

The knowledge of women with endometriosis about the disease and family planning

O conhecimento de mulheres portadora de endometriose sobre a doença e o planejamento familiar

El conocimiento de las mujeres con endometriosis sobre la enfermedad y la planificación familiar

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REVISA

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RESUMO

Objetivo: analisar o conhecimento da mulher portadora de endometriose sobre a sua doença e o planejamento familiar. **Método:** trata-se de um estudo quantitativo, transversal e descritivo realizado em maio de 2021 junto a 20 mulheres com endometriose inscritas em grupo específico no Instagram. Aplicou-se, via google forms, um questionário sociodemográfico e clínicos e um instrumento para avaliação do conhecimento das mulheres. Utilizou-se a estatística descritiva para a análise dos dados que ocorreu no Statistical Package for Social Science, versão 25,0. **Resultados:** embora 70% das mulheres saibam o que é planejamento familiar, houve predomínio daquelas que possuem dúvida a respeito da doença (85%), que não sabem qual serviço de saúde do Sistema Único é responsável pelo planejamento familiar(65%) e que não conhecem o seu direito ao planejamento familiar ou a fertilização in vitro(80%). Ainda, predominaram mulheres que possuem “algum conhecimento” da doença (40%). **Conclusão:** O conhecimento das mulheres a respeito da endometriose e planejamento familiar é limitado, sendo desconhecidos aspectos relativos à doença, ao acesso aos serviços de saúde e aos direitos sociais envolvidos.

Descritores: Planejamento Familiar; Endometriose; Saúde da Mulher.

ABSTRACT

Objective: to analyze the knowledge of women with endometriosis about the disease and family planning. **Method:** this is a quantitative, cross-sectional and descriptive study carried out in May 2021 with 20 women with endometriosis registered in a specific group on Instagram. A sociodemographic and clinical questionnaire and an instrument for assessing women's knowledge were applied via google forms. Descriptive statistics were used to analyze the data that occurred in the Statistical Package for Social Science, version 25.0. **Results:** although 70% of women know what family planning is, there was a predominance of those who have doubts about the disease (85%), who do not know which health service in the Unified System is responsible for family planning (65%) and who he does not know his right to family planning or in vitro fertilization (80%). Still, women with “some knowledge” of the disease predominated (40%). **Conclusion:** Women's knowledge about endometriosis and family planning is limited, being unknown related to the disease, access to health services and the social rights involved.

Descriptors: Family Planning; Endometriosis; Women's Health.

RESUMEN

Objetivo: analizar el conocimiento de las mujeres con endometriosis sobre la enfermedad y la planificación familiar. **Método:** se trata de un estudio cuantitativo, transversal y descriptivo realizado en mayo de 2021 con 20 mujeres con endometriosis inscritas en un grupo específico en Instagram. Se aplicó un cuestionario sociodemográfico y clínico y un instrumento para evaluar el conocimiento de las mujeres a través de formularios de google. Se utilizó estadística descriptiva para analizar los datos que ocurrieron en el Paquete Estadístico para Ciencias Sociales, versión 25.0. **Resultados:** si bien el 70% de las mujeres sabe qué es la planificación familiar, hubo predominio de las que tienen dudas sobre la enfermedad (85%), que desconocen qué servicio de salud del Sistema Unificado se encarga de la planificación familiar (65%) y quien desconoce su derecho a la planificación familiar o la fecundación in vitro (80%). Aún así, predominaron las mujeres con “algún conocimiento” de la enfermedad (40%). **Conclusión:** El conocimiento de las mujeres sobre la endometriosis y la planificación familiar es limitado, se desconoce su relación con la enfermedad, el acceso a los servicios de salud y los derechos sociales involucrados.

Descritores: Planificación Familiar; Endometriosis; Salud de la Mujer.

