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MASTECTOMIZED WOMAN

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RESEARCH

FALLING ILL AND SURVIVING BREAST CANCER: THE EXPERIENCE OF MASTECTOMIZED WOMAN

O ADOECER E SOBREVIVER AO CÂNCER DE MAMA: A VIVÊNCIA DA MULHER MASTECTOMIZADA

CAER ENFERMA Y SOBREVIVIR AL CÁNCER DE MAMA: LA EXPERIENCIA DE LA MUJER MASTECTOMIZADA

Cíntia Mourão Pereira¹, Bruna Knob Pinto², Rosani Manfrin Muniz³, Daniela Habekost Cardoso⁴, Wanessa Pasolius Wexel⁵

ABSTRACT

Objective: The study aims to know the experience of mastectomized woman face to falling ill and surviving breast cancer. **Method:** It is a qualitative study, carried out with five women that have survived breast cancer, were mastectomized, had a high degree of resilience and were treated at the Oncology Unit of the Teaching Hospital in southern Brazil. Data collection has occurred at home, from august to October 2011, through semi-structured interviews and thematic analysis. The ethical aspects were respected. **Results:** The experience of cancer was permeated by many feelings for these women, but they have found strength in the support of their family, friends, religion and faith. After the treatments, they have sought alternative ways to survive with quality. **Conclusions:** Nursing has a key role in evaluating needs of the mastectomized woman and contributing to her social reintegration. **Descriptors:** Neoplasia, Mastectomy, Survival, Nursing.

RESUMO

Objetivo: Conhecer a vivência da mulher mastectomizada frente ao adoecer e sobreviver ao câncer de mama. **Método:** Trata-se de um estudo qualitativo desenvolvido com cinco mulheres sobreviventes ao câncer de mama, mastectomizada e com alto grau de resiliência atendidas na Unidade de Oncologia do Hospital Escola (UFPEL) Pelotas/RS. A coleta dos dados ocorreu no domicílio das informantes, de agosto a outubro de 2011, por meio de entrevistas semiestruturadas e a análise foi a temática. **Resultados:** Os resultados apontam que a vivência do câncer para estas mulheres foi permeada por sentimentos, mas que encontraram força no apoio da família, amigos, religião e na fé. Após os tratamentos elas procuraram caminhos alternativos para sobreviver com qualidade. **Conclusões:** A enfermagem tem um papel fundamental na avaliação das necessidades da mulher mastectomizada, promover a articulação dos cuidados com a equipe multiprofissional e contribuir para a reinserção social. **Descritores:** Neoplasia, Mastectomia, Sobrevivência, Enfermagem.

RESUMEN

Objetivo: Conocer la experiencia de la mujer mastectomizada frente al caer enferma y sobrevivir al cáncer de mama. **Método:** Se trata de un estudio cualitativo llevado a cabo con cinco mujeres sobrevivientes al cáncer de mama, mastectomizadas y con alto grado de resiliencia, tratadas en la Unidad de Oncología del Hospital de Enseñanza en el sur de Brasil. La recolección de los datos ocurrió en el hogar, entre agosto y octubre de 2011, a través de entrevistas semi-estructuradas y el análisis temático. Los aspectos éticos fueron respetados. **Resultados:** La experiencia del cáncer para estas mujeres fue permeada por muchos sentimientos, pero han encontrado la fuerza en el apoyo de la familia, los amigos, la religión y la fe. Después de los tratamientos, ellas buscaron formas alternativas para sobrevivir con calidad. **Conclusiones:** La enfermería tiene un papel clave en la evaluación de las necesidades de la mujer mastectomizada y en contribuir a la reinserción social. **Descriptor:** Neoplasia, Mastectomía, Supervivencia, Enfermería.

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INTRODUCTION

Historically, the cancer is seen as a disease that leads inevitably to death. Despite advances in medicine over the past decades, in relation to the treatment of cancer, as pharmacological and surgical procedures and the advent of radiotherapy, he still carries the stigma of fatal disease.¹

According to the National Cancer Institute,² cancer is responsible for about 13% of all causes of death in the world; more than 7 million people die annually because of this disease, and breast cancer is the second most frequent type and the most common among women, accounting for 22% of new cases each year.

On the other hand, when the cancer is detected at an early stage, the treatment offers highest rates of curability. With regard to breast cancer, the world's population, the average survival after diagnosis is five of 61%, in developing countries this index reaches 57% and in developed countries this survival increases to 73%.³ However, despite the growing number of survivors, yet there are few studies that explore the path of survival after cancer treatment.

