

# Meanings of Chronic pain in Breast Cancer Survival

doi: <https://doi.org/10.32635/2176-9745.RBC.2021v67n1.1143>

*Significados da Dor Crônica na Sobrevivência ao Câncer de Mama*

*Significados del Dolor Crónico en la Supervivencia del Cáncer de Mama*

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## ABSTRACT

**Introduction:** Chronic pain is a common problem in breast cancer survivors. **Objective:** Understand the meanings attributed by women breast cancer survivors to the experience of living with chronic pain. **Method:** To reach the objectives, a qualitative research based on hermeneutic-dialectic was carried out in a reference oncology hospital in Rio de Janeiro. Semi-structured interviews were conducted with six long-term breast cancer survivors between July and October 2018. **Results:** Four broad social meanings are highlighted in the empirical material: pain as a result of treatment; pain as a kinesthetic process; pain as a tribute to the disease suffered; and pain as an expression of affections and attachments. These are narratives that accentuate the experience lived while searching for an explanation for the full pain felt. Survival is experienced as a process of transition, acceptance and construction of new biographical identities that are only possible to be understood and cared for taking into account the biological, emotional, social and spiritual dimensions. **Conclusion:** The narratives start from a pain as fragmentation, murmur and monologue of the body, to a situation of conviviality, expression of affections and acceptance of pain as a transition to survival. The study reinforces the need for structuring a care line that has as basic core the active and qualified listening of pain narratives for the development of humanized care in cancer survival.

**Key words:** Chronic Pain; Survivorship; Breast Neoplasms; Qualitative Research.

## RESUMO

**Introdução:** A dor crônica é um problema comum em sobreviventes de câncer de mama. **Objetivo:** Compreender os significados atribuídos por mulheres, sobreviventes de câncer de mama, à experiência de viver com dor crônica. **Método:** Para alcance dos objetivos, realizou-se uma pesquisa qualitativa com base na hermenêutica-dialética, em hospital de referência em oncologia do Rio de Janeiro. Foram realizadas entrevistas semiestruturadas com seis sobreviventes de câncer de mama de longo prazo, entre julho e outubro de 2018. **Resultados:** Quatro abrangentes sentidos sociais ganham relevo no material empírico: dor como consequência do tratamento; dor como um processo cenestésico; dor como tributo à doença sofrida; e dor como expressão de afetos e apegos. São relatos que apontam para um balanço da experiência como busca de uma explicação para a dor total sentida. A sobrevivência é experienciada como um processo de transição, aceitação e construção de novas identidades biográficas que só são possíveis de serem compreendidas e cuidadas, levando-se em conta as dimensões biológica, emocional, social e espiritual. **Conclusão:** As narrativas partem de uma dor como fragmentação, murmúrio e monólogo do corpo, para uma situação de convívio, expressão de afetos e aceitação da dor como transição para sobrevivência. O estudo reforça a necessidade da estruturação de uma linha de cuidados que tenha na escuta ativa e qualificada das narrativas de dor o ponto básico para o desenvolvimento de um cuidado na sobrevivência ao câncer humanizado.

