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# Difficulties Faced by Physicians in the Diagnosis of Endometriosis in the Brazilian Public Health System

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## Abstract

Endometriosis is a clinical and recurrent condition characterized by the presence of functional endometrial tissue outside the uterine cavity and myometrium. It is estimated that 6% to 10% of women of reproductive age, 50% to 60% of adolescents and adults with pelvic pain, and up to 50% of women with infertility are pregnant from the condition. However, this proportion tends to be even greater due to the difficulty in diagnosing it: because it presents different symptoms, lack of information from health professionals, and a high-cost diagnostic test. Another aggravating factor is the average time from the onset of symptoms to the medical diagnosis, which even today ranges from five to ten years; this delay has consequences for disease progression, as it prevents early treatment, which is important for improving pain levels and physical and psychological well-being. Aware of these mishaps, it is therefore important to assess the difficulties faced by doctors in the diagnosis of endometriosis in the public health system, in Brazil, the Unified Health System (SUS). With this purpose, a cross sectional was carried out, developed in the virtual environment using traffic in Google forms, with the difficulties quantified in the Likert scale. Participating physicians pointed out a medium difficulty for patients with endometriosis to access the consultation (58%) and moderate difficulty (52%) to perform an ultrasound examination; also signaled great difficulty in performing magnetic resonance imaging (77%) and laparotomy (61%) in these patients. It is hoped that knowledge about the

difficulties faced by physicians in the diagnosis of endometriosis in the SUS will give these physicians a voice and corroborate, even if minimally, so that there is more research that provokes the search for these difficulties, in order to improving the quality of life of these women.

## Keywords

Endometriosis, Diagnosis, Public Health System

## 1. Introduction

Endometriosis can be defined as the presence of extrauterine endometrial tissue, responsible for causing pain and intense suffering in women of childbearing age [1]. As quoted by TORRES *et al.* [2], the disease was first described in 1860 in Germany by analyzing necropsy material of an ectopic tissue similar to endometrial tissue.

The pathology is one of the most common and affects women usually of reproductive age. There is no exact proportion of the number of women affected by the disease, but it is estimated that on average 6% to 10% of women of reproductive age suffer from endometriosis, of which 3% of postmenopausal women and 40% of infertile women are also affected [2].

In Brazil, the numbers are worrying, because, according to the data from the Ministry of Health, there are about 7 million women affected, even so, the diagnosis is still deficient [2].

According to Greene *et al.* [3], the etiology and pathogenesis of endometriosis are still uncertain, what is known is that there is a formation and development of ectopic endometriosis foci adding also genetic, hormonal, and immunological factors. Despite not having a certain origin, several theories have been described, such as the Retrograde Menstruation Theory, described by Sampson in 1927, which he describes as the cause of the reflux of endometrial tissue that occurs at the time of menstruation, through the fallopian tubes, with subsequent implantation and enlargement of the peritoneum and ovaries [3].

Endometriosis presents a variety of symptoms, such as: infertility, pelvic pain, dysmenorrhea and dyspareunia, and a heavy menstrual flow. However, it happens that some cases are asymptomatic and all symptoms depend on their location and the extent of the disease involvement. Thus, chronic pain affects about 15% to 80% of patients, 20% may be asymptomatic, and 25% to 35% have infertility. The most prevalent sites of endometriotic foci are: ovaries, peritoneal surface, rectovaginal, abdominal cavity, pleura, and pericardium [4].

The first symptoms begin in early adolescence in about 40% - 50% of the cases, but the diagnosis is only established around the age of 30. The infertility, probably, is caused by adhesions generated by the pathology as well as by the inefficiency of ovulation and fertilization, but it can also be related to the stage of the disease [2].

An important condition to be addressed is the lack of information about endometriosis by the population in general, as well as by health professionals, favoring cases of underdiagnosis and generating an obstacle to obtaining data and consequently earlier treatment of the disease [2].

The diagnosis of endometriosis is still an obstacle to overcome because it is a multifactorial disease with several clinical manifestations, which makes it easy to be confused with other diseases and difficult to confirm. On the other hand, the diagnosis when made early can relieve the symptoms and improve the quality of life of patients [2].

Furthermore, although there is no specific method for detection, the diagnosis of endometriosis can be strongly suggested by transvaginal ultrasound and nuclear magnetic resonance imaging of the pelvis, but they do not have adequate sensitivity and specificity, and may not show sites of advanced disease [5]. The biomarker CA-125 shows adequate sensitivity only in cases of moderate or severe endometriosis [6].

The gold standard test to obtain an accurate diagnosis is laparoscopy because it is more accurate in sizing and analyzing the correct position of the endometriosis foci, but it is an invasive method, with risks inherent to the procedure itself and high financial cost [6].

