

SOCIAL SUPPORT NETWORK OF WOMEN WITH BREAST CANCER

Rede de apoio social à mulher com câncer de mama

Red de apoyo social a la mujer con cáncer de mama

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ABSTRACT

Objective: the study's purpose has been to know the social support network for breast cancer-bearing women, who were participating in a support group from the *Rio Grande do Sul* State. **Method:** it is a descriptive-exploratory study with a qualitative approach, which was performed by the participation of women from a support group. The data analysis carried out according to the technique of Thematic Analysis of Minayo resulted in four themes, as follows: family and friends as social support network providers; therapeutic groups in the support network framework; healthcare team as members of the support network; religiosity, faith and spirituality as part of the social support network to relieve suffering. **Results:** social support is needed during treatment, both for coping with the pathology and for women to recover from it. The results have shown that families, friends, neighbors and the group are all parts of the women network, who is experiencing cancer. **Conclusion:** providing social support is part of the comprehensive care given by nurses, so recognizing the women's needs is important to plan nursing care.

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RESUMÉN

Objetivo: conocer la red de apoyo social a la mujer con cáncer de mama, integrante de grupo de apoyo de Rio Grande do Sul. **Método:** estudio cualitativo, exploratorio, descriptivo, realizado con mujeres de un grupo de apoyo. El análisis de datos, conforme Minayo, determinó cuatro temáticas: familia y amigos como proveedores de red de apoyo social; grupos terapéuticos en el contexto de red de apoyo; equipo de salud como integrante de red de apoyo; religiosidad, fe y espiritualidad integrando red de apoyo social para mitigación del sufrimiento. **Resultados:** el apoyo social es necesario durante el tratamiento, para afrontar la patología y la recuperación de la mujer. La familia, vecinos, amigos y grupo forman parte de la red de la mujer que experimenta un cáncer. **Conclusión:** proveer apoyo social forma parte del cuidado integral del enfermero, y reconocer las necesidades de la mujer es importante para la planificación de enfermería.

Descriptor: Apoyo social; Enfermería; Cuidado de enfermería; Educación; Neoplasias de la mama.

INTRODUCTION

Female breast cancer is the type of neoplasm that affects women the world over, in both developing and developed countries. It represents the world's largest cause of cancer death in women, with about 14,388 deaths in 2013, 181 men and 14,206 women. In Brazil, mortality rates for breast cancer remain high, probably because the disease is still diagnosed in advanced stages, and its incidence increases rapidly and progressively above 35 years old, but rarely below this age group. Furthermore, by the year 2016, 57,960 new cases of breast cancer are expected.¹

According to the National Cancer Institute,² the *Rio Grande do Sul* State is the second Brazilian state with the highest incidence of this neoplasm, estimated around 74.30 cases per 100,000 women.

Female breast cancer is a cause of intense suffering since surgery mutilates the organ that symbolizes femininity, sexuality, and motherhood. From the time of diagnosis, women bearing breast cancer experience negative feelings such as anxiety, fear, depression, anguish, and despair, but there are those who go through a period called the process of denial of the disease. Since this process, usually in the initial phase of the disease, the prognosis of cancer, the patients deny the illness that consists in the partial or total refusal of the perception of the fact that they are ill.³

When experiencing the diagnosis of cancer and the experience of being submitted to mastectomy, the woman begins a long and new trajectory in her life, ranging from the acceptance of the disease to the readjustment and

psychosocial adjustments, since breast cancer causes a condition of vulnerability and considerable emotional losses. This fact brings great and significant changes in the daily life of women, whose uncertainty about the future adds to the despair and fear of dying.⁴

In this sense, the social support network represents the link of social relationships that each maintains, including closer relationships (such as family and close friends) and more formal relationships (other individuals and groups). Although much studied, there is no consensus among researchers regarding the concept of social support. One way of explaining social support is as a function of social networks. It is considered the main function and also the promoter of the construction of the networks.⁵

The social support network can be understood as a set of meaningful connections or links that are part of the people who regularly interact with the person bearing cancer, such as family members, neighbors, friends, health professionals, co-workers.⁶ Thus, this network, through its various components and established links, interconnects with other networks, then influencing and being influenced by them.

