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Significações e (re)posicionamentos na trajetória de vida de mulheres com endometriose no Brasil

Meaning Making and (re)positioning in the life trajectory of women with endometriosis in Brazil

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RESUMO: O presente artigo teve como objetivo analisar as significações e os (re) posicionamentos de mulheres com endometriose em suas trajetórias desenvolvimentais. Partindo de uma perspectiva sociointeracionista de desenvolvimento humano, dialogamos com a Teoria do Posicionamento como base para pensar processos de constituição do self a partir de uma perspectiva relacional. Foram realizadas entrevistas semiestruturadas com 6 mulheres cisgênero brasileiras, entre 22 e 46 anos, que possuíam o diagnóstico de endometriose. Foi realizada uma análise de posicionamento a partir das dimensões eu-eu, eu-outro e eu-discurso dominante. Observou-se diferentes processos de (re)posicionamentos. Na dimensão eu-eu, a presença de fortes sintomas desencadeou um posicionamento de diferenciação frente às outras mulheres. O questionamento do outro acerca da presença dos sintomas promoveu uma sensação de solidão, gerando, inclusive, um maior distanciamento de outras pessoas na dimensão eu-outro. Com a chegada do diagnóstico, algumas participantes relataram maior reconhecimento social e mais segurança para colocar-se em suas relações, bem como maior investimento nos cuidados de si. Na relação com o discurso dominante, foram reproduzidas e renegociadas expectativas sociais atribuídas à mulher, bem como houve reposicionamentos diante da autoridade médica. Ressaltamos a importância de protagonizar a narrativa das mulheres para sensibilizar profissionais de saúde sobre transformações psicológicas das mulheres no percurso de diagnóstico e tratamento da endometriose.

Palavras-chave: Endometriose; Posicionamento; Curso De Vida.

ABSTRACT: The aim of this article was to analyze the meanings and (re)positionings of Brazilian women with endometriosis in their developmental trajectories. From a social interactionist perspective of human development, we used Positioning Theory as a basis for understanding processes of constitution of the self. Semi-structured interviews were

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conducted with six cisgender Brazilian women, aged between 22 and 46, who had been diagnosed with endometriosis. A positioning analysis was carried out based on the dimensions called self-self, self-other and self-dominant discourse. Different processes of (re)positioning were observed. In the self-self dimension, the presence of strong symptoms triggered a positioning of differentiation from other women. When others questioned the presence of symptoms, it promoted a feeling of loneliness, generating distance from other people in the self-other dimension. With the arrival of the diagnosis, some of the participants reported greater social recognition and more security in their relationships, as well as greater investment in self-care. Regarding the dominant discourse, social expectations attributed to women were reproduced and renegotiated, as well as repositioning in the face of medical authority. We emphasize the importance of focusing on women's narratives in order to sensitize health professionals to women's psychological transformations during the diagnosis and treatment of endometriosis.

Keywords: Endometriosis; Positioning; Life Course.

Introdução

Although it does not yet have a known cause, endometriosis is considered to be a chronic disease associated with menstruation, characterized by the growth of endometrial tissue outside the uterine cavity, and capable of generating acute and chronic pain (Agarwal et al., 2019; Zondervan et al., 2020). Cisgender women with endometriosis report frequent, chronic and/or severe pain, fatigue, malaise, infertility and describe significant impacts of the disease associated with poor quality of life (Bellelis et al., 2010; Fernley, 2021; Hunsche et al., 2023; Nácul & Spritzer, 2010; National Institute for Health and Care Excellence, 2017; Rodrigues et al., 2020; Silva et al., 2021).

Pain is considered the main symptom associated with poor quality of life in women with endometriosis, especially dysmenorrhea (intense pelvic pain during menstruation), chronic pelvic pain and dyspareunia [genital pain that appears shortly before, during or after sexual intercourse] (Szypłowska et al., 2023). Similar results were found in Brazil through an observational study, whereas the greater and more intense the pain, the lower the quality of life (Fonseca et al., 2018). Symptoms such as depression, anxiety, stress, anguish and loss of productivity were also highlighted in another Brazilian study, revealing that the emotional state of women diagnosed with the disease is compromised, creating a vicious cycle that tends to worsen the physical symptoms (Sousa et al., 2015).

Considerations about whether the disease can remain stable or whether remission is possible are still inconclusive (National Institute for Health and Care Excellence, 2017). Some Brazilian interviewees revealed worsening symptoms over time, as well as shorter intervals between pain crises (Silva et al., 2021). The clinical picture of patients affected by endometriosis is quite variable (Zondervan et al., 2020), and many women are asymptomatic, which can make it more difficult to achieve a final diagnosis and compile data about the disease (Nácul & Spritzer, 2010).

The literature shows a consensus regarding the uncertainty of the diagnosis and the delay in achieving it (Bellelis et al., 2010; Nácul & Spritzer, 2010; National Institute for Health and Care Excellence, 2017; Silva et al., 2021). Part of this difficulty is due to the non specific clinical presentation of the disease, but also to factors such as the devaluation of complaints by health professionals and acquaintances (Zanden et al., 2021), stigma and naturalization of female pain, especially in relation to menstruation and childbirth, and the difficulty in establishing a differential diagnosis, which can result in erroneous test reports (Fernley, 2021; Seear, 2009; Silva et al., 2021).

