

Experience of women after mastectomy

Vivência de mulheres após a mastectomia

Experiencia de la mujer después de la mastectomía

Iranildo Bezerra Rodrigues¹, Leila Batista Ribeiro², Gabriele Soares da Silva³, Marcus Vinícius Ribeiro Ferreira⁴, Everton Aurélio Dias Campos⁵, Diana Ferreira Pacheco⁶, Wanderlan Cabral Neves⁷, Yanne Gonçalves Bruno Silveira⁸

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REVISA

1. Centro Universitário Planalto do Distrito Federal. Brasília, Federal District, Brazil. <https://orcid.org/0000-0002-6406-9651>
2. Centro Universitário Planalto do Distrito Federal. Brasília, Federal District, Brazil. <https://orcid.org/0000-0001-6399-6966>
3. Centro Universitário Planalto do Distrito Federal. Brasília, Federal District, Brazil. <https://orcid.org/0000-0001-9534-1403>
4. Universidade de São Paulo. Sao Paulo, Sao Paulo, Brazil. <https://orcid.org/0000-0002-8124-0262>
5. Universidade de Brasília. Brasília, Federal District, Brazil. <https://orcid.org/0000-0001-6255-0196>
6. Universidade de Brasília. Brasília, Federal District, Brazil. <https://orcid.org/0000-0002-7203-9962>
7. Universidade Católica de Brasília. Brasília, Federal District, Brazil. <https://orcid.org/0000-0002-8124-0262>
8. Centro Universitário Planalto do Distrito Federal. Brasília, Federal District, Brazil. <https://orcid.org/0000-0003-0115-715X>

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RESUMO

Objetivo: descrever a vivência de mulheres após a mastectomia na Rede Feminina de Combate ao Câncer, tendo como problema de pesquisa a seguinte questão: De que maneira a Mastectomia influencia na vivência da mulher? **Método:** Foi utilizada a abordagem qualitativa e método de história oral seguindo os pressupostos de Halbwachs. A coleta dos dados deu-se por meio de entrevista com mulheres cadastradas na Rede Feminina, que receberam nomes fictícios de países e que foram submetidas à mastectomia. **Resultados:** Foram entrevistadas 04 participantes com idade mínima de 47 e máxima de 76 anos e com diferentes graus de escolaridade, que responderam os questionamentos a respeito de sua vivência pós a mastectomia. **Conclusão:** A discussão apresenta-se por meio de 05 categorias que descrevem a vivência destas mulheres em relação à autoimagem, espiritualidade, sexualidade e até relacionada às relações afetivas que foram grandemente influenciadas pelo aparecimento do câncer e posteriormente à mastectomia.

Descritores: Mastectomia; Saúde da Mulher; Enfermagem.

ABSTRACT

Objective: to describe the experience of women after mastectomy in the Women's Network for the Fight against Cancer, having as a research problem the following question: How does mastectomy influence women's experience? **Method:** A qualitative approach and oral history method were used following the assumptions of Halbwachs. Data collection took place through interviews with women registered in the Women's Network, who received fictitious names of countries and who underwent mastectomy. **Results:** 04 participants were interviewed with a minimum age of 47 and a maximum of 76 years and with different levels of education, who answered questions about their experience after mastectomy. **Conclusion:** The discussion is presented through 05 categories that describe the experience of these women in relation to self-image, spirituality, sexuality and even related to affective relationships that were greatly influenced by the onset of cancer and after the mastectomy.

Descriptors: Mastectomy; Women's Health; Nursing.

RESUMEN

Objetivo: describir la experiencia de las mujeres después de la mastectomía en la Red de Mujeres de Lucha contra el Cáncer, teniendo como problema de investigación la siguiente pregunta: ¿Cómo influye la mastectomía en la experiencia de las mujeres? **Método:** Se utilizó un enfoque cualitativo y método de historia oral siguiendo los supuestos de Halbwachs. La recolección de datos ocurrió a través de entrevistas con mujeres registradas en la Red de Mujeres, que recibieron nombres ficticios de países y que se sometieron a mastectomía. **Resultados:** Se entrevistó a 04 participantes con una edad mínima de 47 y máxima de 76 años y con diferentes niveles de escolaridad, quienes respondieron preguntas sobre su experiencia después de la mastectomía. **Conclusión:** La discusión se presenta a través de 05 categorías que describen la experiencia de estas mujeres en relación a la autoimagen, espiritualidad, sexualidad e incluso en relación a las relaciones afectivas que fueron muy influenciadas por la aparición del cáncer y después de la mastectomía.

