

## Mastectomized woman in breast cancer: experience of everyday activities

Mulher mastectomizada por câncer de mama: vivência das atividades cotidianas

Mujer mastectomizadas por el cáncer de mama: experiencia de las actividades cotidianas

*Leticia Valente Dias<sup>1</sup>; Rosani Manfrin Muniz<sup>2</sup>; Aline da Costa Viegas<sup>3</sup>; Daniela Habekost Cardoso<sup>4</sup>; Debora Eduarda Duarte do Amaral<sup>5</sup>; Bruna Knob Pinto<sup>6</sup>*

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### ABSTRACT

**Objective:** To know the experience of women who underwent mastectomy for breast cancer in relation to their daily activities. **Method:** it is a qualitative study with six women in oncological follow-up in a teaching hospital in Southern Brazil. Data were collected through semi-structured interviews, from March to June 2015, and analyzed according to the operative proposal. **Results:** Before the mastectomy, the participants reported retaining the full performance of their functional capabilities. After the procedure, they reported difficulties in self-care actions, work and household chores. Adoption of coping strategies was needed to overcome the everyday barriers. **Conclusion:** Each woman is able to conduct her own life even when facing adverse situations. Family support, friends, faith, and the availability of health services helped the woman to adapt to changes resulting from mastectomy.

**Descriptors:** Breast neoplasms, Mastectomy, Survival, Daily living activities.

### RESUMO

**Objetivo:** Conhecer a vivência de mulheres mastectomizadas por câncer de mama em relação às atividades cotidianas. **Método:** Estudo qualitativo, com seis mulheres em acompanhamento oncológico em um hospital de ensino do sul do Brasil. Os dados foram coletados

<sup>1</sup> Nurse. Resident of the Integrated Multiprofessional Health Residency Program of the School Hospital of the Federal University of Pelotas. Email: [leticia\\_diazz@hotmail.com](mailto:leticia_diazz@hotmail.com)

<sup>2</sup> Nurse. PhD in Nursing. Faculty of Nursing, Federal University of Pelotas. Email: [romaniz@terra.com.br](mailto:romaniz@terra.com.br)

<sup>3</sup> Nurse in the Best in Home Program at the School Hospital of the Federal University of Pelotas. Master of Science. PhD student at the Graduate Program in Nursing, Federal University of Pelotas. Email: [alinecviegas@hotmail.com](mailto:alinecviegas@hotmail.com)

<sup>4</sup> Nurse of the Municipality of Pelotas. Master of Science. PhD student at the Graduate Program in Nursing, Federal University of Pelotas. Email: [danielahabekost@yahoo.com.br](mailto:danielahabekost@yahoo.com.br)

<sup>5</sup> Nurse. Master of Science. PhD student at the Graduate Program in Nursing, Federal University of Pelotas. Substitute Professor at the Faculty of Nursing, Federal University of Pelotas. Email: [deboraamaralp@gmail.com](mailto:deboraamaralp@gmail.com)

<sup>6</sup> Nurse of the City Hall of Capão do Leal. Master of Science. PhD student in the Nursing Graduate Program. Email: [brunaknob@hotmail.com](mailto:brunaknob@hotmail.com)

por meio de entrevistas semiestruturadas, de março a junho de 2015, e analisados conforme a proposta operativa. **Resultados:** Antes da mastectomia, as participantes referiram-se em pleno desempenho de suas capacidades funcionais. Após o procedimento, relataram dificuldades para ações de autocuidado, trabalho e tarefas domésticas. Adoção de estratégias de enfrentamento foi necessária para vencer as barreiras cotidianas. **Conclusão:** Cada mulher é capaz de conduzir sua caminhada mesmo passando por situações adversas. O apoio da família, amigos, a fé, e a disponibilidade dos serviços de saúde auxiliaram a mulher a se adaptar às alterações decorrentes da mastectomia.

**Descritores:** Neoplasia da mama, Mastectomia, Sobrevivência, Atividades cotidianas.

## RESUMEN

**Objetivo:** Conocer la experiencia de las mujeres que se sometieron a mastectomía por cáncer de mama en relación con sus actividades diarias. **Método:** Se trata de un estudio cualitativo con seis mujeres en la asistencia cáncer en un hospital universitario en el Brasil. Los datos fueron recolectados a través de entrevistas semiestruturadas y se analizaron como la propuesta operativa. **Resultados:** Antes de la mastectomía, los participantes informaron directamente el rendimiento de sus capacidades funcionales. Después del procedimiento, reportaron dificultades en acciones de autocuidado, el trabajo y las tareas del hogar. Era necesaria la adopción de estrategias de afrontamiento para superar las barreras cotidianas. **Conclusión:** Cada mujer es capaz de llevar a cabo su pie incluso a través de situaciones adversas. Apoyo a la familia, los amigos, la fe y la disponibilidad de los servicios de salud ayudó a la mujer para adaptarse a los cambios resultantes de la mastectomía.