**Palavras-chave:** Dor Crônica; Sobrevivência; Neoplasias da Mama; Pesquisa Qualitativa.

## RESUMEN

**Introducción:** El dolor crónico es un problema común en los supervivientes de cáncer de mama. **Objetivo:** Comprender los significados atribuidos por las mujeres, sobrevivientes de cáncer de mama, a la experiencia de vivir con dolor crónico. **Método:** Se realizó una investigación cualitativa con base en la hermenéutica-dialéctica, en hospital de referencia en oncología de Río de Janeiro. Se realizaron entrevistas semiestructuradas con seis sobrevivientes de cáncer de mama a largo plazo entre julio y octubre de 2018. **Resultados:** En el material empírico se destacan cuatro significados sociales amplios: dolor como resultado del tratamiento; El dolor como proceso cenestésico; El dolor como tributo a la enfermedad sufrida; y el dolor como expresión de afectos y apegos. Se trata de relatos que apuntan a un equilibrio de la experiencia como búsqueda de una explicación al dolor total sentido. La supervivencia se vive como un proceso de transición, aceptación y construcción de nuevas identidades biográficas que solo se pueden comprender y cuidar teniendo en cuenta las dimensiones biológica, emocional, social y espiritual. **Conclusión:** Las narrativas parten de un dolor como fragmentación, murmullo y monólogo del cuerpo, a una situación de convivencia, expresión de afectos y aceptación del dolor como transición a la supervivencia. El estudio refuerza la necesidad de la estructuración de una línea de cuidados que tenga en la escucha activa y calificada de las narrativas de dolor el punto básico para el desarrollo de un cuidado en la supervivencia al cáncer humanizado.

**Palabras claves:** Dolor Crónico; Supervivencia; Neoplasias de la Mama; Investigación Cualitativa.

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## INTRODUCTION

Breast cancer, except non-melanoma skin cancer, is the second most common worldwide and among women with nearly 2.1 million new cases in the world<sup>1</sup>. In Brazil, the estimates indicate for each year of the triennium 2020-2022, 66 thousand new cases of breast cancer<sup>2</sup>. Because of new forms of diagnosis and treatment, the number of persons who manage to survive for long periods is increasing, bringing innumerable challenges to the social and health system.

Since the decade of 1980 the concept of survival in oncology is discussed. For Mullan<sup>3</sup>, survivorship commences when the disease is diagnosed because it is in this moment that the patients are compelled to cope with their finitude and adjustments start to be made for their immediate and long-term future. The author believes that the experience of survival should be understood as a long journey, not only the pursue of cure and/or treatment but also understanding and mitigation of the clinical, emotional and social impacts throughout the process since the diagnosis until the end of the individual's life. Pain is one of the problems that affects cancer survivals, it can take months, years or even the whole life<sup>4</sup>.

Mullan's<sup>3</sup> definition of survivorship, in the perspective of the pain encompasses the disease since the diagnosis (when the tumor itself can be the cause of the pain), through the treatment (usually resulting in pain) until a state of cure (where more persistent forms of pain are encountered frequently)<sup>5</sup>.

In this sense, more than a definition in biomedical terms, chronic pain is understood as an unpleasant persistent sensory and emotional experience associated to a potential or actual tissue damage or described in terms of such damage. Pain, therefore, is what the individual says it is feeling and suffering<sup>6-8</sup>. In clinical terms, the International Association for the Study of Pain (IASP) defines chronic pain as a recurring or persistent pain for more than three months and can be caused by cancer itself and/or its treatment<sup>8</sup>.

All breast cancer therapeutic modalities alone or combined have the potential to cause chronic pain<sup>9</sup>. 41% of breast cancer survivors, it should be noticed, complain of pain from one to five years post-treatment<sup>4</sup>.

Chronic pain in breast cancer survivors has little known elements and unaddressed in the current lines of care and protocols, mainly in relation to issues that transcend the biomedical approach. Few studies address and record the peculiarities and necessities of this group from its experiences and what they lived through<sup>4</sup>.

The objective of this article is to understand the meaning breast cancer women survivors attribute to the

experience of living with chronic pain. It is expected that its results provide health professionals more information about the challenges and singular difficulties long term breast cancer survivors with chronic pain must cope with in order to develop proper therapeutic interventions to improve care and quality of life.

## METHOD

Exploratory, qualitative, hermeneutic-dialectic-based study. The union of hermeneutic and dialectic allows the concurrent conduction of comprehensive and critical study of the symbolic attributions of life experiences<sup>10</sup>.

The study was carried out in a reference oncology hospital of Rio de Janeiro, from July to October 2018. The selection of the participants was based in convenience sampling from survey of medical charts according to the following inclusion criteria: women older than 18 years, neoplastic disease-free, with time of diagnosis of any subtype of breast cancer of at least five years with medical diagnosis of chronic pain resulting from oncology treatment, registered and followed up in pain control specialized clinic who completed the oncologic treatment.