Moreover, social support can be seen as a process of interaction between people or groups of people, who through systematic contact establish bonds of friendship and information, receiving material, emotional, affective support, which contributes to the reciprocal well-being and builds positive factors in the prevention and maintenance of health.⁷

The relationship between social support and breast cancer has been identified as an important strategy in adapting to the disease, since the social support network is considered a protective and recuperative factor for the health of cancer-bearing women, since it prevents them from giving up dealing with the different phases of treatment and that the coping of the disease is more positive.⁴ Social support has a direct effect on well-being, promoting the improvement of the psycho-emotional aspects of individuals in the health-disease process. This support includes emotional, material or instrumental and educational or informational support. In this perspective, the woman bearing breast cancer, facing frailty and feeling helpless, does need the support and appreciation of social networks.

Social support can also be defined as the quality with which interpersonal relationships meet certain needs. Concomitant to this, perceived support has been related to psychological well-being, the degree of satisfaction with life, self-esteem and the low occurrence of anxiety.⁴ Hence, it is understood that it is based on the reciprocity of help among the individuals, groups and institutions.

Considering the aforementioned aspects, the following research question was elaborated: What is the social support network dynamics for women diagnosed with breast cancer? The present study meant to know the social support network for breast cancer-bearing women, who were participating in a support group from the countryside of the *Rio Grande do Sul* State.

METHODS

It is a descriptive-exploratory study with a qualitative approach, which was performed from August 2015 to July 2016, after approval by the Research Ethics Committee from the *Universidade Franciscana (UFN)* located in *Santa Maria* city, *Rio Grande do Sul* State, under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] No. 54430916.0.0000.5306, approval number of research 1,508,031, and according to Resolution No. 466/2012 from December 12th, 2012 (National Health Council).

The study participants were women members of a support group for breast cancer-bearing women. The group was formed in 2009 by a nurse, with the participation of women diagnosed with breast cancer and/or mastectomy. The meetings are held every two weeks and open to the community. The choice of participants was guided by the following inclusion criteria: women who participated in the group for more than six months with history and diagnosis of breast cancer, over 18 years old and who accepted to participate in the research. We excluded women with less than six months of participation in the group, under the age of 18 years old and those who due to the treatment or complications of the disease were not able to respond to the study. Six women participated of this study, all of them were within the age group from 37 to 62 years old.

The participants were identified with the letter W that means woman and followed by Arabic number according to the order of the interviews (W1, W2) and so forth. After obtaining consent for participation, semi-structured interviews were performed with the participants. The interviewing questions were as following: When did you find out you had cancer? Who was the first person to tell you the diagnosis? Were you alone when the physician informed you about the illness? Who are the people that help you the most during cancer treatment?

The interviews were carried out at the women's homes, aiming to provide a welcoming environment. They were also scheduled, recorded, transcribed, interpreted and analyzed through the technique of Thematic Analysis of Minayo.⁸

RESULTS

The results were organized in four themes, as follows: family and friends as social support network providers; therapeutic groups in the support network framework; healthcare team as members of the support network; religiosity, faith and spirituality as part of the social support network to relieve suffering.

Family and friends as social support network providers

The diagnosis disclosure for the woman bearing breast cancer is a practice performed by medical professionals, and when she receives the diagnosis, she experiences the sensation of having cancer (feeling of fear, anguish, and questioning).

[...] we're kind of like this... you think, why me? Why me? Because I've always tried to help everyone [...]. (W1)

At the time, I got depressed because I was alone, I called my friend and she came back... I never accepted it as if it was cancer, I accepted it as something else that appeared [...]. (W3)

The woman's discovery of cancer causes pain. In this process of suffering and impact when receiving the diagnosis, the woman searches for family and friends as the first representatives of this social support network. In the women's speeches, the most significant signifiers were the husband, the children, and friends.