In this sense, to understand that the life of a cancer triggers a new reflection on life, because, once installed the disease, the person needs a lot of changes in everyday habits,⁴ becomes important that these cancer survivors, representatives of a new reality in the health services, have necessary assistance to transpose this trajectory with quality. In this way, aiming to provide appropriate care to this growing population, health professionals must meet the specific needs of each one, in order to develop interventions aimed at improving the welfare and quality of life of cancer survivors.⁵

Reflecting on the experience of women against breast cancer, it can be observed in the R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3837-46

majority of them, feelings such as anxiety facing the treatment, fear of disfigurement and disability⁶possible, once one of the most suitable treatments for women with this diagnosis is still mastectomy. This is a dreaded intervention, because it results in the mutilation of a body region, interfering in the physical, emotional and social status of these women, reflecting particularly on their self-esteem.⁷

Taking into account the important gap in knowledge related to cancer survival, this study aims to explore the experiences of women mastectomizada front to sicken and survive breast cancer.

METHODOLOGY

This is a qualitative study, exploratory and descriptive character, being a subproject of the survey titled "resilience as a coping strategy for surviving the cancer". This research, quantitative and qualitative character, obtained approval of the Research Ethics Committee of the College of Nursing/UFPel, in opinion number 31/2009 and funding of the research support Foundation of the State of Rio Grande do Sul (FAPERGS) case number 0902702. The collection of data from quantitative part, that characterized the population and degree of resilience (on this scale scores have a range that varies from 25 to 175 points, with 25 to 120 scores indicating lower resilience, of 125 to 145 indicating moderately low to moderate resilience and scores greater than 145 indicating moderately high to high resilience)⁸ occurred in the period from March to June 2010in the city of Pelotas/RS and featured a sample of adult cancer survivors, 264 met in Oncology Unit of the Hospital School (UFPel). The qualitative part of the survey is still in development and this study from this phase of the research.

The choice of informants took place in two stages. First were selected, quantitative database, only women breast cancer survivors, in staging I and II, mastectomized and with a high degree of resilience,⁸ which resulted in the occurrence of 50 women. Later, phone contacts, inviting these women and informing the research goals, being selected for this study the first five who agreed to participate.

The data collection, held in the period from August to October 2011, occurred in the homes of informants. Were carried out, on average, four meetings with each informant, previously scheduled, in which the data were collected through semi-structured interview, recorded and transcribed in full in order to know the context of informants.

This study is in accordance with the resolution No. 196/96 of the National Health Council/MS, about Research with Human Beings and 311/2007 resolution of the code of ethics of nursing professionals. Have been secured, the informants, the anonymity, by means of their identification by means of the initials of the name (ex: AM), the right to withdraw at any time from the research and free access to information when you are interested in. In addition, considering that the informants had already provided their consent in the previous step (the quantitative part of the research) through the signing of informed consent (TFCC), in this step have been consulted only for the continuity of the study.

Data analysis was performed according to what determines the thematic analysis, which is to identify the nuclei of meaning that make up the communication, whose frequency presence expresses some meaning to the aim pursued. This kind of analysis is performed in three steps: Organization of data, classification of data and final analysis.⁹

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RESULTS AND DISCUSSION

The analysis of the interviews made it possible to identify how the informants have experienced breast cancer, what helped these women to confront and overcome the disease and become a survivor.

The results have been grouped into three themes: Feelings of women against breast cancer and mastectomy; Factors related to survival to breast cancer and mastectomy and paths traversed by women after the treatments.

Feelings of women against breast cancer and mastectomy

This theme deals with the feelings of the women interviewed when encountering the disease diagnosis, as well as the shape of these survivors have faced this trajectory.

Since the discovery of the lump until confirmation of the diagnosis of breast cancer, women experiencing various feelings such as anxiety, uncertainty, fear, guilt, which may remain constant during the illness and even after the end of the treatments, influencing the entire process of survival.^{10,11}

In this sense, the woman, to experience a process of illness, which can weaken it and decrease their self-reliance and passes to experience a trajectory of significant changes in their daily lives. Given this, the informants report their feelings against the disease:

[...] I was nervous, stressed to the treatment, I thought I was going to die, because everyone was saying that this is very dangerous for those who have to do breast surgery [...]. (AB).

[...] I think I also walked with depression, you know, was all-knowing. Is awesome! (CF)

Some feelings are evidenced by women with breast cancer, which are fruit of the social imaginary of a disease that causes pain and suffering and that can be fatal. In this sense, the

cancer is among the diseases that cause fear and concerns in population, creating a stigmatized image of grief, distaste and death. So breast cancer, in addition to these thoughts, encompasses also the fear of mutilation connected by mastectomy.¹²

The treatments are moments of extreme anguish and fear for women, who have great stress related to the side effects, as well as the possibility of relapse of the disease by the uncertainty of successful treatment.

