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Daily life attitudes of women with moderate or severe chronic pelvic pain. A qualitative study



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ABSTRACT

Objective: How a woman copes with the pain might play a significant role in the management of chronic pelvic pain. This study aimed to understand the attitudes adopted by women with chronic pelvic pain (CPP) to deal with daily life problems caused by the illness.

Study design: We conducted a qualitative study including 58 women diagnosed with chronic pelvic pain regardless of the cause. To collect the data, we used semi-structured interviews with the key question: "How do you handle the pain in your daily life?". The interviews were audio-recorded and transcribed. We conducted a qualitative thematic analysis of transcribed texts following the sequence: 1) initial reading; 2) preliminary identification of codes; 3) identification of themes; 4) review of themes; 5) nominating the themes in categories; 6) final study synthesis. The analysis was performed with the aid of the RQDA package in the R environment.

Results: Daily life attitudes varied from submission to the pain to positive coping. We identified five major categories: 1) shaping life by pain; 2) isolating from social contact; 3) avoiding sexual relationship; 4) seeking pain relief; 5) seeking positive strategies. Positive strategies were more frequent in older women.

Conclusion: Women with chronic pelvic pain adopted a broad spectrum of attitudes to deal with the pain in daily life. The depth understanding of patient perspectives has the potential to improve the multidisciplinary care of this debilitating condition.

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Introduction

Pain is an experience that reflects a person's apprehension of a threat to their physical or existential integrity [1]. Chronic pelvic pain (CPP) is defined as nonmenstrual pelvic pain of six or more months duration that is severe enough to cause functional disability or require medical or surgical treatment [2]. CPP affects 3.8%–24% of women worldwide [3]. Most affected women are in reproductive age. In the Brazilian public health system, the prevalence of CPP is about 15 % for women in the reproductive age [4]. CPP is frequently associated with impaired quality of life with negative repercussions in several aspects of personal, marital, family, and social life social [5,6].

Patients adopt a broad set of coping strategies to deal with the pain and its consequences [7]. Understanding coping strategies can have a substantial influence on CPP management [8,9]. Lazarus and Folkman described a framework classifying coping strategies in problem-focused or emotion-focused. Problem-focused strategies are associated with constructive attitudes and emotion-focused strategies with tolerance and adaptation of life to the health problem [10]. Coping can be active when used to control or to function despite the pain, or passive when the patient withdraws or surrenders control over the illness [11]. The successful management of CPP is challenging. The diagnosis and specific treatment of the primary cause are essential; however, to address mental and emotional wellness is also very important. In this context, it is critical to understand the patient's perceptions about how to face the challenges of living with CPP. Life experiences of women with CPP are multidimensional. Cognitive, emotional, behavioral, motivational, and cultural influences modulate the response to the pain [12]. The meaning of these complex attitudes is not well described by pre-designed questionnaires or surveys.

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But, semi-structured interviews are very effective to explore thoughts, feelings, and beliefs [13].

In this study we applied semi-structured interviews to understand the attitudes adopted by women with moderate or severe CPP in the context of the public health system in Brazil.

Methods

We designed a phenomenological descriptive qualitative study with thematic analysis [14]. The setting of the study was the pelvic pain ambulatory of the University Hospital of Ribeirao Preto Medical School of the University of Sao Paulo. It is a tertiary teaching hospital in the Northeast of Sao Paulo state in Brazil. The research project was approved by the institutional Research Ethics Committee (CAAE: 49999615.4.0000.5440). All participants signed informed consent to participate before entry in the study.

Study participants

We included a total of 58 women with chronic pelvic pain (no menstrual pelvic pain of six or more months duration that is severe enough to cause functional disability or require medical or surgical treatment) and the age of 18 years or older. Participants were recruited during the first medical appointment at the pelvic pain ambulatory. The exclusion criteria were: mild pain (VAS < 45 mm), pregnancy, cancer, or severe psychiatric disorders, such as schizophrenia, that could limit accurate communication during the interview. Women with symptoms of anxiety or depression could be included. Three participants reported previous use of antidepressants.

New participants were included until the saturation of the main themes was achieved, as proposed by Guest et al. [15].

The diagnosis of the cause and intensity of the pain were obtained from the medical records. The intensity of the pain was recorded using a 0–100 mm visual analog scale (VAS) and classified as mild pain (5–44 mm), moderate pain (45–74 mm), and severe pain (75–100 mm) [16].

