

## PERCEPTIONS, FEELINGS AND PHYSICAL AND EMOTIONAL EXPERIENCES OF WOMAN AFTER BREAST CANCER

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### ABSTRACT

**Introduction:** Breast cancer has the highest incidence worldwide. Recently, breast cancer was considered a major public health problem due to the high morbidity and mortality. The objective was to characterize the coping strategies of the disease developed by these women after breast cancer. **Methods:** We used a qualitative approach, a study of descriptive, which are collected through structured interview technique and processed by content analysis. Participants were twenty women with mastectomies, married, with more than twelve months after surgery and without breast reconstruction. **Results:** Two themes were constructed from the analysis of their statements: 1) Physical changes after breast cancer, which was understood as a change in lifestyle and acceptance of the modified body and 2) emotional changes after breast cancer and coping initiatives, built based on the emotional findings after illness. **Conclusion:** Breast cancer is a disease which characterizes risks to life and brings with it a series of experiments to women. The changes and difficulties caused by the disease imply adaptations and adjustments, both physical (due to sequels) and emotional (guilt, anger and negativity), enabling the experience of different feelings, even after twelve months of surgery.

**Key words:** mastectomy, perception, physical therapy, breast cancer, professional support.

### INTRODUCTION

On present day, breast cancer is the most frequent on female population and the type of cancer, and equally common in the world, being the fifth death cause. The medium post-life, on world population, after five years of diagnoses, is of 61%<sup>1</sup>. The World Health Organization (OMS) estimates that until 2020 this incidence increases 104%<sup>2,3</sup>. Between the years of 2011 and 2012, over 52.680 women have been diagnosed in Brazil<sup>1</sup>.

The data from the National Institute of Cancer (INCA) reveals that breast cancer is frequent in 3 of 5 regions in Brazil: southeast, south and central-west, where significant death rates are found<sup>1</sup>. The National Politics of Oncologic Attention says that

the health secretaries of states and cities, along with the Health Ministry, are responsible for organizing and provide cancers treatment. The utilized methods can be divided into local: surgery and radiotherapy, or systemic: chemotherapy, hormone therapy and biological therapy<sup>1</sup>.

Before this scenario and, considering that the breast is one of the sexual objects of attraction connected to the body image, it is understood that women may deal with metaphors, beliefs and stigmas during the first phases of the disease and in the post-cancer<sup>4,5</sup>. Such factors end up surrounding the female identity of these women. Previous researches, conducted by different professionals, testify that the evolution of the basic surgical techniques decreases the esthetic sequelae

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responsible for the altered perception of the breast, what doesn't stop, even so, the presence of the physical, emotional and social discomfort<sup>6,7</sup>.

Different studies proves that, beyond physical experiences identified as limitations of the lymphedema, of the reduction of amplitude from movement and the constant condition of pain<sup>8-11</sup>, there are association from these experiences to emotional, represented by sufferings, fears and stigma<sup>11-13</sup>. These behaviors considered to be adverse, may optimize the decline of the quality of life and the social and professional well being<sup>4-6</sup>.

In the last years, a major part of the studies was limited to solely explore the physical aspects or emotional of post breast cancer women. The publications are not interested in understanding and searching explanations about these events and the way they relate. Therefore, such thematic still remains unexplored, the uncertainties along the process of sickness are obscure and the social

relevance is consensual. Considering the gap existent in the national and international scenario, the goal of this study is to comprehend the perceptions, feelings and physical and emotional experiences lived in the everyday women with mastectomies.

## METHODS

### Design and population of the study

It is a descriptive study, with a qualitative approach of data, focusing in the individual and attempting to comprehend the human phenomena under question. By the qualitative characteristic of the research, participated in this study 20 women with ages varying from 32 to 60 years old. As established, controlled himself ages, education and surgical time. Such information are found on Table 01.

