

PAIN INTENSITY, DEPRESSIVE SYMPTOMS AND QUALITY OF LIFE IN WOMEN WITH AND WITHOUT CHRONIC PELVIC PAIN: A QUALI-QUANTITATIVE ANALYSIS

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RESUMO

Este estudo teve como objetivo determinar a QV geral e a presença de sintomas depressivos em mulheres com DPC, analisando sua associação com dados clínicos e sociodemográficos; comparar seus resultados com um grupo controle sem dor; e avaliar qualitativamente os fatores associados ao sofrimento em mulheres com DPC. Métodos: Utilizou-se um desenho exploratório sequencial quantitativo e qualitativo. Na fase quantitativa, a intensidade da dor, a qualidade de vida geral (QV) pelo SF-12 e os sintomas depressivos pelo Inventário de Depressão de Beck (BDI) foram avaliados em mulheres com DPC por qualquer causa (n=103) e em controles assintomáticos (n=86). A análise dos dados foi realizada por meio dos testes Mann Whitney U, Kruskal-Wallis e Spearman's rho no SPSS versão 20.2. Na etapa qualitativa, foram realizadas entrevistas narrativas individuais em mulheres com DPC por endometriose (n=29). Resultados: Mais de 50% das mulheres com DPC queixaram-se de dispareunia profunda e de dismenorreia progressiva, com pontuação média na escala visual analógica (EVA) de 8,21. Mulheres com DPC apresentaram escores de QV significativamente mais altos em ambos os domínios do SF-12 e escores de BDI mais baixos do que os controles. Relatos qualitativos demonstraram as formas em que a DPC se associou a limitações físicas, isolamento social e sofrimento mental. Conclusão: A DPC afetou diversos aspectos da vida das mulheres, incluindo saúde física, saúde mental, autoimagem, trabalho e relações sociais.

Palavras-chave: Dor Pélvica; Endometriose; Depressão; Qualidade de Vida; Pesquisa Qualitativa.

ABSTRACT

This study aimed to determine general QoL and presence of depressive symptoms in women with CPP, analyzing their association with clinical and sociodemographic data; to compare their results with a pain-free control group; and to qualitatively assess the factors associated with distress in women with CPP. Methods: A quantitative and qualitative, sequential exploratory design was used. In the quantitative phase, pain intensity, general quality of life (QoL) using the SF-12 and depressive symptoms according to Beck's Depression Inventory (BDI) were assessed in women with CPP due to any cause (n=103) and in asymptomatic controls (n=86). Data analysis was performed using Mann Whitney U, Kruskal-Wallis and Spearman's rho tests in SPSS version 20.2. In the qualitative stage, individual narrative interviews were conducted on women with CPP due to endometriosis (n=29). Results: Over 50% of women with CPP complained of deep dyspareunia and of progressive dysmenorrhea, with a mean visual analog scale (VAS) score of 8.21. Women with CPP showed significantly higher QoL scores in both SF-12 domains and lower BDI scores than controls. Qualitative reports demonstrated the ways in which CPP associated with physical limitations, social isolation and mental suffering. Conclusion: CPP affected several aspects of women's lives, including physical health, mental health, self-image, work and social relationships.

Keywords: Pelvic pain; Endometriosis; Depression; Quality of Life; Qualitative Research.

INTRODUÇÃO

Chronic pelvic pain (CPP) is defined as pain of at least six months' duration, affecting daily activities and quality of life (QoL) ^(1, 2). Its prevalence ranges from 5.7 to 26.6% ⁽³⁾, thus making it a common issue among women, potentially needing medical or surgical treatments ⁽¹⁾. Due to a broad list of clinical presentations and possible causes ⁽⁴⁾, diagnosis and therapeutic management of this condition can be challenging, making its annual associated costs reach US\$ 3 billion ⁽⁵⁾.

Women with CPP have a longstanding history of pain, whether mild or intense, that often results in work impairment, inability to perform physical activities and significant psychiatric burden ⁽⁴⁾. When compared to healthy women, those with CPP use more medications and undergo more gynecological surgeries ⁽⁶⁾. In a psychosocial analysis, they also have disorders such as depression and anxiety more commonly, thus being predisposed to social isolation ⁽⁷⁾. This, in addition negatively affecting their adherence to treatment, interferes with QoL. As a result, such patients frequently need holistic and interdisciplinary care ^(4, 8).