It is precisely these factors that characterize what the Brazilian study by Silva et al. (2021) called the "peregrination to diagnosis". The term coined by the authors describes what for many women corresponds to the painful, sometimes incessant movement in search for diagnosis, with an average delay of 6 to 7 years between the onset of symptoms and definitive diagnosis in developed and developing countries. A Brazilian cohort study of 200 women found that the average time between the first symptoms and diagnosis was 7 years, with differences related to the clinical presentation of the disease, age and infertility (Arruda et al., 2003). The consequences of this delay have a negative impact on patients' lives, women live without adequate treatment, are exposed to more serious outcomes, greater risks of infertility and damage to underlying organs (Silva et al., 2021).

In Brazil, there seems to be a predominance of white women with a high level of education as the sociodemographic characterization profile of studies on endometriosis (Arruda et al., 2003; Bellelis et al., 2010; Florentino et al., 2019; Fonseca et al., 2018; Sousa et al., 2015). According to Silva et al. (2021), these data may suggest that non-white women with a lower level of education may have more difficulty in gaining access to a diagnosis of endometriosis, compared to white women with better social conditions.

The Brazilian health services system, including professionals and institutions and/or companies, belongs to public and private organizations. There are various interests that run through the services, from ensuring people's health to making a profit for businessmen and workers (Paim, 2009). In this way, access to diagnosis of endometriosis can be seen as an exclusionary process, since people with better social conditions often choose to pay for health plans that guarantee access to services more quickly and less time-consuming diagnostic responses.

There is a gap in the national literature regarding the trajectory of these women until their diagnosis (Silva et al., 2021), which points to the urgency of research that focuses on the narratives of these people living with the disease. This paper addresses the interest (or rather, the necessity) to listen to these women, approaching the diagnosis of endometriosis from their perspective.

Meaning making through language is an important process in human development. From a social interactionist perspective, we understand that development takes place in a complex, multidetermined, situational and procedural way (Carvalho et al., 2012; Rossetti-Ferreira et al., 2004). Taking this into consideration, we present the theoretical-methodological perspective of the Network of Meanings. Forged in the Brazilian context, this perspective is aligned with authors who defend the discursive nature and semiotic character of human constitution, thus highlighting the "centrality of interactions in the processes of production and transaction of meanings and senses, in the co-construction of the act, in the action of signifying (meaning making) in the constitution and development of people" (Rossetti-Ferreira et al., 2004, p. 24).

Imagistically, the authors evoke the metaphor of a network, made up of a mesh of semiotic elements that are constituted and influenced dynamically and continuously by each other. It is understood that the articulation of the elements incites a set of possible meanings, circumscribed by the historical-cultural context and, nevertheless, susceptible to transformation (Rossetti-Ferreira et al., 2004). According to them, we find ourselves immersed in this mesh, at the same time constituting it and being constituted by it, contributing to "constraining possible paths for (our) own development, the development of other people in their surroundings and the situation in which they find themselves participating" (Rossetti-Ferreira et al., 2004, p. 24).

In other words, human development is neither linear nor totally predictable, and imposes the existence of losses and gains. We are active agents and participants in our own developmental processes, as well as those of others, while we are also subjected to a set of senses and meanings, visions of the world and of ourselves. Our personal choices also have cultural influences, attributed to the social expectations of the context in which we live and create (Rossetti-Ferreira et al., 2004; Zittoun, 2009). Therefore, telling a story, creating a storyline and thinking about the events that surround us are activities pertinent to narratives to which we attribute value and qualifications, immersed in cultural practices situated in time and space.

The network of meanings, based on a sociohistorical view of human development, understands that it is through interactions that people are mutually constituted. It is in these relationships that people assign, assume and negotiate roles and positions during their trajectories (Rossetti-Ferreira et al., 2004).

Based on Discursive Psychology, Positioning Theory approaches interactive processes and the constitution of the *self* from a relational perspective. From a social constructionist perspective, it seeks to understand how psychological phenomena are produced in discursive practices in everyday social situations. Therefore, the concept of positioning has been used to think about how identities are build discursively, highlighting a fluid and dynamic notion of *self* (Oliveira et al., 2004), which relates to the idea of multiplicity of the person proposed by the Network of Meanings (Rossetti-Ferreira et al., 2004). When telling their own story, people position themselves in a relational and reflexive way. The first, because it is an interactive process in which the positions of the *self* are negotiated; and the second, because people position themselves or are being positioned in the dialog. It is important to emphasize that the positions of the interlocutors are not fixed and can change as the interaction develops (Oliveira et al., 2004).

In turn, Moutinho and De Conti (2016) align their propositions with Michael Bamberg, proposing a continuity between "positioning oneself" in the subject-world direction, and "being positioned" in the world-subject direction. Positioning takes place in the encounter between values, ideologies and cultural norms. Position is a construction of meanings in which the narrator assumes a moral place in relation to: themselves; to other characters in the narrative and in relation to the dominant discourse (Moutinho & De Conti, 2016).

