

# I discovered that I have breast cancer: meanings in the collective subject discourse

*Descobri que tenho câncer de mama: significados no discurso do sujeito coletivo*

*Descubrí que tengo cáncer de mama: significados en el discurso del sujeto colectivo*

## ABSTRACT

**Objective:** To know the contemporary meanings of breast cancer diagnosis. **Method:** Narrative research conducted with 11 women diagnosed with breast cancer, undergoing chemotherapy, in remission of the disease. The narratives were collected between August and December 2018 by interviews which were recorded, transcribed and analyzed using the Collective Subject Discourse technique. **Results:** From the analysis four central ideas emerged and in this study three central ideas will be presented: Discovering breast cancer; Current feelings and; Advice to women with breast cancer. **Conclusion:** The discourse reveals the fear and distress of women, especially in the phase of diagnosis and remission, despite advances in disease control of the present times. In addition, it reveals changes in living after diagnosis. Knowing the meaning of the disease allows better nursing planning. **Descriptors:** Breast Neoplasms; Nursing; Oncology; Speech.


## RESUMO

**Objetivo:** Conhecer significados contemporâneos do diagnóstico de câncer de mama. **Método:** Pesquisa narrativa realizada com 11 mulheres com diagnóstico de câncer de mama, submetidas à quimioterapia, em remissão da doença. As narrativas foram coletadas, entre agosto e dezembro de 2018, por entrevistas gravadas, transcritas e analisadas pela técnica do Discurso do Sujeito Coletivo. **Resultados:** Da análise emergiram quatro ideias centrais e neste estudo serão apresentadas três ideias centrais: Descobrir o câncer de mama; Sentimentos atuais e; Conselhos às mulheres com câncer de mama. **Conclusão:** O discurso revela o medo e os sofrimentos das mulheres, em especial, na fase do diagnóstico e de remissão do câncer, apesar dos avanços no controle da doença dos tempos atuais. Além disso, revela as mudanças no viver após o diagnóstico. Conhecer o significado da doença permite melhor planejamento de enfermagem. **Descritores:** Neoplasias da Mama; Enfermagem; Oncologia; Discurso.


## RESUMEN

**Objetivo:** Conocer los significados contemporáneos del diagnóstico de cáncer de mama. **Método:** Investigación narrativa realizada con 11 mujeres diagnosticadas con cáncer de mama, en tratamiento de quimioterapia, en remisión de la enfermedad. Las narrativas fueron recolectadas, entre agosto y diciembre de 2018, a través de entrevistas grabadas, transcritas y analizadas mediante la técnica del Discurso del Sujeto Colectivo. **Resultados:** Del análisis surgieron cuatro ideas centrales y en este estudio se presentarán tres: Descubrir el cáncer de mama; Sentimientos actuales y; Consejos a mujeres con cáncer de mama. **Conclusión:** El discurso revela el miedo y el sufrimiento de las mujeres, especialmente en la fase de diagnóstico y remisión del cáncer, a pesar de los avances en el control de la enfermedad en los últimos tiempos. Además, revela los cambios en la vida después del diagnóstico. Conocer el significado de la enfermedad permite una mejor planificación de enfermería. **Descriptor:** Neoplasias de la Mama; Enfermería; Oncología Médica; Discurso.


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## INTRODUCTION

Breast cancer remains a global public health dilemma and the most common tumor in females. Awareness of the disease, health care, associated with advances in diagnostic and therapeutic methods had a positive impact on the recognition and screening of this cancer. However, the disease remains fatal for many women. Among all malignant neoplasms, breast cancer is considered one of the leading causes of death for postmenopausal women (23% of all cancer deaths). But even though it is a global problem, it is still diagnosed in advanced stages<sup>(1)</sup>.

In the psychological evaluation of women with breast cancer, a significant emotional and social impact is evidenced<sup>(1)</sup>. Study reveals that the disease affects well-being, family life, sexual and gynecological health. In this context, nursing professionals should maintain actions and investigations that cover the impact of the disease, and should consider social, family, professional and health development transformations, which also affect living with breast cancer<sup>(2)</sup>.

