FEELINGS LIVED BY WOMEN WITH MASTECTOMY
SENTIMENTOS VIVENCIADOS PELAS MULHERES MASTECTOMIZADAS
SENTIMIENTOS VIVIDOS POR LAS MUJERES CON MASTECTOMÍA

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ABSTRACT

Objective: to reveal the feelings of women with mastectomy. **Method:** this is a quantitative, qualitative, descriptive and exploratory study. The population universe consisted of 35 women who are part of the "Amigas viva a vida" association and sample consisted of 25. The data collection instrument was a semi-structured questionnaire, statistical data were analyzed according to their variables and qualitative data were analyzed by the DSC. The results were expressed in tables and figures. **Results:** Regarding the clinical aspects, most participants performed a total mastectomy, and half had the mammary reconstruction. The loss of the breast resulted in physical damage, but the way each one went through the process of illness and treatment was associated with the meanings that attributed the disease. **Conclusion:** After the treatment, the feelings experienced by the women were similar, but that sadness and the pain were always present. Thus, the results of this study provide a new perspective on the scientific community promoting new possibilities for thematic approaches with women with mastectomy. **Descriptors:** Women's Health; Mastectomy; Emotions; Breast neoplasms; Self-image; Psychological Trauma.

RESUMO

Objetivo: desvelar os sentimentos das mulheres mastectomizadas. **Método:** estudo quantiquantitativo, descritivo e exploratório. O universo populacional foi de 35 mulheres que fazem parte da associação "Amigas viva a vida" e amostra foi constituída por 25. O instrumento de coleta de dados foi um questionário semiestruturado, os dados estatísticos foram analisados de acordo com suas variáveis e os dados qualitativos foram analisados pelo DSC. Os resultados foram expressos em tabelas e figuras. **Resultados:** em relação aos aspectos clínicos, a maioria realizou mastectomia total e a metade a reconstrução mamária. A perda da mama acarretou em prejuízos físicos, porém, a forma como cada uma passou pelo processo de adoecimento e tratamento estava associada aos significados que atribuíram a doença. **Conclusão:** após o tratamento, os sentimentos vivenciados pelas mulheres foram parecidos, mas que a tristeza, a dor estiveram sempre presentes. Assim, os resultados desse estudo proporcionam um novo olhar na comunidade científica promovendo novas possibilidades de abordagens temáticas com as mulheres mastectomizadas. **Descritores:** Saúde da Mulher; Mastectomia; Emoções; Neoplasias da Mama; Autoimagem; Trauma Psicológico.

RESUMEN

Objetivo: desvelar los sentimientos de las mujeres con mastectomía. **Método:** estudio cuantitativo y cualitativo, descriptivo y exploratorio. El universo populacional fue de 35 mujeres que forman parte de la asociación "Amigas viva a vida" y la muestra fue constituída por 25. El instrumento de recolección de datos fue un cuestionario semi-estructurado, los datos estadísticos fueron analizados de acuerdo con sus variables y los datos cualitativos fueron analizados por el DSC. Los resultados fueron expresados en tablas y figuras. **Resultados:** en relación a los aspectos clínicos, la mayoría realizó mastectomía total, y la mitad la reconstrucción mamaria. La pérdida de la mama tuvo perjuicios físicos, pero, la forma como cada una pasó por el proceso de enfermarse y tratamiento está asociado a los significados que atribuyeron a la enfermedad. **Conclusión:** después del tratamiento, los sentimientos vividos por las mujeres fueron parecidos, pero que la tristeza, y el dolor estuvieron siempre presentes. Así, los resultados de ese estudio proporcionan un nuevo punto de vista en la comunidad científica promoviendo nuevas posibilidades de enfoques temáticas con las mujeres con mastectomía. **Descriptores:** Salud de la Mujer; Mastectomía; Emociones; Neoplasias de la Mama; Autoimagen; Trauma Psicológico.

