

Hope, Fear, and Health-Related Quality of Life Perceived by Women with Breast Cancer

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Esperança, Medo e Qualidade de vida Relacionada à Saúde na Percepção de Mulheres com Câncer de Mama

Esperanza, Miedo y Calidad de Vida Relacionada a la Percepción de Mujeres con Cáncer de Mama

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ABSTRACT

Introduction: The period of diagnosis and treatment of breast cancer is tough, full of uncertainties, and associated with a high morbidity and mortality rate. **Objective:** To understand the meaning that women with breast cancer under treatment in a university hospital attribute to their experience of fear masked by the feeling of hope and investigate the participants' perception of quality of life while coping with the disease. **Method:** Quantitative, qualitative study conducted with 78 women. For the quantitative evaluation, the scores of the Medical Outcomes Study 36 – Item Short – Form Health Survey (SF-36) and the Herth Hope Scale were evaluated. For the qualitative analysis, narratives were conducted with 10 of these women who were analyzed using phenomenological investigation methods. **Results:** Low scores were detected in the functional capacity and mental health domains of SF-36, which imply in a negative impact on the quality of life and a high index of hope scores, which is a positive factor. Three central classes emerged from 243 segments of the participants' narratives, through meaningful statements and their corresponding meaning units. **Conclusion:** The experience of the diagnosis and treatment period includes coping, cognizance of the disease, clinical consultation (doctors, teams), from exaltation to despair, and the paradox between fear and hope. It was discussed the essence of the experience the participants lived and shared in light of the theory of the disease as a rupture of the biographic narrative. The study highlights implications for the teams of physicians, SUS – National Health System coordinators, and other healthcare professionals.

Key words: Breast Neoplasms/psychology; Quality of Life; Hope; Emotions; Fear.

RESUMO

Introdução: O período de diagnóstico e tratamento do câncer de mama é difícil, permeado de incertezas e associado a uma alta taxa de morbimortalidade. **Objetivo:** Conhecer o significado que as mulheres com câncer de mama em tratamento em um hospital universitário atribuíram à sua experiência de medo mascarado pelo sentimento de esperança, bem como investigar a percepção da qualidade de vida no enfrentamento da doença. **Método:** Estudo quanti-qualitativo com 78 mulheres. Para a avaliação quantitativa, avaliaram-se os escores do *Medical Outcomes Study 36 – Item Short – Form Health Survey* (SF-36) e da Escala de Esperança de Herth. Para a análise qualitativa, conduziram-se narrativas com dez dessas mulheres que foram analisadas por meio de métodos fenomenológicos de investigação. **Resultados:** Foram detectados escores reduzidos nos domínios capacidade funcional e saúde mental do SF-36 que implicam em impacto negativo na qualidade de vida e alto índice nos escores de esperança, o que é um fator positivo. Três classes centrais emergiram de 243 segmentos das narrativas por meio de declarações significativas e unidades de significado correspondentes. **Conclusão:** A experiência do período de diagnóstico e tratamento inclui enfrentamento, conhecimento da doença, assistência clínica (médicos, equipes), exaltação ao desespero e o paradoxo entre o medo e a esperança. Foi discutida a essência da experiência vivenciada e compartilhada pelas participantes à luz da teoria da doença, como uma ruptura da narrativa biográfica. O estudo destaca implicações para a equipe de médicos, coordenadores do Sistema Único de Saúde e outros profissionais da saúde.

Palavras-chave: Neoplasias da Mama/psicologia; Qualidade de Vida; Esperança; Emoções; Medo.

RESUMEN

Introducción: El período de diagnóstico y tratamiento del cáncer de mama es difícil, puesto que presenta muchas incertidumbres y está asociado con una alta tasa de morbilidad. **Objetivo:** Conocer el significado que las mujeres con cáncer de mama en tratamiento en un hospital universitario le atribuyeron a su experiencia de temor enmascarado por el sentimiento de esperanza, así como investigar la percepción de la calidad de vida al enfrentar la enfermedad. **Método:** Estudio cuantitativo y cualitativo con 78 mujeres. Para la evaluación cuantitativa, evaluamos las puntuaciones del *Medical Outcomes Study 36 – Item Short – Form Health Survey* (SF-36) y la Escala de Esperanza de Herth. Para el análisis cualitativo, se realizaron narrativas con 10 de estas mujeres que fueron analizadas utilizando métodos de investigación fenomenológica. **Resultados:** Se detectó que la capacidad funcional y de salud mental del SF-36 se redujeron, y al mismo tiempo se presentó un alto índice de Esperanza lo que implica un impacto negativo en la calidad de vida y un alto índice de puntajes de esperanza, lo cual es un factor positivo. Surgieron tres clases centrales de entre los 243 segmentos de las entrevistas a través de declaraciones significativas y sus respectivas unidades de significado. **Conclusión:** El experimento, durante el periodo de diagnóstico y tratamiento, incluye el enfrentamiento, el conocimiento de la enfermedad, la asistencia clínica (médicos, equipos), la exaltación a la desesperación y una paradoja entre el miedo y la esperanza. Se discutió la esencia de la experiencia vivida y compartida por las participantes a la luz de la teoría de la enfermedad, como una ruptura de la narrativa biográfica. El estudio destaca las implicaciones para el equipo de médicos, coordinadores del Sistema Único de Salud de Brasil y otros profesionales de la salud.

