

SUFFERING AMONG PATIENTS WITH CANCER UNDERGOING NEUROTOXIC CHEMOTHERAPY: A PHENOMENOLOGICAL APPROACH

Angelo Braga Mendonça¹ 

Eliane Ramos Pereira¹ 

Carinne Magnago² 

Rose Mary Costa Rosa Andrade Silva¹ 

Adriana de Oliveira Martins³ 

Diva Cristina Morett Romano Leão¹ 

¹Universidade Federal Fluminense, Escola de Enfermagem, Programa Acadêmico em Ciências do Cuidado em Saúde. Niterói, Rio de Janeiro, Brasil.

²Universidade de São Paulo, Faculdade de Saúde Pública. São Paulo, São Paulo, Brasil.

³Universidade do Estado do Rio de Janeiro. Rio de Janeiro, Rio de Janeiro, Brasil.

ABSTRACT

Objective: reveal experiences of cancer patients undergoing neurotoxic chemotherapy.

Method: phenomenology-based, qualitative study, carried out with nine adult patients in antineoplastic neurotoxic treatment, interviewed in June and July 2018. The testimonies were analyzed using an empirical comprehensive model.

Results: the following categories were delineated: nerves on edge: perception of limitations caused by neuropathic pain induced by chemotherapy; chemotherapy drains me of energy; the suffering of starting again; the suffering of enduring it; alone in a desert, I heard the cry of my silence; chemotherapy: an infusion of hope; and there is no suffering on earth that heaven cannot heal.

Conclusion: the study presented various meanings of suffering that emerge from experiences with neurotoxic treatment and found that many dimensions of suffering interpenetrate, making it impossible to disassociate them.

DESCRIPTORS: Psychological stress. Combined chemotherapy. Neoplasms. Small fiber neuropathy. Qualitative study.

HOW CITED: Mendonça AB, Pereira ER, Magnago C, Silva RMCRA, Martins AO, Leão DCMR. Suffering among patients with cancer undergoing neurotoxic chemotherapy: a phenomenological approach. *Texto Contexto Enferm* [Internet]. 2020 [cited YEAR MONTH DAY]; 29:e20190285. Available from: <https://doi.org/10.1590/1980-265X-TCE-2019-0285>

SOFRIMENTO DE PACIENTES COM CÂNCER EM QUIMIOTERAPIA NEUROTÓXICA: UMA ABORDAGEM FENOMENOLÓGICA

RESUMO

Objetivo: desvelar experiências de pacientes com câncer que se submeteram à terapia com quimioterápicos neurotóxicos.

Método: estudo qualitativo, fundamentado na fenomenologia, realizado com nove pacientes adultos em tratamento com antineoplásicos neurotóxicos, entrevistados em junho e julho de 2018. Os depoimentos foram analisados segundo o modelo empírico-compreensivo.

Resultados: foram reveladas as categorias: com os nervos à flor da pele – percepção das limitações provocadas pela dor neuropática induzida pela quimioterapia –; a quimioterapia que acaba com a minha energia; o sofrimento de recomeçar; o sofrimento de suportar; sozinho, em um deserto, ouvi o grito do meu silêncio; quimioterapia – uma infusão de esperança –; e, não há sofrimentos na Terra que o céu não possa curar.

Conclusão: o estudo apresentou vários significados de sofrimento que emergem da experiência com o tratamento neurotóxico, relatando que muitas das dimensões do sofrimento interpenetram-se, sendo impossível dissociá-las.

DESCRITORES: Estresse psicológico. Quimioterapia combinada. Neoplasias. Neuropatia de pequenas fibras. Pesquisa qualitativa.

SUFRIMIENTO DE PACIENTES CON CÁNCER EN QUIMIOTERAPIA NEUROTÓXICA: UN ABORDAJE FENOMENOLÓGICO

RESUMEN

Objetivo: revelar experiencias de pacientes con cáncer que se sometieron a terapia con quimioterápicos neurotóxicos.

Método: Estudio cualitativo fundamentado en la fenomenología, realizado con nueve pacientes adultos tratados con antineoplásicos neurotóxicos, entrevistados entre junio y julio de 2018. Los testimonios fueron analizados según el modelo empírico-compreensivo.

Resultados: se determinaron las categorías: Con los nervios a flor de piel –percepción de limitaciones provocadas por el dolor neuropático inducido por la quimioterapia–, La quimioterapia que acaba con mi energía; El sufrimiento de recomenzar; El sufrimiento de soportar; Solo, en un desierto, oí el grito de mi silencio; Quimioterapia –una infusión de esperanza–; y No hay sufrimiento en la tierra que el cielo no pueda curar.

Conclusión: el estudio presentó varios significados de sufrimiento que surgen de la experiencia con el tratamiento neurotóxico, manifestando que muchas de las dimensiones del sufrimiento se entrecruzan, siendo imposible disociarlas.

DESCRIPTORES: Estrés psicológico. Quimioterapia combinada. Neoplasias. Neuropatía de fibras pequeñas. Investigación cualitativa.

INTRODUCTION

Suffering can be defined as a complex negative affective-cognitive state, characterized by a sensation of impotence and depletion of personal resources that would enable sufferers to confront this threat.¹ For people with cancer, suffering has multiple causes, which vary depending on the moment lived and can range from waiting for the diagnosis and staging to the treatment and palliation stage. To contend with suffering, cancer patients use different coping strategies. Coping is understood as a set of cognitive and behavioral efforts by an individual to manage stressors which are considered to exceed their adaptive capacity.² If these resources converge with a spiritual and/or religious dimension, it is referred to as religious and spiritual coping. In examining this association, spirituality was found to be a unique way of experiencing a sense of connection with others, nature and/or a superior being that imparts meaning to existence and transcends the suffering.³

Data from the literature shows that this phenomenon has not been reported and treated much in cancer care units. The reasons for failure to recognize it include the fact that patients do not feel comfortable talking about their anguish, fear of being stigmatized for receiving psycho-therapeutic care and assuming that professionals may not be available or competent to deal with psychological issues.⁴ Therefore, it is important to understand the suffering experienced by cancer patients undergoing chemotherapy, since studies have found that it has a significant impact on quality of life⁵ and the incidence and severity of adverse effects.⁶ Furthermore, there are few studies that investigate the topic within the context of chemotherapy, since most of them examine the experiences of patients who no longer have any therapeutic possibilities.

