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ENFRENTAMENTO DE MULHERES QUE VIVENCIARAM O CÂNCER DE MAMA

FACING WOMEN WHO LIVED BREAST CANCER

ENFRENTAMIENTO DE MUJERES QUE VIVIENDO EL CÁNCER DE MAMA

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RESUMO

Objetivo: conhecer as mulheres que recebem o diagnóstico do câncer de mama. **Método:** Estudo qualitativo que utilizou, como referencial teórico, o Interacionismo Simbólico e como metodológico, a Teoria Fundamentada em Dados. Foram entrevistadas treze mulheres em quimioterapia, de um município mineiro, no mês de janeiro de 2014 e, após a análise, surgiu a teoria "Para vivenciar o câncer de mama é necessário que haja um enfrentamento". **Resultados:** a metodologia permitiu a discussão em três categorias para debate da teoria, sendo elas: recebendo a notícia do diagnóstico e da necessidade dos tratamentos; adaptação ao tratamento; experiências anteriores frente à doença. Verificamos que o enfrentamento surgiu, em todas as etapas da doença, como forma de superar os tratamentos e os aspectos sociais que o câncer trás. **Conclusão:** A teoria construída neste estudo demostra que a mulher que vivencia o câncer de mama utiliza-se de aspectos de resiliência para enfrentar a sociedade, da família para oferecer suporte e de aspectos da experiência de vida. Este estudo contribui para impulsionar mudanças, transformações e inovações, tanto em nível pessoal, como profissional e institucional na assistência a essas mulheres.

Descritores: Neoplasias da mama; Diagnóstico; Enfermagem.

ABSTRACT

Objective: to know how women are diagnosed with breast cancer. **Method:** Qualitative study that used, as theoretical reference, the Symbolic Interactionism and, as methodological, the Theory Based on Data. We interviewed thirteen women in chemotherapy from a town in Minas Gerais in January 2014 and, after the analysis, came up the following the theory: "To experience breast cancer, it's necessary to be a confrontation". **Results:** the methodology allowed the discussion in three categories to debate the theory. They are: receiving the news about the diagnosis and the necessity for treatments; adaptation to treatment; previous experiences in the face of the disease. We verified that the confrontation arose in all stages of the disease as a way to overcome the treatments and the social aspects that the cancer brings. **Conclusion:** The theory constructed in this study shows that women who experience breast cancer need some resilience to face the society as a whole; family support; and some aspects of life experience. This study contributes to stimulate changes, transformations and innovations, both personally, professionally and institutionally, in these women care.

Descriptors: Breast neoplasms; Diagnosis; Nursing.

RESUMEN

Objetivo: conocer cómo las mujeres reciben el diagnóstico del cáncer de mama. **Método:** Estudio cualitativo que utilizó como referencial teórico el Interaccionismo Simbólico y, como metodológico, la Teoría Fundamentada en Datos. Se entrevistaron a trece mujeres en quimioterapia de un municipio minero, en el mes de enero de 2014 y, tras el análisis, surgió la teoría "Para vivir el cáncer de mama es necesario que haya un enfrentamiento". **Resultados:** la metodología permitió la discusión en tres categorías para debate de la teoría. Son ellas: recibiendo la noticia del diagnóstico y de la necesidad de los tratamientos; adaptación al tratamiento; experiencias anteriores frente a la enfermedad. Verificamos que el enfrentamiento surgió en todas las etapas de la enfermedad como forma de superar los tratamientos y los aspectos sociales que el cáncer aporta. **Conclusión:** La teoría construida en este estudio demuestra que la mujer que vive el cáncer de mama utiliza la resiliencia para enfrentar la sociedad; la familia para el soporte; y los aspectos de la experiencia de vida. Este estudio contribuye a impulsar cambios, transformaciones e innovaciones, tanto a nivel personal, como profesional e institucional en la asistencia a esas mujeres

Descriptores: Neoplasias de la mama; Diagnóstico; Enfermería.

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INTRODUCTION

Receiving the diagnostic of breast cancer is a process full of meanings, since the disease and its treatments promote a series of transformations in the lives of those who receive it, altering their body, their emotional state, and their routine⁽¹⁾.

However, as the treatment takes a long time (around 12 months), these feelings can suffer many changes when in face of each therapy stage, body reactions, family support, among other factors. Thus, it is of great importance that the health team recognize the needs of these women, providing them with support and attention⁽²⁾.