Descritores: Mastectomía; La Salud De La Mujer; Enfermería.

ORIGINAL

Introduction

Breast cancer is a disease caused by the disorderly multiplication of breast cells. This process generates abnormal cells that multiply and create a tumor. There are some types of breast cancer, so it can arise in different ways. While some types have rapid development, others grow more slowly. These distinct behaviors are due to the nature of each tumor. Breast cancer is the most common type of disease among women worldwide and in Brazil, after non-melanoma skin, corresponding to about 25% of new cases each year. In Brazil this number is 29%.¹

There are several factors for the development of breast cancer in women. Age is one of the most important risk factors for the disease. About four out of five cases occur after the age of 50. Other factors that increase the risk of the disease are: environmental and behavioral factors (obesity and overweight after menopause, alcohol consumption and frequent exposure to ionizing radiation), factors of reproductive and hormonal history (first menstruation before 12 years, stop menstruating (menopause) after 55 years and have done postmenopausal hormone replacement, mainly for more than five years) and genetic and hereditary factors (cases of breast cancer in the family, especially before the age of 50, family history of ovarian cancer).¹

Some healthy habits such as physical activity, eating healthily, avoiding alcohol and using synthetic hormones can prevent about 30% of breast cancer cases.¹

Breast cancer can be seen in early stages, in some cases by signs and symptoms such as nodule, reddish-retracted or orange peel-like breast skin, changes in the areola, small nodules in the armpits or neck, and spontaneous outflow of abnormal fluid from the nipples. These signs and symptoms should always be investigated by a health professional to assess the risk of cancer. Imaging tests such as mammography, ultrasound or magnetic resonance imaging are used for the investigation, in addition to clinical examination of the breasts. Confirmation only and made with the result of a biopsy, a technique that removes a fragment of the nodule or lesion, by means of a puncture or small surgery.¹

There are several forms of treatment for breast cancer, which depends on the type and stage of the disease. Local treatments aim to treat the tumor locally without reaching the rest of the body, including surgery and radiotherapy; systemic treatments are done through the use of oral or bloodstream medications. According to the type of breast cancer, different types of systemic treatments can be used as chemotherapy, hormone therapy, target therapy and immunotherapy. Most women with breast cancer will have some kind of surgery to remove the tumor. Depending on the type of tumor and staging of the disease, you will also need other forms of treatment.²

Mastectomy is one of the ways to treat breast cancer consisting of the removal of the entire breast with surgery. This is usually done when a woman cannot be treated with breast-conservative surgery, which saves most of the breast. Mastectomy may also be an option rather than conservative surgery, for reasons people.²

There are some types of mastectomy, depends on how the surgery is done and while tissue and removed.² - Simple mastectomy. It is the most common and used in the treatment of breast cancer. In this procedure, removes the entire breast with surgery, including the nipple, but does not remove the axillary lymph nodes and muscle tissue under the breast.² - Double mastectomy. She is performed in both breasts, this procedure is sometimes preventive, for women at high risk of developing cancer in the other breast, such as those who have mutation in the BRCA gene.² - Skin-sparing mastectomy. For the immediate mamaria reconstruction of some women. In this procedure, most of the breast skin and preserved. In these cases the same amount of tissue is removed as in simple mastectomy surgery.² - Nipple-Sparing Mastectomy. This is a variation of skin-sparing mastectomy. This is an option for women who have small early stage tumor on the outside of the breast, with no signs of skin disease or near the nipple. The procedure removes breast tissue, but breast skin and nipple are preserved, followed by breast reconstruction.² - Modified Radical Mastectomy. Modified radical mastectomy is simple mastectomy with the removal of axillary lymph nodes, called axillary lymph node dissection.² - Radical mastectomy. In this process, the doctor removes the entire breast, axillary lymph nodes and pectoral muscles. This surgery can be done for larger tumors that are growing in the pectoral muscles.² Given this assumption, this study is based on the following research question: How does mastectomy influence women's experiences?