**Table 01:** Characterization of samples of women with mastectomy on treatment in the mastology sector in Carmela Dutra Maternity in Florianopolis/SC

	N	%
<b>AGE</b>		
< 40 anos	4	20
40 - 45 anos	4	20
46 - 50 anos	3	15
> 50 anos	9	45
<b>SCHOLARSHIP</b>		
1 <sup>o</sup> degree uncomplete	7	35
1 <sup>o</sup> degree complete	6	30
2 <sup>o</sup> degree uncomplete	1	5
2 <sup>o</sup> degree complete	5	25
superior uncomplete	0	0
superior complete	1	5
<b>TIME OF SURGERY</b>		
1 - 2 anos	6	30
2 - 3 anos	12	60
> 3 anos	2	10

### The data collect

The research was developed in three stages. The first consisted on the identification of women with breast cancer diagnosis by available records in the maternity ambulatory, related to years 2007 until 2009. In the second stage, sought to verify if women filled the criteria of research inclusion, to know: being submitted to mastectomy for at least 12 months, being married, to be in age level from 30 to 60, and not to have performed mammary reconstruction. The third stage was the moment of appliance of the interview, allowing the production of content: facts, beliefs, ways of thinking and feeling, opinions, feelings, conducts and behavior, related to the period of post breast cancer treatment. According to Minayo ( ), the qualitative research responds to much private questions, therefore, the samples selected represents the

population at state. During the process of the present research, was utilized the semi structured form of interview, which combines opened and closed questions, allowing the participant to articulate over the thematic, without preset conditions on the researcher.

### The data analysis

The treatment of the data followed the proposal defined by Minayo<sup>16</sup>, which prescribes the following steps to analysis of the contents: 1) ordination of data from the interviews, from the set of observation material and institutional documents, 2) classification of data with the presupposition and questions to be investigated by the researcher, from the collected material and 3) final analysis of the significance and specificity of data, which was performed, after, by an external auditor.

The categorization adopted after the followed steps was represented from two thematic unities: 1) physical modifications after breast cancer, 2) emotional modifications after breast cancer and initiatives of confrontment. For better comprehension, the first two categories were divided into subcategories, culminating in regroup of categories analyzed in the exercise of comprehension and data discussing, excusing exhausting steps from the categorization, as follows: 1) identifying the physical altering, a) changing lifestyle, b) accepting the partially mutilated body, and 2) identifying the emotional altering and expressions of confrontment: a) knowing the emotional implications, b) managing the marriage after breast cancer.

This research had the approval of the research project by the Ethic Committee on Human Research of Carmela Dutra Maternity MCD (CAAE - 0037.0.233.000-10). All participants accepted to participate in the research and signed the Free Consent and Clarified.

## RESULTS

The statements presented at this study are related to the perceptions, to the feelings and to the experiences of women after the critical phase of diagnosis and breast cancer treatment. Therefore, were described the developed themes according to the statements on which the lines have received flowers names.

### Physical altering after breast cancer

#### a) Changing lifestyle

The physical altering due to the disease were the limitation of amplitude of movement from the ipsilateral arm, the edema and/or lymphedema, the postural dysfunction, the muscular weakness. These difficulties generate the surging of multiple feelings and uncertain around her lifestyle. Women go through primarily, in the domestic environment and, later, on the professional to adjust to her daily life, seeking to retake their lives. The feelings generated are the expression of their impotency, limitation, inferiority and, even so, the physical dependency, as can be visualized from the following lines:

*"Well, what changes a bit is the restriction we have in the arm. Of not lifting weight, of not abusing on some cleansing that we care so much! I have learned to live with it, but I'd like to have my normal arm" (Rosa).*

*"With anything it swallows, even if I don't do nothing! But today I've learned to deal with it" (Margarida).*

#### b) Accepting the partially mutilated body

Soon after the mastectomy, the woman experience the feeling of being "imperfect", disfigured, out of the patterns of feminine symbolism, so far culturally imposed.

*"The looks changes a lot because, what is taken from a woman is the major vanity, which is the mamma. It is a mutilated organ, like if you had lost an arm" (heavy carried voice – Lisiantus).*

It is this moment which she passes trough acceptance of her new body, feeling sorry for the occurred, or even so, accepting the new condition.