Palabras clave: Neoplasias de la Mama/psicología; Calidad de Vida; Esperanza; Emociones; Miedo.

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INTRODUCTION

According to the World Health Organization (WHO) cancer is the leading health problem and the second cause of death worldwide¹. Breast cancer is the most frequently diagnosed among women and the main cause of mortality in the developed and in development countries².

Several studies have investigated aspects of the lives of women with breast cancer utilizing standard questionnaires focused to social support, body image, quality of life (QoL) and psychological responses³⁻⁵. However, the association of a qualitative study to compare the findings reached through questionnaires with an investigation about the perception of the QoL and hope and how fear of progression of the disease is part of the life of patients with breast cancer is still missing.

The experience of sickening creates antagonistic feelings in the human being as fear of disease progression and hope of cure⁶. These dichotomic feelings bring uncertainties to the individual about its life perspectives⁶. From the first physiopathological manifestations in the organism up to diagnosis, treatment and follow-up, women with cancer experience antagonistic feelings of fear and hope and this reflects in their daily life and how they resignify their perspectives of life⁷.

Regardless of the tendency of improvement of the management and treatment of the patients, breast cancer continues to affect the general QoL and health-related quality of life (HRQoL) in the diagnosis, during treatment and after recovery⁸. QoL is a multilayered and broad concept incorporating the physical, psychosocial, and spiritual domains of the life of an individual⁸. The HRQoL reflects to what extent the well-being of the individual in these areas is impacted by a disease or its related treatment⁸.

The fear of disease progression defined as the subjective probability of negative results is associated with unfavorable biopsychosocial factors related to the individual and its perceptions, mainly in regard to adjusting to the limitations imposed by the disease and poor prognosis⁹. In counterpart, the hope of cure defined as the subjective likelihood of good outcomes boosts positive meanings for the daily life of the individuals, overcoming the negativity of the life-threatening diseases and ensuring well-being and adaptation to the stress factors the sickening has caused⁹.

As health is the ability to adapt and self-manage the daily changes that ensure the biopsychosocial balance, hope pushes the individual to move forward¹⁰. It functions as support for many future possibilities because it nourishes the ability to dream and move on amidst the difficulties, strengthening the resilience in face of the sickening process and treatment¹¹⁻¹³.

Like HRQoL, hope and fear are very important phenomena for the human being, it is advised that healthcare professionals include the analysis of HRQoL in their care process and identify the dichotomy between fear of disease progression and hope. Thus, they will be able to offer to the patients better support and quality of the services and demystify these concepts through education and promotion of health, developing the understanding of the personal relevance of these three phenomena in the post-diagnosis daily life and treatment of the patients with breast cancer¹³.

The use of the phenomenological approach facilitates the man's search for meaning in its life without confounding or merging with other phenomena¹⁴. Therefore, the aim of the current study was to know the meaning women with breast cancer in treatment in a university hospital attribute to their experience of fear disguised by the feeling of hope and investigate the perception of QoL while coping with the disease.

METHOD

Cross-sectional and quanti-qualitative study with women with breast cancer carried out in the Oncology of "Hospital de Clínicas da Universidade Federal de Uberlândia" (HC/UFU), Uberlândia (MG), Brazil. Upon approval by the Institutional Review Board (CAAE: 80679417.5.0000.5152/Report 2.527.653) data were collected to evaluate the impact of the disease in the perception of the QoL and in the level of hope and cure. The qualitative evaluation was utilized to identify the meaning of the disease for this group of women. Patients older than 18 years of age were enrolled with cognitive capacity to understand and respond to the data collection instruments and who agreed to join the study by signing the Informed Consent Form. Those who signed and decided to quit were excluded.

