Female Psychological Experiences Regarding Crohn's Disease: A Case Report

Vivências Psicológicas Femininas Acerca da Doença de Crohn: Um Relato de Caso
Vivencias Psicológicas Femeninas Acerca de la Enfermedad de Crohn: Un Estudio de Caso

RESUMO
Objetivo: Explorar as experiências psicológicas femininas relacionadas à Doença de Crohn por meio de um relato de caso. **Método:** relato de caso de uma paciente de 20 anos diagnosticada com Doença de Crohn, residente no município de Rafael Fernandes – RN, em 2009. Os dados foram coletados por meio de uma entrevista semiestruturada composta por perguntas abertas e aprofundadas, e foram subsequentemente submetidos à Análise Qualitativa de Conteúdo. **Resultados:** emergiram três categorias: 1) A Odisséia em Busca de um Diagnóstico e Tratamento; 2) A Posição da Pessoa com Doença de Crohn na Redefinição da Dinâmica Familiar; e 3) Experiências como Indivíduo Ostomizado: do confronto com o espelho à transformação do guarda-roupa. **Conclusão:** O principal fator associado à progressão clínica da Doença de Crohn e suas complicações relacionadas estava ligado às dificuldades em estabelecer um diagnóstico precoce. A família desempenhou um papel protetor na promoção da adesão ao tratamento; no entanto, em certas circunstâncias, ela prejudicou a autonomia da paciente no autocuidado e na inclusão social. Por fim, o estágio da doença em que se observou o maior comprometimento da feminilidade correspondeu ao período durante o qual a paciente apresentava uma ostomia.
DESCRIPTORES: Doença de Crohn; Ostomia; Adaptação Psicológica; Relações Profissional-Paciente; Relato de Caso.

ABSTRACT
Objective: To explore female psychological experiences related to Crohn's Disease through a case report. **Method:** a case report of a 20-year-old female patient diagnosed with Crohn's Disease, residing in the municipality of Rafael Fernandes – RN, in 2009. Data were collected through a semi-structured interview comprising open-ended, in-depth questions, and were subsequently subjected to Qualitative Content Analysis. **Results:** three categories emerged: 1) The Odyssey in Search of a Diagnosis and Treatment; 2) The Position of the Person with Crohn's Disease in the Redefinition of Family Dynamics; and 3) Experiences as an Ostomized Individual: from confronting the mirror to a wardrobe transformation. **Conclusion:** The primary factor associated with the clinical progression of Crohn's Disease and its related complications was linked to difficulties in establishing an early diagnosis. The family played a protective role in fostering treatment adherence; however, in certain circumstances, it hindered the patient's autonomy in self-care and social inclusion. Finally, the stage of the disease in which the greatest impairment of femininity was observed corresponded to the period during which the patient had an ostomy.
DESCRIPTORS: Crohn's Disease; Ostomy; Adaptation Psychological; Professional-Patient Relations; Case Report.

RESUMEN
Objetivo: Examinar las vivencias psicológicas femeninas relacionadas con la Enfermedad de Crohn a través de un estudio de caso. **Método:** un reporte de caso de una paciente de 20 años, con diagnóstico de Enfermedad de Crohn, residente en el municipio de Rafael Fernandes – RN, en el año 2009. Los datos fueron recolectados mediante una entrevista semiestructurada con preguntas abiertas y en profundidad, posteriormente sometida a Análisis de Contenido Cualitativo. **Resultados:** emergieron tres categorías: 1) La odisea en la búsqueda de un diagnóstico y tratamiento; 2) El lugar de la persona con Enfermedad de Crohn en la redefinición de la dinámica familiar; y 3) Vivencias como persona ostomizada: del enfrentamiento con el espejo a la transformación del guardarropa. **Conclusión:** El principal factor asociado a la evolución clínica de la Enfermedad de Crohn con complicaciones relacionadas se vinculó a las dificultades en el establecimiento de un diagnóstico precoz. La familia desempeñó un papel protector en la adherencia al tratamiento por parte de la paciente, aunque en algunas situaciones dificultó su autonomía para el autocuidado y la inclusión social. Finalmente, la etapa de la enfermedad en la que se observó mayor afectación de la feminidad correspondió al período en que la paciente presentó una ostomía.
DESCRIPTORES: Enfermedad de Crohn; Ostomía; Adaptación Psicológica; Relaciones Profesional-Paciente; Estudio de Caso.

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INTRODUCTION

Crohn's Disease (CD) is an inflammatory condition, characterized by a transmural pattern and chronic manifestation, which may affect any segment of the gastrointestinal tract (GIT) [1, 2, 3, 4]. Its occurrence in Latin America remains relatively low [5], although an increase in incidence has been documented in western countries over the past 50 years [6].

Of unknown etiology and without a definitive cure, CD is believed to result from a complex interplay between genetic susceptibility, environmental factors, and alterations in the gastrointestinal microbiota, leading to dys-

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regulation of both innate and adaptive immune responses [7]. Its clinical presentation is typically characterized by abdominal pain, chronic diarrhea, weight loss, and fatigue [1, 7].