Based on this, we inquire: how do Brazilian women describe their relationship with endometriosis? What thoughts do they have about themselves as women affected by the disease? Has there been any change over time? What meanings do they attribute to these changes? What cultural norms are related to their meaning making? Which characters appear in their narratives? In this direction, the aim of this article was to analyze the meanings and (re)positionings of women with endometriosis in their developmental trajectories.

Method

First Author's reflexivity

Being part of this research was a challenge and a pleasant surprise. Being a woman with endometriosis was what motivated me to research this topic. After seeking some Brazilian literature and searching for studies done through womens' perspective, I noticed their scarcity and realized that the desire to do research with this group also qualified as a necessity.

I'd like to emphasize the importance of the expression "research with", precisely because the research was *ours* from the beginning to the product of our interviews. It confirmed me that we can't research alone: we need a network to handle it. It also reminded me of the responsibility of words and our role as researchers specifically in the difficult task of transforming what we've been offered into a product. And I hope this paper is the first of many of these products. It can't be the final one. It's impossible to transpose everything we've exchanged into a few pages with character limitations and other pre-established criteria. Nevertheless, I hope that we have managed to solidify something about the relationship between women with endometriosis from their own perspective.

Surrounding myself with women in a situation similar to mine allowed multiple situations of identification, which I had never had due to lack of references from women with endometriosis around me. The sense of sharing and acceptance made me think that the story of these women was, in part, also mine and of many others, despite limitations and idiosyncrasies. I can say that my relationship with the disease and with the diagnosis - which I've been living with for eight years - changed radically after my contact with them, and so I feel I owe a lot to these women. And for that, I thank them very much.

Participants

The participants were six cisgender Brazilian women, between 22 and 46 years old, who were diagnosed with endometriosis and had access to the private healthcare system. The determining criteria for the participants were being a cisgender woman and living with the diagnosis of the disease, with no other criteria relating to socioeconomic level, social class, profession, race/color, religion, education, age group and sexual orientation (Table 01).

Table 1

Characteristics of the participants

Fictitious name	Age	Race	Time spent living with symptoms	Time with diagnosis
Taylor	25	brown	since adolescence, beginning of menstruation	1 year
Flor de Lis	46	brown	13 years	21 years
Mila	22	brown	from the first menstruation	6 years
Daniela	36	mixed-race	uncertain, as she used contraceptives continuously for many years	13 years
Raquel	31	white	dyspareunia (noticed and associated with endometriosis only after diagnosis)	9 months
Albina	24	white	7 years	2 years

Note. Race was self-declared. In foreign countries, especially in the North of the Globe, all of these women would possibly be read as “Latinas”. In Brazil they could be considered white, brown, etc. Self-perception of whiteness and the privileges associated with it can be hampered by the ideology of “racial democracy”, which covers up discriminatory processes between white and black people (Schucman & Melo, 2022).
Fonte. Elaborado pelos autores.

Data collection procedures

The data collection instrument consisted of a semi-structured interview, with questions about the diagnosis, prior knowledge of endometriosis, feelings related to the experience and confirmation of the disease, experiencing symptoms, self-perception as a woman with endometriosis and changes in self-perception before and after the final diagnosis. In addition, questions were raised regarding health insurance, access to treatments and support network. The contact with potential participants was made via an invitation on social networks such as *Instagram* and *WhatsApp*. Interested women got in touch by email to schedule interviews, which were face-to-face (n=2) and online (n=4), according to the participants' preferences. The interviews lasted between 17 and 48 minutes in length and were performed by the first author in the second half of 2022, in a location agreed with each participant. The project was approved by [anonymized for submission]. All participants provided written informed consent prior to enrollment in the study.

Data analysis

Based on the material provided by the interviews, we analyzed meanings and (re)positionings. The theoretical-methodological perspective of the Network of Meanings helped us to reflect on the interrelationship between biographical, contextual and temporal elements in identity and developmental processes (Rossetti-Ferreira et al., 2004). A positioning analysis was carried out, using the model proposed by Moutinho and De Conti (2016), highlighting the dimensions of self-self, self-other and self-dominant discourse. As the authors argue, personal narratives are the result of a dialogue with dominant social discourses and also processes in which the same discourses are reconstructed at the level of social relations. The position depends on the place assumed by the narrator in their self-self relations, or on the way they evaluate themselves; self-other, in relation to other characters in the narrative, and self- dominant discourse (Moutinho & De Conti, 2016).

Moutinho and De Conti (2016) also define other narrative elements, such as characters, activities, explanatory resources, qualifiers and context. The analytical indicator characters represent the agents of the narrative who assume a different status and are considered important in the narration, such as living and abstract beings. Together, activity, qualifier and explanatory resources help to make sense of how the characters refer to themselves by the actions they do (activity), by the ways they adjective themselves and others (qualifier) and how they explain events (explanatory resources). Context, in turn, encompasses the relationship with place, time and the speaker's social relations.

Results and Discussion

We organized the positioning analysis based on the dimensions of self-self, self-other and self-dominant discourse (Moutinho & De Conti, 2016). We emphasize that this organization is a didactic strategy to visualize different dimensions of the meanings and positions of women with endometriosis. However, we understand that these dimensions are interrelated, mutually constituting each other, since the self-positionings are relational and situated in a social-historical context.

