

## Chronic pelvic pain in women: the path to outpatient discharge

Dor pélvica crônica em mulheres: o caminho para a alta ambulatorial

Dolor pélvico crónico en mujeres: el camino hacia el alta ambulatoria

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## Abstract

**Objective:** To understand the meaning of chronic pelvic pain from the perspective of diagnosed women and analyze the determining factors for outpatient discharge.

**Methods:** This is qualitative research, using strategic social research as its theoretical methodological framework. 14 women participated in the study, seven of whom were undergoing outpatient follow-up and seven who were discharged from the gynecology outpatient clinic of a university hospital in the city of Goiânia, Goiás, Brazil. Semi-structured interviews were carried out with guiding questions. The analysis of results was based on the thematic modality of content analysis, according to Bardin.

**Results:** Data analysis culminated in three thematic categories: "Before the pain", "Living with the pain" and "Treating the pain". Parental emotional abandonment, grief, disagreement with parents and childhood difficulties were prominent before the onset of pain. The onset of pain was related to the birth of children, menarche, surgeries and family conflicts. Living with pain promoted great suffering, fear, harm to relationships and work activity. The improvement in emotional state and financial conditions, the resolution of marital conflicts, the opportunity to express oneself and talk to other patients, the use of medication and some surgical procedures were decisive for pain control and outpatient discharge.

**Conclusion:** Chronic pelvic pain was related to socioeconomic, emotional and physical suffering. The resolution of these aspects contributed to outpatient discharge.

## Resumo

**Objetivo:** Compreender o significado da dor pélvica crônica sob a ótica das mulheres diagnosticadas e analisar os fatores determinantes para a alta ambulatorial.

**Métodos:** Pesquisa de natureza qualitativa, tendo como referencial teórico metodológico a Pesquisa Social do tipo Estratégica. Participaram do estudo 14 mulheres, sendo sete em seguimento ambulatorial e sete que receberam alta, no ambulatório de ginecologia de um hospital universitário no município de Goiânia, Goiás, Brasil. Foram realizadas entrevistas semiestruturadas, com questões norteadoras. A análise dos resultados baseou-se na modalidade temática da análise de conteúdo, segundo Bardin.

**Resultados:** A análise dos dados culminou em três categorias temáticas: "Antes da dor", "Convivendo com a dor" e "Tratando a dor". O abandono afetivo parental, o luto, o desentendimento com os pais e dificuldades na infância foram proeminentes antes do início da dor. O surgimento da dor relacionou-se ao nascimento dos filhos, menarca, cirurgias e conflitos familiares. A convivência com a dor promoveu grande sofrimento, medo, prejuízo aos relacionamentos e à atividade laboral. A melhora do estado emocional e das condições

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financeiras, a resolução dos conflitos matrimoniais, a oportunidade de poder expressar-se e conversar com outras pacientes, o uso de medicamentos e alguns procedimentos cirúrgicos foram determinantes para o controle da dor e da alta ambulatorial.

**Conclusão:** A dor pélvica crônica relacionou-se a sofrimentos socioeconômicos, emocionais e físicos. A resolução destes aspectos contribuíram para a alta ambulatorial.

## Resumen

**Objetivo:** Comprender el significado del dolor pélvico crónico bajo la perspectiva de mujeres diagnosticadas y analizar los factores determinantes para el alta ambulatoria.

**Métodos:** Investigación de naturaleza cualitativa, que utilizó el marco referencial teórico metodológico de la investigación social estratégica. Participaron en el estudio 14 mujeres, de las cuales siete estaban realizando seguimiento ambulatorio y siete fueron dadas de alta, en consultorios externos de ginecología de un hospital universitario en el municipio de Goiânia, Goiás, Brasil. Se realizaron entrevistas semiestructuradas, con preguntas orientadoras. El análisis de los resultados se basó en la modalidad temática del análisis de contenido, de acuerdo con Bardin.

