Original Article
https://doi.org/10.1590/1983-1447.2025.20250023.en

Assessment of distress levels in female breast cancer survivors: A longitudinal analysis

Avaliação do nível de distress em mulheres sobreviventes de câncer de mama: estudo longitudinal

Evaluación del nivel de angustia de las mujeres sobrevivientes de cáncer de mama: estudio longitudinal

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How to cite this article:
Matsubara MGS, Santana KVA, Bergerot CD, De Domenico EBL. Assessment of distress levels in female breast cancer survivors: A longitudinal analysis. Rev Gaúcha Enferm. 2025;46:e20250023. https://doi.org/10.1590/1983-1447.2025.20250023.en

ABSTRACT

Objectives: To assess the level of distress and its correlation with sociodemographic and clinical characteristics of female breast cancer survivors.

Method: Descriptive-analytical, longitudinal, and quantitative study conducted at a cancer center in Brazil between 2021 and 2022, at three moments: three (T1), six (T2), and nine (T3) months after the completion of surgical and clinical cancer treatment (excluding endocrine therapy). The sociodemographic and clinical characterization questionnaire and the Distress Thermometer were applied, in addition to a 35-item list of problems, distributed across five domains: practical, family, emotional, spiritual, and physical. Data Analysis: Statistical tests applied included the Chi-square test, Mann-Whitney's U, Kruskal-Wallis, and the independence test, with a significance level of $p \leq 0.05$.

Results: The study involved 101 participants, mostly married or in common law marriage. A distress level >4 was observed in most participants. Emotional, spiritual, and physical problems were the most frequently reported. Older women experienced higher distress at T1 and T3, while women with higher education levels reported significantly higher distress at T2 and T3.

Conclusion: Most of the women experienced emotional, spiritual, and physical issues, and the need for a multidimensional approach in the care of breast cancer survivors stood out.

Descriptors: Cancer survivors; Breast neoplasms; Quality of life; Psychological distress.

RESUMO

Objetivos: Avaliar o nível de *distress* e sua correlação com características sociodemográficas e clínicas de mulheres sobreviventes de câncer de mama.

Método: Estudo descritivo-analítico, longitudinal e quantitativo, realizado em um *cancer center* no Brasil entre 2021 e 2022, nos tempos três (T1), seis (T2) e nove (T3) meses do término de tratamento oncológico cirúrgico e clínico (exceto terapia endócrina). Foram aplicados o questionário de caracterização sociodemográfica e clínica e o Termômetro de *Distress* com uma lista de problemas com 35 itens, distribuídos em cinco domínios: prático, familiar, emocional, espiritual e físico. Análise dos dados: teste de independência, Qui-quadrado, não paramétrico U de Mann-Whitney e Kruskal-Wallis ($p \leq 0,05$).

Resultados: Composto por 101 participantes, a maioria era casada ou mantinha união estável, e o *distress* avaliado foi > 4. Os problemas mais incidentes foram os emocionais, espirituais e físicos. Mulheres com idade mais avançada demonstraram aumento do nível *distress* no T1 e T3, e quanto maior o grau de instrução, maiores os níveis de *distress*, com significância estatística em T2 e T3.

Conclusão: A maioria das mulheres apresentou problemas emocionais, espirituais e físicos, o que enfatiza a necessidade de uma abordagem multidimensional no cuidado das sobreviventes de câncer de mama.

Descritores: Sobreviventes de câncer; Neoplasias da mama; Qualidade de vida; Angústia psicológica.

RESUMEN

Objetivos: Evaluar el nivel de *distress* y su correlación con las características sociodemográficas y clínicas de mujeres sobrevivientes de cáncer de mama.

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Método: Estudio descriptivo-analítico, longitudinal y cuantitativo, realizado en un centro oncológico en Brasil entre 2021 y 2022, en tres momentos: tres (T1), seis (T2) y nueve (T3) meses después de la finalización del tratamiento oncológico quirúrgico y clínico (excepto la terapia endocrina). Se aplicaron el cuestionario de caracterización sociodemográfica y clínica, el Termómetro de *Distress*, y una lista de problemas con 35 elementos, distribuidos en cinco dominios: práctico, familiar, emocional, espiritual y físico. Análisis de los datos: prueba de independencia, Chi-cuadrado, teste no paramétrico U de Mann-Whitney y Kruskal-Wallis ($p \leq 0,05$).
Resultados: Participaron 101 mujeres, la mayoría casadas o en una unión estable, con un nivel de *distress* > 4. Los problemas más frecuentes fueron emocionales, espirituales y físicos. Las mujeres de mayor edad presentaron un aumento en el nivel de *distress* en T1 y T3, mientras que aquellas con mayor nivel educativo también mostraron mayores niveles de *distress*, con significancia estadística en T2 y T3.
Conclusión: La mayoría de las mujeres presentó problemas emocionales, espirituales y físicos, lo que resalta la necesidad de un enfoque multidimensional en el cuidado de las sobrevivientes de cáncer de mama.
Descriptores: Supervivientes de Cáncer; Neoplasias de la Mama; Calidad de Vida; Distrés Psicológico.

