

## Stressors in Breast Cancer Post-Treatment: a Qualitative Approach

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With the increasing effectiveness of breast cancer treatment, the scientific interest in investigating the quality of life of survivors has increased. However, research addressing the post-treatment period is still scarce. The aim of this study was to identify the stressors present in the lives of women in the one to five years post-diagnosis period. The sample was composed of 16 women assisted at a specialized mastectomy rehabilitation service. Data were collected through semi-structured interviews and analyzed using content analysis. The results indicate conflicts with self-image and alteration in the feeling of autonomy, fear in relation to the evolution of the condition, feelings of guilt about the disorder generated in the family, experience of disturbing social situations and a desire to return to their professional occupation. These results reveal the existence of stressors in this phase and the importance of support offered by psychosocial rehabilitation services for this population.

Descriptors: Breast Neoplasms; Rehabilitation; Stress, Psychological; Mental Health; Adaptation, Psychological.

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## **Estressores pós-tratamento do câncer de mama: um enfoque qualitativo**

Com a crescente resolutividade do tratamento do câncer de mama, tem aumentado o interesse científico pela investigação da qualidade de vida das sobreviventes. No entanto, ainda são escassas as pesquisas que abordam o período pós-tratamento. Este estudo teve por objetivo identificar os estressores presentes na vida de mulheres, no período de um a cinco anos pós-diagnóstico. Foram investigadas 16 mulheres, atendidas em um serviço especializado em reabilitação de mastectomizadas. Os dados foram coletados mediante entrevista semiestruturada e analisados por meio da análise de conteúdo. Os resultados indicaram conflitos com a autoimagem e alteração na sensação de autossuficiência, medo em relação à evolução do quadro, sentimento de culpa pelo transtorno gerado na família, vivência de situações sociais perturbadoras e desejo de retornar à ocupação profissional. Esses resultados reforçam a existência de estressores nessa fase e a importância do apoio oferecido pelos serviços de reabilitação psicossocial, junto a essa população.

Descritores: Neoplasias da Mama; Reabilitação; Estresse Psicológico; Saúde Mental; Adaptação Psicológica.

## **Factores estresantes del post-tratamiento del cáncer de mama: un enfoque cualitativo**

Con la creciente resolutividad del tratamiento del cáncer de mama, ha aumentado el interés científico por la investigación de la calidad de vida de las sobrevivientes. Sin embargo, todavía son escasas las investigaciones que abordan el período post-tratamiento. Este estudio tuvo por objetivo identificar los factores estresantes presentes en la vida de mujeres en el período de uno a cinco años post-diagnóstico. Fueron investigadas 16 mujeres atendidas en un servicio especializado en rehabilitación de mastectomizadas. Los datos fueron recolectados mediante entrevista semiestruturada y analizados por medio del análisis de contenido. Los resultados indicaron conflictos con la autoimagen, alteración en la sensación de autosuficiencia, miedo en relación a la evolución del cuadro, sentimiento de culpa por el trastorno generado en la familia, vivencia de situaciones sociales perturbadoras y, deseo de retornar a la ocupación profesional. Esos resultados refuerzan la comprobación de la existencia de factores estresantes en esta fase y la importancia del apoyo ofrecido por los servicios de rehabilitación psicossocial junto a esa población.

Descriptores: Neoplasias de la Mama; Rehabilitación; Estrés Psicológico; Salud Mental Adaptación Psicológica.

## **Introduction**

The survival of breast cancer is considered to be a process that begins at diagnosis and does not cease, lasting until the end of the life<sup>(1)</sup>. Studies have shown that survival is associated with several changes that impact the life of the woman in different phases, each with its specific demands, which affect the psychosocial adjustment in a singular manner<sup>(2)</sup>.

