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# ORIGINAL RESEARCH PAPER

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# Distress in the context of cancer and chemotherapy: A mixed-method study

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#### Abstract

**Background:** There are controversial results about the effects of cancer and chemotherapy on the perception of distress.

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**Aims:** The purpose to the study is to explore the meaning of the distress experienced by patients with cancer and verify whether the cancer diagnosis, stage and receiving chemotherapy influence this experience.

**Design:** This is a mixed-methods study with cancer patients.

**Methods:** Data were collected in 2018 using a phenomenological interview (n = 18) and one suffering inventory (n = 100). Qualitative analysis was performed using the empirical-comprehensive model and quantitative using statistical tests. The results were triangulated.

**Results:** Distress originated from difficulties faced in health services, diagnosis confirmation, beginning treatment and interruption of life projects. Patients mobilized resources in the spiritual dimension that allowed them to redefine their distress positively. Chemotherapy brought hope back and promoted healing expectations. Higher average scores for distress were found in patients with advanced stage and receiving palliative chemotherapy. Not having begun chemotherapy and having head and neck cancer were associated with higher average scores for distress.

**Conclusion:** Distress was greater among patients who had not yet begun chemotherapy; nearness of death and difficulty talking about feelings caused distress; distress was redefined by mobilization of spiritual resources.

#### KEYWORDS

cancer, chemotherapy, nursing, psychological distress, suffering

All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the manuscript. Furthermore, each author certifies that this material or similar material has not been and will not be submitted to or published in any other journal.

#### Summary statement

What is already known about this topic?

- There are conflicting results about distress between patients with cancer.
- The distress of cancer patients has been little reported or treated in cancer care units.
- There are no mixed-method studies on distress in chemotherapy patients that have combined a measuring instrument and a phenomenological approach.

What this paper adds?

- Distress among patients with cancer derives from elements that relate to health services, as well as the individual's ability to deal with the situation.
- Distress is greater among patients who have not begun chemotherapy and those who have head and neck cancer diagnoses.
- Phenomenological method can complement the use of scales to assess the subjective experience of distress in the context of cancer and chemotherapy.

Implications of this paper

- Distress evaluation must encompass listening and the use of measurement instruments to strengthen the implementation of patient-centred nursing care.
- Nurses are in a unique position to identify and approach distress, because they are often at the side of patients throughout the course of treatment.
- Professional training for reporting of difficult news is required.

# 1 | INTRODUCTION

The cancer survival rate continues to increase because of advances in treatment. However, the experience of living with this disease is still distressing, not only because cancer is usually associated with the idea of non-healing, but also because of the pain and physical load related to the symptoms and side effects of treatment, and psychological and emotional implications that can make patients' condition worse (Lee et al., 2018; Xing et al., 2018). This distress experience has high prevalence, with estimated rates ranging from 25% to 47% in Western countries and 30% to 50% in Asian countries (Bergerot et al., 2015; Wang et al., 2017). Consequently, it is necessary to understand this experience in order to support interventions that can lead to relief, improve quality of life and mental health, and reduce costs associated with hospital and outpatient cancer care (Compen et al., 2018; Wen et al., 2017).

In 2018, the National Comprehensive Cancer Network (2018) proposed distress as the sixth vital sign, recommending its assessment after checking temperature, pulse rate, respiration rate, blood pressure and pain. In Brazil, the setting of this study, the lack of standardized instruments intended to evaluate distress has contributed to this phenomenon, which has received little attention in cancer care units across the country. Distress is a multifactorial phenomenon that involves existential, physical, social and psychological aspects. It can lead to severe vulnerability and discomfort, loss of control and identity, and feelings of having insufficient personal resources to face the disease, its symptoms and its treatment (Albrecht & Rosenzweig, 2014; Riba et al., 2019). Some patients perceive antineoplastic treatment as physically bearable. For others, however, going through this treatment can be equal to the distress itself (Lai et al., 2017). Some studies have shown that patients who receive chemotherapy are more prone to report distress (Enns et al., 2013; Oh & Cho, 2020), whereas other investigations have consistently described the opposite result (Chiu et al., 2016; Paiva et al., 2014). These divergences point to the need to develop mixed-method studies, which have potential to reveal new findings related to the experience of distress in patients with cancer.

# 1.1 | Aims

The aim of the study was to explore the meaning of the distress experienced by patients with cancer and verify whether the cancer diagnosis, stage and receiving chemotherapy influence this experience.

# 2 | METHODS

#### 2.1 | Design

This was a convergent parallel mixed-method study that integrated a cross-sectional quantitative study and a qualitative component based on phenomenology. The collection and analysis of quantitative and qualitative data were implemented simultaneously and in parallel, and

were addressed with equal priority, kept independent and subsequently compared with determine convergences, divergences, and combinations (Fetters et al., 2013).