INTRODUCTION

Breast cancer is the most common neoplasm in women around the world, being the main cause of death by cancer in this group. In 2022, breast cancer caused 670,00 deaths globally, being the type of cancer most commonly diagnosed in women in 157 of the 185 countries investigated[1]. In Brazil, estimates predict that, from 2023-2025,73,610 new cases of breast cancer will be diagnosed, representing an incidence rate of 66.54 per 100,00 women, making it the main cause of death in the female population[2]. Advances in diagnostic techniques and multimodal treatments have contributed to significantly increase long-term survival rates, with more than 7.8 million women surviving for five years after their diagnosis, worldwide[3].

The American Society of Clinical Oncology (ASCO), partnered with the Institute of Medicine, defines cancer survival as the period that begins with the diagnosis and continues throughout the entire patient's life. This period is divided in three stages: acute, prolonged, and permanent survival. Acute survival starts with the diagnosis and lasts until the end of the initial treatment. Prolonged survival starts after the initial treatment is finished, and continues for several months, focusing on the effects of the cancer and their treatment. Permanent survival starts years after the treatment ends, emphasizing the management of long term effects, risk reduction, and health promotion[4].

Surviving breast cancer is no easy task, and many survivors, at some point, experience distress, which has a multifactorial origin and is related to the diagnosis or the oncological treatment. The National Comprehensive Cancer Network (NCCN) defines distress as a negative and multifactorial emotional experience, which may vary from common feelings of vulnerability, sadness, and fear, to more serious conditions, such as anxiety and depression, thus impacting one's ability to deal with cancer and its treatment[5]. Distress can involve psychological, physical, practical, spiritual, and social issues, negatively affecting qualify of life (QoL), treatment efficiency, and the recovery and survival of patients[6].

Considering the evidence about the importance of identifying distress, the NCCN recommends, from 1999, that all cancer patients should be evaluated[6]. In 2007, this evaluation was recognized as the sixth vital sign, something as important as the vital physical signs if one is to provide integral follow-up to cancer patients[6]. This reflects the need for an integral approach to patient care, considering not only their physical aspects, but also emotional and psychological ones. Additionally, the International Psycho-Oncology Society reiterated this perspective, promoting the idea that integrating of distress assessments into the continuous care of the cancer patient is a central aspect of a person-centered practice that takes into account the global wellbeing of the patient[7,8].

Every day, the NCCN elaborates and updates the Distress Management guideline, a multidisciplinary manual that lays down care standards to evaluate and manage distress. Their directives include criteria to identify and stratify the severity of the distress, risk factors, periods of greater vulnerability during oncological treatment, and specific recommendations for intervention[5]. The guideline also provides guidance about how to use the Distress Thermometer (DT), a validated tool to screen for emotional suffering, in addition to providing strategies to manage symptoms and therapeutic recommendations customized for

each level of distress found[5]. This approach has been essential to promote more sensitive and individualized care, recognizing that effective distress control can significantly help improve QoL, optimizing treatment results and improving the resilience of patients[5,9].

A systematic review whose goal was reviewing the prevalence of psychological distress in cancer patients in the Southeast of Asia found that further studies are needed to incerase the understanding of these complex symptoms. Additionally, given that clinically significant psychological suffering has been identified, it is important to adopting appropriate therapeutic interventions to promote the QoL of these patients[10]. In this context, and considering the scarcity of studies on the topic, its high prevalence, and the fact that distress is not well recognized, diagnosed, and treated by health workers, it is essential to understand its occurrence, and the factors that influence it[5–6,10]. Identifying these variables can help raise awareness among professionals, guide the formulation of more appropriate interventions and, especially, allow cancer care to be individualized, by using better tools to deal with emotional suffering. Therefore, considering the relevance of this issue, and especially the relevance of investigating these influences to elaborate a care plan that is in line with the specific needs of women who are survivors of breast cancer, this study aimed to evaluate distress levels and their correlation with sociodemographic and clinical characteristics of breast cancer survivors.

METHOD

This a descriptive-analytical, longitudinal and quantitative study, carried out according to the tool Strengthening the reporting of observational studies in epidemiology (STROBE).

The target-population of the study included women diagnosed with breast cancer, who had finished their main treatment (except endocrine therapy), from January to July, 2021. The participants were attended in a cancer center in the city of São Paulo, Brazil, a private institution that provides care for both supplementary health patients and those from the Single Health System (SUS). Patients were recruited using patient electronic records (PER), with the following inclusion criteria: being female, over 18 years old, diagnosed with breast cancer, undergo clinical therapies with anti-neoplastic chemotherapy, radiotherapy, and surgical treatments, receiving care in the institution for at least three months. The study excluded all patients who had not been through surgical procedures to treat breast cancer; with a history of other types of cancer, except non-melanoma skin cancer; who were not fluent in Portuguese; and those who had psychiatric disorders registered in medical records which made it impossible filling in the DT. Participants were invited to participate in the study via phone or, in case they did not answer, via personal interaction in the waiting room, before the medical appointment.

