



Experiences of women regarding their pathways to the diagnosis of endometriosis

Experiências das mulheres quanto às suas trajetórias até o diagnóstico de endometriose
Experiencias de mujeres en cuanto a sus trayectorias hasta el diagnóstico de endometriosis

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ABSTRACT

Objectives: to describe the experiences of women on their trajectories from the beginning of symptoms to the diagnosis of endometriosis. **Method:** descriptive, qualitative research, conducted with ten women diagnosed with endometriosis in the city of Rio de Janeiro (RJ), Brazil. Audio recorded semi-structured interviews were collected and later submitted to Content Analysis using Atlas.ti 8 software. **Results:** without the diagnosis of endometriosis, women experience strong symptoms from the menarche. This situation has a negative impact on different spheres of life, including the devaluation of their complaints in their circles of coexistence. Thus, the importance of the support network in this situation is understood. Faced with this context, women wander through various professionals until the definitive diagnosis. **Final considerations and implications for practice:** the trajectories of these women are marked by the devaluation of their complaints by health professionals and people close to them, by the naturalization of female pain and by the difficulty in establishing a differential diagnosis. However, the individual's ability to recognize the presence of a pathology, the knowledge about endometriosis and the professional's experience facilitated the diagnosis. In the context of nursing care, understanding this trajectory can promote active listening, better appreciation of complaints, clinical assessment and referral to early diagnosis.

Keywords: Endometriosis; Clinical Diagnosis; Pelvic Pain; Women's Health; Gynecology.

RESUMO

Objetivo: descrever as experiências das mulheres sobre as suas trajetórias desde o início dos sintomas até o diagnóstico da endometriose. **Método:** pesquisa descritiva, qualitativa, realizada com dez mulheres com diagnóstico de endometriose no município do Rio de Janeiro (RJ), Brasil. Coletaram-se entrevistas semiestruturadas áudio gravadas e posteriormente submetidas à Análise de Conteúdo por meio do *software* Atlas.ti 8. **Resultados:** sem o diagnóstico de endometriose, as mulheres vivenciam sintomas fortes desde a menarca. Essa situação repercute negativamente em diferentes esferas da vida, inclusive pela desvalorização de suas queixas em seus círculos de convivência. Assim, entende-se a importância da rede de apoio perante essa situação. Diante desse contexto, as mulheres peregrinam por diversos profissionais até o diagnóstico definitivo. **Considerações finais e implicações para a prática:** as trajetórias dessas mulheres são marcadas pela desvalorização de suas queixas por profissionais de saúde e pessoas próximas, pela naturalização da dor feminina e pela dificuldade em estabelecer um diagnóstico diferencial. No entanto, a capacidade individual de reconhecer a presença de uma patologia, o conhecimento sobre a endometriose e a experiência do profissional facilitaram o diagnóstico. No contexto da assistência de Enfermagem, entender essa trajetória pode promover a escuta ativa, melhor valorização das queixas, avaliação clínica e o encaminhamento para o diagnóstico precoce.

Palavras-chave: Endometriose; Diagnóstico Clínico; Dor Pélvica; Saúde da Mulher; Ginecologia.

RESUMEN

Objetivo: describir las vivencias de las mujeres en sus trayectorias desde el inicio de los síntomas hasta el diagnóstico de endometriosis. **Método:** investigación descriptiva cualitativa realizada con diez mujeres diagnosticadas con endometriosis en la ciudad de Rio de Janeiro (RJ), Brasil. Se recogieron entrevistas semiestructuradas grabadas en audio y posteriormente se sometieron a Análisis de Contenido utilizando el *software* Atlas.ti 8. **Resultados:** sin el diagnóstico de endometriosis, las mujeres experimentan síntomas fuertes desde la menarquia. Esta situación tiene un impacto negativo en diferentes ámbitos de la vida, incluso por la devaluación de sus quejas en sus círculos de convivencia. Así, se comprende la importancia de la red de apoyo en esta situación. Ante este contexto, las mujeres deambulan por diferentes profesionales hasta el diagnóstico definitivo. **Consideraciones finales e implicaciones para la práctica:** las trayectorias de estas mujeres están marcadas por la devaluación de sus quejas por parte de los profesionales de la salud y personas cercanas, por la naturalización del dolor femenino y por la dificultad para establecer un diagnóstico diferencial. Sin embargo, la capacidad del individuo para reconocer la presencia de una patología, el conocimiento sobre la endometriosis y la experiencia del profesional facilitaron el diagnóstico. En el contexto del cuidado de enfermería, comprender esta trayectoria puede promover la escucha activa, mejor valoración de las quejas, evaluación clínica y la derivación para diagnóstico precoz.