**Resultados:** El análisis de los datos culminó en tres categorías temáticas: Antes del dolor, Convivir con el dolor y Tratar el dolor. El abandono afectivo parental, el duelo, falta de entendimiento con los padres y dificultades en la infancia fueron prominentes antes del inicio del dolor. El surgimiento del dolor se relacionó con el nacimiento de los hijos, menarca, cirugías y conflictos familiares. La convivencia con el dolor causó gran sufrimiento, miedo, perjuicio en las relaciones y en la actividad laboral. La mejora del estado emocional y de las condiciones financieras, la resolución de los conflictos matrimoniales, la oportunidad de poder expresarse y hablar con otras pacientes, el uso de medicamentos y algunos procedimientos quirúrgicos fueron determinantes para el control del dolor y el alta ambulatoria.

**Conclusión:** El dolor pélvico crónico se relacionó con el sufrimiento socioeconómico, emocional y físico. La resolución de estos aspectos contribuyó al alta ambulatoria.

## Introduction

Chronic pelvic pain (CPP) is defined as pain in the pelvic region that persists for at least six months, being intense and distressing. CPP can be intermittent, recurrent and non-cyclical and reduces patients' quality of life.<sup>(1)</sup>

CPP is more common in women. In Brazil, the prevalence in women varies from 11.5 to 19%.<sup>(2,3)</sup> The high prevalence of CPP in this population results in high expenses for the health sector. It is estimated that Australia spends \$6.5 billion annually related to CPP.<sup>(4)</sup>

CPP is a disease with its own pathophysiology and treatment must be solid. Once a specific diagnosis has been made that has triggered CPP, it is important to treat that condition. However, when there is no precise diagnosis, which is the rule (around 60%), treatment aims to control pain.<sup>(5)</sup> It is already known that a biopsychosocial approach is relevant in understanding and managing women with CPP.<sup>(6)</sup> However, the search for a specific diagnosis of CPP would require the indication of laparoscopy in all these women, increasing cost and morbidity, without influencing patients' quality of life.<sup>(7,8)</sup> The main organic diagnosis found in these women, proven to be related to CPP, is endometriosis, in around 1/3 of them. It is already covered

by treatment when drug-induced amenorrhea (pain worsens during the perimenstrual period in 80% of cases), and surgery is only justified if refractory to initial clinical/psychotherapeutic treatment.<sup>(7,9)</sup>

A study carried out in an outpatient clinic of a university hospital in central Brazil showed that women with CPP showed an average reduction in the pain scale of 39% (7.9 to 4.8 on the visual analogue pain scale) with different treatments. However, the remission rate was low, since among the 230 patients analyzed, only 12 (5%) were discharged from the outpatient clinic, the criterion of which was a pain scale  $\leq 2$  for at least one year.<sup>(7)</sup>

Previous studies have mapped sociodemographic and clinical aspects of women with CPP, and have also observed that their quality of life and sexuality are affected and that they have a high frequency of anxiety and depression.<sup>(7-10)</sup>

It is assumed that CPP has its origins in social relationships, portraying a subjective issue for women. Therefore, this study uses social research, proposed by Minayo, as a theoretical methodological reference. Social research has a historical burden and reflects positions in relation to reality, moments of development and social dynamics, being relevant for deepening the meanings of CPP.<sup>(11)</sup>

Outpatient discharge is a challenge for health services that care for women with CPP. It is neces-

sary to advance in understanding the phenomena involved in the illness and recovery of these women's health. It is believed that the findings of this study can contribute to improving care for women with CPP by identifying aspects related to their perception of pain. Data on the topic is scarce and needs to take sociocultural aspects into account. In this sense, this study aimed to understand the meaning of CPP from the perspective of diagnosed women and analyze the determining factors for outpatient discharge.