In Brazil, as many women seek help and initial guidance in Unidades Básicas de Saúde (Basic Health Units) or Unidades de Pronto Atendimento (Emergency Care Units), we must be aware of the costs and the difficulty of a more effective diagnostic investigation, besides that this patient is first seen by non-specialized doctors who may not suspect endometriosis [6].

Thus, investigating the difficulties faced by physicians in diagnosing endometriosis in the Brazilian health care system, the Sistema Único de Saúde (SUS), may contribute, even minimally, instigating better care provided to these women, in reducing the negative impacts generated by endometriosis, improving their quality of life. At the same time, it is intended to give a voice to the physicians who face these difficulties in SUS.

## 2. Methods

A clinical trial was conducted. Gynecologists and obstetricians who are or have been (in the last five years) employed by SUS, from several Brazilian states, participated in the study. We chose to conduct the questionnaire in the virtual environment (*Google forms*), in order to have the opportunity to reach the largest possible number of experts in Brazil available to participate, facilitating and speeding up the work, as well as the collection of results and discussion. There is a form (Google Forms) available for each doctor to point out the degree of difficulty found in each of the items on a Likert scale (none, little, medium, or great), with room to point out other difficulties or other observations.

The items of the questionnaire, in relation to the Degree of difficulty encountered by the physician in the diagnosis of Endometriosis in the SUS, were:

- Access to gynecological consultation
- Time available for the physician to perform the anamnesis
- Difficulty in performing ultrasonography
- Difficulty with CT scans
- Difficulty with an MRI scan
- Difficulty performing a laparotomy

For data evaluation, the interquartile range was used (IQR). The data were analyzed using IBM SPSS Statistics 22.0 statistical analysis software. To present the data we use the bar graph. The normality of the tests was previously checked by the Kruskal-Wallis test in the same software.

## 3. Results

The sample was composed of 52 gynecologists who work or have worked for the SUS in the last five years, of which 46% live in the Northeast region, 44% in the Southeast region, 2% in the North region, 2% in the Midwest region, and 6% in the South region.

The degree of difficulty faced in diagnosing endometriosis by the gynecologists participating in this study was, in ascending order: difficulty in access to gynecological consultation 5%, difficulty in the time available for the doctor to perform the anamnesis 8%, difficulty in performing ultrasonography 10%, difficulty in performing tomography 22%, difficulty in performing a laparotomy 25%, difficulty in performing an MRI 30% (**Figure 1**).

Regarding the degree of difficulty in diagnosing endometriosis in relation to *access to gynecological consultation*, 27% reported that they had little difficulty, 58% had medium difficulty, 11% had great difficulty, and 4% had no difficulty.

In the context of the degree of difficulty in diagnosing endometriosis in relation to the *time available for the physician to perform the anamnesis*, 31% report that they had little difficulty in firming a diagnosis, 36% medium difficulty, 23% great difficulty, and 10% had no difficulty.

With regard to the degree of difficulty in diagnosing endometriosis in relation to *performing an ultrasound*, 19% report that they had little difficulty, 52% had medium difficulty, 25% had great difficulty, and 4% had no difficulty.

In the context of the degree of difficulty in diagnosing endometriosis in relation to *performing CT scans*, 10% report that they had little difficulty, 21% medium difficulty, 61% great difficulty, and 8% no difficulty.

Regarding the degree of difficulty in diagnosing endometriosis in relation to *performing an MRI scan*, 6% report that they had little difficulty in firming a diagnosis, 13% had medium difficulty, 77% had great difficulty, and 4% had no difficulty.

With regard to the degree of difficulty in diagnosing endometriosis in relation to the difficulty in *performing a laparotomy*, 6% report that they had little difficulty, 25% medium difficulty, 61% great difficulty, and 8% had no difficulty (**Table 1**).

When asked, "Do you identify any other difficulty in the diagnosis of endometriosis in SUS?" 46% of the physicians said yes and 54% of the doctors said

