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RESEARCH

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The diagnosis way towards rehabilitation: feelings and support network of women experiencing cancer and mastectomy

O caminho do diagnóstico à reabilitação: os sentimentos e rede de apoio das mulheres que vivenciam o câncer e a mastectomia

El camino del diagnóstico a la rehabilitación: los sentimientos y red de apoyo de las mujeres que viven el cancer y la mastectomía

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ABSTRACT

Objective: The study's goal has been to know the feelings of women before the diagnosis of breast cancer and the need for mastectomy, identifying their support network in coping with the disease. **Methods:** It is a descriptive-exploratory study with a qualitative approach. A script with semi-structured questions was used for data collection and the data arrangement occurred through content analysis. **Results:** There were ten mastectomized women residing in *Chapecó* city, *Santa Catarina* State. The feelings about the cancer diagnosis ranged from despair and fear of death, up to the effort to overcome it. Regarding the feelings associated with experiencing the mastectomy, the shock came out, also negative thinking, understanding of the need to removing the breast and resilience. The support networks were described mainly as family, friends, and faith. **Conclusion:** When facing the diagnosis, women come up with many uncertainties; therefore, it is necessary stimulating health professionals to support women in the disease coping process.

Descriptors: Women's health, breast cancer, mastectomy, feelings.

RESUMO

Trata-se de um estudo descritivo, exploratório, de abordagem qualitativa, com o objetivo de conhecer os sentimentos das mulheres diante do diagnóstico do câncer de mama e da necessidade da mastectomia, identificando sua rede de apoio no enfrentamento da doença. Contou-se com dez mulheres mastectomizadas, residentes em *Chapecó/SC*. Para coleta dos dados, utilizou-se um roteiro com questões semiestruturadas e a organização dos dados ocorreu por meio da análise de conteúdo. Os sentimentos diante do diagnóstico de câncer vão desde o desespero, o medo da morte, até o esforço pela superação. Quanto ao sentimento na vivência da mastectomia surgiu o abalo, o pensamento negativo, a compreensão da necessidade de retirar a mama e a resiliência. As redes de apoio foram evidenciadas pela

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família, pelos amigos e pela fé. Conclui-se que ao se depararem com o diagnóstico, muitas são as incertezas da mulher, tornando-se necessário o despertamento dos profissionais da saúde em apoiar a mulher no enfrentamento desta doença.

Descritores: Saúde da Mulher, Câncer de mama, Mastectomia, Sentimentos.

RESUMEN

Se trata de un estudio descriptivo, exploratorio, de abordaje cualitativo, con el objetivo de conocer los sentimientos de las mujeres ante el diagnóstico del cáncer de mama y la necesidad de la mastectomía, identificando su red de apoyo en el enfrentamiento de la enfermedad. Se contó con diez mujeres mastectomizadas, residentes en Chapecó/SC. Para la recolección de los datos, se utilizó un itinerario con cuestiones semiestructuradas y la organización de los datos ocurrió a través del análisis de contenido. Los sentimientos ante el diagnóstico de cáncer van desde la desesperación, el miedo a la muerte, hasta el esfuerzo por la superación. En cuanto al sentimiento en la vivencia de la mastectomía surgió el temblor, pensamiento negativo, comprensión de la necesidad de retirar la mama y resiliencia. Las redes de apoyo fueron evidenciadas por la familia, amigos y la fe. Se concluye que al encontrarse con el diagnóstico, muchas son las incertidumbres de la mujer, haciéndose necesario el despertar de los profesionales de la salud en apoyar a la mujer en el enfrentamiento de esta enfermedad.

Descritores: Salud de la Mujer; Câncer de mama; Mastectomía; Sentimentos.

INTRODUCTION

From the twentieth century, with the incorporation of the Women's Health Program in the context of national policies, the Ministry of Health began to identify the needs of women, based on the population profile of this clientele. Women's health care policies have evolved and incorporated a part of the female population that is not easily perceived, as well as to include the emerging health problems, with a view to promoting the improvement of the living conditions and health of Brazilian women, seeking strengthen the qualification and humanization of integrality to women's health, without discrimination of any kind in the *Sistema Único de Saúde (SUS)* [Unified Health System].¹

The fact is that women's health is a topic that has been gaining a lot of space over time due to the significant growth of specific diseases of this public, such as breast cancer.