After the impact triggered by the diagnosis, the first year is filled with treatment, which includes surgery to remove the tumor mass, chemotherapy, radiotherapy and, in some cases, hormone therapy<sup>(3)</sup>. After this period, patients must continue to submit to periodical examinations to monitor their condition. From the second to the fifth year, the period herein referred to

as *post-treatment*, the medical follow-ups, though less frequent, continue in order to trace the possibility of metastasis or eventual disease recurrence. If there is remission, the patient enters the so-called disease-free period<sup>(1)</sup>, where the follow-up examinations are spaced progressively, usually retaining a frequency of annual monitoring for control.

In examining the articles relating to the topic of breast cancer published in this journal in recent years it was perceived that the recent scientific literature has been occupied with the psychosocial aspects of women with this diagnosis<sup>(4-6)</sup>. However, the work in the area is still focuses more on the diagnosis and treatment period, with a lower volume of publications dedicated to patients in the post-treatment period<sup>(7)</sup>. The rehabilitation that the survivors of breast cancer require is a process that takes place permanently. For this reason, studies that address the psychosocial condition in the post-treatment period are required in order to understand the specificities and needs, so as to contribute to the direction of studies related to care production.

Given these assumptions, the aim of this study was to identify the stressors experienced during the post-treatment period of breast cancer. This proposal is justified in view of the need for research that focuses on this phase of survival, to support intervention proposals at the rehabilitation stage.

## Method

### Study type

A qualitative study with a cross-sectional descriptive design was carried out.

### Theoretical framework

Stress can be conceptualized as a process of adapting the organism to an aversive event. In this process, triggered by stimuli known as stressors, the individual responds with physiological, cognitive and behavioral alterations<sup>(8)</sup>.

The state of stress is related to an adaptive response of the organism. This is a necessary mechanism, since it makes the individual more aware in dangerous situations and can even act as a survival mechanism in some cases. However, the stress level must be maintained at an appropriate level, because levels below those necessary generate a state of lack of reactivity, whereas levels above can lead to exhaustion of the organism, increasing its susceptibility to the development of physical and mental diseases<sup>(9)</sup>.

The probability of developing negative psychosocial repercussions, such as installation of a condition of stress is more likely the higher the intensity, frequency and duration of the set of stressors to which the individual is exposed. However, it is known that the interpretation of the stimuli, as well as the choice of responses for dealing with them, beyond the characteristics of the event, depend on the personal resources and environmental conditions available<sup>(10-11)</sup>. The form of coping, therefore, depends on the subjective evaluation that the individual gives to the stressor, which means that each person may react differently to the same stimulus.

This study focused on the aspect of the theory of stress related to stressors, defined as any stimulus capable of provoking the breakdown of internal homeostasis of the organism. In other words, this work sought to identify the situations related to breast cancer, which were considered by participants as responsible for altering the sense of psychological well-being<sup>(12)</sup>.

The experience of the breast cancer post-treatment period exposes women to many stressors, consistent with coping with a complex chronic disease that threatens their physical integrity and requires intensive care. Besides the physical consequences, emotional, family, work and life relationship repercussions also persist as a result of intrusive treatment and the uncertainties about the evolution of the condition. This whole condition of life tests the adaptive capacity of the patient<sup>(2)</sup>.

Knowing the specific stressors of the post-treatment period, considering the demands of adjustment that they raise, is essential for the adequate planning of assistance activities for rehabilitation purposes.

### Participants

The sample was composed of 16 women who had undergone mastectomy (total or partial), radiotherapy and/or chemotherapy and who were within the period between of one to five years post-diagnosis. In addition to these inclusion criteria, the women who agreed to participate voluntarily in the research and signed the free prior informed consent form were recruited.

The sample was constituted from a preliminary survey of the medical records of the Center for Teaching, Research and Assistance in Rehabilitation of Mastectomies (REMA), of the Department of Maternal-Infant Nursing and Public Health of the School of Nursing of Ribeirao Preto, University of Sao Paulo. From this list, comprised of women who met the pre-established criteria, the number of participants was limited by the criterion of data saturation, understood as the point

where the information being analyzed became recurrent and repetitive<sup>(13)</sup>.

