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REFLECTION STUDY

Endometriosis and adolescence: diagnostic delay and the role of nursing

Endometriosis y adolescencia: retraso diagnóstico y papel de la enfermería

Endometriose e adolescência: atraso diagnóstico e o papel da enfermagem

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Endometriosis (EDM) is a chronic gynecological disease that affects between 5 and 15% of women of childbearing age, characterized by the ectopic presence of the endometrium. It is considered progressive, immunological and estrogen dependent. In EDM, endometrial cell foci are found in atypical places such as: peritoneum, ovary, rectum, fallopian tube, among others. These foci have a vascular supply that enables their growth, and, during menstruation, they bleed, triggering an inflammatory reaction, mediated by prostaglandins, with subsequent fibrosis and adherence to adjacent organs. Women affected by EDM may present a diverse clinical picture, in some cases being asymptomatic. However, most of them present symptoms of varying intensity, such as: dysmenorrhea, ovulatory pain, fatigue, and the genitourinary/penetration pain disorder, also called dyspareunia[1-3].

It is estimated that there are 176 million women in the world with EDM and around 7 million in Brazil. According to the Information Technology Department of the Unified Health System (DATASUS), from January 2009 to July 2013, Brazil had 71,818 admissions due to EDM. Recent studies reveal that cases of EDM in adolescents have grown considerably, even in its profound form. According to the April 2005 publication of the American Congress of Obstetricians and Gynecologists (ACOG) Committee on Adolescence, there is a clear relationship between pelvic pain in adolescence, especially in cases of primary dysmenorrhea, and EDM. The incidence of the disease is highly variable, between 19% and 73% of cases undergoing laparoscopy, and a prevalence of 47% in laparoscopic findings. It is estimated that 38% of adolescents with pelvic pain are affected by EDM[4].

The adolescents' physical and psychological changes are divided into initial (10 to 14 years old), medium (14 to 17 years old) and late (after 17 years old). During this period, there is development of secondary sexual characters, and in women, consequently, the menarche that signals the transition from childhood to reproductive age5. The early and intense onset of pelvic pain may indicate the presence of profound disease in adult women. Some main symptoms and clinical markers have been described in the literature and are predictive of the risk of EDM in adolescence, namely: chronic or acyclic pelvic pain; menarche before age 12; severe dysmenorrhea; use of anti-inflammatory drugs for dysmenorrhea; dysmenorrhea resistant to the use of anti-inflammatory drugs or hormonal treatment; dyspareunia; pain on bowel movement, cyclic; history of benign ovarian cysts; family history of EDM. Questions related to these predictive factors for adolescents should be asked during nursing consultations (NC). The early diagnosis and treatment of EDM is related to a reduction in the progression of the disease, although this is not a consensus in the literature. Data point to spontaneous regression in 42% of cases, 29% of disease stabilization and 29% of progression. It is a disease with imprecise and difficult-to-diagnose pathophysiology, which complicates decision-making, especially when the diagnosis appears in adolescence[6].

The gynecologist plays an important role in this stage of a woman's life, because in addition to attending and guiding these young women, he will be responsible for directing them regarding infectious diseases, genital physiology and other pathophysiologies, including EDM[5].

This understanding is reinterpreted, the importance of this role is not only in the hands of the gynecologist, but of all health professionals who work with adolescents. Not in search of a mandatory agenda for carrying out tests and procedures with a view to nosological diagnoses, but for the opportunity of a relational space for health promotion. And this space should not only be allocated to specialist medical professionals. Nurses are responsible for providing assistance that values the complaints of young women seeking care and a careful look/follow-up of their cases, respecting their individualities, seeking the best possible alternatives for their reception and care. As well as handling sensitive situations such as suspected EDM.

Adolescence is characterized by a stage in life marked by marked changes and of different dimensions that allow the adolescent to experience their changes and face adverse and conflicting situations. These circumstances do not earn sensitive listening, either from family members or professionals. As regards the field of health, there is a warning for a still concrete deficiency in the training of professionals to care for these young people[7].

In this sense, this article aims to: discuss the relationship between endometriosis and adolescence in the focus of early/late diagnosis and correlate the role of nursing in this context.

Methodology

This is a reflective study. It uses references from random search in virtual and physical libraries, therefore, the methodological search marks were not used for integrative or systematic reviews. In addition to the methodological source on which the authors are based, greater research supported and illuminated the writing of this article[8,9].

A general and advanced search was undertaken in the Virtual Health Library (VHL), PubMed and Capes Periodicals to verify publications related to EDM and adolescent health that could support the bibliographic narrative, even to point out that there are few studies on EDM in adolescence when compared to unrestricted searches on the subject. A search was carried out in the previously indicated databases with the following descriptors (Decs and Mesh) “endometriosis” and “endometriosis “AND” adolescents”.