When administered in rounds, chemotherapy can cause significant toxicity and undesirable effects,⁷ such as peripheral neuropathy, which is a serious side effect associated with various antineoplastic agents routinely used in cancer treatments.

Chemotherapeutic drugs such as platinum derivatives, taxanes, vinca alkaloids and bortezomib are often indicated as part of a standard protocol to combat various types of cancer. They can cause temporary or permanent damage, with a prevalence ranging from 16% to 95%, whose main symptoms are paresthesias, cognitive alterations, dysesthesia due to exposure to cold, numbness, difficulty holding objects, pain and loss of deep tendon reflexes. The morbidity associated with these adverse effects can lead to physical incapacities, mental alterations, fall risk, reduced dose of pharmaceuticals and cessation of treatment.⁸⁻¹¹

Although recent studies have made progress in the identification of predictors,¹¹ measurement tools and interventions to reduce damage,¹⁰⁻¹¹ there is still a major gap in the literature regarding the emotional and psychic impacts of peripheral neuropathy. From this perspective, the objectives of this study address this gap because it reflects the perception of patients receiving neurotoxic agents not as a set of kinesthetic and sensory alterations, understood in Cartesian thinking as linear stimulus-response causality, but as a bodily attitude that sheds light on the notion of perception, interwoven with movement and intentionality. Through the above, this unique study sought to uncover the experiences of cancer patients receiving neurotoxic chemotherapy.

METHOD

This is a qualitative study, based on the phenomenology of Maurice Merleau-Ponty. According to the philosopher, knowledge is built on the basis of rigorous science, which is the search for essences, aimed at restoring things in themselves as part of a lived, experienced, but not completely finished, world. His theoretical model added a critical and renewed vision to transcendental phenomenology in that it contextualized the knowledge of essences within a space, time and lived world.¹²

Considered the core of phenomenology, intentionality can be defined as the direction of consciousness to understand the world. Unlike Husserl, the concept of intentionality for Merleau-Ponty is shaped much more within an “I can” rather than “I think”. This active potential resides in the body itself, a vehicle for being in the world and a receptacle of existence.¹³ Through it, the modifications caused by chemotherapy acquire new meanings. Therefore, to know how patients interpret the effects of neurotoxic therapy, as well as the social, cultural and historical aspects surrounding the experience, an existential phenomenological approach was used, whose main issue focuses on how man creates meaning in his world.

The study was conducted in a chemotherapy outpatient clinic of one of the units of a reference center for cancer education and control in Brazil, located in the city of Rio de Janeiro, RJ. The target population was comprised of all the patients undergoing chemotherapy at the study site, in June 2018. To determine the sample, which was intentional in nature, patients were considered who had been followed up on for at least three months and had the minimum means of expressing themselves with words. The exclusion criteria were patients receiving psychiatric care, those with performance status (PS) greater than three, and those who were seriously ill, manifesting acute adverse effects, such as vomiting, diarrhea and infusion reactions.

The data was obtained in June and July 2018 through a phenomenological interview, based on the following trigger questions: “What feelings arose from your chemotherapy experience?” and “How do you perceive chemotherapy in your life?”. The inclusion of more subjects was suspended due to theoretical saturation, i.e., when the researchers assumed that new themes or types of statements would not add new elements to support the desired theorization.¹⁴ In the end, the sample was comprised of nine witnesses, identified in this study by the letter E, followed by a number. The data collection instrument was a semi-structured questionnaire for gathering data related to the sociodemographic and clinical characterization of the participants; and a script containing questions from the phenomenological interview. The main researcher, a master’s student with a specialization in cancer nursing, was responsible for conducting the interviews, carried out in an institution that has provided direct care for 15 years for patients undergoing chemotherapy. The interviews lasted an average of 45 minutes and took place in a quiet room used for nursing consultations. After being recorded on digital equipment, they were duplicated and stored in an electronic archive. The process ended with feedback to the participants on the researcher’s understanding of the experiences shared and thanking them for their participation.

For the study design, the list of verifications from the Consolidated Criteria for Reporting Qualitative Research (COREQ) was checked off. To maintain scientific rigor, the criteria of credibility, transferability, reliability and confirmation potential, suggested by Lincoln and Guba, were used.¹⁵ Therefore, the data was collected at different times and triangulated based on distinct sources, seeking a maximum variation of participants, in terms of sociodemographic and clinical profile. The data was characterized by three researchers from a literal and full transcription of the recorded audios. To obtain a detailed description of the conscious experience, contextual information was included which revealed emotion present in the narratives of the subjects (pauses, silence, repetition of words, crying and changes of intonation). To validate the analysis, the researchers reviewed their interpretations and tracked data that challenged the characterization through searching for negative cases.

To enhance the quality of the data, prolonged engagement and persistent observation were adopted.¹⁶ The data was collected after a nursing consultation performed by the researcher in order to strengthen the bond with the participants and break down barriers that could hinder the sharing of personal experiences. In regard to the last strategy, monitoring patients for at least two hours while they received chemotherapy and observing how they reacted to its effects, enabled taking field notes and gaining an understanding of the experience outside the range of verbal language.

The testimonies were analyzed using the empirical comprehensive model proposed by Amedeo Giorgi,¹⁷ based on the following stages: (1) phenomenological suspension; (2) careful reading of the data set, in order grasp the meaning of the whole; (3) delineation of the meaning units (MU); (4) transformation of the patient's language (MU) into scientific language (psychological insights), maintaining the focus on the phenomenon in question; (5) synthesis and integration of the psychological insights into analytical categories; and (6) elaboration of an intellection consistent with the area of knowledge, thereby revealing to the scientific community the core and invariable structure of the experience investigated.