In Brazil, 57,960 new cases were estimated for the year 2016. Between 2009 and 2014 the number of cases of the disease increased by 13.4%, representing an increase rate of 2% per year. This type of cancer is the largest cause of cancer deaths in women worldwide, with approximately 522,000 deaths estimated in 2012. Although this type of cancer is considered relatively good, if diagnosed and treated in a timely manner, mortality rates in Brazil remain high, totaling 14 deaths per 100,000 women.²

The word cancer, by itself, represents a word of suffering, a devastating disease, and most of the time, when you receive the diagnosis, you think of death. In view of the diagnosis of breast cancer, the need for a mastectomy, which usually has an impact, is often highlighted, and may affect women's self-esteem.

When experiencing 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 readaptation and psychosocial adjustments, since breast cancer causes a condition of vulnerability and emotional losses considerable.³

Mastectomy is considered a mutilating surgery, which imposes functional limitations on women, especially in daily activities. Furthermore, the breasts symbolize motherhood and female sensuality, which reveals the fear of women in losing them.⁴ The breast removal often generates a negative repercussion for the woman, especially with regard to her body self-image, implying also in possible isolation behaviors due to sadness due to mutilation, shame, and fear of other people's prejudice.⁵

Mastectomy, when associated with chemotherapy, becomes even more aggravating as a result of side effects, especially hair loss, which may reveal ineffective responses that are reflected in fear, depression, anguish, and sadness.⁶ A worrying characteristic common to diagnosed women with breast cancer is the issue of aesthetics, concern with physical beauty, and may have a broader meaning. Feeling beautiful makes the woman feel good and consequently has a better life quality.⁷

Given the aforesaid context, this manuscript aims to know the feelings of mastectomized women before the diagnosis of breast cancer and the need for mastectomy, then identifying their support network in the disease coping process.

METHODS

It is a descriptive-exploratory study with a qualitative approach that integrates part of a research project during the Nursing Graduation Course at *Universidade Federal da Fronteira Sul*.

The research was carried out in *Chapecó* city, *Santa Catarina* State. Ten mastectomized women participated in the study and were counted on the support of the Community Health Agents of the municipality to identify the participants and their residences.

The criterion for choosing the participants was to have performed mastectomy until December 2016, since the data collection was performed during the first half of 2017 and also, to be residents in the aforementioned municipality. The interview took place in the house of the participants of the study, in a pre-scheduled way, in order to have an available and propitious moment, seeking not to disturb their tasks.

Data collection took place through a script containing semi-structured questions, involving data about the profile and feelings when diagnosed with the disease and the need to perform the mastectomy, as well as the support network throughout the process.

To keep the participants confidential, it was decided to name them by the name of Disney princesses, remembering that there are several stories of the princesses, just as there are many stories of women who experience mastectomy,

having the same background, but that differs the experience for each woman, since each being is singular.

The data were organized and analyzed according to the Bardin content analysis,⁸ which is a set of techniques of analysis of the communications, in order to obtain, by systematic and objective procedures of description of the content of the messages, the inference of knowledge regarding the conditions of production/reception (inferred variables) of these messages.

The first moment consisted of the pre-analysis, in which the floating reading of the data obtained in the interviews was carried out, the construction of a table with the data collected, choosing documents for the constitution of the data taken into account to be submitted to the analytical procedures. In the second moment, the analysis material was explored, with the organization of the data, with three categories: "Unveiling the feelings of facing the breast cancer diagnosis"; "I'll have to go through a mastectomy procedure. What now?" and "The importance of support when experiencing cancer and mastectomy."

This study was performed according to the Resolution No. 466/12, which regulates research involving human subjects and was approved by the Ethics Committee from the *Universidade Federal da Fronteira Sul*, Legal Opinion No. 1.992.802.

RESULTS AND DISCUSSION

The study had the participation of 10 mastectomized women, within the age group from 33 to 78 years old. The time of the mastectomy procedure ranged from 24 to 1 year(s) ago. Nonetheless, all reports, even of those women who have already performed mastectomy for years, were intensely expressed, as if they had performed the mastectomy a short time ago, drawing the attention of the researchers involved in the process.

