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Impact of endometriosis drug treatment on women's professional, sexual and economic issues

Impacto del tratamiento farmacológico de la endometriosis en los problemas profesionales, sexuales y económicos de las mujeres

Impacto do tratamento medicamentoso da endometriose nas questões profissionais, sexuais e econômicas das mulheres

ABSTRACT

Objective: evaluate the improvement in the quality of women's lives with endometriosis under drug treatment and the delay in diagnosis. Method: the study happened through an online survey via the GoogleForms® platform, aimed at women diagnosed with endometriosis. Result: a total of 476 women (between 19 and 38 years old) living in the city of Joinville and Region were interviewed, the vast majority in the stages I and II of endometriosis. The interview raised informations about the time since diagnosis, medications and therapeutic treatments used, levels of professional commitment, sexual life and economic impact before and after diagnosis and treatment. Conclusion: the diagnosis and correct treatment for endometriosis, which eases the symptoms and extra expenses, help to reduce the social, economic and professional impacts on the lives of women with this disease.

DESCRIPTORS: Endometriosis; Health Care Quality; Access and Evaluation; Women's health.

RESUMEN

Objetivo: evaluar la mejora en la calidad de vida de mujeres con endometriosis en tratamiento farmacológico y el retraso en el diagnóstico. Método: el estudio se realizó a través de una encuesta en línea a través de la plataforma GoogleForms®, dirigido a mujeres diagnosticadas con endometriosis. Resultado: se entrevistó a un total de 476 mujeres (entre 19 y 38 años) residentes en la ciudad de Joinville y Región, la gran mayoría en las etapas I y II de la endometriosis. La entrevista recogió datos sobre tiempo hasta el diagnóstico, medicamentos y terapias utilizadas, grados de compromiso profesional, vida sexual e impacto económico antes y después del diagnóstico y tratamiento. Conclusión: el correcto diagnóstico y tratamiento de la endometriosis, aliviando los síntomas y los gastos extras, ayudan a reducir los impactos sociales, económicos y profesionales en la vida de las mujeres con esta enfermedad.

DESCRIPTORES: Endometriosis; Calidad; Acceso y Evaluación de la Atención de Salud; Salud de la Mujer.

RESUMO

Objetivo: avaliar a melhora da qualidade de vida das mulheres com endometriose sob o tratamento medicamentoso e a demora no diagnóstico. Método: o estudo se deu por meio de inquérito on-line via plataforma GoogleForms®, dirigido à mulheres diagnosticadas com endometriose. Resultado: foram entrevistadas um total de 476 mulheres (entre 19 e 38 anos de idade) residentes na cidade de Joinville e Região, a grande maioria nos estágios I e II de endometriose. A entrevista levantou dados sobre tempo até diagnóstico, medicamentos e terapêuticas utilizados, graus de comprometimento profissional, vida sexual e impacto econômico antes e após diagnóstico e tratamento. Conclusão: o diagnóstico e tratamento correto para a endometriose, amenizando a sintomatologia e gastos extras, auxiliam na redução dos impactos sociais, econômicos e profissionais na vida das mulheres com essa doença.

DESCRIPTORIOS: Endometriose; Qualidade; Acesso e Avaliação da Assistência à Saúde; Saúde da Mulher.

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INTRODUCTION

Endometriosis is an inflammatory disease caused by endometrial cells that, instead of being expelled through the vaginal canal, follow a path known as "retrograde menstruation", in which they exit through the fallopian tubes and adhere to tissues of nearby organs where they attach and cause an inflammatory process. It is a clinical condition that affects 6,5 million women in Brazil and 176 million worldwide.¹

This inflammation causes severe pain that intensifies during the menstrual period, leading to being confused with severe menstrual cramps. This intense pain can disable patients from performing their usual activities, a factor that is aggravated by the delay - on average 6 years - in having a definitive diagnosis, as it can be confused with menstrual cramps and access to exams is slow in the Unified System of Health. Among the characteristics that affect the quality of life of women, there are discomfort during sexual intercourse, intestinal and urinary bleeding and difficulty in getting pregnant - 40% of women with endometriosis are sterile.¹

The delay in defining the diagnosis implies a long waiting period that

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is accompanied by not only pain, but also significant psychological and social impacts for women, in which the reversal of such conditions only occurs upon confirmation of the diagnosis and onset of indicated pharmacological treatment.

