Women live with this problem for a long time (oftentimes from childhood to adulthood) unaware of the diagnosis and its consequent treatment. A significant number of women first becomes aware of the diagnosis when they experience difficulties in conceiving a baby.²⁰ Based on these assumptions, the objective of this study was to inform (in the sense of *to alert*) about the signs and symptoms of endometriosis referred to in the literature, and their importance in the reduction of delay in diagnosis.

The first step to take on the way to achieving the final diagnosis is to not disregard the first signs and symptoms of the disease. They should be correctly identified and correlated to the suspicion of endometriosis. Signs and symptoms are variable among women. They may be inexistent (asymptomatic women) or highly severe (leading to incapacitation). Their intensity may vary with time, and it is not necessarily proportional to the extension of the disease.^{2-4,14-5}

Furthermore, some risk factors are pointed out as related to endometriosis, considering factors that increase exposure to estrogen as a higher risk of developing the disease.¹ Among them, there is family history, uterine malformations, early menarche (< 12 years old), short menstrual cycles (less than 28 days), prolonged menstrual flow (>1 week), dysmenorrhea, stress, caffeine and alcohol consumption, nulliparity, fewer gestations (1 or 2), late gestations, and infertility.^{1-3,6}

In overweight women, since they experience a greater exposure to estrogen, there seems to be a kind of protection, attributed to higher rates of chronic anovulation and menstrual irregularities.¹ The supposition that Caucasian women with higher education levels are more vulnerable to the disease is being refuted, since these rates are more related to the access to specialized health care services.¹⁴

The main signs and symptoms related to endometriosis, according to the literature, are listed on Table 1.^{1,3-5,7,9-14,18-9,21-3}

Table 1. Signs, symptoms, and some complications related to endometriosis.

Signs and symptoms	Information
Dysmenorrhea	It is the painful menstruation. It may be primary (related to an increase in prostaglandin production) or secondary (related to a pelvic or uterine disease).
Menorrhea	Abnormally heavy and prolonged menses (excessive in duration and/or amount).
(Deep)	Painful coitus, with differential diagnosis - primary dysmenorrhea; pelvic inflammatory disease;
Dyspareunia	irritable colon syndrome.
Infertility	Incapability of conceiving after a year of regular sexual intercourse without the use of contraception, or the incapability of carrying a pregnancy to term.
Chronic pelvic pain (CPP)	Lower abdominal pain or pelvic pain (of an intermittent or chronic character, and incapacitating intensity) for at least 6 months. Usually, women with CPP experience emotional and osteomuscular alterations, as well as alterations in other tracts. CPP is therefore characterized as a syndrome.
Ovulatory pain	Mittelschmerz (<i>middle pain</i>), also known as <i>mid-cycle pain</i> , is characterized by pain during ovulation. It is related to the contact of follicular fluid from follicles (that ruptured) with the peritoneal cavity. Women may also experience severe lower abdominal pain, heaviness sensation, clear secretion and, eventually, blood secretion, lasting up to 72 hours.
Pain radiating to the thighs	It is a common sign, suggesting deep endometrial implants located in sites with a higher number of nerve endings. Affection of the sciatic nerve.
Urinary	Located in the bladder. For instance: Cyclic, painful urination.
Dysfunctions	
Intestinal	Located in the intestine. Pain while defecating (cyclic) and diarrhea, for instance. Constipation may be present, caused by preventing evacuation due to pain.
Dysfunctions	
Pelvic adhesences	Due to the liberation of prostaglandins, which promote the appearance of adhesions, with varying degrees of anatomical distortions. There is internal bleeding (of the lesions), blood degeneration and tissue detachment, inflammation of the areas and scar tissue formation.
Pelvic mass	For instance, purplish mass in posterior fornix.
Fatigue	Resulting from the disease process.
Depression	Resulting from the disease process.
Irritability	Resulting from the disease process.
Sleep disorder	Resulting from the disease process.