The research project was submitted to the Research Ethics Committee of the university and institution where the study was conducted. The recommendations of Resolution 466/12 of the National Health Council, including the signing of two copies of a free and informed consent form, were followed.

RESULTS

This study was based on a sample of nine cancer patients and was heterogeneous in terms of diagnosis and treatment protocols. Six of the subjects were men and three were women. The age of the participants ranged from 44 to 77 years. All the participants interviewed were undergoing treatment with bortezomib, taxanes and platinum derivatives, in current or previous regimes. Obtaining field notes contributed to a dense and contextualized description of the results.

The transformed MU and analytical categories are summarized in Chart 1.

Nerves on edge: perception of limitations caused by neuropathic pain induced by chemotherapy

Patients who received neurotoxic antineoplastic drugs, in addition to experiencing physical suffering caused by peripheral neuropathy, faced the suffering of feeling limited in supplying their own needs. When finding themselves forced to live with the neurotoxic effects of the treatment, they not only had to deal with a reduction in their functional capacities, but also the feeling of uselessness when seeing themselves become dependent on family members to perform daily activities.

You no longer have the life you once had. Now, you can't do much. Being dependent on others is bad [...]. That used to happen when I did the other chemotherapy that gave me shock sensations [sensitive peripheral neuropathy], making me dependent on my sister to get things from the fridge. [...] Numb hands limit you a lot and prevent you from doing things (E1).

My hair didn't fall out, but there were some side effects that set my nerves on edge. This leg was asleep; this foot here and big toe also hurt. Due to this effect, my skin feels smooth, sensitive and like it's burning. My foot swells (E9).

Chart 1 – Psychological insights and analytical categories resulting from the phenomenological analysis of the testimonies. Rio de Janeiro, RJ, Brazil. (n=9)

Psychological insights	Analytical categories
Perceived sensory alterations; ceased activities; psychic agitation; emotional lack of control; dependency.	Nerves on edge: perception of limitations caused by peripheral neuropathy induced by chemotherapy.
Reducing the voltage; disability; dejected; getting weak; hopelessness; the disease is winning.	Chemotherapy drains me of energy.
Losing battle; object of study; the earth opened up again; walking toward death.	The suffering of starting again.
A necessary evil; you cannot avoid it, so you face it; the price of victory; the weight of defeat; there is nowhere to run; a necessary evil.	The suffering of enduring.
Abandonment; solitude; asking for help; existential emptiness.	Alone in a desert, I heard the cry of my silence.
Hope for a cure; hope for relief from the physical symptoms; hope to live a little longer; hope for a better future; life opportunity.	Chemotherapy: an infusion of hope.
Drawing close to God; divine intercession; chemotherapy delegated by a divine power; faith in healing; being thankful to God.	There is no suffering on earth that heaven cannot heal.

Chemotherapy drains me of energy

This category arose from the suffering that the participants described as they saw their energy levels progressively decrease because of multiple rounds of chemotherapy. They talked about suffering from lack of sufficient strength to start the day, get out of bed and perform and complete daily activities. Physical strength was translated into volts, illustrating a concern about energy levels when limits and functional capacities were exceeded, thereby provoking sudden dyspnea. Surrendering and giving in to fatigue brought on feelings of hopelessness and fear that the evolution of the disease will end in death.

My body is getting weaker and weaker all the time. Drugs are given to kill that which is bad but are also killing that which is good. I'm getting weak and you know where I'm going to end up? Dying (E3).

It destroys your body and your courage (E1).

It makes you lose heart and not want to do anything.

You just feel like staying in bed (E4).

This uselessness makes me feel very, very worried. Why? Because I was always plugged in at 440V, and now, at most, I have to be at 127V. More and more I can't do things because I'm increasingly out of breath. It's fine I stay calm, but there's more to life than just staying calm (E8).

The suffering of starting again

After chemotherapy, many patients go into clinical control periods to monitor the absence, stability or progression of the disease. At the end of the programmed rounds, they start to plan a more promising future. When taken by surprise at the recurrence of the disease, the patients had to once again deal with the same toxic effects experienced in the beginning; this time, however, with the complication of less likelihood of being healed and, consequently, greater psychological stress. In a different context, the suffering of starting again occurred when standard chemotherapy caused neurotoxicity and prevented the continuation of conventional treatment, leading to a change of protocol.

[...] *The doctor told me it would come back, but we prayed for it not to. I'm moving into the third round of chemotherapy, and there are more and more drugs. Chemotherapy is every six months [...]* (E3).

I think it's a type of experiment each time the chemotherapy is changed. [change of protocol after grade 3 neurotoxicity] (patient cries) (E1).

The suffering of enduring

The belief that the disease follows a progressive and irreversible course makes it an irremediable, insidious and highly destructive evil. Therefore, patients perceive chemotherapy as “a necessary evil”, since they view the disease as the harbinger of physical, psychological and moral decline, which is worse than the toxic effects of the treatment.

Chemotherapy is meant for me to get better, but it has consequences. So, I endure it (E9).

For it [the cancer] not to kill me, I have to kill it (E8).

If it can be avoided, great, but if not, then you have to face it! That's where the suffering lies. There has to be a battle in order to have a victory (E5).

Alone in a desert, I heard the cry of my silence

This category reveals the feeling of social and emotional solitude experienced during treatment.

[...] *people say: “let me help you,” but then they're not there when you need them* (E3).

I feel like I'm alone in a desert (E2).

I feel abandoned in terms of being accompanied (E8).

Chemotherapy: an infusion of hope

This category illustrates the many types of hope attributed by patients to chemotherapy. These include the hope of staying alive; achieving control over the disease and relief from the signs and symptoms; and a definitive cure, with total liberation from the suffering caused by cancer.