[...] at the time it was horrible, no doubt, in the early days you is really bad, but then goes going. I had a lot of fear of chemotherapy [...]. (AG)

[...] When I discovered the disease I was terrified, I was saying, I'll do the surgery and get on the table, I will not come over to the House [...] was pretty hard [...] it looked like I was going to die of something. (AB)

[...] came home without cheer for anything, because it is very strong that thing that will entering (chemotherapy) and we get so bad, but then passed, until you reach the next [...]. (CF)

In the face of breast cancer noted the difficulty of women, both during the discovery of diagnosis as during treatments, because they feel helpless and suffering from the effects of the treatment, and have to face daily with the insecurity of a possible cure.¹³

In this way, it can be seen in the testimonials that the diagnosis of cancer has cultural aspects built throughout the lives of women with senses and contradictory expectations of suffering and death and also about the cure¹⁴. Thus, the different feelings of women regarding breast cancer, allow us to grasp how much it is painful for them both the disease as mastectomy.

The feelings experienced on the fact of having a significant disease and conflict caused by

partial or complete loss of the breast, the informants:

[...] It was an uncomfortable thing, be aware that there's one thing here that is no longer the same, never will be the same thing. A very delicate! (CF)

[...] When came the result, saw that I had to take everything, the entire breast, everywhere under his arm, aimed rocked [...]. (SM)

It is evident that the bodily changes resulting from the total or partial mastectomy had great significance for the lives of these women, mostly for treatment of permanent changes and aesthetically outside the standards imposed by society.

However, to two informants, the loss of a "portion" of the breast can be seen with more ease, even conformist, since the fact of having breast cancer, as well as its consequences as a work of God.

It is a change, after all is a piece you're missing. But I faced a good, I've always been a realistic person [...] (AG)

It is only slightly smaller than the other, but it was little difference from each other, get with it. God wanted to as well! What am I gonna do? (AB)

In this way, to accept the diagnosis of cancer as destination for God reserved, these women face the disease more selfless, accepting the mastectomy as divine work, although impressive and with consequences front of his self-image.

While the articulate informants with the disease, the individual action plan is reconciled with the sense of the sacred and moral superiority or spiritual attributes which prevent the separation of their health condition before and after treatment.¹⁵

In addition, the power attributed to the divine enables the satisfaction of needs that are

beyond the control of human beings, avoiding feelings of fear of the future.

In this sense, one can perceive in the accounts of informants, the desire to continue living, the willpower to face the disease and survive, despite the mutilations and often conflicting feelings.

Factors related to survival to breast cancer and mastectomy

The disease is one of the most dreaded adversities and, when it is chronic and serious as cancer, can lead to great existential suffering. However, the meaning of cancer in a person's life that goes or went through this situation is very particular and personal; Thus, this experience only has meaning to the subject that the experience and can only be understood from subject.¹⁶

During the period of treatment and after treatment the woman finds herself in situations that make it impossible to restrict or hinder their daily practices, as well as their relationship with the social environment, as demonstrated by the following reports:

After I did the radio, I came home and had no desire to do anything was when it started to give me those of not knowing where they were. After surgery I took care to lift a bucket to make heavy things, this hand never, but it's weird, after I started to improve breast, started the problem in the head [...]. (AB)

[...] I was who could no longer walk. The medication made me so badly that I couldn't take the kids at school, I came back and had to lie in bed so tired I was. I did nothing and was tired, and not my shape I'm always acting and doing things ... that was me liquidating remedy [...]. (CF)

[...] cleaning at the top are the girls, what they do, because I cannot, the arm does not raise, the arm was hard [...]. (SM)

According to the accounts of women can be noted the difficulty in continuing the daily

routines. The effects of medications used to treat affected directly the lives of these survivors. Some felt discouraged, but all reported inability to somehow to perform the tasks of daily life.

Like all potentially lethal disease, cancer brings the loss of healthy body, making women feel more vulnerable and fragile, and intensify the lack of control and mastery over one's own life.¹⁷ In addition, the woman becomes dependent, especially during the period of treatment and surgical post by adverse effects, needing help to carry out household chores that once played with tranquility. We also observed that, once finalized, the uncomfortable treatments persisted, demanding confrontation and constant adaptations.

Thus, it appears that the image of a healthy body and the feeling of well-being no longer exist, as changes occur in appearance and in the functions of the organism; making the individual often dependent, which carries feelings of guilt and concern for considering himself a burden to his family.¹⁸

Front of the limiting factors in the daily lives of the survivors, there is the need of the help of family or friends to the achievement of personal care or even domestic.

