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Meaning of Breast Cancer in Women's Discourse

Theme: Chronic Care.

Contribution to the subject: the results of this research portray the collective discourse of women who attribute meaning to the breast cancer diagnosis; therefore, it contributes to improving the Nursing approach to women who survived this disease.

ABSTRACT

Objective: To reveal the meaning of breast cancer. **Materials and method:** A narrative research study that selected, using the snow-ball technique, 11 women (data saturation) diagnosed with breast cancer, on disease remission, and living in the region of Florianópolis (Brazil). Semi-structured interviews were conducted between August and December 2018, and they were subjected to the Collective Subject Discourse technique. Four central ideas emerged from the analysis of the narratives; this article presents the central ideal called "Meaning of the breast cancer diagnosis", which has eight sense categories. **Results:** The central idea covers the following categories: "Suffering when facing the diagnosis", "Fear of the disease and of death", "Professional inability for bad news", "Initiatives to streamline treatment", "Concern and affection with the family members as a driving force to face cancer", "Difficulties with the family members", "Support from the family members, from the professionals and/or from the support group", and "Faith and spirituality". **Conclusions:** The discourse reveals that the meaning of the disease diagnosis is linked to the need for treatment, to the support provided by faith, family members, the health team, and support groups, and to the difficulties faced with family members and professionals. These results should imply the provision of specific Nursing care from the diagnostic phase until after cancer remission/survival.

KEYWORDS (SOURCE: DECS)

Breast neoplasms; nursing; oncology nursing; speech; women's health.

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Significado del cáncer de mama en el discurso de las mujeres

RESUMEN

Objetivo: revelar el significado del diagnóstico de cáncer de mama. **Materiales y método:** investigación narrativa, que seleccionó, desde la técnica bola de nieve, 11 mujeres (saturación de los datos), con diagnóstico de cáncer de mama, en remisión de la enfermedad, habitantes de Florianópolis (Brasil). Se aplicó la entrevista semiestructurada, entre agosto y diciembre del 2018, sometida a la técnica del discurso de sujeto colectivo. Del análisis de las narrativas, emergieron cuatro ideas centrales; en el artículo, se presenta la idea central "significado del diagnóstico del cáncer de mama", que cuenta con ocho categorías de sentido. **Resultados:** la idea central abarca las categorías "El sufrimiento ante el diagnóstico", "Miedo a la enfermedad y la muerte", "Inhabilidad profesional para las malas noticias", "Iniciativas para agilizar el tratamiento", "Preocupación y afecto con los familiares como resorte impulsador para enfrentarse al cáncer", "Dificultades con los familiares", "Apoyo de los familiares, de los profesionales y/o del grupo de apoyo" e "Fe y espiritualidad". **Conclusiones:** el discurso evidencia que el significado del diagnóstico de la enfermedad se vincula a la necesidad del tratamiento, al apoyo de la fe, de familiares, del equipo de salud y de grupos de apoyo, a las dificultades enfrentadas con familiares y profesionales. Estos resultados deben implicar la previsión de cuidados de enfermería específicos desde la fase diagnóstica hasta después de la remisión/sobrevivencia del cáncer.

PALABRAS CLAVE (FUENTE: DeCS)

Neoplasias de la mama; enfermería; enfermería oncológica; habla; discurso; salud de la mujer.

