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# CHEMOTHERAPY-RELATED FATIGUE: THE PERSPECTIVE OF WOMEN WITH BREAST CANCER

## Fadiga secundária à quimioterapia na perspectiva da mulher com câncer de mama

## La fatiga secundaria a la quimioterapia en la perspectiva de la mujer con cáncer de mama

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## ABSTRACT

**Objective:** to describe contributing factors for the occurrence of chemotherapy-related fatigue and relief strategies derived from cultural knowledge. **Methods:** a prospective and mixed study, with 47 women with breast cancer and fatigue, conducted at a University Hospital. We analyzed answers to the open questions of the revised Piper Fatigue Scale and submitted to the Content Analysis. **Results:** six categories were described as causes for fatigue: Fear and worry; chemotherapy; emotional and psychological states; problems in family relationships; changes in self-image; and physical effort to perform daily activities. Five categories were identified as relief: Seek God; bath; rest; entertain; and cry. **Conclusion:** in the face of underestimating patients' complaints by professionals, women start seeking relief strategies based on their cultural knowledge. The appreciation of knowledge is essential for definition of effective actions, that can improve quality of life and decrease negative effects of fatigue.

**Descriptors:** Fatigue; Chemotherapy; Quality of life; Breast cancer; Qualitative research.

### RESUMO

**Objetivo:** descrever os fatores coadjuvantes para ocorrência da fadiga secundária à quimioterapia e recursos do conhecimento cultural, utilizados para alívio. **Método:** estudo prospectivo, misto, realizado com 47 mulheres com câncer de mama e fadiga, em um hospital universitário. Foram analisadas respostas das questões abertas da Escala de Fadiga de Piper Revisada, que foram submetidas à Análise de Conteúdo. **Resultados:** como causas para a fadiga foram descritas seis categorias: Medo e preocupação; quimioterapia; estado emocional/psicológico; desajustes no relacionamento familiar; alteração na autoimagem; esforço físico/atividades diárias. Cinco categorias foram

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apontadas como recursos para alívio: Buscar a Deus; banho; repouso; medidas de distração; chorar. **Conclusão:** diante da subvalorização das queixas, relacionadas à fadiga, pelos profissionais, as mulheres passam a buscar por estratégias de alívio no conhecimento cultural. A valorização dos saberes é essencial para definição de condutas efetivas, que possibilitem melhoria da qualidade de vida e redução dos efeitos negativos da fadiga.

**Descritores:** Fadiga; Quimioterapia; Qualidade de vida; Câncer de mama; Pesquisa qualitativa.

### RESUMÉN

**Objetivo:** describir factores coadyuvantes para la ocurrencia de fatiga secundaria a la quimioterapia y recursos del conocimiento cultural, utilizados para alivio. **Método:** estudio prospectivo, mixto, con 47 mujeres con cáncer de mama y fatiga, realizado en un hospital universitario. Se analizaron las respuestas de las preguntas de la Escala de Fatiga de Piper Revisada, que fueron sometidas al Análisis de Contenido. **Resultados:** como causas se describieron seis categorías: Miedo y preocupación; quimioterapia; estado emocional/psicológico; desajustes en la relación familiar; cambio en la autoimagen; esfuerzo físico / actividades diarias. Cinco categorías fueron apuntadas como alivio: Buscar a Dios; baño; descanso; medidas de distracción; llorar. **Conclusión:** frente a la subvaloración de las quejas, por los profesionales, las mujeres pasan a buscar estrategias en conocimiento cultural. La valorización del conocimiento es esencial para conductas efectivas, que permiten mejorar la calidad de vida y reducir los efectos negativos de la fatiga.