The study location was an adult chemotherapy outpatient clinic in a Brazilian national public reference centre for cancer education and control in the city of Rio de Janeiro, Rio de Janeiro state, Brazil. The chemotherapy outpatient clinic has 15 chairs and 2 beds, maintaining an occupancy rate of 80% throughout its period of operation (12 h a day). In this treatment unit, there are four different appointment slots based on the duration of the chemotherapy protocols, which range from 30 min to 10 h.

# 2.2 | Participants

Sample size calculation was carried out using G-Power software, based on the average number of people who came in to receive cancer treatment during the 12 months prior to data collection. A test power equal to 80% and a level of significance equal to 5% were adopted. The resulting probability sample consisted of 100 patients.

The present study included patients of both genders, 18 years or older, with a confirmed diagnosis of neoplasia, who had received an order to begin treatment or were under outpatient chemotherapy treatment, with good orientation to space and time, good cognitive capacity and absence of diagnosed psychiatric issues. The exclusion criteria were people with a performance status score equal to or higher than 3 on the Eastern Cooperative Oncology Group (ECOG) scale; signs of impairment in activities of daily living (Oken et al., 1982); or being unable for any reason to participate in data collection. The purpose of the ECOG scale was to exclude critically ill patients, who are potentially unable to reflect on issues from the Subjective Experiences of Suffering in Illness Inventory (IESSD, as per its abbreviation in Portuguese) or engage in a phenomenological interview. None of the participants declined the invitation to be part of the study.

## 2.3 | Data collection

Data were gathered in June and July 2018 by the principal author, who has an MSc degree and is an oncology nurse at the study location. Initially, a sociodemographic and clinical characterization form was filled out based on information obtained in medical records and from the patients.

In the subsequent step, qualitative data were collected using individual phenomenological interviews, which had the objective of allowing the researchers to understand the distress experience in the cancer and chemotherapy context. The following questions were presented to the participants: What feelings emerged from the cancer diagnosis? What feelings emerged from the experience of undergoing chemotherapy? How do you perceive chemotherapy in your life? The interviews lasted 45 min, on average, were conducted in a room intended for nursing appointments and were recorded using digital equipment for complete transcription afterwards. Quantitative data were obtained by applying the IESSD (Gameiro, 2000; Sá et al., 2019). This instrument evaluates the experience of global distress from the total score on 44 items that are answered using a five-level Likert scale: (1) it does not correspond to what happens to me at all; (2) it corresponds a little; (3) it corresponds well; (4) it corresponds very much; (5) it totally corresponds to what happens to me. Among the 44 items, five express experiences of positive distress and, consequently, their opposite values are considered in the calculation of the global distress score. The IESSD showed high internal consistency, with a global Cronbach's alpha equal to 0.94, as seen in previous studies (Alves et al., 2012; Gameiro, 2000). The content, structural and convergent validity of the IESSD was examined and confirmed by its author. Regarding the score interval, 220 was established as the maximum and 44 as the minimum of distress (Gameiro, 2000).

The participants were recruited immediately after the completion of a regular nursing appointment, at which time the fulfilment of the eligibility criteria was verified, and data were collected. Gathering quantitative elements continued until the calculated sample size was reached. Collection of qualitative elements proceeded until theoretical saturation was reached, after 18 participants had been selected deliberately for showing higher chances of contributing to the subject under discussion, considering, however, the inclusion of an equal number of patients who had not undergone the first chemotherapy cycle and patients who had already completed at least four cycles.

#### 2.4 | Ethical considerations

All the participants signed consent forms. The study was also approved by the research ethics committee of the institution where the investigation was carried out, according to Brazilian law. Authorization to use the scale was granted by the author of the inventory via email.

#### 2.5 | Data analyses

The recordings made during the phenomenological interviews were analysed according to Amedeo Giorgi's (2008a, 2008b) comprehensive-empirical model. The following steps were carried out: (1) indepth reading of the data; (2) differentiation of meaning units; (3) conversion of the patients' language into scientific language (psychological insights); (4) summary and integration of the psychological insights into analytical categories. Once the codification was complete, nomothetic analysis was carried out, aiming to bring together the perceptions of all the participants and reveal the central structure of the experience, reaching general and invariable truths about the examined phenomenon (Sadala, 2002).

Quantitative data were tabulated and processed using SPSS software version 20.0 by applying descriptive and inferential statistics. Data normality was verified using the Shapiro–Wilk test. The parametric Student's *t* test and analysis of variance (ANOVA), followed by 4 of 14 WILEY-

Tukey's test, were applied when there was statistical significance, considering the characteristics of the variables and the 5% level of significance. The tests were oriented towards verifying whether the distress averages measured using the IESSD varied depending on cancer type, stage and chemotherapy modality, treatment time and number of previous regimens.

The contiguous approach was used to integrate the findings, involving presentation of the qualitative and quantitative results for different topics, followed by concurrent triangulation of the results (Fetters et al., 2013) in the interpretation phase, seeking to extract meta-inferences and conclusions about the investigated phenomenon (Figure 1). For that, mixed-methods legitimation strategies were reviewed and applied (Table 1).