Palabras clave: Endometriosis; Diagnóstico Clínico; Dolor Pélvico; Salud de la Mujer; Ginecología.

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INTRODUCTION

Endometriosis is a gynecological disorder, resulting from the presence of ectopic endometrial tissue, which affects between five and 15% of women of reproductive age in the world.¹⁻³ In Brazil, estimates of the prevalence of endometriosis indicate that around seven million Brazilians suffer from this pathology.⁴ Nevertheless, it is believed that the epidemiological data reported are still inconclusive. The difficulty in gathering reliable information is mainly due to the difficulty in accessing definitive, surgical diagnosis and the trivialization of female symptoms by society, as well as health professionals.^{5,6}

At the national level, the disease is relatively unknown to the general population. Patients often receive their diagnosis late, although most develop the initial symptoms during adolescence. Without a definitive diagnosis for their complaints, most women find it difficult to report their menstrual irregularities or seek to hide them to avoid stigmatization due to cultural traits, which tend to naturalize pain during the menstrual period.⁵

The analysis of the average time of diagnosis of endometriosis in developed and developing countries identified a delay of 6.7 years from the onset of symptoms to definitive diagnosis. It is noteworthy that women sought medical appointments within an average time of up to one year after the first symptoms and those who used public health services had a greater delay, on average, of 8.5 years, when compared to those who used private services, with an average of 5.5 years.⁷ Furthermore, the sociodemographic characterization of these women has made it possible to identify a predominance of the white population with a high level of schooling, which contributes to understanding that access to the diagnosis of endometriosis can be a quite excluding process.⁸

Delay in diagnosis should be treated as a point of intense concern, as it may result in late or inadequate treatment, as well as develop more serious outcomes, such as an increased risk of infertility and underlying organ damage. The signs and symptoms of endometriosis, when unmanaged, directly affect women's quality of life and contribute to loss of productivity or inability to perform work.^{9,10}

Thus, this article is justified by the need to fill a gap in the national literature regarding the trajectory to the diagnosis of endometriosis from the perspective of women. It is understood that the theme permeates issues that go beyond the biomedical model, such as the cultural construction of the feminine and the professional-patient relationship. Therefore, these reports gain relevance to explain the negligence related to this condition. In the context of nursing care, women's experiences can stimulate professionals to provide more humanized care and promote active listening, appreciation of the patient's complaints, clinical evaluation and referral for early diagnosis.

Faced with this, the guiding question is: "What is the experience of women about their trajectories since the appearance of symptoms until the definitive diagnosis of endometriosis? The objective is to describe the experiences of women on their trajectories from the onset of symptoms to the diagnosis of endometriosis.

METHOD

This is a descriptive research with a qualitative approach. The choice for this method emerged for the descriptions about the experiences of the participants, being the phenomenon of the study. The aim is to describe the findings from the meanings, motives, aspirations, beliefs, values and attitudes of these women.¹¹

Women were recruited intentionally based on inclusion criteria: to be 18 years old or older with a diagnosis of endometriosis; to be a resident in the municipality of Rio de Janeiro; to participate in closed groups of an internet social network and to accept to participate in the study. The exclusion criteria were established: to have endometriosis, but to be asymptomatic.

The interlocution with social actors in the collection of the statements of this research allowed an approximation with the phenomenon studied. Despite the homogeneity of the sample, it reflects the subjectivity and interpersonal relations of this specific group, corroborating the socioeconomic profile identified in the national and international contexts.⁸ Thus, the saturation point occurred both by the volume of data and by the level of detail and deepening on the trajectories of these women, demonstrating the various dimensions of the research object.¹²

The capture of potential study participants took place through an online social network. Initially, an initial search for closed groups on the social network was performed using the word "endometriosis"; then, only groups formed by women diagnosed with endometriosis were selected, observing the content of posts or comments on the topic. After the group selection process, authorization was requested to participate as a member of the selected closed group.

Subsequently, the stage of recruitment of participants took place and the researchers created a post in the group in which the justification of the research, objectives and criteria for inclusion and exclusion to participate in the study were clarified. As the possible candidates to participate in the study expressed interest in contributing, the researchers contacted each other individually by private message, still in the social network, and scheduled a later meeting for interviews. It is worth noting that no participant refused to participate or interrupted their participation in the research.