## Methods

Qualitative research was carried out, considering the subjectivity raised by the CPP theme. Qualitative research works with the raw material of experiences and works with people and their achievements, understanding them as social actors. It also seeks to understand relationships, values, attitudes, beliefs, habits and representations based on a set of socially generated human phenomena and, thus, enable the understanding and interpretation of reality.<sup>(11)</sup>

The study of CPP is directed towards social research, proposed by Minayo, as a theoretical methodological reference.<sup>(11)</sup> Among the five modalities of social research proposed by Bulmer, strategic research is more appropriate for this study, as this type of research is based on social science theories, but is oriented towards concrete, focal problems that arise in society, proving to be appropriate for knowledge and intervention of CPP.<sup>(11)</sup>

A total of 14 women participated in the study, seven who were still undergoing outpatient follow-up due to the lack of discharge criteria and seven who had already been discharged. For outpatient discharge, women must have a pain scale  $\leq 2$  for at least one year, without continuous use of any pain medication.<sup>(7)</sup> The choice of participants was random and notebooks were used that contained records of all the women treated. Data saturation occurred with 14 participants.<sup>(11)</sup>

Women with CPP undergoing outpatient treatment or who had been discharged from an outpatient clinic, aged 18 years or older, who were not

pregnant or had a history of pregnancy in the last 12 months, were included.

The study was carried out in the gynecology outpatient clinic of a university hospital in the city of Goiânia, Goiás, Brazil, which has been treating women with CPP for 25 years. The outpatient clinic is a reference in the region, being one of the few specialized in CPP in women in Brazil. There are records of all women treated, both those who have already been discharged and those with ongoing treatment.

Data were collected through interviews with a semi-structured questionnaire and field observation. The questionnaire contained the following guiding questions: What is it like to live with CPP? What do you think of the treatment you received at the outpatient clinic? What factors do you consider important for being discharged from the outpatient clinic? What factors do you consider important for not being discharged from the outpatient clinic?

The researchers attended the gynecology outpatient clinic to learn about the environment and create bonds with women through field observation. Furthermore, they obtained access to records containing the name and telephone number of patients who were discharged from the outpatient clinic and those undergoing treatment. Randomly, they scheduled interviews with the women that were carried out via video call and/or in person on scheduled dates, depending on women's availability between September 2021 and January 2022. In both cases, a safe and private environment was guaranteed, where they could explain freely without interruption. There was no refusal to participate.

The interviews were conducted, recorded and, later, transcribed by the researchers in full using Microsoft Office Word 2019<sup>®</sup>, with spelling adjustments to facilitate reader understanding, but without changing the meaning of statements, forming the *corpus* of analysis. Data were analyzed using content analysis proposed by Bardin.<sup>(12)</sup> This technique consists of three major stages: 1) pre-analysis; 2) material exploration; 3) treatment of results, inference and interpretation. Data analysis was carried out using systematic and objective procedures to describe what was obtained in the responses to the questionnaire.<sup>(12)</sup>

First, a skim reading of all interviews was carried out, followed by the identification and organization of similar and appreciative excerpts from women's speeches into clusters of meaning in line with the study objectives. As no previous categories of analysis were established, from the grouping of nuclei by convergence of themes, we arrived at subcategories, which were regrouped and emerged into three categories, which represent the phenomenon studied.

To designate who each fragment of speech belongs to and to preserve participant anonymity, guaranteeing narrative confidentiality, we chose the generic term "Woman", represented by the letter "W", followed by an Arabic number according to the chronological order of the interviews.

Participants were informed about the study and signed the Informed Consent Form. The research was approved by the institution's Research Ethics Committee, under Opinion 4.654.237 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 45022721.8.0000.5078, in compliance with Resolution 466/2012 of the Brazilian National Health Council, which had its guidelines and criteria respected.<sup>(13)</sup> The study met the CONSOLIDATED criteria for Reporting Qualitative research (COREQ) guidelines, respecting the 32 criteria in its three domains.<sup>(14)</sup>

## Results

Regarding sociodemographic and clinical profile, participants had the following characteristics: mean age of 42.5 years; 57.1% were married; 85.7% had children; and menarche occurred until the age of 14. On average, they studied for 10 years, had felt pelvic pain for 12 years, had an initial pain scale of 8.6 and, at the time of the interview, 3.1. The seven women undergoing outpatient follow-up had a pain scale between 5 and 8, while the seven who were discharged from the outpatient clinic had a pain score  $\leq 2$ . The average outpatient follow-up was 5.2 years. Based on interview analysis, inference and interpretation, three categories of content

emerged, namely: before the pain, living with the pain and treating the pain.