To help fight breast cancer, the *Tell Your Story campaign* was launched, when it sought narratives of inspiring stories of coping with cancer, in order to provide hope, comfort and courage to many people whose lives are “touched” by breast cancer. However, the diagnosis of the disease is fraught with conflicting emotions of anxiety, anger, and sadness. The author comments that when this campaign asked for “inspiring” cancer stories on her website, what should be understood is that uplifting narratives with a happy ending were very welcome, but stories with opposite contexts would be effectively silenced. Unfortunately, not all people who receive a diagnosis of breast cancer have successful treatment and recovery<sup>(3)</sup>.

Thus, understanding the disease in the perception of women themselves remains a challenge, since the singularities are many and the sum of these singularities allows the understanding of the phenomenon that is continuously transformed. Knowing the

experiences and their meanings, in the face of any and all outcomes, enable professionals to know the truth and from the truth they can make better decisions to provide health care.

This scenario associated with the magnitude of breast cancer, current and expected for the coming decades, led to the need to pay attention to the meaning of breast cancer, as many diagnostic and therapeutic advances are added to the current arsenal of combating the disease, in addition to the increases in multiprofessional care and social changes. However, in clinical practice it is observed that scientific advances have little changed the social representations of the disease. So, one wonders, given the new advances in health in breast cancer control, do the meanings remain the same? Previous studies indicate that coping with the disease causes significant emotional impact<sup>(1)</sup> and is full of anxieties caused by the diagnosis, fear of disease and death, impossibility to work and need for changes in habits<sup>(4-5)</sup>, with success stories, but also significant losses and difficulties<sup>(3)</sup>. The objective of this study is justified: to know contemporary meanings of the diagnosis of breast cancer.

## METHOD

This is a narrative research conducted with women aged 18 years or older, diagnosed with breast cancer, living in the metropolitan region of Florianópolis (Santa Catarina, Brazil), submitted to chemotherapy in the last ten years, in remission of the disease (according to women’s reports), and may be undergoing treatment with hormone therapy. The origin was defined considering that the region has a reference institution in cancer care in the State. Women relapsing from the disease or experiencing a cancer diagnosis with a family member would be excluded from the investigation, but in the selection of participants no cases were found.

For the selection of participants, the research proposal was first presented to the members of a support group for women with breast cancer and the interest of the group for inclusion in

the study was verified. In view of the women's expression of interest, it was agreed that the Group Coordinator would provide a list with names and contacts of the members, but it was also agreed that the women contacted themselves could suggest names of other women for inclusion in the study, including non-members of the group (snowball technique). Contacts with the women were made via telephone (phone call or text message via mobile app). The number of women included in the study (11 women) was established when no additional information was identified in the collected narratives (evidenced in the data analysis carried out concomitantly with the data collection). It is recorded that this group is linked to an oncology institution, but serves women from various institutions.

Contact with women followed the sequence of names on the list forwarded by the Group Coordination. Each woman interviewed was asked to indicate another woman. If there was no indication, a new woman on the list was passed on by the group coordinator to the researchers and was subsequently contacted. The list provided by the group coordinator contained 20 names; five women were indicated without being on the list, and two accepted inclusion in the study; consequently, from the list of women from the support group, nine women were selected, when data saturation was reached.

For data collection, which took place between August and December 2018, an interview was recorded, transcribed and carried out in an environment chosen by the participant. The first four interviews were conducted by two researchers in order to standardize the approach. Sequential interviews were conducted with the presence of the participant and a single researcher. The researcher responsible for this study has been working for 30 years in Oncology, with clinical, teaching and investigative experience in the context of breast cancer. The researcher responsible for the totality of data collection was a nursing student, a volunteer scholarship holder.

The triggering questions of the narratives covered the meaning of breast cancer, current feelings and what each would like to say to another woman who was receiving the diagnosis of the disease. The narratives reached a mean of 60 minutes in length. The anonymity of the participants was guaranteed with the use of pseudonyms defined by the researchers.

For data analysis, we opted for the technique of the Collective Subject Discourse (CSD). The CSD is a method that rescues social representation through the reconstitution of the collective empirical entity, in the form of a discourse issued in the first person singular, as if it were a collectivity that speaks in the person of an individual. It is composed of different key expressions of individual discourses, grouped into categories of collective meaning (stage of coding the narratives) and that make up the central ideas<sup>(6-7)</sup>.

The key expressions are excerpts from the narratives that must be highlighted by the researcher and that reveal the essence of the discourse content. The categories of meaning group socio-cognitive schemes that portray the socially shared ways of knowing or representing and interacting with the world and with everyday life, and that reveal possible awareness of such actors in a given historical moment. The central idea is the linguistic expression that reveals, describes, and names a homogeneous set of key expressions/categories of meaning. Discourse, as collective testimonies, translates the way social representations are perceived/felt by a society, a group or a certain culture<sup>(6-7)</sup>.