I'm in a reference hospital, which is very good. So, I hope to overcome this. I hope I'll get better here (E6).

What comforts me is knowing that chemotherapy is a hope that I will improve (E2).

[...] *Another thing, which I say and repeat, is that life gave me a cancer and God has given me the opportunity to learn things through this cancer* (E8).

There is no suffering on earth that heaven cannot heal

Religion and spirituality are dimensions of a human being, addressed in this category, which express the search for love, divine protection and a desire to connect with transcendental forces that may relieve suffering that is not physical.

I turned my thoughts again toward God and calmed down. That's when I improved (E1).

Treatment and the spiritual are factors that are interlinked and help. Whatever the problem, a person's faith helps a lot [...] (E8).

I got closer to Him because I was rather distant. I wanted to be in peace. Being close to God as a result of the disease. Like it or not, He's helping me. It's the faith you have to keep on going (E7).

The results lead one to believe that many thematic categories interpenetrate, indicating that patients fluctuate between times of deep suffering and faith, hope and gratitude (Figure 1).



Figure 1 – Rubin's vase

Source: Miyahara.¹² Prepared by John Smithson, 2007 (public domain)

The figure - adapted from Rubin's vase - offers a holistic reading of the experience, represented by interdependent constituents of the same lived phenomenon; in the image, it is possible to distinguish two faces facing each other (experiences of suffering) or a chalice in the middle (faith, hope and gratitude). The optical illusion groups the ideographic perspectives of the narratives, disclosing the mutable, contextual and dynamic nature of suffering and hope reflected in the perceptive experience of patients.

DISCUSSION

The side effects of chemotherapy affect various systems of the human organism and are difficult to cope with, especially neuropathic pain and fatigue, as mentioned in this study. In the psychic domain, it was found that patients learn to live with the toxic effects of chemotherapy, revealing an awareness of being in the world not as sick beings, but as beings fighting for their lives.¹⁸

Based on an analysis of the patients' descriptions, fatigue related to chemotherapy can be understood as an adverse effect that is difficult to describe, since it cannot be compared with tiredness experienced in normal situations. The symptoms of fatigue associated with chemotherapy can start suddenly and differ from other pathophysiological conditions since they are not responsive to sleep and rest. Fatigue is usually greater in magnitude and persistence and can physically and emotionally drain patients and family members.¹⁹ In this study, the patients described themselves as being too tired to perform any activities, were frustrated at recognizing they were no longer the same and worried that fatigue meant that they were not well and that the disease was winning.

In the psychosomatic domain, functional incapacity resulting from fatigue was aggravated by peripheral neuropathy, provoking feelings that undermine the quality of “(re)existing” of patients. From the moment a being confronts the reality of existing with an incurable disease, various existential projects tend to be canceled or modified by the lived experience,²⁰ and physical events affect this dimension. The negative effects of fatigue and neuropsychomotor changes, extended to social relationships, were linked to feelings of abandonment reported by the patients. According to Merleau-Ponty, the body is our anchor to this world, through which we engage in relationships with the things in it and with others.¹³

This new prism recognizes the sensory alterations unleashed by neuropathy not as a static quality or consciousness, but as a bodily attitude replete with intentionality and movement. To break the notion of body-object, the author dismisses the idea that the sense organs behave as passive receptors and argues that the same body that touches is also touched by others. Similarly, how a person feels as a body and how they perceive themselves as an object does not translate into opposite things, but inextricably linked things.²¹ Thus, the situation of dependence made those who are sick feel isolated and more prone to loneliness, using the metaphor “alone in a desert” to express the existential void.

Phenomenological analysis makes it clear that a human being is a being-in-the-world, always existing in relationship to something or someone.²² The other’s body serves, in this aspect, as an intermediary, since for a person to be in the world it requires the presence of the other, without which that person would have no world. It is this being-with-another where men can visualize the possibility of being with someone - not only as an object of care, but in an engaging and meaningful manner.¹⁸

The lack of this affectionate relationship can precipitate or exacerbate spiritual anguish, understood as the result of the feeling that emotional solitude can cause in a person. Definition of the spiritual suffering diagnosis corroborates this result, since it considers not only an impaired ability to integrate meaning into existence, but to connect with oneself, others and life.^{20,23} In summary, physical incapacities, combined with the perception of an insufficient social support network, can greatly affect mental health during rounds of neurotoxic chemotherapy. This makes patients feel devalued, unable to recognize their identity and their social role, rendering them more susceptible to solitude, pain and harmful effects in the spiritual dimension. Therefore, the role of nurses is essential for promoting family and social support during chemotherapy, to help patients feel loved and recognized in their uniqueness, when they perceive themselves as participants and contributors to progress in the environment in which they live.

The category “Nerves on edge” refers to the intense emotional reactions that accompany physical impairments generated in the peripheral nervous system. The patients experienced states of irritability that exceeded the physical dimension of peripheral neuropathy, placing mental balance on a fine line between control and lack of control. As repeated infusions of chemotherapeutic drugs cause decreased sensitivity in the hands and feet, compromising the sense of surface, relief and touch, they increase sensitivity to stress, resulting in an emotional lability which results in psychological suffering. The “state of nerves” reflects agitated emotions that cannot be controlled - a way of reacting to sensitive changes when they cannot be understood or prevented - which accentuates the anxiety, tension and anger. These feelings express the difficulty in exploring, feeling and communicating with the world.