**Descriptores:** Fatiga; Tratamiento farmacológico; Calidad de vida; Neoplasias de la mama; Investigación cualitativa.

## INTRODUCTION

It is estimated that in 2018-2019 breast cancer will be the most frequent disease among women in Brazil.[1] Among the therapeutic options for breast cancer, chemotherapy (CT) has been presented as the option of choice for most women, being performed by the administration of combined antineoplastic drugs.[2]

Among the main CT-related adverse reactions is chemotherapy-related fatigue (CRF). This is considered the longest lasting adverse effect and significantly increases in consecutive cycles of chemotherapy.[3]

CRF can affect an individual's ability to tolerate treatment, which may result in discontinuity/abandonment, and to participate in essential activities of daily living, thereby impairing their quality of life (QoL).[4]

CRF is capable of causing damage that affects various dimensions of a person's life with cancer but is not always recognized by professionals involved in treatment. Thus, knowing fatigue better and appreciating this ailment is of utmost importance in defining the most effective behaviors and treatments.[5]

Fatigue has been a constant complaint in patients' reports and its "invisible" nature can lead to a lack of understanding among family, friends and health professionals regarding their experiences.[6] Thus, understanding women's experience related to fatigue is of great importance and is therefore an important object of attention and investigation.

Given the above, the present study has as its guiding question: What are the main factors that contribute to the occurrence of CRF and what are the main resources used for its relief, from the perspective of women with breast cancer? Therefore, this study aims to describe the factors identified as contributing factors for the occurrence of CRF and the resources derived from cultural knowledge used by participants to relieve fatigue.

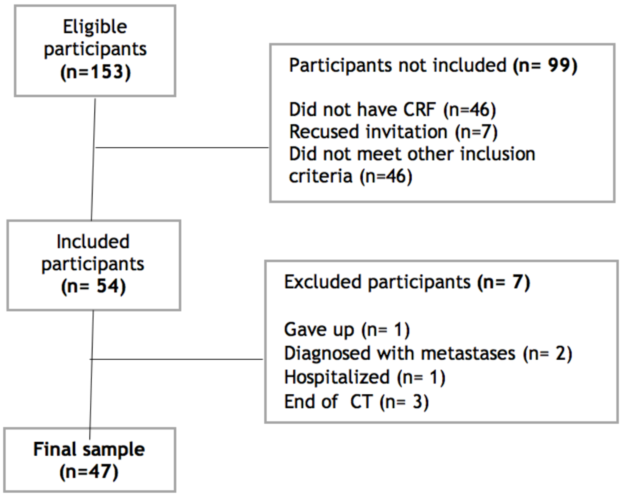
## METHODOLOGY

This is a prospective study, part of a larger research project, in which CRF and QOL were investigated quantitatively and qualitatively.

The research was conducted from May 2017 to March 2018, in the Oncology Outpatient Clinic of a University Hospital of Triangulo Mineiro, in the context of an extension project (EP). This article will present the results of the qualitative research.

The final sample consisted of 47 women. We included women diagnosed with breast cancer, without distant metastasis, older than 18 years, in CT, with CRF, without pre-treatment fatigue, with preserved cognitive ability, participants of the EP and formally interested in participating in the research confirmed by signing the Informed Consent Form (ICF). Women who dropped out after starting, who had their treatment changed after the start of the study, who had distant metastases during treatment, and who missed follow-up consultations due to reasons such as hospitalization, were excluded. The process is summarized in the Participants Inclusion Flowchart (Figure 1).

**Figure 1 -** Participants Inclusion Flowchart. Uberlândia, MG, Brazil, 2018



Data were collected at two points in time, at the time of CRF diagnosis (T1), and the subsequent chemotherapy cycle (T2). The estimated time for each collection was 40 minutes.

For qualitative investigation we used the open questions of the revised Piper Fatigue Scale (PFS-R); and their responses were audio-recorded with the permission of the participants.[7] In addition to the quantitative assessment of CRF, this instrument allows us to qualitatively assess other aspects related to CRF, in order to better understand this phenomenon, from the perspective of the affected woman.

All participants in this study answered the following questions in T1 and T2: "Overall, what do you think causes or contributes to your fatigue?"; "In general, what relieves your fatigue most is:…"; "Is there anything else you would like to say to better describe your fatigue?"; "Are you feeling any other symptoms now?"