For the elaboration of the CSD, the *software* CSDSoft<sup>(7)</sup> was used; the sequence of the presentation of the key expressions and the categories of meaning that formed the CSD was carried out by the researchers. The entire analysis process was carried out by one researcher and sequentially reviewed by a second researcher. Divergent points were discussed and agreed upon.

From the analysis emerged four central ideas: Meaning of breast cancer diagnosis; Discovering

breast cancer; Current feelings; Advice to women with breast cancer; 21 thematic categories with their respective key expressions. This article presents the central ideas: Discovering breast cancer; Current feelings and; Advice to women with breast cancer. Considering the volume of the results obtained, the Meaning of breast cancer category was presented in another article<sup>(8)</sup>.

To discuss the data, updated publications related to the theme were used, with the Social Representations<sup>(6,9)</sup> and with a three-dimensional evaluation of the narratives, which includes the temporal; social; and place dimension, as these dimensions are understood as dimensions that allow the experience of the individual in the world, which constitutes him as an individual belonging to a society<sup>(10)</sup>.

The Informed Consent Form was applied before the interviews. The guidelines for the development of research with human beings were followed, with ethical appreciation registered under opinion 2,565,680 issued by the Research Ethics Committee of the study proponent.

## RESULTS

The participants (11 women) were aged between 43 and 72 years; most (eight) in the age group of 40 to 59 years, with diagnoses between five years or more. In all women, the diagnoses occurred between two and 11 years. Sequentially, the CSD is presented with its respective central ideas.

### Discovering breast cancer

The central idea "Discovering breast cancer" has three categories of meaning: Early symptoms of cancer, Failures in listening and in valuing complaints by professionals and, Advanced disease. The discourse reveals the initial symptomatology, the search for medical help and the advancement of the disease. The first symptoms revealed by the women were local (hooked) pain, breast deformities, appearance of nodules. The diagnosis of the disease, in most cases, was strongly influenced by the emergence of the symptomatology of the disease and

a smaller number of women were diagnosed due to the performance of imaging tests.

The women pointed out that observation and touching the body itself allowed the perception that something was altered in the body, that the family helped in this process of analyzing changes in the breast and the search for professional care was the way to seek diagnosis and treatment as early as possible. Another aspect highlighted was the inability of professionals or professional negligence that hindered early diagnosis. The CSD that gave rise to this central idea is presented below.

#### *First symptoms*

*"I discovered the nodule myself (Selina, 2018). I always get my checkup in March. (...) I did the mammogram and gave nothing (Maria, 2018). In July I retired, so to leave my job we do all the exams. (...) in July I had nothing, but in October I had (Selina, 2018). [...] when i took off my bathrobe to take a shower, I looked at my breast and it was all marked, it looked like an orange [...]" (Maria, 2018). (...) When I felt a hook I thought it was muscular, but I got it on my head and I lay on the bed to dry myself and I felt like it was a pinhead (Selina, 2018). At first I saw that my breast was changing, that the breast beak was entering (Ana, 2018). (...) I called my gynecologist, he said: come here now let's do an ultrasound so we can see what this is. 'Then you already gave the suspicion! and marked the biopsy (Maria, 2018). I felt the lumps and after I talked to the physician I already knew it was a serious thing (Alice, 2018). I had a mammogram and nothing came up. And you see... it's something you could see. Then I said to him, 'Doctor, didn't anything come up?' And he said, 'Just in case, let's do an ultrasound.' (...) Since he was an oncologist, he wrote me a letter and sent me to the hospital. (...) Then they already fit me there (Lena, 2018). Because I have BRCA2... (Ana, 2018)".*

#### *Failures in hearing and valuing complaints by professionals*

*"I came from an incorrect diagnosis for six months, a physician, who said that I had nothing, but my breast was totally transformed. I went for six*

months insisting that I had a violent family history of cancer and she said I was paranoid. So, this was one of the things that hurt the most in the process, negligence (Ana, 2018). And when we went for the mammogram, the mammogram girl unfortunately was stupid with me (Selina, 2018). Actually, my gynecologist went to a mastologist. Then, she got there, she looked, she looked and in my exam she said: 'it needs a magnetization of the breast', it was an observation below. I thought, 'Well, trust the mastologist.' I took it, she [the physician] looked, looked at my tests. (...) I said, 'Okay, what about these tests that the radiologist indicated down there?' She said, "No, you don't have to." (...) I looked for another physician (...) He said: 'we will obey the request we already had here' [referring to the indication of the radiologist to perform new tests] (Linda, 2018)".