# 3 | RESULTS

# 3.1 | Qualitative results

Eighteen of the 100 patients included in the sample participated in the phenomenological interview; of those, nine were in the process of treatment and nine had just begun treatment. The interviews yielded seven analytical themes.

# 3.1.1 | Theme 1: Walking the rocky road: Therapeutic itinerary for cancer diagnosis

When asked about the feelings that emerged from the diagnosis, the interviewees spared no effort in providing detailed reports about the difficulties of obtaining a definitive result in public services. Their trajectory through different health facilities, together with the several diagnostic possibilities considered by professionals, was pervaded by intense emotional distress:

I had been rushing around for a year and a half to find out what I had. It was a long time until the biopsy was carried out. After I could find a place, scheduling the exam was another difficulty. Then I scheduled it and had more problems getting the result. And the doctors who performed the test did not tell me exactly what I had. (I17)

# 3.1.2 | Theme 2: Diagnosis impact

This topic revealed the distress experienced by patients when they found out they had cancer and the impact of the diagnosis. Many showed themselves to be clearly scared by the signs and symptoms of the disease in its acute phase:

> You are hard hit when you find out you have this disease; it is very strong. At first, I was quite scared, quite upset, and felt unwell for a few days. (I5)

The interviews also brought up the patients' distress with the physicians' lack of sensitivity when communicating the diagnostic report:

The doctor received me, looked at the tests, and said, out of the blue: 'Listen, you have cancer'. I thought he could have said it differently. I did not fall on the ground only because I was sitting. (I23)

# 3.1.3 | Theme 3: In search of a meaning for the disease

Confrontation with existential issues was inevitable and occurred at different times for each patient. The questioning about life and death that originated from this confrontation expressed the search for a logic that would explain the disease. This spiritual dimension of distress takes on a significant value when the end is envisioned as a real and close possibility.

You have got to have a lot of strength not think you are being punished. These thoughts cross your mind, although you know God punishes no one. (I1)



FIGURE 1 Flowchart showing the mixedmethod strategy used

# TABLE 1 Main threats and strategies adopted to legitimize the results obtained with the mixed parallel convergent method

Legitimation threats	Strategies to circumvent the threat
Issues in data collection	
Transferability of meta-inference (Creswell & Plano Clark, 2017; Onwuegbuzie & Johnson, 2006).	Do not select for the qualitative phase individuals who were not part of the quantitative sampling (Onwuegbuzie & Johnson, 2006).
Inadequate sample size for quantitative and phenomenological method (Benge et al., 2012; Creswell & Plano Clark, 2017; Giorgi, 2008a).	Proceed to the sample calculation for the quantitative approach (Creswell & Plano Clark, 2017). For the phenomenological interview, the number of participants was defined by theoretical saturation (the point at which the collection of additional data does not produce new elements to subsidize the desired theorization), verified by 3 researchers. The strategy sought to prevent a large number of participants from compromising the discovery of different meanings (Giorgi, 2008a).
Introduce bias from one method to another during data collection (Creswell & Plano Clark, 2017).	A phenomenological interview was conducted before the subjects answered the quantitative approach questionnaire. The purpose of the sequence was not to influence the participants' responses with inventory items, valuing their sincerity.
Biased phenomenological question (not assuming a reductionist attitude). Surface issues that do not give access to the lived world of the human being (Giorgi, 2008b).	<ul> <li>Use of the "trigger issues" technique proposed by Amatuzzi (1993).</li> <li>The aim of the technique is to encourage the subjects, through open questions, to expand their own experiences, allowing the researcher to understand the subject's experiences.</li> <li>The questions were specifically designed for this study so as not to induce descriptions of positive or negative experiences of suffering (neutral character). To elaborate the "triggering questions," the indirect approach method was used, which was, for this purpose, started by the constructions "how you perceive" and "what were your feelings." In the middle of the interview, the interrogative form "what is this experience for you" was used only to capture experiences of pre-reflective suffering or when subjects reported tacit meanings that needed to be better understood (Stelter, 2000).</li> </ul>
Questionnaire validity (Creswell & Plano Clark, 2017; Polit & Beck, 2018).	In order to ensure the <i>clarity and sensitivity</i> of the questionnaire to the pycho-emotional state of interviewees, the principal investigator performed a pretest with some participants in field (Polit & Beck, 2018).
Rigor in the collection of qualitative data (Lincoln & Guba, 1985).	To maintain reliability, the following strategies suggested by Lincoln and Guba (1985) were adopted: <i>Prolonged involvement</i> with participants during the chemotherapy administration period (a minimum of 3 hours), as well as observation and recording in field notes of how they reacted to their effects. For triangulation, information was obtained from family and friends who attended the treatment sessions.
Selection bias in quantitative sampling (Creswell & Plano Clark, 2017; Polit & Beck, 2018).	Selection of participants with consecutive sampling.
Observation bias ( <i>Reactivity</i> ) (Polit & Beck, 2018; Onwuegbuzie & Leech, 2007)	The quantitative questionnaire was self-administered, as it was understood that the presence of the investigator could overvalue or mask the suffering reported in the instrument. However, when doubts arose, these were clarified.
Data analysis	
Researcher bias (Onwuegbuzie & Johnson, 2006)	Inside-Outside legitimation (Onwuegbuzie & Johnson, 2006). An external researcher was invited to analyze the categories, the gross quantitative data, and to give an opinion regarding the quality of the meta-inferences. Questions were asked to challenge the evidence found.
Illogical comparisons of databases (Creswell & Plano Clark, 2017)	Present <i>psychological insights</i> that correspond to the statistical results in the convergence matrix (Creswell & Plano Clark, 2017).