The material used for this study consists of national and international articles found in these databases, based on these searches, as well as publications from agencies such as the Ministry of Health (MS), World Health Organization (WHO), FEBRASGO, books reference (from the personal collections of the authors of the article and those found in physical libraries). The search for the data took place in 2017/2018.

Results and Discussion

The analytical material selected should relate to the field of women's health, specifically regarding EDM and adolescence, meeting the proposed objectives. Two questions supported this reflection: what factors interfere in the search for an early diagnosis of EDM in adolescence? How can nurses contribute, in primary care settings, to reduce this problem? From the reading and analysis of the material, two categories were outlined for discussion, described below, both bringing strategies to contribute to the care provided by the nurse.

Understanding reductionisms about endometriosis: caution as a coping strategy

The classification of endometriosis as a disease of modern women is one of the metaphors that emerges on this topic. First, tense adverbs are, per se, loaded with snags and, in this sense, should be avoided, mainly, when referring to a disease still little explored, with imprecise etiology. Even though the historical records point to periods of the Classical and Ancient Ages, it is still a disease that has remained unexplored by science for a long time. Diseases with imprecise etiology are those most likely to create metaphors. Considering that the etiology of EDM has been studied frequently over the last 30 years and that its etiopathogenesis remains undefined, it is possible to understand why so many metaphors are born from it. Likewise, linking to EDM aspects of a possible subversion of the feminine nature is a mistake that must be eliminated[9-12].

In this debate, it is situated that the histological discovery of EDM is attributed to the Austrian researcher Karl Freiherr Von Rokitansky, in 1860. However, in the periods that preceded the histological discovery, there was a kind of obscurantism related to the disease for physicians and scientists. Although several complex ailments have been observed and studied, EDM seems to have been invisible to medicine for a long time. This invisibility in medical history is so evident that even in the important encyclopedias of the history of medicine, such as Cambridge World History of Human Disease (1983) and Encyclopedia of Medical History (1985), already in the 20th century, there is no allusion to it[11].

It was only in 1960 that Daniel Shroen described in detail, in his dissertation, several symptoms that were very similar to EDM. In the 20th century, with advances in medicine, the evolution of surgical techniques, studies in histology and endocrinology were made possible, being essential for the increase of understanding about the pathophysiology, diagnosis, and treatment of EDM. In 1927, John Albert Sampson published an article in which he reaffirmed the theory of retrograde menstruation as a factor in the onset of the disease, naming the term 'endometriosis' for the first time. In the 1930s and 1940s, several anatomical locations of EDM were described in the literature and cases were more frequently found in adolescents[11].

Even though many women have retrograde menstruation, not all develop EDM. This happens because the menstrual tissue that undergoes reflux into the peritoneal cavity is eliminated by immune cells, such as macrophages, NK (Natural Killer) cells and lymphocytes, that is, retrograde menstruation is an expected event from the point of view physiological. In the etiopathogenic aspect, there are several theories studied about the genesis of EDM. Therefore, the defense of the idea that given the imprecision of the etiology of this disease, in the process of elucidation, is used here, professionals and researchers need to refrain

from metaphorical judgments about the disease and the feminine, as they bias their analysis. Be careful not to incur reductionisms about women, particularly those related to gender issues[9,10,12,13].

The Brazilian Federation of Gynecology and Obstetrics Associations (FEBRASGO) once even mentioned EDM as a disease of the current female standard of living, its recent publication no longer uses this type of classification. Regarding the modernity of the disease as a form of classification, if it is still found in some studies, it is necessary to place, in a poignant way, an epistemic critique. This form of categorization based on the feminine, reproduction and/or women is largely attributed to socially constructed gender issues. This reading of EDM is seventies and eighties, with therapeutic proposals based on gender roles, as they recommended women to return to their 'traditional domestic duties' as a 'clinical indication' to achieve a cure[14,15].

Adolescence and endometriosis: between silence and the search for other coping strategies

The delay in the diagnosis of EDM is still a challenge to be overcome so that, in perspective, there is an adequate management of the disease and an improvement in the quality of life of women affected by this problem. In Brazil, the time elapsed from the onset of symptoms to diagnosis is, on average, 4 years for women with infertility and 7.4 years for those with pelvic pain. The incidence of EDM in adolescents is related to pelvic pain that progresses over time. In adolescents with dysmenorrhea and chronic pelvic pain, it is estimated that 45% to 70% of them may have EDM. Some symptoms are referred to as predictors of EDM: chronic pain; severe dysmenorrhea unresponsive to nonsteroidal anti-inflammatory drugs (NSAIDs) and oral hormonal contraceptives (AHO); and pains that compromise daily activities. Adolescents undergoing videolaparoscopy (VDL) due to pelvic pain not responsive to NSAIDs and AHOs, had an incidence of 20% to 70% of EDM[7,13].

