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Palliative Oncology Treatments and Hopelessness: An Analysis of Associated Clinical and Psychosocial Factors

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Authors' contributions

This work was carried out in collaboration between both authors. Author DBS managed the literature searches, designed the study, wrote the protocol, and wrote the first draft of the manuscript. Author FLO designed the study, wrote the protocol, analysed the data, and revised the first draft of the manuscript. Both authors read and approved the final manuscript.

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ABSTRACT

One of the psychological symptoms of major concern in palliative care is hopelessness because it is a risk factor for poor treatment adherence, suicidal ideation, suicide, and the desire for a premature death.

Objectives: To identify the psychosocial and clinical factors associated with hopelessness after beginning palliative oncology treatment.

Methods: 66 patients with advanced cancer were evaluated using the following instruments: a) Beck Hopelessness Scale, b) Quality of Life Questionnaire - EORTC-QLQ-C30, c) Hospital Anxiety and Depression Scale, d) Coping Strategies Inventory, at two times: at the first consultation in the palliative care outpatient clinic and at the first medical return visit.

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Results: The relative absence of information about palliative care treatment was associated with hopelessness after the beginning the palliative treatment (p=0.043). With regard to coping strategies, the use of social support mechanisms (p=0.033), problem resolution (p=0.033), and positive reevaluation (p=0.037) were associated with decreases in hopelessness, which indicates that these strategies have a protective character. Social support (p=0.007) and constipation (p=0.038) significantly predicted hopelessness at the first medical return visit according to the multiple linear regression analysis. The experiences of hope among the patients at the beginning of the palliative treatment did not decrease. Few correlations were found between the different clinical and psychological variables studied, and few parameters predicted hopelessness. **Conclusion:** The offer of information and the promotion of therapeutic interventions favoring use of coping strategies less focused on emotion thereby allowing more active coping with the situation were found to be.

Keywords: Cancer; oncology; palliative care; hopelessness; quality of life.

1. INTRODUCTION

In recent decades, the population has progressively aged, and the prevalence of cancer and other chronic diseases has increased. Due to the development of innumerable therapeutics, many deadly diseases have become chronic diseases, which have led to greater longevity of the carriers of these diseases. However, regardless of the efforts of investigators and their accumulated knowledge, death continues to be a certainty, undermining the hope of a cure and the preservation of life; thus, patients require special care [1].

Based on previous studies, cancer is a global public health problem. The World Health Organization (WHO) predicted that 27 million people will be diagnosed with cancer, 17 million people will die due to cancer, and 75 million people will live with cancer in 2030. This increase will be strongest in countries with low to average incomes [2].

Therefore, criteria and recommendations have been established for palliative care based on the difficulty of evaluating and caring for human suffering. These treatments are indicated for patients who have exhausted all other possibilities of disease maintenance or life prolonging treatments, which are associated with moderate to intense suffering. Rather, these patients opt to maintain comfort and dignity, considering they might have only 6 months to 1 year left to live [3]. According reported by Higginson [4], between 15-25% of cancer deaths received inpatient hospice care and 25-65% specialist care services.

One of the primary principles of palliative care is the consideration of death as a natural and expected event in the presence of a disease that threatens the life cycle. Furthermore, this care emphasizes that life can still be lived. This "lens change" allow patients to view the world in new ways with humility. Thus, the maintenance of hope (i.e., the expectation that a desired goal can be achieved) [5], in palliative treatment is essential because it allows patients to live their last days in the fullest manner possible, mediating the final transition, the acceptance of death, and their consequent reconciliation with life [6-8]. On the other hand, hopelessness is present in about 13-28% of cancer patients [9]. It is seen as a risk factor for suicide, suicidal ideation and desire to premature death, trending to be associated with depressive disorders [10-12]. The appearance of hopelessness is associated with a sense of psychological despair, being determined by the patient's understanding of his disease, which involves the prognosis, the perception of little control over the evolution of the disease, and powerlessness's feelings [13].

According to previous studies, a life lived with hope has an extremely important effect on patients at the end of their lives and can positively influence their adaptation to disease and reduce their psychological distress as well as increase their psychosocial well-being and quality of life [8,14,15].