The answers to the open-ended questions of the PFS-R were audio-recorded, which allowed for a broader approach, transcribed, and submitted to Content Analysis.[8] This analysis consists of pre-analysis, material exploration or coding, treatment of results, inference and interpretation.

We observed that in other studies that evaluated fatigue in cancer patients through the PFS-R, additional data obtained through open questions were submitted to content analysis, but without exploring the participants' statements, which may be explained by absence of audio recording.[9-10]

This study was approved by the Research Ethics Committee, according to CAAE 63777816.7.0000.5152. All participants were requested to sign a consent form, in accordance with Resolution 466/12 of the National Health Council, and anonymity was maintained for all participants by using flower names as pseudonyms.

## RESULTS AND DISCUSSION

Majority of women were between 50 and 69 years of age (55.32%), white (61.70%), married (44.68%), with Incomplete Elementary School education (53.19%), who perform activities of the category of service workers and sales (78.72%), who identified themselves as Catholic (38.30%), in line with previous studies.[11-12]

Regarding the predominant age group among the participants, it is noteworthy that it coincides with the age group for which the Unified Health System (SUS) offers mammography every two years, thus contributing to the diagnosis in this age group.[13]

The category of service workers and salespeople that includes domestic service workers in general, including women who claim to be "homemakers" and maids, was prevalent among the participants. Housework remains one of the main forms of work of Brazilian women, with women still being the ones responsible for the care of the home, family and child rearing.[14]

In a study that aimed to profile women with breast cancer treated with CT, in the same hospital where this study was conducted, 20.51% women were housewives and 8.2% women were retired, with a lack of own financial resources or on retirement income.[15] Financial difficulties directly impact the QOL of these women, as the health system cannot assume additional expenses resulting from the treatment.

Regarding religion, despite the majority declaring themselves Catholic, we observed a considerable number of evangelicals (31.91%), which is in line with the religious transition that is taking place in Brazil. Changes in the distribution of religious affiliations have been accelerating; growth of evangelical congregations is a broad and general phenomenon while the number of those who claim to be Catholics is shrinking.[16]

Based on the analysis of the answers to the open questions of the PFS-R, we established categories that bring up the subjective aspects of the evaluation of the CRF based on the participants' statements.

### What causes chemotherapy-related fatigue?

When participants were asked what causes or contributes to the occurrence of fatigue, CT was considered the main cause. In addition to CT, other factors were indicated as shown in the following table (Table 1).

**Table 1 -** Causes of fatigue reported by study participants. Uberlândia, MG, Brazil, 2018

| Cause | N | | % | |
|---|---|---|---|---|
| | **T1*** | **T2**** | **T1*** | **T2**** |
| Fear and worry | 4 | 3 | 8,51 | 6,39 |
| Chemotherapy | 21 | 27 | 44,68 | 57,45 |
| Emotional/psychological state | 12 | 11 | 25,53 | 23,40 |
| Difficulties in family relationships | 3 | 0 | 6,38 | 0,00 |
| Changes in self-image | 2 | 1 | 4,26 | 2,13 |
| Physical effort/daily activities | 2 | 4 | 4,26 | 8,51 |
| Did not respond | 3 | 1 | 6,38 | 2,13 |

Source: Survey Data

* First collection at the time of diagnosis of fatigue

** Second collection in subsequent chemotherapy cycle

Such findings are similar to those found in other studies. In a study that assessed QOL and fatigue in patients with malignant neoplasms in CT, 41% of respondents said treatment was the cause of fatigue, followed by cancer itself, physical efforts, and emotional factors.10

Following are excerpts from the statements of two participants, which illustrate well how CT and factors such as emotional/psychological state are considered as causes of fatigue:

> *What causes the fatigue is ... the chemo ... once I finish the chemotherapy pass about five days, begins the fatigue, you understand? I think it's the medication that causes this fatigue. It's a great despair, in the legs, in the back, you know? Your own body tires you ... you want to walk, you can't. I feel it all. It's because my psychological state affects me in this fatigue, I already realized that.* (Vinca)

> *Well what I think ... is the treatment. The treatment because I did not feel this way and it was after chemotherapy that I started to feel this way. So what changed was that. So ... concern. This gets worse.* (Semânia)

The belief that CT and emotional state cause fatigue can be seen in participant Vinca's statement.