*"After I did the operation I felt much better. I didn't feel bad about the way I look, I wasn't sad" (Lirio).*

*"Do what? Worst things happend right?" (risos – Girassol)*

On the other hand, some women receive surgical treatment of mastectomy on hopes to achieve the cure for cancer. The grow the representation that this cure may be obtained with the subtraction of the organ (as if the disease was limited to a region) reaching so, an end to her breast cancer. This expectation can be observed in the lines of Lisiantus and Margarida:

*"It was good, good that I ripped it off... it is over!" (Lisiantus).*

*"It really is an ugly surgery. But I was fine, I had to cure myself, it didn't help keeping the breast" (Margarida).*

Other women, however, suffer with fear of intimidation in the social means. They consider breast cancer a bad viewed disease, which brings a long suffering, developing by consequence a new perception over her appearance.

*"I can't look myself in the mirror (...) the part there, I kind of turn on side, I think it is kind of psychological of us anyway!" (Lisiantus)*

*"The surgery was good. The rest I don't want to know!" (Acacia).*

### Emotional altering after breast cancer and expressions of confrontment

#### a) Knowing the emotional implications

During all the experience with cancer, the feminine feelings floats constantly. The breast cancer disorganize the female universe. Feelings, such as uncertainties regarding life, with the possibility of cure and the low of moral are easily identified in the testimonials. The female express feelings of guilt, anger and negativity, the never healing stigma that the disease presents makes dreams and future projects turn into an uncertain.

*"I didn't ask to have cancer! I didn't say: "Hey, come here, sign on a contract with me for so long!" (Astromelia)*

*"So, what changed is, I don't have dream, I can't have dreams. Planning my life, I can't. I just think about today. Live today! (Hortencia)*

Beyond the uncertain future and the altered body, women fear the imminence of the comeback of cancer, even after the treatment. They create, gradually, a psychological dependence of the medical treatment and live along with the idea that life is being constantly threatened.

*"Only in five years I will stop the medication and, then how am I going to be? And after? I'm dying so he tells me to take something else, because in my head I have to keep taking medicine so the cancer won't come back" (Amarilis)*

With all the emotional weight and the search for comfort and health, these women realize that cancer has gathered experiences, new meanings and/or senses for the reformulation of their lives.

*"I think that today is a phase of my life. That I had to walk through that, in order to change some things. Give value to other things I didn't, and today I really do" (Lisantus).*

#### **b) Managing marriage on post mastectomy**

The impact of the disease in cases which prognostic is uncertain or doubtful, leads the woman to add greater size to her marital relationship. Besides, when the symbolism of the female body is disfigured by the loss of the breast, feelings of frustration and fear emerge, for they believe that marital life cannot endure face to a partially mutilated body or of an anatomically altered mama. In this context, the feeling of fragile experienced, in the initial phase of the disease, gives place, carefully, to a more positive and confident behavior:

*"Suddenly (...) it is us who puts him (the husband) out of the house. Then, he already said he will have me without the mama (...)" (Lisantus).*

When the couple cannot overcome the natural process of the disease and the circumstances to come, sexuality is presented as some thing distant, making it difficult to sustain sexual life. However, it can be observed that, when an opened communication is taken, there is disposition to regain marital life and, by consequence, sexual.

*"My body misses the hormones, I miss physicality (...), that I feel at the skin, it is the libido itself. I have to find a way to get over it because I can't believe that my marriage is going to last this way" (Amarilis).*

*"I don't make too much effort (...), he also concerns for he feels he is going to hurt me" (Gérbera).*

## **DISCUSSION**

This study reveals that the obligation of women to socially and professionally live with the physical limitations of the superior member,

associated to inferiority feelings, explain partially the suffering reported<sup>17-18</sup>. The lymphedema, which is considered the abnormal accumulation of protein and liquid in the interstitial space, origins motor instability in the arm and forearm, plus important functional kinesio limitations. Some emotional altering such as frustration and multiple conflicts may appear during or after this period of greater tension and become sized by physical restrictions.