The data collection period occurred between December 2016 and January 2017. The interviews were conducted individually and in person in public places chosen by the interviewees in order to promote reception and safety to the participant. The selected environments were places far from the traffic of people to ensure maximum privacy for the interviewees. The dialogues were recorded on audio, through a digital recorder, and literally transcribed for later analysis. The average interview time was 40 minutes. Transcriptions were made available to the respective interviewees for verification purposes, but there was no request for alteration of content.

The data collection instrument contained a semi-structured interview script. The triggering questions were: "Tell me about your experience at the beginning of the symptoms. How did you get to the diagnosis of endometriosis?". These questions were

accompanied by topics, introduced throughout the interview, in order to conduct the discussion and direct the questions and the unclarified information, such as symptoms, repercussions on personal life, repercussions on work, pilgrimage to diagnosis, costs, exams, consultations and the devaluation of complaints.

Before answering the questions, all participants were informed about the objectives of the research and consented to participate by signing the Free and Informed Consent Term (FICT).

The analysis of the content of the interviews was conducted using the qualitative analysis software Atlas.ti 8 and, for data processing, the thematic/category content research of Bardin was used.¹³ Based on the reading and interpretation of the messages, the meanings were understood, followed by the codification process and concluded by the inference of the data.

The coding approach was carried out by two independent coders and occurred in three stages: identification of codes and Registration Units (RU), excerpts from the interviews highlighted with different colors, through the inductive method of data analysis; grouping of UR for the elaboration of themes; formation of categories and subcategories.

The discrepancies that emerged were resolved by consensus between both encoders. The results of this step were made available to the study participants in order to evaluate the reliability, credibility and generalization of the findings.

The inferences occurred based on semantic groupings. Categories and subcategories were described by explanatory texts, illustrated with the coding trees elaborated in the software and exemplified with the UR for each corresponding subcategory. Finally, the discussion of the content analyzed in the categories was conducted based on the scientific literature in order to validate the findings of this study.

This research was approved by the Research Ethics Committee of the Universidade do Estado do Rio de Janeiro (CAAE: 1,650,425/2016). All the ethical precepts of Resolution 466/2012, of the National Health Council, were respected, guaranteeing the confidentiality and integrity of the participants. To keep the anonymity in the speeches, it was adopted the nomination with the initial letter "E" of endometriosis, followed by the number of order of accomplishment of the interview, for example, "E1, E2, E3...".

RESULTS

Ten women were interviewed in the study, aged between 18 and 38 years old and with marital status mostly married (n=7). There was a predominance (n=7) of the white population and the prevalence of high education, where five had completed higher education, followed by two with incomplete higher education and two with complete secondary education.

The average time between the onset of symptoms and the date of diagnosis was 6.5 years. Most women (n=6) reported pelvic pain as the main complaint; then there were complaints of dysmenorrhea (n=4), dyspareunia (n=3), infertility (n=3), and intense flow (n=2).

In total, 104 units of records were identified in the interview transcripts, which were grouped into two categories and six

subcategories. The experiences of women regarding the trajectories to the diagnosis of endometriosis were systematized in the thematic categories: "Suffering with symptoms without the diagnosis of endometriosis" and "Pilgrimage to the diagnosis of endometriosis" (Figure 1).

Suffering from symptoms without the diagnosis of endometriosis

In this category, a total of 50 registration units and three subcategories were identified. The initial suffering of those living with the symptoms of endometriosis goes through three important conditions: the strong symptoms experienced since the first menstruation, the negative repercussions in different spheres of women's lives, and the importance of a support network in the face of this situation.

Strong symptoms since the first menstruation, called menarche

The participants reported that, since the menarche, they suffered from pain above the acceptable threshold, they never had a painless menstrual cycle, referring to strong colic, disabling and present even outside the menstrual period. They believe that endometriosis began to develop from the first menstruation.

Then, since the first menstruation, it was with pain. I never, in my life, remember having had a menstruation, a painless cycle. (E10)

Common physical symptoms mentioned were pelvic pain, dysmenorrhea, dyspareunia and infertility. They also described symptoms associated with intestinal physiology, such as diarrhea, constipation, pain and bleeding when evacuating. In addition, there are gynecological dysfunctions such as menstrual irregularity and intense menstrual flow.