For this reason, it is important for nurses to be able to administer care without ignoring the physical, emotional and psychological factors involved in neuropathic pain, which can lead to a high level of suffering among those who are sick. Recognizing and acting early are considered essential interventions for prevention of complications resulting from neurotoxicity, since it is a prevalent condition during chemotherapy treatment and does not respond much to conventional drugs, where the only alternative, in some situations, is discontinuation of the causal agent.²⁴

Previous studies have focused on misinformation, functional limitations and impaired quality of life of patients facing peripheral neuropathy.²⁵⁻²⁶ These findings are consistent with the themes “Nerves on edge” and “Chemotherapy drains me of energy”. However, knowing how the dimensions of suffering interact and stay connected remains a mystery. The present study shows that these aspects are interrelated and should guide nursing care from the perspective of resolving the suffering of patients undergoing neurotoxic treatment. The tendency to only focus efforts on reducing functional impairments is an obstacle for alleviating them. In view of this, the present study promotes important advances in practice since it clarifies the nature of the interface between the dimensions of suffering and the importance of the context for this assessment.

From this angle, the present study found that when the physical symptoms of patients are disproportional with the extension of sensory-motor impairments, the presence of socio-relational suffering should be considered. The perceived lack of relationships, when they were most needed, emerged as a key piece for revealing the rupture of the subject-body with the world. At this point, recurrences and increased neuropathy represent periods of greater vulnerability to suffering. Loss of autonomy and control over one’s body was complicated by the fear of becoming a burden for the family, solitude, awareness of the progression of the disease and the proximity of death.

Intense and negative feelings were also attributed to the suffering of starting again, due to a recurrence of the disease or dose-limiting toxicity of the pharmaceuticals. According to current evidence, a local relapse is considered a strong risk indicator for systemic disease in many oncological-hematological tumors. Patients who develop it as a first event have a greater risk of distant metastasis and must fight against a worse prognosis.

And, while it does not affect survival in certain situations, there is significant psychological morbidity associated with the emotional trauma resulting from frustrated expectations. In the same category, lack of information regarding medical decisions to switch protocols in the event of disease progression or neurotoxicity, caused the participants to feel that they were objects of clinical research due to not understanding the therapeutic strategies used to overcome the resistance to pharmaceutical drugs and prevention of dose-limiting toxicity. Similarly, the systematic review revealed that patients are not adequately warned about peripheral neuropathy before starting chemotherapy. According to the study, lack of information makes communication of symptoms difficult, increasing the risk of permanent damage and,²⁶ possibly, suffering.

In this study, chemotherapy was also viewed as “something to be borne/endured”, since patients understand the need for treatment to control the disease and prevent fatal consequences. The possibility of local progression and distant metastases was perceived as a more devastating and corrosive evil than the adverse effects of antineoplastic therapy. Therefore, at the same time they suffer from these effects, patients emphasize its importance in the face of a higher pursuit, which is to again become a being without the disease.²⁷⁻²⁸ Although feeling shaken and emotionally weakened by not seeing any other way to stay alive, their religious beliefs also enabled them to move through the experience of treatment with more faith and hope, boosting their conviction that better days would come.

Therefore, the subjective experience of suffering related to the disease involves not only the construction of interpretations and attribution of meanings but is also accompanied by different coping mechanisms to deal with and adapt to the new context, in order to regulate emotions and allow patients to remain active for the preservation of life. Despite the negative aspects of the experience, the literature highlights the positive and creative potential that may emerge in the face of suffering which, depending on how it is perceived and confronted, can promote the search for new meanings for life and death, leading to new ways to face and life and living.²⁹

From this perspective, it was found that while chemotherapy was frightening, it was able to renew spirituality and hope in the patients from this study. Although the disease caused a revolution in the patients' and family members' lives, it could be seen that over the course of treatment, it enabled reconstruction of their meaning of "existing". The particular way of interpreting events that challenged their beliefs led some patients to develop an intrinsic strength for the will to live.³⁰ Spirituality, in this sense, is a multidimensional and complex human dimension that can give people comfort and inner peace. Like suffering, it is a universal, subjective and unique experience,^{1,4,20} influenced by the culture and life story of each person. The need and search for the divine on the part of the participants in this study varied, prompting a search for the meaning of life, while also being able to help transcend suffering. The presence of God, faith and praying for healing permeated the participants' narratives with vivid emotion as they discussed the feelings that arise from the experience of undergoing chemotherapy.

Religion and spirituality can provide, in this aspect, an interpretative lens through which patients perceive and reassign meaning to suffering. Therefore, as in this investigation, spirituality - expressed through prayer and divine intercession - yielded positive results in other studies, providing relief from tension, increased hope and less anxiety in the face of the uncertainty of the prognosis.^{20,30}

According to this paradigm, suffering and hope are neither ambiguous nor mutually exclusive. Phenomenological analyses reveal that the essence of the phenomenon is the co-existence of its parts; and the boundary between suffering, faith, hope and gratitude is at the core of the experience (black outline in Figure 2).

The model captures the perception of phenomenological content, illustrating how distinct elements combine in one unified whole.



Figure 2 – Core of the experience

Source: Miyahara.¹² Adapted by John Smithson, 2007 (public domain)

The way in which the image (Figure 1) is interpreted depends on how the figure is viewed; perceiving either the lighter or darker color as the background. Rubin's vase is designed so that the observer's choice between the silhouette of the vase or the profile of faces can prevent one or another interpretation at first view. However, when looking only at the limit between them, the image remains single. From this angle, suffering and hope are neither ambiguous nor mutually exclusive. The sum of their parts represents more than the whole, showing that these emotions are continuous and maintain an interchange in the phenomenon investigated, constituting the essence of the experience. The transition of images in Figure 2 reflects the work of a phenomenological investigation. Little by little, the individual characteristics of a phenomenon are reduced to arrive at its invariant essence or structure (highlighting the shape in black). This process is called eidetic variation of the object under study and highlights the intentionality of consciousness as a total structure of a being.^{13,17}

Peripheral neuropathy, considered, *a priori*, a physical dimension of suffering, can provoke a state of psychological stress due to perceived functional incapacities and limitations, evolving, in some cases, to chronic pain and fatigue.³¹ This finding was identified in various recent studies, which placed pain, fatigue and psychic changes in the same grouping of symptoms.^{11,32} In this regard, the literature shows that physical and psychological symptoms of suffering are noted more frequently in patients with nociceptive pain.³²

This, unlike neuropathic pain, may not be considered a threat. If individuals recognize they have control over it, it can result in them feeling pain, but without experiencing suffering. This clarifies strong correlations identified between psychic suffering and severity of neuropathy in patients with colorectal cancer.¹¹ The results show how the affected existential domain is able to intervene in the painful experience, and thereby cause anxiety and depression when people do not understand why they are suffering or there is no expectation of improvement, given the persistence of the symptoms even after the causal stimulus has ceased.