The sample size was based on a linear regression, considering a medium effect size, a power of 0.80, and a significance level of 0.05. As a result, the estimated sample included 55 participants, and 46 were added (83.6%) to compensate potential losses and ensure the results are representative and statistically robust[11]. The dependent variable was the distress level and the issues reported by the participants, as measured using the DT. The independent variables were age, marital status, beliefs, socioeconomic class, educational level, comorbidities, pathological staging, histological type, molecular subtype, type of treatment, and type of surgery. The dependent variables were collected using interviews, while the independent ones were obtained using the PER.

Data collection took place individually, in private rooms, conducted by the main researcher, nurses with post-graduation in oncology, and oncology nursing residents, from July 2021 to May 2022, in three meetings. These took place when the patients received outpatient care in follow-up consultations or when they underwent exams, three (T1), six (T2), and nine (T3) months after the surgical and clinical treatment was over (except in cases of endocrine therapy). In the first meeting, an informed consent was applied, followed by a sociodemographic and clinical characterization questionnaire. We also gathered information from the PER and the application of the DT. In later meetings, only the DT was applied.

The distress was assessed using the DT, which was translated and validated into Portuguese in 2009 by Decat[12]. The results of this study presented a sensitivity of 82% and a specificity of 98%, suggesting that the DT is a viable and effective tool to evaluate psychological distress[12]. The DA is a visual, analogical tool, which

allows the respondent to classify their own distress level in the prior week using a scale from 0 (no distress) to 10 (extreme distress). Results of 4 or higher indicate distress from moderate to high. This instrument also identifies the main causes of distress in a list of problems (LP) with 35 items, divided into five domains: practical (five items), family (two items), emotional (six items), spiritual (one item), and physical (21 items). This instrument is widely used in Brazil and easy to apply. It comes with orientations as to when and how to use it, on whom to apply, and how to treat[12–13].

Variables were described using means, medians, standard deviations, minimum and maximum values, and absolute and relative frequencies (%). Data normality was evaluated using the Shapiro-Wilk test. The variables that presented a normal distribution according to this test were analyzed using Pearson's correlation test. The variables that did not present a normal distribution were analyzed using the non-parametric tests of Mann-Whitney and Kruskal-Wallis. The association between categorical variables was evaluated using the independence test and the chi-squared. The analyses were conducted using the applications R (version 3.5) and IBM SPSS (version 25). The significance level was 5%, considering ≤ 0.05 as statistically significant. Data analysis sought to identify the factors correlated to the distress level in women breast cancer survivals, in order to give support to strategies to improve psychological monitoring and the QoL of these patients. Additionally, we attempted to provide outcomes for this study, with information related to the identification of the intensity of the distress and its correlation with sociodemographic and clinical variables in the different stages of the post-treatment period.

Before this research was conducted, it was approved by the Research Ethics Committee of the Universidade Federal de São Paulo / Escola Paulista de Enfermagem, under opinion 3.203.556/2019 and CAE: 04281018.5.1001.5505, according to regulatory norms and standards for research with human beings. It was also approved by the Research Ethics Committee of the Antônio Prudent Foundation, under opinion 3.203.556/2019 and CAE: 04281018.5.3001.5432. The participants that agreed to participate signed the consent form and were informed about the goals and type of participation, having their anonymity and secrecy ensured and the choice to withdraw their consent at any moment, according to Resolution No. 466/12.

RESULTS

The study included 101 women breast cancer survivors, with different clinical and sociodemographic characteristics (Table 1).

61.4% of participants had a distress level > 4 at T1, 66.3% at T2, and 59.0% at T3. We found a significant correlation, albeit weak and positive, between age and distress level, indicating that advanced age was associated to an increase in distress at T1 and T3. Regarding the educational level, higher educational levels were associated to higher distress levels, especially at T2 and T3, as Table 2 shows.

The most common issues in the LP were emotional, spiritual, and physical (Figure 1). The frequency of issues reported was similar between T1 and T3, with an increase in family and spiritual/religious issues. This analysis considered all patients who reported at least one issue in the domains of the LP.

Among practical domains, health insurance/financial issues and house chores stood out. In the family domain, the item "partner" was the most frequently mentioned at the moments T2 and T3. Regarding emotional issues, "worry" was the most common at all times of evaluation. In the physical issues domain, pain, and trouble remembering/concentrating were the most commonly reported, with a perceptible increase in T3.

Figure 2 shows the most frequently reported problems, stratified by distress level, at the three evaluation moments. The three most commonly mentioned items were from the domains emotional problems and physical problems, and represented more than 50.0% of the general reports. The ones that stood out were "worry" (68.9%), "memory/concentration" (51.3%), and "nervousness" (50.7%). Among practical issues, 21.2% of participants mentioned "house chores".