Unveiling the feelings of facing the breast cancer diagnosis

The timing of the diagnosis of breast cancer is extremely delicate and painful. Countless feelings invade women, psychological stress, loss of self-esteem, anxiety, guilt, fear, depression, despair, and uncertainty when faced with a threat to the future.⁹ Therefore, cancer cannot be considered only as a clinical disease, since it affects the individual's life in the biological, psychological and social spheres.¹⁰

The word cancer is associated with a very strong stigma, death,¹¹ thus, when diagnosed with breast cancer, women are faced with a series of emotional conflicts, in which death and loss of the breast represent a constant threat for her and for her family as well.

The emotional shock before the diagnosis, a feeling reported in several studies,¹²⁻¹⁴ was also identified in the majority of the participants of this research:

[...] at first, it was a shock [...] I did not believe [...]
(Cinderella)

[...] I freaked out... it seemed like that day, the floor underneath us was gone, it was very scary [...] but it was very... very sad. (Rapunzel)

[...] I lost the ground [...] I thought it could happen to anyone but me. (Beautiful)

Although breast cancer has a good prognosis, since the evolution of technology and the diversity of treatments,¹³ this emotional shock is inevitable in the diagnosis.¹⁰ Fear is activated by potentially threatening situations or real dangers¹⁵ and discovering itself with cancer, considered a threat to life, intensifies despair and fear of death, making them the most present feelings in users and their families.¹³ The fear of death was reported in numerous speeches:

[...] at that moment you do not know if it will improve or if you will die, because cancer is a heavy word [...]
(Rapunzel)

[...] I thought I was going to die, the first thing that comes is about dying [...] it was a feeling of dying; I did not know what to do. (Beautiful)

[...] I was sure I was going to die... (Alice)

According to the literature, at the time of diagnosis, the main concern of the people is with their survival, staying alive is considered more important than the loss of the breast, and only after distancing the possibility of death, breast excision and its consequences. In this sense, two remarkable moments are highlighted by the women affected by the disease. The first one represented by the discovery of cancer, the diagnosis and treatment, and the second moment, after the surgical procedure in which the woman overcomes the fear of death, resumes her routine, her social relationships, leisure activities, work, and family. At that moment, the woman encounters reality, they arise to the concerns related to her body, so she re-evaluates and re-elaborates her potentialities and ways of relating to her own body and to others.¹³

There are aspects that influence the reaction towards the breast cancer diagnosis, so the particularities and the moment in which this woman is in her life, as well as her history of life, social, economic and familiar context must be considered.^{9,13} In this sense, in addition to the shock and fear of death, positive feelings of strength and hope were observed in the perspective of overcoming the disease:

[...] having that thought that the cancer had no cure, then I realized that no, that if I fought I had a chance, and it was going [...] (Alice)

[...] I did not go into despair... I only asked God to leave me because I had two children, [...] I had to think about living and then I took my life back [...] (Wendy)

Another factor observed was the commotion and richness of details described during the interviews, such as how they felt at that time, if they were accompanied, the clinician's words, how was the day, the weather and the clothes they wore when they received the diagnosis, as a deeply marked moment, as a watershed in their lives and that will be forever enshrined in their memories.

From the day of diagnosis, the need arises to carry out the treatment, fight for survival and against the disease, which is extremely painful, experienced by various fears and uncertainties about the future and that cause transformation in women's lives.

Many women, although clinically cured, are unable to overcome the feelings and consequences brought about by illness and surgery, while others perceive the experience as positive, beginning to recognize, value and thank life and health, with the desire to overcome the disease, a great example of strength, security, and inspiration.¹⁶

I'll have to go through a mastectomy procedure. What now?

During their life courses, the study participants have learned that they would have to perform the mastectomy and the feeling was different for each woman, from the understanding that would be the best for their disease, until the breast removal.