The diagnosis of CD is established by exclusion, and in cases of strong clinical suspicion, evidence suggests that colonoscopy and biochemical tests may assist in clinical reasoning [8]. Current management strategies aim to achieve and maintain deep, sustained remission, thereby preventing complications and halting disease progression, with the goal of avoiding surgical intervention [8].

Nevertheless, it is estimated that half of patients with CD will require at least one surgical intervention throughout their lifetime [9], due to complications such as obstruction, fistula formation, intestinal perforation, and peritonitis, as well as due to non-responsiveness and/or drug toxicity leading to clinical refractoriness [1, 8]. Within the context of surgical management, the creation of an ostomy may emerge as a life-preserving alternative.

The relevance of this study is grounded in the recognition that certain aspects of CD are difficult to manage, generating anxiety within healthcare teams, as well as suffering in patients that transcends biological dimensions and extends into psychosocial and spiritual domains. Accordingly, the present study aimed to explore female psychological experiences related to Crohn's Disease through a case report.

METHOD

This is a case report conducted with a 20-year-old female patiente with a confirmed diagnosis of Crohn's Disease in 2009, residing in the municipality of Rafael Fernandes – RN, Brazil. Data were collected through a semi-structured interview consisting of open-ended, in-depth questions, conducted based on the following guiding question: "*Tell me about your experiences as a person with Crohn's Disease*". The entire interview was audio-recorded and subsequently subjected to Qualitative Content Analysis, structured into five steps as described by Bohm and Sundqvist (2025)[10]: meaning units, distillation, coding, categorization, and reporting the results.

Ethical principles to safeguard the participant's physical and psychological integrity were ensured through approval of the project by the Research Ethics Committee – REC (CAAE No. 0013.0.405.000-09). Artificial intelligence was used exclusively to assist in the translation of the manuscript.

Following analysis of the interview, three categories emerged, namely: 1) The Odyssey in Search of a Diagnosis and Treatment; 2) The Position of the Person with CD in the Redefinition of Family Dynamics; and 3) Experiences as an Ostomized Individual: from confronting the mirror to a wardrobe transformation.

CASE REPORT

The Odyssey in Search of a Diagnosis and Treatment

CD presents with a highly nonspecific clinical profile, and the absence of pathognomonic signs often results in delays in accurate diagnosis and appropriate treatment, thereby causing significant impairment to patients' quality of life:

The first symptom I noticed in myself was abdominal pain, and these pains were only that for a while [...] the physician did not identify the disease but prescribed other medications and treatments that relieved the pain [...] However, over time it would recur, with greater intensity and at shorter intervals. The episodes became more frequent throughout the day [forced swallowing, teary eyes, and expression of crying], more intense, and were later accompanied by diarrhea. And then all those other consequences followed.

Pain emerges as the primary symptom associated with suffering, capable of altering daily habits and leading to the adoption of anorexic behaviors due to the perceived relationship between pain and food intake, thus establishing a cycle of physiological debilitation: experiencing pain and restricting food intake, which further exacerbates nutrient malabsorption due to the inflammatory process and losses during diarrheal episodes.

Sometimes I wouldn't eat, can you believe it? because of the pain [...]. I weighed only 37 kg before surgery. [...] It was only after the first surgery that I received the diagnosis, and it was already a very severe case; therefore, I consider the first surgery as a complication of the disease, since it had already reached an advanced stage.

Despite the severity at diagnosis in this case, healthcare teams involved in managing disease progression must remain sensitive to events that are perceived and symbolized as traumatic by the patient. In this context, the patient reports a sense of abandonment in the operating room and expresses fear of pain, as well as awareness that surgical intervention does not provide a cure:

In the surgery room, you feel very alone [...] it really feels like leaving everything in God's hands. [...] because I have already suffered a lot and gone through intense pain, I am always afraid of experiencing pain in the postoperative period; my fear is always pain. I know that surgery does not cure the disease, but...

Another aspect to be considered by healthcare teams in the management of CD is the improvement of therapeutic communication. The patient's statements repeatedly reveal her desire for

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information regarding the disease, her new condition as an ostomized individual, prognosis, and therapeutic perspectives:

It was not anticipated that I would undergo surgery and end up with an ostomy. [...] I received the information after anesthesia, so I was still somewhat disoriented; I was not even shocked, because I did not really understand what it was."

Thus, information should be provided progressively, in accordance with each stage of treatment, in order to enhance patient education and adherence. Discharge guidance is particularly crucial, as it marks the transition to patient autonomy in self-care. In the following excerpt, the patient's distress in response to peritonitis with anastomotic dehiscence is evident:

"[already at home] *It started with fever, and one side of my abdomen became red and painful; then, when I went to have lunch, I felt something, a liquid running down my abdomen [...]. I think it was one of the worst moments I experienced with this disease: my abdomen opening and feces coming out from inside* [expression of anguish]."