The analysis of the association between the distress level in women who survived breast cancer and the LP variables, in the three moments of evaluation, was statistically significant in regard to emotional problems, especially "depression" (p=0.001) and "worry" (p=0.007). Additionally, the number of significantly associated problems increased over time, with 6 at T1, 11 at T2, and 14 at T3, as Table 3 shows.

Table 1 – Sociodemographic and clinical data of women survivors of breast cancer (n=101). São Paulo, SP, Brazil, 2022

Sociodemographic and clinical data	n (%)
Age	
Mean (standard deviation)	54.2 (12.3)
Minimum-maximum	-29
Marital status	
Married/common law marriage	66 (65.3)
Single	18 (17.8)
Widow	10 (9.9)
Divorced	7 (6.9)
Educational level	
Higher education	76 (75.2)
High school	17 (16.8)
Elementary school	8 (7.9)
Socioeconomic class	
Class A	27 (26.7)
Class B	64 (63.3)
Class C	10 (10.0)
Belief	
Catholic	59 (58.4)
Protestant	14 (13.9)
Spiritist	12 (11.9)
Other	13 (12.9)
None	3 (3.0)
Comorbidities	
Yes	70 (69.3)
No	31 (30.7)

Table 1 – Cont.

Sociodemographic and clinical data	n (%)
Uses endocrine therapy	
Yes	84 (83.2)
No	17 (16.8)
Histological type of breast cancer	
Ductal carcinoma in situ	23 (22.8)
Ductal invasive carcinoma	67 (66.3)
Lobular carcinoma in situ	2 (2.0)
Invasive lobular carcinoma	9 (8.9)
Molecular subtype	
Luminal A	36 (35.6)
Luminal B	52 (51.5)
Triple negative	8 (7.9)
HER2 enriched	3 (3.0)
Not analyzed	2 (2.0)
Pathology staging	
0	19 (18.8)
I	31 (30.7)
II	35 (34.7)
III	13 (12.9)
IV	3 (3.0)
Treatment	
Surgery	9 (8.9)
Surgery + antineoplastic CT*	5 (5.0)
Surgery + RDT†	50 (49.5)
Surgery + antineoplastic CT* + RDT‡	37 (36.6)

Table 1 – Cont.

Sociodemographic and clinical data	n (%)
Type of surgery	
Segmental resection	61 (60.4)
Mastectomy	30 (29.7)
Adenomastectomy	10 (9.9)

Source: Research Data, 2022.
*CT= Chemotherapy; †RDT= Radiotherapy.

Table 2 – Correlation between distress level and sociodemographic and clinical variables in women survivors of breast cancer at the moments of evaluation. (n=101). São Paulo, SP, Brazil, 2022

Variable	Distress level					
	T1*		T2*		T3*	
	Mean (SD)†	p	Mean (SD)†	p	Mean (SD)†	p
Age		**0.04**		0.45		**0.02**
r-value	-205		-.0075		-225	
Comorbidities		0.64		0.59		0.80
Yes	4.2 (2.8)		4.6 (2.3)		4.7 (2.8)	
No	4.5 (2.9)		4.9 (2.6)		4.5 (2.7)	
Marital status		0.37		0.24		0.21
Single	5.1 (2.5)		5.7 (1.9)		6.0 (1.7)	
Married/common law marriage	4.0 (2.8)		4.6 (2.4)		4.4 (2.8)	
Divorced	3.7 (2.4)		4.5 (3.2)		4.0 (3.5)	
Widow	5.3 (3.6)		3.9 (2.4)		4.3 (3.3)	
Belief		0.16		0.49		0.09
Catholic	4.4 (2.7)		4.8 (2.6)		4.8 (3.0)	
Protestant	4.2 (2.7)		4.1 (2.2)		5.7 (2.4)	
Afro Brazilian	5.3 (2.8)		7.0 (0.0)		2.3 (2.5)	

Table 2 – Cont.