Meanings and (re)positioning in the self-self dimension

One of the transversal elements in the women's experience in the self-self dimension was the relationship with the symptoms of the disease, mainly pain (dysmenorrhea, dyspareunia and chronic pelvic pain). Women also reported psychological symptoms linked to the impacts of the disease on their lives and the way they faced them. Some of them were: loneliness, fear, distrust and disbelief in health professionals, mood instability, depression and anxiety, which corroborate the systematic review study on the social and psychological impacts of endometriosis on women's lives (Culley et al., 2013). The interviewees reported living with feelings of displacement, strangeness and insufficiency within themselves.

In their meaning making processes, the presence of loneliness was evident, which was already noted in literature (Cole et al., 2021; Culley et al., 2013). In the participants' experience, it intensified whenever others doubted about the presence of symptoms:

> That was the worst, because it's that feeling of loneliness, you know? You're alone and sometimes you think it's made up, no, it's not possible, no, I didn't think I made it up, because the pain was huge, but it's as if I couldn't manage it like other people do (Flor de Lis).
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> Everyone menstruates, everyone feels cramps, everyone feels bad, with swollen breasts and swollen hips too… and why does it seem so disabling to me? (Albina).

In this sense, endometriosis may be responsible for a condition of self-imposed loneliness, in which the person affected by the disease sometimes position themselves as different from others:

> Since I perceive myself as a woman with endometriosis, [...] therefore I have some issues that some women do not have. And I think a big part of this perception is also feeling alone, in the sense that people don't talk much [about it], you know? (Albina).

When asked about her perception of herself as a woman with endometriosis, Flor de Lis positioned herself as "a woman who battles", as she feels that the "war does not end", whether it's enlightening people about the disease, embracing others or even worrying about the effects of the disease on her daughters. For her, the relationship with endometriosis was described as something endless that has brought obstacles in different areas of her life.

This feeling of loneliness also appeared in the search for a diagnosis and in the experience with the symptoms, as described by Taylor:

> I was researching my symptoms even before I was diagnosed, I was always researching, trying to find out what it was because no one said anything... And that's how I discovered that endometriosis existed, I started researching about it, reading articles... looking for doctors who talked about this, about the disease, and I had it in my head that I had endometriosis, that's why I kept changing doctors, but they couldn't figure out if I had it or not (Taylor).

This excerpt also points out to the importance of investing in training professionals to deal with endometriosis. In some narratives, the feeling of being different from others provoked self-questioning about their own health situation:

> When you arrive at the emergency room there is a pain scale, right, from zero to ten, and the nurse always asks “how much pain are you feeling?”. And I don’t know if this happens to other people, I believe so, but I always think “does this really hurt? or is it in my head?”, “are other people more tolerant to pain than me?” (Albina).

However, the self-other dimension was important in the process of discovering the disease, as it allowed the comparison of experiences with other women around them. The participants were able to differentiate themselves through the presence of intense and prolonged symptoms. The majority of interviewees said they knew there was something “wrong” with them as they recognized that their experiences with menstrual cycles were not the same as those of people close to them.

When diagnosed, some women reported feeling relief, which showed a change in their relationship with themselves. Once again, the positioning of oneself in the self-self dimension was also strongly marked by the gaze of others. Relief and comfort were present in Taylor and Albina's speeches, as these participants associated being diagnosed to a moment that enabled social recognition and validation of their complaints and symptoms, providing a new meaning to the trajectory, even though, there were also negative feelings, such as fear:

> [I felt] relieved, but really, really scared [crying], because it was worse than I imagined, because I knew that deep endometriosis was the worst type, [...] I started crying... with relief and fear, at least I had the diagnosis, right?... (Taylor).
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> Finally, someone told me something, not necessarily definitive, but something concrete, you know? Something like “you have this and we can treat it this way”. Because until then I was just stuffing myself with medication without knowing exactly why I felt so much pain... (Albina).

Some participants began to perceive themselves as stronger and more confident in themselves. As Taylor said:

> I think I'm stronger knowing that I'm moving forward, that I'm improving [crying], I can now talk about this with my therapist, something I didn't do before: I was in therapy but I didn't talk about it (Taylor).

Similarly, Flor de Lis reported the development of strategies to deal with the disease, which also denotes a change in position regarding herself and endometriosis:

> After the diagnosis, you know where you are standing, even if you are stepping on horrible ground, you know where you are, right? [...] But I think we can find ways to fight it… When we feel the pain, we think that there will be no mechanism to fight it and we think that it will be like this for the rest of your life, that you will

> die. I think that endometriosis may bring this idea to me that you can solve it, you can chase it, you know? That you are not alone, and it will pass, one day, even if it's just a little, but it will pass (Flor de Lis).

According to Moradi et al. (2014), women believe they have learned lessons from living with endometriosis (Raquel), how to feel more determined, strong (Taylor) and courageous (Flor de Lis), in addition to listening more to their bodies (Raquel and Mila), being more aware of themselves (Mila), having their pain tolerance increased (Albina and Daniela), and even understanding and can helping other women with the same or similar symptoms (Flor de Lis).

With the diagnosis, a series of changes in the self-self relationship were observed, as women understood the need to care about the impacts of the disease throughout their lives, which includes medical appointments and exams, the use of medications and surgical procedures.