### Before the pain

When reporting on factors of great personal impact before the emergence of CPP, patients highlighted parental emotional abandonment, the pain of grief and disagreements with their parents, as illustrated by interviewees' statements below:

*"When I was 4 years old, she abandoned me, right"* (W1)

*"The one who raised me is not my father"* (W3)

*"I feel this pain since I lost my father"* (W1)

*"My father hurt me a lot"* (W13)

Moreover, difficulties experienced in childhood, sexual abuse, abortion:

*"My father was a truck driver. He would come home every year"* (W4)

*"At the age of 11, I was raped by my cousin, I got pregnant and my family had an abortion on me"* (W2)

Marital dysfunction, betrayal in abusive relationships and children's suicide attempts also appeared in interviewees' statements:

*"I had the first child and then came the disturbances, betrayal, betrayal on his part"* (W9)

*"It was an abusive relationship"* (W5)

*"My eldest son became depressed and tried to commit suicide"* (W1)

Furthermore, psychiatric disorders, such as depression, are present in women's speech, being common after marital separation.

*"(...) I had a really disturbed relationship (...) I had the onset of depression"* (W9)

Some events were perceived by the interviewees as coinciding with the onset of pain. The onset of pain was related to the birth of children, menarche, surgical procedures and family conflicts.

*“As soon as I had my daughter by cesarean section, the pain started” (W8)*

*“I felt this pain since I got my first period” (W10)*

*“After I had the operation, this pain came... I had the operation to stop it from creating any more” (W3)*

*“The pain started when I separated from my children’s father” (W9)*

*“The pain started when my 12-year-old daughter went to live with her father” (W2)*

### Living with the pain

The interviewees showed that living with pain promotes great suffering, harm to relationships, dyspareunia, compromises work activity and causes fear.

*“I haven’t even been living together, I’ve been suffering” (W3)*

*“I couldn’t have a relationship (...) then the husband leaves” (W8)*

*“At my work, right? The cramps came and I had to lie down” (W2)*

*“I was also afraid of having a more serious illness” (W12)*

Worsening pain intensity was associated with times when the interviewees were sad, agitated, bereaved, stressed, menstruating, periods of conflict with their spouses and hysterectomy.

*“Whenever I was very sad, very nervous, I felt a lot of pain” (W13)*

*“I got a lot worse after my mother died” (W4)*

*“Your life fluctuates and your pain fluctuates too” (W5)*

*“I didn’t even like to think about menstruating” (W8)*

*“It was an abusive relationship (...) I felt worse, right?” (W11)*

*“When I took out the uterus, I was more likely to die than to live” (W2)*

*“The uterus removal ruined everything” (W3)*

The reduction in pain intensity was associated by participants with the use of medication, family constellation, therapy, rest and work activity.

*“Only with primolut nor did I feel any pain” (W7)*

*“If I don’t take antidepressants, the pain gets worse” (W1)*

*“The constellation helped a lot” (W8)*

*“And then through therapy, follow-up, I got better” (W11)*

*“When I calm down, when I lie down a little, I get better” (W6)*

*“If you stop doing something you kill yourself” (W4)*

Some of the interviewees received family support during their pain experience, while others felt alone and not supported during the period.

*“My family (...) is my base” (W3)*

*“No support, you know?” (W8)*

### Treating the pain

Women seen on an outpatient basis reported having a good relationship with the outpatient clinic.

*“You have great affection for us” (W11)*

*“The follow-up I did here helped a lot” (W10)*

*“Understanding what we are going through, which is not a fussy” (W11)*

When asked what were the fundamental factors that still prevented outpatient discharge, most interviewees were unable to list them; however, some participants reported forgiveness and the fact that they had not had their uterus removed.