Data collection

We used semi-structured interviews with the key question, "How do you deal with the pain in your daily life?". A female nurse with three years of experience in qualitative interviews (BHM) accompanied by a physiotherapy student in training (TLP) conducted the interviews. The interviews were on the same day of the recruitment if the participant was available or on a scheduled date otherwise. The interviews were conducted in Portuguese, audio-recorded, and transcribed at verbatim.

Data analyses

We used thematic analysis according to the method described by Braun and Clarke [14], with the following sequence: 1) initial reading; 2) preliminary identification of codes; 3) identification of themes; 4) review of themes; 5) nominating the themes in categories; 6) final study synthesis. Data coding and analysis were conducted using the RQDA library in the R environment.

We built a heat map with the frequency of categories of codes to explore any possible relationship between the categories and pain etiology, pain intensity, and women's age.

We relied on the assessment of individuals external to the project to ensure the validity of the results [17]. Our data were obtained during a doctoral thesis development, and there were two moments of external assessment. First, after the data collection and preliminary analysis, we had an extensive discussion of the study, with two experienced researchers not involved in the data collection or analysis. Then, after completing the analysis and the interpretation of the results, the final report was again assessed by the same two external individuals and for an additional one. We used translation and back translation to ensure the accuracy of the quotations presented in this article. We also used the COREQ checklist aims to improve the transparency of our report [18].

Results

Characteristics of the participants

All 58 participants were from the public health system. The participants' age ranged from 22 to 57 years, with a median of 41 years. Endometriosis was the diagnosis in 34 cases (59%), chronic pelvic pain without specific etiology in 13 cases (22%), myofascial pain in five cases (9%), pelvic adhesion in three cases (5%), pelvic varices in one case, irritable bowel syndrome in one case, and interstitial cystitis in one case. Thirty participants presented severe pain (52%) and 28 moderate pain (48%).

Daily life attitudes

We identified 49 codes during the preliminary analysis. From the initial coding, we nominated five major categories: 1) shaping life by pain (17 codes); 2) isolating from social contact (5 codes); 3) avoiding sexual relationship (3 codes); 4) seeking pain relief (6 codes); 5) seeking positive strategies (18 codes). Coded interviews contained a total of 328 codes that were positioned along a broad spectrum, represented in Fig. 1. The attitudes went from a total submission (the condition placed in the left side of the arrow) to positive coping (placed on the right side).

Shaping life by pain

The category shaping life by pain expresses submission to the pain. Women reported living in the function of the adversities caused by the pain. The apathy was a characteristic of this category. Some women reported dismay with daily life activities. We also identified the feeling of losing life control. This feeling was associated with easy crying, irritability, and sometimes depression.

Some quotations to exemplify this category were:

"My life is like a horror movie. Sometimes I am good, and suddenly I start feeling pain again. The pain commands my life."

"... the pain is the cause of everything in my life ..."

"I feel like lying down, a weakness that I can't explain, I don't feel like doing anything, it seems that my body is heavy."

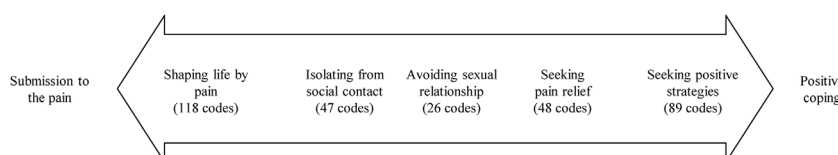


Fig. 1. Representation of the attitudes of women with chronic pelvic pain facing daily life with pain.

Isolating from social contact

Women described progressive physical and psychological limitations, followed by loss of autonomy. This feeling led to a voluntary reduction of social interactions and isolation. Because of the daily routine of pain, women reported avoiding even close relatives. The isolation usually started at home. The fear of fell sick out of their home also contributed to promoting physical and psychological introspection.

Some quotations to exemplify this category were:

"In the last two years, I have had no social contact. I have no friends. Lately, I do not wish to live with anyone".
"I feel I cannot live in a society when I am in pain. I have to lock myself in the room and not look at anyone because of the pain".