We observed changes in positioning related to self-care in other areas of life also impacted by the disease, such as nutrition (Albina and Raquel), physical exercises (Albina and Mila) and psychological care (Taylor). Raquel's report exemplifies the concern with self-care and indicates the repositioning towards a more attentive version of herself:

> I wasn't as careful as I am with food… even though I've never been one to eat a lot of junk food. But anyway, I've changed a lot in relation to that (Raquel).

At the same time, Albina highlighted an additional concern in her relationship with endometriosis. She said: “The point is not grasping exactly how my body works, you know? It’s as if, suddenly, the slightest perception of [menstruation] blood, like it's something super abnormal, as if it is a sign that I should be worried”. Once she was aware of her condition, the participant showed to be more alert to anything that could be potentially related to endometriosis. Taylor also pointed out the fear regarding the return of painful symptoms, a common fear associated with women with endometriosis, precisely because past experiences led them to believe that they would never be free from pain (Denny, 2009).

In Mila's report, we observed a nuance regarding the change in positions and yet, the preservation of her *self*-perception. This “other character”, endometriosis itself, sometimes appeared as something external and uncontrollable, and sometimes as a constituent part of herself, that she learned to deal with:

> I think that when you have something that binds you forever, like a disease, like endometriosis, which has no cure, it will be yours forever, you start to see yourself differently, to notice things about yourself that make you feel like “is this mine or is this a result of this aspect that I discovered is mine?” But I don't feel any different, I learned that regardless of whether or not I knew I had endometriosis, I had it and I was already me, at that moment. So, the idea I had of myself, after a lot of thinking about it, hasn't changed. If I realize I have issues that come from this disease, obviously, like anyone who has a condition like endometriosis, but it doesn't change my vision about myself (Mila).

Self care and loneliness were two dimensions closely related, as many women were delegated as the sole responsible for seeking this kind of care. Many sentences confirm their feeling of exclusive responsibility for taking care of themselves: “I know it’s something *I* need to monitor” (Daniela); “*I* can make it decrease” (Raquel). In Taylor's case, this pattern generated an idiosyncratic consequence: the pressure on self care reached such a point that she developed an eating disorder. We therefore observed a borderline relationship between care and control, which sometimes generated a feeling of vigilance that could even lead to illness.

In other cases, the confirmation of endometriosis also brought reflections about the desire to get pregnant, especially since endometriosis is commonly associated with infertility (Bellelis et al., 2010; Nácul & Spritzer, 2010; National Institute for Health and Care Excellence, 2017; Silva et al., 2021). This occurred in different ways: for Daniela it was the feeling of apprehension due to her strong desire to be a mother; as for Raquel, the need to anticipate a matter that hasn't been planned by her and her partner.

Meanings and (re)positioning in the self-other dimension

One of the aspects that stood out in the relationship between self and other was the questioning of the existence of the pain and its intensity. The participants associated this to specific characters in their narratives, such as doctors and other health professionals, and people close to them - friends and family. As the symptoms of endometriosis are typically trivialized by doctors (Cole et al., 2021; Grogan et al., 2018), it was not surprising that friends and family also had difficulty understanding the potential seriousness of this condition. Disbelief in their reports demonstrated a lack of support from the health team (Grogan et al., 2018) and was considered an additional factor of distress for women, in the same way as having their experiences with symptoms reduced to psychosomatic or displaced from reality (Cole et al., 2021).

For Mila and Albina, the presence of symptoms had an impact on their social relationships and activities. In Mila's case, living with the symptoms prevented her from doing school activities and as a result, she had her word questioned:

> The school principal called my parents to tell them to investigate because I could be faking it [feeling pain] to skip exams [...] The principal himself said 'look, maybe she's lying, maybe she's just lazy', you know? (Mila).

In Albina's trajectory, we observed a different positioning regarding her relationships, as she decided to hide details of her condition from others, motivated by the fear of judgment, lack of understanding, shame and strangeness. The "other" was seen as someone who did not understand what she was going through:

> There was this distance between me and my friends, growing up, you know, this part of adolescence, young adulthood… Because every time I tried to bring this up there was always an obstacle, or a lot of questions, and then these questions sometimes left me in a very uncomfortable place. Because between asking in a healthy way and asking in a way as if I had to self-validate the way I felt, as if I had to justify my pain all the time, and especially in this process that I didn't have a diagnosis, I couldn't say "oh this is what causes and I feel this way", you know? It was something that I just preferred not to get into, so sometimes I was feeling bad and said "oh, I'm sick", I didn't say I had cramps anymore, I said I was sick because no one questioned much, but if I said I had cramps, "take some tea with I don't know what", "take some medication", "do this, do that", "put on a hot water bag", a hot water bag never solved anything for me (Albina).

Hiding symptoms from people who were close to her was interpreted as a self-silencing[1] strategy, which also relates to the feeling of self-imposed loneliness. With this, we do not aim to hold the person responsible for the loneliness experienced, but to affirm that interactions have effects on the way the person sees themselves and how they relate to others.