**Descriptor:** Neoplasias de la mama, Mastectomía, Supervivencia, Actividades cotidianas.

## INTRODUCTION

In the group of chronic non-transmissible diseases, cancer has received great attention due to its increasing expansion and magnitude, with an estimate of 600,000 new cases for the years 2016 and 2017. With the exception of non-melanoma skin cancer, breast cancer will be the most frequent among women, equivalent to 28.1% of the cases.<sup>1</sup>

The diagnosis of breast cancer, associated with the need for mastectomy as essential therapy, causes the woman to face a perplexed situation: that of living with body changes or, otherwise, the possibility of losing her life. In this sense, the only alternative she has is to remove the breast in order to maintain life.<sup>2</sup>

In this context, in which women experience the disease and the mutilation treatment, significant difficulties arise in daily activities. And over time, the frequency of problems related to autonomy and independence increases due to the reduction of functionality.<sup>3</sup>

This condition of illness demands for people feelings, such as the suffering related to the abandonment of certain daily activities, especially those that involve their social participation, due to the changes in the lifestyle brought about by the illness.<sup>4</sup>

Therefore, the importance of this study is justified since, when the experience of mastectomized women is known, health professionals may have subsidies to help them find ways to have a better quality of life.<sup>2</sup> Facing the panorama,

the question: what is the experience of women who are breast mastectomized in relation to their daily activities? The objective was to know the experience of breast cancer mastectomized women in relation to daily activities.

## METHOD

The present study is characterized by a qualitative, exploratory and descriptive approach, being a subproject of the research titled "Resilience as a coping strategy for the survivor of cancer". The data collection site was the domicile of the participants, from March to June 2015. Six women who underwent mastectomy due to breast cancer were followed up at the oncology outpatient clinic of a teaching hospital in the South of Brazil, after the minimum period of one year subsequent to the completion of chemotherapy and radiotherapy. The search for the women of the study occurred in the database of said research.

The inclusion criteria were: female and mastectomized due to breast cancer; have completed chemotherapy and radiotherapy for at least one year; 18 years of age or over; communicate verbally in Portuguese; residing in the urban perimeter; permit the use of the recorder during the interview; allow publication of the study in events and periodicals of the area.

To maintain the participants' anonymity, they were identified by the use of the term "participant" followed by the age and order of the interviews. This research was approved by the Research Ethics Committee of the Faculty of Nursing of the Federal University of Pelotas under protocol number 985,765 on March 14, 2015, yet the same research complied with the ethical norms established by Council Resolution 466/12 National Health System<sup>5</sup> and the Code of Ethics for Nursing Professionals.<sup>6</sup>

Data collection was performed through a semi-structured interview, containing questions related to their daily activities. The analysis of the data was based on the precepts of the operational proposal,<sup>7</sup> with the following steps: data ordering, data classification, final analysis and final report.

The research data will be stored for a period of five years under the responsibility of researchers in digital media. After this period the files will be deleted, the audio recordings will also be erased and the printed documents will be cremated.

## RESULTS AND DISCUSSION

From the analysis of the material produced, the data were categorized in the following units of direction: My life before mastectomy; Today, what do I do!? Giving voice to the mastectomized woman; and Between limitations and facilitations: the development of daily activities.

### My life before mastectomy

To understand how a mastectomized woman experiences her condition on a daily basis, it becomes interesting to consider her perceptions about her past life in order to establish the impact produced by the mastectomy in an

extended sense of functionality, that is, the one that is not limited to the physical sphere.

When reminded of actions taken prior to the illness and the surgical act, women report mainly remunerated and domestic work activities.