I was talking to him who felt pain, a lot of pain in penetration and a lot of colic. (E5)

Back pain, leg pain, pain to evacuate [...] An absurd, long and intense flow [...] With lots of vomit. Only that didn't pass. (E10)

Besides the physical symptoms, the women also presented psychological symptoms. The most discussed psychological experiences included stress and anguish in relation to the context in which they were inserted, characterized as "pain in the soul" and "emotional pain".

So, besides the physical pain, the emotional pain too, right? (E2)

It's complicated, right? It's not just a physical pain, it's a pain in the soul... It's very bad... (E7)

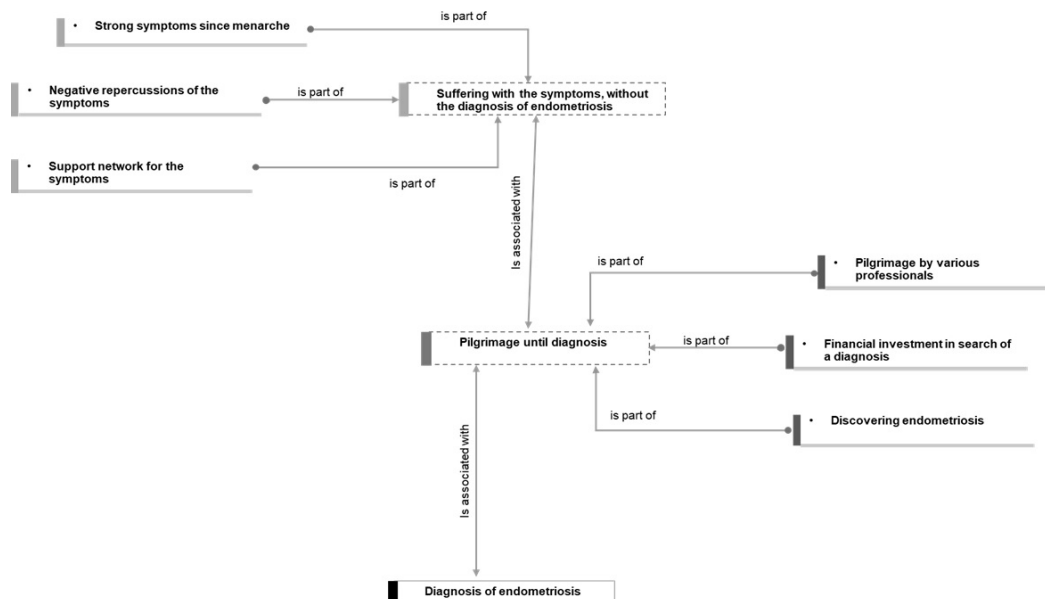


Figure 1. Coding tree for women’s trajectories until the endometriosis diagnosis elaborated in Atlas.ti 8 software.

Source: Atlas.ti.8.

Negative repercussions of symptoms

Many women conveyed the feeling that their circles of coexistence devalued their complaints. Participants perceived personal judgments about their symptoms as “nonsense”, “freshness”, or “little woman thing. The perception that their symptoms were ignored reveals a lack of empathy on the part of those who should welcome them. The real or perceived absence of social support has a direct impact on the emotional state of these women.

And the person, at work, says that he understands, but he doesn’t understand: “Because having colic is freshness” [...] so, this is complicated, because people stay: “no, I super understand”, but they don’t understand anything. (E1)

You think it’s silly, fresh, but I couldn’t even get out of bed, I wanted to faint [...] so I always heard funny, right? Because people don’t understand what it is... (E8)

During the conversation, it was revealed that the symptoms of the disease worsened over time and that the intervals between the pain crises were getting shorter and shorter. Not only did the disease worsen the health condition of women, but it also aroused a feeling of impotence when they realized that the use of painkillers and antispasmodics provided relief from the pain related to endometriosis, but it was not enough to eliminate the symptom or cure the disease. The shared experiences mention that the drugs stopped having the desired effect and therefore, periodically, there was an exchange of medication.

It never happened, no matter how much medicine I took [...] it took a long time. (E6)

It only got worse [...] it was pain medication... because an [antispasmodic and analgesic] can’t do anything... No medicine can cure... No medicine takes away the pain ... no relief [...] no relief at all ... All fantasy story. (E7)

With the inefficiency of painkillers, the participants often went to the emergency room, during the crises, where they used intravenous drugs for the immediate relief of pain. Despite the social and personal conception that the symptoms were considered normal, the low effectiveness of the drugs and the frequent search for emergency services pointed to the fact that the picture was not physiological.