*“I think it’s because I can’t forgive my mother yet” (W1)*

*“I wanted it to be removed, for me it’s a solution, to remove my uterus” (W7)*

The interviewees who were discharged from the outpatient clinic expressed fear that in the event of a recurrence of pain, they would not be able to access the outpatient clinic. When asked what was decisive in achieving pain control and outpatient discharge, the interviewees pointed out the improvement in their emotional state and financial conditions, the resolution of marital conflicts, the opportunity to express themselves and talk to other people, the use of medication and surgical procedures, such as the removal of tubes and oophorectomy.

*“Doctor, don’t discharge me, it’s difficult to get a place later, right?” (W13)*

*“In the same way that what made me feel pain, feel sick, was my psychology, my healing too, right?” (W11)*

*“And learn to let go of what takes away our peace” (W10)*

*“It wasn’t just treatment. The financial part improved, the marital part improved, that’s where everything improved” (W8)*

*“There are other people we can talk to (...) there are people worse off than us (W8)*

*“Taking the medication (...) I’m not menstruating (...) there’s no pain” (W12)*

*“The removal of the tubes (...) wow, wonderful (W14)*

*“It was the solution for me, endometrioma surgery on the ovary” (W5)*

Six of seven patients in the follow-up group received surgery: three, hysterectomy, and the others polypectomy, myomectomy and ovarian cystectomy.

## Discussion

The women participating in this study revealed the repercussions of CPP in different social spheres, highlighting the great impact on their quality of life. Furthermore, the interviewees’ speech allows the analysis, inference and interpretation of results of possible triggering factors and/or worsening of pain, factors that favor the reduction of pain and determining factors for outpatient discharge. However, the etiology of CPP is complex, requiring multidirectional diagnostic analyzes since the experience of pain and its processing involves many variables.<sup>(15)</sup>

The results of this study indicate that the relationship with parents has a great influence on interviewees’ lives. Patients who still live with CPP highlight that before the onset of pain they experienced parental emotional abandonment or constant disagreements with their parents. Poor parental care during childhood has been associated with the development and persistence of chronic pain in adulthood.<sup>(16)</sup> Other authors have linked inappropriate or traumatic bonding with parents to an increase in emotional and functional disorders in women with primary dysmenorrhea.<sup>(17)</sup> Still, another study reported a significantly higher frequency of low maternal care, as well as relationship difficulties, in women with CPP than in those without CPP.<sup>(18)</sup> Therefore, these studies are consistent with the findings of the current study. However, the majority

of women who were discharged from an outpatient clinic indicated that they had good relationships with their predecessors. Therefore, it is possible to assume that the perception of better parental support has a positive influence on the evolution of the CPP condition.

Marital dysfunctions were the most common phenomenon reported by participants; however, disagreement with parents is more emphasized by women still in outpatient follow-up, while marital dysfunctions are highlighted by those who were discharged. These findings are corroborated by a study with 230 women with CPP, which observed conflicts with partners, other family members and family traumas, such as abandonment by parents, early and/or tragic deaths of people close to them.<sup>(7)</sup> Therefore, it is possible to assume that marital dysfunctions may be a facilitating factor for the emergence of CPP, but that they do not exert the same influence as parental conflicts on the evolution of pain. It is also easier to break off a relationship with romantic partners than with parents. This brings into focus the relevance of the psychosocial approach to relationships and family trauma in women with CPP.

In the present study, all interviewees suffered some type of impactful event in their personal lives before the onset of CPP. Among the reports, it is possible to highlight suffering due to sexual abuse, induced abortion, mourning for the loss of a close family member, a child's attempted suicide, depression and financial difficulties that impacted childhood development. This is corroborated in the literature, since women with CPP are significantly more neglected and abused in childhood, they suffer more from social stressors and anxiety and depression compared to the population without pain.<sup>(19)</sup> This reinforces how important it is to provide, both in the investigation and treatment of these women, a socio-emotional approach, in addition to the biological.