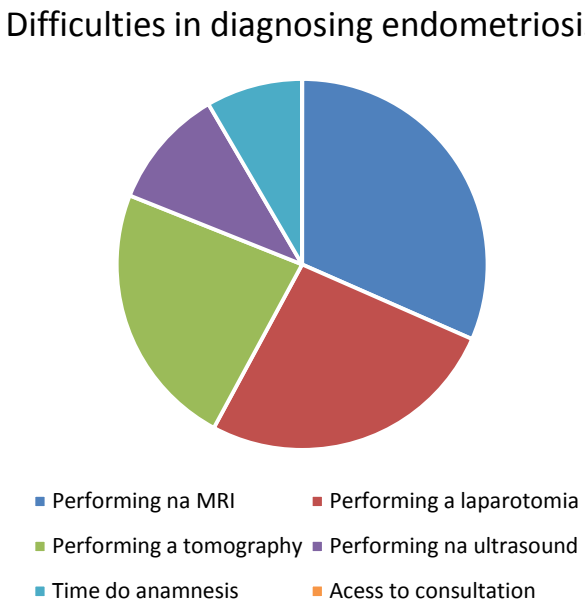


**Figure 1.** Degree of difficulty encountered in the diagnosis of endometriosis.

**Table 1.** Degree of difficulty encountered in the diagnosis of endometriosis.

| Difficult | Degree of difficulty in diagnosing endometriosis | | | |
|---|---|---|---|---|
| | Little | Medium | Great | No difficulty |
| Access to consultation | 27% | 58% | 11% | 4% |
| Time for anamnesis | 31% | 36% | 23% | 10% |
| Performing an Ultrasound | 19% | 52% | 25% | 4% |
| Performing a CT Scan | 10% | 21% | 61% | 8% |
| Performing an MRI | 6% | 13% | 77% | 4% |
| Performing a Laparotomy | 6% | 25% | 61% | 8% |

no. With regard to other difficulties, the gynecological physicians cited: "Lack of multi-professional teams", "Training of the teams", "The city hall does not authorize CT and MRI", "Delay for patients to get to see a gynecologist", "There is no mapping of endometriosis in SUS", "The lack of offer of endovaginal ultrasound to research endometriosis. Effective and low-cost method compared to CT and MRI", "Waiting time for specialized consultation", "The non-valuation or underestimation of the pain complaint by some professionals. Many arrive after a pilgrimage, without progress in the propaedeutic", "SUS Basic Health Unit (UBS) physicians' knowledge of gynecological complaints about endometriosis", "Referral time", "physicians' lack of clarification", "Dissemination of information about it".

## 4. Discussion

According to the demographic data of the gynecologists participating in this study, most of them are from the northeastern and southeastern regions of Bra-

zil, especially the states of Alagoas and São Paulo, respectively, probably because they are the states where the researchers live or have more contacts. It is interesting to note the similarity in the answers of the participating physicians, even living in such culturally and economically different cities, denoting that SUS works in an equivalent way in several regions of Brazil.

In this study 69% of the gynecologists reported on average the great difficulty for patients to access gynecological consultation, alerting us to the failure of adequate and accessible health services in Brazil. Similar to some parts of the world, especially in rural and remote areas, where women may have difficulty in finding qualified health professionals and well-equipped medical facilities [7].

The difficulty in making a gynecological appointment is an obstacle, reflecting the geographical and financial barriers that many women may face, in addition to the impasse of finding free time at work or other obligations to attend medical appointments. Another factor that contributes to the difficulty in performing medical follow-ups is the lack of awareness and education about endometriosis [8].

In relation to the time available for the physician to perform the anamnesis, in this study, only 10% considered the time sufficient to perform an adequate anamnesis for the diagnosis of endometriosis, may denote the overload of gynecologists in the SUS or as Silva *et al.* [9] point out, trigger in many women the perception that some physicians did not value their complaints the way they should, being interpreted as neglect or lack of interest on the part of professionals.

Silva *et al.* [9] state that the biggest challenge in obtaining important information for the diagnosis of endometriosis is due to the difficulty in accessing a definitive and reliable surgical diagnosis. This analysis corroborates the data that were found in this research, where 98% revealed great to medium difficulty in performing an MRI, 86% pointed out great to medium difficulty in performing a video-laparotomy, 82% have great to medium difficulty in performing a CT scan, and 77% revealed great to medium difficulty in performing a transvaginal ultrasound.

As a result, in addition to physical and even psychological suffering, patients with endometriosis end up having significant financial expenses, with several exams to get an accurate diagnosis, even having the initial care in the public service [10].

When asked about "other difficulties in the diagnosis of endometriosis", the lack of training was cited and represents a failure to update by some professionals, as well as the need for protocols involving different medical specialties for the diagnosis and treatment of endometriosis, as pointed out by the MINISTRY OF HEALTH; SYRIAN-LEBANESE INSTITUTE OF EDUCATION AND RESEARCH [11].

Participants in this survey reported the lack of multidisciplinary follow-up as an issue, as due to the many facets of endometriosis, it is important to have a multidisciplinary team to create a proper treatment plan. The MINISTRY OF

HEALTH; SYRIAN LEBANESE INSTITUTE OF EDUCATION AND RESEARCH themselves state that the presence of different professionals and care perspectives contributes to more complete and comprehensive care for women suffering from endometriosis [11].

## 5. Conclusion

Endometriosis, a highly prevalent disease with a high biopsychosocial impact on an individual and public health level, still presents high diagnostic difficulties worldwide. Knowing the difficulties faced by physicians who work in the Brazilian public health system in diagnosing endometriosis is to give them a voice, answering their expectations in the search for their patients' health. It is also hoped that this study favors research in this area, corroborating, even if minimally, so that there are more works that provoke the search for improvements in these difficulties, thus reducing the suffering of women with endometriosis.

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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