The participants were aged between 35 and 75 years (mean:  $61.06 \pm 11.46$ ) and were between 12 and 44 months into the post-diagnosis period (mean:  $26.44 \pm 9.70$ ). Regarding the mammary surgical procedure performed, nine women (56.3%) had undergone partial removal of the breast (conserving surgery), whereas seven (43.8%) had the entire breast removed (total mastectomy). Eleven women (68.8%) underwent chemotherapy procedure, and the number of cycles varied between six and 12. Regarding radiotherapy, 14 women (87.5%) underwent this procedure, and the number of cycles varied between 25 and 100. When collecting data, 12 women (75%) were on hormone therapy.

### Instruments and materials

The semi-structured interview, a portable tape recorder and cassette tapes were used for data collection. The semi-structured interview is characterized by the prior formulation of questions, based on theories and hypotheses related to the object of study, extracted from literature and from the previous experience of the researchers. There is flexibility in the sequence and on the examination of other issues that may arise during the interview, provided they relate to the objective of the study, which can generate new hypotheses originating from the responses obtained.

The instrument consisted of two parts: the first investigated the sociodemographic and clinical characteristics of the participants; and the second encompassed a script for the semi-structured interview with questions related to perceived stressors in the post-treatment period. The interview script, specially formulated for the purpose of this study, was previously examined in terms of clarity and appropriateness of language, in a pilot study with three patients, who were later discarded from the research.

### Procedure

Data were collected between May and December 2003. The interviews were conducted individually, face-to-face and audio-recorded with the consent of participants, in a place (rehabilitation service room or participant's residence) with adequate conditions of comfort and privacy. The audio recordings were transcribed verbatim and in full, concurrent with the data collection. To organize the results of interviews, the interviews were subjected to content analysis,

identifying the units of meaning contained in the speech of participants<sup>(14)</sup> that had a relationship to the definition of stressors<sup>(12)</sup>. The project was approved by the Research Ethics Committee of the School of Nursing of Ribeirao Preto (process nº 0368/2003).

## Results and Discussion

The narratives obtained allowed the identification of a wide range of life situations of participants. These situations were, for them, evaluated as stressful. Such events could be classified into four units of meaning, according to the source of origin: 1) the body itself, altered by the treatment of breast cancer, 2) the mind, by the recurrence of thoughts and feelings regarding their own health condition, 3) the social universe, evaluated by conflicts experienced both in the family as well as in broader social relationships, 4) the work aspect, through changes experienced in productive capacity. With this, it is realized that the post-treatment period of breast cancer, far from being free from "new" sources of stress, proved to be a time when the adaptive necessity to the condition imposed by the illness was still present in the various aspects of the life of the participants.

### 1) Stressors originating from the body changed by the treatment: The scars of cancer

Among the stressors arising from the interaction with physical sequelae of the treatment of breast cancer, the loss of the breast was significantly mentioned. In this study all participants had undergone surgery on the breast which had been partially or totally removed. The scientific literature is rich in accounts of the loss of a body part being experienced as harm to the self-image and, therefore, affecting the psychic condition of the person affected, triggering a painful process of mourning<sup>(15)</sup>. Among the surgical interventions for various types of cancers, breast cancer, leaves a visible mark on the body, reminding the women of the situation of permanent loss. In addition, psychological and cultural meanings attributed to the female organ potentiate traumatic experiences. The breast is a corporal symbol of sensuality, sexuality and maternity, i.e. it is an organ that is intimately related to the issue of female identity, a receptacle of multiple and deep personal meanings<sup>(5)</sup>.