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INTRODUCTION

Breast cancer ranked first in female neoplasms and it is the second most common type of cancer in the world. In Brazil, about 22% of new cases of cancer in women annually are breast cancer. Among the Brazilian states with the highest number of cases, Paraíba is the seventh in the ranking for this type of cancer in the country.¹

The three main methods of screening for breast cancer are mammography, clinical examination, and self-examination. The self-examination has great importance in the early detection of neoplasia since it is a more practical method of being performed since it allows the woman to examine herself.²

Due to the high incidence, breast cancer is the most feared by the female, mainly due to the consequences of treatment that can be devastating and mutilate. The treatment consists basically of surgery and chemotherapy, radiotherapy and hormone therapy. In most cases, two or more therapeutic approaches are associated, depending on the clinical and psychological conditions of the patient.³

Breast surgeries are performed primarily to establish control over the tumor, from the removal of cells that have mutated. The type of surgery may vary from case to case, from lumpectomy to radical mastectomy.⁴

Mastectomy is the most frequently performed breast surgery. It consists of removal of the breast, whether or not it can cover surrounding tissues, removal of lymph nodes from the axillary region and pectoral muscles.⁵

Mastectomy is considered a mutilation that causes a series of physical and emotional consequences in women, mainly in the perception of sexuality, body image, in their social roles and quality of life. Many women have depression, low self-esteem, inferiority, despair, fear of recurrence, physical discomfort, reduction of activities.³

Another study affirms that it is very important to know the epidemiological profile of this population so it is possible to plan and monitor health actions aimed at this group of women. This statement shows the importance and the problematic of this research to identify the main sociodemographic characteristics and the feeling of the women with mastectomy.⁴

The justification of this study is obtained through the capture of the problems experienced by the woman with mastectomy and the academic interest of seeking

information about women who have undergone some kind of surgery or treatment for breast cancer, showing the feelings experienced by these women, especially those who underwent a total mastectomy.

With this, it is questioned: What are the feelings experienced by women after mastectomy?

OBJECTIVE

- To unmask the feelings of women with mastectomy.

METHOD

This is a quantitative, qualitative, descriptive and exploratory study. Exploratory research has as the main purpose to develop, clarify and modify concepts and ideas to formulate more precise problems or searchable hypotheses for later studies. The quantitative and qualitative method was adopted, since the data collection consisted of closed questions, being a systematic procedure for the description and explanation of this study.⁶

The population universe is 35 women with mastectomy who are part of the association “Amigas viva a vida” and sample was constituted by 25 women. “Amigas viva a vida” is an association for women who have been diagnosed with breast cancer, providing social and emotional assistance to these women. As inclusion criteria, there were women over 18 years old and who frequently attend meetings. The exclusion criteria were not being residents of the city of Patos-PB, women who did not perform breast surgery and who do not frequently go to the meetings.

The instrument used for data collection was through a structured questionnaire prepared by the authors.⁷ The data collection was performed in October 2017 through an individual interview, with an estimated time of approximately 15 minutes, in a quiet place, in their care service place, where there was an explanation about the research. The quantitative data were submitted to descriptive statistical analysis and available through tables with the help of the Excel Office 2007 program. The qualitative data were analyzed by the Collective Subject Discourse (DSC)⁸, in which the subjects' questionnaire, and distributed in figures respecting the reliability of the answers given. All the data were discussed in the light of the scientific literature, is described through the distribution of the variables.

The project was registered in the Brazil Platform, aiming at its referral to the

Research Ethics Committee of the Faculdades Integradas de Patos - FIP, with CAEE: 69588417.3.0000.5181, being supported by ethical aspects in research involving human beings, as described in Resolution 466/12 of

the National Health Council, which regulates research involving human beings.⁹

RESULTS

Table 1. Characterization of the sample in relation to demographic partner data. (n = 25). Patos (PB), Brazil, 2017.

Variables	n (%)
Age Group:	
Between 31 and 40 years old	4 (16)
41 years old and over	21(84)
Marital status:	
Single	5 (20)
Married	15 (60)
Widow	2 (8)
Divorced	3 (12)
Degree of Instruction:	
Incomplete Elementary School	4 (16)
Complete primary education	3 (12)
Complete high school	4 (16)
Full Higher Education	14 (56)
Salary income:	
Less than 1 minimum wage	4 (16)
1 minimum wage	2 (8)
2 to 3 minimum wages	9 (36)
3 to 4 minimum wages	5 (20)
More than 4 minimum wages	5 (20)
Total	25 (100)