Internal mechanisms can also play differential roles in confronting the conditions of a disease and death. These so-called "coping mechanisms" can ameliorate or complicate the experience of difficult and critical situations such as illness and death depending on how and when they are used [16,17]. In the context of coping with difficult situations, psychopathological conditions such as depression and anxiety as well as low quality of life increase in importance. These conditions can

negatively affect the course and manner of coping during the terminal phase of cancer [16], increasing experiences of hopelessness.

Understanding the clinical and psychosocial variables associated with hope/hopelessness in patients undergoing palliative oncology treatments is important primarily to develop specific therapeutics that seek to reduce the effect of the disease on patients' daily routines. To our knowledge, studies have yet to identify the variables that predict hope/hopelessness in palliative care. The extant literature includes correlational studies of quality of life and the appearance of psychological symptoms. The objective of the current study was to identify the psychosocial and clinical factors associated with hopelessness after beginning palliative oncology care and possible predictors.

2. MATERIALS AND METHODS

2.1 Participants

This study was performed in an oncology palliative care unit (PCU) that offers services to outpatient, inpatient and home care, based on hospice model. A prospective cohort design was employed to analyze a convenience sample with the following criteria: a) Male and female patients who were at least 18 years old with advanced neoplasia without the therapeutic possibility of a cure receiving care for the first time in the outpatient clinic of the PCU were included; b) participants who were illiterate, unable to respond to the instruments, hospitalized between the two data collection times, absent during the second period of data collection, with severely compromised cognitive functions, or who provided incomplete or incorrect answers to the instruments were excluded.

2.2 Instruments

The following instruments were used to collect data:

 a) The Beck Hopelessness Scale (BHS) is a self-applied dichotomous scale (Yes/No) that was translated and adapted for the Brazilian population by Cunha [18]. The BHS includes 20 items that consist of statements involving thoughts of hopelessness. For each item the subject must indicate if agree (right) or disagree (wrong) of each statement. The total score is the sum of the individual items, which varies from zero to 20, with the higher score indicates a higher level of hopelessness;

- The European Organization for the b) Research and Treatment of Cancer Quality of Life Core Questionnaire-Cancer 30 (EORTC QLQ-C30) is a self-applied questionnaire, adapted and validated for the Brazilian population by Machado et al. [19]. The EORTC QLQ-C30 is composed of 30 questions that are scored using scales with multiple items as well as single items comprising five functional scales, three symptoms scales, one global health and quality of life scale, and one scale concerning the financial effect of the treatment and the disease. In addition, six other items evaluated the symptoms commonly reported by those with cancer [20];
- c) The Hospital Anxiety and Depression Scale (HADS) is a self-applied questionnaire validated for the Brazilian population by Botega et al. [21]. The HADS contains 14 items: seven evaluate anxiety (HADS-A), and seven evaluate depression (HADS-D);
- d) Folkman and Lazarus's Coping Strategies Inventory is a self-applied questionnaire validated for the Brazilian population by Savóia et al. [22]. This survey is composed of 66 items, each scored on a 4-point Likert scale (0= I did not use this strategy, 3= used in large quantity) that are grouped into eight distinct factors: Confrontation, separation, self-control, social support, acceptance of responsibility, escapeavoidance, problem resolution and positive reevaluation. The higher the score, the greater is the use of such coping strategy;
- e) The Structured Interview for Sociodemographic and Clinical Characterization is composed of 38 items related to patients' sociodemographic and clinical data created specifically for the objectives of the present study.

2.3 Ethics Statement

The local ethics committee (Hospital de Câncer de Barretos) approved this study (Number 208/2009), and participation began after signing an informed consent form according to the requirements of Resolution 196/96, which regulates human-subjects research.

2.4 Data Collection

The data were collected individually at two distinct times. In the first phase (P1), patients were approached when they first arrived at the outpatient clinic of the PCU prior to any type of medical consultation. The second stage of data collection (P2) occurred when the patients arrived at the PCU for their medical follow-up visit (approximately 30 days after their first medical consultation), during which all instruments were completed a second time.

2.5 Data Analyses

The data were analyzed using SPSS after being grouped in a database. The following statistical techniques were used: a) descriptive statistics were used to evaluate the sociodemographic and clinical characteristics; b) Mann-Whitney U and Kruskall-Wallis tests were used for group comparisons; c) Spearman's rank correlation test was used to analyze the correlation of the variables; and d) a multiple linear regression was used to study the possible predictors of hopelessness. Only the variables that had p-values less than or equal to 0.20 in the previously performed simple association tests were included in the multivariate analysis. A significance level of p<0.05 was adopted.