For the quantitative approach, the data were keyed in, *a priori*, in the software G*Power 3.1.9.2 to calculate the minimum sample size considering the test of hypothesis of the multiple linear regression and assuming an effect size of 0.10, alpha of 0.05 and power of the test of 0.80 in a population of 256 women. In these conditions, the minimum necessary sample was 64 participants. A margin of 20 percent points for possible misses and withdrawal was added, which resulted in a final sample of 78 participants.

The qualitative approach considered the criteria of saturation of data proposed by Strauss and Corbin¹⁵ where the number of participants is completed as soon as the objectives of the investigation are met, so no new themes emerges. This objective was met as soon as the narratives of ten of the women enrolled in the study were collected.

The participants responded to a sociodemographic collecting instrument (age, marital status, color, education, family income and household), and clinical and therapeutic data (time of diagnosis, tumor subtype, clinical staging, menopausal status, and type of chemotherapy). In addition, they reported risk factors for the disease (age, reproductive history and endocrine, behavioral, environmental, genetic, and hereditary factors).

The Brazilian version of the Herth Hope Scale^{16,17} was utilized to evaluate hope. It consists of 12 affirmative items with four Likert-type options of response (disagree, strongly disagree, agree, and strongly agree). The score ranges from 12 to 48 points, as high the score, higher is the level of hope.

In order to evaluate the HRQoL, the Medical Outcomes Study 36 – Item Short – Form Health Survey (SF-36), version RAND validated to Brazil was utilized¹⁸. SF-36 presents a final score ranging from 0 to 100 corresponding to poor and best HRQoL, respectively¹⁸.

Two investigators collected the narratives of the participants to evaluate the patients' feelings towards the disease. They were students of the Medical School of UFU-MG which offers an innovative curricula: since the beginning, the students participate of the care to the patients, including Oncology.

Based in the postulates of Husserl¹⁹, it was selected the contemporaneous phenomenological approach to find the meaning of the diagnosis and breast cancer treatment. According to Husserl¹⁹, the essence of what is seen is captured, of what the object is in itself, that is, "directed toward an object by virtue of itself".

According to Creswell²⁰, transcendental phenomenology has four basic assumptions. In the first, knowledge begins with the description of the experience trying to absorb it. In the second, phenomenology attempts to exclude judgments about what is real until more certainty is acquired, a process called *epoche*²⁰. In the third, the intentionality of the consciousness postulates that the reality of an object is closely related to its consciousness and the meaning found within it²⁰. Finally, in the fourth assumption, phenomenology requires the refusal of the dichotomy subject-object and reality is just what the individual²⁰ experiences.

According to Moustakas²¹, the phenomenological study delves into the experience lived and reported by the players in order to understand exactly the unwavering essence of an experience. In the case of this study, receive the diagnosis of cancer and go through the treatment are experiences in themselves when interventions occur, and results are unknown. But as what the patients consider is the experience lived and not merely variables and scores of

an evaluation instrument²², phenomenology was elected as the theory of this qualitative investigation.

QUANTITATIVE DATA

The Shapiro Wilk test was utilized for normality of the distributions. Descriptive statistics was adopted for sociodemographic, clinical, therapeutic characterization in addition to risk factors for breast cancer of the study participants.

The methodological quality of the QoL was verified with the COSMIN²³ Checklist and through the analysis of floor and ceiling effects of data related to hope for each item of the instruments utilized. The reliability of the instruments was tested through Cronbach alpha, being ideal above 0.7²⁴. The scores of the SF-36 domains were compared among one another by the chi-square test.

The mean scores of hope and HRQoL were compared according to the time of diagnosis in less than one year, from one to three years and higher than five years through ANOVA-One Way with Tukey *post-hoc* to detect differences. The level of significance was 5%.

The data were analyzed with the SPSS Statistics (IBM Corp., issued in 2014 for Windows, version 24.0, NY, EUA).

QUALITATIVE DATA

In order to ensure that the participants felt at ease to share their experiences and were not coerced, the interviews initiated requesting them to "help us to understand their unique experiences and become co-investigators with us"²⁵. The triggering phrase: "Would you tell me the history of your illness?" was utilized as protocol to steer the interviews.

The narratives were recorded and fully transcribed by the authors. To ensure the anonymity, the names of the participants were changed to flowers further to any information capable of identifying them.

The data were analyzed through the dialectic hermeneutic described by Minayo²⁶. Thus, the methodological trajectory of this study consisted in the recording and transcription of each narrative, registry of the first impressions in a field diary and summary of important and recurring terms and topics to facilitate the comprehension of the logics and meanings from the narratives. This practice called hermeneutic contributed for the interpretive process because it was dynamic and seamless. The interpretive process occurred along the field work and kept a dialogue with the contents that emerged and with the feelings built up in each narrative. Therefore, the logic of the group of participants was being gradually apprehended within a dynamic of part whole.