The changes and difficulties caused by the disease and treatment imply adaptations and adjustments, both physical and emotional, allowing the knowledge of various feelings:¹⁷

[...] nobody ever saw me cry because I took my breast, I never despaired. I had to be strong because of my children, they despaired [...] (Wendy)

Wendy's report shows that she was not shocked at having to perform mastectomy to show support for her children, and that she was challenging and resilient. But to demonstrate tranquility can be a strategy of escape from reality or a way of exposing that the affliction would bring no benefit to the new condition, reflecting the state of resilience.¹⁸

Some mastectomized women demonstrated an understanding of mastectomy:

[...] I think God would leave me to health from now on [...] (Jasmin)

No problem, I do not care, I wanted to be free of both the tumor and the disease. (Snow White)

The diagnosis of breast cancer is more terrifying than the loss of the breast, making them feel the need to remove the tumor as quickly as possible. Although the mastectomy represents a moment of significant anxiety for the woman, at the same time, it symbolizes the possibility of cure.¹⁹

Throughout the experience with cancer, feminine feelings constantly oscillate, disorganizing the woman's

universe. Feelings such as uncertainties about life, the possibility of healing and the abatement are easily identified in the statements:¹⁷

I felt something like that when I went to take a shower; I asked myself, how did I become so different? [...] (Jasmin)

The changes directly reflect women's self-image and self-esteem, mainly because they provoke the emergence of physical characteristics that differ from those imposed as beauty standards defined by society, focusing on the woman's capacity to recognize her body and herself.²⁰

In the research, the negative feeling about the need for mastectomy also emerged:

[...] I had negative thinking; I had no good thinking (Alice)

Breast cancer is a disease that carries a stigma that generates strong psychological repercussions, which favors the fall of the woman's self-esteem, which may even hamper her treatment and bring a variety of negative feelings, such as fear, anxiety, anguish and emotional overload. Women become vulnerable to this stress situation, which contributes to an imbalance in their social, biological and subjective aspects.²¹

The mastectomy breaks the unity of the female body, being necessary to rethink it as the same and a new body, in the sense of enabling the improvement of the relations with the others. Therefore, the health team should be prepared to listen and counsel, especially with regard to breast loss and psychological repercussions.¹⁸

The perception that the woman who carries a breast cancer diagnosis has of herself can be understood as a reformulation and reconstruction of a new identity, resignifying her present and future life. Once they come to live with a stigmatizing disease, live with negative feelings and face the treatment and its consequences, they are left with signs of insecurity, uncertainties, and anguishes.²²

There is no question of the diversity of feelings in a woman who discovers breast cancer and who will face a mastectomy. Feelings such as fear, insecurity, guilt, among others, will most likely arise, and it is up to health professionals to be prepared and sensitive to recognize them, to help them cope with their reality in the most courageous way possible.²³

The importance of support when experiencing cancer and mastectomy

Generally the motivation for coping with the disease and treatment is related to the support received during this period, be it family, children, husband, friends, faith in God, religiosity or spirituality, are factors that encourage women, making them strong and secure at the moment.¹²

From the diagnosis of breast cancer, other experiences are unleashed in the life of women, such as acceptance of treatment, coping with adverse effects related to

medications, mastectomy, personal rehabilitation and rehabilitation to a new way of performing tasks before easily. Given this perspective, the support of the family emerges as an important support for the women to experience this whole process with a little more tranquility and confidence:

I had a lot of support from my family, from my sisters, especially from one who is more my companion, [...] she supported me very, very, very [...] (Wendy)

[...] My family supported me a lot, also my relatives [...] (Rapunzel)

My mother supported me the most, and my daughter helped me a lot. (Beautiful)

Family support stands out with regard to coping with the anxieties, uncertainties, mixed feelings and difficulties expressed by women who have gone through this process.^{10,24,25} Therefore, the complicity and support provided by the companions of these princesses showed themselves very positively. A well-structured marriage provides social support by inhibiting the effects of stress,²⁴ as evidenced in the reports of some women:

Besides husband, he was a companion, he was a friend, that was all. I always say: if I complain, I do sin. (Snow White)

[...] my husband, he is a very wonderful person, and he accompanied me in everything. (Rapunzel)

[...] my husband, he supported me a lot [...] (Alice)

On the other hand, a poor marital relationship, the loss of a partner or even the fact that it is misplaced can cause an increase in stress, having detrimental effects on the proper organic functioning.²⁴ The lack of support from the husband was evidenced in speech of some study participants, who sadly reported:

[...] I lost my husband, he could not stand the disease. (Beautiful)

[...] the husband when he knew that I was going to take the breast... "he threw me away", then he abandoned me (Tiana)