3. RESULTS

In total, 85 patients participated in P1 only, and 66 patients participated in P1 and P2, the latter of which constituted the final sample. Nineteen patients were excluded for the following reasons: death (N=3), missing at follow-up visit (N=7), study attrition (N=2) and hospitalization between the first and second data collection (N=7).

Slightly more than half of the sample (59.1%) was female. The average age was 49.78 years (SD=12.60 years). Of all the participants, 47 (71.2%) were married or in a stable relationship, and 54 (81.8%) had a companion. Furthermore, 51 (77.3%) participants had children, 37 (56.1%) were literate or had an elementary education, and 77.3% unemployed when the data were collected. More than 85% of the sample (n=57) practiced a religion, with the large majority being Catholic (69.7%).

With regard to the clinical characteristics of the sample, slightly more than half of the patients had never used tobacco (50%) or alcohol

(54.5%). Regarding psychological conditions, only 12% of the participants had received previous psychiatric treatment, and 7.6% were currently in treatment (no patient had current or past psychotic disorder). Slightly more than 10% of participants were using psychiatric medications when the data were collected. The most prevalent types of cancer in the current sample were breast and those related to the female reproductive system. Of all the cancers, 46 (69.7%) showed metastases, and 50 (75.8%) did not have local recurrences of the disease. The majority of patients had previously undergone chemotherapy (34.8%) or received a combination of two or more anti-neoplastic treatments (34.8%). At data collection. 37 (56.1%) and 55 (83.3%) patients had ceased chemotherapy or radiation therapy, respectively. Pain was present in 41 (62.1%) patients. In total, 58 (87.9%) patients did not have an alternative treatment in addition to their conventional treatment.

The evaluation of hopelessness, anxiety, depression, and quality of life before and after 30 days of palliative care did not indicate significant alterations except for diminished fatigue. These data are shown in Table 1.

No significant differences in the level of hopelessness were found among patients after 30 days of palliative treatment with regard to the different sociodemographic variables (see Table 2).

However, "Having information about palliative care" was significant (p=0.043) with regard to hopelessness (see Table 3). Thus, participants who were aware of this information showed lower scores of hopelessness after the beginning their treatment compared with those that did not have this information.

Hopelessness was correlated with the psychological and quality of life variables from the HADS, Coping Inventory, and EORTC QLQ-C30. Following coping strategies were found to be significantly related to hopelessness: social support, problem resolution, and positive reevaluation. Table 4 shows the weak and inversely proportional correlation coefficients. Therefore, these results indicate that decreases in the use of these coping strategies increase hopelessness. The separation coping domain was non-significantly negatively correlated with hopelessness.

Variable	P1	P2	p-value	
	Average (SD)	Average (SD)		
BHS	6.33 (3.94)	6.39 (4.12)	0.98	
HAD-A	5.37 (3.41)	5.59 (3.99)	0.97	
HAD-D	4.43 (3.16)	5.18 (3.58)	0.23	
EORTC Global health	73.10 (17.03)	73.73 (21.29)	0.44	
EORTC Physical	65.05 (23.91)	67.77 (23.34)	0.56	
EORTC Functional	66.16 (31.07)	69.69 (32.80)	0.38	
EORTC Emotional	67.80 (27.26)	68.68 (26.23)	0.90	
EORTC Cognitive	76.01 (30.40)	76.76 (29.65)	0.84	
EORTC Social harm	70.20 (33.39)	78.03 (29.69)	0.11	
EORTC Fatigue	35.85 (24.79)	27.60 (24.51)	0.03	
EORTC Nausea	12.12 (20.78)	12.12 (20.78)	0.79	
EORTC Pain	49.74 (35.38)	38.88 (33.37)	0.07	
EORTC Dyspnea	12.12 (24.55)	11.61 (23.01)	0.92	
EORTC Insomnia	32.82 (40.29)	33.33 (40.08)	0.91	
EORTC Lack of appetite	30.30 (39.10)	24.24 (36.30)	0.34	
EORTC Constipation	23.23 (36.50)	24.24 (35.82)	0.77	
EORTC Diarrhea	8.58 (20.51)	7.57 (25.34)	0.26	
EORTC Financial difficulty	30.30 (38.21)	28.28 (32.68)	0.91	