Later, the narratives were analyzed critically and reflexively, consistent with the philosophy dialectic hermeneutic which considers that the discourse of this group of participants is related to the narratives and experiences of each individual in relation to: (i) the other; (ii) the immediate context of the institution where these narratives were produced and broadly, (iii) the historical context where everyone was involved²⁶.

With the objective of analyzing the data in its totality, the systematic listening of the participants' narratives was conducted in parallel to the transcription of the interviews. In addition, the reading of the sociodemographic and quantitative results was resumed. In the first readings of the narratives transcription, a predominantly hermeneutic process to make observations about the recurring affirmations or which were directly connected to the study object was initiated. Based in these observations, the textual contexts were submitted to a lexicographic analysis with the software *Interface de R pour Analyses Multidimensionnel de Textes et de Questionnaires* (IRAMUTEQ), which grouped the narratives in similar semantic units and separated the classes of significant affirmations using the Descending Hierarchical Classification (DHC)²⁷. From the textual and structural description of the phenomena, a general and specific correspondence factor analysis (CFA) was conducted with the same software in order to identify the content of the narratives based in the higher frequency of the words evoked within the emerging classes²⁷. Next, the semantic units generated presenting expressivity and relevance to understand the experience of the patients were analyzed. The classes formed with the units of meaning taken from the participants' narratives were named similarly to a thematic analysis in a content analysis²⁶. With the themes identified and characterized, the interpretive process was initiated for the categorization and further analysis also called dialectic²⁶.

RESULTS

QUANTITATIVE DATA

78 women formed the population of the study with mean age of 55.8 ± 11.7 years. Of these, 42.3% were married ($p < 0.005$), 23.1% single and the remaining, divorced or widow. For the classification of color, most claimed they were White (56.4%) ($p < 0.005$), followed by Brown (32.1%), Black (9%) and Yellow (2.6%). Catholicism was claimed as main religion (48.7%) with significant difference ($p < 0.005$), followed by evangelical (28.2%) and spiritism (10.3%). Most of the patients had low monthly income, living with between one ($p < 0.005$) and three minimum wages (91%), low education level ($p < 0.005$), with predominance of incomplete elementary

school (42.3%). In addition, more than half of the participants (51.3%) claimed their family consisted of at least three individuals ($p < 0.005$) (Table 1). These results are reported according to the STROBE – Strengthening the Reporting of Observational Studies in Epidemiology guidelines.

In Table 2, nearly 72.4% of the participants of this study were older than 50 years of age and 50% of the sample used oral contraceptives during their lifetime. More than 59% were chronic alcohol users, nearly 28.2% were active and secondhand smokers and around 35% had family history of breast cancer.

For the clinical, hormone and therapeutic characteristics of the study's participants, the mean time of diagnosis was 2.7 ± 2.4 years and these women were in postmenopause (74.4%; $n=58$), with predominance of invasive ductal carcinoma (85.9%; $n=67$), presented clinical stage oscillating in equivalent proportion between stages II and III and were mostly in adjuvant chemotherapy regimen (89.5%; $n=69$).

In Table 3, it is shown that the level of hope of the participants was close to the total score of the instrument (48 points), and that the mean of the scores of most of the domains of QoL was median (above 60 points), except the domains functional capacity (28.2 ± 39.6) and mental health (30.8 ± 43.3).

Table 4 shows there was no difference in the perception of the participants' HRQoL ($p > 0.005$) or change of health perceived along the time of diagnosis ($p > 0.005$) but hope of cure diminished for the women with diagnosis above 5 years ($p < 0.005$).

QUALITATIVE DATA

Ten women with breast cancer told their experiences, their mean age was 58 ± 8 years and time of diagnosis of 3 ± 2 years in average. All of them had invasive ductal carcinoma, clinical staging I (10%, $n=1$), oscillating in equivalent proportion among stages II (30%, $n=3$), III (30%, $n=3$) and IV (30%, $n=3$) and were in adjuvant (70%; $n=7$) and neoadjuvant (30%, $n=3$) chemotherapy.

The general *corpus* consisted of ten narratives separated in 243 segments of text (ST), 209 of which (86.01%) were selected. 7,756 occurrences emerged (words, forms, or terms) of which 3,918 were different and 773 occurred only once. The content analyzed was categorized and generated classes 1 with 71 ST (33.97%); 2 with 59 ST (28.23%) and 3 with 79 ST (37.80%).