Introduction

Endometriosis is an inflammatory condition, defined by tissue lesions similar to the endometrium, but outside the uterine cavity with the presence of pelvic pain, infertility and pain during sexual practice. Studies show that endometriosis affects about 176 million women of their reproductive age worldwide, affecting about 5% to 15% of these women of reproductive age, 20% to 40% of women with endometriosis have difficulties getting pregnant and 30% to 50% are infertile.¹

According to the Ministry of Health, complications from Endometriosis occur through the appearance of endometrioma, which are cysts installed in the ovaries, which can compromise the woman's fertility. Other organs that can also be affected are: Bladder, vagina, appendix and large intestine². According to the Ministry of Health (2012) in Brazil, one in ten women have Endometriosis.² Between 2009 and 2013, they were about 71,818 hospitalizations were pointed out due to complications from endometriosis.³

There is a difficulty in finding nursing professionals who provide assistance to women with endometriosis in Brazil, considering that the role of the specialist nurse in women's health is more focused on pregnancy and childbirth.⁴ In 2018, Law No. 8,438/ 2018 that instituted the Endometriosis and Infertility Prevention Week in Sergipe's official calendar. This week begins in the month of March, also known as "yellow March" for the worldwide awareness of Endometriosis, in which they promote an information campaign on the identification of disease and treatment, but it is noteworthy that, due to the recent innovations, there are women who do not have information about it.⁵

According to the Legislative Assembly of the State of Sergipe in a public hearing held at the Legislative School, in order to discuss prevention of Endometriosis and Infertility, it was reported that there are obstacles, such as the inaccuracy of relevant information about the disease, thus causing the lack knowledge that causes ineffective diagnosis and treatment. In addition, it was also observed that about 7 million women in Brazil are carriers of Endometriosis and Infertile.⁵

Thus, according to the Constitution of the Federative Republic of Brazil, women, men and couples have the right to family planning and are supported by article 226, paragraph 7, and by Law 9,263, of 1996, which regulates it. Thus women with Endometriosis have their rights guaranteed by law regarding drug or surgical treatments for family planning or fertilization.⁶ Based on these data, the question is: Do women with endometriosis have knowledge about their disease and about the family planning?

In this sense, the aim of the study was to analyze the knowledge of women with endometriosis about their disease and family planning.

Method

This is a quantitative, cross-sectional and descriptive study. Data collection took place digitally in May 2021 with 20 women belonging to a group dedicated to endometriosis and hosted on the Instagram digital platform. Women following a page dedicated to Endometriosis on Instagram were included; who accepted to participate in the survey between May 1st and May 30th, 2021; carrier

of ovarian, deep and/or intestinal endometriosis; and aged 18 years or over. Those who were in the group but had no medical diagnosis of endometriosis were excluded.

To approach the subjects, the study was initially disclosed to the aforementioned group, and the Informed Consent Form (FICF) and a research protocol were then sent through a link from the Google Forms platform to the participants. When opening the link, the consent form was first presented and, only after its signature, the research was started from the protocol prepared by the authors.

The research protocol consisted of demographic and clinical data and specific questions to assess women's knowledge. As sociodemographic data, the following were included: age, marital status and education level. In the clinical evaluation, questions were asked about previous pregnancy, access to health services, guidance received or not in the health service, the guarantee of rights to family planning by health professionals in the service.

The assessment of women's knowledge about endometriosis was carried out through 6 questions, 2 of which were open and 4 closed. The open questions were evaluated through thematic analysis, obtaining thematic categories from the similarities in the subjects' speeches. The closed questions had two answer options, yes and no, with a score of 1 being established for correct answers and 0 for incorrect answers or those that indicate lack of knowledge about the item in question. Thus, the final score of each subject ranged from 0 to 4, with 0 being no knowledge about the subject, 1 -Some knowledge, 2-Good knowledge, 3-Great knowledge; 4- Excellent knowledge.

To organize and analyze the data, a database was created in the Excel program (Office 2010) and the Statistical Package for Social Sciences (Version 25.0) was used. Qualitative variables were presented in absolute values (n) and percentages (n%). Quantitative variables were exposed in descriptive measures: minimum and maximum values, mean and standard deviation. The Wordle system was used to construct the word cloud for the questions: "What is Endometriosis for you?" and "What is your biggest complaint about the disease?". This technique consists of using different font sizes and fonts according to the frequency of words in the analyzed text 7.