The aim of this study was to describe the experience of mastectomized women at the Women's Cancer Network Institute in Brasília, Federal District. The study becomes relevant because it may present data on women who underwent mastectomy, being useful also for health professionals in academic training or not.

Methodology

The methodology for this study was a qualitative approach and oral history method following the assumptions of Halbwachs.³ The historical methodology is always based on some narrative. Data collection was through an interview recorded with an appropriate equipment through a smartphone and was later transcribed by the researchers, following the ethical principles and anonymity, reliability and confidentiality of the data.

The place of the interview chosen by the participant was at her residence. Data were collected from September 20 to October 20,

2020. Five (5) women who agreed to participate in the study with the following inclusion criteria were chosen: To be considered as such, the women who agreed to participate in the research met the following inclusion criteria: signed authorization, aged 18 years or older, is in good mental health, was willing to participate in the research and sign the Informed Consent and is part of the Women's Network to Combat Cancer in Brasilia. Women who presented the following exclusion criteria were excluded from the study: age below 18 years, not having good mental health, not being willing to participate in the research or lack of signature of the Informed Consent, and if she is not a patient of the Women's Network to Combat Cancer in Brasilia. Exclusion factors were not: race, different creeds and cultures, sexual options and different socioeconomic factors.

The study was approved by the Ethics and Research Committee (CEP) on August 28, 2020 under opinion number 4,244,091.

Results and Discussion

The participants of this study received fictitious names as a way to maintain their anonymity according to the following table:

Table 1- Profile of study participants, 2021.

Identification	Age	Education Level	Marital Status	Time of Mastectomy
Cuba	59	Primary education	Single	18 years
Chile	47	High School	Married	2 years
Paraguay	51	Higher education	Single	5 years
Mexico	76	Higher education	Married	23 years

The discussion of this study gave rise to 05 categories that best fit the participants' reports, as presented below.

The post-mastectomy experience

The participants of this study reported their experiences after mastectomy, where there were significant and impactful changes in life, such as: the way of seeing life, discomfort and physical pain, self-acceptance, self-image and the fear of a recurrence of cancer, according to the following reports.

My life has changed a lot, the way I see life, even family, you know? With friends... I've learned to value family a lot, and many friendships that have never abandoned me. (CUBA).

[...] has the discomfort ne? because, whether or not this stirs a little with the posture, I end up putting the shoulder inward [...] God gave me conformism, acceptance. I know that and a phase, I'm waiting to do my breast reconstruction, so so, it's more this question of self-esteem even right? [...] I'm looking forward to doing the reconstruction, of course ne? For an improvement in self-esteem, this issue of you being able to

wear a bikini, wear a bathing suit, I could not do that after the mastectomy, but what about this (CHILE).

[...] it was very difficult, it took me a long time to accept myself and look in the mirror [...] it seemed like I wasn't the one who was seeing it there, it felt like I was watching a movie [...] it was very difficult for you to face, it's very ugly [...] you feel like you're missing something, your body shows you that this [...] you start having shoulder pain, pain in the arms, back pain and itching in the nipple, and I did not have it (PARAGUAY).

[...] Every time I went to the doctor, I was very tense, very worried, thinking I had come back ne? [...] the difficulty with the left arm from which it was, the side that was operated. I adapted, because with this arm I can't push too hard, get hot. I can't do a lot of things because all the lymph nodes were taken. (MEXICO).