The identification of the signs and symptoms listed above in centers for women's health is essential for raising the suspicion of disease and searching for diagnosis. This way treatment can be started soon and the chances of stopping disease progression increase, since endometriosis is characterized by four stages: I (minimum), II (mild), III (moderate) and IV (severe). Endometriosis diagnostic methods involve clinical examination (inspection and palpation of lesions through vaginal and rectal touch examination), level of serum marker CA-125 (collected on days 1 and 2 of the menstrual cycle, because it can be elevated - above 100 UI/ml), transvaginal ultrasonography and magnetic resonance imaging, with limited value for the diagnosis of superficial lesions;^{2-3,11,14} Moreover, the following tests can be requested: color Doppler velocimetry, computed tomography, measurement of serum C-reactive protein and anticardiolipin antibodies, among others.^{5,11}

Nurses may contribute to the process of detecting or raising the suspicion of endometriosis during nursing consultation (NC), an important favorable location/time/space for the Systematization of Nursing Assistance (SNA). The NC, as a methodological instrument for the implementation of SNA, has five stages. One of these stages is data collection or nursing history, during which signs and symptoms of endometriosis may be identified.²⁴ During gynecological examination, pain may be revealed: during uterine mobilization, in the uterosacral ligaments, in the cervix and in the adnexal region. Uterine retroversion and increased ovarian volume (which are suggestive of endometriosis but are not specific of the disease) may also be detected. Moreover, the presence of palpable nodules in the posterior vaginal fornix or recto vaginal septum, thickening of the uterosacral ligaments, and violaceous lesions in the vagina are usually suggestive of deep infiltrating endometriosis.^{6,11}

Final diagnosis is only possible through the visualization of the process: the laparoscopy (preferably videolaparoscopy). This examination allows a direct view of the abdominal cavity (internal organs) through the insertion of a flexible fiberoptic instrument, passed through a small incision in the abdominal wall. Peritoneal foci may be identified as typical (black, brown, blue or red cysts with or without fibrosis) or as atypical (petechiae, vesicles, plaques, retractions, yellow, white or red nodules).

Adhesions, peritoneal defects or changes in vascularization may also be found. A biopsy of the implant tissue is performed for diagnosis confirmation.^{2-3,7,11,13-4,18-9}

Some studies^{1,10,17,21,23} point out some reasons for the delay in the diagnosis of endometriosis. Basically, the delay is due to the unspecificity of signs and symptoms, which are usually regarded as natural. Also, *menstrual pain* is generally linked to the fact (or essence) of being "woman". Numerous women have to see several health professionals (sometimes 5 or more physicians) before the disease is finally diagnosed.^{10,17} Physicians defer ordering tests for medical investigation, which usually leads to debilitation of health. Women complain that even though there is sometimes the opportunity of achieving an early diagnosis, this chance is frequently missed.²³

The unspecificity of the clinical condition and the eventual lack of access to diagnostic methods may explain the delay in the diagnosis of endometriosis.¹ Besides, gynecologists seem not to believe that endometriosis may occur in adolescents or during menopausal transition.²³ Unfortunately, women have their symptoms dismissed and trivialized by health professionals, which lead to a significant delay between the onset of symptoms and the final diagnosis. 61% of these women are told that *nothing is wrong* the first time they look for professional help.¹⁷ For this reason, an important strategy for the reduction of delay is knowing and taking into account the signs and symptoms of endometriosis, as well as not taking them for granted during consultations.