The category “Alone in a desert, I heard the cry of my silence” expressed the need to see oneself through the eyes of another and the strong consequences of social solitude, experienced as a greater emotional suffering than that caused by restrictions on social interaction due to chemotherapy. The narratives reveal that solitude was also present as an ontic experience, typical of beings as beings, even if the patient is surrounded by family members and friends. It is the moment when the individual is released from everything foreign to him in order to come face to face with himself. For this accompanied loneliness, increased density of relationships does not promote healing.³³

With respect to connections established between the physical and spiritual dimensions of suffering, when patients experience fatigue in the psychosomatic domain they not only report lack of energy and courage, but also discouragement and hopelessness, which hinders unlocking new perspectives and opportunities. Suffering of this type, therefore, transcended the physical limits and incapacities generated as a result. It also undermined the energy that a fully and healthily lived spirituality is able to provide, helping people feel good and guided in their choices.

The empirical comprehensive analysis made it possible to perceive the core structure of the experience related to the suffering of undergoing neurotoxic chemotherapy, which revealed that the treatment and disease cause feelings of limitation, abandonment and uselessness, when patients see themselves unable to perform the simplest daily activities or interact in their social environment, and bear inevitable adverse effects that do not respond much to conventional drugs. However, the same treatment that entraps, impacting on the quality of life and functionality of patients, is able to transform attitudes and bring forth new potential in the face of the need to transcend the physical suffering. Spirituality, in this regard, served as a path for overcoming pain, interconnecting hope with feelings of gratitude and faith.

Last, the high rates of physical and psychic morbidity in patients receiving neurotoxic agents confirm that nurses will probably have to deal with these problems during some stage of the treatment, which makes this work timely and relevant. To this end, they need to develop ethical and technical competencies through training programs and ongoing education. Among the challenges to assess suffering are the engagement of patients with a low level of education, with impaired verbal and nonverbal capabilities for reporting their perceptions. The different meanings attributed to this experience suggest that individualized approaches should be implemented, taking into consideration cultural, religious and clinical contexts.

Thus, the study found that narratives on pain and suffering should not be discouraged but can be converted into a valuable therapeutic resource, when conducted empirically. Field notes, resulting from observations and dialogue while patients receive chemotherapy, suggest that healing effects and personal empowerment may occur during narratives in relation to suffering. It is understood that, through dialogue, meaning can be attributed to events and evoke positive experiences in the face of suffering - experiences that the person was not aware of up until that point. In this sense, helping patients to integrate suffering into their life stories is the first step for them to be able to assimilate the experience, imparting a valid meaning to it. Consequently, nurses are in a unique position for identification and first approach since they are often alongside patients during crises of suffering. Understanding the causes of these crises as much as possible and removing or transmuting the elements that revitalize and maintain them should be goals in contemporary nursing.

The main limitation of this study was the exclusion of seriously ill individuals who were experiencing adverse effects that prevented them from participating in an interview. Therefore, the results do not reflect the experience of patients with extreme toxicity, nor can they be transferred to the population of patients treated in private institutions, since they reflect the reality of a public institution that primarily provides care for low-income patients. Nevertheless, the results highlight the importance of a systematic assessment of the suffering of cancer patients. Furthermore, it draws attention to the factors that affect their ability to communicate during chemotherapy, since what they share - largely linked to physical complaints - can express a tendency to seek help only when associated with the toxic effects of chemotherapy, overlooking or being unaware of its potential to cause psychic and spiritual harm.

FINAL CONSIDERATIONS

The study revealed that cancer and neurotoxic therapy can lead to states of physical, psychological and spiritual suffering, as well as positive experiences, indicating that there is an evident continuity in these dimensions, making it impossible to dissociate them. With chemotherapy, it was also found that the experience can be viewed from a positive angle through the mobilization of different psychosocial and spiritual resources. The phenomenological analysis showed that, even in situations of intense suffering, the treatment can produce positive meanings.

The coping strategies found suggest that they can serve to regulate suffering in times of uncertainty or extreme anguish. In this respect, despite the fact that the disease and its treatment usher in multi-dimensional suffering, as patients are confronted with solitude, dependence and fear of death, they also promote full awareness which generates self-knowledge and the ability to reorganize one's emotions. Therefore, living with chemotherapy and fighting cancer makes many patients feel challenged to discover a new meaning for life, in addition to understanding that living and getting sick with cancer are not asynchronous, since the disease is an inseparable state from the condition of living.