For Semânia, the role of CT in causing fatigue is clear, since she realizes that this symptom was nonexistent before the start of the treatment. She also admits that psychological changes such as worry also encouraged fatigue thus endorsing Vinca's statement.

Anxiety and fear are almost always present in patients undergoing CT. Fear is related to the adverse effects that treatment commonly causes, including fatigue.[17] CT can cause psychosocial damage and self-image problems due to alopecia, sexual dysfunction, anxiety and fear.[18]

Regarding family relationships, sometimes the family is so shaken by the diagnosis of the disease and the treatment that it becomes unbalanced and therefore unable to offer the support that women so much need and expect, which may impact their recovery.[17]

## What relieves chemotherapy-related fatigue?

Next, in Table 2, we present the main resources for fatigue relief indicated by the participants. Resting was mentioned as the main strategy. Social support, tea consumption, use of painkillers, being alone, use of sleeping pills were mentioned, but they did not fit into any of the categories.

**Table 2 -** Resources for fatigue relief reported by the study participants. Uberlândia, MG, Brazil, 2018

| Relief measures | N | | % | |
|---|---|---|---|---|
| | T1* | T2** | T1* | T2** |
| Search for God | 4 | 1 | 8,51 | 2,13 |
| Bath | 1 | 3 | 2,13 | 6,38 |
| Rest | 25 | 22 | 53,19 | 46,8 |
| Distraction | 9 | 14 | 19,16 | 29,79 |
| Cry | 2 | 1 | 4,26 | 2,13 |
| Other | 6 | 6 | 12,77 | 12,77 |

Source: Survey Data

* First collection at the time of diagnosis of fatigue

** Second collection in subsequent chemotherapy cycle

Our results support the findings of prior studies. In a qualitative study that assessed whether the Self-Regulation Model contributes to understanding of CRF, participants reported that being optimistic, not giving in to fatigue, exercising, support of others, recognizing one's limits, sleeping, taking breaks, and resting are relief strategies.[6]

In another previous study, 40% of participants reported that resting reduced fatigue, followed by some distracting recreational activity such as talking, praying, religious activities.[10]

In our study, for the fatigued woman, rest – which is an energy conservation measure - has become one of the main resources for CRF relief:

> *I rest ... when I see that I can't handle it, I rest ... a little.* (Torênia)

> *I try to lie down, relax a little and think about good things, right, reading a bit helps a lot.* (Semânia)

Measures of distraction, such as manual labor, and the search for God through the Bible, were also identified by the participants as measures that alleviate fatigue:

> *I engage in my crafts. I make a rug, crochet, I do handiwork.* (Torênia)

> *The Bible, very good that it strengthens us and brings tranquility and peace as well.* (Semânia)

When dealing with situations resulting from CT, women often use mechanisms that encourage their adaptation. In this context, they often talk to friends, go out and have fun, change their eating habits, take the time to forget their problems, and even seek support from religion/spirituality.[17-18]

Spirituality and religious practice are extremely important in facing breast cancer, as they encourage women, positively influencing the entire course of illness. In a study that aimed to explore the perception of women with breast cancer in relation to spirituality as a coping strategy, it was highlighted as a strategy that provides serenity and comfort in the face of disease.[19]

## CRF's repercussions on QOL

When we asked the participants about something they would like to say and/or explain better about fatigue, only six (12.77%) women spoke up. However, through their statements, we realized the impact of emotional/psychological state on the occurrence of fatigue, how this reaction impacted their daily activities, and how its effect is generally lasting.