Among the several treatment stages, chemotherapy is considered the most difficult phase. Although this phase is of great importance for the recovery of women with breast cancer, there are many side effects such as nausea, vomiting, mucositis, alopecia, and weight gain. Besides, it can lead to ovarian failure, decrease in testosterone and estrogen, which menopause. It can also cause vaginal atrophy, vaginal lubrication, decrease in libido, anorgasmia, and dyspareunia, interfering in the sexual life. Women can face various value judgments that comes along chemotherapy. Besides these physical factors, the woman coexists with feelings of finitude and mercy⁽³⁻⁵⁾.

Therefore, to answer the question: How does breast cancer affect the daily life of women?, this study aimed to explore the experience of coping behavior and the main strategies that women use in dealing with a breast cancer diagnosis.

METHODOLOGY

Symbolic Interactionism (SI) was used as qualitative approach to interpret and understand internal aspects of human conduct, which is the way people perceive the facts around them and how to act in relation to their convictions, allowing researchers or health professionals to judge the investigated phenomenon⁽²⁾.

In order to understand the theoretical perspective of SI, it is necessary to perceive relevant concepts of interactions, such as mind, self, symbols, social interaction, and society described by Mead and explained by Blumer in 1937⁽⁶⁾.

The self, ego, is the element in which we act. Symbols are used with the intention to improve communication between individuals and

the individual with himself. This communication is made by using symbols and social interaction is based on their interpretation. Finally, society is characterized as being dynamic, the individuals interact between themselves, and they define and change the direction of theirs actions⁽⁶⁾.

Symbolic Interactionism is based on three principles: The sense that things represents to the human being, things that become meaningful to a person from his or her own interpretation, and the feeling that things represents to a person due to his or her interaction with others. These principles provide knowledge based on the reality of the person, from the interactions with others, considering what is happening in the present (2,6).

The methodological framework adopted in this work was the Grounded Theory, which emphasizes the importance of knowing. understanding, and interpreting the nature of events and situations whether in the past or in present. The Grounded Theory was developed by the sociologists Barney G. Glaser and Anselm L. Strauss in the early 1960s⁽⁸⁾. Although Glaser and Strauss developed together the Basic Theory, they later took different paths. Thus, the present study was guided by the conceptions of Strauss and Corbin.

The Grounded Theory methodology allows a technical systematization and collection and analysis procedures that enable the researcher to develop sociological theories about the world of the individuals, since it reaches meaning, compatibility between theory and real observation, generalization and reproducibility, accuracy, rigour, and verification⁽⁸⁾.

In this method, the data analysis is performed through data coding process and occurs through three distinct but complementary and integrated phases: open, axial, and selective coding. Thus, Grounded Theory has the purpose to construct a theoretical model that facilitates the understanding of social phenomena from the perspective of the investigated individuals. The categorized data are represented by diagrams and tables to promote their reflection⁽⁷⁾.

According the Grounded Theory, the data were manually organized, respecting the steps proposed by this method. The interview was transcribed and analyzed. Careful reading of the words and sentences was performed in order to verify the open codes, which is the first stage of the data analysis process. Following this process, excerpts presenting the essence of the message were selected from each interview⁽⁷⁾.

After this step, a new interview reading was performed focusing on the open codes. This process, the second stage of data analysis, described as axial coding, allowed the approximation of the social facts, contributing to the knowledge and reflection of the emerging data. With this analysis, it was possible to group similar codes into categories and subcategories. Finally, the third and last stage of data analysis, the selective coding, was carried out with the objective to refine and integrate classes, revealing a category that was central, including all the others, and leading to the emergence of the main theory of this study, which was defined as: "To deal with breast cancer you must outbrave it".

The present study was developed in an oncology department in one municipality in Minas Gerais, in the south region of the state. Women who had the diagnosis of breast cancer and were in the chemotherapy phase were interviewed. The inclusion criteria were: to be a woman, to have been diagnosed with breast cancer, to have undergone surgical treatment to remove the tumour, and to be under chemotherapy treatment. The exclusion criteria was: women who were receiving palliative treatment.

The final samples consisted of 13 women and the criteria for the interviews was the understanding of the object under study and information repetition. The data collection was performed between January 8 and 29, 2014 through a recorded interview, with the following guiding question: "How did you get the diagnosis of breast cancer?".