Significado do câncer de mama no discurso das mulheres

RESUMO

Objetivo: revelar o significado do diagnóstico de câncer de mama. **Materiais e método:** pesquisa narrativa, que selecionou, pela técnica bola de neve, 11 mulheres (saturação dos dados), com diagnóstico de câncer de mama, em remissão da doença, residentes na região de Florianópolis (Brasil). Aplicou-se entrevista semiestruturada, entre agosto e dezembro de 2018, submetida à técnica do discurso do sujeito coletivo. Da análise das narrativas, emergiram quatro ideias centrais; neste artigo, apresenta-se a ideia central "significado do diagnóstico de câncer de mama", que conta com oito categorias de sentido. **Resultados:** a ideia central abrange as categorias "O sofrimento diante do diagnóstico", "Medo da doença e da morte", "Inabilidade profissional para as más notícias", "Iniciativas para agilizar o tratamento", "Preocupação e afeto com os familiares como mola impulsionadora para o enfrentamento do câncer", "Dificuldades com os familiares", "Apoio dos familiares, dos profissionais e/ou do grupo de apoio" e "Fé e espiritualidade". **Conclusões:** o discurso revela que o significado do diagnóstico da doença vincula-se à necessidade do tratamento, ao apoio da fé, de familiares, da equipe de saúde e de grupos de apoio, às dificuldades enfrentadas com familiares e profissionais. Esses resultados devem implicar a previsão de cuidados de enfermagem específicos desde a fase diagnóstica até após a remissão/sobrevivência do câncer.

PALAVRAS-CHAVE (FONTE: DeCS)

Neoplasias da mama; enfermagem; enfermagem oncológica; discurso; saúde das mulheres.

Introduction

The incidence of breast cancer alone justifies the continuous need to conduct studies on this theme. In 2020, there were nearly two million new cases worldwide, approximately 684,000 deaths, and an estimate of almost eight million prevalent cases (1). In Santa Catarina (Brazil), the locus of this study, 3,370 new cases of breast cancer are estimated for 2021 (2).

Despite such high incidence and mortality values, the survival rates, mainly in the short- and long-term, have been increasing, considering early diagnosis and new treatments. This increased survival requires greater attention from Oncology Nursing, as fear of the disease remains in patients who survived cancer, and the diagnosis period is still a challenge for the women (3), who describe it as conflicting, stressful, and characterized by a denial of the disease (4, 5).

In addition to that, several studies reveal that the disease affects emotional well-being and that there is impaired family and personal coping, as well as sexual and gynecological changes. Consequently, Nursing professionals must be aware of the impact caused by breast cancer in the social and family life of these women. These professionals need to understand the disease to improve the provision of care (6-8).

Thus, considering the magnitude of breast cancer, the predicted significant increase in the incidence rates for the next decades, the changes in the sociodemographic conditions, and the advances in diagnosis and treatment, which may change the meaning of the disease, new studies can contribute to expanding understanding on the phenomenon and to providing excellent Nursing care. The starting point is the assumption that the meaning of breast cancer is full of anxieties resulting from the diagnosis, fear of the disease and death, the impossibility of working, and need to change habits (9). In this sense, there is due reason to develop this study, which aims at revealing the meaning of the breast cancer diagnosis.

This study is part of a macro-project jointly developed by three universities, from Brazil, Colombia, and Mexico, and presents data linked to Brazil.

Materials and methods

A narrative research study, conducted in the metropolitan region of Florianópolis (Santa Catarina, Brazil), a city that has an institution that is a reference for Oncology treatments. The participants were women aged over 18 years old, diagnosed with breast cancer, who underwent chemotherapy in the last ten years, were on disease remission (verified by absence of the disease as reported by the women), and who may be undergoing treatment with hormone therapy. Women with a new cancer diagnosis or with some family members diagnosed with cancer were excluded. The exclusion criteria were defined with ethical concern, considering the psychological issues pertinent at the time, which could influence the meaning of the disease and/or trigger emotional harm or of other types.

To select the women, it was defined that the snowball technique was to be developed where, for the choice of the first woman, it was decided to present the project to the members of the Gama Institute (Support Group for Mastectomized Women), which has 40 active participants. The choice of this initial setting was because this group has been active for nearly 20 years and for it being representative from the social point of view. It is noted that all women in the region where the study was conducted are assisted by the public health system and treated in the setting where the support group operates. In addition to that, this group frequently welcomes women treated in the private network who seek the public health system during the hormone therapy phase due to their financial conditions. It is also worth mentioning that the profile of the group is quite heterogeneous, including women from all age groups and socioeconomic levels, as well as those who were diagnosed with cancer at different stages of the disease.