REFERENCES

1. Chapman CR, Gavrin J. Suffering: the contributions of persistent pain. *Lancet* [Internet]. 1999 [cited 2018 Aug 25]; 353(9171):2233-7. Available from: [https://doi.org/10.1016/S0140-6736\(99\)01308-2](https://doi.org/10.1016/S0140-6736(99)01308-2)
2. Folkman S, Lazarus RS, Dunkel-Schetter C, DeLongis A, Gruen RJ. Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *J Pers Soc Psychol* [Internet]. 1986 [cited 2018 Aug 29];50(5):992-1003. Available from: <https://doi.org/10.1037/0022-3514.50.5.992>
3. Weathers E, McCarthy G, Coffey A. Concept Analysis of Spirituality: An Evolutionary Approach. *Nurs Forum* [Internet]. 2016 [cited 2018 Aug 29];51(2):79-96. Available from: <https://doi.org/10.1111/nuf.12128>
4. Han D-Y, Lin Y-Y, Liao S-C, Lee M-B, Thornicroft G, Wu C-Y. Analysis of the barriers of mental distress disclosure in medical inpatients in Taiwan. *Int J Soc Psychiatry* [Internet]. 2015 [cited 2018 Aug 28];61(5):446-55. Available from: <https://doi.org/10.1177/0020764014552865>
5. Singh H, Kaur K, Banipal S, Singh S, Bala R. Quality of life in cancer patients undergoing chemotherapy in a tertiary care center in Malwa Region of Punjab. *Indian J Palliat Care* [Internet]. 2014 [cited 2018 Aug 17];20(2):116-22. Available from: <https://doi.org/10.4103/0973-1075.132627>
6. Grassi L, Berardi MA, Ruffilli F, Meggiolaro E, Andritsch E, Sirgo A, et al. Role of psychosocial variables on chemotherapy-induced nausea and vomiting and health-related quality of life among cancer patients: A European study. *Psychother Psychosom* [Internet]. 2015 [cited 2018 Aug 17];84(6):339-47. Available from: <https://doi.org/10.1159/000431256>
7. Cherwin C, Kwekkeboom K. Prevalence, duration, severity, and distress of chemotherapy-related gastrointestinal symptoms in patients with a hematologic malignancy. *Oncol Nurse Forum* [Internet]. 2016 [cited 2018 Aug 23];43(5):561-71. Available from: <https://doi.org/10.1188/16.ONF.43-05AP>
8. Carozzi VA, Canta A, Chiorazzi A. Chemotherapy-induced peripheral neuropathy: What do we know about mechanisms? *Neurosci Lett* [Internet]. 2015 [cited 2019 Aug 30];596:90-107. Available from: <https://doi.org/10.1016/j.neulet.2014.10.014>.
9. Brewer JR, Morrison G, Dolan ME, Fleming GF. Chemotherapy-induced peripheral neuropathy: Current status and progress *Gynecol Oncol*. [Internet] 2016 [cited 2019 Aug 30];140(1):176-83. Available from: <https://doi.org/10.1016/j.ygyno.2015.11.011>
10. Izgu N, Ozdemir L, Bugdayci Basal F. Effect of aromatherapy massage on chemotherapy-induced peripheral neuropathic pain and fatigue in patients receiving oxaliplatin: an open label quasi-randomized controlled pilot study. *Cancer Nurs* [Internet]. 2019 [cited 2019 Aug 30];42(2):139-147. Available from: <https://doi.org/10.1097/NCC.0000000000000577>
11. Hsu SY, Huang WS, Lee SH, Chu TP, Lin YC, Lu CH, et al. Incidence, severity, longitudinal trends and predictors of acute and chronic oxaliplatin-induced peripheral neuropathy in Taiwanese patients with colorectal cancer. *Eur J Cancer Care (Engl)* [Internet]. 2019 [cited 2019 Aug 30];28(2):e12976. Available from: <https://doi.org/10.1111/ecc.12976>
12. Miyahara K, Witkowski O. The integrated structure of consciousness: phenomenal content, subjective attitude, and noetic complex. *Phenomenal Cogn Sci* [Internet]. 2019 [cited 2019 Sept 03];18(4):731-58. Available from: <https://doi.org/10.1007/s11097-018-9608-5>
13. Sadala MA, Ferreira RC. Phenomenology as a method to investigate the experience lived: a perspective from Husserl and Merleau Ponty's thought. *J Adv Nurs* [Internet]. 2002 [cited 2019 Aug 30];37(3):282-93. Available from: <https://doi.org/10.1046/j.1365-2648.2002.02071.x>
14. Nascimento LCN, Souza TV, Oliveira ICS, Moraes JRMM, Aguiar, RCB, Silva LF. Theoretical saturation in qualitative research: an experience report in interview with schoolchildren. *Rev. Bras Enferm* [Internet]. 2020 [cited 2020 Mar 01];71(1):228-33. Available from: <https://doi.org/10.1590/0034-7167-2016-0616>

15. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Beverly Hills, CA(US): Sage Publications; 1985.
16. Polit DF, Beck CH. *Fundamentos de pesquisa em enfermagem. Avaliação de evidências para a prática de enfermagem*. Porto Alegre, RS(BR): Artmed; 2018.
17. Giorgi A. Difficulties encountered in the application of the phenomenological method in the social sciences. *Indo-Pacific J Phenomenology* [Internet]. 2008 [cited 2019 Aug 30]; 8(1):1-9. Available from: <https://doi.org/10.1080/20797222.2008.11433956>
18. Sales CA, Molina MAS. O significado do câncer no cotidiano de mulheres em tratamento quimioterápico. *Rev Bras Enferm* [Internet]. 2004 [cited 2018 Jul 14];57(6):720-3. Available from: <https://doi.org/10.1590/S0034-71672004000600018>
19. Kim H-J, Malone PS, Barsevick AM. Subgroups of Cancer Patients with Unique Pain and Fatigue Experience During Chemotherapy. *J Pain Symptom Manag* [Internet]. 2014 [cited 2018 Aug 19];48(4):558-68. Available from: <https://doi.org/10.1016/j.jpainsymman.2013.10.025>
20. Caldeira S, Carvalho EC, Vieira M. Between spiritual wellbeing and spiritual distress: possible related factors in elderly patients with cancer. *Rev Latino-Am Enfermagem* [Internet]. 2014 [cited 2018 Aug 24];22(1):28-34. Available from: <https://doi.org/10.1590/0104-1169.3073.2382>
21. Nóbrega TP. Corpo, percepção e conhecimento em Merleau-Ponty. *Estud Psicol* [Internet]. 2008 [cited 2019 Aug 30];13(2):141-8. Available from: <https://doi.org/10.1590/S1413-294X2008000200006>
22. Carvalho PAL, Malhado SCB, Constâncio TOS, Ribeiro IJS, Boery RNON, Sena ELS. Human care in light of Merleau-Ponty's phenomenology. *Texto Contexto Enferm* [Internet]. 2019 [cited 2019 Sept 07]; 28:e20170249. Available from: <https://doi.org/10.1590/1980-265X-TCE-2017-0249>
23. Caldeira S, Timmins F, Carvalho EC, Vieira M. Spiritual Well-Being and Spiritual Distress in Cancer Patients Undergoing Chemotherapy: Utilizing the SWBQ as Component of Holistic Nursing Diagnosis. *J Relig Health* [Internet]. 2017 [cited 2019 Aug 30];56(4):1489-502. Available from: <https://doi.org/10.1007/s10943-017-0390-4>
24. Fujii A, Yamada Y, Takayama K, Nakano T, Kishimoto J. Longitudinal assessment of pain management with the pain management index in cancer outpatients receiving chemotherapy. *Support Care Cancer* [Internet]. 2017 [cited 2018 Aug 25]; 25(3):925-32. Available from: <https://doi.org/10.1007/s00520-016-3482-x>
25. Tanay MAL, Armes J, Ream E. The experience of chemotherapy-induced peripheral neuropathy in adult cancer patients: a qualitative thematic synthesis *Eur J Cancer Care (Engl)* [Internet]. 2017 [cited 2018 Aug 29]; 26(5):e12443. Available from: <https://doi.org/10.1111/ecc.12443>
26. Tanay MA, Armes J. Lived experiences and support needs of women who developed chemotherapy-induced peripheral neuropathy following treatment for breast and ovarian cancer. *Eur J Cancer Care (Engl)* [Internet]. 2019 [cited 2020 Feb 20];28(3):e13011. Available from: <https://doi.org/10.1111/ecc.13011>
27. Wakiuchi J, Marcon SS, Oliveira DC, Sales CA. Chemotherapy under the perspective of the person with cancer: a structural analysis. *Texto Contexto Enferm* [Internet]. 2019 [cited 2019 Aug 30];28:e20180025. Available from: <https://doi.org/10.1590/1980-265X-TCE-2018-0025>
28. Vianna D, Claro LL, Mendes AA, Silva AN, Bucci DA, Sá PT, et al. Infusion of Life: Patient perceptions of expressive therapy during chemotherapy sessions. *Eur J Cancer Care (Engl)* [Internet]. 2013 [cited 2018 Aug 22];22(3):377-88. Available from: <https://doi.org/10.1111/ecc.12041>
29. Gaston-Johansson A, Reddick B. The relationship among coping strategies, religious coping, and spirituality in African American women with breast cancer receiving chemotherapy. *Oncol Nurse Forum* [Internet]. 2013 [cited 2018 Aug 22];40(2):120-31. Available from: <https://doi.org/10.1188/13.ONF.120-131>

30. Ramírez-Perdomo CA, Rodríguez-Velez ME, Perdomo-Romero AY. Uncertainty in the face of the cancer diagnosis. *Texto Contexto Enferm* [Internet]. 2018 [cited 2019 Aug 30];27(4):1-9. Available from: <https://doi.org/10.1590/0104-07072018005040017>
31. Bonhof CS, van de Poll-Franse LV, Vissers PAJ, Wasowicz DK, Wegdam JA, Révész D, et al. Anxiety and depression mediate the association between chemotherapy-induced peripheral neuropathy and fatigue: Results from the population-based profiles registry. *Psychooncology* [Internet]. 2019 [cited 2019 Aug 30];28(9):1926-33. Available from: <https://doi.org/10.1002/pon.5176>
32. Ulas S, Eyigor S, Caramat I. Quality of Life and Neuropathic Pain in Hospitalized Cancer Patients: A Comparative Analysis of Patients in Palliative Care Wards Versus Those in General Wards. *Indian J Palliat Care*. [Internet]. 2018 [cited 2018 Aug 24];24(3):325-33. Available from: https://doi.org/10.4103/IJPC.IJPC_12_18
33. Tiilikainen E, Seppänen M. Lost and unfulfilled relationships behind emotional loneliness in old age. *Ageing and Society* [Internet]. 2017 [cited 2019 Sept 09];37(5):1068-78. Available from: <https://doi.org/10.1017/S0144686X16000040>

NOTES

ORIGIN OF THE ARTICLE

Extracted from the dissertation – The suffering and spirituality of cancer patients in chemotherapy treatment: systematization of nursing care in the spiritual dimension, submitted in the Graduate Studies Program of Professional Nursing, of Universidade Federal Fluminense, in 2019.

CONTRIBUTION OF AUTHORITY

Study design: Mendonça AB, Pereira ER.

Data collection: Mendonça AB.

Data analysis and interpretation: Mendonça AB, Pereira ER, Magnago C.

Discussion of the results: Mendonça AB, Magnago C, Silva RMCRA, Martins AO, Leão DCMR.

Writing and/or critical review of the content: Mendonça AB, Magnago C.

Review and final approval of the final version: Mendonça AB, Pereira ER, Magnago C, Silva RMCRA, Leão DCMR.

FUNDING INFORMATION

This study was done with the support of the Coordination for the Improvement of Higher Education Personnel (CAPES) - Financing code 001.

APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved by the Research Ethics Committee of Universidade Federal Fluminense, Opinion No. 2.592.770/2018, CAAE: 85411817.2.0000.5243; National Cancer Institute José de Alencar Gomes Da Silva, Opinion No. 2.657.077/2018, CAAE 85411817.2.3001.5274.

CONFLICTS OF INTEREST

There are no conflicts of interest.

HISTORICAL

Received: September 27, 2019.

Approved: March 05, 2020.

CORRESPONDING AUTHOR

Angelo Braga Mendonça

angeloprimax@gmail.com