According to the literature, surgery for removal of tumor mass does not only change just the body image of women, but also their self-image<sup>(2,16)</sup>. In this study five participants reported experiences related to a change in self-image. *I know that I don't have a breast, understand? And*

*that the breast is one of the feminine attributes, understand? Then I know this. (5) Ah, it's a mutilation. When you go to put on your clothes.... it looks ugly. (12)*

Other physical sequelae resulting from treatment for breast cancer were verbalized, such as limitations in movement due to, for example, the removal of axillary lymph nodes or burns resulting from radiotherapy. *I've always been a very resourceful person in the work, that whole thing, and I'm limited now, right. Cannot take the broom, cannot do this, cannot do that, cannot do ironing, and this, for me, is a hindrance, because I always did, right, work on my little piece of land in my garden. (15)*

Participants explained that the lymphedema in the arm ipsilateral to the operated breast limited their lives. Of the eight participants who had developed this condition, five verbalized the inconvenience brought about by swelling in the arm. Of the eight participants who had not developed it, four reported fear of it and saw the possibility of contracting it as a permanent worry in their lives. *God save me from those swollen arms, holy mother. (11)* The findings of this study corroborate the literature, which indicates lymphedema as the most feared of the sequelae resulting from breast cancer treatment<sup>(17)</sup>.

## **2) Stressors originating from the mental universe: Narratives concerning the fear and guilt**

Cancer treatment has benefited from technological innovations that result in increased rates of survival. Even so, neoplasms bring up the sensation of vulnerability faced with close contact with finitude and the possibility of death.

Studies show the fear of relapse as one of the aspects most related to chronic stress in women undergoing rehabilitation for breast cancer<sup>(18-19)</sup>. Present in the discourse of eight participants was the discomfort experienced by the possibility of recurrence of the disease, through intrusive thoughts based on conceptions that cancer is incurable, it can spread at any moment and can strike any part of the body by metastasis. *For example, you broke a leg: you go there and plaster, don't you plaster? Now the cancer may come to the other parts of the body. When you have cancer once, you're never free, like, never again will I have. (8)*

In some moments of post-treatment the contact with the possibility of relapse becomes more acute, as happens on the eve of the periodic consultations<sup>(20)</sup>. Four participants mentioned anticipatory anxiety in their discourses, experienced during these periods of waiting for the next routine examination, as well as worrying about the results. The fears were intrinsically related to

the uncertainty about the consistency of the improvement and the possibility of recurrence. *This afternoon I'm going to do a mammogram. I'm worried. (3)*

There were also two women who expressed the fear of the experience of a terminal state, where they imagined being unable to care for themselves and totally dependent on care from others. Interpreted in the light of their own discourses, the terminality was related to loss of independence and autonomy, as well as the possibility of becoming an inconvenient burden to family members. *I'm 75 years old and until now I have been an independent woman. The only fear I have is to stay in bed suffering and to make work for others. (6)*

The possibility of not being able to care for children was a concern in the narrative of one participant. Here, the focus has been placed on the fear of failing to adequately perform her role as a mother, which suggests anxiety faced with the possibility of disruption of one of the support pillars of female identity. The implicit meaning of this experience leads to feelings of guilt for having been sick and, thus, to affect, adversely, the organization of the quotidian routine and the routine of family members. It calls attention to the fact that this woman was younger (44 years) than the mean of the participant population of this study and, unlike most, child-rearing was still continuing and was a source of intense concern.

The low number of participants who referred to a fear of failing to complete the process of education of children cannot be considered an estimate of the occurrence of this stressor in women in the post-treatment period of breast cancer. This is because the mean age of study participants (61 years) pointed to an essentially elderly group who, therefore, had already completed the task of rearing their offspring and preparing them for life. *We think about not being able to get to the end, as is said, to care for them (children) or to deliver the position they need. Because not about me dying, I think only about the way I leave my sons. It's a thing we cannot avoid, as well. (1)*