*I was cleaning the house. Cooked up, I went to the stove. (Participant 4, 60).*

*I always worked, worked as a domestic worker, a cleaning lady. I would leave one service and enter the other to support my children. And then I went to the restaurant, I stayed four years as a cook. (Participant 2, 57).*

*I worked in a restaurant. And I took care of the house, I did all the work ... I got up, doing something at home and went to work, spent the day working, worked eight or ten hours sometimes. And I would go home and take care of the house again, my daughter [...] these things from home, from day to day. (Participant 5, 53).*

It is possible to observe that before the change of health condition, the participants exercised remunerated activities without abstaining from domestic activities. Thus, it is possible to infer the participation of these women in the family environment and the value given to these activities, despite the double working day, in- and outside the household.

In the present context, despite the fact that women have gained more freedom in choosing their activities, in an extremely consumerist society, the option to work outside the household increases the family income, so that at the end of the work day, women also accumulate services, besides being culturally responsible for the care of their children.<sup>8</sup>

Women's manual works, such as handicrafts, are also linked to the daily routine, in voluntary work, as can be evidenced in one of the participant's statements:

*I did only volunteer work, with a more or less social assistance. I was doing jobs like this: one day a week I was doing manual work there, like embroideries and knitting jobs that were for those bazaars carried out at the end of the year. (Participant 3, 77).*

It is again observed the dedication given to activities related to the female universe with the development of social actions. It is noted that participant 3 sought to reproduce her skills in favor of volunteering, demonstrating her quest to interact in different environments other than home and remunerated labor, referring to an active participation.

The testimony of the same participant still revealed, within her daily activities, religious actions as a way of exercising charity.

*Well, I worked there at the Spiritist Center where I did all the Spiritist Doctrine, and there I did work like that [...] as a priestess, as a lifeguard, doing those prayers in homes*

*where people could not go to the house. So they made a group to do that work. (Participant 3, 77).*

Manual labor such as handicrafts are commonly inserted into the lives of women in childhood, in domestic spaces linked to family relationships, in which female figures predominate in their learning.<sup>9</sup> Volunteer activities are described as a strategy to increase psychological well-being for the elderly volunteers, with a predominance of females in these spaces.<sup>10</sup> Possibly the dedication and importance given to voluntary work, by the participant, relate to the positivity of the meaning of these actions in her life before the mastectomy.

Closing this unity of meaning, a brief notion of the previous experience of women in the study is reached. Before the mastectomy, they were active, healthy people, in full performance of their functional capabilities, independent in their daily lives. They exercised activities in common and distinct environments, emphasizing the domestic and work environment, carrying with them their singularities and generalizations in their routines.

### **Today, what do I do!? Giving voice to the mastectomized woman**

After experiencing the cancer and having undergone surgical removal of the breast, the women reported that the tasks, previously developed almost spontaneously, acquired a degree of difficulty.

*No housekeeping. So, I clean, sweep, remove dust. These kind of things, but great things, I do not do. (Participant 3, 77).*

*Now I do not want to go to the stove anymore, but a lot has changed [...]. And cleaning, I cannot do that anymore, wash clothes, these things I cannot do. I cannot be stirring too much on the stove, the fire, the heat hurts my arm. The only thing I do, which I can do even more or less, is to pull the covers off my bed, yet I cannot shake the covers. Such heavy things I cannot do. (Participant 4, 60).*

*I do the housework [...] but there are things like changing a gas canister, which was something I used to do alone, today I cannot do it. Carrying heavy things inside the house, washing the window, washing a liner, these things I cannot do more, there is no way. The arm falls asleep, it starts to ache and it is not possible to stretch [...] clothes on the rope, if the rope is too high, I cannot do it either. Anything that has to lift your arm too much, it makes it very difficult. (Participant 5, 53).*

*I make my food, that's what I can do. I wipe the house with a cloth, but my house is dirtier. So if I cannot do it, I'll leave it like this, I even get embarrassed ... to wash big clothes, to wash the house and also to rub it, it's difficult for me too, because we have no strength in our arms. (Participant 6, 60).*

The study participants report their physical impairment and difficulty after illness, where domestic activities took

on another paradigm in their lives. In this new way of life, women find themselves unable to exercise their role of caring for the home and family. The woman facing her limitations often has the concern of maintaining and caring for the family, as she is the main responsible for the domestic activities, food, children and general organization. In this perspective, it is stressed that the lack of women can affect every family structure and, often, generate the need to reorganize everyday activities.<sup>11</sup>

The work for the production of income also underwent modifications due to the corporal alteration experienced by the participants.