The women were approached and invited to participate in this research and upon agreement, two copies of the Agreement Form was signed. The study was submitted to the Research Ethics Committee (REC) of the Federal University of Alfenas – UNIFAL-MG in accordance with the Resolution of the National Health Council (NHC) number 466 from 12 December, 2012 and approved with the Opinion 478,376⁽⁹⁾.

RESULTS AND DISCUSSIONS

With the purpose to provide more information about the participants of this work, the socioeconomic and pathological data collected from the interview and the medical file are presented here. In order to ensure the secrecy of the data and the names of the women, they were identified with the letter I from interview and the number corresponding to which order they occurred as it is shown in Table 1.

Table 1 – Socioeconomic and pathologic data from the participants of the study. Passos-MG, 2015.

				<u> </u>		
Interview	Age in years	Civil State	Education	Professional	Affected Breast	Cancer Stage
l1	43	married	Incomplete	Retired	Right	IIA
			Basic education			
12	32	married	High School	Merchant	Left	IIB
13	60	married	University	Pedagogue	Right	IIA
14	39	married	High School	Housewife	Right	IIA
15	37	married	University	Self-employed	Right	IIB
16	59	widow	University	Teacher	Left	IIA
17	61	married	Incomplete	Cleaning Lady	Left	IIA
			Basic Education			
18	54	married	Incomplete	Cleaning Lady	Right	IIIA
			Basic Education			
19	60	married	Basic Education	Merchant	Right	IIA
I10	56	divorced	Incomplete	Farmer	Left	IIIA
			basic education			
l11	50	married	Incomplete	Housewife	Left	IIIB
			basic education			
l12	50	married	University	Lawyer	Left	IIA
I13	42	single	High School	Nursing	Left	IIA
				Technician		

Source: Research Data.

The data in Table 1 show that 38% of the participants were less than 50 years old and 23%

of them had stage III cancer. Since the data were collected during chemotherapy, these advanced

stages were already expected. The left breast was the most affected one in 54% of the cases.

The fact that the participants showed more advanced tumours may suggest delays in the search for medical help or even failures in the primary health care services.

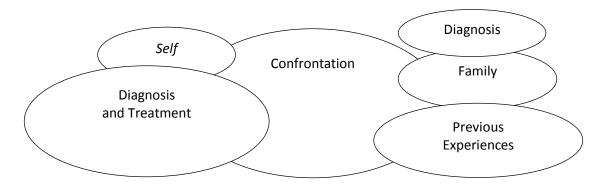
Regarding the affected breast, there was a predominance of the left one. This differ from other studies that indicate that the right breast is usually the most affected⁽¹¹⁾.

Recent studies have showed a growing concern with the increase of young women

affected by breast cancer. This study shows that indeed this is a fact. In this sense, it is important to remember that breast cancer in young women deserves special attention, since it is more aggressive and usually discovered in more advanced stages, which, consequently, decreases the effectivity of the treatment⁽¹²⁾.

After the analysis of each interview according to the proposed methodology, the diagram below (Figure 1) was created, which refers to the categorized data.

Figure 1 – Diagram: Facing breast cancer. Passos, 2015.



In the above diagram (Figure 1), the central category originated the Basic Theory: "To deal with breast cancer you must outbrave it" This confrontation occurred gradually and they could be classified in three categories since the diagnosis: 1 – Receiving the diagnosis and the need of treatment; 2 – Adaptation to the treatment; 3 – Previous experience with the disease.

1 - Receiving the diagnosis and the need for treatment

Our society has fear of breast cancer, especially women, due to its high mortality and mutilation index, affecting the self-esteem and social interaction of the sick person, since it interferes in the personal, afetive, and personal life⁽¹³⁾.

When the woman receives the diagnosis of breast cancer, she faces emotional instability, marked by frustrations, conflicts, fears, and insecurity. These feelings come from the thought of possible death and the association with the incurable nature of the disease. The confirmation of the diagnosis has a significant impact on the life of the patient and her family, and the feeling of perplexity is present⁽¹⁴⁾.

Regarding to this first moment, the women interviewed in this work commented that when they received the diagnosis of breast cancer they came across something that seemed frightening to them, because they could die at any moment:

"Because it is like I'm telling you: cancer is scary! Cancer is scary! Anyone who receives the diagnosis gets scared. So, for me it is scary, and for everyone too." (19)

As participant IS explains, the woman in her relation to herself felt weakened by her new situation with the diagnosis. She was frightened by the possibility of death because this is how she sees breast cancer.