Table 1. Indicators of hopelessness, anxiety, depression, and quality of life before and after beginning palliative treatment

SD=Standard Deviation, HAD-A=Anxiety, EORTC=Quality of life, BHS=Hopelessness, HAD-D=Depression

Table 2. Indicators of hopelessness after beginning palliative treatment (P2) as a function of sociodemographic variables

Variable	n	Average	SD	p-value
Gender				
Masculine	27	6.48	4.15	0.849
Feminine	39	6.33	4.16	
Marital status				
Married/Stable union	47	6.68	4.32	0.313
Single/Divorced	19	5.68	3.59	
Education				
Elementary	29	6.03	3.84	0.636
Secondary/Higher	37	6.67	4.35	
Professional status				
Active	14	5.00	3.50	0.168
Inactive	52	6.82	4.25	
Children				
Yes	51	6.17	4.05	0.494
No	15	7.13	4.42	
Religion				
Catholic	46	6.36	4.22	0.900
Non-catholic	20	6.45	3.97	
Attend church				
Yes	57	6.12	4.14	0.149
No	9	8.11	3.78	
Companion				
Yes	54	6.77	4.22	0.127
No	12	4.66	3.25	

n=Number of participants, SD=Standard deviation

Variable	n	Average	SD	p-value
Cancer: Specialties				•
Female reproductive system	10	6.10	4.67	
Breast	21	6.38	4.15	
Chest	5	7.60	5.36	0.983
Head and neck	8	6.62	4.13	
High/Low digestive	9	5.77	4.17	
Others	13	6.46	3.84	
Palliative care information				
Yes	32	5.40	4.26	0.043*
No	34	7.32	3.81	
Previous treatment				
No treatment	9	5.44	3.39	
Surgery	2	11.5	0.70	
Radiation therapy	9	7.00	3.31	0.254
Chemotherapy	23	5.52	3.77	
Combined	23	6.95	4.87	
Current chemotherapy				
Yes	29	6.79	4.08	0.360
No	37	6.08	4.18	
Current radiation therapy				
Yes	9	6.22	4.32	0.749
No	57	6.63	4.04	
Pain				
Yes	41	6.58	4.32	0.633
No	25	6.08	3.83	
Previous psychiatric treatment				
Yes	8	7.62	4.40	0.324
No	58	6.22	4.09	
Current psychiatric treatment				
Yes	5	8.80	4.60	0.169
No	61	6.19	4.06	

Table 3. Indicators of hopelessness after beginning palliative treatment (P2) as a function of the variables related to illness and treatments

*significance, SD=Standard deviation, n=Number of participants

A multiple linear regression used these variables as joint predictors and revealed that only the social support coping (p=0.007) and EORTC QLQ-C30 constipation (p=0.038) variables independently predicted hopelessness. Thus, the increase of each social support coping unit predicted a decrease of 0.317 in hopelessness, and an increase for each EORTC QLQ-C30 constipation unit predicted an increase of 0.028 in hopelessness, which is a positive correlation. These informations are showed in Table 5.

4. DISCUSSION

Palliative care focuses on the importance of a patient's dignity while sick, vulnerable, and limited. This care accepts death as a natural life stage and emphasizes that life itself must be lived intensely until the end [23]. Furthermore, centers that provide this care help those who are

sick "beyond the possibility of a cure" to live as actively as possible until their death. Because the lifetime of a patient with an advanced disease is limited, each hour is significant. However, one psychological symptom that is of great concern during this period is hopelessness because it is a risk factor for suicide, suicidal ideation, and the desire for a premature death [24,25]. These outcomes are common reactions in patients with cancer who find themselves in the palliative phase of treatment [26].

Hopelessness and its opposite (hope) might be important psychological constructs to understand and adapt to stress and terminal illness [27]. Thus, hope and hopelessness play active roles in the process of death and coping with palliative oncology treatment [28]. Therefore, understanding the physical and psychological variables that can influence hope and hopelessness over the course of palliative treatment is important.