Being a mother and being diagnosed with breast cancer engenders an arduous and constant need for conciliation of roles<sup>(18,21-22)</sup>. But in addition, another adversity afflicted these women: the possibility of the occurrence of breast cancer in their daughters, due to the knowledge of risk factors related to heredity. Four narratives encountered in this study were about the increased risk of developing breast cancer in the daughters, since, they, their mothers, had the disease. Here, again, the guilt for the illness was made explicit. The participants also speculated that if breast cancer

had happened or would happen to a daughter, they would feel much more impacted than they felt when they themselves were affected. *The only thing that worries me is the disease in my daughters. Not in me.* (6)

### 3) Stressors originating from social relationships: Out of rhythm with the world

Messages originating from the social environment influence the way women view, interpret and confront their disease<sup>(23)</sup>. The influence that family and social context can perform during the post-treatment process can occur in both a positive and negative way. From the narratives of the women in this study it can be appreciated that various aspects of social life were experienced as stressful, i.e. acted negatively on psychosocial adjustment, such as the deaths of people they knew due to cancer or contact with sick people, which somehow evinced their fragile situation. Death due to cancer, of people of the family and social network was highlighted by five women as a stressor event. The speed with which cancer can advance and the suffering that comes from living with terminal patients led them to the idea of a troublesome, stealthy and potentially fatal disease. *A neighbor, who helped me when I got sick, got cancer and died really quickly. Also I have a young friend that her one is spreading everywhere.* (9)

Three women also spoke about people from the family and social environment who, imbued with the belief that cancer is an incurable disease, referred to the patients through speech or attitudes which related to the situation of vulnerability, to the imminent risk of death. *A person came there, I heard from the living room: 'Oh, of this she will not get better no'. (...) The group thinks that they can talk about anything, that they can think anything, that people will not suffer.* (1)

One participant spoke of the social distancing from relatives, due to a mistaken belief that cancer was a contagious disease, highlighting the issue of stigma surrounding the disease. *His sisters (husband) seemed that they were afraid to come to our house. Of catching it. Of it being a contagious disease. They said this.* (1)

Two participants reported situations in which family members were so unsettled, from an emotional point of view, that the women themselves saw the need to show themselves as strong, despite being fragile, in order to minimize their concerns. *Instead of them (children) cheering me up, it's me cheering them up, I'm saying that I'm well, that this is nothing. In my heart I know it is very serious, but so I don't let them think I'm gonna die, you know, those things they keep thinking.* (16)

Here, again, there is the discomfort of the participants with the fact that, with their illness, changes were generated in the family dynamics. They felt responsible to repair this damage and imagined that the best way to do so would be to show themselves as strong and unshakable, despite their own fragilities and needs for emotional support. The family environment was not able to accept them in their new condition of ill health.

### 4) Stressors originating from the work situation: Notes concerning non-productivity

Due to the new situation established by the advent of breast cancer, five participants reported their distancing from professional activity. The therapeutics of breast cancer, invasive and potentially disruptive, led to these patients temporarily leaving their occupations, in order to devote themselves to treatment. However, with the completion of treatment, none of the participants that had, until the event of diagnosis, exercised professional activity had resumed their occupation. Among the reasons mentioned for this non-resumption of work activities were: the physical limitations resulting from the treatment of breast cancer, which is incompatible with the exercise of the former function; the difficulty of reconciling the roles; a change in priorities of life, which excluded the occupation previously pursued. Finally, having passed or not through a cognitive reevaluation<sup>(24)</sup>, all of them pointed to the discomfort arising from the imposition of leaving work: one more break with quotidian life. *I was a cleaner every day. I worked until the day before the surgery. Now that I'm not working I try to think it's just for a period, a phase. But there are times that this period leaves me upset.* (3)

Among the women who had stopped work, two planned to resume their formal occupational activities. These participants were younger (35 and 37 years old, respectively). For them, beyond the desire to occupy their time with a useful and socially valued activity, a crucial motive for the resumption of productive function was the financial hardship they faced due to their absence from work. In both cases, the sustenance of the family depended solely on the husband. *Financial difficulties bother me, because now it's just my husband who is working, right.* (3)

The decline in living standards, in these cases, was combined with the uncomfortable sense of not contributing and, with this, burdening the family financially. This circumstance attested, constantly, to their condition of dependence, functioning as a living

reminder of the limitations caused by the disease. Financial difficulties and the feeling of being a *burden* to the family, brought up by two participants, encompass two of the factors most evidenced by the literature dedicated to the difficulties experienced post-breast cancer<sup>(18,21)</sup>.