### Advanced disease

"When I heard about the diagnosis I already knew that something was not right, that it was serious (Alice, 2008). It's all right. I asked the girl: does the result take long? She said, '10 to 15 days.' The other day, about 7 o'clock in the morning, "Dona Maria can come and get her result." Then he was already growing [referring to the tumor]. (...) and they [the physicians] said they were not going to do [referring to surgery] because they had no support at the time (...) (Maria, 2018). Because I wear 50 [referring to the bra number], so I have a big volume. ... and when she [ultrasound technique] put [refers to ultrasound] she saw the point. She immediately passed me to the people of the ultrasound next door [referring to the room next door for checking the result]. And then there was my friend the technician. And he said, 'Weren't you here these days?' And I: I was! But I'm feeling something here. (...) I want you to press here.' Then he passed the gel and when he pressed it he saw it. 'Really Selina' (Selina, 2018). I had to take off my whole breast. Not much left. (...) I use the expander, all this methodology that does not leave you so mutilated. Because in fact we are mutilated (Ana, 2018)".

### Current feelings

The central idea, Current feelings, groups four categories of meaning: Fear of disease recurrence; Self-care and self-perception transforming thinking, acting and feeling; Focus on short-term plans; Transformations only in the period of diagnosis. The speech emphasizes the fear of recurrence of the disease.

The approach with the team and the access to the monitoring exams provide the woman with a sense of security. At the time of discharge from treatment, some speeches mentioned that the feeling is of being alone and the loss of the feeling of control over the disease and the risk of recurrence.

Self-care and self-perception of oneself and one's social, professional and family position is an item identified in CSD. In the discourse it is understood that her perception of life and society changed after cancer. Many describe themselves as more human, more empathetic, or even spending more time with family and other activities they were not so willing to do before. In addition to providing more time for themselves, changes in habits and quality of life.

In contrast, meanings were found that describe the changes in perceptions and habits and that after the remission of the disease the old habits returned. There was still emphasis on short-term plans, of living now and not later, as there is uncertainty about the future. The CSD of this central idea is presented below.

### Fear of disease recurrence

She [the physician] said, "Did you graduate now? Go to work. [referring to discharge from cancer treatment] And I said: '(...) Can I come by sometimes?' (laughs). It gives that feeling of 'Bye' anyway. We want to be monitored, make sure that someone is there. But, they [health team] will be there (Ana, 2018). I continue to maintain the necessary periodic examinations (...). They just moved me to six months. Every visit you go to, a little fear you always have. It will never be the same again (Linda, 2018). It's good because, at the same time that we don't like to go

there [referring to the cancer treatment unit], you are sure that you are monitored. But, I'm sure it won't appear anywhere (Selina, 2018). I think if I get into that rhythm again. He may be able to come back. That's why I want to be calmer again (Lilian, 2018)."

### **Self-care and self-perception transforming thinking, acting and feeling**

"If I go to the hospital to clean the catheter and if I see someone who is already in a very bad state, I can't, because it hurts me. Then they say, 'Ah! You have to separate from the pain of the other.' But I can't, the pain of the other hurts me. I've been through it (Linda, 2018) I had to go through all this to change my way of seeing, of looking at people, of treating people. But, I think it's so cool that I know people who didn't have to go through this to be like this. I think like this: 'It's good that I managed to get to, like this..., I'm getting better, being a little better (Nina, 2018). Being separated, in fact today it's as if I have 60% with them [the children] and 40% they are with the father. I have to be okay. I know that, I'm not guilty of this [refers to divorce], I know my talents, my qualities and today I just thank you. That today I am free, I live well, I have my children, my work (Aline, 2018). (...) And I always say (...) we need to value ourselves more, value work more, value ourselves as a mother, as a wife, as a daughter, as a friend. Have an understanding of people (Nina, 2018). People say I've changed. Not just for talking more, but for guiding more. Before, I was much more into listening, giving my opinion without thinking about the consequences of my opinion. Not today (...) (Selina, 2018). I was very homely, don't leave the house for anything. To leave home was the biggest job, laziness, a thing. Now, you've called for anything... you can call me to help. I'll go. And this was after this experience (Lena, 2018). (...) I don't care as much as I used to. (...) I think more about myself now. The first place, second place, Third place I (Eli, 2018). So, I put this in my mind, that I had to think about myself (Aline, 2018). I'm happier. I am much more forward with people. We can't be that closed to the world. We have to let things happen (Lena, 2018). We become more human. We value the smallest things, which before we did not value. Forgive more, be more human" (Eva, 2018).