Table 1 shows demographic partner data for the study data. Regarding the age group, it can be observed that most of the sample was 41 years old or older with 21 (84%) of the women interviewed, the other 4 (16%) were between 31 and 40 years old. The highest number of married women was 15 (60%), 5 (20%) were single, 2 (8%) were widows and 3 (12%) were divorced women. According to the degree of education, 14 (56%) had completed

higher education, 4 (16%) incomplete elementary school, 3 (12%) complete elementary school and 4 (16%) complete. In the wage income variable, it is perceived that 9 (36%) receive between 2 and 3 minimum wages, 4 (16%) less than one minimum wage, 2 (8%) one minimum wage, 5 (20%) between 3 and 4 minimum wages and 5 (20%) more than 4 minimum wages.

Table 2. Characterization of the sample regarding the type of mastectomy and time of accomplishment. (n = 25). Patos (PB), Brazil, 2017.

Variables	n (%)
Type of mastectomy:	
Total mastectomy	24 (96)
Partial mastectomy	1 (4)
Time of accomplishment:	
Less than 1 year	1 (4)
More than 2 years	4 (16)
More than 5 years	10 (40)
More than 10 years	10 (40)
Total	25 (100)

Table 2 shows the data related to the type of mastectomy and the time of surgery. Regarding the type of surgery, 24 (96%) of the women underwent total mastectomy and only 1 (4%) underwent a partial mastectomy.

Regarding the time the surgery was performed, the results were similar, in which 10 (40%) underwent surgery more than 10 years, 10 (40%) over 5 years, 4 (16%) more years 1 (4%) less than 1 year.

Table 3. Characterization of the sample regarding Quality of life in daily activities, social and sexual and breast reconstruction. Mastectomized women (n = 25). Patos (PB), Brazil, 2017.

Variables	n (%)
Daily routine:	
Yes	23 (92)
No	2 (8)
Social relations:	
Yes	6 (24)
No	19 (76)
Family Relationships:	
Yes	15 (60)
No	10 (40)
Sex life:	
Yes	23 (92)
No	2 (8)
Breast reconstruction:	
Yes	12 (52)
No	12 (48)
Total	25 (100)

Table 3 shows the quality of life of women in daily social and sexual activities and submitted to breast reconstruction. According to the daily routine, 23 (92%) women stated that there were changes in the routine while 2 (8%) said that there were no changes. Regarding the family relationship, 15 (60%) of them said that there were changes and 10 (40%) did not identify any changes. In the

sexual life variable, the majority of women, 23 (92%), affirmed that there were no changes and only 3 (8%) reported that there was a change in sexuality.

Regarding breast reconstruction, the results were similar, 13 (52%) reported having performed the reconstruction, while 12 (48%) reported no.

Central ideas	Women's Feelings About Breast Cancer
Negative feelings	<i>Without floor (M3, M4, M10, M12, M13, M14, M16, M18, M20, M22.)</i> <i>Sadness (M1, M2, M7, M11, M15, M23, M24.)</i> <i>It was an unpleasant, shocking, traumatic experience (M14)</i> <i>I almost sank (M17).</i>
Feelings of acceptance	<i>I was not surprised, because there were several cases of cancers in my family (M5)</i> <i>I felt strong (M6)</i> <i>Nothing I thought would be something simple (M9, M21).</i>

Figure 1. Feelings of women diagnosed with breast cancer. Patos (PB), Brazil, 2017.

In Figure 1, the central ideas regarding the feelings experienced by women in the process of finding the disease are described, from the question: What did you feel when you received the diagnosis of breast cancer? The central ideas were divided into two classes:

negative feelings and feelings of acceptance. According to these central ideas, it can be seen that most women experienced negative feelings related to the diagnosis, such as despair, sadness, worry and fear of death.

Central ideas	Feelings of women with mastectomy
Feelings of Mutilation	<i>Mutilated</i> (M22, M24, M25, M20, M18, M17, M14). <i>I lost a piece of me</i> (M21, M19, M15, M1, M6, M3). <i>I almost sank</i> (M17).
Negative feelings	<i>I felt sadness and at the same time hope to continue to live</i> (M8, M1) <i>Between receiving the diagnosis of cancer and removing the breast... removing the breast was worse, I felt a lot of sadness</i> (M5). <i>Despair when I saw myself without the breast</i> (M13, M10) <i>I felt inferior, I did not want to look in the mirror</i> (M11)
Feeling of relieve	<i>Relief</i> (M7, M16, M14, M9, M3, M2)

Figure 2. Feelings of mastectomized women. Patos (PB), Brazil, 2017.