> *This fatigue is physical as well as a mental, that gets worse when I go through a pressure or stress situation. I may be fine and if I go through a stressful situation, it aggravates everything, even my physical health.* (Orchid)

> *Look, for me I'm not calm, fatigue represents inertia! Because my spirit is not to stand still, I like to act. So it looks like I'm in an inertia, there, catatonic, still, and I don't like it.* (Semânia)

> *In terms of treatment, the worst is fatigue. Because you finish the chemotherapy, after seven days that nausea, that weakness, you begin to eat, it is already passing ... and the fatigue does not pass during this period. Fatigue will pass when you are almost due for the next chemotherapy.* (Vinca)

In a qualitative study on CRF, participants stated that people do not understand fatigue well. Therefore, because they don't want to worry their family or friends, and don't want to appear to be complaining, they feel pressured by families to return to their usual routine. All these factors are stressors and potentially worsen fatigue.[6]

Today, it is common for women to work outside the home to enjoy themselves, to perform professionally, and to contribute to household expenses.[17] Thus, for the fatigued woman, the fact that she wants and needs to perform her activities and is failing to do so is at least distressing, as is the case of Semânia.

Participant Vinca's statement allows us to understand clearly the persistent effect of fatigue, which remains after the improvement of all other major adverse effects of CT. Such an account attests to the definition of fatigue as a harrowing, persistent condition.[13]

Few women reported feeling other symptoms at the time of the interview. In T1, 10 women (21.27%) expressed: "chest tightness", cough, itching, pain or nausea. At T2, they reported pain, tiredness, dryness in the mouth, numbness in the hands and feet, dizziness, burning eyes, nausea.

In oncology, different groupings of symptoms, related to disease and treatment may occur.[20] These symptoms, cited by participants, when associated with fatigue, can further impair QOL.

CRF has impacted the lives of women with breast cancer as well as QOL. The identification of fatigue, its correct stratification and therapeutic approach are fundamental steps to be performed by professionals involved in cancer patient care.[21]

Health professionals need knowledge and sensitivity to understand the suffering generated by the various reactions to cancer treatment and nursing professionals are important actors in this process, especially in the evaluation and helping patients in the management of CRF, in order to preserve QOL.[22] Lack of knowledge, devaluation, and normalization of a subjective symptom are the main factors that delay the diagnosis of fatigue.

In this context, normalization is not limited to professionals, but also extends to patients, who, due to the lack of adequate assistance and guidance regarding fatigue, do not care, considering it to be "normal" during CT. What is normal in certain situations, can become pathological in another situation. It is the individual who evaluates this transformation, for it is she who suffers the consequences that the new situation imposes.

In this context, what characterizes health is the ability to tolerate breaches of the usual norm and to institute new norms in the face of the new condition. Thus, as fatigue becomes more persistent and intense, women, because they do not have professional guidance, look for strategies specific to their cultural environment, which can bring them relief.

Culture defines knowledge, practices and values that determine people's behavior in the face of life events. In this sense, bringing science to the cultural reality of each community, without disregarding the knowledge of "common sense", is extremely important. By linking cultural and scientific knowledge it is possible to build new knowledge and practices.[24]

## FINAL CONSIDERATIONS

The participants in this study demonstrated the importance of CT as the main cause for the occurrence of CRF and how the emotional state may contribute to the worsening of this symptom.

The lasting effect of CRF was evident in the participants' statements, referring to its persistent characteristic. Among the strategies derived from cultural knowledge, rest was identified as the main strategy for CRF relief.

CRF has been neglected by many professionals who assist this population, reflecting the lack of guidelines for management and symptom relief. Thus, patients and caregivers often find themselves unaware of the phenomenon and seek only common-sense strategies for relief, which does not always lead to positive results. The importance of attentive listening and professional guidance, focused on effective practices, must be considered.

Thus, we highlight the role of the multidisciplinary team in seeking proper management of fatigue, along with patients and caregivers, and the development of further studies aimed at improving the care provided to these women.

Ensuring person-centered care, which envisions acting on the harmful nature of CRF, should enable these women to maintain or even improve their QoL, mitigating the negative effects of CRF.

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