The economic dependence, due the difficulty to go back to work, and the feeling of inferiority for not being able to perform daily functions can create a possible deficit of life quality. According to Cangussu et al.<sup>19</sup>, depressive symptoms are revealed more frequently in the presence of pain and limitation of movement in the superior member. Moskowitz<sup>20</sup> relates that the survivors of breast cancer re-join work with lines of anxiety and/or depression, signs of physical tiredness and cognitive limitations on labor activities.

It is noticed, therefore, that the need of adaptation to a new life style is marked by emotional suffering linked to physical limitations of the superior member with lymphedema. Such difficulties in conciliate the body altering were, equally, approached in previous researches<sup>21-22</sup>. In addition, can be observed that when feeling obligated to get used to their new appearance, they end up ignoring many motor restrictions of the affected member, what would tend to miss caring, for not performing with safety and comfort, such adaptation.

This way, it is noticed that the acceptance of the body partially mutilated and the perception of her new appearance constitute a difficult and painful process. However, this step is important so there is value and improvement of quality of life and the self care, as discussed by some authors<sup>5,6,23</sup>. Being so, questions referring the shoulder functionality, to the impossibility to re-take the labor activity and the branch of acceptance of her mutilated body, propels reflective actions surrounding esthetic concepts (as shaving of the affected area and lymphedema) and new life styles (obstacles or physical restrictions).

It is relevant to observe that after the appearance of breast cancer, the feelings of guilt and sorrow blossom in the woman by the non realization and/or conquests projected previously the disease<sup>24,25</sup>. Andresen et al<sup>27</sup> relate that the woman with breast cancer gets disoriented by modifications in her life and, mainly, by uncertainties face the effective cure. Being so, she fades, in a first moment, with the physical and emotional sequel and, after, with the return of her social and laboring life.

Little more than half of researched women (60%) had the disease diagnosis among two and three years before the collect, and this time can have influence in the instability and emotional adaptation. Facing these circumstances, they realize the experience with the disease and the treatment it self gathered never seen values to their

lives and to people, propelling other behaviors, face to the new identity, constantly, remolded<sup>26</sup>.

Regarding the marital state, Andersen et al.<sup>27</sup> and Nasiri et al.<sup>28</sup> protrude that the couple that did not already presented a good communication between themselves, when facing the problem, cannot maintain intimacy, so needed to the sexual life's maintenance, and without this communication it can extinguish the relationship. On the other hand, women that have a good level of understanding with their partner, can re-establish their sexual life during the time of recovery from the disease, given the support, the interest and attention displayed in this trajectory. The emotional pains (guilt, anger and negativity) lived in the family context may promote collisions even with the marital fusion, which can strongly threaten the affective social sexual life.

In this context, when identified a serious disease, of few possibilities of cure, these women are conducted to self knowledge, re-discovering interests and values many times abandoned with time<sup>27</sup>. Being so, the facing of the context is born, in every woman, from her perceptions and from her feelings around the disease. The daily search for the control of negative feelings and embarrassments after the breast cancer promotes slowly the

emotional evolution and/or the overcoming of the difficulty regarding herself, specially the family, the friends and/or society – minimizing, the physical and emotional discomfort lived.

Breast cancer is a disease characterized by risks to life and brings along a series of experiences to women. The changes and difficulties that are origin by the disease implicates the adaptations and adjustments, such physical (due to incapacities and sequels) as emotional (guilt, anger, negativity), making possible the knowledge of numerous sentiments, even after, twelve months of surgery.

In this sense, the women sentiments who have been through mastectomy vary with the currency of the clinical surgical treatment and may contribute to a better comprehension of the social related process. It was noticed that, in a first moment, the displayed suffering by women passing through the sequels left by the disease, by the difficulty in re-taking her labor activity and by the perception of inferiority due the limitation of the superior member. Afterwards, is noticed the non satisfaction and anguish by the slow return to her daily life, turning the rehabilitating movement slow, facing the uncertainties in the thin relation between living and getting sick.

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