In general, few changes were observed in the current sample with regard to global hopelessness from P1 to P2. In studying the initial level of hopelessness, below average comparison indicators were also noted by Cunha [18] (average=9.20 and SD=4.72). These indicators remained approximately stable over 1 month without significant differences. This finding is notable because it is contrary to the evidence found in the literature showing that the presence of hopelessness, although undesirable,

is common. In particular, some patients occasionally feel a great sense of hopelessness [29]. The results from studies of patients in palliative care show a greater risk for hopelessness compared with the general population [30].

In the present study, symptoms of psychopathology as measured by the HADS were not related to hopelessness even after 1 month of treatment. These results are also contrary to the literature, which shows a strong association between patients with advanced cancer and symptoms of anxiety and depression

Table 4. Correlations between the level of hopelessness after beginning pallia	ative care
(P2) and other psychological and clinical variables	

Variable	BHS		
	r	p-value	
HAD-A	0.002	0.990	
HAD-D	-0.037	0.768	
Coping confronting	-0.057	0.647	
Coping separation	-0.214	0.084	
Coping self-control	-0.074	0.555	
Coping social support	-0.263	0.033 *	
Coping acceptance of responsibility	-0.189	0.128	
Coping escape avoidance	-0.001	0.994	
Coping problem resolution	-0.263	0.033 *	
Coping positive reevaluation	-0.258	0.037 *	
EORTC Global health	0.083	0.510	
EORTC Physical	0.058	0.645	
EORTC Functional	0.053	0.675	
EORTC Emotional	-0.036	0.775	
EORTC Cognitive	-0.105	0.403	
EORTC Social	0.044	0.724	
EORTC Fatigue	-0.056	0.655	
EORTC Nausea	-0.045	0.722	
EORTC Pain	-0.004	0.974	
EORTC Dyspnea	-0.006	0.962	
EORTC Insomnia	0.094	0.453	
EORTC Appetite	-0.141	0.259	
EORTC Constipation	0.165	0.186	
EORTC Diarrhea	-0.077	0.540	
EORTC Financial	-0.090	0.471	

r=Pearson's Correlation Coefficient; *significance HAD-A=Anxiety; EORTC=Quality of life; HAD-D=Depression

 Table 5. Estimate of the final multiple linear regression parameter considering the variable

 hopelessness in response the second time collection (P2)

Variable	β	ICC 95%	p-value	
Constant	9,13	6,50 - 11,76	<0,001*	
Coping social support	-0,317	-0,5450,090	0,007 *	
EORTC constipation	0,028	0,002 - 0,054	0,038 *	

 β = Beta; *significance

[31-33]. However, recent studies have found results with regard to anxiety similar to those in the present study, which indicates that this symptom is not directly related to the gravity of a clinical illness or the proximity of death [33,34].

Thus, anxiety and depression did not predict hopelessness in the current sample. The following possible explanations were considered for the low levels of anxiety and depression. a) The differentiated and humanized treatment offered by the institution that cared for the participants who comprised the sample (which was based on the hospice model) features an agreeable and humanized environment. In addition, a complete multidisciplinary team specialized in this type of care treats patients (physician, nurse, nutritionist, psychologist, social worker, occupational therapist). This model of assistance and physical space produces an environment conducive to the realization of wishes and farewells as well as the attribution of new meaning to life events. This environment strengthens the individual care provided to the patients, which is extended to their relatives. b) Psychological/psychiatric antecedents (i.e., the presence of previous or current disorders or the use of psychotropics) existed in only a small percentage of the sample. Thus, the sample was mentally healthy.

The results of this study revealed an improvement in the majority of symptoms when the different indicators of the EORTC QLQ-C30 were analyzed after 30 days of palliative treatment, after which relative improvements in the quality of life of the patients were observed. The only quality of life components that deteriorated after beginning this care was constipation. Interestingly, constipation predicted hopelessness; in other words, the increase of constipation proportionally increased the risk of hopelessness by 0.03 times (p=0.038). This finding is difficult to explain using a linear model. Previous studies were not found to support this association. However, constipation is one of the most frequent gastrointestinal symptoms in advanced cancer, potentially affecting 90% of patients who regularly use opioids, and causes physical and psychological disorders to emerge [35]. This symptom generates physical discomfort and malaise and is associated with decreases in quality of life after physical disabilities cause greater emotional vulnerabilities in patients [36]. Patients often erroneously associate this malaise and deteriorating quality of life with

tumor progression and even the shortening of their lives, which triggers feelings of hopelessness. Other quality of life characteristics were not significant.