*Now I can do my normal job. I'm doing my activities, sewing too. I take care of myself so as not to force too much with the arm on the side that I did the surgery. I take care of myself, [take care] of that side [operated arm], of the other side [healthy arm] I do my normal service. (Participant 1, 58).*

Although the participant 1 was able to maintain the role of seamstress, it is evidenced the commitment of the homolateral arm to the surgery and imply the need of strategies to be able to carry out its work. On the other hand, the remunerated activities performed by the participants 5 and 6 had to be abandoned after the mastectomy.

*I just stopped working outside, in this case. It's just that I worked in a restaurant, now I do not work anymore, I work only at home. (Participant 5, 53).*

*I worked, then I could not work anymore. Then I was operated and the person does not stay the same, because then we lose the strength of the arms. (Participant 6, 60).*

The reduction in the occupational performance can cause feelings of incapacity and devaluation, considering the expectations deposited in relation to the physical body with the productive and social world. Thus, the limitations after mastectomy, besides making it difficult for them to stay productive, still compromise, if they keep working, the satisfaction expected by the woman from doing these activities.<sup>12</sup>

It is needed to consider work on their socialization circumstances. The abandonment of work activities brings with it a decrease in the diversity of experiences and interpersonal relationships provided by the work environment. It is assumed that these women, by limiting the environment in which they perform their daily activities, also minimize their social network, restricting them to their close friends and family members.

Returning to the question of the female social role and its influence on daily activities, one can perceive the tendency to perform family care, although the woman lives with her functional limitations and also needs cares.

*I have a grandson who is 10 years old, and I try to help the daughter with this grandson at home, going to get him at*

*school, or if he's at home, paying attention to him, because he is a child, is not it? [...] For me the family comes first. And on a daily basis, I care more about them than I do with myself. (Participant 3, 77).*

*I help, I do things for my husband to take to work, I help my daughter when she leaves for service, for college. (Participant 5, 53).*

Continuing to take care of actions in the family reaffirms the woman's capacity as a capable person, indicating that her limitations can be overcome in favor of the well-being of her loved ones. The woman is considered as the principal executor of the functions related to the care, be they family, domicile and community.

Although most women have satisfactory functional rehabilitation after treatment for breast cancer, the impact on the activities of daily living, work, and quality of life is prolonged. Issues related to well-being, social and family participation should be considered by the multidisciplinary health team during the rehabilitation process, through specialized groups and programs to the mastectomized woman.<sup>13</sup>

As for the actions of self-care, these were described by the deponents as the care with their own health and through basic activities of daily life. It is noteworthy that the sickness and surgical procedure have made the participant 3 increase her interest in the care of her own health. However, the same situations generated loss of autonomy in the ability of participants 4 and 5 to take care of themselves.

*I'm doing my check-ups, this I do, I do not fail, I do the exams she (doctor) tells me to do, that I do. (Participant 3, 77).*

*The difficulty remained for everything, even for combing myself [...] Now I can take a shower by myself. There was a time when I could not take a shower by myself. (Participant 4, 60).*

*I have some difficulty. Washing the head is something we have a bit of difficulty [...] When you have to paint a hair, do something like that I cannot do it anymore. (Participant 5, 53).*

Limitations to relatively simple activities of self-care were a source of discontent for the women in the study and potential triggers of embarrassment due to the need to ask for help for basic actions. That makes them look for strategies to overcome difficulties or abandon the practice of some tasks. Accepting yourself as a dependent being can become a difficult and painful process.

Disability, temporary or irreversible, is a multidimensional phenomenon that results from the interaction between people and their physical and social environment, that is, the interaction of health characteristics with contextual factors produces changes in functional capacity.<sup>14</sup>

At the conclusion of this unit, it is emphasized that, while some women demonstrate good performance for more complex actions, others suffer impairments in their capacity to perform simple tasks. Reflecting on these findings, the

question is: why are women in similar physical condition more dependent than others for their daily activities?

It is believed that the explanation lies in the singularity of the mastectomy experience for each one and other internal and external factors, such as adaptability, beliefs, cultural values, support network, social circle and availability of health services, among others. Again, the notions of capacity, incapacity and autonomy are perceived in its complexity.

### **Between limitations and facilitations: the development of everyday activities**

Mastectomized women find different ways to overcome the difficulties that arise in their daily lives, among them the use of their support networks. Some have mentioned the core family and circle of friends as aid components when they realize the need for help with some tasks. There are also those who, due to a favorable financial condition, delegate functions of greater physical effort to service providers.

