ASSISTANCE TO MASTECTOMIZED WOMEN: FAMILY PERCEPTIONS AND THE AWAKENING OF HEALTH PROMOTION

ASSISTÊNCIA ÀS MULHERES MASTECTOMIZADAS: PERCEPÇÕES DE FAMILIARES E O DESPERTAR DA PROMOÇÃO DA SAÚDE

ASISTENCIA A MUJERES MASTECTOMIZADAS: PERCEPCIONES DE LOS FAMILIARES Y DESPERTAR DE LA PROMOCIÓN DE LA SALUD

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How to quote this article: Souza JB, Walker F, Schleicher ML, Reis L, Manorov M, Martins EL. Assistance to mastectomized women: perceptions of family members and the awakening of health promotion. Rev baiana enferm. 2019;33:e33566.

Objective: to understand the perceptions of family members of mastectomized women about health care and the need to promote health after experiencing breast cancer in the family. Method: a descriptive, exploratory study with a qualitative approach, with the participation of nine relatives of women mastectomized between 2012 and 2018. The interviews took place in 2018, through semi-structured questions. The data were structured according to Bardin's content analysis. Results: the potentialities highlighted in the assistance were welcoming, professional attention and organization, while the weaknesses were slowness, lack of professionals in the face of demand and lack of psychological support; and in search of health promotion, the strengthening of self-care after the experience of cancer was highlighted. Conclusion: the assistance potentialities faced mainly the slowness of the system, compromising the quality of care, but preventive actions emerged as a source of encouragement for self-care in health promotion.

Descriptors: Breast Neoplasms. Family Relationships. Health Assistance. Health Promotion.

Objetivo: compreender as percepções dos familiares de mulheres mastectomizadas sobre a assistência em saúde e a necessidade de promover a saúde após a vivência do câncer de mama na família. Método: estudo descritivo, exploratório, de abordagem qualitativa, com a participação de nove familiares de mulheres mastectomizadas entre 2012 e 2018. As entrevistas ocorreram em 2018, por meio de questões semiestruturadas. Os dados foram

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estruturados conforme análise de conteúdo de Bardin. Resultados: as potencialidades destacadas na assistência foram acolhimento, atenção dos profissionais e organização, enquanto as fragilidades foram lentidão, falta de profissionais diante da demanda e falta de apoio psicológico; e em busca da promoção da saúde destacou-se o fortalecimento do autocuidado após a vivência do câncer. Conclusão: as potencialidades assistenciais enfrentavam principalmente a lentidão do sistema, comprometendo a qualidade do atendimento, mas as ações preventivas surgiam como fonte de estímulo ao autocuidado na promoção da saúde.

Descritores: Neoplasias da Mama. Relações Familiares. Assistência à Saúde. Promoção da Saúde.

Objetivo: comprender las percepciones de los familiares de mujeres mastectomizadas sobre la asistencia a la salud como también respecto de la necesidad de promover la salud después de haber transitado la experiencia del cáncer de mama en la familia.

Método: estudio descriptivo y exploratorio, de enfoque cualitativo, con la participación de nueve familiares de mujeres mastectomizadas entre 2012 y 2018. Las entrevistas tuvieron lugar en 2018, por medio de un cuestionario semiestructurado. La estructuración de datos se llevó a cabo de acuerdo con la técnica de análisis de contenido de Bardin. Resultados: los factores positivos que se destacaron en la asistencia fueron: receptividad, atención de los profesionales y organización. En lo atinente a las falencias, se registró la lentitud, la falta de profesionales en relación a la demanda y la ausencia de apoyo psicológico. En aras de promover la salud se destacó el fortalecimiento del autocuidado después de la experiencia del cáncer. Conclusión: Los factores positivos de la asistencia a la salud sufrían el embate de la lentitud del sistema, lo que comprometía la calidad de la atención suministrada, sin embargo, las medidas preventivas se erigieron como fuente de estímulo al autocuidado en la promoción de la salud.

Descriptores: Neoplasias da Mama. Relaciones Familiares. Asistencia a la Salud. Promoción de la Salud.

Introduction

Worldwide, breast cancer, one of the diseases that most affects women, is caused by the uncontrolled multiplication of breast cells(1). This cancer is the second most common type of cancer worldwide, totaling 2.09 million cases in 2018, and the fifth form of cancer that causes the most deaths, with 627 thousand deaths in the same year(2). In Brazil, in 2018, the estimate of new cases of breast cancer in women was 59,700, constituting 29.5% of new cases of neoplasms. According to the primary location of the tumor in the breast, the mortality of Brazilian women in 2015 was 15,403 deaths, which represents 16.2% of cancer deaths in the country(1).