After the study was presented to the aforementioned support group and the women had expressed their interest in participating in the research, it was agreed that the group coordinator would provide a list of telephone numbers for contacting the eligible women, and that the women contacted could indicate other women. The number of people included in the study (11 women) was defined by data saturation (data repetition with no addition of new information [10]), identified in the analysis phase, which was conducted simultaneously with data collection.

To select the women (via telephone contacts or through WhatsApp), the sequence of names in the list forwarded by the group

coordinator was followed. Each woman who was interviewed was asked to indicate another. In case there was no indication, a new woman from the list provided was contacted. The list provided by the group coordinator had 20 names; five women were indicated without being in this list, of which two agreed to be included in the study; consequently, nine women from the support group's list were selected, when data saturation was reached.

The interviews were conducted in a private environment, chosen by the participant (in her house, in a square, or in a room of the teaching institution that proposed this study); they were recorded and transcribed and involved the presence of the interviewed participant and the researcher. The first four interviews were conducted jointly by two researchers (researcher in charge and main researcher, both with no relationship with the study participants) to standardize the approach (the interviews were conducted alternately by the researchers).

The researcher in charge of this study has worked for 30 years in Oncology, with clinical, teaching and research experience in the context of breast cancer. The researcher in charge of the entire data collection process was a Nursing student, a voluntary scholarship holder.

The interviews investigated the age and year of the breast cancer diagnosis, meaning of breast cancer, current feelings, and what each participant would like to say to another woman who was been diagnosed with breast cancer. Complementary questions (Could you further explain this concept?) But, how did that happen? Could you tell a little more about this meaning?) were included, whenever necessary, to explore the time dimension (past experiences that influence the current reality), the social dimension (personal, social and cultural experiences that impact on narratives), and the place dimension (the environment as an influencing factor of the meanings expressed in the narratives [11]). The interviews lasted a mean of 60 minutes. To preserve the participants' anonymity, pseudonyms were adopted, which were defined by the researchers. The study's ethical appreciation is recorded under Opinion No. 2,565,680.

For data analysis, the Collective Subject Discourse (CSD) was applied, conducted by two researchers. CSD is a method that retrieves the social representation by reconstituting an empirical collective entity, in the form of a discourse produced in the first

person singular, as if a collective group speaking through an individual. It consists of different key expressions from the individual speeches, grouped into collective sense categories (stage for coding the narratives) and which make up the central ideas.

The key expressions are excerpts from the narratives which must be highlighted by the researcher and reveal the essence of the discourse content. The sense categories gather social-cognitive schemes that portray the socially shared ways of knowing or representing and interacting with the world and with everyday life, and which reveal possible awareness of these actors at a given historical moment. The central idea is the linguistic expression that reveals, describes and designates a homogeneous set of key expressions/sense categories. As collective statements, discourse translates how the social representations are perceived/felt by a given society, a group or a culture (12, 13).

The CSDs were elaborated using the DSCSoft software (14, 15); and the presentation sequence of the key expressions and sense categories that comprise the CSD was conducted by the researchers. The entire analysis process was performed by a researcher and subsequently reviewed by a second researcher. Any divergences were discussed and agreed upon.

Four central ideas emerged from the analysis, namely: "Meaning of the breast cancer diagnosis"; "Finding out about breast cancer"; "Current feelings"; and "Advice to women with breast cancer"; 21 sense categories were related to the central ideas, which represented a significant information volume. Given the above, this article was chosen to present the CSD related to the central idea called "Meaning of the breast cancer diagnosis".

Semi-structured interviews were conducted for data collection, between August and December 2018. The participants signed the Free and Informed Consent Form. After the analysis, all of the research findings were presented to the Gamma Institute, during a meeting of the group of women.

Results

The 11 participants were aged between 43 and 72 years old; of this total, eight belonged to the age group between 40 and 59 years old. The time since the diagnoses ranged between two and 11 years; and most of the women (six) were diagnosed with breast cancer at least five years ago.