Grogan et al. (2018) link the act of hiding symptoms from family and friends to the fact that they do not consider endometriosis to be a legitimate disease, which was also observed in the experiences of Mila, Taylor and Flor de Lis. As we will see later, these

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[1] The term "self-silencing" was used in the article by Cole et al. (2021) to refer to situations in which women judge themselves through the eyes of other people.

behaviors are connected to the self-dominant discourse dimension elements such as the social normalization of female pain.

For Taylor and Flor de Lis, the lack of support from those close to them came after endometriosis surgery, when they felt that friends and family disappointed them by not understanding the relevance of the procedure in their trajectories. Regarding this, Taylor said:

> I don't talk about it much, after the surgery. I talk more with my therapist, because it's like people relativize it, you know? Even my best friends… I was very disappointed [crying]. The day I was diagnosed, I was very scared, they were like “hey, but you're going to have surgery, everything will be fine, you'll be cured and that's it” (Taylor).

In her account, we observed the movement of self-silencing as people she expected to count on were unable to offer the support she would have liked, and as they also minimized something that was important to her.

However, the arrival of the diagnosis also brought these participants (Taylor, Flor de Lis, Albina and Mila) social recognition and validation of their complaints from others and themselves. The diagnosis was recognized as a tool that allowed women to take the following path of positioning: I take control of myself and now I have the possibility of being socially recognized, even though this process is challenging and has obstacles, as Taylor reported earlier. The exit from a place of invisibility and ignorance has led to behavioral changes reported in the self-self dimension, as well as repositioning in the self-other dimension. As Mila said: “The people around me know I have it, which makes it much easier. So, since the diagnosis, I've never suffered anything like what happened at school”.

We also observed repercussions on the sexual-affective relationships of all the participants. This happened mainly due to the symptom of dyspareunia, which has significant social and psychological impacts (Culley et al., 2013), and it was described by the women as a hindering element in relationships. According to them, the association of the symptom with endometriosis was not immediate, since sex was commonly described as a pain-generating experience in cisgender women:

> I thought it was normal. So, when I was diagnosed, I still hadn't had sex, but when it started, I always thought it was a normal thing [to feel pain during intercourse]. Several of my friends told me “it’s common, it will last for a while, then it will go away”. It never did. It never went away and I started thinking “is there something wrong?” (Mila).

Albina described the pain during sexual intercourse as unbearable to the point that the symptom disrupted the dynamics of her emotional partnership. In her report, endometriosis emerged negatively as a central character, being placed as a “third person” in the relationship. In some cases, pain also appeared as a character, associated with endometriosis and linked to the feeling of insufficiency. This had a significant impact on Taylor's trajectory, who assumed a position based on the “exclusion” of the affective-sexual dimension of her life:

> I felt a lot of pain in what they call a ‘deep’ relationship, right? [...] The loss of my virginity was horrible and I already felt the symptoms two years before that and I didn't know it affected me in that way, so in my head the problem was me. It ended all the relationships I've had since last year… Even before the diagnosis, I excluded this part of my life and my therapist keeps insisting that I get back into it but I can't... (Taylor).

Other characters featured prominently in the interviews of all the participants: all health professionals, but especially doctors. The latter were seen sometimes as allies and sometimes as oppressors, as in other findings in literature (Facchin et al., 2018):

> I felt a little strange, I said “it's not possible that this is normal” and the doctor said “no, you are a softie, there are people who experience much worse”. I felt this fear and I felt a little out of place “what is this pain?” (Flor de Lis).
>
> This process of going to different doctors several times and having them say that my pain was somewhat relative, you know? It's also a complicated thing, because there comes a point where you even ask yourself “is it nonsense?” (Albina)

“The doctor” represented a vital character in the processes of self-loneliness and self-silencing positioning, since their opinion modified the participants’ views about their own health conditions. At other times, the doctor appeared as an encouraging and supporting character in the search for an accurate diagnosis, and some participants attributed to them the closure of the incessant search they had been on.

The post-diagnosis period was marked by the quest to find other women in the same situation, as well as a greater understanding of the disease and its impacts. This stimulated participants Taylor, Flor de Lis and Albina to seek groups and communities of other women with endometriosis. These groups were essential strategies for obtaining information, comfort and support and for “spreading the word” about endometriosis among others. In fact, the literature has shown that women consider other women with endometriosis to be the most useful and valuable source of information (Culley et al., 2013). In the words of Flor de Lis:

> Women's groups saved me. I went out looking on the internet. There was no whatsapp or anything, but we had lots of groups, many forums. So, in these forums I met several people with endometriosis, and they were very important support. I

> didn't have any psychological support or anything, it was really support from people in the same situation (Flor de Lis).

It is also relevant to mention the position of the participants regarding the researcher who interviewed them. Most of the interviewees were enthusiastic about taking part in the research, recognizing its importance as a way of breaking with the invisibility that still shrouds the disease. As Albina said *"I just want to thank you for the initiative, because I think it's really very interesting"*. She also emphasized the importance of the study being done through a psychological perspective, since it is a scarcely explored dimension.

The fact that the researcher responsible for the interviews was also a woman with endometriosis positioned her in the relationship with the interviewees as someone who shared the experiences. In this way she became a support figure.