There are risk factors for the development of breast cancer, such as age (mainly after 50 years old), physical inactivity, obesity, overweight, radiation exposure, alcohol consumption, the use of hormonal contraceptives and the family history of breast cancer. However, some factors can be controlled. Therefore, Brazil has implemented actions to prevent breast cancer, especially those related to lifestyle and early diagnosis(1).

The prevention of breast cancer is one of the priorities of the Brazilian Public Health System (*Sistema* Único *de Saúde*, SUS) to reduce the cases of the disease and its mortality, which occurs through the control of modifiable factors, such as healthy eating, adequate body weight and physical activity, which makes it possible to reduce the risk of development by up to 28%(3). Allied to this, early detection is sought, effected by advising women to perform breast self-examination and the annual mammography exam. Screening of women aged 50 to 69, using mammography, is one of the strategies of the SUS to identify lesions suggestive of cancer and make the referral for investigation, diagnosis and treatment(4).

In locally advanced tumors, mastectomy is indicated, a surgical intervention, considered a radical method that interferes with the physical, social and emotional shape of the woman(5). The woman undergoing the procedure and her family members tend to drive changes in lifestyle, promoting new perceptions, beliefs and habits, which influence the process of acceptance and adaptation(6).

The experience of breast cancer begins when the woman shares the suspicion of the disease due to the presence of a lump in the breast.

Thus, the family begins to exercise a monitoring role, remaining vigilant for symptoms that may appear. Often, the family is faced with the woman's confrontation when trying to convince her to seek professional help, becoming a difficult process until the acceptance of the search for treatment(7).

Despite the technologies developed in the oncology area, the association between cancer and the end of life is still very present. The family environment breaks its balance when one of its members cannot or do not get to perform its role in that context, requiring adaptation in the face of breast cancer. Thus, involvement with the disease goes beyond the patient, comprising the family structure(8). Family members bear the responsibility to comfort, assist in decisions and encourage the overcoming of the current health condition, facing a new meaning of the role of women in the family(7). When women become ill, many responsibilities are transferred to their families, increasing their demands and destabilizing the family dynamics. This aspect, in particular, can generate sadness, fear, conflict of roles and abandonment of family's social life(8).

The care after mastectomy is of paramount importance, as well as monitoring the woman and her family members by health professionals, aiming at an integral physical and emotional care, directed towards qualified listening strategies, incentive to self-care and participation in groups(9). Notwithstanding advances in treatment, it is necessary to integrally comprise the care for the diagnosed woman and her family(10).

The present study is justified to reflect about the perceptions of family members about health assistance in health in breast cancer and its impacts on the life of the woman and all those around her. This study presents as a research question: What are the perceptions of family members of mastectomized women about health care and the need to promote health after experiencing breast cancer?

The objective is to understand the perceptions of family members of mastectomized women about health care, as well as about the need to promote health, after experiencing breast cancer in the family.

Method

It is an exploratory and descriptive research, with a qualitative approach, which integrates a matrix research project of a Federal University in the South of Brazil. Qualitative research allows for better understanding and interpretation of phenomena based on their meanings and contexts, providing a more comprehensive view of the problems(11).

Inclusion criteria considered: being a family member of a mastectomized woman who actively participated in the whole process of experiencing and treating breast cancer, between the years 2012 and 2018, and being over 18 years old. The relative (husband, mother, father, siblings and children) was indicated by the mastectomized women. The temporal delimitation was proposed from 2012, based on Law No. 12,732, of 2012, which established the 60-day period, after the diagnosis in a pathological report of malignant neoplasia, for the beginning of treatment(12). As exclusion criterion, it was established that they would be relatives of mastectomized women who underwent all breast cancer diagnosis and treatment by the private health system.

The selection of participants took place in two stages. In the first, mastectomized women were identified between 2012 and 2018, users of the SUS, residing in a municipality in western Santa Catarina state, and contacted with the support of the Family Health Strategy (*Estratégia Saúde da Família*, ESF) teams, through home visits mediated by Community Health Agents (*Agentes Comunitárias de Saúde*, ACS). In the second moment, the family members appointed by the women who experienced the trajectory of cancer and mastectomy were identified. Subsequently, family members were invited to participate in the research, making a total of nine people. After the repetition of information, the collection ended.