Among the main impacts, the difficulty of exercising a profession stands out due to the need for absence due to intense pain, affective difficulties due to difficulty in performing the sexual act, marked by pain and lack of pleasure due to this clinical condition; in addition to the financial issue for access to tests that confirm the disease to start treatment, many of which are available in the SUS after a long waiting list. In these scenarios, the question that guides this research is "What is the perception of improvement obtained by women, in the professional life, sexual life and financial aspects with the use of medications, compared to not using it during the waiting period for the diagnosis?" These would be positive and in terms of time without the use of medication, thus demonstrating improvements in aspects of professional, sexual and financial life; since these are the situations that most afflict women with endometriosis.^{1,2}

The article aims to assess the improvement in the quality of life of women with drug treatment and the delay in diagnosis. Furthermore, it will address the difficulties generated for the patient to be affected by the disease and obtain a late diagnosis. Not only the symptoms, but also the treatments will be covered in the article for a complete understanding of the disease.

METHOD

This study was carried out through an online survey of women diagnosed with endometriosis. It was developed in a virtualized way via the GoogleForms® platform due to the COVID-19 pandemic. It was a survey with several questions about delay in diagnosis, opinions about aspects of quality of life most affected by endometriosis. As

it involves human beings, this project was submitted to the Research Ethics Committee (CEP) of UNIVILLE, being approved with registration CAA 26897619.2.0000.5366.

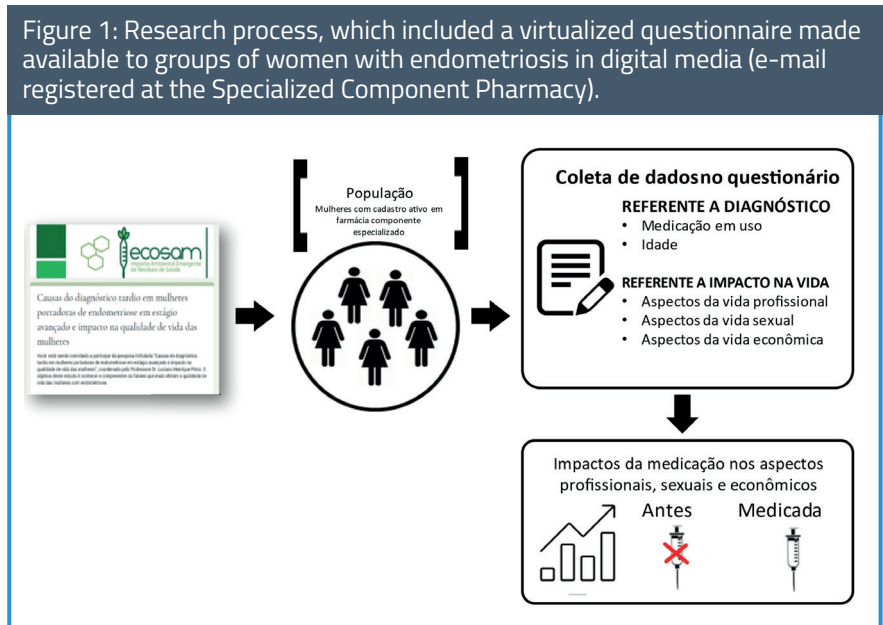
The studied population consisted of women – between 18 and 35 years old – who reported having been diagnosed with endometriosis; registered in Joinville's exceptional drug dispensing program, who answered the questionnaire via e-mail. Women who did not fit these conditions, who did not accept to participate in the research or who incompletely filled out the questionnaire were excluded from the research. The study was observational, document analysis and interviews. The data and information collected corresponded to: [a] Patient characteristics: age, family history, general habits; [b] Aspects of diagnosis: delay time, misdiagnosis and [c] main difficulties: impact on sexual, economic and professional life (Figure 1). Incomplete questionnaires, with conflicting data and from women without a confirmed diagnosis of endometriosis, assessed by their description of examinations and consultations until diagnosis, were excluded from the study.

Data were plotted in an Excel® spreadsheet and grouped according to the study variables raised above. The data plotted in an Excel spreadsheet were expressed as graphs for analysis and discussion of results.