The Position of the Person with Crohn's Disease in the Redefinition of Family Dynamics

It is common that when a family member undergoes an illness process, such as CD, family dynamics are altered through the redefinition of roles and future planning based on the management of the current condition:

My family stayed with me the entire time, and I think they suffered alongside me, especially regarding the diagnostic process. If I changed my rhythm of life, my entire family changed as well, completely. If I did not go out, my parents would not go out either, and I felt bad about that.

The following excerpt conveys the patient's perception of being a burden to her family, as well as the impact on her functional capacity to perform routine activities, resulting from both disease exacerbation and the protective attitudes of family members:

Every time the pain came, I had to undergo more tests, and my mother spent a lot of money, and everything became a source of concern for me. I remember that, since we could not afford domestic help, household tasks were divided, and I was seen as the one who could not do anything, you know? [crying].

However, it is important to consider that family involvement in the treatment of a member with CD contributes to improved coping and therapeutic adherence. What becomes evident is that, within this new family arrangement, the person with CD assumes the role of an agent of change, or of resignation.

I believe that nothing happens by chance. This disease came into my life, and I have no doubt that it served both me and my family, for our benefit. During the process, it is very difficult to understand..., and it even strengthened my faith and that of my family.

Experiences as an Ostomized Individual: from confronting the mirror to a wardrobe transformation

Autonomy in ostomy self-care for the patient with CD was impaired during the immediate postoperative period and was described with a certain degree of aversion. This becomes even more understandable when considering that such autonomy was constrained by multiple agents, including family members and healthcare professionals, throughout the course of the disease.

At the beginning, it was very difficult; I did nothing, I could barely... even removing the bag was done by my father, I could not do anything. I blocked myself; I could not even touch it. I do not know if it was fear, something I had never seen up close and suddenly it was part of me; because I had a grandfather who experienced this condition, but I had never even seen a colostomy bag.

With regard to ostomies, their mutilating aspect is not limited to the physical body, but extends to the entire psychosocial sphere:

I felt very restricted; I stopped studying, stayed at home, and no longer went out. I did not want to live with that for the rest of my life. I think that was my greatest fear. [...] So I never considered the possibility of being in a relationship while having an ostomy.

Living with an ostomy required the reconstruction of a new body image, particularly because the collecting device becomes incorporated into the individual's body. Confrontation with the mirror evokes the memory of the previous body, which corresponds to the desired ideal, whereas the current, altered body is rejected:

[Long silence]... *without the stoma protection, it was still easier to look at than with the bag, because I looked more like I used to be. And I would look at myself and place my hand over it, saying: 'when I remove this, my abdomen will look like this again, it will return to how it was before.' Not that I was abnormal [...], but who wants to live with an ostomy for the rest of their life?*

The patient employed adaptations in clothing as a strategy to reconstruct her body image, which is dynamic and varies according to the stage of the disease. Ostomy reversal surgery thus becomes symbolically associated with the restoration of her sensuality, sexuality, and social life:

I no longer wear bikinis; I have to wear a swimsuit [laughs]. *I am a very discreet person, so I tried - not exactly to hide it - but not to draw attention to the ostomies. It was not appropriate to wear shorts and a blouse with that exposed, so I only wore dresses and loose blouses... After the surgery,*

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there was a true transformation in my wardrobe; I went back to wearing my pants, my tight clothes… I returned to who I used to be and I still enjoy wearing my dresses. I also went back to parties, returned to college, and resumed my life! [...] Today, I still have scars that I do not show to everyone, but they do not bother me. I feel happy to have them, but if I could undergo plastic surgery, I would [laughs]. *But thank God I have them, because I am no longer ostomized..."*

FINAL CONSIDERATIONS

An individual with a chronic disease may experience a wide range of emotional responses, including distressing feelings and regressive behaviors. In this process of revisiting earlier emotional states, the patient often feels the need for support and protection from individuals who previously provided care and affection, and who are once again called upon to fulfill these roles. Similarly, when the family is confronted with the absence of one of its members due to disease progression, it becomes more vulnerable to imbalance due to the threat of loss - whether temporary or permanent - of one of its sources of reference and support [11].

Individuals with chronic diseases, such as CD, despite the burden of stress and imposed limitations, should be encouraged by healthcare professionals to maintain a lifestyle as close to normal as possible. By understanding the nature of these limitations and the need for ongoing interaction with hospital or outpatient services, they may continue to pursue their life projects, functioning as healthy individuals for the majority of the time [11].

The present case allows us to infer that the primary factor underlying the clinical progression of CD with associated complications was related to difficulties in establishing an early diagnosis, thereby delaying more protective and conservative treatment approaches.

Although family members played a decisive role in coping with CD, the adoption of overprotective attitudes appears to have hindered the patient's autonomy in engaging in self-care and social participation. Such impairments may also have been exacerbated by insufficient communication and a lack of commitment to health education among the professionals involved in managing the case.

Finally, with regard to psychological experiences related to CD, the stage of the disease in which the greatest impairment of femininity was observed was when the patient was ostomized. This period was marked by social isolation and rejection of body image, with negative repercussions on the domain and expression of her sexuality.

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