In Figure 1 there are three classes divided in two branches A and B of the total *corpus* in analysis. The subcorpus A, Coping, consists of Class 1 – Hope, the emotional feeling of the participant while coping with the disease, including the pursue of strength in

Table 1. Sociodemographic characteristics of women with breast cancer enrolled in the study (n=78)

Variable	Measurement	X2 (N; DF); P value
Age (years), mean \pm SD	55.8 \pm 11.7	
Marital Status, n (%)		
Married	33 (42.3)	13.4 (76;3); <0.0004
Single	18 (23.1)	
Divorced	12 (15.4)	
Widow	15 (19.2)	
Color, n (%)		
White	44 (56.4)	56.1 (76;3); <0.000
Black	7 (9.0)	
Brown	25 (32.1)	
Yellow	2 (2.6)	
Religion, n (%)		
Catholic	38 (48.7)	78.7 (76;5); <0.000
Spiritist	8 (10.3)	
Evangelic	22 (28.2)	
Umbanda	3 (3.8)	
Other	1 (1.3)	
No religion	6 (7.7)	
Income (MW), n (%)		
<1	3 (5.1)	58.3 (76; 4); <0.000
1 to 3	71 (91)	
>3	2 (3.8)	
Education, n (%)		
Incomplete elementary school	33 (42.3)	67.2 (76; 6); <0.000
Complete elementary school	17 (21.8)	
Incomplete High School	6 (7.7)	
Complete High School	13 (16.7)	
Incomplete university	3 (3.8)	
Complete university	5 (6.4)	
Post-graduation	1 (1.3)	
Number of individuals in the household, n (%)		
1	8 (10.3)	58.3 (76;4); <0.000
2	19 (24.4)	
3	40 (51.3)	
4	10 (12.8)	
>4	1 (1.3)	

Captions: MW = monthly minimum wage estimated for the Brazilian population; SD = standard deviation; X2 = chi-square; N = population; DF = degrees of freedom.

the spirituality and in the persons close to her. The subcorpus B, Biological Aspects is represented by Class 2, called The disease. The discourse of the Class 3 – Clinical Care – is the network offered to provide care (Figure 1).

The words associated with Class 1 in Figure 1 can be identified. The extracts below justify the dimension of this class:

So, I'm super cool with this. Each day I'm happier. I feel nothing. I'm very happy, always up. I prayed

Table 2. Risk factors for breast cancer claimed by the study's participants (n=78)

Risk factors	Measurement
Age > 50 years, n (%)	55 (72.4)
Endocrine and reproductive history, n (%)	
Nulliparity	9 (11.5)
Use of oral contraceptives	39 (50)
Hormone replacement therapy	17 (21.8)
Behavioral and environmental, n (%)	
Alcohol use	47 (60.3)
Smoking	22 (28.2)
Living with smoker	22 (28.2)
Genetics and hereditary, n (%)	
Breast cancer in the family	27 (34.6)

Table 3. Mean of scores and reliability (Cronbach's alpha) of the domains SF-36-RAND and Herth Hope Scale of the study's participants (n=78)

Variable	Mean ± SD	Cronbach's alpha
FA	68.2 ± 21.5	0.9
FC	28.2 ± 39.6	0.8
HGS	59.9 ± 15.5	0.6
Pain	60.6 ± 25.2	0.6
VT	63.3 ± 17.5	0.7
EA	64.2 ± 18	0.7
SA	65.9 ± 23.8	0.6
MH	30.8 ± 43.3	0.8
HHI	40.2 ± 5.2	0.9

Captions: SD = standard deviation; FA = physical aspects; FC = functional capacity; HGS = health general status; VT = vitality; EA = emotional aspects; SA = social aspects; MH = mental health; HHI = Herth Hope Index).

Table 4. Comparison among the means of the scores of health-related quality of life, hope, and change of perception of health of women with breast cancer according to the time of diagnosis in years

Variables	< 1 year (n=15)	1 to 3 years (n=36)	> 5 years (n= 27)	F (DF); P value
FA	78.0±18.0	65.0±20.1	67.1±23.3	2.06(2); 0.134
FC	28.3±40.0	25.0±39.2	32.4±40.9	0.26 (2); 0.768
MH	22.2±41.2	30.5±43.2	30.8±43.3	0.47 (2); 0.627
VT	56.7±12.5	65.7±18.4	63.7±18.2	1.45 (2); 0.242
EA	60.0±17.2	66.4±19.8	62.8±16.0	0.74 (2); 0.481
SA	56.9±22.3	71.3±21.6	63.6±26.1	2.21 (2); 0.116
Pain	55.9±23.7	60.9±26.1	60.6±25.2	0.35 (2); 0.704
HGS	56.3±14.0	59.2±16.6	42.0±15.0	0.89 (2); 0.412
HHI	42.0±5.6 ^A	41.6±4.6 ^A	37.0±4.4 ^B	8.49 (2); 0.000
CH	43.3±17.6	55.6±24.4	53.2±22.2	1.76 (2); 0.180