Meanings and (re)positioning in the dominant self-discourse dimension

In the self-dominant discourse dimension, we will address two elements that were presented in a significant way and are linked to the social context in which the participants live. The first refers to gender expectations associated with women's social place, which permeate cisheteronormativity, as well as the normalization of female pain, as something inherent to these people's experience. Next, we will address the social role of doctors as health authorities, which, associated with gender norms, has sometimes led to situations of violence and silencing of women.

In the reports of participants such as Mila, Albina and Taylor, we were able to observe how normative perspectives about sexual relations were associated with the feeling of insufficiency. Gender expectations about femininity and sex in cisheterosexual couples interfere with the way women with endometriosis make sense of themselves, promoting ruptures in some identity dimensions. It is common for women with endometriosis to feel guilty for not being able to meet normative expectations regarding sexual relations (e.g. penetration) in their relationships (Hudson et al., 2016).

The ability to get pregnant and have children as a fundamental constitution of what “it means to be a woman” was also present in the speeches, especially from Raquel, Daniela and Flor de Lis, supporting previous research in the study of the identity of women with endometriosis (Cole et al., 2021; Hudson et al., 2016). Hudson et al. (2016) says that the emphasis on the topic of motherhood, when brought to women with conditions that affect fertility and/or menstruation, can make them feel that they have failed in fulfilling their role as a woman. In her report, Flor de Lis simultaneously reproduced and renegotiated this social place designated for women, when stating her desire to be a mother, but considering possibilities other than pregnancy: *“*If I want to, I'll have a child. I don't know how they'll come, if they’ll come by adoption, but they'll come somehow”.

Another aspect observed in the dominant discourse was the normalization of women's pain, corroborating ideas such as that women came into the world to feel pain, or even the discourse that pain is part of the experience of menstruating and should therefore be accepted. Thus, women who complain are labeled as “weak” and “exaggerated”. These labels adhere to women's identities, even more so when placed by people considered important (Facchin et al., 2018). This relativization of women's pain was observed in the following excerpts:

> You know what's funny? [referring to the symptoms] It’s not like a regular period, but everyone treated it as if it was. I don't remember specifically when it started [...] but I do remember that it was something that was there in my adolescence. But people talked, it was never like "oh, what an unusual thing”, it was more like “oh, women feel cramps when they menstruate, she feels it more than others, bear

> with it". It was just too different, too discrepant for people to treat it naturally, you know? (Mila).
>
> I didn't go to the hospital so many times out of weakness, I didn't cry because I have a low tolerance to pain, I didn't miss a certain party of a friend or, I don't know, lied around on Christmas because I wanted to, or I just wanted to "draw attention", or something like that. Which were things I've heard. It's because I really couldn't do it, because it hurt, because I was really ill" (Albina).

It is noted how the dominant social narrative influenced women's positioning about themselves and their behaviors, as they internalized the discourse of others who questioned their complaints. A similar situation was found in studies with the same public (Cole et al., 2021; Facchin et al., 2018), which described that women internalized perceptions of themselves as "crazy" and questioned their own sanity due to the trivialization of their symptoms by others, especially health professionals. It's evident how the dominant discourse constitutes the relationship with the self (self-self), demonstrating that these dimensions are co-constitutive. The acceptance of the dominant social narrative by the characters generates a lack of support for women affected by the disease (Cole et al., 2021; Grogan et al., 2018), a point also observed in this research in the self-other dimension.

Cole et al. (2021) also highlight that in an attempt to maintain their social roles as good partners, mothers, daughters and patients, women with endometriosis symptoms choose strategies that are incompatible with taking care of themselves and their health conditions, strategies such as self-silencing, signaled in the self-other dimension.

In this research, repositioning was associated with taking a leading role in their own treatment, when women sought out other doctors and alternative forms of care. This was a strategy of self-managing endometriosis through lifestyle changes, going against the arbitrariness present in medical discourses on treatment. According to Raquel:

> I don't really like the idea. But I've been preparing myself since the diagnosis, I'm preparing myself psychologically to understand that I'm going to take this medication, just like a person with high blood pressure has to take medication and there's no point in going against it. I even researched natural ways to fight this disease, to protect myself, but it's very unsafe, there aren't any doctors here that work with this and I'm not going to do this alone because it's risky (Raquel).

We observed a predilection among health professionals for hormonal treatments to control symptoms, as it is seen in literature (Denny, 2009). However, the possibility of these forms of treatment are scarce, involving practical and financial difficulties that can pose a risk to women (Culley et al., 2013). Raquel's position demonstrated a certain rupture with the system, when she decided to seek strategies beyond medical care, considered hegemonic in our society. However, since it escapes the standard of health treatments, she reports a difficulty in finding means or professionals willing to work with alternative forms of care.

According to Young et al. (2020), doctors, especially gynecologists, were recognized by women with endometriosis as authorities with decision-making power over their lives - even more so during surgeries. The study demonstrated that women navigated between their own knowledge incorporated with the clinical experience of professionals (Young et al., 2020). As Flor de Lis said:

> In my lack of scientific knowledge, but in my experience, the first pregnancy was kind of a cure for me. Because since the first pregnancy I started to feel much less pain, even less than after the treatment (Flor de Lis).