This sense of frailty and impotence is reinforced when she interprets the meaning of the diagnosis in her relationship with the others and with the world:

"Because in people's minds, they think (...) you have cancer! You are a weakened person, you are dying! They think like that, that we are in a wheelchair (laughs)" (I4).

When faced with cancer diagnosis, women considered it a devastating disease regarding their relation to themselves, with others, and with the world. This was confirmed by the fact that the affected organ is the breast, a symbol of

their femininity. In the next step, when they understood the need to treat the disease, their sense of fragility and impotence increased because if they needed a surgical procedure⁽¹²⁾, they could lose the affected breast.

"In the first moment, I could not accept that I need to go through this treatment. In every step there is something to fear. The first one was the removal of my breast because I did not make a reconstruction at that time." (I5)

In this sense, some authors affirm that the female breast has a social symbolism. Breasts are considered the symbol of the feminine, since they are responsible for provide women with pleasure sensations, being related to sexuality, fertility, and maternity⁽²⁾.

The need for treatment also showed to women other possibilities besides surgery, such as chemotherapy, which is a treatment that usually causes hair and body hairs to fall, injuring female vanity⁽¹⁵⁾.

This concern is due to the fact that, in our society, woman hair is considered a female identity and they are expected to have long and tidy hair⁽¹⁶⁾.

In this context, the participants of this study reported that breast cancer brought a triple issue: the fear of dying, the sadness due to the breast loss, and concern about hair loss, a fact also found in another study⁽¹⁷⁾.

"When you say you have cancer, the first thing people look is if you still have your breasts! Then, they look at your hair to see if it has fallen! It is the most interesting thing!" (I3)

"When the news come, it is scary! Then, it comes the surgery (...) it is very fast. You have the diagnosis, you lose your breast, then the chemotherapy is coming. So, it does not give you much time for reasoning (...). After the first chemotherapy session, when the hair falls, is when you can relax and think: (...) Now, let me breathe! Let me think about my life! Because, in the beginning everything is new. Later, there is no more news, you already know more or less what to expect!" (I13)

In the first stage, when they received the terrible diagnosis and the need to have a cancer treatment, in order to avoid the finitude, women begin to show signs that they need to face the battle that is in front of them as a breast cancer patient. Then, the confrontation occurs with the treatments accomplishment.

The meaning attributed by these women to the diagnosis of breast cancer reveals that human

beings perceive themselves and thus, can communicate with them themselves, which makes them the object of their own action. Women use the concept of the self when they recognize their own ideas and the concepts of others. Thus, in certain situations, they evaluate, observe, interpret, and formulate individual or joint actions against the object, which, in this case, is breast cancer.

From the interpretation of these objects and the reflection of them through talking and body expression, it becomes a symbolic interaction and these objects become symbols.

"We have first to think that God helps! We also help ourselves thinking we will be cured. Do not ever be discouraged! Do not let yourself down and repeat like this: I will not get worse, I will not dye...I still have many years to live" (I1).

"But I, even when the doctor told me – it is carcinoma...you have to do chemotherapy, you will need a surgery and all needs to be fast – I said: Oh my God! Do I have to cry? (...) you know, I don't know if it is because I lost a nineteen-year-old daughter, after this pain, you know...maybe we get a bit cold, but I was not scared by the news." (I12).

These reports indicate that women are aware of their disease severity, but the perception that they have to confront the problem is present and the cure becomes their primary objective and religious faith becomes an alternative to face the treatment.

When these women experience losses that brought a lot of suffering, like the loss of a child or a loved one in the family, it is perceived that they develop resilience. This is defined as the potentialities and personal resources that make possible to cope with adverse situations and how the individual can pass through these situations and be stronger despite the risk factors⁽¹⁸⁾.

The woman with breast cancer turns to herself, in which the self can be described as the difficulty to look in the mirror and notice a lack of one breast, and there is no hair, and the "me" refers to her self-image and self-esteem and her own thoughts. Checking her reflections in the mirror is how the woman is self-analyzed after seeing the image of mutilated body and disfigured face due to the lack of hair.