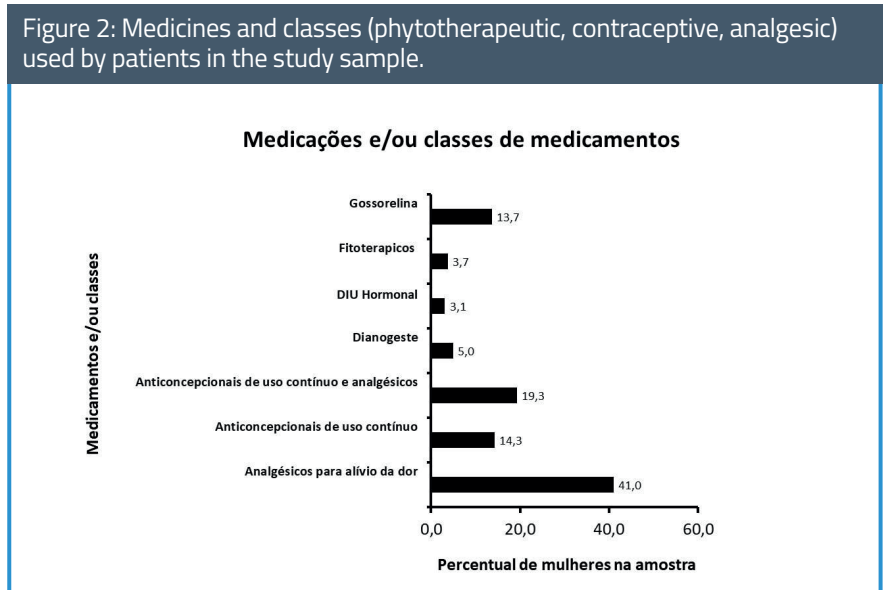
RESULTS AND DISCUSSION

A total of 476 women living in the city of Joinville and Region were interviewed. Age ranged from 19 years to 38 years, with the majority (96%) married or in a stable relationship. The vast majority were in Stages I and II of the disease, with a 6-year waiting period for diagnosis from the first disabling pain. The main medications and classes of use at the time of the interview are listed in Figure 2:

The results demonstrated the pre-



Source: Researchers



Source: Search Results

sence of different and diverse medications and therapeutic classes for the treatment of endometriosis and, mainly, for the symptomatic relief of pelvic pain. The total number of medications and therapies used was 586, some of them used in associations, highlighting the association between contraceptives and analgesics (Figure 2).

The treatment of endometriosis oc-

curs according to the way it manifests itself, there are 4 stages of this disease,³ classified by the number of detectable nodules, with up to 5 nodules being Stage I (with symptomatic treatment and use of contraceptives), Stage II, in which there are 6 to 15 nodules (with treatment based on contraceptives, or contraceptives and analgesics) ; Stage III, in which there are 16 to 40 nodules

(here already recommending the use of GnRH analogues, among others) and Stage IV; characterized by having more than 41 nodules, in which, in addition to the treatment provided for in III, the uterus can also be removed.⁴

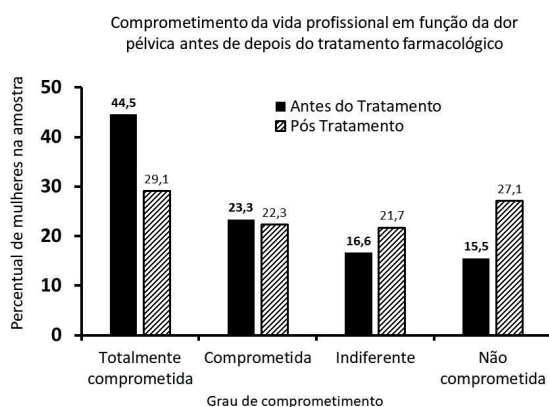
However, the delay before having a definitive diagnosis and access to correct medication has different impacts on women's lives, one of the main ones being their ability to perform professional activities when in pain. This was then a variable included in this study, whose results are shown in Figure 3:

The narratives of women with endometriosis reveal intense pain, which directly affects their work relationships, in terms of presence and concentration. The pain is described as excruciating, disabling, which immobilizes these women. Thus, many women end up missing work because they are unable to carry out their activities normally.² Thus, patients with endometriosis may show a decrease in productivity at work, a high rate of absenteeism, a decrease in monthly earnings and a lower chance of promotion and career advancement.⁵ This condition, from the perspective of the total impairment of work activities, was reported by about 44% of women, with a decrease of 15% when they started to be treated with medication. The group of women who cited no impairment rose from 15,5% to 27,1% when undergoing treatment, showing that drug therapy somehow contributes to the improvement of work activities.²

In addition to pain, increased menstrual flow, a symptom of the disease, also causes great discomfort. There are reports of shame, fear and anguish related to the experience of getting dirty with menstruation and feeling exposed. In other words, in addition to constantly living with this pain, these women also live with the fear of social exposure and shame, and this issue is also a reason for concern.^{2,6}

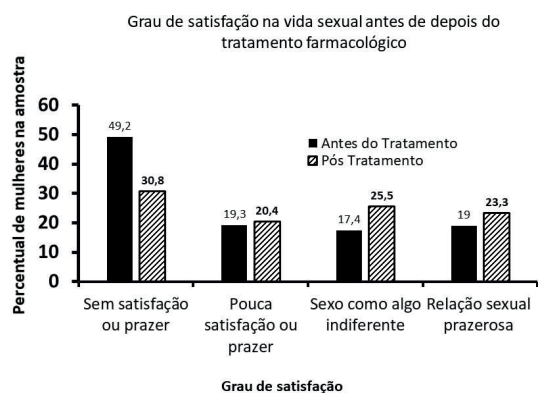
However, another aspect often observed in women with endometriosis concerns the quality of their sexual life.

Figure 3: Work life satisfaction scale. Before treatment 44.5% said they had a commitment to their professional life due to absence from work and difficulty concentrating. After treatment, the degree of impairment dropped to 29%.