It stopped in the emergency room because the medicine was no longer effective [...] every month, it was ready to take an injection in the vein [...] then, in adolescence, it really got worse, right? Every month it was first-aid, that could not be normal. (E4)

Moreover, among the shared stories, it was observed that endometriosis also has repercussions in the workplace, when it reduces professional performance and its perceptions of symptoms are devalued. The frequent complaints seem to be irrelevant in the midst of the labor market’s need for production. In response to this context, absenteeism or presentism is perceived due to the lack of physical and emotional conditions to work.

Because no matter how much you justify that you pass out, that you faint, the person is not worried. She wants to know if, in the end, the number will be beating and if she will have done the amount that the contract says. So, this is very difficult. (E1)

But I have been (to work) dragging myself [...] there, I go drugged, but I go [...] I have been, many times, asking to die in the subway with a lot of colic... bleeding to death. [...] I always go because I think I'll be misunderstood, do you understand? (E2)

Some women have transmitted the idea that the symptoms have an impact on social life when they prevent them from performing pleasurable activities or affect their love relationships.

But I saw that it was just getting bad and I was getting away from my husband. (E5)

I even went on a trip with my husband to my brother's house in Rio das Ostras. In the middle of a party, I had to leave because I had a very bad time and it was suddenly. (E7)

Support network in the face of symptoms

Despite complaints about the devaluation of the intense symptoms of endometriosis by people from their close social group, they recognized a specific social support, especially by those with more affective ties. In different degrees and forms, family, companions and friends were mentioned as the main support network in the midst of the symptoms.

But they have always supported me a lot: "Let's look for another doctor"; "Didn't you like it? let's look for another one"; "Take an exam". In the family matter, all quiet, thank God. (E1)

So, I've got a darkness... I have a wonderful husband and he helps me... he is very understanding. (E7)

One day I couldn't stand it. My friends told me: "You must have endometriosis" (...) so I went to the doctor. (E3)

Pilgrimage to diagnosis

In this category, a total of 54 registration units and three subcategories were identified. The trajectories of women until obtaining the diagnosis of endometriosis have favorable and difficult points that were raised in the analysis of the reports.

Pilgrimage by various professionals

In the search for professionals to respond to their demands, many women realized that some did not value their complaints as they should. This problem is interpreted as carelessness or lack of interest on the part of professionals, as observed in the registration units analyzed.

Ah, at that time, it was menstrual colic... that's all they talked about... Take a [antispasmodic] in your vein and go home... That's all I heard: "ah, menstrual colic". (E4)

That's where I said: it's carelessness... it's lack of interest from doctors [...] So, many had no patience... then they cut: "Ah, that's a colic, put a hot water bag in it"...(E7)

Although there are a variety of tests to identify endometriosis, there are many uncertainties in diagnosis. The difficulty in making a differential diagnosis was one of the problems pointed out by the participants in which, many times, their symptoms were associated with sexually transmitted infections or any other type of infection.

Every time you go to the gynecologist, he always passes antibiotic, ointment. It's always the same thing. [...] you have a wound in your uterus, "ah, it's inflammation". (E8)

And after that, I started to feel pain in the relationship and looked for the gynecologist and, at first, she investigated STD. Then I did all the chlamydia exams, gonorrhea, exams that the health plan didn't cover [...] because the doctor hit the chlamydia key, mainly. (E9)

Financial investment in search of diagnosis

The difficulties of professionals in identifying the clinical picture of endometriosis trigger financial costs for patients. Expenses with private network specialists and several requested exams were observed in the women's reports.

According to these experiences, health plans are alternatives that help lower the cost of illness, and public health care has been defined as "time consuming" and "difficult to access".

I've already spent about three thousand reais on a doctor... On top [...] and to get a decent diagnosis, you have to go to a private doctor. (E2)

No, the costs are always; with the health plan it is not so much because the exams are expensive and the plan covers. (E3)

And it took time because, as I told you, the public hospital business... They had exams done that had nothing to do with. (E7)

The expenses with some tests seemed to be unfeasible when, despite accessing several technologies, it was not possible to identify signs of the disease. However, the exams worked as a key piece to confirm the diagnosis of endometriosis.