Captions: FA = physical aspects; FC = functional capacity; MH = mental health; VT = vitality; EA= emotional aspects; SA = social aspects; HGS = health general status; HHI = Herth Hope Index; CH = change in health; F = test F; DF = degree of freedom; a and b = means with different rates in the rows have p<0.05.

to God. God always game me strength. And now I asked for much more strength. And I'm doing well. I moved on and I have hope (*Flor de Lis*).

We have to talk with God, you know? Thank God. Without Him, we have no strength, and we plunge into sadness, fear. So, we hope everything is going to be all right. And God at the top of everything (*Jasmin*).

Class 2 identified as dimension of the disease emphasizes the evocation of the words that can be found both in Figure 1 and in the extracts below:

You see, someone who does mammography, doesn't drink, doesn't smoke, doesn't do anything wrong and out of the blues has cancer? I was outraged. But later it changed, you see? My cancer didn't spread from the breast, didn't go to the lung, it was localized (*Margarida*).

My mother had in the past. She passed away due to breast cancer, I always had mammography and when I got the news, I was not shocked. I will get myself treated. I already did mammography because of my mother. I went with her only in the beginning of the treatment, then she stopped and went on her own. Resumed treatment later, almost in the end of her life. For more than ten years she had cancer and she lasted a long time (*Tulipa*).

In Figure 1 it is possible to identify the words associated with the dimension of healthcare listed in Class 3. The fragments below extracted from a few narratives are examples of this category

I went back to the doctor, talked with him. He thought it was absurd. But we discussed it later.