The treatments indicated for disease control encompassed four therapeutic sequences: four women required surgery, chemotherapy, radiation therapy and hormone therapy; four required surgery, chemotherapy and hormone therapy; two required surgery, chemotherapy and hormone therapy; and one required surgery, chemotherapy and radiation therapy.

The CSD related to the central idea called "Meaning of the breast cancer diagnosis" emerged from eight sense categories, according to what is presented below.

Central idea: Meaning of breast cancer and Collective Subject Discourse

"Suffering when facing the diagnosis" category

It was horrible. (Maria); In the diagnosis phase [...] I could not but cry. (Lilian); When I went to the clinic to fetch the result, I opened the envelope and saw it, I went there alone, in my car... I didn't see the traffic lights, I didn't see anything. I was crying when I got home. (Maria); When I read, I read carcinoma, carcinoma is cancer, how can I say I don't have anything? I didn't believe it. I thought that it wasn't happening to me. (Nina); I felt helpless. (Linda); My emotions were hidden behind the carpet. It was the worst experience in my entire life. A shock, the greatest I've ever had. Because I didn't understand what cancer was. (Eva); And there's also that distress of having to tell the family. I remember going out of "X" [treatment unit], sitting on the sidewalk, and calling my brother-in-law. The entire family already knew that I was going to the doctor. I said: "It's confirmed. [...] Tell mother and father." (Ana); All that takes some time. I was sad, frustrated, it's quite complicated. (Linda)

"Fear of the disease and of death" category

Real fear, I felt at the diagnosis. I was very afraid. (Lilian); The breast cancer diagnosis, [...] that of cancer, is quite linked to death. (Ana); In emotional terms, it was a surprise to me. I thought that I was going to die. (Lena); I thought: "I'm going to die." (Eli); You get scared. (Lena); Although I can't believe it yet. The first thing you think is: how much time do I have left? [...]. Because, when you go there and the doctor tells you that you have cancer, you want to know at what stage it is. So, all the tests are made to map where it is. That's terrifying. It was the worst phase of my life. You can be the most well-structured person,

the happiest person in the world, but it's a surprise, you think about death. Because you have an incurable disease, which has no cure. (Lilian)

"Professional inability for bad news" category

I worked many years taking care of people. You notice when the doctor or the nurse are afraid, you perceive it in the air. (Alice); Then, what the doctor told me: "You have cancer." Like this, closer than we are now. She said: "You'll lose one or both breasts." I mean, she was so straightforward that she ended up frightening me. [...] My head could not digest the first word, what to say about the second. [...] When she told me: "What you have is cancer", for me, it was as if she had said: "Here's your death sentence." I think that if she had spoken more calmly, I wouldn't have been so afraid. (Eva)

"Initiatives to streamline treatment" category

I cried, I yelled, and I told her [the doctor]: "Ok, explain everything to me. Where should I go? What should I do?" I started to be practical, I went there right away. I had to see a mastologist, I saw him that same day. I had to do a biopsy and I went after it right away. Then I shaved and donated my hair. [...] I wanted a solution. Let's be practical now. I cried, cried, cried, let's be practical now... (Nina); I did everything alone. I paid some money to get the results in two days. [...] My head needed a solution. (Selina)

"Concern and affection with the family members as a driving force to face cancer" category

I have two children. [...] At that moment, I only thought of them. I said: "Dear God, what will become of those two? Who's going to take care of them if I die?" I started wondering. I'll have to leave them with my brother, because my mother is already dead, my father had come to live with me too, he didn't know about my situation, he also died shortly after that. I thought: "I'll have to leave them with someone." My family gave me a lot of strength. My brother, my neighbors too. (Lena); My 10-year-old daughter... I told her: "Darling, it's like this... If you want to cry, you can cry." Then she said: "I'm not going to cry, mum." And I said: "Really? You don't feel like crying?" She said: "No. First, because I trust in God's strength and also because I trust in the doctors who will start treating you now. And I also trust in your strength." Then it was me who cried. (Ana)