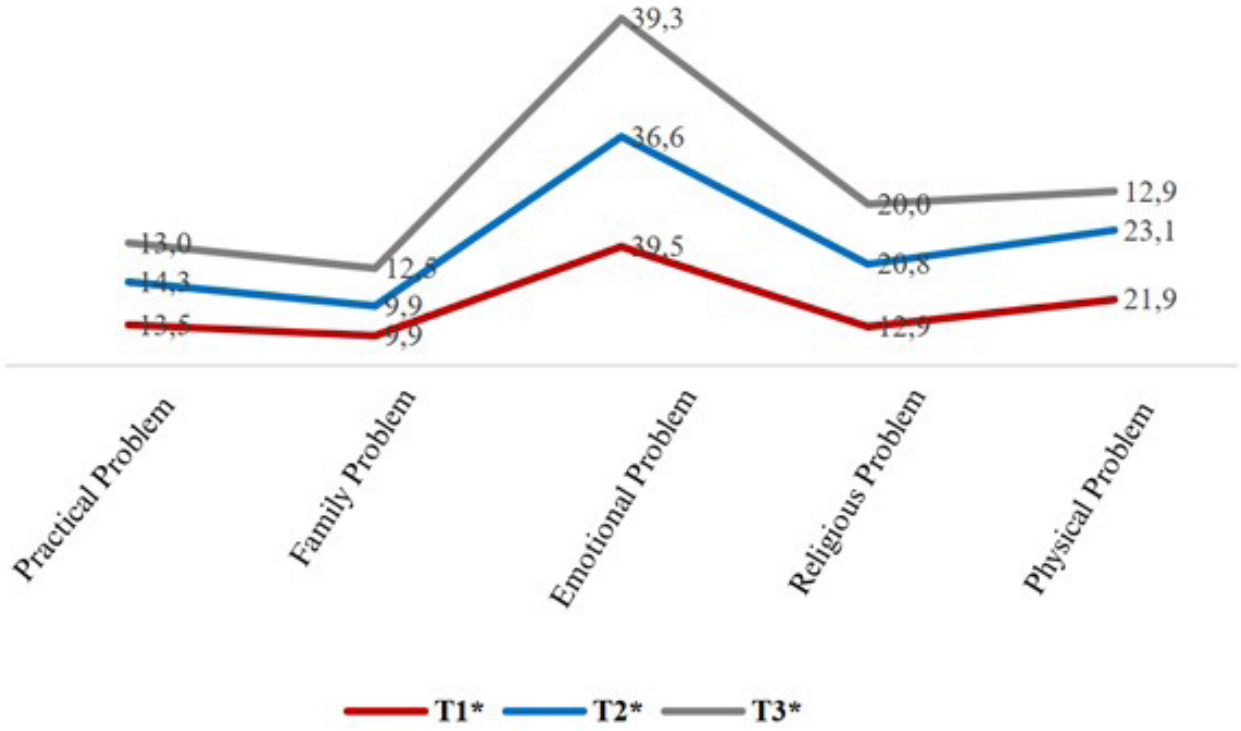
Variable	Distress level					
	T1*		T2*		T3*	
	Mean (SD)†	p	Mean (SD)†	p	Mean (SD)†	p
Spiritist	4.3 (3.0)		5.0 (1.6)		4.5 (2.1)	
Judaism	1.0 (-)		3.0 (-)		3.0 (-)	
None	7.0 (2.0)		5.0 (3.6)		7.0 (1.0)	
Other	2.4 (3.0)		4.1 (2.3)		2.7 (2.0)	
Educational level		0.13		**0.04**		**0.02**
Elementary school	2.5 (2.6)		4.1 (2.6)		1.5 (3.0)	
High school	5.1 (2.9)		6.1 (2.1)		6.2 (2.1)	
Higher education	4.3 (2.8)		4.7 (2.3)		4.6 (2.7)	
Socioeconomic class		0.75		0.60		0.51
Class A	4.2 (3.0)		4.9 (2.5)		4.4 (2.8)	
Class B	4.1 (2.6)		4.7 (2.5)		4.8 (2.7)	
Class C	5.1 (3.0)		4.5 (1.5)		4.0 (3.3)	
Class D	3.3 (0.5)		3.0 (1.0)		7.0 (1.0)	
Uses endocrine therapy		0.54		0.051		0.38
Yes	4.3 (2.7)		4.9 (2.4)		4.5 (2.7)	
No	3.9 (3.2)		3.7 (2.2)		5.2 (3.2)	
Staging		0.08		0.83		0.81
0	5.0 (2.6)		5.2 (2.5)		4.9 (2.7)	
I	4.6 (3.3)		4.8 (2.4)		4.5 (2.7)	
II	3.4 (2.5)		4.4 (2.4)		4.8 (3.0)	
III	4.0 (2.1)		4.9 (2.3)		4.6 (2.9)	
IV	7.3 (0.5)		5.0 (2.0)		3.0 (2.0)	

Table 2 – Cont.

Variable	Distress level					
	T1*		T2*		T3*	
	Mean (SD)†	p	Mean (SD)†	p	Mean (SD)†	p
Treatment		0.50		0.95		0.19
Surgery	5.3 (2.7)		5.1 (2.4)		6.5 (1.6)	
Surgery + antineoplastic CT‡	3.6 (2.0)		5.2 (1.6)		4.0 (2.5)	
Surgery + RDT§	4.5 (3.2)		4.6 (2.5)		4.5 (2.8)	
Surgery + antineoplastic CT‡ + RDT§	3.8 (2.4)		4.7 (2.4)		4.5 (2.9)	