#### TABLE 1 (Continued)

Legitimation threats	Strategies to circumvent the threat
Issues in data collection	
Researcher's ability to collect and analyze qualitative and quantitative data (Collins et al., 2012; Creswell & Plano Clark, 2017).	The study included researchers from different methodological traditions, with expertise in phenomenology and quantitative research methods (Creswell & Plano Clark, 2017).
Rigor in qualitative analysis (Lincoln & Guba, 1985).	<i>Negative cases</i> with potential to refute the categories found were reviewed and interpretations continuously refined. During the search for evidence of disconfirmation, cases of positive experiences of suffering were revealed. The findings led to the inclusion of a new category: <i>Redefining life with gratitude, faith,</i> <i>and hope.</i> A precise description of the context in which the study was developed allows other researchers to assess how well the qualitative findings of the study can be transferred to their reality (Lincoln & Guba, 1985).
Interconnection of the reliability criteria of different traditions in the scientific community (Collins et al., 2012).	The researchers combined criteria of validity, reliability, and legitimation of quantitative, qualitative, and mixed-methods research (Collins et al., 2012).
Data interpretation	
Epistemological and axiological conflicts in the interpretation phase of the merged results (Collins et al., 2012; Creswell & Plano Clark, 2017; Onwuegbuzie & Johnson, 2006).	Legitimation of pragmatic attitude (Collins et al., 2012). Qualitative and quantitative researchers negotiated their differences based on the general objective of the study and on the practical developments of the conclusions. For the production of meta-inferences, different philosophical values acted synergistically, transforming the weakness of the method into a strong point of the study.
Not interpreting the data in the light of the social sciences (Creswell & Plano Clark, 2017).	Qualitative data were coded, categorized, and interpreted by researchers with a phenomenological background without knowledge of the quantitative database and the content of their analyses.
Assigning more weight to one type of data than the other (Creswell & Plano Clark, 2017).	Maintain balance in the presentation of qualitative and quantitative findings.
Formulation of different inferences for the qualitative and quantitative data set (Collins et al., 2012; Creswell & Plano Clark, 2017; Onwuegbuzie & Johnson, 2006).	Proposition of meta-inferences based on database fusion (convergence matrix). The results obtained with descriptive and inferential statistics were linked to the most significant themes and findings of the phenomenological interview. The strategy resulted in inferences with higher quality than expected for an isolated approach. Based on the <i>cognitive</i> <i>process of Gestalt switching</i> , the conclusions reflect, above all, a mixed worldview (commensurability) (Collins et al., 2012).
Threats to external validity (Collins et al., 2012; Creswell & Plano Clark, 2017; Onwuegbuzie & Johnson, 2006).	To present, within the limitations of the study, populations of people for whom integrated results cannot be generalized (Creswell & Plano Clark, 2017).

# 3.1.4 | Theme 4: The distress of initiating chemotherapy

Chemotherapy produces different toxic effects in the body. Some of them, such as mucositis; neurotoxicity; and pulmonary, renal and cardiac toxicity, are relatively little known because information about them is not widely disseminated. Others, including nausea, vomiting, loss of appetite and alopecia, are well-known by the general population, and can be greatly feared by people who need to undergo this treatment. Fear, experienced as intense distress, aroused other feelings related to the dread of what could happen in the first session, such as loneliness, the expectation of new symptoms and denial: Today I am nervous because I do not know how this chemotherapy thing is. I could not even sleep well. I am afraid of feeling unwell and finding nobody around me (I22) (patient who had not begun the treatment yet)

# 3.1.5 | Theme 5: Chronos: The time that devours us

This theme revealed chronological time that was stolen from the patients by the countless obligations at health services, including long wait times in the chemotherapy outpatient clinic, duration of the sessions for application of cytotoxic drugs, time spent

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commuting from home to the health unit and frequent visits to the clinic to collect blood samples and attend multiprofessional appointments.

The distress of spending the whole day here. I came today and I will have to come back tomorrow. (I22)

This theme also showed lost existential time, interrupting life projects and expectations of a better future because of the uncertainty of the prognosis. Fear of dying suddenly resulted in considerable anguish for the participants.