Although they valued knowledge about their bodies, women also accepted medical discourse for fear of suffering any consequences, such as inadequate or ineffective care. This became explicit when the participants stated that they knew something was wrong with them despite the medical discourse denying their complaints. In these cases, women used empirical experience to recognize their conditions. There is an interesting repositioning taking place: even though they considered doctors an authority figure in relation to their treatment, the participants sought to legitimize their experience and questioned certain health practices.

Other women have already warned about the importance of gynecologists and other health professionals having a better and greater understanding of endometriosis, as they themselves needed to be experts in their health conditions due to the lack of professional preparation (Grogan et al., 2018). This is reflected in the reports of Taylor, Flor de Lis and Albina. Facchin et al. (2018) alerted that when communication between doctor and patient was considered poor, women commonly used the Internet to obtain information, which resulted in increased stress and in some cases, undue self-medication, since the material found was not specific.

For Taylor, Flor de Lis and Albina, the so-called peregrination to diagnosis was in line with other findings (Cole et al., 2021; Culley et al., 2013; Facchin et al., 2018; Grogan et al., 2018; Silva et al., 2021). We also observed the presence of gynecological violence, which according to Cárdenas Castro et al. (2020) includes all practices carried out by members of the healthcare team that can lead to a woman's loss of autonomy and her ability to decide freely about her body and sexuality. In the present work, the trivialization of symptoms, negligence of health professionals, denial of information and treatment, and invasive procedures without consent were seen as cases of gynecological violence:

> I only received the diagnosis after waking up from surgery without an ovary [crying]. And then he [the doctor] said “you have endometriosis, you can't have children anymore, you'll have to undergo treatment, but get used to the fact that you won't have children”. He said that he had kept one ovary and both tubes, removed several spots (endometriosis lesions) and part of the intestine, and then came the diagnosis of stage 4 endometriosis, which is the most severe [...] I felt mutilated, [...] it was an internal mutilation, and people didn't understand this hole I had in me. [...] So, it was, it was a shock. That feeling of mutilation was because I wasn't going to be a mother anymore, not in the way I had thought[...] I think the first feeling was this, of mutilation and loneliness because it seemed to me that doctors at the time, health professionals, they had little knowledge, that was what, the year 2000, 2001... (Flor de Lis).

In Flor de Lis’ words, the doctor’s speech upon arrival of the diagnosis represented a true “vaticinium” for her. We observed, however, a firm position on her part, contrary to medical opinion when she added: “I won't allow it, I won't allow myself to feel that again”. Despite recognizing the importance of medical care, the women's experience of successive frustrations and violence made them, to some degree, question professionals and procedures used to treat the disease.

Conclusion

The interviewees had different experiences and yet similar elements in their trajectories with endometriosis. In the self-self dimension, one of the common elements was experiencing the symptoms of the disease, mainly pain. In their meaning making processes, the presence of loneliness was evident, sometimes self-imposed, and sometimes intensified by others doubting the existence of their symptoms. With the final diagnosis, positive feelings, such as relief, and negative feelings, such as fear, were reported, which led to different positions in each trajectory. Some participants reported greater investment in self-care, assuming a posture of vigilance, and began to perceive themselves as stronger and more confident. The women also described the development of strategies to deal with the disease, which denotes a change in their positions regarding themselves and endometriosis.

One of the aspects that stood out in the self-other relationship was the questioning, by others, of the existence of pain and its intensity. This was observed in relationships with friends and family, as well as doctors and other health professionals. Women's positions in this dimension were linked to a certain distance in their different relationships, as a way of protecting themselves. Contacting other women with endometriosis was one of the few spaces for recognition. The discovery of the diagnosis promoted different (re)positionings, and worked as a tool for social legitimation, demanding recognition from others and making women safer to express themselves in their relationships.

The dominant discourse was present in all temporal dimensions and presented itself through gender expectations associated with women's social place, as well as the normalization of female pain. The social place of the doctor as an authority in the health field was also highlighted. In this dimension, women's repositioning processes were related to the reproduction-renegotiation of these gender roles, as well as a tension in medical centrality, assuming a more active role in the search and consolidation of their treatment.

Some findings in the present work reflect ideas that already exist in the literature about the experience with endometriosis, such as the variability of the relationship with the disease throughout life, marked by complex and multifaceted processes. However, this study brings a dimension less observed in literature, by allowing women to be protagonists, talking about their own experiences. In this sense, we consider that this research has the potential to sensitize different social actors about the complexities and particularities of the disease. We highlight the importance of raising awareness and training doctors and other health professionals, as they play a significant role in the diagnosis and treatment of endometriosis, and whose stance has a considerable impact on the trajectory of women. Considering the benefits that groups of women with endometriosis brought to the participants, we encourage these groups to be supported by professionals and institutions, acting as a driver of change in health practices.

As limitations of the article, we list the homogeneity of the sample in relation to social class and access to the private health system in our country. Social markers such as race and class can constraint different experiences regarding access to healthcare. Furthermore, we observed aspects that can be explored in future studies. One example is how religious discourse is related to the meaning making processes regarding endometriosis.

It is also important to address that this research does not intend to generalize the results, but rather illustrate possible meanings and (re)positionings experienced by women in their trajectories. As discussed above, these meanings and positions are multiple and can change over time, causing alterations in women's relationship with endometriosis throughout their lives.

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