Figure 2 summarizes the main feelings experienced by women who underwent mastectomy, being able to observe that the feeling of mutilation, sadness, and relief are the most common among women.

DISCUSSION

It can be verified in other studies that most women with mastectomy are in an average of 40 years old, this factor is also perceived in this research where it was observed that the majority of the sample is between 41 years or more.¹⁰ Age is a factor that directly influences the quality of life of women undergoing breast cancer treatment. According to the authors, studies indicate that younger women tend to experience higher levels of quality of life than older women. However, there is evidence that older women tend to have a better quality of life after treatment compared to younger women, this may be due to the difficulty of younger women to adapt to the new condition, and/or the fact that older women value less the breast and femininity.¹¹

Older women tend not to verbalize and/or show great longings about self-image, sexuality, femininity, “being a mother” and “being a woman.”¹²

A research aimed at evaluating women's feelings about the diagnosis of breast cancer identified that 80% of the women were married and only 20% were widows.¹³ For married women, the presence of a partner contributes to the confrontation because they receive support in the face of the new reality and behavior in the search for healthcare.¹⁴

Regarding family income, the behavior related to breast cancer prevention is related to the best socioeconomic level and education level, which is associated with higher rates of preventive practices, due to the opportunities of information, helping in possible early diagnosis and interrupt the progression of the disease still in its initial stage.¹

According to a study in which the quality of life of 50 women affected by breast cancer was studied, it can be noticed a difference between the data collected when compared to this study. On the type of surgery, the majority of the sample, 29 (58 %), underwent partial mastectomy, while the remaining 21 (42%) underwent a total mastectomy. Regarding the time of surgery, the data are also different from that of the study, the majority of the women, 16 (32%), underwent surgery between 2 and 3 years, 6 (12%) between 1 and 2 years, 11 (22%) from 3 to 6 years, 6 (12%) from 6 to 7 years, 7 (14%) from 7 to 9 years and only 4 (8%).¹⁵

In partial mastectomy or conservative surgery, only part of the mammary gland that contains the tumor is removed, this procedure is often a treatment option for women with early breast cancer because it allows it to preserve most of the breast, although they increase not very significantly the rate of local recurrence of the tumor. Total mastectomy, in turn, is a surgical procedure that removes the entire mammary gland and pectoral muscles to reduce the incidence and improve the life expectancy of women considered to be at high risk.¹⁶

In a study of 20 women with mastectomy, when asked if there were changes in their daily routines after mastectomy, 14 (70%) responded that yes. These data agree with our survey, in which most respondents said there were routine changes after surgery.¹⁷ The withdrawal of the breast leaves the upper limb with limited movements. Thus, domestic activities become difficult to perform.¹⁴

Regarding the family change, in another study, 100% of the women interviewed claimed that there was no change by the family members. These data are in agreement with the data of our research, in which most also affirm no changes. According to the authors, despite the great impact of breast

cancer on the patient, the presence of affection, complicity, and union in the families is observed in families, seeking a better coping of the problem.¹⁸

The family is part of the context in which the woman is inserted, is a major source of support for coping with cancer and its consequences, before, during and after the surgical procedure. Therefore, family-centered care should pay particular attention to the relationships established between them, since they are important determinants of the health/illness process.¹⁴

Data from a study on the sexual and affective life of women with mastectomy were found, where 9 (75%) of the respondents reported changes in their sexual lives, while 3 (25%) reported no. These data do not correspond to the data of this research in which the majority, 23 (92%), affirmed that there were no changes in their sexuality. According to the authors, it is common for women to show a decrease in the frequency of sexual relations, and/or changes in sexual behavior, in which women avoid stripping and being touched by their partners.¹⁹

Regarding mastectomy, it is notable that women who performed breast reconstruction had better scores in all aspects evaluated when compared with women who did not perform the reconstruction.¹⁵ In another study about the evaluation of the quality of life of women submitted to mastectomy showed that only 4 women out of 37 had undergone breast reconstruction.²⁰