### **Focus on short-term plans**

"I was a person of longer plans. And today I have no longer plan for 5 or 6 years. I don't know. I prefer to leave the plan for this month, for the following week (Selina, 2018). So I was full of projects, I did not-stop. And that's it. Always focusing on tomorrow, not the long term because we never even know what will happen (Ana, 2018). It was a way to put a brake on my life. I had just retired and was still in that position. I think it was a thing to say like, 'No, it's not like that. Easy. Don't leave it till later. Do whatever you want now'" (Selina, 2018).

### **Transformations only in the period of diagnosis**

"Oh! now I'm back to [...] what I was before. I'm back to being mad. It used to be Zen. Nothing would hurt me. During treatment. All love. I forgave everything. I had gratitude for everything. Not now (laughs). Now I'm back again, I'm getting mad. I'm already demanding things (Lilian, 2018). But then I went back to my normal rhythm, normal life. And during the treatment no, everything was fine. It was a tremendous peace (Lilian, 2018). Now I'm in another phase, but from time to time I try to go back to that, so that I don't have those behaviors again; Of course I'll never be the person I was before, but it's still hard (Nina, 2018)."

### **Advice for women diagnosed with breast cancer**

The central idea Advice to women diagnosed with breast cancer groups the following categories: Maintain habits of spirituality and meeting with oneself and family; Maintain distance from companions who can bring bad energies; Maintain always informed about everything about the disease and treatment; Talk about the disease and not internalize it; Reserve positive thoughts and/or calmness; Practice self-care.

The discourse reveals that the maintenance of faith and belief in healing are essential for overcoming the period. Relying on family and friends for emotional support are also

foundations for recovery and for maintaining willpower during the diagnosis phase.

Positive thoughts and calmness were revealed as a way to alleviate the traumas that occurred during this period. Conversely, the discourse portrays the damage of social distancing, which impairs recovery and emotional support, highlighting the overload of negative feelings and thoughts of people, including family members who worsen the situation faced with their speech.

The speech also draws attention to women's empowerment over the disease, which is fundamental for confidence in the treatment, in the team and in themselves. The reports state that understanding the disease helps women express their feelings.

The speech also advises women who are receiving the diagnosis of breast cancer to dialogue and not hide the diagnosis of cancer so as not to become a psychological burden and impair the discernment regarding what is cancer and the prognosis of the disease, as well as recommends the practice of self-care. In the discourse they consider quality of life, the search for physical activities or hobbies, psychological care and respect for treatment as key parts during cancer treatment. The CSD of this central idea is presented below.

### *Maintain habits of spirituality and encounter with oneself and family*

*"... clings to God that he will give you an answer (Eli, 2018) ... have a lot of faith, believe in healing and turn to God. Even the cancer that is incurable I think if you have faith, this power that God has given within us, heals. It is faith and patience that you have to have (Lilian, 2018). And that God is up there and helps us get through it all. You have to overcome it. Have strength and faith. We are all there in the fight. Every day (Lena, 2018). There are so many people praying for me. I have to give these people an answer. "I won't die." You see everyone is rooting for you. We receive a lot of support, as I did, from family and friends (Lena, 2018). Don't lose faith, hold on to God. It counts with the family (Ana,*

*2018). (...) Everything will be fine, but have... faith in the physicians, who are also prepared to take care of us (Linda, 2018)."*

### *Keeping away from companies that can bring bad energy*

*"Try to stay away from people who put you down. This is what you find the most, as incredible as it may seem (Linda, 2018). Sometimes within your family there are people who suck you, there are people who are there, but in fact they are using you, no matter how much you are related, but what are you going to do? Distance you, you apologize. And there's no other way, there's no other way. You have to come and say to yourself: 'This person is my relative, but unfortunately he does not bring me good energy, or does not help me, does not add to me, only brings me problems'. So, in this sense of knowing how to filter your friendships, your family, your work, your choices (Aline, 2018) You have to know how to choose well, so that each day is pleasant (Aline, 2018)".*