# 3.1.6 | Theme 6: Redefining life with gratitude, faith, and hope

This theme presented the resources used by patients to mitigate distress, most of which were of a religious and spiritual nature. The reports allowed identification of the search for comfort through the practice of prayer, which proved to be one of the ways chosen by the patients to find peace and hope, reconcile with God and get close to sacredness. They also emphasized beliefs that cancer healing is subordinate to God's will, which made the interviewees surrender to it as a proof of their faith.

I know that chemotherapy is part of the treatment, so I considered it was in God's hands. I let God do his job. (I64)

I healed once and now, with faith in God, I will heal again. (I8)

# 3.1.7 | Theme 7: Listening to the unspeakable

Anguish also showed in the silence of the patients or their difficulty putting words together, reflecting conscious and repressed distress in some, and unconscious distress in others. Unconscious distress was captured in the reports of some participants, who, during the interview, put negative feelings in parentheses, as if they wanted to move away from the experience, or even communicated through gestures and looks.

I can't speak. (I6) (Requested the opportunity to write about their feelings).

# 3.2 | Quantitative results

One hundred people with a cancer diagnosis participated in the present study, including people with orders to begin therapy (n = 15) or being in chemotherapy (n = 85), with an average age of 56.6 years (SD 13.2 years). The prevailing neoplasia sites were of intestinal (24%) and haematologic origin (17%); 78% of the patients were at advanced cancer stages (III and IV) and 67% were going through palliative treatment.

Analysis of the distress experience, measured using the IESSD, yielded an average score equal to 106.2 (SD 31.9), a result much lower than the maximum possible score of 220 points, suggesting a low distress level in the examined sample. Among the IESSD items that reached the highest averages, the following stood out: *I think I will get better* (4.44); *I hope I can still make my dreams come true* (4.10); and *I think I will recover my strength* (3.89).

Table 2 shows that the highest global distress averages were obtained for men, people with a low level of education, and those belonging to the 40- to 59-year-old age group.

Regarding the clinical variables, higher global distress averages were obtained for patients diagnosed with head and neck cancer, those who were at an advanced stage and those who had not yet begun treatment. Among the patients whose chemotherapy was in progress, higher scores were registered for those whose treatment

 TABLE 2
 Global distress averages according to gender, age group, and level of education

			Global distress	
Variables		N	x	SD
Gender	Female	47	105.1	29.0
	Male	53	107.2	34.7
Age group	18 to 24 years	03	84.0	8.7
	25 to 39 years	08	103.5	28.2
	40 to 59 years	42	107.9	32.1
	≥60 years	47	106.5	33.6
Level of education	No formal education or incomplete elementary school	36	115.0	35.7
	Complete elementary school and incomplete high school	24	101.6	29.6
	Complete high school and incomplete higher education	22	101.3	26.0
	Complete higher education	17	100.6	33.7
	Did not answer	01	101.0	-

Note: Rio de Janeiro, RJ, Brazil (n = 100).

#### TABLE 3 Analysis of global distress averages according to clinical variables

			Global distress			
Variables		N	x	SD	Test value	p value
Cancer type	Colon	24	90.4	31.1	2.344 <sup>b</sup>	0.02
	Hematologic	17	104.6	28.8		
	Lung	16	114.9	24.0		
	Multiple myeloma	15	107.5	29.2		
	Head and neck	08	134.6	33.8		
	Stomach	06	109.8	41.7		
	Gallbladder and pancreatic	05	122.4	42.6		
	Prostate	04	111.3	30.6		
	Other topographies	05	85.4	19.5		
Stage	I	01	108.0	-	0.131 <sup>b</sup>	0.97
	II	01	101.0	-		
	III	21	102.5	28.2		
	IV	57	108.1	34.8		
	Not yet determined	20	104.9	30.5		
Chemotherapy treatment	Not initiated	15	124.8	39.1	2.505 <sup>c</sup>	0.01
	In progress	85	102.9	29.7		
Time undergoing chemotherapy <sup>a</sup>	Up to 3 months	22	107.0	28.8	1.619 <sup>b</sup>	0.14
	Between 3 and 8 months	23	95.3	29.8		
	8 8 months and 1 year	08	106.1	29.7		
	Between 1 and 2 years	08	119.8	20.9		
	Between 2 and 3 years	09	93.9	30.0		
	Between 3 and 4 years	07	98.9	36.2		
	Over 4 years	08	107.0	33.6		
Chemotherapy modality <sup>a</sup>	Curative	12	96.2	24.9	1.475 <sup>b</sup>	0.23
	Adjuvant	08	85.1	32.0		
	Neoadjuvant	05	105.2	26.4		
	Palliative	60	106.4	30.1		
Number of previous chemotherapy regimens <sup>a</sup>	No previous treatment	41	100.7	28.9	0.403 <sup>b</sup>	0.75
	1	14	104.2	35.6		
	2	21	108.4	29.6		
	3 or more	09	97.9	26.3		

Note: Rio de Janeiro, RJ, Brazil (n = 100).