When the influences of the different variables related to hopelessness were evaluated, simple group comparisons revealed that only "Having information about palliative care" was significant. variable significantly and positively This influenced the beginning of palliative treatment (p=0.043); regardless, this variable was not significant when evaluated using a multiple regression model with regard to treatment progression (p=0.208). This finding is consistent with the findings of many studies that attest to importance of information [37,38]. the Regardless of this evidence, the stereotyped and prejudiced view that patients become more hopeless and depressed when informed about palliative care causes many healthcare professionals to avoid communicating this socalled "bad news" to their patients for fear of triggering a cascade of psychiatric symptoms [37]. This myth must be debunked.

Pain was present in 41 (62.1%) patients. However, pain did not significantly change over the course of the 1-month treatment, which indicates that this variable did not directly affect the maintenance or decrease of hope. This finding differs from the extant literature, which shows that this symptom not only triggers anxiety [39,40], depression [41,42], suicide risk [43], and decreases in quality of life [44,45] but also increases manifestations of hopelessness.

The way in which pain was evaluated might explain this divergence; in other words, pain was measured superficially (without information about intensity, duration, use of medication, or correct dosage). In addition, one must always consider the concept of "total pain" in palliative care, which consists of the combination of physical, spiritual, social, and psychological conditions that determine suffering at the end of life [46].

Social support, problem resolution, and positive reevaluation were significant coping strategies. The only significant strategy that focused on the problem was problem resolution. Over the course of 1 month of palliative treatment, the patients used many coping resources focused on emotion (e.g., positive reevaluation and social support); the primary role of these resources was to decrease the disagreeable physical sensations of stress [47]. The coping mechanisms used by the participants did not alter the stressful situation per se; rather, they helped them to address emotions and thereby maintain positive self-esteem, hope, and wellbeing during the first 30 days of this care approach.

Another interesting finding is related to the association between the social support strategies and hopelessness because the linear regression analysis revealed that the former variable was a 0.317:1 risk factor for the latter (p=0.007); in other words, as this strategy was employed less after beginning palliative treatment, hopelessness increased among patients who returned for consultation. This finding might occur because social support facilitates the search for a solution to a situation with regard to the emotional factors involved in support [47], often from significant others (relatives and friends) and professionals. This finding is supported by Brothers et al. [48] who evaluated women with recurrent breast cancer. These authors concluded that women with feelings of hopelessness who practiced coping strategies that lacked the social support factor showed the strongest physical and depressive symptoms. Therefore, the psychoeducational and psychotherapeutic groups offered by the health system (e.g., resources for reinforcing and maintaining this type of support) are important [47].

5. CONCLUSIONS

Contrary to expectations, patient hope did not decrease from the beginning of palliative treatment and showed few correlations with the clinical and psychological variables studied. Moreover, few parameters predicted hopelessness.

The development of this study and its results indicate a probable positive influence of palliative treatment, especially that offered by the institution from which the sample originated. This treatment followed a hospice model, which as mentioned above, might have exerted a differential and positive influence on the maintenance of hope. In addition, the admission of patients into this treatment modality, the provision of information, and the promotion of therapeutic interventions that favor the use of proactive coping strategies and permit handling the reality of the illness in the most satisfactory manner were positive. These practices may

favor the benefits from the palliative treatment, reinforcing the basic precepts of this practice: Reduce psychological distress, increase the psychosocial well-being and quality of life and death.

However, these findings call attention to the need for better investigations of physical symptoms and their direct influence on emotional symptoms, particularly with regard to intestinal constipation.

Importantly, the present study has some limitations. For instance. the use of questionnaires/self-applied scales eliminated the most debilitated patients from participation in this study. Although they showed interest in participating in the present study, they were excluded from the sample. It is emphasized that the assessment of coping strategies in homogeneous samples according to the initial pathology is appropriate since the type and tumor location could exert influence on the coping strategies used. This and the fact that the sample is a convenience sample can favor bias selection/information. Another limitation relates to the evaluation of the clinical indicators collected via self-reports, such as pain. As mentioned previously, this variable should be better investigated.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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