Despite its major impact on QoL, data on CPP remain obscure, especially in Brazil. With this in mind, the objective of this study was to determine general QoL and presence of depressive symptoms in women with CPP, analyzing their association with clinical and sociodemographic data; to compare their results with a pain-free control group; and to qualitatively assess the factors associated with distress in women with CPP due to endometriosis, a common cause of this symptom ⁽⁹⁾.

MATERIAIS E MÉTODOS

This mixed method study used a sequential explanatory design in two distinct phases: ⁽¹⁾ quantitative and ⁽²⁾ qualitative approach. In this approach, data collection in each stage are performed separately, but share a connection ⁽¹⁰⁾. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines were followed.

First, a quantitative, case-control analysis was performed on patients from clinics at a tertiary care hospital in Brazil. Women in the "case" group were consecutive patients with a medical diagnosis of CPP seen in the Chronic Pelvic Pain outpatient service during the year of 2016. Controls were asymptomatic women drawn from the Family Planning outpatient service. Participants who did not

sign a consent form for this study were excluded. Ultimately, a sample of 103 cases and 86 controls was obtained.

Participants' quantitative data were collected using a portfolio containing questions on socioeconomic characteristics, clinical data (including pain intensity), and the 12-Item Short Form Survey (SF-12) and Beck Depression Inventory (BDI) tools⁽¹¹⁻¹⁴⁾. This portfolio was applied by specialized nurses on women's first appointment in the previously mentioned service, in a room separate from the waiting area.

Women in the case group were invited to participate in the qualitative phase of the study. Thirty-five eligible women in the case group participated; six did not complete the interview, resulting in a final sample of 29 cases. All of them had endometriosis. In this phase, comprehensive individual interviews were conducted based on Fritz Shütze's narrative interview method ⁽¹⁵⁾. Interviews lasted from 30 to 150 minutes. Immediately after each encounter, recordings and notes were transcribed and orality marks were removed. After the structured narrative was constructed, the interviewee checked and validated it. Saturation was considered to be reached when no new categories emerged ⁽¹⁶⁾.

To preserve patients' anonymity, qualitative data are presented using the letter "A" with specific numbers, followed by time from symptom onset to presumptive diagnosis and time from diagnosis to access to specialized care, separated by semicolons. Assessment of pain intensity, QoL and depressive symptoms

Pain intensity was assessed using the Visual Analog Scale (VAS), which uses a patient-referred score ranging from 0-10 to categorizes pain as absent (score 0), mild (1-3), moderate (4-7) or severe (8-10) ⁽¹⁷⁾.

The SF-12 was used to assess general QoL. It consists of 12 items with Likert scale response options, where the domains physical functioning, role-physical, pain, general health, vitality, social functioning, role-emotional and mental health are evaluated. Final physical (PD) and mental health domain (MHD) scores, each ranging from 0-100, are obtained. Higher scores indicate better QoL ⁽¹⁴⁾.

BDI was used to evaluate depressive symptoms. It comprises 21 items, each with four answer choices of increasing gravity. Scores 0-11 corres-

pond to normal results or minimal depression; while scores 12-19, 20-35 and 36-63 represent mild, moderate and severe depression, respectively (18).

Statistical analysis

Data analysis was performed using the Statistical Package for Social Sciences (SPSS) software for Windows®, version 20.2. Kolmogorov-Smirnov test was used to test for normality. Measures of position and dispersion were used for a descriptive analysis of variables. Mann-Whitney U was used for comparisons between independent samples and the Kruskal-Wallis test for comparisons of two or more non-parametric groups of independent numerical variables, while Spearman’s rho test was used to check for correlations in categorical and ordinal data. A p-value <0.05 was considered statistically significant.

Ethical Approval

This research involved human participants; all procedures performed were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study. This research has been approved by the Ethics Committee at Maternity School Assis Chateaubriand (MEAC), under the protocol number 1.387.693.

RESULTADOS

The majority of women in the CPP group were married, had nine to twelve years of schooling and a mean age of 33.15 years (**Table 1**). Controls had a mean age of 26.1; this age difference was not statistically significant.