In compliance with the Guidelines and Regulatory Norms for Research Involving Human Beings (CNS Resolution 466/12), this study was submitted to the Research Ethics Committee (CER) of the proposing institution, being approved on April 28, 2021 under opinion number 4.678 .003. In addition, along with the presentation of the study and its objectives, a Free and Informed Consent Form was made available for download with the instruments, which was signed, authorizing voluntary participation in the research.

Results

The study population consisted of 20 patients with Endometriosis registered on an Instagram page focused on this topic. Table 1 shows the sociodemographic data of these women.

Table 1- Sociodemographic data of patients with Endometriosis registered on an Instagram page. (n=20). Brasilia, 2021.

Categorical Variables			
Variable	Category	n	%
Marital status	Single	8	40,0
	Married/Living with a partner	12	60,0
	Divorced / Separated	0	0
	Widow	0	0
Education Level	Basic Education	0	0
	High School	13	70,0
	University Education	7	30,0
Continuous variables			
Variable	Minimum maximum	Average	DP*
Age	21- 44	30,8	6,8

*Standard deviation

According to Table 1, there is a predominance of women who are married/living with a partner (60%), who have completed high school (70%) and who have, on average, 30.8 years (SD 3.8) deity. Table 2 presents the clinical data of patients with Endometriosis.

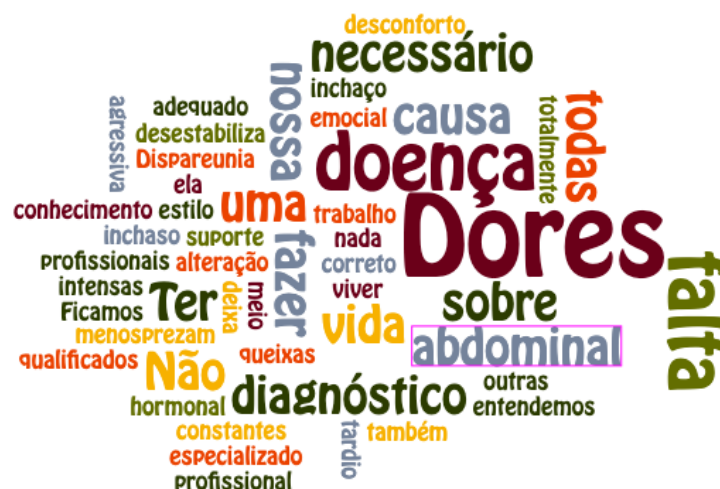
Table 2- Clinical data of women with endometriosis registered on an Instagram page (n=20). Federal District, 2021.

Variable	Category	n	%
What led you to question whether you were a carrier of Endometriosis?	By chance/routine consultations	6	30,0
	Pain/Intense Cramps	14	70,0
Have you ever gotten pregnant? If so, did you have difficulties with this?	Yes with difficulty	3	15,0
	yes without difficulty	5	25,0
	No but wish and keep trying	4	20,0
	never got pregnant	8	40,0
If you went to a Family Planning Health Service, what was your experience like? Did you have guidelines on your right?	Sought and got directions	0	0
	Searched, but had no directions	5	25,0
	Never searched / is unaware of the subject	15	75,0
Did you ever feel bad about seeking your right to family planning and it was somehow denied? If yes, tell me about this situation.	It was felt that the right was neglected	0	0
	He didn't feel his right denied	6	30,0
	Didn't search / Never needed	14	70,0

Table 2 shows that the presence of severe pain and cramps (70%) was what most led women to question whether they had endometriosis. Still, women who never got pregnant predominated (40%), who never sought the health service (75%) and did not seek and/or did not need to use this service so far (70%). Table 3 presents the quantitative assessment of women's knowledge about endometriosis and family planning.

Table 3- Quantitative assessment of women's knowledge about endometriosis and family planning (n=20). Federal District, 2021

Analysis by Question	Reply	n	%
Do you have questions about Endometriosis?	Yes	17	85,0
	No	3	15,0
Do you know what family planning is?	Yes	14	70,0
	No	6	30,0



In Figure 2, it can be seen that, when asked about the meaning of endometriosis, the words that most appear in the women's answers are: pain, disease, diagnosis and abdominal pain.