In the patient undergoing surgical treatment of breast cancer, the stigma of the disease, mutilation, aesthetics, the limitation of activities of daily living after surgery, the routine of tests, treatments (chemotherapy, radiotherapy) and the short and medium-term effects are not the only disorders shown. Breast failure or modification brings physical, psychosocial, sexual and emotional impacts that will directly affect your quality of life. ⁴

The feeling of bodily integrity is indispensable for the human being. The well-being related to this condition is expressed in the way each one sees himself and, as a result, in the activities they develop. Within this situation, mastectomy is established as a situation of withdrawal of part of the competence to perform tasks and self-esteem; imposing a decline in quality of life, which also concerns the level of physical activity of women submitted to it. ⁵

Mastectomy remains the most used strategy for the treatment of breast cancer; In addition, breast withdrawal and other fundamental treatments for the complete elimination of cancer cells that contribute to the emergence of physical and psychological complications, factors that can influence in a harmful way to these women. ⁶

Post-mastectomy spirituality

The participants of this study reported the importance of faith in God after undergoing surgery. a more direct contact with God, hope and faith at this time, as follows:

[...] I think treatment is both, religion and medicine, because I think without God doctors wouldn't have such a great intelligence to take care of us. [...] I try to do my part, because what God has done in my life is a miracle even (CUBA).

[...] spirituality, faith, strength, hope in God. That's of the utmost importance ne? Your psychological has to be fine for you to face the treatment and be well (CHILE).

[...] after this happened to me I started to have a direct connection with God, [...] it's amazing I felt that God listened to me, so I already put it in my head that God was listening to me [...] God does not just hold my hand, he carries me in his lap and holds me in both hands as if a baby had learned to walk (PARAGUAY).

[...] without you believing in God, having a faith, established in what you believe, in the God you believe, you do not walk. [...] I say thus, that this disease has three strands that lead to healing: first is God, second is his head and third is the doctor. If you don't have these three pillars you don't get there (MEXICO).

Religious beliefs and practices contribute to the rescue of forces lost at each stage of treatment, offering emotional support, and reliving life expectancy in the future.⁷

Spirituality appears as an expression of identity and perception of personal life, erected from history itself, experiences and longings. In this sense, faith and the search for spirituality have the power to alleviate the suffering of the patient, involving the suffering of family members, allowing a change of thought about the fact of illness.⁸

The experience of illness increases religious convictions, where faith plays a fundamental role in going through the disease process in an affirmative way.⁹

Self-image post mastectomy

The participants of this study reported that body image is a cause for concern for them, leading to changes in their daily life, such as not looking in the mirror, clothing-related deprivation and weight gain.

[...] so I'm quiet, I've never had prejudice at all, I'm quiet, I walk on the street good, I feel beautiful. Even at the time of treatment, doing chemotherapy and bald, I never gave up my lipstick or my earring, ever (CUBA).

[...] sometimes I have a certain deprivation, I can not wear everything I wanted, sometimes I will wear a blouse, a dress, a more low-cut thing, i can not use [...] there is a change there, sometimes I look in the mirror and I do not like what I see (CHILE).

[...] if looking in the mirror was very difficult, it took me a long time to accept myself and look at myself in the mirror. [...] I started to notice that I no longer looked in the mirror, when I was going to pass cream, when I was going to moisturize the body, when I was going to do simple things. [...] You feel like something's missing, your body shows you something's missing. [...] suddenly you see yourself without a breast, having to touch your life, having to want to survive, which is the most important (PARAGUAY).

"I was upset because I put on a lot of fat [...] I've always been very careful to wear a proper bra, wear suitable clothes that for example [...] What really upset me was that the arm swelled too much ne? I had to do a lot of lymphatic drainage (MEXICO).

Breasts, in addition to aesthetic appearance, have serious meaning in women's sex lives. Mastectomy, considered by many women as mutilation, can constitute several emotional signs.¹⁰

The breast is one of the symbols of female identity and its reconstruction is of great importance for the patient to regain self-esteem, thus helping to recover the disease and restore social activities, bringing these women to good levels of quality of life, besides the effects being aesthetically satisfactory.⁵

Such representations of the woman's body, of perfection and beauty, are reactions of a social construction in the way of idealizing the female body, requiring its good shape. These elements are socially shared and influence the self-esteem of women who undergo changes in the body.¹¹

Post-mastectomy sexuality

The need to create this category was somewhat thought-provoking, in the sense that when asking about sexuality for these women, they answered something related to the presence of the partner or to the sexual encounter itself, as if sexuality was summing up to just that. It is also important to elucidate that sexuality is related to self-esteem, self-confidence, self-image, desire and others, which would make it partly difficult to maintain an affective and intimate relationship, as follows:

[...] husband at the time had not already, as for this there did not change much no, but so, it was an impact for treatment, changes psychologically, much changed for me (CUBA).