EDM is an (almost) silent disease. More than that, it is a silenced disease. Silent for being associated with symptoms related to menstruation, in some cases of insidious onset, and to be perceived as something normal. Silenced by a gender culture that attributes to women the experience of monthly cramps, when painful, as something intrinsic to the female body and tolerable. Severe pains being misinterpreted as part of a woman's physiology and nature. Silenced by the trivialization of symptoms, which are often announced since adolescence and, for this reason, the careful look of health professionals is essential. Unfortunately, sometimes due to lack of knowledge about EDM, sometimes due to institutional violence, these same professionals normalize the symptoms and, through the scientific discourse, legitimize the absence of a diagnosis, leading to a delay in diagnosis that could be identified early[9,16].

This silencing is also present in professional training books, as well as in government programs and policies. In the book Fundamentals of Pediatric Nursing, the only mention of the term endometriosis occurs only when secondary dysmenorrhea is addressed, without any further elaboration on the topic. In the Adolescent Health: skills and abilities manual, EDM is mentioned briefly when secondary dysmenorrhea is also addressed. A simple search with the descriptor endometriosis in the Catalog of Information on Nursing Research and Researchers, between 2001 and 2015, by the Brazilian Nursing Association (ABEN), Center for Studies and Research in Nursing (CEPEn), did not identify any study About the subject. The catalogs concentrate the scientific production of nursing within the scope of the Stricto sensu, that is, it was revealed that, until then, there was no production of nursing dissertations and theses on EDM[17,18].

There is no mention of EDM in the National Guidelines for Comprehensive Health Care for Adolescents and Youth in Health Promotion, Protection and Recovery. brings no guidance regarding EDM to these professionals. EDM is not addressed in the 'National Policy for Comprehensive Care for Women's Health (PNAISM)', from 2004 to 2011. Nor in the National Policy Plan for Women 2013-2015[19-22].

The inexistence or superficiality of the EDM approach was found in specific literature on women and adolescents, therefore, it was decided to expand the search beyond this universe. Therefore, it was necessary to return attention to the disease itself, that is, a chronic disease that, although not presenting high mortality rates, is known to express high morbidity, with significant impacts on the lives of the female population affected by it.

Based on this aspect, it is possible to outline a discussion, albeit incipient, about the need to create strategies to minimize the invisibility of EDM for health professionals. This discussion has as its starting point the Ordinance No. 4279 of December 30, 2010, which establishes guidelines for the organization of the Health Care Network within the scope of the Unified Health System (SUS). The Ordinance in question demonstrates the MS's concern with the current epidemiological profile of our country, with a predominance of chronic diseases. It is noticed, however, that the guidelines outlined are aimed at chronic diseases that have a great impact on morbidity and mortality rates, such as, for example, those associated with the cardiocirculatory system and cancer[5,23].

There are some strategies to treat EDM, the Clinical Protocol and Therapeutic Guidelines for Endometriosis, approved in 2016, through Ordinance No. 879. the definitive diagnostic issue, by laparoscopic route, related to young women with chronic pain[24].

To identify EDM early, it should be considered that the manifestations of the disease begin in adolescence, as adult women report the onset of pelvic symptoms before the age of 20 years. This proportion can reach 70% of teenagers[25]. About the symptoms mentioned by them, dysmenorrhea is the most reported, especially the one that interferes with daily life, leading to the loss of school attendance. Adolescents often experience bladder and bowel symptoms usually associated with their menstrual period (eg, diarrhea) as well as nausea and headache. Intense pain usually occurs on the first day of the cycle and

pain intensity may increase over time, as well as its frequency, and may persist throughout the month and, therefore, progressive[6,14,25]. Other symptoms found are abdominal distension and early satiety[25,26].

The initial marks or signs of the disease are severe primary dysmenorrhea; family history of EDM; school absenteeism during menstruation; and use of AHO to treat pelvic pain. Many teenagers with dysmenorrhea do not seek medical attention. About 98% of adolescents use non-pharmacological methods such as rest and warm compresses, on their own or through family influence. Self-medication with simple analgesics is also triggered[4,27].

However, in this article, the question is: what is the role of the nurse in this scenario? After all, this professional is not responsible for diagnosing the disease, nor is it expected to propose such an activity that is exclusive to the physician. That is not what this discussion is about. It is about elevating care translated into active and attentive listening to adolescents; valuing complaints; EC and in the fight against reductionism, which contribute nothing to the assisted adolescents.

The potential silencing that contributes to the delay in the medical diagnosis of EDM is, as assumed, related to a simplified search for a resolution for dysmenorrhea, also linked to a trivialization of the adolescents' complaints about their menstrual status. The non-perpetuation of the devaluation of menstrual complaints should be an initial concern of the nurse.