Source: Search Results

Figure 4: Sex life satisfaction scale. Before treatment 19% said they were satisfied with their sex life. After treatment, the degree of impairment rose to 23%. Dissatisfaction dropped from 49,2% to 30,8%.



Source: Search Results

⁷ Pain during sexual intercourse, called dyspareunia, is one of the symptoms most described by patients with endometriosis. In addition to pain in fact, fear of self affects desire, arousal and human sexual response through the cognitive and emotional elaboration of pain. The disease also affects sexual interest and activity, as well as previous sexual satisfaction and pleasure and the ability to reach orgasm. ⁸ In figure 4 we have the profile of the group of women with their responses before and after drug treatment.

Within drug treatment, most women reported using analgesics and/or contraceptives. Analgesics, despite being effective in relieving pain, are harmful if used in excess and can cause reduced libido. ^{7,9} Contraceptives are highly recommended for the treatment of endometriosis. ¹⁰ They are very effective and few adverse effects are reported, not impairing libido. Dienogest has the same effect in treating endometriosis as contraceptive medications, ¹¹ but there may be loss of libido. ⁷ The hormonal IUD does not alter libido. In turn, danazol and goserelin can decrease libido and cause decreased

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lubrication. ⁹

Considering the problems experienced by these women, drug treatment is a good alternative, as it has the potential to improve not only the woman's pain, but also her sex life, ¹² indicating that dyspareunia is the factor that most reflects the low satisfaction of the sexual act, and the occurrence of adverse effects on libido is not so influential.

The importance that drug treatment brings to the quality of life of women is again noted, and that the issue of delay in diagnosis is once again an impacting factor for their well-being. ¹

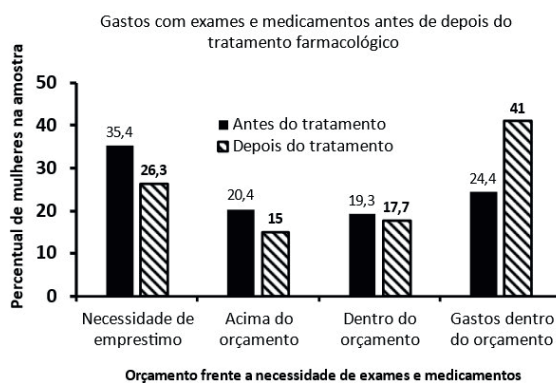
But the diagnosis still has problems with regard to its process itself, which includes the search for examinations and consultations by specialists that are not so quickly offered by the SUS, which in a way obliges the woman to pay for certain health procedures, which also affects your budget, as shown in Figure 5:

The graph in figure 5 shows the expenses of women before the start of treatment, showing that 35,4% of these women declared they had to resort to loans for the purchase of exams and medications, also counting on the help of friends and family for such expenses. This situation dropped about 9% after treatment, indicating that such a drop may be due to the lack of cost of exams. Furthermore, 24,9% of women declared that they had expenses within their budgets before starting treatment.

In terms of the number of women for whom the treatment fit into the budget, the number rose from 24,9% to 41%.

These cost data before and after the start of drug treatment showed that, when making a correct and rapid diagnosis and starting the treatment properly, the unnecessary expenses with a large number of tests and various medications to control symptoms and pain decrease considerably. ¹³ This further highlights the need to raise awareness among the population to seek professional care, in addition to

Figure 5: Expenses perception scale within the family budget. Before treatment 35% said they had spent more than allowed and had the help of friends and family. post-treatment the degree of budgetary commitment dropped to 26,3%.



Source: Search Results

having health professionals trained to know the necessary tests and availability of treatments.

Even though endometriosis is an impactful disease, access to services, diagnosis and treatments is scarce.^{6,14} What happens to these women, many times, is the so-called institutional violence of institutions providing public services -such as hospitals, health centers and the judiciary – perpetuated by people who should guarantee humanized care, preventive and, also, repairing damage.¹⁴ In hospitals, negligence and disregard for users are not uncommon, meaning that patients' basic needs are not met, or even involving unnecessary and/or undesirable procedures.¹⁵

In this way, women begin a pilgrimage for access to diagnosis, treatment and care: they run into hostile scenarios and with different professionals where violence appears in the quick and poorly enlightening service; in the

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migration of women by different professionals, including in health plans; in the professionals' misinformation/lack of knowledge about the disease and its clinical management; in the lack of access to specialized services; the high cost of private consultations and proposed treatments.

CONCLUSION

From the studies carried out, it is therefore concluded that after women are diagnosed with endometriosis and are correctly treated with medications such as contraceptives, analgesics and herbal medicines, the social, economic and professional impacts improve considerably. Thus, demonstrating the great importance of quick diagnosis, aiming at improving the quality of life of these women from the positive effects generated by the treatment. ■

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