Regarding interviewees' statements about living with pain, losses were observed in relationships, work productivity and an impact on the psychological sphere. These findings are congruent with those of other authors who reported worse quality of life

for women with CPP.<sup>(8,20)</sup> The worsening of pain related to the adverse emotional state in participants' daily lives was noted. Although this is commonly noticed in conversation circles with women with CPP, we were unable to access this report in the literature. When they realize that this also happens to other women, they can learn strategies from each other to deal with emotionally stressful situations and avoid triggering pain crises.

Most women with CPP undergoing outpatient follow-up were unable to list the factors that prevented their outpatient discharge. Some of them reported a lack of forgiveness towards their mother and the failure to perform a hysterectomy. The report of worsening pain with the mothers' death, difficult childhood and adolescence, dysfunctional parenting, lack of control over anxiety and stress, lack of rest and tranquility due to overwork suggest that overcoming or giving new meaning to these difficulties can favor outpatient discharge. Cognitive behavioral therapy, family constellation and mindfulness are possibilities to help with these difficulties.<sup>(21)</sup> In this group, the use of medication and participation in family constellation were factors in reducing pain, as previously observed.<sup>(7)</sup>

In this study, the empathy of medical professionals contributed to pain relief and outpatient discharge of women with CPP. Two studies endorsed this finding, reporting that empathy in the doctor-patient relationship, doctors' skill and patients' optimism optimize chronic pain treatment.<sup>(22,23)</sup> The fear of being discharged and not gaining access to the outpatient clinic seems to make outpatient discharge difficult.

According to participants' perception, the improvement in the emotional state, the improvement in financial conditions, the resolution of marital conflicts (separation or reconciliation), the opportunity to express themselves and talk to other patients, the use of medications (especially those that interrupt menstruation), the confirmation that they do not have a serious illness and surgical procedures (salpingectomy for hydrosalpinx and oophorectomy for endometrioma) were decisive factors for being discharged from the out-

patient clinic. Some of these aspects were suggested in previous studies.<sup>(19,21)</sup> Qualitative research like this has the potential to increase perceptions about the care of women with CPP.<sup>(24)</sup> There have also been reports of worsening pain with hysterectomy. One study reported that four percent of CPP cases arise after hysterectomy.<sup>(7)</sup> Therefore, hysterectomy, even though it represents hope of curing CPP for some women, does not seem to be the solution for their outpatient discharge. It seems useful only in well-selected cases, in the absence of central hypersensitization, as previously reported.<sup>(25)</sup> With these new understandings, it is expected that women with CPP can benefit from care in primary care by general clinicians and gynecologists, in addition to nursing professionals trained in this type of care, as already occurs with other diseases, as suggested in the literature.<sup>(26)</sup>

Outpatient care that investigates, analyzes and treats women with CPP through a multidisciplinary team that is attentive and empathetic to the socio-emotional and biological factors that have marked their stories and lives can improve health care and favor their outpatient discharge.

## Conclusion

It is concluded that the study objectives were achieved, because, in the analysis, inference and interpretation of the perception of women with CPP, living with pain caused damage to their relationships, their work productivity and their psychological sphere; their adverse emotional state, on a daily basis, worsens their pain; marital dysfunction and parental resentment were common in women with CPP, the latter making outpatient discharge difficult. Medical professionals' empathy, the improvement of their emotional state and financial conditions, the resolution of marital conflicts, the opportunity to express themselves and talk to other patients as well as the use of medication, the knowledge of absence of disease serious condition and some specific surgical procedures were decisive for outpatient discharge.

## Collaborations

Jesus LM, Sousa MBD, Oliveira NP, Santos LF, Conde DM, Pacheco LR and Deus JM declare that they contributed to study design, data analysis and interpretation, relevant critical review of intellectual content, writing of the article and approval of the final version to be published.

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