In this sense, the woman starts to build a new self to manage this experience and relies on social factors to establish herself with a new selfimage. To overcome this situation, the woman relies on religiosity and previous experiences of

suffering to overcome adversity and continue moving forward.

2 - Treatment adaptation

Adapting to breast cancer treatment is difficult, since if everything goes well, the woman will pass the first undergoing therapy, whether in surgery, chemotherapy, radiotherapy or hormone therapy, being theses process isolated or in association to others.

During the initial treatment period, in the first year, the woman faces a series of transformations, both in her body and in her life in general. At each stage of the treatment, there is a type of physical and psychological suffering that affects women, since first they face the breast mutilation, one part of her body valued by the woman, and then due to the chemotherapeutic treatment, causing fall of the hair and/or body hair.

Thus, the breast cancer treatment can bring different feelings and emotions, leading to several difficulties that may decrease adherence to the treatment, since this is an important step to cope with the disease⁽¹³⁾.

"Losses during treatment are more difficult than the treatment itself. Since May I'm in treatment and I already lost the breast, then the hair (...) so, I think this is the most difficult part...the losses during the treatment!" (I2)

"There are several steps: the first is the paperwork and examinations...this turn us inside out...now is the new phase." (16).

However, some women try not to suffer in advance, in order to alleviate anxiety, but it is known that this is not always possible and the uncertainties regarding the treatment are many.

"I'm seeing, therefore, that all the steps I'm going through have been easier than I imagine, so one advice I follow is...do not suffer in advance, so I'm trying to do this!" (I5).

"I used to say that this disease is not difficult, the difficulty is the limit of it!" (19).

The sequelae of breast cancer treatment need to be measured regarding the physical and psychological limitations of the patient, and the health professionals need to be aware of the impact this disease and its treatment has on these women life quality. It is observed that there are few programs available for the physical and psychological rehabilitation of women with breast cancer. Together with this, there are still factors of difficulty of locomotion

due to financial or operational reasons, which lead women to find trouble in accessing specialized professional to assist in their rehabilitation process⁽¹⁹⁾.

During the breast cancer treatment, the physical changes do not end with the loss of the breast. There is also the involvement of the homolateral arm to the breast as a consequence of the removal of part of all lymphatic system, which leads to a reduction in the lymph drainage and accumulation of the lymph liquid in this arm, which hinders and causes movement limitations.

"Sometimes, in the end of the day, it looks like I have a ball under my arm." (I4)

"Look at this arm (...) I cannot do anything with it or it swells. I cannot let it hurt, I cannot...so it's the disease that gives your limitations. The difficulty is to accept it."(I9)

"Thank God, I feel good, only what I complain is the pain in the arm, because I cannot move it...if I do, it loses its strength and here (...) seem to have a lump, it seems that I hit it and every little thing I cry with pain." (I10)

This fact leads to changes in the women daily life within the family, since the woman has difficulties to perform the household tasks, considered by the group as their responsibility since this activities are related to the female figure in the house. Thus, the beginning of changes in the family structure can be observed. Many tasks that previously were performed by these women are now performed by other family members⁽²⁰⁾.

"I have someone who makes the iron service for me, and sometimes, I iron the clothes of my boy with the other hand, to do not force the one that I doing physiotherapy." (I4)

"Since everybody in my house worked and I was healthy, I was used to do everything. When they arrived everything was ready! (...) they did not make any coffee. Now everybody needs to do something!"(I8)

It is not only the arm movement that changes. Others precautions need to be incorporate into the woman's daily life, like avoiding to be exposure to the sun or be away from the heat of fire, taking care to do not get hurt or cut, try to not make too much efforts, do not carry weight and do not perform repetitive movements with the affected arm. Faced with this measurements, the daily life limitations can lead to subjective aspects, causing discomfort due to the feeling of lack of autonomy⁽²¹⁾.

"I always did everything! I used to sell furniture, to make lunch and dinner (...) in my own store, they all had lunch there with me!" (19)

"Someday I cry because I'm nervous to see many things that need to be done and I'm not able to do so. But crying will not solve the problem, these things need to wait." (I10)

The decrease in the arm movement ends up interfering in the daily activities, which cause discomfort to sleep and to drive, disturbances in the posture, a reduction in the capacity for physical work, and the ability to perform household chores. These limitations causes psychological discomforts for the women since they are constantly facing the disease and the possibility of not being fully recovered. Thus, the cancer treatment is seeing as the responsible for permanent changes in their life that could persist even after the end⁽²²⁾.