One woman said that she had already had the experience of not being given a job that she was seeking, which she interpreted as having occurred because of her illness. *In the place where I worked, I worked six years there. Me and my husband. And the firm closed. Then he opened after almost a year. Then he telephoned calling him. And he said: 'tell your wife that I will not call her because you have a little baby'. And I know all this stuff is a lie, because how many girls that work there have little babies... He is afraid to complicate things for him, because of my problem, I don't know...* (8)

With this verbalization, once again the theme of the social stigma experienced by the cancer sufferer was evident. This same participant, in the course of the interview, reported that she, in seeking employment, did not mention her health condition, because she imagined that, if she did, she would not manage to obtain a place in the labor market. *Because I will not go, also, arrive and say: 'Oh, I'm a sufferer of this'. Imagine! I will stay quiet, in my place. Or nobody will give me a job.* (8)

## Final Considerations

Even though these women had been living with breast cancer for at least one year and had finished the surgical therapeutics, chemotherapy and/or radiotherapy, it was noted that a wide range of stressors related to the disease were still present in their lives. The loss of the breast, and other sequelae resulting from breast cancer and its treatment were now inherent aspects of the life of the mastectomized. These were living marks that constantly refresh the memory of the illness, producing psychic suffering and distress. The physical limitations of the arm and of the alterations in the daily life prove to be responsible for a feeling of deficit in their level of autonomy.

With the cancer diagnosis, contact with the possibility of death was clearly made present in the lives of women. The sense of control during episodes of life was diminished and the fear of relapse became a constant, intensified during some episodes, such as periodic examinations to control the disease or with post-treatment complications. However, fear of recurrence was not only related to death. Participants also revealed

the fear of the loss of autonomy and suffering related to the terminality.

The feeling of helplessness that accompanied the illness and initial phase of treatment tended to be prolonged, causing the participants concern about the fate of their children, both in the sense of failing to complete the mission of bringing them up (for younger women) and in the sense of fear of development of the disease in their daughters. It can be seen, with this, that knowledge about the role of heredity as a risk factor for breast cancer was subjectively incorporated by these women.

Some social events were mentioned by study participants as factors that generated emotional distress. Disturbing social experiences mentioned were: being with terminal patients in health services, cancer deaths of people they knew, and the social agents that stigmatized them. The combination of these factors referred constantly to the feeling of helplessness faced with the vulnerability and the potential lethality inherent in the diagnosis.

The distancing from the professional occupation that they performed at the time before the cancer was related to the feeling of a decline in productive capacity and discomfort aroused by the idea of burdening family and friends. The reversal of roles - from caregiver to the object of care - was not a smooth transition, or experienced without conflict. The results showed that the acceptance of the alteration in the role of caregiver proved an arduous task. Accustomed, throughout life, to give help, they found it difficult to ask for it. The difficulty in accepting the role opposite to that which they always played damaged the roles of wife and mother, which are strongly associated with the care of others. Therefore, for women with breast cancer, coping with the changes produced in social roles should be added to the disturbances of the disease itself, since they can no longer carry out all the functions that they performed before becoming ill.

By demonstrating the existence of a wide range of stressors in the post-treatment period, the results of this study reinforce the need to consolidate and enlarge the spaces of physical and psychosocial rehabilitation to ensure the integrality of the permanent care to this population. The specific data relating to the post-treatment universe are expanding the already established knowledge by providing subsidies necessary to conduct interventions with women who are experiencing this phase of surviving breast cancer.

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