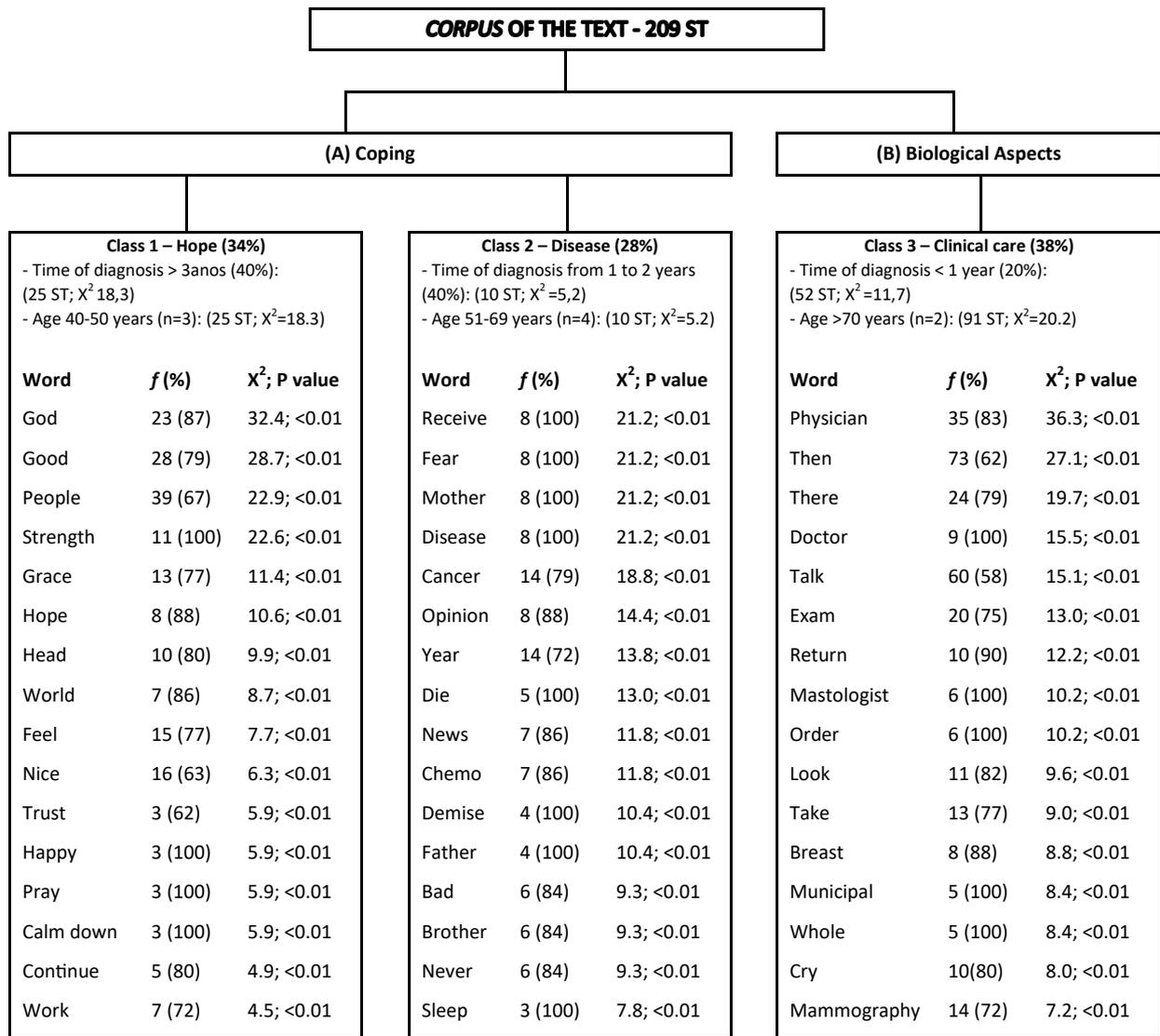


Figure 1. Descending hierarchical classification of the words mentioned by the patients in each class according to age-range and time of diagnosis

Then he asked another mammography. It showed a much larger lump. Was when I started treatment in my hometown. Looked for an oncologist, did all the exams, they took a small piece for biopsy, then it appeared. And, I was transferred here (*Violeta*).

I noticed a small lump. I always do breast self-exam. And I noticed a very tiny lump. I said: there is a tiny lump here. Went right away to the health facility near my house and said: have a tiny lump here and want to see a doctor now! For them to squeeze me in right now (*Orquídea*).

DISCUSSION

The results of the study investigating women with breast cancer confirmed the hypothesis that the disease and its treatment change the perception of their HRQoL and

keep the hope of overall improvement. However, based in the narratives, after five years of disease, the fear of relapse is real. With the onset of the first symptoms, diagnosis, treatment and follow-up, women fighting against breast cancer have their lives modified and face several personal, social, and family obstacles.

With the sociodemographic questionnaire it was possible to identify relevant issues of the patients like age, marital status, color, religion, education, and number of individuals in the household. The mean age of the participants concurs with the findings of the National Cancer Institute José Alencar Gomes da Silva (INCA), which reports a progressive growth of breast cancer after 35 years of age and higher incidence after 50 years²⁸. These data are consistent with the standards analyzed in a recent Brazilian study that concluded that the sociodemographic characteristics, similar to the present

study, are actual markers of social vulnerability²⁹. This same study affirms that low education level, low income and family are negative determinants on their own because they impact the access to services, late diagnosis, and poor conditions of recovery (social and family support) during the treatment of the disease²⁹, which demonstrates the necessity of strategies to overcome or at least minimize these effects³⁰.

It was also demonstrated in this study that some patients' risk factors remain. According to Balekouzou et al.³¹, the utilization of oral contraceptives and alcoholic beverages use are associated with the development of breast cancer and classified as modifiable risk factors and need to be addressed during prevention and treatment of breast pathologies. On the other hand, there is the family history, a non-modifiable risk factor because of the genetic association and high probability of expression of oncogenes BRCA1 and BRCA. In addition to triggering the onset of breast cancer, these genes are associated with the most aggressive subtypes³².

Through the Herth Hope Scale, it was seen that most of the patients (nearly 90%) had positive perspectives with the treatment and prognosis of their health condition, but the narratives revealed a dichotomy between fear and hope. Several positive perspectives held direct association with religiosity and beliefs which allowed each patient to attach to an unfathomable faith as some extracts reveal: "and also faith in God trying always to look for God to get strength" and "with faith in God, I look for, always tried to get strength from God, which has been supporting me so far".

Regardless of the limitations imposed by the disease and expressive modifications in the daily life, great part of the patients kept their basic activities as cleaning the house, taking care of the family, and interact with friends. The patients concurred that family support, conviviality and faith are essential tools to nourish the hope of cure and overcoming the disease. However, there was report of change in the marital relationship with complaints that the intimate contact was shaken and that the breast removal stirred the self-esteem of most of the patients, which matches the reports of Bucher-Maluschke et al.³³ and of Fanakidou et al.³, when concluding that breast reconstruction is not a panacea for patients with breast cancer in improving their HRQoL.