Avoiding sexual relationship

The fear of pain led women to avoid intimacy. There were reports of sexual relationships only to satisfy the partner. Many complained of marriage disruptions. This theme was present even in homoaffective relationships. In other statements, women commented on the partner's consent for sexual abstinence, a moment that they interpreted as something positive. The friendship and comprehension within the marriage were essential factors to sustain the relationship.

Some quotations to exemplify this category were:

"I always feel pain in the relationship. I try to avoid having sex as I can".
"I couldn't even think about having a sexual relationship. My marriage was in a horrible situation . . . "
"I am married. I want to have a relationship with my husband, but I feel pain and lose the desire . . . "

Seeking pain relief

Many women reported self-medication as an effective action to obtain relief and try to maintain a functional life. Even if the cause

of the pain was not clear, medicines were seen as a temporary solution for the suffering. We identified a conflicting attitude towards self-medication. Some reported the unsuccessful attempts of alternative strategies to cope with the pain before turning back to medicines.

Some quotations to exemplify this category were:

"No . . . there's no way to deal with the pain without medicines".
"I do what everyone does, self-medication."
"I drink tea. If it doesn't work, I take medicine again".

Seeking positive strategies

Positive attitudes in face of the adversities of the pain, in general, led to the perception of improvement in the quality of life. Some women report feeling better with physical activity. Others find comfort in labor activities. Some women tried to cope with the pain by fighting against the adversities or by learning how to live with the disease. It was also frequent the reference for finding comfort in religious faith.

Some quotations to exemplify this category were:

"It is usually the job that helps me to forget the pain."
"But I don't let myself get down because of that. I live today. I don't let the pain get me down."
"I ask God for strength, because if He doesn't give me strength . . . no medicine take the pain away."

Coping categories and women's characteristics

The distribution of the frequency of code categories according to pain etiology, pain intensity, and age group are shown in Fig. 2. The frequency of codes concentrates on the extreme of the spectrum for endometriosis, chronic pelvic pain, and miscellaneous causes. There was a tendency towards the submission spectrum for patients with pelvic adhesions and myofascial pain.

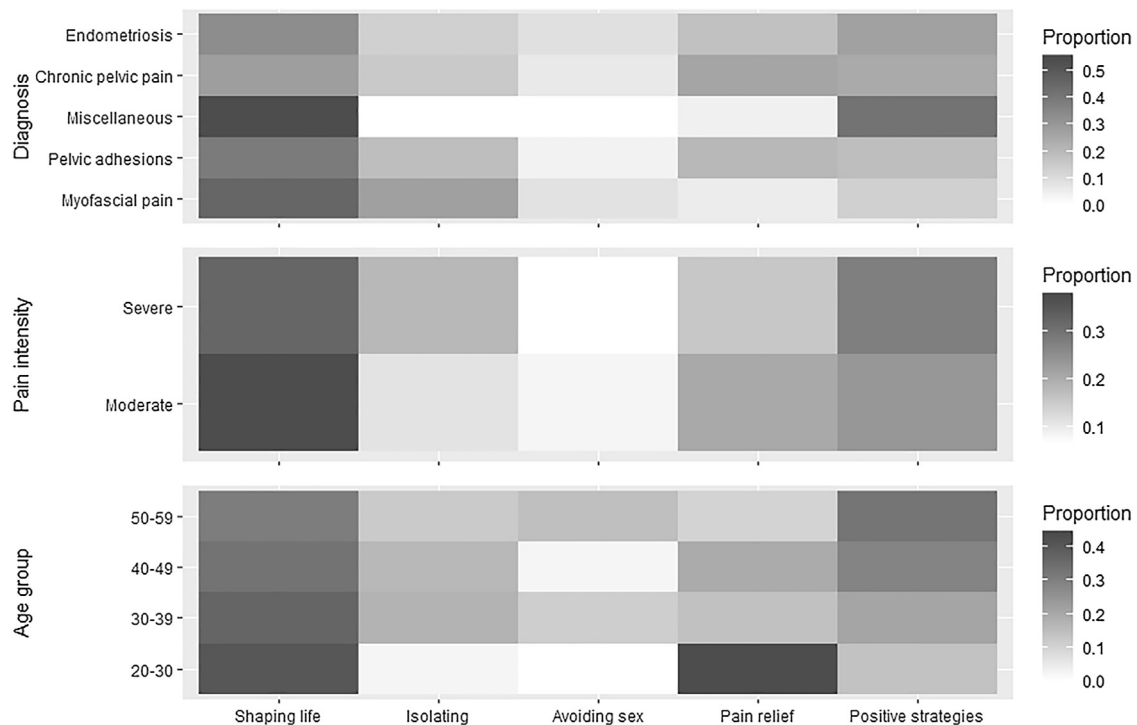


Fig. 2. Heat map of code frequency according to age group, pain intensity and diagnosis.