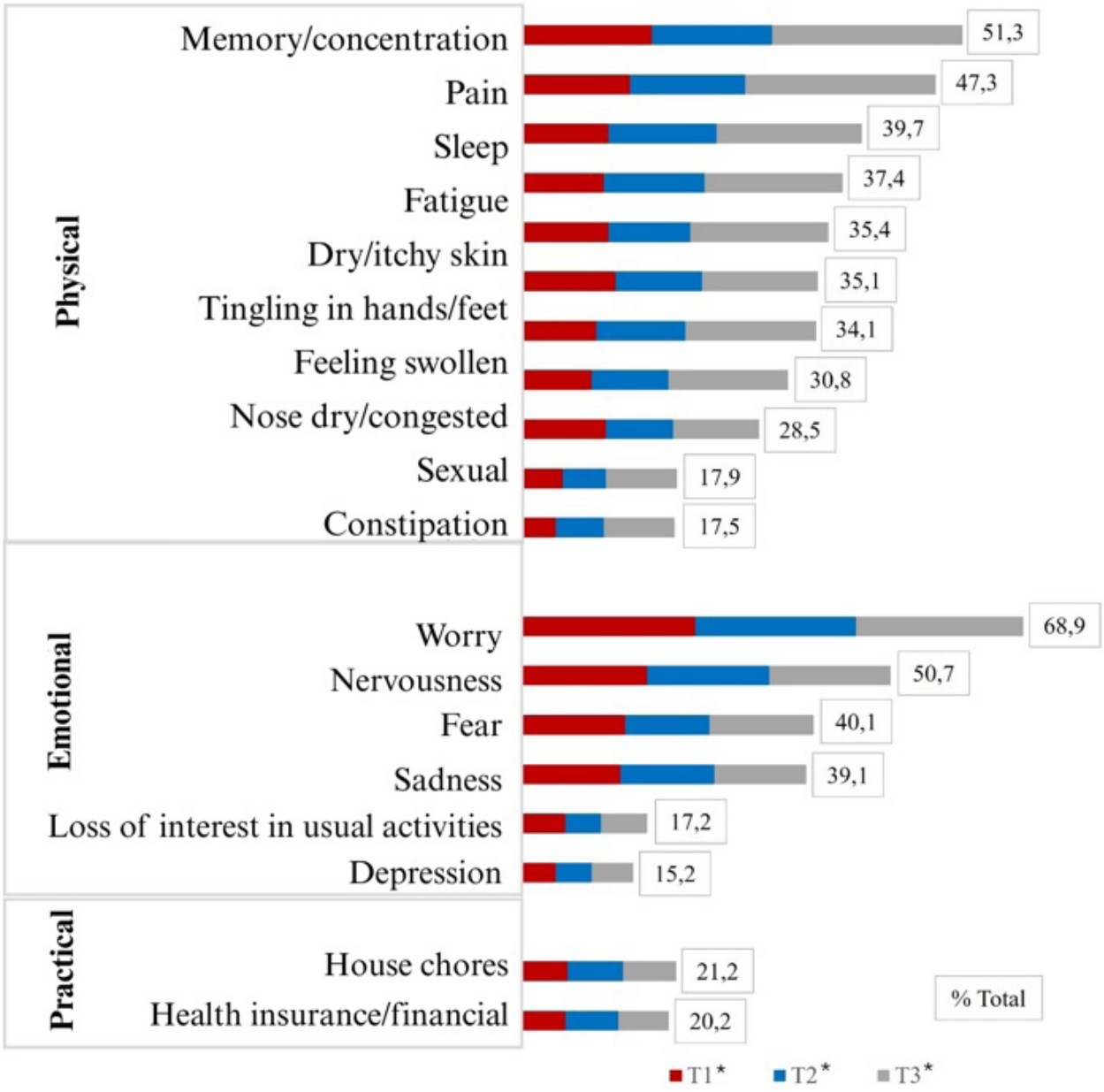
Source: Research Data, 2022.
*Months after the end of treatment: T1= 3 months, T2= 6 months, and T3= 9 months; †SD – Standard deviation; ‡CT= Chemotherapy; §RDT= Radiotherapy.
Statistically significant difference for $p \leq 0.05$.

Figure 1 – Categorical frequency of problems reported at the three evaluation moments.



Source: Research Data, 2022.
*Months after the end of treatment: T1= 3 months, T2= 6 months, and T3= 9 months.

Figure 2 – Most frequently reported problems, stratified by suffering level, over the three evaluation moments.



Source: Research Data, 2022.
*Months after the end of treatment: T1= 3 months, T2= 6 months, and T3= 9 months.

DISCUSSION

This study evaluated distress in women survivors of breast cancer, identifying high levels of distress associated with emotional, spiritual, and physical problems, and presenting a significant correlation with older age groups and higher educational levels. The main problems reported were "worry", "memory/concentration" difficulties and "nervousness". The analysis indicated that several of these problems presented statistical significance in the three moments of the evaluation, and the number of issues increased over time. These results corroborate the findings of similar investigations[14–17]. Meta-analysis studies about the prevalence and incidence of distress in women with breast cancer suggest that from 50% to 52% of them presented with this condition[14,28].