He took a test, he didn't accuse anything. (E6)

The first thing was an ultra and he put as an indication that it could be endometriosis. But I would have to do a more specific exam, which was the resonance with intestinal preparation. What it really indicated was the resonance and the CA-125 that, at that time, if I'm not mistaken, mine was five hundred and little, very high. (E8)

Finally, discovering endometriosis

In the trajectories of women, in order to achieve the definitive diagnosis, some points were extremely important for these positive outcomes. Some women discussed about infertility, citing the difficulty of conception as one of the factors that allowed the discovery of endometriosis, because from this condition, they sought for information and specialized professionals.

I said, "Oh, but I want to get pregnant. But I wouldn't get pregnant [...] then my husband did the spermogram and everything was fine... It was all right and I didn't want to see the child [...] it was in October 2014 that I began to want to be a mother... The diagnosis was August 2015. (E2)

Facing the complexity in establishing the differential diagnosis and the difficulty of some professionals in recognizing the clinical picture, it is important to emphasize that the experience and professional competence were primordial factors to be able to identify and conduct endometriosis.

But it was only with the help of this, the experienced... From 13 to 25 years old, nobody would find out. (E7)

There is an endometriosis center in São Paulo, my mother marked and we went [...] there, I commented what I was going through, suffering. There, she did the whole endometriosis research and everything beat. Then she said to me: "I think you have endometriosis". (E10)

Among the main factors that made it possible to end this trajectory, it is worth mentioning that the individual capacity of women to recognize the presence of an established pathology is the most important. Thus, erroneous and professional test reports that devalue their symptomatic complaints are not impeding the search for diagnosis of the disease.

I knew it was not normal this weird pain, I knew it was not normal and I kept searching. (E3)

I'll look, it's not in my head. Then I started to look for the treatment from there. (E5)

And then they said it was painful ovulation, he did an ultra: "Ah, it's painful ovulation". Then I would say, "People, but nobody feels the same pain as I do... there was something different about it". [...] but I spent seven years saying that I felt a lot of pain... seeing that it was not normal. (E10)

DISCUSSION

In this study, the sociodemographic characterization of the women interviewed with the diagnosis of endometriosis showed that there was a predominance of the white population with a high level of schooling, with the majority of the population in Brazil being brown and black women.¹⁴ These findings are similar to

those of a systematic review study² and it may be suggested that non-white women with less education may have more difficulty in accessing endometriosis diagnosis than white women.

In a research that aimed to evaluate the experience of 4,334 women who were diagnosed with endometriosis through surgical intervention, the results identified that they were predominantly white (3,696 - 94.4%). Other researches carried out in Brazil also found that some surgical interventions, such as cesarean section, are much more frequent among white women than among non-white women and less frequent among users of the public sector and with less schooling.^{8,14-16}

The results of this and other studies have made it possible to understand how women who have endometriosis but face a tortuous path to obtain the definitive diagnosis. This difficulty in establishing a diagnosis has a negative impact on their lives, since, until they achieve it, they tend to live with the symptoms without proper treatment.^{2,6,8,17}

Although the participants related the origin of their complaints to early adolescence, this experience was not a sufficient factor to raise suspicions about the presence of endometriosis. According to the American College Obstetricians and Gynecologists, the prevalence of endometriosis in adolescents is still unknown. However, two-thirds of adolescents who reported suffering from chronic pelvic pain or dysmenorrhea, without responding correctly to the use of nonsteroidal anti-inflammatory drugs or hormone therapy, were later diagnosed with endometriosis by laparoscopy.¹⁸ Therefore, the symptoms manifested at the beginning of the fertile age should be better observed and valued when an early and adequate diagnosis is aimed at.

As recommended by the National Institute for Health and Clinical Excellence (NICE), women, including youths aged 17 and under, who present one or more of the following signs and symptoms are considered suspected cases of endometriosis: chronic pelvic pain; dysmenorrhea that prevents daily activities; deep dyspareunia; gastrointestinal symptoms that occur periodically; cyclic symptoms of urinary dysfunction such as dysuria and hematuria; infertility associated with one or more of the previous complaints.³ In this sense, it was observed that all the experiences discussed in this study were clinical pictures of endometriosis in which the participants presented signs and symptoms expected for this suspicion, since the beginning of the disease, as well as identified in other studies as well.^{2,6,8,17}