The family goes beyond treatment and healing. The family offer affective support and are caretakers, as the following lines show:

He is my safe haven, my best companion, he has never abandoned me, never, never... he left his job, he did everything to come here, to accompany me [...]. (W6)

Regarding the friends, the patients emphasized how important friends are to them:

She conveys confidence, tranquility, agility, is a person that makes me excited to go strong, you know, that gives strength.... (W5)

[...] friends become family. (W6)

Therapeutic groups in the support network framework

Social isolation and shame while facing mutilation can be minimized by sharing the yearnings in self-help groups. The support group is seen as a place of socialization. In the group there is the creation of links, and also serves as an educational tool and an integral part of the healthcare network. Furthermore, the women signal that the group has become a family. The group causes encouragement to the woman because it motivates her to help others, who also need care, demonstrated in the following statements:

A group was created here in the city, to support women who had breast cancer, and they invited me to participate and I was very happy because I got there and I saw that what I was going through had other women who also passed, maybe well more brave than I, that I admired, because they shared it naturally... I started to participate in the group, and I felt very welcomed; but because I did not do therapy with anyone, I think I have saturated the ears of who I went there [...]. (W2)

The group contributed a lot in the voluntary segment... now I am part of the Municipal Council of the Elderly...

I spent every day in the asylum... I do not stop, the home of boys and girls... where there is one, someone helping, there I am [...]. (W4)

It is important for the person to have support, support from family, friends, look for support groups... (W1)

Here is the group [...] coordinated by the nurse [...] then this group is for people who are going through cancer or have already faced breast cancer and it has become a family, so friendship, you know? One gives support to the other, the exchange of experiences, and in this group, which is very valid, there are lectures with nutritionists, with physiotherapists, with psychologists [...] this is important even to guide people. (W5)

Therefore, the support group is recognized as a social network, and as it was perceived here, the support group allows the relationship and interaction between women, the exchange of experiences and knowledge and stimulates social involvement.

Healthcare team as members of the support network

The healthcare team is not always the main social support network for the woman, as revealed here, because it is considered as an integral part of the treatment and resolution of problems. Although family members, friends, and neighbors are considered the first choice to help sharing the diagnosis and contributing to recovery, the healthcare team appears to be encouraging to women bearing cancer, adhering to treatment, and hoping that everything will work out.

In the participants' speeches, the healthcare team despite appearing numerous times, it was summed up in two nursing professionals and the physician, as an integral part of the care. Their presence in the speeches is due to the fact that they are always present, in order to achieve integral care and quality of patients, as shown in the following statements:

The people from the clinic were always like this, great people. So... if you get that affection, that support, you feel better [...]. (W1)

He was much more than a doctor at that time, because he was a friend, he was my brother, he was my family... and then a very dear nurse also came along... (W2)

At the beginning of the treatment, the person who gave me a very good push and helped me was the nurse [...]. (W6)

In this study, as the healthcare team is concerned, the social support network is formed by the nursing team and the physician, so it is not a multidisciplinary team, which is expected to be in order to provide a quality service

to the network. The statements strongly present the presence of nursing professionals and the physician, but these have contributed to assist women in their integrality, offer help according to the needs and provide means of coping with the situations experienced.

Religiosity, faith and spirituality as part of the social support network to relieve suffering

Participants reveal how much religiosity, faith, and spirituality are part of the social support network. Regardless of the type of religion and belief, it is perceived as a source of energy and strength.

I asked God to help me, that I could win, I did the surgery, I did the treatment [...] and I think, that people have to have that strength, have to have that faith, that will be okay, believe in God. (W1)

[...] it is based on positive thinking, the power of the mind, that also helped me a lot in healing the disease... I always thought that I would heal myself, I always held God's hand and I thought I would heal me [...] you bind yourself to God. (W4)

[...] a lot of faith, a lot of prayers... I thank God every day. (W5)

In the participants' speeches, faith and spirituality have proved to be strong supporters within this social support network. It is noticed how much they are linked to the rehabilitation, the cure of the patients, the permanence of adherence to the treatment and the difficulties, appear as a pillar of sustainability.