<sup>a</sup>Considering only patients under chemotherapy (n = 85).

<sup>b</sup>F factor (analysis of variance).

<sup>c</sup>Student's t test.

time ranged from 1 to 2 years, the ones who were treated palliatively and those who received multiple chemotherapy regimens (Table 3).

The statistical tests showed a significant value for the variables *cancer type* (p = 0.02), with a statistically significant difference confirmed by Tukey's test for the distress averages of patients with head and neck, and colon and rectal cancer (p = 0.02), and *having the treatment in progress* (p = 0.01) (Table 3).

Although the applied analytical tests did not demonstrate an influence for most of the examined variables on distress averages, convergence was found between the patients' reports and the quantitative results. This allowed the authors to create metainferences about the studied phenomenon, according to the convergence matrix shown in Figure 2.

# 4 | DISCUSSION

The present mixed-method study allowed an analysis of the subjective distress experience in a sample of cancer patients by combining reports obtained during phenomenological interviews and quantitative measures that express global distress.

QUANTITATIVE results Subjective Experiences of Suffering in META-INFERENCES	<ul> <li>Higher distress averages (p&lt;0.05) were obtained for patients with carcer who patients who had not yet begun chemodherapy have not begun chemotherapy</li> </ul>	<ul> <li>Higher distress averages were obtained for patients</li> <li>The proximity of death under paliative and neoadjuvant treatment (IV)</li> <li>patients with cancer (p&gt;0.05)</li> </ul>	<ul> <li>Lower distress averages (p&lt;0.05) were obtained for patients whose chemotherapy was in progress</li> <li>Once chemotherapy was indiated, the treatment time and the number of chemotherapy lines did not influence the global distress score (p&gt;0.05)</li> <li>Among the invertory items, those that showed the lighest averages and frequency for the 5 score on the lighest averages and frequency for the 5 score on the mobilization of religious can still make my strength."</li> </ul>	<ul> <li>The difficulty of talking</li> <li>Analysis of the distress experience resulted in an about feelings hinders the average score equal to 106.2, suggesting a low level of understanding of distress, solval distress</li> </ul>
QUALITATIVE results Phenomenological interview	Distress expressed because of:	Distress expressed because of : < interruption of life projects < itear of dying	<ul> <li>The distress experience strengthened the developmentof optimistic meanings for life</li> <li>Chemothenapy is perceived as a strategy to achieve healing, relief from symptoms, and expectation of a better future and quality of life</li> </ul>	<ul> <li>Non-reported distress because of difficulty exposing emotions or phonoarticular limitations, but perceived through gestures, postures, and behaviors during the</li> </ul>
- Ibemes	Therapeutic finerary for cancer diagnosis Diagnosis impact The distress of initiating chemotherapy	The time that devours us In search of a meaning for the disease	In search of a meaning for the disease Redefining life with gratitude, faith, and hope	Listening to the

Themes

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Convergence matrix of qualitative and quantitative results

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distress

averages (p<0.05)

Listening to the unspeakable

The theme Walking the rocky road revealed anguish in the face of the possibility of a cancer diagnosis. The theme Diagnosis impact unveiled feelings of anger and frustration when the disease was confirmed, especially about the coldness with which the physicians informed patients of the diagnosis. Similar to the 'thud' and 'impact' revealed in this study, research on the experience of American men with prostate cancer also revealed words such as 'shock' and 'surprise' used in the speech of those interviewed when they reported on the fright that they felt at the time of diagnosis, because they were not aware that the signs and symptoms presented at the acute stage were something more serious, or simply used to relate the sudden manner in which the news was transmitted (Maliski et al., 2010). In the theme The distress of initiating chemotherapy, fear of facing the unknown, in this case treatment and its effects, was observed, in agreement with the result that showed a higher global distress average score among patients who had not yet undergone the first treatment cvcle.

These themes make the beginning of the trajectory of the experience of living with cancer and receiving chemotherapy explicit. During the first week, the patients may feel 'numb' or even in a state of shock, given that the race against time can take them away from reality before they can thoroughly process and take in the diagnosis. Once it is confirmed and there is no defined treatment plan vet. patients may experience high levels of psychological distress about the disease progress. This time is described as the 'limbo' period, during which perception about the treatment delay and awareness of the risks and prognosis increase the experienced distress (Cardoso et al., 2016).

It is suggested that the initial anguish caused by the diagnosis and fear about beginning treatment take significant time to disappear, and time is possibly the most important factor shaping these negative feelings about treatment, especially when there is satisfactory control of the toxic effects and the patients achieve some relief from the characteristic signs and symptoms of cancer's acute phase. This could explain the fact that longer treatments were not invariably associated with higher distress averages.