Six semi-structured individual interviews guided by a specific study-focused script targeted to survival and chronic pain control resulting from the oncologic treatment produced the material. An oncology expert investigator conducted the interviews. Given the interpretative-critical tradition to which this study is aligned with, the sample close out was based in the principle of "information power"<sup>11</sup>.

The participants were invited to join soon after their consultations at the pain ambulatory and none of them refused. The one-time interviews lasted 40 minutes in average in secured rooms at the hospital unit, tape-recorded and transcribed later for comprehensive reading. Sociodemographic (age, race, education, marital status, religion, place of birth and origin) and clinical profiles (and antineoplastic treatment, time since the end of the treatment, disease-free survival, treatment-related time of pain, time of follow-up at the Pain Clinic) of the participants were obtained.

For organization, analysis and interpretation of the material the following procedures were carried out: (a) comprehensive reading; (b) coding of the material and identification of the subjacent feelings from the interviewees' narratives; (c) problematization of ideas and feelings present in the narratives and articulation with sociocultural meanings; (d) elaboration of the synthesis of the empirical data, information from other studies about the theme, theoretical/conceptual reference of the study and additional theoretical inputs deemed necessary.

The investigators categorized and analyzed jointly considering convergences and divergences and recurrence of citations from the narratives. The interviews were transcribed literally. The authors validated each transcription independently. All the transcriptions were verified and compared with the original recording and field notes of the interviewer. The coding of fragments of the narratives from the transcriptions followed the same notation: E (interviewee), followed by Arabic number according to the chronologic order of the interviews. It was adopted the thematic analysis of the narrative aligned with the critical-interpretative approach to interpret the material articulated with the clinical and sociocultural contexts<sup>12</sup>.

The theoretical reference that served as base for the analysis and synthesis of the meanings of the empirical material was the conception of pain from a biopsychosocial model where chronic pain is understood as a reciprocal and dynamic process among biological, psychological, sociocultural and spiritual variables<sup>13</sup>. Within this conceptual horizon, it can be found: the definition of IASP<sup>6</sup>; the classification of Cicely Saunders of total pain through its encompassing and full vision of pain and palliation<sup>14</sup>; Le Breton<sup>15-17</sup> and Zborowski<sup>18</sup> sociocultural approaches of pain. All of them functioning as counterpoint to the strictly biological and medicalizing approaches that pursue to control pain within a standard.

The Institutional Review Board of the institution, CAAE: 91180218.7.0000.5274 approved the study which complied with the national clinical trial legislation.

## RESULTS AND DISCUSSION

The participants' profile encompasses ages between 48 and 67 years, most of them retired (83%) and single (66%). Two (33%) did not complete elementary school, two (33%) completed elementary school, one (16%) completed high school and one (16%), completed university. Half of them claimed they were Caucasian and half, Brown. 50% claimed they were Catholic, 33%, Evangelic and 16% did not declare their religious belief. Four interviewees (66%) were born in Rio de Janeiro, one (16%) in Minas Gerais and one (16%) in Paraíba. Despite the profiles' heterogeneity, there was no difference in relation to the understanding and difficulties in attributing meanings and coping with chronic pain.

Regarding clinical history, all of them underwent surgical and chemotherapy treatment for breast cancer and 83% submitted to radiotherapy and axillary emptying. More than half of the participants (66%) have also submitted to hormone suppression (66%). The time of cancer diagnosis varied from five to 15 years (median of 8.5 years). The time of oncologic treatment related pain

ranged from four to 14 years (median of 8.5 years). It was noticed a delay of the beginning of the specialized follow up at the Pain Clinic, considering that the median time to begin follow up at the clinic was 7.5 years (ranging from two to nine years).