Herein, the results showed that the phase of diagnosis and treatment tend to be the most difficult. At this time, women need the emotional support of family, friends, neighbors, and informative support from the healthcare team.

Family protection and support in health and disease reduce social isolation, aiding decision-making strategies for choosing and evaluating treatments. The family as a group of economic cooperation, coexistence, division of responsibilities and obligations among its members favors giving and receiving support and care.⁹

Nowadays, the family is conceived as a complex unit, characterized by the relations of its members, within a peculiar framework. Such relationships are expressed by interpersonal and environmental influences, thus constituting a complex interactional system, whose subjects have defined social functions. At this juncture, the family emerges as a privileged space, where health care and life support can be offered to its members. In the context of chronicity, this situation surrounds itself, especially in the experience of cancer.¹⁰

Participation in support groups is critical for women to deal with the situation, which makes it easier for women to address the issue of cancer, receive information about treatment, improve quality of life and family interaction.

It also alleviates psychosocial problems such as anger, anxiety, depression, and fear of death. In this space, many women share their lives and exchange experiences and experiences that contribute to other women overcome situations suffered in being sick with breast cancer.

Thus, when receiving support, the patient understands himself as important in the social network and responds positively to the challenges, adopting positive behaviors such as initiating or maintaining actions that promote his or her well-being in the circle of coexistence and that adds to the treatment,¹¹ being protagonists of their own care.

Positive effects of support and social networks on behavior, adjustment, and management of chronic diseases, relationships between patients with health services and professionals, adherence to treatments, improvement of people's life quality, adoption of new styles of life and prevention of disease risks. Social support is necessary for the promotion and maintenance of physical and mental health.⁹

Among the fundamental aspects of facing the disease is the faith, spirituality, and philosophy of life of each one. The role of health professionals in the spiritual culture of women and the family encompasses integral and systemic attention and uses this culture to encourage the patient in overcoming difficulties. Prayers, meditations, and rituals broaden the bond with the sacred, allowing to reflect the situation, making it malleable, reestablishing its balance.¹²

The registered nurse, integrated with the speech of women who experience breast cancer in this support network, occupies an important place with the patients in the day-to-day of the therapeutic route, since it is the one who welcomes, assesses, performs procedures and directs the women towards the interdisciplinary team. As such professional is accessible to talk or clarify doubts, it is often recognized as the main link between healthcare team members.¹³

CONCLUSIONS

The results have shown that families, friends, neighbors and the group are all parts of the women network, who is experiencing cancer. Religiousness, faith, and spirituality are necessary for the treatment process in all phases of coping with the disease. Nonetheless, the healthcare team, with emphasis on nursing team and the physician, are required for recovery, support for adherence and motivation, and also for patients to persist in the treatment, as well as for giving hope ensuring that everything will be fine.

Social support is necessary during treatment, to cope with the pathology and recovery of the disease. It is fundamental that the nursing team know who is involved in the social support of the women that are experiencing cancer, so they are able to promote and empower the quality of life and well-being of those users.

Providing social support is part of the integral care of nurses and recognizing the real needs of women's support is important for planning care and nursing interventions. The entire support network presented by the woman bearing

breast cancer, from the family, friends, support group and healthcare team, they are all involved in her care.

It was understood that the social support network presented by women is systemic because it is composed of elements that interact with each other and that form the structure of the relationships necessary for the protection and strengthening of this woman in the therapeutic experience of being sick.

It was noticed that there is still fragility in the services of support networks for breast cancer-bearing women, not only by the professionals, but of the public health system, something that is constantly evolving, but that needs to undergo modifications to qualify the care users. Social support is important in community involvement, strengthening self-esteem, identity and the will to live, and also towards the citizenship development of cancer-bearing women.

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