According to a retrospective case series study, which evaluated 898 women undergoing laparoscopic surgical treatment with a diagnosis of EDM, secondary dysmenorrhea is the main symptom of the disease with a prevalence of 62.2%. The first step of a health professional is not to underestimate the adolescents' complaints, misinterpreting these symptoms as physiological changes or classifying pain as psychological pain. A fact that, untimely, occurs, as identified in a survey carried out from the narratives of women with EDM[9,26].

About pain, a scale was created to help professionals from their own experience with EDM and other women. Her interest arose from three interesting points, namely: (1) the way in which women with EDM seek to react to the devaluation of their complaints, that is, in the so-called unreliable complaints; (2) the use of biomedical knowledge duly researched by women as a way of transiting and dialoguing with experts, a way to cross the expert-law barrier and (3) the frontier work that associative groups of women with EDM do to keep this expert-law in place[26].

The scale is unique, as it is the result of a collective construction in the relationship of women who join a group, a common vocabulary, a standard of their experiences. There are two crucial points, two objects in common: it is a scale developed with the contribution of the women's community and it was designed based on a common knowledge.

The scale is divided into three columns, the first with Arabic numerals from 0 to 10 to represent levels of pain, zero for no pain and ten for pain that leads to unconsciousness. The second column represents the functional impairment related to pain, whether in terms of concentration, work, sleep, social and physical activities. Finally, the third column identifies whether pain requires the use of analgesics, citing names of medications, their level of effectiveness and durability in controlling pain. The scale signals signs and symptoms as ways to classify pain: nausea, dizziness, delirium, moaning, conversational capacity until syncope[26].

As mentioned above, adolescents with extreme pain that do not respond to NSAIDs and AHOs are prone to diseases and their pain complaints cannot be devalued, as it is this silencing that we must deconstruct. The Mankoski Scale can be useful if used in the care provided to women, as when classifying a symptom, it points to the problem to be investigated.

Regarding care related to chronic pain, identification of the symptom and treatment with non-steroidal analgesics is not enough. For this purpose, Ordinance No. 1.083/12 approves the Clinical Protocol and Therapeutic Guidelines for Chronic Pain and points out that pain must be systematically evaluated (measured, for example, through the Visual Analog Scale - EVA - and classified as nociceptive, neuropathic, or mixed). The pharmacological approach to pain, when of nociceptive or mixed origin, must meet the WHO Analgesic Scale, organized into three stages: stage 1 – analgesic and antidepressant plus adjuvant drug; 2- analgesic and antidepressant plus adjuvant drug plus weak opioid; 3- analgesic and antidepressant plus adjuvant drug plus strong opioid. Adjuvant drugs refer to those intended for the treatment of comorbidities. In neuropathic pain, the treatment base involves the use of tricyclic antidepressants and antiepileptics[26].

Every space of care the woman must provide relationships that enable the identification of problems, including the signs and symptoms of EDM. Suspicion is caring, insofar as it is a disease, usually camouflaged by a gender culture that demands stoicism from women, trivializing their complaints. Nurses play a key role in the suspected diagnosis of the problem, not only in the care of adult women, but in care programs for adolescents. The most valuable space for this contribution to women's health is located within the EC. And, exactly, in one of the stages of this, where data collection or nursing history is dedicated, diagnostic suspicion may arise. The gynecological physical examination can also contribute with indicators: pain during uterine mobilization, uterosacral ligaments, cervix, and adnexa; find palpable nodules in the posterior vaginal fornix or rectovaginal septum. Finally, counseling, education and support are care strategies. From there, interdisciplinarity will contribute to investigation, treatment, monitoring and even regulation of cases for specialized units[1,9].

Conclusion

Knowing the main signs and symptoms of endometriosis is essential for early identification, especially if the disease appears in adolescence. It is a disease silenced by a gender culture, which at the same time devalues complaints related to menstruation and demands overcoming when they are very intense. This identification

can and should happen in PHC units, educational groups, and the EC. In addition, within the EC, scales for evaluating pain and how adolescents react to proposed drug treatments should be used, as a form of observational and prospective assessment. The SC must be a relational space, for active and sensitive listening (including 'listening in silence' to understand what the woman has to say), for negotiation of care, that is, an encounter that generates possibilities.

However, for a suspected diagnosis, qualified knowledge about the disease by health professionals is necessary. Therefore, in terms of perspectives, it is necessary to value the inclusion of the topic in reference books for adolescent and women's health, as they are instruments for professional training. The reference documents for training and continuing education of academics and professionals are inconsistent when it comes to EDM. This should be a concern, that is, actions that encourage the inclusion of chapters on EDM in future updates of didactic-pedagogical materials. As well as an incentive to include the theme in the teaching plans of health schools.

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