### *Always keep informed about everything about the disease and treatment*

*"Prevent. Works with prevention, better always prevent than remedy (...) seek knowledge (Ana, 2018). You have to trust the treatment and if you are not sure, change physicians. Because if you're not sure what he's going to tell you, you change the procedure. There are many forms of treatment today. Today, I can even talk. Today, it's nice to talk to some people in the sense of saying, 'Go after it.' See what's best for you. And today's physician doesn't just give you one option. It opens up a lot of options for you. Try it. He didn't like the chemo going to immunotherapy; he didn't like the immunotherapy having other alternative therapies. Many alternatives (Selina, 2018). You get a lot of the disease label, this cancer thing equals death or treatment equals suffering. Fear kills more than disease. People who receive the diagnosis and refuse to be treated it is pure ignorance. For ignoring the truth of the facts. The wrong information makes you more prejudiced towards treatment. (...) We have to continue taking care of ourselves, preventing, distrusting the physicians who say that it is okay if we feel that it is not okay.*

Medicine doesn't know everything and humans are flawed. That was one of the great lessons I took (Ana, 2018)."

### *Talk about the disease instead of internalizing it*

"Sometimes people don't want to talk because it's still taboo to talk about cancer. I didn't find that. But those who are out and those who have never had it still see the cancer diagnosis as a death certificate. You still see it! I've never seen it. But people still see it. (Selina, 2018). (...) You still have this prejudice about not talking to your family. Where it suffers from it, (...) then it comes the worst death sentence, which is to take the disease inside. Shut up.(...) But talking to people about it, I talk freely. I have no prejudice whatsoever (Eva, 2018). Because we have to open this space. And put to people: 'Look, I'm going through a situation and I need you to understand me, to help me'. It's not as simple as you might think. And if that person is not so close to you, they are not supposed to be, and new people will appear, and other people you will meet who will be much more important and, sometimes, will be important for your entire life (Nina, 2018)."

### *Practice self-care*

"(...) take care of food and do the right treatment (Alice, 2018). Listen to what your physician has to do, do all the tests that have to be done. Trust the team. Strictly follow. (Ana, 2018) (...) The most important thing is the quality of life. Thinking well about the quality of life,(...) is effectively you rest the mind (Aline, 2018). One day a friend said to me: 'Wow... you took care of yourself so much. What good is it?' Then I was thinking, 'I took care of myself so much and what good did it do?' Looking back, I think it was good. My body wasn't that weak (Eli, 2018). But, life is one, life is short, focus and work so that each day is pleasant (Aline, 2018). It's a time when you have to stop and think about everything you've done, that sometimes complained about this, that or got very angry at things that happened, or didn't happen. (...) Then you have a different thought today. If you can fix it, if you can't, patience,

do what (Nina, 2018). So that's what I say, look for that time. Oh, 'but I can't do that anymore', look for other things, you can read a book. 'Oh, I can't do my races on the Beira Mar anymore', but you can take pictures, you can read a book, you can do something manual, a knitting, a very simple thing. Look for a therapeutic group, go there and do a water aerobics. Of course, sometimes the person is not financially able, but she will try. She will be able to find a space for her there (Nina, 2018)."

### *Preserve positive thoughts and/or calmness*

"With cancer, we only think about dying first: 'I'm going to die, I'm already there thinking I'm going to have to fix my coffin.' But no; I am there, firm and strong (Lena, 2018). Easy; take a deep breath. It's a cancer diagnosis, not a death diagnosis. It is not a death sentence. It is cancer, not death (Ana, 2018). Go in faith that you will survive. Go with faith and believe (Eli, 2018). Everything passes. (...) we go through the ups and downs of life, but you will hold on (Aline, 2018). (...) I think so, that it is no use being sad, if you like and have children (Maria, 2018). Survive. Survive. It'll hurt you, but you survive. Sure, you fall, but you survive. Don't fall, don't fall (Eli, 2018). Do not freak out. Do everything the physician tells you to do, all right (Lena, 2018). (...) Be patient with everything that is happening. With the changes of the body, the hair and such. Everything passes away. If you have willpower, if you have love and have faith (Lilian, 2018). Some will be physically ill, others better. But, in general, we overcome, we manage, thank God, and we will touch life. Do you have the little ghost? Yes. But, you become more and more distant from the ghost of return (Ana, 2018). I would say (...) that it will be difficult, that it will not be easy, but that as I managed, she will also be able to recover (Linda, 2018). (...) Try to review things at this point. Try to value yourself, try not to value certain things, this issue of hair [referring to hair loss]. Each one reacts in a way, I will not criticize the people who are more vain, when I saw, I was not so vain, so it did not hit me so much. Is it hard to get through this? Yeah, but we have to make this period as easy as possible (Nina, 2018)."