Table 1 - Clinical and sociodemographic data of women with chronic pelvic pain

Variables	Number of subjects (% frequency)
RELATIONSHIP STATUS	
Single	34 (36.6)
Married	59 (63.4)
Divorced	0 (0)
SCHOOLING (YEARS OF FORMAL EDUCATION)	
0-8	14 (13.6)
9-12	61 (59.2)
>12	14 (13.6)
PRIMARY DYSMENORRHEA	
Yes	58 (56.3)
No	45 (43.7)
SECONDARY DYSMENORRHEA	
Yes	24 (23.5)
No	78 (76.5)
PROGRESSIVE DYSMENORRHEA	
Yes	62 (60.2)
No	41 (39.6)
WORK IMPAIRMENT	
Yes	57 (56.4)
No	44 (43.6)
SOCIAL ISOLATION	
Yes	67 (63.7)
No	27 (36.3)
DEEP DYSPAREUNIA	
Yes	60 (58.3)
No	43 (41.7)

Over half of women with CPP complained of deep dyspareunia and/or progressive dysmenorrhea, with a mean VAS score of 8.21 (±1.84). Over 50% of cases also claimed to be socially isolated and/or impaired for work activities.

A narrative from A16 (9 years; 36 months) illustrates how the association between CPP and social isolation is established: “I lost track of how many times I heard ‘it will go away once you get married’ or ‘wow, you’re weak. My mom spent my life saying I was too sensitive for pain and that she couldn’t stand to hear me complain anymore”. When chronic pain patients lack social or familiar support, they can introject such assumptions and isolate themselves, as A16 says: “After hearing such things for so long you stop sharing. Before, I used to say I couldn’t go out because of my cramps, then I stopped replying messages so I didn’t have to hear about how weak I was”.

In addition to social isolation, patients had their professional relationships affected, mainly due to work impairment, as A20 (13 years; 3 months) describes: “Every month I had to call in sick at work for at least a week. People start wondering whether you are irresponsible or a liar, and

joke about it. So, for a week I wouldn't work and, during the other ones, I had to hear people's jokes. It kept getting harder. I cried in the restroom several times until I ended up quitting my job".

Moreover, conjugal relationships were also affected by CPP. Dyspareunia was referred by 72% patients involved in the qualitative phase; the impact of this symptom is described by A25 (15 years; 36 months): "My marriage was hanging by a thread because I felt pain every time we had sex. I heard it all: that I didn't love my husband. That I should get a shrink. That it was due to vaginal dryness. Even my husband thought I was seeing someone else. We almost separated".

When comparing cases and controls, the latter showed significantly higher QoL scores in both SF-12 domains and lower BDI scores, indicating that controls had better QoL and less depressive symptoms than women with CPP (**Table 2**). Schooling was not associated with QoL or BDI scores.

Table 2 - SF-12 physical and mental health domain results and BDI scores in cases and controls

Variables	Cases	Controls	p value
	Mean (±SD)		
Physical health	43.44 (±22.41)	91.91(±15.81)	<0.01*
Mental health	53.47(±19.91)	84.47(±16.50)	<0.01*
BDI	13.31(±9.32)	4.00(±8.00)	<0.01*

*Mann-Whitney U test.

When assessing BDI items solely from cases, most women reported frequent feelings of sadness, tiredness and irritation; feeling worried about their health status; not enjoying things the way they used to; decreased interest in sex; appetite changes and sleep disturbances. Within cases, women with work impairment and/or social isolation had more depressive symptoms than women without such complaints, although no significant differences were seen between these two subgroups in SF-12 scores (**Table 3**).

Table 3 - Associations between clinical complaints, SF-12 domains and BDI scores in womans with cronic pelvic pain

Variables	SF-12	BDI
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	p-value	
Social isolation	0,45	<0,01*
Work impairment	0,82	0,01*
Primary dysmenorrhea	0,28	0,64
Secondary dysmenorrhea	0,71	0,97
Progressive dysmenorrhea	0,66	0,47

*Mann-Whitney U test.