The results of the present article present the most relevant meanings highlighted in the interviews. These are narratives that point to a summary of the experience in search for an explanation for the total pain felt as a unique, integrated, and multidimensional experience<sup>14</sup>, encompassing physical, emotional, social, and spiritual suffering. The narratives of the categories "Pain as consequence of treatment", "Pain as a kinesthetic process" and "Pain as a tribute to the disease suffered" are marked by the experience of a singular suffering that coexist with the survival of these women. In the category "Pain as expression of affections and attachments", the narratives point out the construction of new feelings and meanings for the pain felt, that is, a process of transition, acceptance and construction of new biographical identities that are possible to be understood only and cared considering the biological, emotional and social dimensions of these women as unique subjects in the expression and enunciation of their pain suffered.

These meanings and feelings approach similar studies about the theme of chronic pain in breast cancer survivors<sup>19-24</sup>. These studies describe experiences lived of suffering and uncertainties about the future. Likewise, these are studies where the participants make their pains normal in many ways: as a necessary step towards recovery, as proof of the treatment effectiveness or even as a permanent condition which you must learn to live with<sup>20</sup>. It is clear in all the studies the necessity the breast cancer survivors have to be well informed, cared and investigated in their complaints and narratives, since chronic pain compromises the quality of life of these patients<sup>21-24</sup>.

### PAIN AS A CONSEQUENCE OF THE TREATMENT

Pain as a consequence of the treatment translates the meaning of the formulation still fragmented of an explanation of the pain as a biological process involving the oncologic treatment:

The doctor [of the Pain Clinic] told me there are persons who underwent surgery and do not feel anything. And there are others that have [pain] for the rest of the life. (...) It started after all this, the surgery, chemo, radio, after they did all this, after all this, before, there was nothing (E6).

In this and other narratives, the participants identified the physical aspect of the body pain, but it is not enough to explain it:

Probably must be where they cut, from where they took out something, it must have hurt something (E4).

It was because of the chemotherapy treatment. It was a nervous lesion resulting from chemotherapy (E2).

Le Breton<sup>15,16</sup> reinforces that anatomy and physiology fail to explain the personal, social, and cultural and even contextual variations that affect the individuals at the moment of a painful experience. This occurs because the attitude towards pain is not merely mechanic or physiologic, but also mediated by culture, individual adjustments and subjective meanings attributed to its presence.

According to Le Breton<sup>16</sup> anthropologic approach, pain is impregnated with the social, the cultural and the relational, the result of education. This situation surfaces for these study participants, furthermore with the biomedical explanations learned and gathered from cancer diagnosis and treatment.

I understood from what the physician and I talked. I learn from anyone or somebody, I gather something was severed from the nervous system and it is tender (E1).

The explanation of the pain, however, does not fall out from the connection with social symbolizations<sup>15,16</sup>. Zborowski<sup>18</sup> in his sociologic approach about the pain indicates that reactions to pain as expressed by participants of different cultural groups do not necessarily reflect similar attitudes to pain. These reactive patterns in their manifestations can have different functions and serve to different purposes.

IASP<sup>6</sup> defines pain as an “unpleasant sensory and emotional experience associated to an actual or potential tissue damage or described in terms of such damage”. Therefore, pain is what the individual says it feels and suffers. In this sense, “total pain”, a term used by Cicely Saunders, is a unique, integrated and multidimensional experience<sup>14</sup>, encompassing all of the physical, emotional, social and spiritual suffering where the nature of the pain in the body goes beyond the physical aspects and of a purely organic structure whose logic and functioning is symbolic<sup>25</sup>. As the individual is singular, it is not possible to surmise that everyone will respond similarly to the external interventions or will keep their responses equally in the long-term<sup>18</sup>.

Therefore, it was concluded that the pain resulting from the oncologic treatment is symbolic and manifested functionally as norms of biomedical jargon and logic

that rule and permeate the patients’ interactions, social justifications, and narratives. Regardless of this, there are other social mechanisms that can impact the expressions and manifestations of the pain felt. Health professionals should pay attention to these relations to better support their patients in their necessities of care.