## DISCUSSION

The first thematic category reveals that the women performed the screening periodically, but, despite this, they were the ones who perceived the changes in the breast. The meaning of this experience is related to complaints not heard by professionals, or to reports that did not point out the correct diagnosis, postponing the diagnosis of breast cancer and causing more advanced diseases and worse prognoses, especially in the medium and long term. For happy-ending success stories, early diagnosis is a necessity as well as a right for all women. However, it is not at all uncommon to come across stories opposed to this, as well revealed in the CSD.

For the early diagnosis of breast cancer, opportunistic screening is recommended, covering clinical examination of the breasts, imaging tests and random palpation of the breasts or self-examination of the breasts<sup>(11)</sup>. A study argues that some factors can lead to incorrect reports, making it difficult to diagnose early, such as patient positioning errors on mammography, low quality mammography, errors in the interpretation of images, dense breasts and even the sizes and characteristics of the breast lesion. It also discusses that for a comprehensive clinical evaluation, anamnesis with qualified listening and a detailed physical examination are essential for accurate diagnosis, as well as humanization that collaborate for more effective care and timely treatment, with a view to improving the quality of life of women with breast cancer<sup>(12)</sup>.

A study that included 12,847 Brazilian women shows that breast cancer is perceived for the first time (66.2% of cases) by the patients themselves when they observe any change in the breast. Detection by mammography or another imaging test occurs in 30.1% of cases, while in only 3.7% the initial suspicion was from a health professional. This same study looked at the percentages of patients who remained alive (survival) up to five years after diagnosis. Five-year survival according to the disease stage at the beginning of treatment was 88.3%

for stage I, 78.5% for stage II, 43% for stage III and 7.9% for stage IV<sup>(13)</sup>.

Another Brazilian study that included 417 women with breast cancer identified that 10-year survival was equivalent to 60.5% for those diagnosed in stage II, 10.9% in stage III and 0% for stage IV. Among these women, 45.8% were diagnosed in stage III and IV of the disease and 86.6% in stage II, III and IV<sup>(14)</sup>. Thus, the direct relationship between late diagnosis and the high mortality rate ten years after diagnosis is evident. This condition, in addition to the epidemiological impact, impacts the quality of life and the meaning of the disease for those who face it.

From the three-dimensional evaluation in this first thematic category, the dimension time<sup>(10)</sup> stands out, as the discourses portray the difficulty for early diagnosis and attempts to reduce this time, however, despite the struggle and health complaints, late diagnosis was a certainty for most. In this sense, time meant greater discomfort and generated anxieties, fears and also showed dehumanization on the part of professionals in the diagnosis phase of the disease, a stage full of anxieties, which hinders even logical thinking.

A study<sup>(15)</sup> on the social representations of breast cancer infers that the diagnostic phase of the disease is perceived as a peculiar stage when women start to assume the role of patients, but that they nevertheless seek strength to move forward, as found in this investigation. Another study states that when women received the diagnosis of breast cancer, they were faced with frightening experiences, which cause the feeling of death at any moment, of fragility in the face of their new situation, of impotence in the face of themselves and others (of the world)<sup>(4)</sup>.

The second thematic category declares a range of feelings, when again the fear felt by women was identified, now of recurrence and the link with choices to live in the present time (time dimension). This category also states that health care (place dimension) in the face of remission of the disease takes on another dimension,

that of safety, because fear accompanies women in this period and the performance of follow-up exams are generators of uncertainties, but also, generators of expectations of the continuity of the diagnosis of remission of the disease.

In this perspective, a study<sup>(16)</sup> points out that the meaning of cancer is linked to the finitude of life and the fragility of women. Another perception of the authors, both found in the discourses revealed in this article, shows that the broader view of women is linked to self-care, faith and optimism, boosting the production of rearrangements for the maintenance of daily life, even when faced with the understanding of the finitude imposed by cancer.