Data collection took place in the second half of 2018, at the participants' homes, at a more comfortable date and time for them. The interview was conducted, using semi-structured questions that involved: the family member's perception of health care for women during the trajectory of breast cancer, the need to promote health after overcoming cancer and the strengths and weaknesses in health care, as well as your suggestions to mitigate these weaknesses. Before starting the interviews, the study participants received and signed the Free and Informed Consent Form (FICF) in two copies. One remained in their possession and the second was returned to the researcher. The interviews were recorded and later transcribed in full.

In order to maintain the anonymity of the participants, it was opted for the use of codenames for precious stones, given that these stones reflect the energy, strength, vibrations and light that family members represented in the lives of mastectomized women in the cancer discovery process, treatment and overcoming.

To organize and analyze the data, Bardin(13) content analysis was used, consisting of a pre-analysis stages, necessary to systematize the ideas after reading the data obtained in the interviews, followed by the material exploration stage, in which three choices were defined: choice of units, choice of counting rules and choice of categories. These were established as follows: "Potentialities and weaknesses in the therapeutic itinerary of breast cancer: perceptions of family members" and "Possibilities to promote health after the experience of breast cancer in the family". Subsequently, the data were interpreted based on studies that deal with the theme.

The research project was approved by the Research Ethics Committee (*Comitê de* Ética *em Pesquisa*, CEP) of the Federal University of Fronteira Sul, with Opinion No. 2,634,165, and obeyed the ethical precepts for research with human beings.

Results and Discussion

Of the nine study participants, four were female and five males: four children, three husbands, a mother and a sister of mastectomized women. The family members participating in the research were the main caregivers of women during the experience of breast cancer and were aged between 24 and 69 years old. As for schooling, two had incomplete elementary education, two had completed high school, one had incomplete undergraduate degree, two had completed undergraduate degree and two with graduate degrees. As for the occupation of family members, one was an accountant, three retired, a social worker, one worked with general services, another self-employed, a teacher and one housewife.

Potentialities and weaknesses in the therapeutic itinerary of breast cancer: perceptions of family members

Due to feelings of anguish and apprehension, in addition to support for women and their families, the assistance and qualified treatment of breast cancer are associated with survival. It is of utmost importance for the family member to have confidence in the health team, which is configured through humanized care, interaction, effective communication and the dedication of the team(14). Reports from the participants valued the welcoming and care of the health professionals from the SUS:

> *They are very attentive* [...] *in the oncology ward they are very helpful and very understanding.* (Sapphire).
>
> [...] *if we needed anything, they were always ready to go for it* [...] *I think there was nothing missing.* (Diamond).
>
> [...] *I think the SUS is to be congratulated* [...] *I have nothing to complain about it* [...] (Pearl).
>
> [...] *the health professionals at the hospital are all attentive to us* [...] (Amber).
>
> [...] *they gave all the attention she needed* [...] (Emerald).
>
> [...] *we were very, very well attended. The SUS is sometimes better than a health insurance plan.* (Amber).

Health teams need to be trained and prepared to provide care jointly and integrally in the context of cancer, aiming at the well-being of women and their family nucleus, in order to facilitate safety in the care environment(14). The functioning of the health system was praised by some participants:

> *Agile... everything very organized!* (Amber).
>
> [...] *everything worked as planned/expected by the SUS itself* [...] (Pearl).

However, there are still barriers in the service network that need to be overcome, characterized as challenges that require efforts from health professionals. The structure of the health service, as well as the characteristics of the care profile, such as the number of users undergoing cancer treatment, directly influence the effectiveness of care(15). The main weakness shown in health care in the SUS was the slowness of services, coupled with the insufficiency of professionals in relation to the public of care and the excess of bureaucracy:

> [...] *through the SUS, things are always time consuming, it is not for now.* (Ruby).
>
> [...] *it took 60 days to get the mammogram result. It took too long.* (Quartz).
>
> [...] *we had to wait* [...] *the delay does not depend on the professionals; it depends on the health system.* (Emerald).
>
> [...] *had to go a long way, go to the Health Department to authorize, took too long to authorize, or did not authorize.* (Emerald).
>
> [...] *many people with this disease and few professionals.* (Emerald).
>
> [...] *the demand is great* [...] *long lines waiting and a lot of bureaucracy.* (Ruby).