Law 12,802 mandates immediate breast reconstruction surgery in cases of mutilation resulting from cancer treatment. When there are technical conditions, the reconstruction should be done in the same surgical time. In cases of immediate reconstruction, the patient will be accompanied by a specialist and will be assured of reconstruction of the breast after reaching the necessary clinical conditions.²¹

Even though the surgery is offered for free, the number of women performing breast reconstruction is still low. Comparing the number of women with mastectomy with the number of reconstructed breasts through SUS, it is possible to verify that less than a third of SUS users have access to immediate breast reconstruction.²²

Some women are interested in performing breast reconstruction, but they are affected by doubts and fears, mainly pain. Other women are still unaware of the right to plastic surgery by the public network in the case of mutilation resulting from the treatment of breast cancer.²⁰

When evaluating the feelings reported and responded by them, these feelings are considered to be normal, considering the severity of the disease and how the therapeutic procedure is traumatic in the lives of these women. On the other hand, it may be noted that a minority of the women said tranquility when receiving the diagnosis of breast cancer. In this situation, the women wanted to feel strong to face the disease and the difficult treatment.

In a study of 14 women at the Oncology Referral Hospital in Campina Grande-PB, in the face of the discovery of cancer, despair was the most reported feeling, as well as fear and deep sadness, a fact also observed in this study.²³

The emotions experienced by women with cancer, from acceptance of diagnosis to treatment directly influence the health/disease process. Anger, despair, sadness, restlessness, anxiety, anguish, fear and grief are common feelings during this period, although each patient experiences each stage in a particular way.¹³

Pain after mastectomy is common and has several causes and adjectives that are different according to the individuality of each woman. Often, women who develop pain have a functional impairment and significant emotional impairment. Also, the symptom, when present, can cause changes in body image and be a factor that limits the performance of activities of daily living and leisure.²⁴

According to a study in which 7 women who underwent a mastectomy at a reference hospital in oncology in the city of João Pessoa-PB, we can identify that a minority of the sample presented feelings of indifference and tranquility when receiving the diagnosis of breast cancer, these facts were also observed in our research. According to the authors, to demonstrate tranquility, perhaps, was a strategy of escape from reality, or as a way of exposing that the affliction would not bring any benefit to the prognosis, or could be a reflection of the state of resilience.¹

Regarding the feeling post-mastectomy, it is perceived according to the central ideas that most women experienced negative emotions the response of breast removal. The sadness of losing the breast is something impossible to avoid since it is the symbol of motherhood, sexuality, and sensuality, women feel mutilated, disfigured, it can be said that the woman when subjected to mastectomy castrate her femininity. In contrast, the minority of the women felt relief after performing the surgery, because, despite the

mammary, perch removed the tumor that so badly compromised her life, the mastectomy showed them hope of a cure.

Another study showed that the removal of the breast appeared as something that brought distress, suffering, and depression to the interviewees, a fact also observed in this study.¹³ The sadness for the loss of the breast is the feeling most reported by women, the mutilation of a part of the body, produces changes in body image, mainly because the body now presents itself outside the standards of beauty defined by society.²³ The concerns and desires of breast withdrawal associated with low self-esteem, not feeling woman and absence of meaning in life as a result of mutilation, are very present in mastectomized women.²⁵

The loss of the breast is understood as the only way to the long-awaited cure, the mastectomy conveys relief. The woman creates a conception that it will no longer be necessary to worry about cancer, that the loss of the organ took with the disease.²

CONCLUSION

When discovering breast cancer, the woman faces a difficult reality and countless feelings are part of that context. Most of the women presented a feeling of sadness, despair, and fear began to experience the expectation of an uncertain future, full of difficulties, accompanied by fear of death and mutilation. After the mastectomy procedure, it was noticed that the feelings experienced by them were sometimes pain, sadness, suffering, but also relief from carrying the disease with the part of their body. The way each woman went through the treatment was associated with the meanings attributed to the disease.

Thus, the essence of this study gives a new look to the scientific community, sending information that is sometimes not strictly spoken because it is personal feelings, in this way, providing new ideas of studies on the subject.

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