## PAIN AS KINESTHETIC PROCESS

Pain as a kinesthetic process defines the total pain felt as a pool of perceptions and feelings interconnected by sensorial processes. They are representations that carry the consciousness and emotion of the own body, its position, its movement, its posture in relation to the world around and in relation to its several parts and segments.

Sometimes, it seems it is going to tear up, I don’t know what is this that pulls so strongly, you understand? [...] Sometimes, you got a shock, at the same time, it is itching, and you feel nothing because all this is dead. Then you scratch, scratch but you don’t find it, where is the itching? (E5).

This and other narratives of this category approach the recent proposal of Williams and Craig<sup>26</sup> for a new definition of Pain for IASP<sup>6</sup>, where pain is “an unpleasant sensory, emotional, cognitive and social experience”<sup>26</sup>. A definition that strengthens even more the perspective of the biopsychosocial model of the pain, where the pathways of pain are feeling, transmission, perception and reaction and the measures of sensitiveness like all the other mechanisms of pain are individual<sup>24</sup>.

I feel like I am in a meat grinder. (...) I squirm just the same. What you do with the meat, to grind the meat. (...) Or a tractor run over me, something like that. It seems I’m broken inside (E2).

The full pain felt translates into suffering formed by sensorial and emotional elements that permeate the socio-symbolic explanations and narratives of these patients. It is a reminder to health professionals that, beyond social mechanisms, the emotional burdens and influences impact the expressions and manifestations of the pain felt. To ignore them means important gaps in a full and humanized care.

## PAIN AS A TRIBUTE TO THE DISEASE SUFFERED

Pain as a tribute to the disease suffered translates a feeling of offering permission to feel and suffer in exchange of remission/cure of cancer. The narratives portray the full pain felt as a karma, a payment for something that intends to cure cancer.

When I got rid of the disease and I had to pay dearly for this. [...] As I got rid of the disease, this is a burden I have to carry now. But it is not very nice, have to pay like this. But, God forbid, never more. I would rather live with the pain than die because of it, instead. God forbid (E1).

For Miceli<sup>27</sup>, pain has a subjective character also and has been historically understood and explained as myth, as mysticism or religiously. Pain and suffering would be inseparable and interpreted socially as punishments imposed by the Gods or even martyrdom and probations to purify and save the soul. Such concepts appear to be in the collective imaginary, since nowadays, patients still blame themselves for the disease and pain, believing that to grow and mature, you need to suffer.

I think this is part of the... How do you say this? I got rid of cancer, but it left a print, you see? (E4).

Cancer was there. The process ended, it ended all. But this ... something is left behind from what we went through, it is a pain, a pain. Do you believe I still feel I'm stuck to cancer? I feel I'm stuck to cancer (E5).

Although bringing a negative sense as seen in the narratives, pain as a tribute and a burden to be cope with, has a meaning that, at the same time, is a remembrance of its survival and hope to continue living. This allows the participants to succeed in coping and give meaning to their lives and the total pain felt.

Health professionals should understand and respect their patients utterance, and at the same time, encourage and guide them about what takes to live a life with pain, considering the possibility of innumerable treatments, and clinical, psychologic care that can help to mitigate the suffering.

## PAIN AS EXPRESSION OF AFFECTION AND ATTACHMENTS

Pain as expression of affection and attachments translates a feeling of resignification, adaptation, and acceptance to live with the pain felt as a mosaic of affection and fondness, of dismay, anger, fight, adaptation, and acceptance.

And I learned to live with. In the beginning it wasn't easy, it was quite tough. I was thinking: 'My God, how this is going to be? Have to live with this like that?'. It is not cool you feel pain and have to learn to live with it. And we end up learning. Eventually, you learn to live with this (E1).

I was going to say some nasty word... It sucks, it sucks (...) I tell you, there are days, (...). I thought

in asking to sever my arm to see if it gets better. Because it hurts (...) (E4).

According to McCracken<sup>28</sup>, the acceptance of the pain leads the patient to know it and control it better, endeavoring to live a satisfactory life, in spite of it. This implies in narratives of lower intensity, less anxiety and depressive symptoms and less physical and psychosocial disability.