A narrative from patient A27 (14 years old; 5 months) illustrates how such types of isolation relate to mental health damages: "I used to be joyful, but after years of feeling pain and hearing people say it was not real, we stopped talking and ended up growing apart. That was about when this sadness and crying started." Her perception is reinforced by A7 (22 years; 36 months): "I remember having friends in my childhood. My problems started after I got my menses. I was in pain on a monthly basis. As time went by, it's no longer just being in pain, you know? You become anxious and irritated. Nobody understands what you're going through, so you just want to stay away [...] I became the sad, angry person nobody wants to be around. I can't stand it myself, so who can blame them?".

Pain itself was pointed out in women's speeches as a cause of harm to mental health. A20 (13 years; 3 months), for instance, recounts: "I was always in pain: before and during my period, during sex, when using the restroom. My boyfriend said that I was anxious, like everyone else did. But I really am anxious. The difference is that it wasn't this anxiety that caused the pain, it was the other way around".

In addition to physical pain, diagnostic delays emerged as relevant causes of harm to women's physical and mental health. A27 (14 years; 5 months) says: "It were 14 years not knowing what I had, and hearing from doctors that, since they couldn't find anything wrong in my ultrasounds, it was all psychological. After you go through that for this long, you are either crazy already or you become so".

Another important cause of mental harm described was negligence from relatives and healthcare professionals. A12 (11 years; 36 months) illustrates this: "During my period, the pain was so deep I couldn't stand up. I had to go to emergency rooms to receive IV medications because pills were not doing it for me anymore. But no one cared. I once heard from a nurse that I was addicted to pain medications, which made me cry really hard that day. I got embarrassed of getting

help and going to the hospital because people thought I was an addict.” At that point, this woman stopped her speech and started to cry and sob. Negligence to women’s pain is not reported exclusively in healthcare professionals. It is incorporated into a system, naturalized and invisible in social structures. A18 (15 years; 24 months) described her family’s oversight and the resulting effect in her self-esteem by narrating: “I spent my whole life hearing I was too weak and sensitive to pain. Sometimes I think, ‘Am I really? Am I weak?’ Maybe this is why I cannot get anything done in life. Because I am weak.” In this circumstance, a woman can introject such assumptions, affecting her self-image.

Moreover, women with superficial or deep dyspareunia had significantly less interest in sex (determined through the BDI question) than those without such symptoms ($p=0.004$ and $p<0.001$, respectively).

Dyspareunia was also associated to harms in self-image by affecting the idealized image patients develop on what it is to “be a woman”. A19 (14 years; 8 months) illustrates this understanding: “I am no longer woman enough for anything. I can’t even have sex with my husband anymore. And you know, a man won’t stay for long if there isn’t any sex. That’s what women do. But I can’t do it. [...] He ended up finding someone else. I can’t fight it or complain about it because I’m not enough of a woman for him”.

Women’s age did not correlate with pain intensity, BDI, PD or MHD scores. However, pain intensity was negatively correlated with PD and MHD of the SF-12, demonstrating that severe pain negatively affects QoL. Moreover, BDI scores were negatively correlated with MHD and PD, while MHD and PD showed a positive correlation (**Table 4**).

Table 4 - Correlations between age, VAS score, SF-12 domains and BDI scores in women with chronic pelvic pain

Variables	SF-12 Physical domain	SF-12 Mental health domain	BDI
Correlation coefficient			
Age	0.066	0.499	0.996
VAS score	-0.308*	-0.229*	0.185
SF-12 Physical domain	-	0.548*	-0.454*
SF-12 Mental health domain	0.548*	-	-0.588*
BDI	-0.454*	-0.588*	-

*Spearman’s rho test

DISCUSSÃO

CPP is known to influence multiple areas in women’s lives, including daily life, social relationships, family planning, work productivity, plans for the future and psychological well-being, among others (11, 19, 20). Despite this widely established impact, specific cause-effect relations between symptoms and affected areas remain obscure (21, 22). Although qualitative assessments cannot establish direct causative relations, patients’ narratives gave important clues as to how psychic suffering associated with CPP started.

Most studies evaluating QoL in women with CPP took place in developed countries or cities with high socioeconomic levels. Women in developing countries or low-income areas, such as Northeast Brazil, have unique socioeconomic characteristics that can influence their pain and QoL perception(23).