The fear of the disease progression was present in different proportions during the process of sickening of each patient. This feeling was expressive and overwhelming at the diagnosis, worsening of the symptoms and side effects of chemotherapy as nausea, weakness, and alopecia. The image of the fragilized body caused fear and blemish the hopes of overcoming as the following extracts reveal: "it was very scaring to me because all of a sudden I worked,

had a normal life and out of the blues it fell on me this diagnosis who freaked me out, I lost my ground" and "I thought I was going to die at any moment, and this was stuck in my mind... And sometimes I couldn't sleep, found myself wondering, is pretty much anguishing".

However, the assistance of the support network played a key role. Some were depressed, while others had anxiety crisis and bargained the treatment, but most coped with these moments positively: "It is tough, but holding to God, God brings the peace we need. We have to love ourselves, first of all, respect ourselves, and believe we are not second-rate than anyone else who is going through this situation".

All these factors together portray an expressive scenario when the scores of the domains of QoL of these patients are analyzed. Great part of the women kept or tried to keep their daily lives unchanged, continue to work and keep active their inter-personal relations. The impact of sickening over the QoL is quite impressive because the perspective of "today" in relation to "yesterday" and to "tomorrow" changes, promoting the practice of plans and the daily activities postponed in view of the good and the new, innovating, reconstructing and resignifying oneself. The study's women express these characteristics clearly as one of the patients said: "sometimes, we live automatically, and it is far from this. You have to soften the life. We don't know what tomorrow will bring, live today as best as you can".

The mixed methodology adopted brought extended comprehension about the results and allowed the confirmation that the diagnosis of cancer provokes emotional negative impact in the patient and its family because culturally it is associated with death, with finitude³³, which is one of the most primitive feelings a person can experience³⁴ for the loss of hope of cure³⁵. Furthermore, one of the aspects of the phenomenology is the understanding of the phenomenon through the perception of whom lives it. It was evident the dichotomy of positive and negative feelings exactly because each individual has its process of biological sickening attached to a sociocultural context, the cultural relativism³⁶. The utilization of the quantitative analysis and of the narratives supported by the theoretical backbone of phenomenology ensued a constant cyclic process of going forward and backward with the analyzes ensured by the dialectic-hermeneutic circle²⁶, which allowed to complete this investigation, detecting the meaning of the feelings of these women without losing the hope and with a moderate perception of QoL.

SF-36 is a generic instrument for QoL and allows comparisons among patients with different chronic conditions. Generic instruments can, nevertheless, be

indifferent to changes of specific conditions as breast cancer because the focus is not the disease, specifically. This methodological limitation is inherent to these instruments. The use of the qualitative methodology in the present study was important to confirm the results of this questionnaire.

The specific implications of the diagnosis and treatment of women with breast cancer refer to the interventions described below that should be implemented based in the results of this study. Initially, the physicians and coordinators of the diagnosis of the National Health System (SUS) should respond better, quickly, and precisely to their patients demands while waiting for the diagnosis. The physicians should also make a shorter description of the scores of the domains of SF-36 helping the patient to understand its situation and itself beyond the scores. Health teams must widen their definition of staff member to include patients and family, in addition to considering their opinions to define the general policies. At last, the health coordinators must develop a network possibly at the Internet to communicate and discuss the issues related to the loss of the self of the past and questions about the dynamic of the cancer treatment. Chat rooms with patients should be a starting point and can be in-person or virtual. Mental health professionals working with this population should consider a work in group or individually when reconstructing a consistent biographical narrative during the period from the diagnosis through the treatment and ending in the follow-up. All the patients of this study were investing in a certain procedure and hoped the medication would work for their lives to resume. But they feared the disease progression which, sometimes, emerges to haunt them. The caring teams for these women should incorporate these measures to minimize, at least, these and other mental symptomatology.

CONCLUSION

For the patients with breast cancer enrolled in this study, the sickening process triggered an array of positive and negative experiences, unleashing diverse feelings, modifying the daily life, and leading to low scores of the domains of functional capacity and mental health of their HRQoL. Identify and accept these results are critical tools to offer humanized healthcare. To own the fact that the experience of sickening is individual and the starting point to suggest solutions and plan the care means to understand and place the patient as protagonist of its history and the healthcare is a mere facilitator of the processes. The patient's coping with the disease and the proposal of effective care by the health team are the positive outcomes of this interaction.

CONTRIBUTIONS

The authors contributed equally in all the stages of the manuscript and approved the final version to be published.

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DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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