"Difficulties with the family members" category

I went out [referring to the day when she fetched the biopsy report] and sat on the sidewalk. Soon after that, a lady came out of the blue and said: Is everything all right with you? And I said: "I've just been diagnosed with cancer" and she said: "Girl, this happened to me" [...] The first thing, be prepared, because your family will go crazy and will drive you crazy. At the beginning, the family gets sick together with you. [...] I cried when nobody could see me, my daughter cried when nobody could see her, my husband cried when nobody could see him. Because I wanted to show strength at the beginning, and strong I was. So, physically strong, emotionally strong, but always terribly afraid. (Ana); My husband kept on denying it. [...] My brother never came to visit me. I think he'd only come if I was dying. And my father came before the chemo, when I did the chemo, he said that he lacked the courage to come see me.[...] And I felt alone. (Aline); People have this mania: "Ah, I won't visit so-and-so because I lack the courage to see her. Funny, isn't it? Then they have courage enough to attend her funeral. (Linda)

"Support from the family members, from the professionals and/or from the support group" category

I had support from my family. (Lena); I think this was also one of the things that made me feel strong at all times. I tried to look at her [daughter] every day and say: "No, she's not going to be alone." So, after that, the entire process was pretty cool. (Ana); It was my kids that went to the doctors. (Maria); What gave me much support was our group [referring to the support group for women with breast cancer in which she participates]. You go to a group like this, where the coordinator of the support group for mastectomized women is wonderful, she's like a mother to us. (Lena); I went to the group during the treatment. [...] it gives you a lot of strength. I went and didn't like it. But I kept going. Because I thought that, if all those women were there and they liked it, it was me who was wrong. There was something wrong with me. But at that time of the disease I didn't have the ability and insight to see. [...] Then I was able to understand that they had already gone through the treatment phase, but I got a sense of that only after I finished my treatment. And now I'm there and I'm happy too. [...] I participate in activities for mastectomized women there. [...] I even went to the health center, where I received more help [referring to the support received after the first appointments in the private network]. (Linda); My oncologist said:

"50 % of the treatment will be yours and 50 %, mine. I will guarantee my share. I'm going to prepare a special formula for you. You're going to be OK. As far as it depends on me, you're going to be fine. But the other 50 % is yours." (Lilian)

"Faith and spirituality" category

I think that I got better only thanks to my faith, because I never lost hope. (Lilian); It's an exercise of determination, faith and hope all the time. (Ana); I clung to God and said: "I'm going to be OK." (Lena); When I found out [...] I went to [...] the Spiritist center. (Selina); It is this faith that we cling to, to these complementary treatments. (Ana); I underwent the spiritual surgery [...] before the physical. [...] When I went to the physical surgery, I was sure that everything was already OK. (Selina); Thanks to Our Lady, I discovered the power of prayer. (Lilian); I believe that, at this moment, it's important that you trust in the doctors, but you know that something between heaven and earth can help you too. (Ana)

Discussion

The most incidental age groups in this study with a qualitative approach are similar to those of the epidemiological studies. The International Agency for Research on Cancer states that, in 2018, of all the women who were diagnosed with cancer, 46 % were aged between 40 and 59 years old (1).

Concerning the treatment modalities reported by the women, the indications were varied. All these modalities are widely indicated and knowingly related to several side effects and to other treatment consequences, such as physical and psychological changes, which can be permanent and/or transient. These changes exert a significant impact on self-esteem, confidence, and sexual and social life (16-18).

Due attention from professionals, friends and relatives contributes to reducing the negative impacts resulting from breast cancer, in addition to constituting a support network that gives women strength to face cancer. Some family compositions were revealed as stressors or even as a source of concern, because women know that their premature death or their living with disabilities can also change family life. In this context, it was revealed that the meanings of breast cancer found in the CSDs and that portray the social representation of the breast cancer diagnosis are strongly influenced by experiences before the disease and by the environment where the women are inserted, with em-

phasis on the family environment and on the health care provided since the diagnostic phase.