*To clean some lining of the house, my husband always helps me. In order to lift the heavier furniture, it is he who does that [...], so I do not overdo on heavy cleanings with my arm so he does it for me. (Participant 1, 58).*

*Each one helps me in some way. He (the son) helps me more at home. The daughter, as she has a car and walks more on the street, helps me more on the street, if I need her to go to the bank, if I need her to go to the notary [...] I have a cleaning lady, but on a daily basis there is only my son and daughter. (Participant 3, 77).*

*There is a friend, we studied together, when she can, she comes in the weekends and does a general cleaning. It helps in the cleaning, in the organization of things, removes dust, because it tires me. (Participant 4, 60).*

*It is my daughter, and my husband, who help me. She helps me in domestic service and being a companion too, because she is a great partner, a great friend. It's the same family that helps the most. Moral support, as I say we have, I have enough moral support from them. (Participant 5, 53).*

*My sister washes the big clothes for me, because she has a machine. Blanket, sometimes I'm crazy to wash it, but I am unable. (Participant 6, 60).*

The support given to the participants can be presented in different ways, from the execution of the activity in its entirety to the offer of company. Receiving the help of loved ones, for the mastectomized woman, seems to partially decrease the burden of not being able to perform some daily activities.

The presence and affection of the family positively impact the lives of people living with cancer, since they are able to alleviate the pain, be it physical or emotional pain and help through difficult times.<sup>15</sup>

The belief in a superior force and faith are also referred to by the participants as strategies that facilitate the

development of daily activities, making them believe that they seek, in the comfort of what is divine, the overcoming of their limitations.

*I think it's faith, it's the strength that we need to have. And the faith that, by God's will, things will even out, because we will rise ... Thank God. That's it. (Participant 3, 77).*

*Faith in God. That's what makes us not lose hope. Because whoever removed a breast, who had cancer, knows that this disease is chronic, is not it? So you are always there, every day you win when you wake up, it is another day of life that you win. So thank God and let's move forward [...] that's what makes it easier: to always have hope! (Participant 4, 60).*

Based on the assumption that cancer can trigger stressful situations throughout the course of the disease, it becomes understandable that spirituality and religiosity gain new meaning in the person's life. In this context, hope also emerges as an important coping tool for adaptation and coexistence with the disease. Spirituality and religiosity affect decision making as well as influence general aspects of health, such as the quality of life of a person with cancer.<sup>16</sup>

Another way to circumvent the barriers of physical performance is to bet on an individualized exercise plan. In the speech of Participant 5 it is observed that the incorporation of these activities constitutes a facilitating factor of the execution of the other daily activities:

*When I'm at the gym I do these things like bodybuilding, I do gymnastics and it helps to do the housework. Helps me stay more normal, you know? If I stop for a while, it will start to give me pain. (Participant 5, 53).*

Being available for the inclusion of physical exercises in her daily life demonstrated a great potential to Participant 5, being seen as strategies to reduce her functional limitations and symptoms based on the corporal consciousness conquered.

The lack of involvement with physical activities is closely associated with greater losses in daily activities. Regular exercise is attributed to the improvement of muscular strength and endurance, flexibility, balance and cardiorespiratory fitness.<sup>17</sup>

In the group of ladies attended by the participant, a space for activities that provide motor stimuli with the production of handicrafts is possible, which, despite the functional restrictions left by the surgery, she set out to accomplish.

*My day is like that and sometimes I have ladies group activities here at the health post which is every Monday afternoon. We do handicrafts, things like that. It's my day-to-day life. (Participant 5, 53).*

When health services, such as the Basic Health Unit (BHU), are concerned with the offer of activities and social participation of its users, a wide field of possibilities opens up, such as the creation of specific groups to promote health

and prevention actions. The same participant cites BHU as an environment conducive to its socialization and production of manual labor.

In the participants' universe, there are also limitations and factors that make it difficult to carry out their activities. Among them, the physical sequelae left by the mastectomy stands out, with emphasis on the loss of physical strength, pain and changes in the corporal sensitivity that interfere in the daily life.

*I have difficulty with this hand, with the right arm, where I did the operation. And no one can imagine what we feel, only someone that did the operation knows [...]. The body looks different. The body's reaction is not the same. Besides the pain that we feel, the itch there in the surgery, you know? I no longer have the ability I had before, not at all. (Participant 4, 60).*

*In winter, specially, it hurts a lot, I have a lot of pain under the arm, in that part that has the mastectomy. It feels numb, it seems the flesh is always dead, you know? You get this feeling. (Participant 5, 53).*

Although there are differences between the time elapsed since the mastectomy, there is similarity in the physical limiting factors. In this sense, attention to the functional limitations of mastectomized women should not be restricted to the period immediately after surgery. Attention to these issues even years after the mastectomy can entail benefits for women, especially as prevention of physical and psychological suffering.