As breast cancer is one of the most feared by women, its meaning brings a compromise of emotions, which makes it necessary to also appreciate the emotional aspects of the disease. From diagnosis to recovery, the scarcity of guidance impairs the understanding of women and their families about the disease and self-care(16). This also occurred in this research, as the participants reported:

> [...] *they have no support* [...] *they have to go in the dark, treading paths to find the solution* [...] *the public network, at this point leaves something to be desired.* (Quartz).
>
> *The chemo and radio, we run into a lack of information* [...] *during chemo, we had little information.* (Emerald).

In view of this, the participants suggest that, in order to improve care for mastectomized women in the SUS, it is necessary to:

> [...] *speeding up the exams and results, when necessary.* (Quartz).
>
> [...] *the SUS had to provide more support for faster surgery.* (Ruby).
>
> *It needs to be more agile, and offer immediate care.* (Turquoise).
>
> *Having more structure, more professionals, to be able to meet the demand, which is very large.* (Ruby).

Health education, a tool that surpasses biomedical assistance, is considered important in building self-care and effective both for promoting the quality of life of women with breast cancer and for improving health system strategies(17). The participants in this study highlighted the need for quality guidance aimed at these women and their families:

> [...] *it would have to make more groups in the guidance community.* (Emerald).
>
> [...] *implementing a support system... of guidance.* (Quartz).

The prevention of breast cancer was remembered by one participant as a mechanism to improve care in the SUS. Prevention actions facilitate early diagnosis, recovery and treatment, mainly by promoting knowledge about the disease, enabling cancer not to progress. This practice must be inserted in public health programs as a strategy for the control of chronic diseases(17):

> [...] *to work more on prevention. There is no priority in prevention* [...] *They do work later, in the healing part.* (Emerald).

In view of the peculiarities experienced in the cancer trajectory, the support of the health team for the woman and her family members is essential, both in physical, psychological and emotional aspects(14). However, due to the barriers that prevent the effectiveness of many oncologic treatments in the SUS, the network of services still depends on the diligence of authorities and health teams, as well as on the legitimacy of public policies and activities that alleviate the difficulties encountered in this path, to achieve comprehensive care, breast cancer prevention and health promotion(15).

Possibilities to promote health after the experience of breast cancer in the family

Cancer, considered a disease that involves the whole family, causes relationships to intensify and exchanges of feelings and anxieties to occur, which can cause positive and negative impacts. Each individual has different behavioral responses to the situation, in addition to changes in the environment, which often influence strengthening, family support and planning to improve the health and well-being of those involved(18).

The experience of cancer implies the search for a better quality of life, with well-being, lifestyle, health and leisure becoming relevant, encompassing physical, social, psychological and economic aspects(19). Leisure activities, carried out in groups or individually and varying according to each person's preferences, provide pleasure, distraction, relaxation and fun, with a tendency to bring friends and family closer together(20). Family unity was also evidenced by the participants of this research after the cancer experience, when they reported:

> [...] *playing canasta or something else, we get distracted...* (Diamond).
>
> *Playing cards and participating in the community meetings they have, a party day, lunch, it helps us.* (Turquoise).
>
> *Our family came together a lot. There was a greater union between brothers, one cares about the other. (*Emerald).
>
> *In the family, one started to support the other. (Sapphire).*

People involved in this experience seek to promote health through self-care. The care with body hygiene is also considered a preventive method because, after bathing, benefits are generated for the individual's health, such as increased self-esteem, relief and comfort, constituting an accessible and simple activity that should be performed daily(21):

> *My plan now is to take care of myself. I'll have time for that.* (Emerald).
>
> *We take care of ourselves more after cancer.* (Diamond).
>
> *In the bath, you prevent yourself and it is very important.* (Amethyst).

After breast cancer treatment, women experience changes in their lifestyle habits, such as the practice of physical exercises in their daily lives, an element that is positively combined with success in overcoming cancer and reducing the risk of recurrence(22). The participants' reports revealed the practice of these activities or the desire to do them:

> [...] *the gymnastics now we do it twice a week...* (Diamond).
>
> [...] *what I do is very little. I need to do more exercises.* (Emerald).

Eating habits were considered as minimizers for health complications, especially whole grains, fruits, vegetables and seeds, which promote health through nutritional and immune improvement, causing people to adopt this daily practice(19), as quoted in some statements:

> *I am more careful than I was before with food.* (Sapphire).
>
> [...] *she was a little careless, now she has improved by eating more vegetables, fruit, healthier food.* (Quartz).
>
> *We eat less fat, fried food, fewer things that are bad.* (Ruby).