According to pain intensity, the codes were also more frequent on the extremes of the spectrum. The frequency of codes in the category “Seeking positive strategies” increases with the age while the frequency of codes in the category “Shaping life by pain” decreases with age. There was a strong predominance of codes associated with the category “Seeking pain relief” in younger patients.

Discussion

Women with chronic pelvic pain develop a broad spectrum of attitudes to deal with their pain. Submission to the pain and positive coping were the extremes of identified categories. Submission to the pain impaired women's relationships with family, friends, partner, and work. On the other side of the spectrum of codes, participants described efforts to keep a healthy life despite the daily life with pain. Age group was the main characteristic associated with the distribution of codes throughout the spectrum of attitudes.

The main strength of our study was the abundance of authentic human experiences reported by women facing chronic pelvic pain. We were able to understand in deep the attitudes of these women to deal with the pain in their daily life. Our study has some limitations. The women enrolled in the study were from a tertiary public hospital, therefore, our results may not apply for women living and coping with the pain and not seeking regular medical care, or those with mild pain who seek care in the private system.

A similar spectrum of attitudes was previously reported. The attitudes varied from acceptance of the pain to adopting a positive approach, and from limiting physical activities to engaging in self-management [9]. Several studies have identified submission to the pain. Passive attitudes are, generally, associated with a negative impact on the quality of life, impairing physical and emotional wellbeing, and reducing productivity [5,19–21].

The predominant underline cause of pain in our study was endometriosis. An Australian study identified endurance and contest as narratives of women facing pain and endometriosis [22], with attitudes being influenced by social background. It is common for women with pelvic pain and endometriosis to develop progressive social isolation [23]. Our data showed a similar proportion of codes representing opposite sides of the spectrum of attitudes in women with endometriosis. This result differs from previous published results, using a quantitative approach. A study using the validated Brief COPE scale [24] showed a predominance of coping focused on the problem in women with endometriosis [25]. Another, using a questionnaire specifically designed for the study [26], identified additional coping mechanisms like seeking awareness and knowledge about their disease, medications, relaxation and stretching activities, dietary changes, social support, spirituality, among others. Quantitative and qualitative data are complementary. Quantitative methods allow us to measure coping mechanisms, and qualitative analysis allows to understand these mechanisms in deep.

Avoiding sexual activity is also a frequent category of behavior adopted by women with CPP. Up to 40 % of women diagnosed with endometriosis and CPP have complaints of sexual life [21]. Many times the women's difficulty in dealing with alterations in sexuality is not well accepted by the partners as observed in women with vulvodynia [27]. In this group of categories, the dominance of the disease is prominent with consequent physical limitations, failures in social interactions, and lost career opportunities [28].

Positive coping occurs when the patient modifies the behavior for better to face the pain. It is associated with self-management of the pain by adopting an improved lifestyle, sometimes based on socialization or dedication to a job [9,20]. Our study identified

attempts of self-management of the pain based on self-medication, commitment to a job, and socialization. Self-medication is an important cultural aspect in Brazil; a recent analysis identified a prevalence of 16 % of self-medication among Brazilians [29]. Pharmacological and nonpharmacological coping strategies were also described for women with dysmenorrhea [8,30].

Our data showed the patients' attitudes facing pain are influenced by age. Older patients rely mainly on positive strategies to face the pain, while younger patients' attitudes leaned towards submission to the pain. The influence of age on the mechanisms of coping was reported for several stressors. Middle-age people use coping mechanisms aiming to solve the problem. But, there is a tendency among younger adults to be passive [31].

Conclusions

The recognition of the attitudes to deal with daily life problems caused by CPP is essential in planning the multidisciplinary and patient centered management of the disease. For instance, when the patient attitudes are towards submission, psychological support is vital to achieving success in the management.

Data statement

The transcription of the interviews used in this article is in Portuguese and can be provided by the corresponding author at a reasonable request.

Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.ejogrb.2020.09.001>.

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