Suffering due to the breast cancer diagnosis was reported by most of the women; therefore, it is inferred that, despite the scientific advances, the pain resulting from this diagnosis is still highlighted as a time of anguish and fear, insecurity about the immediate and future life, with the possibility of leading to depression in some cases.

Several studies point out that the main feelings arising from the cancer diagnosis involve fear, tension, depression, anger and denial; thus, this study corroborates these findings. Conversely, other studies point to women's resilience in facing cancer and to the need for complementary studies on depression, considering the incipient scientific production (3, 19-22). However, in this context of distress, willingness to fight against the disease and to live emerges, and streamlining tests and health appointments is shown to be a support mechanism.

Consequently, women consider the moment when the diagnosis is revealed as one of the most difficult and traumatic periods of their lives. This aspect requires professional skill because how the diagnosis and/or prognosis is explained remains in women's memory, who continuously remember it. Thus, effective communication during the diagnostic process collaborates with reducing the psychological harms (3, 19, 20).

It is inferred that the meaning of death revealed is not only associated with breast cancer but also with all malignant neoplasms because, even today, late diagnoses are common, thus favoring premature deaths.

In this context, the relevance of Nursing consultations is reinforced, from the diagnostic phase, as an opportune moment to demystify the disease and its prognosis and to empower women in cancer survival, based on new experiences and overcomings.

Faith and spirituality were highlighted as strategies to face the disease diagnosis, mitigating and promoting resilience and coping with unexpected situations. From this perspective, the approach involving religiosity/spirituality becomes essential in Oncology care (4). In addition to that, the need to encourage good family relationships and care with the family members is reinforced, to strengthen women with breast cancer (5).

Regarding the care provided by the health team and the support groups, their prominent role was evident in the CSDs. Interaction with women who overcame cancer or are undergoing treatment and verbalizing their stories in the support groups favor the development of coping strategies (22, 24).

About the professionals' inability revealed by the CSD, it is argued that its origin is multifactorial, with emphasis on the complex care context, high care demand and insufficient training. In this scenario, there is a combination of humanization and dehumanization, with a close pain-suffering-pleasure interface in the workplace and in how people live and may exist in the life and work spheres (25). However, those requiring care have the need and the right to humanized care, despite any other adversity associated with the work world.

Regarding the time dimension (11), the CSDs highlight the value of small things, which start to exert an impact on the present time and on the desire of the future time to be lived. In the social dimension, the impacts caused by the breast cancer diagnosis in the different spheres (personal, family, social) and on health care itself stood out. It thus became evident that the cancer diagnosis exerts a negative impact on the relationships with the professionals, contributing as sources of social feelings due to the inability of most of them. In opposition, the welcoming relationship among women themselves and with support groups and specialized professionals, associated with faith/religiosity/spirituality, mitigates the impacts of the disease.

In the place dimension, the moment/place where the diagnosis was discovered represents a dreadful environment characterized by helplessness, loneliness and sadness, which is compounded by the concerns about who will protect her children in case of premature death, where they will stay and who will take care of them.

Conclusions

The results of this research reveal a discourse full of diversities in experiences, concerns and life priorities in facing the disease, with a significant impact on the lives of women with breast cancer. Some women reveal negative feelings such as suffering, fear, difficulties with the family and/or professional inability, whereas others link the period with other feelings, such as faith and spirituality, support from the family members, the

health team and the support groups, as well as initiatives to start the treatment.

The assumption presented in the Introduction of this article is replicated in the CSD found. This reasserts the results published by other authors, which assist in presenting the object of this research and in discussing the findings. In addition to that, at the end of this study, the initial assumption and the meaning are expanded, as there is the addition of the social representations related to the difficulties and concerns with the family members, treatment streamlining and the professionals' inability.

Finally, the limitation of this study consists in the inclusion of women without considering cancer staging, which can change the social representation of the phenomenon. In turn, developing Nursing care practices based on the meanings of the disease will contribute to reducing physical and psychological harms to which these women are exposed in breast cancer survival. Consequently, it is recommended that these practices are investigated in future qualitative and/or quantitative research projects.

Conflict of interests: None declared.

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