[...] the whole family, everyone wanted to stay in the hospital, that's what makes the person. After I had the surgery I came home and I was months. I had visit every day! [...] My husband helps, know that does not (for me) and does [...]. (SM)

[...] Everyone ran to help me know, not to let that bad the situation, because we stay thinking they will no longer be able to do the things that we did, then they gave me a lot of support. My friends ... a lot of people came to visit me here. It's cool we know that is wanted, that there are people who care. (CF)

They gave me all the support, everyone was in the back. My husband, my sisters are always with me, they helped me in everything that was

necessary. My husband also did everything, helped in the House, is always on my side, everyone was worried, but everyone got along. (AG)

Notes - If the testimonials that the help came through the support of family and friends who contributed to the fight against the disease, especially in crisis situations as in the case of the discovery of the diagnosis and the treatment period, being an important protective factor and hearth health of these women.

The support provided by the family and friends is essential in overcoming conflicts such as fear, confusion, anxiety and depression and can provide the optional forms of living woman, even with limitations. In addition, the family affection helps to fight against disease, supply their needs and help the survivor to achieve greater acceptance and behavioral stability.¹¹

The family stands out as main source of support for the woman during the oncological treatment. Family members provide direct or indirect support care, i.e. not just emotional comfort women, but also helps you in your daily practice, assisting in daily tasks, assuming his activities at home and in caring for the children while it is weakened physically and psychologically.^{19,20}

In this way, the support network (friends, family) contributes to tackling the situations experienced and also help the survivor to develop skills to master stress situations and adapt positively and safely to their new condition.

The women interviewed also referred to religion as an important aid in the face of the various stages of the disease.

[...] I went to church, I was those not frequented too. Makes 10 years I'll every Sunday, I will not every day but Sunday are sacred. I grabbed with God. Thanks him I am very well, very well indeed! (MA)

Always went to church. More still held onto me with God, there came out of

this. You have to make sure, God will take me out of this, I have always trusted in God. Can be a problem, because for God nothing is problem. [...] I thank God for being here, because I could have gone, but God said, "Is a little more that life is good." So I'm here! [...]. When you are in a hole that neither family can do anything, you open the Bible and listening to the word of God, you calms down. You're in a situation, and I think that will do, you cannot make a decision without opening the Bible. God speaks straight what is for you to do. (SM)

One can notice that for the interviewed faith in God was essential both to the fight against the disease as for the recovery of the same. For women of this study, God is the only being capable of promoting the alleviation of suffering and the healing of illnesses, so the religious support for attending Church and reading the Bible contributed positively to what they are searching for the path to survival.

Religiosity can be characterized as a source of support for the combat against cancer since the encounter with faith it is possible a rapprochement with the subjectivity that can help the person understand and face the disease positively.²¹ This is because the entire process of illness and survive the cancer creates ambiguity and uncertainty as to the identity, increasing the need to stick to the cultural tradition of religious beliefs and practices, being a condition essential for human survival.¹⁵

So it was realized in this study that religion, as well as the support of family and friends, positively influenced the lives of women, so as to encourage them to overcome obstacles and survive the disease daily, with more peace of mind and willpower.

Path taken by women after treatment

After treatment, the women still live with the disease and with effects caused by it. Need to

resume his life in the social environment, overcome the difficulties and limitations found in everyday activities because of the treatments carried out, as well as maintaining regular contact with doctors, performing the necessary follow-up. In this way, living day after day, surviving beyond cancer.

[...] every two years I always did mammography and now I do from year to year [...] I say to my daughter, she has 40 years and can have (cancer) for my sake. She has to take care and if I find (relapse), already will operate again. I think its better, I'm stronger than the disease. Come on, I have strength! (MA)

[...] these times took on the gynecologist, to the breasts too, as I do every year and everything went good, I did urine blood, the mammography I took to PhD see. But is fine, thank God! Do my queries every year. (AB)

[...] I did an ultrasound now and I have to take to the doctor, I even got scared, because it was in August that I discovered that everything happened. And then everything went well, got nothing, thank God! [...]. (CF)

[...] as we were high risk [...] I have two more sisters, we still always keeping, making periodic review every year, but so far everything is fine. (AG)

In their reports, women have adopted different postures to those preceding the illness, are more concerned with your well-being and your health and want to, to the extent possible, return with activities set aside earlier.

The informants follow their lives with positive thinking in relation to disease, did not abandon the sequential treatment, sought to learn more about the cancer, remain conscious of the possibility of recurrence and attending health services, transforming the disease in a reason to survive every day.