Table 3 – Correlation of the psychological distress of women survivors of breast cancer with the significant variables of the list of problems of the Distress Thermometer, in the three evaluation times (n=101). São Paulo, SP, Brazil, 2022

Issues reported	T1*		T2*		T3*	
	Mean (SD)‡	p	Mean (SD)‡	p	Mean (SD)‡	p
Housekeeping	4.5 (2.8)	0.50	5.6 (2.4)	**0.04**	4.8 (3.1)	0.48
Financial	4.4 (2.8)	0.62	5.6 (2.1)	**0.02**	5.4 (2.5)	0.23
Spouse or partner	4.2 (2.8)	0.56	6.5 (2.0)	**0.00**	5.9 (1.9)	**0.01**
Depression	4.4 (2.9)	**0.00**	6.0 (1.9)	**0.00**	5.8 (2.5)	**0.03**
Nervousness	5.0 (2.9)	**0.01**	5.6 (2.0)	**0.00**	6.3 (2.2)	**0.00**
Fear	5.6 (2.6)	**0.00**	5.4 (2.1)	**0.01**	5.7 (2.3)	**0.00**
Sadness	5.0 (2.8)	0.06	5.3 ((2.1)	**0.04**	5.8 (2.5)	**0.00**
Worry	4.8 (2.8)	**0.00**	5.1 (2.2)	0.07	5.2 (2.7)	**0.02**
Loss of interest in daily activities	5.5 (2.9)	**0.03**	5.8 (1.7)	**0.04**	5.9 (3.0)	**0.02**
Breathing	4.1 (3.3)	0.76	6.4 (2.0)	**0.01**	5.6 (2.1)	0.32
Changes to urination	5.3 (3.8)	0.32	5.5 (2.6)	0.25	6.1 (2.5)	**0.03**
Diarrhoea	6.1 (3.0)	0.06	6.5 (2.1)	0.08	7.0 (3.0)	**0.02**
Eating	5.2 (2.5)	0.16	6.5 (1.7)	**0.00**	7.0 (3.2)	0.05
Indigestion	5.5 (2.9)	0.12	5.7 (1.8)	0.09	6.3 (3.2)	**0.02**
Congested or dry nose	4.8 (3.1)	0.17	5.2 (2.2)	0.31	6.6 (2.3)	**0.00**
Pain	4.7 (3.0)	0.22	5.4 (2.2)	**0.01**	5.0 (2.8)	**0.11**
Dry or dry skin	4.6 (3.1)	0.36	4.7 (2.1)	0.75	6.0 (2.7)	**0.00**
Sleep	5.2 (2.7)	**0.02**	4.9 (2.3)	0.44	5.8 (2.6)	**0.00**

Source: Research Data, 2022.
*Months after the end of treatment: T1= 3 months, T2= 6 months and T3= 9 months; †SD – Standard deviation Statistically significant difference for $p \leq 0.05$.

The psychological suffering of women with breast cancer is related to several factors, including the impact of the diagnosis, the adverse effects of treatment, limitations in everyday activities and professional ones, the availability of social support, and the coping strategies adopted[18]. Additionally, the pain associated with the treatment, changes in physical appearance, and other collateral effects, such as high costs, cognitive and sexual dysfunction, and aesthetic issues, help generate a negative emotional condition that persists in many patients even after the diagnosis[19]. Psychological interventions, such as cognitive-behavioral therapies, mindfulness, and psychosocial support have been found to be effective to reduce distress, promoting resilience and adaptation to the diagnosis and the treatment. These approaches could be explored as primary interventions in the context of the follow-up of breast cancer survivors[5,20–21]. Additionally, the implementation of a care plan that includes multidisciplinary interventions such as spiritual support, as well as integrative and complementary practices (such as art therapy, yoga, and mindfulness), physical activity and educational components, significantly contributes for an improvement in the QoL of cancer patients [6,22–23].

This suffering manifests in different ways over the breast cancer trajectory, with significant differences between the stages of diagnosis, treatment, and survival[24–25]. Studies suggest that higher distress levels take place from one to four weeks after diagnosis, decreasing over the next months [24]. In this study, we found that distress levels decreased from six to twelve months after the treatment was over (except endocrine therapy), confirm this trend in a Brazilian sample. Moreover, social support has an essential role in mitigating psychological suffering[5,9]. Women that have a solid support network tend to present lower levels of distress, reiterating the importance of involving relatives and friends in the therapeutic process[16].

In the analysis of the association between distress and clinical and sociodemographic variables, a systematic review and meta-analysis suggested that factors such as high educational level, advanced stage of the tumor, emotional concerns, lack of health insurance, modified radical mastectomies, and a history of depression, are associated to an increase in psychological suffering. On the other hand, being older and having a higher monthly income were identified as protective factors[14].

In this study, we found a weak and positive significant correlation between distress and age at T1, suggesting that older women suffer more. This association can be related to post-menopause symptoms, such as hot flashes and night sweats[18], in addition to the uncertainties of the post-treatment period, especially for those who provide emotional support to their families[26].