The inability to work is something that intimidates and marginalizes women, since working is one of the ways in which human being express, realize, and identify themselves in the world. Physical inability to develop daily life activities brings feelings that can depress the individual life quality.

However, all these factor requires adaptation from women to make them able to continue living and experience the disease, performing the treatment in order to look for the cure, even if they have to suffer from all the side effects. At this stage, therefore, the confrontation comes through the adaptation to the treatment.

3 - Previous experiences with the disease

The therapy period may have positive or negative effects on the patients and their family members, as they may experience feelings related protection, concern, anxiety, anger, and guilt about the treatment.

The women interviewed in this work reported that coping with the disease was positive if they had a good experience with the disease previously, for example, when someone in the family had cancer and was recovered. In cases where the woman lost someone for the disease, they see the cancer as something extremely negative in their lives.

"I always think about my sister. My oldest sister had a very aggressive breast cancer. She had to remove the breast and even a bit from the arm. Her tumour had 5 centimetres. It was more advanced (...) and comparing with her, my situation is more encouraging. I said like that...people, if her tumour was so big and aggressive and she pass through it and is now healthy and happy, mine is a small one, there is no need to remove my breast, for sure I will win!"(I3)

"The experience I had with my husband was not good because he ended up dying." (I6)

Regarding the chemotherapy consequences, like the alopecia, the women that had some experience before the diagnosis saw it more calmly.

"No, I was not scared (...) I thought like that...this is going to happen anyway, I've seen my sister. Her hair is there again, strong and beautiful. It was normal, I already knew, I've seen other people who did the treatment, so I was not scared." (I1)

For the woman who had previously experienced hair loss from chemotherapy, this situation was seen more calmly, since she knows the treatment steps and knows that to overcome the disease is necessary to face the obstacles and adversities. Hair loss is temporary and a necessary event in the cure of the neoplasia.

Similarly to the present work, others studies show^(20,23) that family support is fundamental for the woman to face this situation and for this treatment period be as calm as possible.

In addition to the family, the nursing team and support groups can also contribute to the wellbeing of people who experience the problem in focus here.

During the chemotherapy treatment, the nursing team has a direct contact with the woman, and they should pay attention to the feelings reported about the side effects, besides given orientation regards the alopecia. This is important because hair loss usually occurs after the second session and it is abrupt⁽²⁾.

Thus, it is necessary to guide the woman about the losses caused by the chemotherapy treatment. It is considered that the anticipated information can diminish the impact at the moment when the hair loss begins.

When the nurses performed their role in the effective orientation, women face it better, and the hair loss starts, they create alternatives, such as the use of scarfs, wigs, hats, among others. However, in cases where this confrontation is negative, the woman tends to hide herself to do not look sick. This non-acceptance might interfere in the immune

systems, leading to a cycle of discouragement in every chemotherapy session and often ended up in a non-complete treatment⁽²⁴⁾.

Therefore, using the Grounded Theory methodology, comes the theory that having breast cancer leads to feelings ranging from incomprehension of why the disease appeared to acceptance actions, reinforcing the importance of a individualized treatment for each woman. The fears and how they face the cancer is perceived differently, depending on their education level: previous experience and family and healthy team support.

It is observed that there is a need to deepen the studies about this problem, taking a higher amount of samples and repeating in other places, since this is the critical phase of the treatment and the woman has contact with the health professionals, especially the nurses, who can assist them in their doubts allowing them to pass through this period with less suffering.

FINAL CONSIDERATIONS

Although the knowledge about cancer is a problem that has been discussed with bigger emphasis in the last years, this study allowed to reflect about the confrontation of the women who had breast cancer diagnosis and to verify that this confrontation is the most present action in this group of women. They reported that they had conflicting feelings and that family support helps to cope the disease in a more positive manner.

The theory constructed in this study allows a better understanding of the reality and awakens to a reflection and critical analysis about it, which leads to avoiding the naturalization and banalization of the studied phenomena, since it includes scientific elements that provide the analysis and understanding of reality, and also contributes for changes, transformations and innovations, personally, professional and institutionally.

We hope that our results subsidize the work of professionals who assist the women with breast cancer and that they consider that during the treatment they should think about aspects that cause suffering, besides guiding them to support groups.

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