Trivializing and neglecting symptoms such as menstrual cramps, intense menstrual flows, irritability, and dyspareunia lead to a delay in diagnosis. What is worse, such symptoms are often *normalized* and attributed to the *essence of being a woman*. Thus, they are not recognized as being so out of the ordinary. One study²¹ pointed out that health professionals, friends, and family members should not refer to this *kind of pain as something normal in women* nor should other women make remarks such as *I also had severe menstrual cramps when I was your age*. The results of this confusion and misinformation may lead to isolation of friends and family, besides the feelings of fear, frustration, and humiliation. Some strategies and attitudes may help to overcome these problems. There is the need for awareness raising campaigns, in order to spread the message that painful menstruation must be evaluated by a professional. Raising

public awareness about endometriosis may facilitate early diagnosis.^{10,17} Having people close to the women who truly valued their complaints was seen as the most common *catalyst factor* that made them search for medical treatment.¹⁷

The control of the symptoms is a proposal of treatment, not the cure, for endometriosis is a recurrent and progressive disease in 30%-60% of the cases. Symptoms should be treated, foci eliminated, progression stopped and recurrences prevented.² Conduct should take into consideration the intensity and severity of the symptoms, the wish for fertility, the degree of the disease, and the therapeutic goals of the women. Means for disease treatment include: pharmacological (Non-steroidal anti-inflammatory drug - NSAID), hormonal (progestin, levonorgestrel-releasing intrauterine system, oral contraceptives, analogues of gonadotrophin releasing hormone, letrozole, danazol and gestrinone) and surgical measures (conservative - with removal of foci, release of adhesions-, and permanent - with a hysterectomy with or without bilateral salpingo-oophorectomy).^{3-6,11-2,20}

Some integrative therapies are effective and indicated for the treatment of endometriosis, although there are not enough evidence to corroborate some of them. Among these therapies are: reflexology, homeopathy, electrical nerve stimulation, nutritional therapy, acupuncture, psycho-emotional balance, stress reduction techniques, massage, vitamin support, and physical activity, especially with aerobic exercise. Yoga and Pilates are viable alternatives.^{2,15,21}

Because this disease substantially affects women's lives (in several aspects of their lives), other actions are valid that will positively contribute to women's health. Counseling, education, and support are self-care strategies. Women look for groups and resources on the internet with the aim of understanding the problem, being accepted, etc. In Brazil, for instance, there is the Brazilian Association of Endometriosis - endometriose.org.br, as well as other support groups for women with endometriosis and their family.^{3-4,14}

The benefits such organizations could provide are varied. They are a means of amplifying awareness of the problem. For instance, March is World Endometriosis Awareness Month, symbolized by a yellow ribbon.¹⁴ In 2005, in Rio de Janeiro, was established the Law number 4.639, which created the official calendar of the State, and designated the

third week of the month of July for endometriosis and infertility prevention.

FINAL REMARKS

Women with EDM have their voices silenced by the fact that their complaints are taken for granted or, even worse, simply dismissed. This culturally imposed silence on women is achieved through gender inequality in education. Women are taught that they should suffer *innate pains*, such as menstrual cramps, labor pain, among others. The infamous expression "women's stuff" is used in order to make women accept a groundless notion that their nature is unfavorable and defective.

Women's physiology is neither imperfect nor smaller than men's physiology. Pathophysiological situations may occur to women (as well as to men), and this should not be metaphorically explained with female inferiorization. These kinds of attitudes negatively contribute to the identification of the real problem, i.e. endometriosis, causing a delay in diagnosis and promoting the complications of disease progression.

Although the diagnosis of the disease endometriosis is a physician's attribution (ICD N80), being able to recognize the main signs and symptoms of the disease is a right of the population. Identifying these signs and symptoms, and making the correlation to the problem is every health professional's duty. There are many challenges to the attention to women with EDM (like guaranteeing access to quality public service and expansion of services on health care) and the early diagnosis is one of them. One first step towards this goal may be to amplify awareness of the problem, in order to contribute to the identification of the main signs and symptoms, stop taking women's complaints for granted, deconstruct myths and start working on new ideas that are fruitful for people's recognition of this important issue.

Maybe then women with EDM will have their voices heard and valued. Perhaps what it takes is to understand and agree that, as Pablo Neruda wrote in one of his poems *even silence has an end*.²⁵

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