The spouse, the children and the parents are the individuals who usually suffer the most and go through moments of great anguish at the time of diagnosis and even during and after treatment.¹⁰ And when the support is not evidenced by the husband and/or partner the feeling of lamentation is expressed in the speeches, as *supra post*. The lack of support of the husband in these moments of illness is considered as a strong aggression to the woman, affecting her self-esteem, in that moment it needs to be accepted, understood and caressed.²⁰

Another source of support, highlighted by women in the experience of mastectomy, was the spiritual approach:

[...] God gave me one more chance [...] (Cinderella)

[...] I believe in this God, because I think that's what saved me. (Beautiful)

I only asked God to leave me because I had two children, and they had just lost their father [...] (Wendy)

[...] but with faith in God we will fight. (Ariel)

The suffering of the pathology causes the inner return to God for the first time, or even a more frequent and intense approach than before.¹⁴ Religion/spirituality is an important support for women in coping with the disease and in maintaining and recovering health.³

In relation to friends, studies^{3,25} show that the most consolidated relationships remain and are strengthened with the advent of cancer, providing well-being to the woman and the family. In this sense, being able to count on friends is fundamental and seen in a very positive way:

[...] I could not imagine how many friends I had. (Cinderella)

[...] my friends, [...] I had friends. (Rapunzel)

The support provided by family and friends is essential in overcoming conflicts such as fear, confusion, anxiety and depression and can provide the princess with optional ways of living, even with the limitations that treatment imposes. Hence, the support network formed essentially by family and friends contributes in a very positive way to face the situations experienced and also helps the princesses to develop skills to master stress situations and adapt in a positive and secure way to their new condition.¹⁵

Throughout the process of diagnosis, treatment and recovery, many changes have taken place in the life of the princesses, but in general they have been able to count on some kind of support, be they family, friends, companions and faith, receiving emotional support, encouragement and strength to fight against the disease.

During the interviews it was noticed that the health team was not commented as a form of support. The health team, particularly the nursing team, plays a key role as an educator and supporter of these princesses. The nursing professionals, as caregivers, should assist, guide, listen and dialogue with users at this time of re-signification of values and negative feelings. Additionally, to provide the family with moments of dialogue, explaining and clarifying their doubts, making them an ally in the treatment,¹⁸ considering how essential it is for these women to be supported by their loved ones.

Bearing this perspective in mind, it was identified that the nursing team could improve their role of caring for people in the various stages of life, in this case, in the process

of illness, treatment, recovery and rehabilitation of these princesses. Therefore, it is urgent to perform a committed and competent nursing role, prioritizing comprehensive and humanizing care.¹² Hence, the importance of studies such as this that bring academics closer to the reality experienced by SUS users, with a view to instigating them to critically reflect and seek strategies to transform this reality, for the best quality assistance to the user, as well as to include their family and companions in the caring process.

CONCLUSIONS

Upon receiving the diagnosis of breast cancer, women are flooded by various feelings, related to uncertainty about their future. Whether or not they will improve, how will the family react, and who can they count on? The reactions to the diagnosis happen in a singular way, but overall, it generates a lot of fear in the beginning.

Faced with the need to perform a mastectomy, a new stage in the life of women begins, with concerns related to self-image and the necessary adaptations to the new established condition. Along with this, they need to face the pain, the consequent reactions of the treatment and sometimes the abandonment.

Herein, the importance of the support provided by the family, companions, friends, and faith is shown, presenting the strong emotion of the princesses in remembering the moments experienced, the difficulties, the overcoming and how some bonds were strengthened, while others fell apart, making this process even more painful.

Children's stories and stories usually end with the traditional "lived happily ever after". Nevertheless, in real life, it was evident that this is not always the case, as some women in this study could not count on their "charming princes" to support them on the path from diagnosis to rehabilitation of breast cancer, while others, even after the difficult trajectory, consider themselves happy and grateful for the victories achieved. Resilience comes to life in women who experience breast cancer, and each one, in her own way, keeps looking for happiness in life.

The support from the health team was not evidenced in the research, which needs to be pondered. These professionals must be motivated to provide better care to the women who experience breast cancer and mastectomy, having in mind that it is not easy to deal with such a delicate moment, which is governed by uncertainties and adaptations.

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