The psychological impact of the disease was also another point raised by women as something beyond the physical symptoms faced and these results resemble those of other researches, allowing us to understand that the negative repercussions on the mental health of the participants were due to the chronic aspect of pain, incorrect diagnosis and limited treatment options. The cultural construction influences the way society views feminine pain complaints, and the fallacy that women should establish identity proximity with their painful sensations prevents the characteristic complaints of endometriosis from being considered genuine. Thus, the pains of childbirth and menstrual cramps are seen

as ideal symbols of the female gender, and those who cannot endure them tend to be seen as inferior or fragile.^{2,6,17}

Women diagnosed with endometriosis had higher levels of depression when compared to healthy women. Those who reported intense complaints of pelvic pain also presented higher levels and statistically significant compared to those who did not report this symptom.^{5,19}

This situation is aggravated by the crises that tend to get worse over time, making analgesics and antispasmodics totally ineffective. The empirical treatment of pain consists of hormonal therapy combined with the use of non-steroidal anti-inflammatory drugs, being a viable option while surgical treatment is not accessible. Women have shown interest in seeking pain relief through the use of integrative and complementary practices such as acupuncture, homeopathy, meditation and diet.^{20,21}

The results of this study point to the demand of women for emergency services for the treatment of symptoms of endometriosis and this may reveal a failure in the organization of primary health care networks. Periodic access to emergency services contributes to the delay in diagnosis, since these services focus only on immediate attention to complaints and not on treatment. The proper management of patients in this system should promote the alleviation of pain complaints, followed by referral to the proper specialty.⁶

In the occupational sphere, similar studies have ratified the findings of this study, in which presentism and absenteeism from work stood out. Absenteeism was related to extreme situations in which the possibilities of medical leave or conditions in which one did not receive support from employers were exhausted. In contrast, presentism was linked to conditions in which the family depended solely on the source of women's income.^{5,10}

Women hide their own conditions from their male colleagues. Thus, it is perceived that issues of female reproductive physiology are still considered "taboos", bearing in mind that, as in this study, there is a concern about the accusations and trials of coworkers. Often, strong symptoms are mistakenly interpreted as pretexts for not performing their tasks or just "female weakness".²²

Endometriosis can negatively affect the social life of women, as the results showed that the women in this research reported feeling pain and discomfort at a level that prevented them from performing their daily activities. A systematic review study of qualitative methods showed that there is a reduction in the participation of social activities associated mainly with debilitating symptoms and structural issues such as the need for an available bathroom and the fear of manifesting symptoms in public.²²

The impact on the social aspect reflects on women's quality of life. Evaluation studies identified the association of the presence of endometriosis with a negative evaluation regarding the domain "social functioning". The limiting nature of the disease in their daily activities makes it difficult to carry out their own activities or attend social events, which develops a level of anxiety in patients due to the unpredictability of the appearance of crises that culminates in a feeling of powerlessness regarding their

state of health and, often, incomprehension on the part of their coexistence cycle.^{17,23}

Social support was fundamental in the fight against the disease, as many women highlighted receiving support from partners, friends and family. A synthesis of studies from developing countries showed that the presence or absence of social support could dictate the confrontation regarding menstrual experiences. This influence becomes important when it helps to conclude activities, promotes emotional support, or even works as a source of information.²⁴

With regard to financial investment, specific expenses were identified in relation to the intense pilgrimage of women in search of professionals and the carrying out of various examinations, as well as labor problems. In the scientific literature, there is a consensus in the cases of endometriosis so that women prioritize the realization of a health plan.^{5,17}

A large cross-sectional study, considered the largest multicentric prospective research on the effects of endometriosis conducted so far, has shown that the trivialization of women's complaints by professionals is a worldwide problem. When patients peregrinate through the diagnosis, they are informed by their doctors that the symptoms presented are considered normal, considering the physiology of the menstrual cycle. The result of how health services incorporate the gender stereotypes reflexes of a distorted social vision towards the feminine. Thus, the symptoms reported are systematically devalued by professionals and the information regarding the pathology follows without having the proper disclosure.^{6,7}

Some attitudes and behaviors of health professionals were described as problems by women in the current study. Many times, there was no interest on the part of professionals in identifying the important aspects of pain, such as quantity, intensity, duration, nature or impact. Classifying the pain of endometriosis as normal reveals a lack of training or updating by some professionals, lack of active listening, treatment of their symptoms and due referrals. It is understood that this form of conduction and care is not directly related to a possible professional malpractice, but it is understood that, although the specialists know about the pathology, this is not enough to identify the disease. Therefore, a large part of the diagnostic delays is attributed to professional malpractice.^{6,22,25}