Discussion

In this study, there was a predominance of women who were married/living with a partner (60%), who had completed high school (70%) and who were, on average, 30.8 years old (SD 3.8). According to a survey of 13 women with endometriosis in the state of Maranhão, the incidence of the age of these women is between 30 and 39 years old, they also describe that the survey participants do not understand about the disease.⁸ A study conducted in the city of São Paulo with 892 women undergoing videolaparoscopy with the purpose of histological confirmation to diagnose Endometriosis reveals that the average age of these women is 33.2 years.⁹ In 2016, it was identified that, among 1008 women with Endometriosis, there was a predominance of married women / living with a partner.¹⁰ Thus, it appears that the results are similar between studies regarding the age of women with Endometriosis and regarding their marital status, predominantly married/living with their partners.

It was observed in this study that the presence of pain and intense cramps (70%) was what most led women to question whether they had endometriosis. Still, women who never became pregnant predominated (40%), who never sought the health service (75%) and did not seek and/or did not need to use this service so far (70%). A survey sought to analyze how patients with the disease reported the symptoms of the disease. The perception of the 20 narratives was that pain is considered intense and aggressive and through them came questions about the disease.¹¹ In 2017, a study whose objective was to analyze the experience of 20 women affected by Endometriosis with the hospital service, it was identified that, when seeking the health service, women were not successful in their care and that they often heard from health professionals that intense pain and cramps were normal. In addition, there were reports that felt violated and commercialized, as they needed money to perform treatments to alleviate pain.¹² It can be observed that the authors brought essential research, showing reports

and experiences that enabled the reader to understand data and statistics from of that matter.

Although 70% of women know what family planning is, there is a predominance of those who have doubts about endometriosis (85%), who do not know which health service provided by the SUS is responsible for family planning (65%) and who do not know their right to Family Planning or In Vitro Fertilization (80%). In addition, women who have some knowledge of the disease, family planning and fertility predominated (40%). A survey of 24 women from a Basic Family Health Unit in Ceará reported that family planning for them meant contraception with the use of oral hormonal contraceptives and male condoms. It was also observed that 10 women reported total lack of knowledge about the subject.¹³ A study with 237 women treated in two reference hospitals in Rio de Janeiro for endometriosis found that 49.5% were infertile.¹⁴ Thus, it can be observed the need for information for women with endometriosis through health education actions by nursing professionals so that they know where and how to find the necessary support when symptoms appear.

Regarding the question "What is endometriosis for you?", the most frequent words in the women's answers in this study were: disease, pain, suffering and disabling, that is, they perceive endometriosis as a disabling disease that involves suffering and ache. About this, in a study with women with Endometriosis, they described pain as "overwhelming" and "overwhelming".¹⁵ In an international research aiming to explore the perceptions of eighteen women about living with endometriosis, Pain was reported as intense and chronic as the main characteristics of the disease, which are capable of interfering with their social, professional and educational development.¹⁶ According to these findings, it can be said that the symptomatology of the disease strongly affects women who have this comorbidity, since the reports on symptoms and how they affect lifestyles have stood out in this and other studies.

About the meaning of endometriosis, the words that most appear in the women's answers were: pain, disease, diagnosis and abdominal pain, that is, they know that it is an abdominal disease that requires diagnosis and involves a lot of pain as a symptom. In a study that aimed to understand the late diagnosis of the disease with 29 participants, it was described that, despite the pain they felt, when they sought help, they did not get it easily. The research also observed structural negligence linked to the gender issue and that, for diagnosis, women needed to seek, on average, 5.3 different physicians.¹⁷ This information is essential for understanding how pain is the most reported characteristic in this study. pathology and that leads women more directly to the search for the diagnosis. However, for this to occur effectively and satisfactorily to them, health professionals with the capacity and knowledge that can help the patient to understand the disease and its symptoms are needed, thus producing good experiences and effective support for women with endometriosis.

Conclusion

Women's knowledge about endometriosis and family planning is limited and important aspects related to the disease, access to health services and the social rights involved are not known by most women with endometriosis.

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