These findings are in accordance with the results of this research, in regard to the lack of association with staging, since most participants were diagnosed in stages I and II; in regard to health insurances, since all participants used this supplementary health service; to radical mastectomy, since more than half participants underwent segmental resection; and to educational level, with greater significance for higher educational levels at T2 and T3. A possible explanation for this result is the fact that people with higher educational levels generally understand better the situation, its development, its prognosis, and the potential impact of the disease, which may make them more sensitive to the prognostic, leading to a more intense psychological burden[14]. Among the domains of the LP, emotional, spiritual/religious, and physical problems were the most commonly reported in all evaluations, a pattern which is consistent with global studies[8,16,25]. The most reported issues were worry (68.9%), memory/concentration trouble (51.3%), nervousness (50.7%), pain (47.3%), and fear (40.1%). These findings are in accordance with international studies, in which emotional symptoms predominate, while physical symptoms, such as pain and cognitive impairment, are more common in women with breast cancer[27–28].

It is worth noting that patients undergoing endocrine therapy deal with physical symptoms, such as cognitive dysfunction and psychological symptoms associated with their treatment[29]. 83.2% of participants in this study made use of this type of therapy, reiterating

how relevant it is to the experience of patients. Although the distress decreased in the different moments, there was an increase in the problems reported over time. A factor that may be associated with this trend is resilience, which plays a crucial role in the adaptation to cancer and in treatment related difficulties [16,30]. Moreover, the long-term impact of endocrine therapy, especially in regard to collateral effects such as cognitive and emotional changes, could be further explored, since these changes can contribute for long-lasting distress.

Thus, it is essential to screen patients early in order to determine a therapeutic plan, as this can improve the QoL, potentially impacting the rates of survival free from disease[5,9]. The NCCN protocol to deal with distress includes: 1) recognize, monitor, register, and treat distress timely in all stages of the disease; 2) identify the level and nature of distress; 3) systematically screen for distress in every medical appointment or at regular intervals; 4) evaluate and conduct distress management according to clinical practice guidelines [31]. This study reiterates how important it is to provide emotional support and screen for distress in clinical routines. The growing use of digital technology for the monitoring of psychological symptoms, such as applications to detect distress earlier and telepsychology platforms, can be a promising approach to ensure a more efficient and individualized management of patient suffering.

Limitations of this study include the fact it was conducted during the COVID-19 pandemic, which may have increased distress levels[14], and the fact it was conducted in a private institution, whose sociodemographic profile is different than that in the national setting, which may compromise our ability to generalize results. Additionally, an important limitation is the fact this study did not analyze the variable preexisting psychiatric conditions, since these comorbidities could significantly influence distress levels.

Despite its limitations, this study substantially helps increase our understanding of psychological suffering and its associated factors, and may be guide the implementation of more effective interventions. Future research should explore distress in different stages of the disease and in long-term follow-up, in order to better understand its impacts over time.

CONCLUSION

The results of this study made it clear that breast cancer has a profound and persistent impact on the mental and emotional well-being of women who survive it. Participants reported high distress levels, with moderate variations over the three moments of evaluation, which reflected continuous emotional suffering of over time. The problems reported progressively increased, especially those from the emotional, spiritual, and physical domains, suggesting that the issues faced by women during and after treatment were complex and intense.

The significant correlation between distress levels, age, and educational level suggests that sociodemographic factors have an important role in psychological suffering. The implementation of interventions that address emotional, spiritual, and physical aspects in a holistic and individualized manner may be crucial to promote well-being and improvements in the QoL of women after a breast cancer diagnosis.

This study contributes to increase our understanding of the psychological impacts of breast cancer in women survivors by exploring relevant gaps in literature. As opposed to traditional approaches, which focus only on active treatment periods, this research analyzed distress in different moments after diagnosis, showing that the emotional suffering persists over time. Moreover, by adopting a multidimensional perspective, including emotional, physical, and spiritual aspects, this study broadens our understanding about the experience lived by the survivors.

Another important advancement was the analysis of the influence of sociodemographic factors, such as age and educational level, which were found to be significantly associated to distress levels. This approach showed that we need more individualized care strategies, that are sensitive to the specificities of each patient. Finally, our findings provide valuable support for the development of long-term emotional support, especially for the period after the treatment, a stage which was not well explored in previous studies. Nevertheless, even though this study provided important information, its limitations regarding sample size and the scope of sociodemographic factors must be taken into account.

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Data and material availability:

The dataset may be accessed upon request to the Corresponding author. Data is not publicly available due to privacy or ethical constraints.

Acknowledgements:

To the National Council for Scientific and Technological Development (CNPq), research productivity scholarship level 2, process PQ 306687/2018-6, for Edvane Birelo Lopes De Domenico. To the Coordination for the Improvement of Higher Education Personnel (CAPES), Capes-PRINT Program, process number 88881.311044/2018-00, Oncology.

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Associate editor:
Carlise Rigon Dalla Nora

Editor-in-chief:
João Lucas Campos de Oliveira

Received: 02.03.2025
Approved: 05.09.2025