But I have to live with pain. It bothers me daily, of course it does. But I'm not going to lay in bed and moan, cry, getting my depression even worse (E3).

Because it constrains you, you see? I don't know the effect for you, but I think it should end, it should. Because you went through the whole process. (...) You were compelled to take these medications every day, every day. If you don't take it, you feel pain (E5).

The survivors' acceptance of the pain was not only a rational decision, but a long process of acceptance and formulation of a new identity involving a complex mixture of unpleasant and uncertain emotions with chronic pain and living with the suffering in the future<sup>29</sup>. While the word pain concentrates in a part of our body, that part that hurts, and, as a matter of fact, disarticulates, the word suffering addresses more the attitude with which the individual can endure this pain and live with it.

Then, I live with my pain. (...) Now, I accept, it's an acceptance I have in my life that must submit to the treatment, did you understand? (E5).

(...) in the beginning it was tough to accept, very tough. Now, I know how it works. But in the beginning was very difficult. (...) you have to adjust. This is the truth, I have to adjust to live my life with pain (E2).

Essentially, suffering is an experience with alterity<sup>30</sup>. The other is always present for the suffering subjectivity. The later seeks the other with its pledge and makes a demand<sup>30</sup>. For Bordelois<sup>31</sup>, the sufferer is compelled to raise pain in its arms as it was a child and summon its entire energy to keep standing, taking it, asking for help, begging to be heard<sup>30</sup>.

This attitude is about the vital and moral possibility of integrating pain in its life without waiving it from it. Therefore, its dimension of activity where dialogue is always present in the experience of suffering.

What I felt before is ... now I'm another person. Because now, I live with the disease [pain] more easily, quite more easily (E1).

The resignification of the pain through the expression of affection is the path the participants presented as vital and identity processes<sup>32</sup> of adaptation and living with pain. The recognition of this process helps both the health team and the patients to provide the best practices and care in clinical situations of chronic diseases where this kind of pain felt is paramount.

## CONCLUSION

The union of hermeneutic with dialect in this article favors a wider comprehension of the experience of chronic pain in long-term breast cancer survivors. Survival is experienced as a transition, acceptance process and construction of new biographical identities that are possible only to be understood and cared within the biological, emotional, social, and spiritual dimensions.

The results suggest an explanation for the pain felt from an assemblage of the experience the interviewees lived. Four comprehensive social meanings stand out from the empiric material. These meanings in biographical terms point to the acceptance and construction of a new identity through the expression of a singular suffering resulting from the total pain these survivors felt. The narratives move from a pain as fragmentation, murmur, and monologue of the body towards a setting of living with, expression of affection and acceptance of the pain as transition to survival.

The study reinforced the necessity of structuring a line of specialized care as implications for the practice at primary, secondary, curative, and palliative levels grounded in the early identification, treatment, and rehabilitation of the chronic pain. Humanized care in cancer survival must be centered in active and qualified listening of the narratives of pain. Care and treat these survivors require not only strictly biological or merely psychic considerations. Integrated emotional, family, sociocultural and economic issues should be weighed.

The thorough analysis of the wide universe of chronic pain associated to the phases of breast cancer survival was not carried out, and the restriction of the field research to one follow up facility of chronic pain are the limitations of this article. As potential unfolding from this article, the importance of increasing the number of studies with long-term breast cancer survivors with chronic pain, mainly in relation to the necessities and actual possibilities of the National Health System to meet them.

## CONTRIBUTIONS

Paloma Gomes contributed substantially for the study conception and/or design, analysis and/or interpretation

of the data and wording. Fernando Lopes Tavares de Lima and Antonio Tadeu Cheriff dos Santos contributed substantially for the study design, analysis and/or interpretation of the data and critical review. All the authors approved the final version to be published.

## DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

## FUNDING SOURCES

None.

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Recebido em 6/7/2020  
Aprovado em 15/9/2020