Age was also not correlated with QoL scores in our sample. This contrasts with findings of a previous study (24), who reported that QoL was negatively affected by the number of symptoms presented by women with CPP and positively affected by their age.

Cases showed decreased physical and mental health QoL compared with controls, which is consistent with findings from previous studies. Lovkvist et al (2016), for example, applied the 36-item Short Form Survey (SF-36, another QoL tool) to 431 women of varying ages with CPP and compared their results to those of the general female population. Women with endometriosis and CPP had significantly lower scores, especially in the vitality, role-physical and general health perception domains. Likewise, Nunes et al (2014) reported worse QoL scores in all domain in women with CPP compared to controls.

Most women in our study referred having a VAS pain score above seven; and pain intensity negatively correlated with QoL in both domains. This partly accounts for the finding of lower QoL in women with CPP, and is consistent with previous reports showing negative correlations of pain intensity in CPP with several SF-36 domains (25, 26).

Influences of CPP on QoL and depression likely relates to consequences of the symptom, but the underlying cause also appears to have some impact. Low QoL in endometriosis, specifically, was explored by Petrelluzzi et al (25) (2008), who com-

pared women with endometriosis to healthy women, with the former showing significantly worse physical and mental health QoL. Further into the impact of the etiology of CPP, Laursen et al (2005) examined 40 women with a history of chronic pain (with similar duration) and 41 healthy controls. Within cases, ten had endometriosis, ten had fibromyalgia/whiplash, ten had chronic lumbar pain and ten had a diagnosis of rheumatoid arthritis. Women with fibromyalgia/whiplash showed significantly lower scores in the role-physical, role-emotional, social functioning, mental health and vitality compared to the endometriosis subgroup. Centini et al (2013) compared women with CPP with endometriosis to women with CPP without this disease. In both groups, pain had a negative impact on QoL; however, the endometriosis group had significantly worse scores in the bodily pain, physical and emotional role domains of the SF-36.

CPP is associated with a wide range of psychiatric symptoms ⁽²⁷⁾. Previous studies using BDI to investigate depression in women with CPP have shown an association between these conditions. Sepulcri and Amaral (2009) found an 85% prevalence of depression in women with CPP due to endometriosis. In our study, cases' mean BDI score corresponded to mild to moderate depression, comparable to that presented by Lorençatto et al (2002), while controls showed no depression.

When correlating QoL and depression in women with CPP, our study found that, the lower QoL, the greater depression scores, similar to what Melis et al (2005) reported. MHD also showed a negative correlation with pain intensity, relating to the results by Lorençatto et al (2006), whose multiple regression logistic analysis reported pain as significantly associated with depressive symptoms. Other than the ones mentioned, so far, no other studies have compared depression levels in women with and without CPP using BDI.

Although women with CPP referred work impairment and social isolation, participants with and without such presentations had similar QoL. However, those with these complaints had higher BDI scores, raising the possibility these variables may be related to the development of depression.

In addition to increased susceptibility to mental disorders, women with pain also show some degree of sexual dysfunction ⁽²⁸⁾. In our sample, a correlation was seen between reported deep or

superficial dyspareunia and lower interest in sex in BDI's question.

Relations that emerged in the quantitative stage were confirmed and deepened in qualitative phase. Patients' narratives also aided in the comprehension of the ways in which CPP associated with social isolation and psychic illness. Such data corroborate the analysis described by a meta-ethnography which showed that, in addition to pain itself and delays in diagnosis, CPP negligence is an important factor associated with burden in women's QoL and mental health ⁽²⁹⁾.

A limitation in our research was the lack of stratification for causes of CPP. Strengths include the analysis of variables besides QoL, pain and depression in the same sample; the use of asymptomatic controls; and its pioneerism as a mixed, quantitative-qualitative design in this area of study. This approach should be expanded in other studies to further comprehend the process of psychic suffering development in women with CPP.

CONCLUSÃO

In this study, women with CPP had lower QoL and worse depression when compared to women without CPP. Worse QoL was also associated with more depressive symptoms. Pain chronicity, diagnostic delays and negligence from healthcare professionals and family members were pointed out in patients' narratives as the main factors associated with mental health burden. Social isolation, work impairment and compromises in life as a couple were considered sources of distress beyond physical pain in women with CPP.

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