A Dutch research pointed out that the experience and competence of professionals, good relationship with their patients, professional guidance and collaboration were the main factors that contributed to the discovery of early diagnosis.⁹ Moreover, the different clinical presentations of endometriosis require the presence of a multidisciplinary body to elaborate an adequate attention plan and different looks and aspects of care contribute to the completeness of care for women. The construction of protocols developed by different specialties for the diagnosis and treatment of endometriosis is also a tool that can contribute to a better resolution in the clinical management.^{17,23}

Another point addressed in this study is the difficulty to get pregnant as important in obtaining the diagnosis of endometriosis

more quickly. This type of association expresses an institutionalized gender issue in the care: the paradigm of the need for female reproductive function to the detriment of other complaints presented. The impact of endometriosis on fertility can affect not only the well-being of patients, but also their personal relationships. The possibility of infertility with the disease manifests feelings of concern and melancholy in the patients, bearing in mind that the social construction of the idea that women should be able to conceive a life results in internal and external judgments around the concept of “real women”.^{6,17,22,26}

The European Society of Human Reproduction and Embryology (ESHRE) recommends that the recommended sequence for the diagnosis of endometriosis should initially be considered a suspect case based on the history, signs and symptoms; then corroborate the suspicion with physical examination and imaging examinations; finally, prove from the histological analysis of samples collected during laparoscopy, the latter considered the gold standard for the diagnosis of the disease. In cases without the result of laparoscopy, empirical treatment based on secondary exams, such as transvaginal ultrasonography, pelvic magnetic resonance imaging and blood biomarkers, among them CA-125.²⁰

Therefore, imaging exams play a dubious role in the diagnosis of endometriosis, because, although they are fundamental pieces to confirm suspicious cases, they are not signs of certainty for the pathology. As for the reports in which, despite performing the tests, it was not possible to identify the pathology, it is attributed to the fact that many times the lesions are microscopic, preventing visualization even through laparoscopy.⁴

Regardless of the geographic context, professionals face similar difficulties and endometriosis is a public health problem that deserves more emphasis and repercussion. The results presented here point to the need for better dissemination of information on endometriosis to the population and health professionals. Therefore, future research on interventions is needed to disseminate knowledge and sensitize society on this very relevant but largely neglected situation.

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

The trajectories of women from the first symptoms in the menarche to the definitive diagnosis of endometriosis are permeated by two aspects: the barriers and the facilitators. The main factors that hinder this path are the devaluation of the patients' complaints by professionals and people living together, the naturalization of female pain, the financial impact of the disease and the difficulty in establishing a differential diagnosis. On the other hand, infertility complaints, individual capacity to recognize the presence of an established pathology, knowledge about endometriosis and the experience/capacitation of the professional allow to end these stories.

Among the limitations of this study, it is worth mentioning the low number of women with different socioeconomic profiles. However,

this reflects the reality regarding the difficulty of universal access and social inequality related to the diagnosis of endometriosis in Brazil, since the research was available, via internet, for the entire population. Moreover, the retrospective character of data collection can interfere in the memory of the participants by telling their own experiences, although all the reports analyzed maintained a coherence, shared similar experiences and could be corroborated by the scientific literature.

The results support future research on general population awareness of endometriosis and the construction of tools to facilitate early diagnosis of the pathology, such as specific screening questionnaires for chronic pelvic pain, gynecological pain assessment scales and clinical management algorithms.

In terms of implications for the practice, this research contributes to the scientific advance by divulging, in an unprecedented way, the path taken by women to the clinical diagnosis of endometriosis in the context of the health services available in Brazil. Psychological aspects and impacts were demonstrated at different levels that can be accessed to create constructive experiences regarding women's health. In addition, reflections on the role of society and professionals can be raised by those who access these results.

AUTHOR'S CONTRIBUTIONS

Study design. Carla Marins Silva, Camilla Freitas da Cunha, Karoline Rangel Neves

Data collection or production. Carla Marins Silva, Camilla Freitas da Cunha, Karoline Rangel Neves

Data analysis. Carla Marins Silva, Camilla Freitas da Cunha, Karoline Rangel Neves, Victor Hugo Alves Mascarenhas, Adriana Caroci-Becker

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