In addition to the care already mentioned, family members see early detection of health problems as relevant, since annual examinations are important to detect early stages of cancer, increasing the likelihood of cure(23). The reports highlighted the periodic examination:

> *I'm always following, I have to be more careful. Whoever went through this has no way of not having this attitude, of being more attentive.* (Emerald).
>
> [...] *any little thing we look after, because we already have it in the family.* (Ruby).
>
> *We usually do routine examinations, with preventive always up to date.* (Amber).

Since 2006, the SUS has had the National Health Promotion Policy (*Política Nacional de Promoção da Saúde*, PNPS), which aims to plan individual and collective care actions, in the short and long term, in primary care, in order to meet the health needs of the population and enrich your biopsychosocial well-being. Some of the items addressed by PNPS today, among others, are adequate and healthy food, promotion of a culture of peace and human rights, bodily practices and physical activities(24). In this sense, a family member addressed the prevention and health promotion actions carried out in the Basic Health Units (*Unidades Básicas de Saúde*, UBSs):

> *There are always campaigns at the health units, there are little folders that talk about healthy eating, exercise.* (Amber).

The UBS provides users with dialogical groups, such as: groups of people with hypertension, diabetes, pregnant women and others. Each group is formed by individuals who share the same clinical need, promoting health education together, stimulating the bond between members and communication about a common objective worked on(25). In this study, this also occurs, as exposed by some family members:

> [...] *there is a lot of groups, the municipality gives lots of things...* (Pearl).
>
> *The health service acts on cervix and breast cancer. If you go after it; you have assistance. There are groups...* (Amethyst).
>
> [...] *the center is available, what is missing is people who use it* [...] *There is the Ecoparque which is also very good.* (Pearl).

The difficulty of adhering to the group activities developed by the UBS is highlighted since, usually, the population seeks immediate results, such as a medical consultation, not being interested in alternative and long-term practices. The lack of dialogue and information from health professionals about the activities carried out by groups in the community, also negatively influences the inclusion and permanence of users(25).

After experiencing breast cancer, the mastectomized woman and her family go through several changes. One of them is the search for a better quality of life, adopting new eating and physical habits, performing routine exams and dedicating more to leisure and group activities, with the purpose of promoting biopsychosocial health and, thus, preventing future diseases(19).

In the development of this study, the absence was evident of specific records in the ESF about women who had cancer and used the SUS for their treatment. The absence of such information emerged as a limiting factor for this research, as it hindered the initial selection of participants, making it necessary to support the ACS, who helped, with their knowledge of the territory and bond with residents, in the location and contact with mastectomized women and their families.

Conclusion

The potentialities predominantly exposed by family members regarding the assistance of the SUS to mastectomized women were humanization, welcoming, willingness of professionals and organization. However, family members pointed out that the SUS still showed weaknesses that reflected in the delay in treatment, with the slowness of assistance, excessive bureaucracy and lack of guidance that would facilitate understanding about breast cancer and treatment for women and their families. In addition, they highlighted the lack of psychological support in the face of the disease and the reduced health team in view of the high demand from users.

When there is a case of cancer, family members also reframe their concepts of health promotion, adopting healthier practices, such as balanced diet, physical exercise and annual exams. Thus, it was evident that prevention and health promotion actions are considered positive in order to encourage women's self-care and family attention in search of quality of life.

Understanding the meanings of the family regarding the experience of breast cancer in terms of the care provided and how this process determines family actions for health promotion allows nursing professionals and other members of the health team to adjust resources, to know the entire progress of the care network and the relevance of care provided in a humanized and comprehensive way, in order to favor the quality of care for women and their families who experience breast cancer, in order to guarantee their rights in the SUS.

Collaborations:

1 – Conception, design, analysis and interpretation of data: Jeane Barros de Souza, Fernanda Walker, Maira Lidia Schleicher, Luana Reis, Maraisa Manorov and Emanuelly Luize Martins;

2 – Writing of the article and relevant critical review of the intellectual content: Jeane Barros de Souza, Fernanda Walker, Maira Lidia Schleicher, Luana Reis, Maraisa Manorov and Emanuelly Luize Martins;

3 – Final approval of the version to be published: Jeane Barros de Souza.

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Received on: September 19, 2019

Approved on: November 19, 2019

Published: March 13, 2020