This inference is supported by Brazilian studies that have found a reduction in distress, anxiety and depression levels after the beginning of chemotherapy (Bergerot et al., 2015; Decat et al., 2011). In contrast, Sahin et al. (2013) showed that despair and depression can be greater in patients whose cancer diagnosis and treatment take more time to be carried out, indicating possible deleterious effects on the perception of distress of the toxicity of cumulative doses of medications and multiple recurrences of the disease. However, these suppositions were not confirmed in the present study, because treatment time and the number of previous chemotherapy regimens did not influence the measured distress averages. These results may reflect the differences in sample size according to the time of chemotherapy; in addition, higher levels of distress were found at the beginning of treatment.

The findings of the present investigation, together with the results reported by Cardoso et al. (2016), suggest that distress can be greater among patients whose diagnosis confirmation and start of antineoplastic therapy were delayed. The stress experienced in both these situations, discovered in the phenomenological interviews, imply the need to promote changes in the public policies that regulate user access to cancer diagnostic and treatment services, as well as the importance of implementing interventions in these services, focused on reducing physical, psychological and moral damage in care for the population with a suspected or confirmed cancer diagnosis.

The analysis of the effect of cancer staging and treatment modality on patient suffering indicated that the mean values were higher in patients undergoing neoadjuvant and palliative treatment; however, the values were similar. The presence of large tumour masses, initially with no possibility of surgical resection, worse performance status and higher incidence of complications from chemotherapy, may have caused more suffering in such cases. Neoadjuvant chemotherapy has several advantages; however, it may increase psychological distress due to the fear of disease progression until the initiation of a definitive treatment (Caudle et al., 2011). Therefore, both neoadiuvant and palliative treatments may cause insecurity about the results of therapy and increase the fear of death and physical disability, compared with patients undergoing curative and adjuvant treatments which aim to eradicate the disease with standard chemotherapy and eliminate micro-metastases after curative surgery, respectively (Yoshikawa et al., 2014). In the present study, the results were not statistically significant, which is consistent with the results of a previous meta-analysis involving patients with cancer. In the meta-analysis, there were no significant differences in the prevalence of distress among different chemotherapy modalities, measured using depression, anxiety and adaptation disorder scales. (Mitchell et al., 2011).

The theme Chronos showed different time perceptions, seen also from an ontological perspective, because chemotherapy limited not only chronological time for performing everyday activities but also existential time, which grants the freedom to create and experience a significant present without dealing with a future that may not happen. For many patients, Kairós, considered the god of creative, timely, fluid and imprecise time, was subdued by Chronos, who reigns in a 'limited time' for death, given that escaping this imminent destiny is perceived as impossible. His dominance is also expressed in the inflexible dates of scheduled chemotherapy days and cycles, in addition to rigid protocols that prompt patients to change their daily routine and life rhythms. As in mythology (Delahaye, 2016), time devours hope because of uncertainties about the prognosis and fear of death, interrupting life projects and expectations of a better future, with a duality existing in perceived time-sometimes a concern creator, sometimes an opportunity devourer.

Sequential, linear and rationalized time is equally relevant and imprisoning in the social sphere. According to Heidegger (1962), one of the essential characteristics of time is amplitude, showing that waiting for chemotherapy can be perceived as endless. From a Merleau-Pontyan perspective, time is not a real relationship, but originates from the relationship with things themselves, in which the I-sick

is complete in their time, which is then split by the disease. For Merleau-Ponty (2012), if a future view is lacking in these patients as a result of the expectation of death, the objective world becomes unable to provide time, existing exclusively to deal with cancer.

The theme *In search of a meaning for the disease* encompasses reports that agree with Merleau-Ponty's reflection (2012) on how perception of imminent death breaks down perspectives on posterity. Additionally, facing death brings about multiple existential reflections that end up strengthening anguish, which can explain the higher global distress averages among patients at advanced stages of cancer and under palliative treatment (p > 0.05). This convergence suggests that proximity of death is a factor that produces existential distress in that population, which is closely related to loss of identity and self-esteem and, consequently, to a desire to shorten their life, as reported by a hermeneutic study carried out with patients receiving palliative care (Mak & Elwyn, 2005).

In the theme Redefining life with gratitude, faith, and hope, it is possible to envisage the possibility of optimistic redirection of the experience of living with cancer and of chemotherapy through mobilization of different psychosocial and spiritual resources. Analysis of the reports indicated that this experience is intensely pervaded by mobilization of coping strategies, especially those of a religious or spiritual nature, oriented towards regulating the emotional response to the problem (Folkman et al., 1986; Lazarus & Folkman, 1984). For some, faith promoted a state of resilience or acceptance; for others, it represented a set of attempts to strengthen the relationship with sacredness and intercession of divine powers, aimed at healing or health recovery. Given this scenario, the qualitative approach allowed for understanding why duration of chemotherapy, possibly associated with toxic effects and disillusionment, did not influence the distress averages in the present study. This result was supported by the high averages attributed to the IESSD items that denote hope, suggesting that it is strongly valued by cancer patients undergoing chemotherapy.