A review study, covering the mental health of breast cancer survivors and physical activity programs, discusses that in the survival phase there is mental suffering, such as fear, depression, anxiety, body image and mood disorder, sexual dysfunction, problems in professional, family and marital life. These problems can influence coping capacity and quality of life. In addition, 30% of breast cancer survivors report feelings of abandonment in the transition between the treatment stage to the follow-up stage, when the disease recurred<sup>(5)</sup>.

As for the rearrangements commented, they are strongly presented in the third thematic category. They are intrinsic rearrangements of women or with other people, especially with family and friends. Others are temporary or perennial rearrangements. This finding is related to the social dimension because it configures social/emotional support for living with breast cancer. A study<sup>(17)</sup> states that the meanings of the disease put women and their partners in a position of fragility and reinforces the relevance of spirituality/religiosity giving strength to the necessary confrontation. Regarding family resilience<sup>(18)</sup>, it has direct and indirect effects on survivors' quality of life and caregiver burden and is positively related to post-traumatic stress.

Complementing the discussion of the third thematic category, two aspects stand out, the search for information, because living with

cancer, with health services and exchanges of experiences with other women highlight the need for knowledge to overcome or control cancer, in addition, contributes to resilience. Thus, the information favors the search for better health. Another aspect is the awareness that it is necessary to disengage from negativity, yours and others and, it is necessary to strengthen positive thoughts, seek to be with people who generate comfort, tranquility and good thoughts. From this perspective, the social and place dimension are clearly stated.

In this context, a study identified that women survivors of breast cancer have good quality of life, however emotional well-being is the most affected, as well as the impact of cancer manifests itself with greater significance on health concerns, feelings about cancer and significance of cancer. States of economic and educational vulnerability cause a lower degree of concern for health and disease. Higher education was linked to a positive view of the disease. In addition, worse quality of life scores were associated with an impact on body changes, negative self-assessment and concern about cancer<sup>(19)</sup>.

Summary of systematic review argues that the quality of life in breast cancer patients has greatly improved in recent years, as several simple but effective interventions, such as physical activity and psychosocial interventions, have shown promising results. Pain, lymphedema, worry, sexual function especially for younger patients and future prospects are among the issues that deserve further consideration to improve quality of life in breast cancer patients<sup>(20)</sup>.

Thus, understanding women's experiences allows a deeper understanding of the meaning of breast cancer. This privileged view does not reveal objective truths, but rather reveals subjective truths within a social context<sup>(3-5)</sup>. The CSD reconstitutes the meaning that the different social actors give to the world they live<sup>(6-7)</sup> and the social representations presented allow the analysis of this living for better nursing actions

present in the three levels of care, places where women travel to better cope with cancer.

## CONCLUSION

The discourse reveals that the meaning of the diagnosis of breast cancer is strongly linked to the diagnosis phase and to the difficulties caused by the health system for early diagnosis, as well as to the limits of professionals to attentive and effective listening. Other highlights are related to the feelings generated by the diagnosis, such as fear and anxieties, especially in the phase of diagnosis and remission of the disease, as fear of recurrence is present. In addition, it is linked to changes in living after diagnosis and in cancer survival. In addition, the experiences of women, which generate countless experiences, allowed the construction of a discourse full of advice for other women which permeates spirituality, information, self-care, positive thinking, distancing from people who generate suffering and the recommendation to talk about their own feelings and the disease.

Comparing the findings of this study with others that reveal the meaning of breast cancer, it can be identified that the meaning linked to suffering, fears, attachments to spirituality, changes in living, easy and difficult confrontations remain the same. It is inferred that the contribution in the construction of knowledge of this study to the context of the meaning of breast cancer is linked to reaffirming the previous meanings, but it is added that advances in disease control have not yet been able to reduce fears and difficulties in coping with the survival of the disease. The late diagnoses of many women and the deficit of the system to ensure early detection are contributing factors to the maintenance of this condition and, that the information configures a strong strategy adopted by women in the current time for their confrontations.

In this context, it is up to nursing to appropriate the meaning of the disease for better nursing planning. Nursing consultation is recommended based on the systematization

of nursing care both in the diagnostic phase and throughout the treatment and remission of the disease, including educational/informative materials, support groups and actions of the multidisciplinary team.

It is considered that this article has the potential to try to capture the feelings involved during the process of breast cancer discovery and its fluctuations during treatment, since women have had the diagnosis for some time. As a weakness: participants are contained in a specific niche.

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