Complications generated by mastectomy, especially when accompanied by lymphadenectomy, lead to changes such as lymphedema, reduced range of motion and muscle strength of the affected upper limb, which lead to negative responses to women's daily activities.<sup>18</sup> In another study, it was also verified that greater muscle strength in relation to palmar grip is directly proportional to the better perception on the overall health of the women after mastectomy.<sup>19</sup>

Despite advances in breast cancer treatment, the post-mastectomy pain syndrome, characterized by chronic neuropathic pain that lasts for more than three months on the surgery side, is a common finding among breast cancer survivors.<sup>20</sup> This symptom may harm other spheres of life by extrapolating physical discomfort. There is a description that the persistence of moderate pain after mastectomy is responsible for higher levels of depression and anxiety.<sup>21</sup>

Psychological symptoms of depression alone appear to have a negative charge on the participant's functional capacity. Following the explanations of some of the participants about limitations of this genre in their daily lives.

*Sometimes I think that what disturb me are certain setbacks, difficulties, that appear, something that went wrong. Or, sometimes we are feeling like, a bit depressed, a little nervous, a disharmony arises, is not it? (Participant 3, 77).*

*I was very depressed, I'm taking medicine for depression. Depression makes it much harder to do things. And you do not feel like getting up sometimes, you do not feel like taking a shower. As much as you accept, I accept myself as I am now, but you, deep down you look and see that you do not have the breast. So you get that thing, you know? That agony, that thing like that. (Participant 4, 60).*

*You look at yourself in the mirror and you reject yourself. And that makes us have low self esteem too. (Participant 5, 53).*

The marks of oncological disease, such as the absence of the breast are marked in the speeches of the participants, demonstrating the dissatisfaction with the body after the mastectomy, being the motive pointed out as a trigger for the onset of depression by Participant 4 and considered an uncomfortable subject for the Participant 5. This discontent with self-image, as well as causing emotional impairment, makes it difficult to expand the possibilities of the "new body."

It is pertinent to point out that depression has a strong influence on the functional capacity of an individual, since depressed people tend to remain more isolated and unmotivated to engage in any type of activity.<sup>22</sup> Many of the women who underwent surgical removal of the breast ends up developing depression as a comorbidity. Considering the dimension of this mental health problem, it is fundamental to recruit the entire support network, both family and health services, to help overcome the fears and anxieties of these women.<sup>23</sup>

At the end of this unit, it is understood that the existing facilities and limitations seem to relate, in many cases, to women's attitudes towards life. Many are the barriers daily overcome by them, be they physical, psychic, affective or social. It is, therefore elucidative that mastectomy is capable of producing a great impact on daily life, but in itself does not extinguish the person's "sea" of possibilities that can still be achieved.

## CONCLUSION

The experience of the mastectomized woman due to breast cancer in relation to the daily activities is wide and surrounded by all the complexity of the individual universe. In this sense, it appears that the incapacities and limitations for daily activities are the result of a set of determinants, defined or not by the characteristic of the woman.

In addition, it is believed that every woman is able to conduct her own path even through adverse situations. The general context and the environment of each one interfere, but they do not yet fully define a person's disability, since a better adaptation is also influenced by individual characteristics.

The participants of this study reported that, before the discovery of the disease, they were able to fully perform all daily activities, both remunerated and domestic, and also devoted time to manual activities.

After the mastectomy, activities previously performed with ease, acquired a degree of difficulty, especially those related to domestic activities. Activities related to self-care, work, religious practices and social activities also had to be adapted, since some of the marks left by the mastectomy also produced psychic suffering, pain, reduction of physical strength, as well as undermining self-esteem.

The support of family, friends, faith, and the availability of health services help to make the experiences of mastectomy less harmful to women. It was noticed that, although some difficulties are part of the process of adaptation of the mastectomized, the woman can still find ways to overcome them, by means of the most varied strategies.

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### Contact of the corresponding author:

Letícia Valente Dias

Federal University of Pelotas

R. Gomes Carneiro, 1 - Centro

ZIP-code: 96010-610

Pelotas – RS, Brazil

E-mail: <leticia\_diazz@hotmail.com>