[...] you can't be that normal thing, just like it was before, [...] I can't be as exposed as I was, [...] but you're kind of private, ashamed, I think it's normal (CHILE).

[...] I was already divorced, had a relationship, but it was over [...] I never had any relationship, I say today that I don't want to have anymore. [...] an independent life option, I don't want to have anymore. What I think is cool about all this is that I did the reconstruction for myself (PARAGUAY).

"I got very cold, for me the sexual relationship was the last thing I thought about in my life, that for my head was very distant, what I wanted was to lie down and settle down (MEXICO).

Women represent more difficult because they are directly affected by the transformation in their bodies, which causes a change in body image, where breast loss is understood in feelings of *acanhado*, inferiority, shame, inhibition and low self-esteem, the woman begins to feel unable to act as a woman before society and partners.¹¹

In addition to compromising their functional skills, mastectomy and treatment have a significant impact both on women's lives and on their family group, social environment and group of friends. The constraints added to the stigmatizing disease often lead women to distance themselves from their social life.¹²

Mutilation modifies self-image and self-concept, leading women to feel less valued, ashamed and repulsive, moving away from social and sexual contacts.¹³

Interpersonal relationships after mastectomy

In the present study, the participants reported the support of the family in a positive way, highlighting the importance of this support to face the day-to-day after mastectomy, as follows:

[...] It was of great importance, my mother, my nephews, so... Family from afar supported me, wow! My family [...] my family was too important in my treatment, very much after, after also, to this day I am the darling of the family (CUBA).

[...] family and very funny, because so, it's not just me, but sometimes at that moment your family that welcomes you, that you tell, is more your friends. A friend who you consider sister for a long time, that you have more this welcome, this affection of people, but outside of that family. My mother does not live here in Brasilia, so I could not have this support, this close welcome (CHILE).

"I had a lot of support from my father, from my mother, and they did everything. [...] always have such a feeling of pity, I felt that they had a lot of pity for me (PARAGUAY).

[...] I knew that all of them (family) were aware, they knew it was a serious thing and that I was in need of help, and that their pity was not going to help me (MEXICO).

Friends are important in supporting and supporting women with breast cancer, but the main and indispensable role is that of the family. The family has to organize themselves in such a situation, since it is the family members who will give the first support to the mastectomized woman, who will respond to the new needs that will appear in the course of the situation, such as the health care of this woman and the social environment.¹²

The repercussion in the family did not refer to the reorganization necessary to respond to the needs of routines and care for women's health, also reaching the other relationships.¹⁴

The presence of the family in the treatment of breast cancer and in the recovery of mastectomized patients plays a very important role, since it is one of the main supports that the patient finds to deal with the stress added to the treatment, such as breast removal, as well as self-image problems and sexuality.⁸

Final considerations

Given the above, the results met the objectives of the study, which showed body self-image, a problem widely cited by the interviewees, who feel uncomfortable, mutilated and impaired by breast failure. On the other hand, they report that their spirituality has changed significantly, in view of the increase of faith and trust in God, according to the belief of each one.

Of the implications that this study has for Nursing, it is important to highlight that, humanized care in order to provide physical and psychological well-being to mastectomized women is the main legacy of this study. In addition, the data presented here are of fundamental importance for nursing professionals, since it helps them in the creation of reception strategies in order to develop a comprehensive and dignified care for women.

Finally, this study leaves open as a suggestion for new research the need to evaluate the feelings of mastectomized women after breast reconstruction. This is due to the fact that the results obtained in this research in relation to experience, spirituality, interpersonal relationship, self-image and sexuality may be different for those women who did breast reconstruction.

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Correspondent Author

Leila Batista Ribeiro

Centro Universitário Planalto do Distrito Federal
Pau Brasil Av. - Lot 2. ZIP: 71916-000-Aguas
Claras. Brasília, Federal District, Brazil.

profaleilaribeiro@gmail.com