In addition to performing the medical follow-up, care for the body, mind, and

prevention are also cited in the case of cancer survival. Some of the informants have reported that before the disease were carefree with regard to health care, focusing on tasks like taking care of the family, the husband of the House, but today, health care is essential for your wellbeing.

I do physical education here in high school with my husband, we make hiking as well. Get up early and go walking to the cemetery, it helps a lot in the body of the people, I do not feel pain to do the exercises and things from home. (AB).

[...] my husband and I went out to take a walk, there on the runway in d., because not only is stopped [...]. (SM).

In view of these women, it can be observed that regular physical activity is an essential body functions stimulant, acting as a supporting role in the control of chronic-degenerative diseases, locomotor system maintenance, in addition to promoting better psychosocial well-being.²²

In this sense, the practice of physical activity with breast cancer is not only shown in post-treatment, but also before and during it, because it can bring benefits such as reducing stress, depression, anxiety, in addition to increased physical and mental disposition, contributing to the better functioning of the entire body.²³

The concern with healthier eating habits was also cited during the interviews as a way of change and adaptation to the new conditions of life in search of survival beyond cancer.

I try to do everything right, take plenty of water, as much fruit. I hardly ate fruit, not now, after I did the surgery I am always looking [...] I read a lot, I like to see news about the disease, I have tried to read a lot about the subject. (MA)

In the international literature, the nutritional attention has been pointed to as an important component in terms of treatment/care

of cancer survivors at all stages. The *American Cancer Society (ACS)*²⁴ warns of the impact of diet on survival after diagnosis of cancer, and may influence survival time free of disease and directs that the cancer survivors follow the recommendations for prevention including: avoid or quit smoking, physical activity and healthy diet and weight maintenance suitable.^{25,26}

The women resumed their lives looking to adopt healthy habits, revealing an increase in care with their health after diagnosis and surgery. During the process of survival, with help from the support network and own efforts, sought to learn from the experiences experienced looking refrain of bad feelings, keeping positive thoughts, believing that this contributes to the recovery of your health and fitness to the new lifestyle.

In addition to the food care and concern for a healthy body, rehabilitation after surgical treatment was another-important fact pointed to by an informant:

I've never been to search and go to the doctor [...] I found that moves with the arm would hurt, but, as the mother has been there I caught a ball and do so (physiotherapy exercise). (CF)

One of the most common complications after surgical treatment, Lymphedema is the most feared by women. The survivors with Lymphedema may have significant problems, including discomfort, pain and difficulty affected extremity functional. So the discovery early can save them from a delay in the implementation of treatment and show better results.²⁷

The Physiotherapeutic Rehabilitation help since the earliest functional recovery, until the prophylaxis of sequels, and decrease recovery time by promoting a faster return to everyday activities and occupational, collaborating with the reintegration of survivors into society, without functional limitations.²⁸

In this context, the importance of maintaining health care related to nutrition, physical exercises and physiotherapy, which, if carried out through a multidimensional and interdisciplinary approach, considering humans as unique and with different needs,²⁹ may provide considerable improvements in the daily activities of these women with reduced pain, improved handling of arm and resulting better quality of life.

CONCLUSION

This study made it possible to know how the woman breast cancer survivor experience this trajectory. It was observed that, in the process of experiencing breast cancer and mastectomy, the woman finds herself in the midst of a whirlwind of feelings such as fear, anxiety, sadness, that end up interfering directly in the way they deal with the disease. However, these same sentiments are superimposed to the trust, safety and strength to face the challenges posed by cancer in order to survive.

During the whole process of survival the interviewed mentioned finding the strength they needed to tackle the disease in the support and care of family, friends, and also by means of religion and faith.

The family had a key role in the survival of women, especially during the reintegration in the social environment, contributing in housework, encouraging the practice of physical activity and good nutrition and promoting emotional and affective support.

The religion also proved to be an important source of social and psychological support. Women in religion saw a support base, giving the disease to something higher and divine believing that they could be cured.

After the treatments, the lives of informants changed, they began to assess the way

lived until then, and to seek new ways of living befitting the consequences left by disease, looking for alternative paths that provide a quality life beyond cancer.

It is important to note that for women-breast cancer survivor is crucial to an interdisciplinary approach, in which nursing plays a key role in the evaluation of your needs and building a plan of care that enhances its entirety and individuality. In addition, nursing should promote linkages with other areas of health, with actions that contribute to a life of quality and for their social reintegration.

It is expected that this would give rise to the development of new research studies that allow to know other realities and ways to experience the illness and survive the cancer.

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