The theme *Listening to the unspeakable* showed the meaning of the distress experience when it cannot be verbalized, revealing the negative impacts of disease and therapeutic interventions on quality of life and well-being in patients with head and neck cancer (Balfe et al., 2016; Charalambous, 2014). In the present study, the distress averages were higher in patients with this cancer topography. This result is similar to those reported in other investigations indicating greater distress in patients with this diagnosis, which is distinguished from other sites by being associated with unfavourable socioeconomic conditions, fragile social support networks, deformities in the face, the odour given off by the tumoural injury, and the need to constantly repeat what they say to be comprehended (Chiu et al., 2016; Enns et al., 2013).

The same theme addressed repressed distress, which may have influenced the global distress score in the present study. According to the literature, in some cultures, control of behaviours and feelings is highly valued (Davitz et al., 1976), and reporting suffering is a sign of weakness (Han et al., 2015). In contrast, other cultures consider that distress can be integrated into life (Oliveira, 2016) or even represent a step towards spiritual evolution. Considering these characteristics, it is possible to understand the influence of cultural aspects on communicating distress, especially in a country with close-knit populations like Brazil.

# 4.1 | Study limitations

Caution is recommended in generalizing the results of the present study, given that the sample was mainly patients at advanced stages of cancer and under palliative treatment, and represents the reality of a single public institution that provides care mostly to low-income patients. Consequently, the meta-inferences drawn can only be applied to similar sociocultural contexts. Furthermore, this study has another limitation, which is inherent to cross-sectional studies. Specifically, the outcome and independent variables were assessed at the same time. Therefore, it was not possible to examine causal relationships among the study variables. Nevertheless, the internal validity of the study was ensured by following procedures that prevent selection and information bias.

# 5 | CONCLUSION

The convergence of qualitative and quantitative results produced meta-inferences capable of providing a deep understanding of the factors that precipitate and aggravate suffering. The superiority of integrated results over an isolated approach not only legitimized the conclusions drawn from the combination of data but also revealed important practical implications. First, it was shown that the phenomenological method can complement the use of scales in the assessment of suffering. Although it is a common phenomenon of human existence, suffering is experienced in a singular way and is dependent on a set of physical, psychological, emotional, and social factors. Different time perceptions elucidated the reason why the number of chemotherapy regimens received in longer treatments was not associated with higher averages of distress. While Chronos represented the experience of a linear temporality that threatens Dasein or being-inthe-world, Kairós symbolized consciousness that awakens after the crisis, able to ponder, accept and allow to live. When and what awakens this consciousness are not only dimensions of suffering that cannot be objectively measured, but also personal discoveries that happen in different parts of the trajectory. We believe that this is a reflection which nurses can encourage.

In addition, phenomenology teaches that for an understanding of the lived experience of another human being, it is necessary to reduce personal judgements (also known as Epoché). This information requires nurse skills in order to recognize signs of suffering through non-verbal behaviours and implies the use of instruments with good receptivity among patients, capable of converting subjective data into objective data in a reliable manner. Nevertheless, the contingent use of such instruments limits the possibilities of effective care. Despite the importance of screening distress and identifying intensity changes in critical periods, understanding the phenomenon from a purely numerical perspective compromises a safe assessment. We stress the risk of interpretations that extrapolate the instrument, because the perspective of what distress is may significantly differ between nurses and patients, and the fact that certain tools may not be suitable to the patient's culture or instruction level. Therefore, guestions that are guided by the phenomenological method expand the knowledge of what the subject believes to constitute suffering, how health actions are perceived, what meaning is attributed to the experience and how the bodily, social, and existential changes induced by treatment are interpreted. We argue, thus, as potentialities of the method, the ability to elucidate the unexpected, the controversial and the novelty of the interpretations. For nurses, these are goals that challenge, but reward practitioners of mixed methods.

Second, considering the results concerning the factors that lead to or increase distress in the cancer and chemotherapy context, the following actions aiming to reduce wait time in outpatient facilities with a high flow of patients are recommended: establishing and meeting care goals (stipulating a minimum and a maximum wait time to infuse the medication); maintaining regular contact with patients by phone to inform them of delays and possible rescheduling; and listening to and recording user complaints in a humanized way.

From the perspective of easing distress triggered by the diagnosis impact, we suggest implementation of permanent education actions addressing the communication of bad news by healthcare professionals. Finally, future research is needed to clarify the meanings of this construct, to compare the accuracy of different measurement instruments, and test the generalizability of meta-inferences in different sociocultural contexts.

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#### CONFLICT OF INTEREST

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

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#### **AUTHORSHIP STATEMENT**

ABM is responsible for the conceptualization, methodology, investigation, data curation, interpretation of data, and writing of the original draft. ERP is responsible for the supervision, visualization, and methodology. CM is responsible for the formal analysis, writing review and editing. RMRCAS is responsible for data curation. MGGS and MALCC are responsible for the interpretation of data.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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