RESEARCH ARTICLE

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Mastectomy and the Meaning Attributed by Patients to Delay in Early Diagnosis of Breast Cancer

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Abstract

Background: Breast cancer is a major public health problem and its early detection (ED) can reduce the number of breast mutilations, morbidity and mortality rates, health costs and negative health outcomes. Given that, this study aimed to assess the meaning attributed by mastectomized women to delay in early detection of their breast cancers. Methods: Qualitative research was conducted with 26 mastectomized women who participated in semi-structured interviews about the meaning of delay in early detection of breast cancer in a reference oncology outpatient clinic in the city of Fortaleza, Ceará, Northeastern Brazil from December 2015 to January 2016. Information was analyzed on the basis of symbolic interactionism. **Results:** After noticing breast changes, women start to ponder about them and experience this moment according to interpretive particularities. Fear of disease, multiple roles in modern society, denial of breast changes, lack of information on the issue, and lack of professionals to encourage their involvement in health care, favor delay in the search for care and therefore in the early detection of breast cancer, which is a determinant of therapeutic success. Conclusion: Women receive limited information and professional support for breast health. Delay in early diagnosis occurred in all the women who participated in the study.

Keywords: Breast cancer- early diagnosis- patient adherence- women's comprehensive health care

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Introduction

Breast cancer (BC) is the most common malignant neoplasm in women worldwide and has become a major public health problem as the challenges of eliminating women's exposure to risk factors and treating precursor lesions have been included in the global health agenda (Moura et al., 2013; Peiris et al., 2017). In this context, knowing the meanings attributed to the early detection (ED) of breast cancer and its determinants implies both political and social relevance for reducing the number of breast mutilations, morbidity and mortality rates, costs, and negative outcomes.

There are well-established risk factors for BC: family history, age of first period, late-onset menopause, pregnancy over the age of 30, nulliparity, no breastfeeding, use of contraceptives, hormone replacement therapies, among others (Peiris et al., 2017).

Breast cancer incidence rates vary worldwide. In 2012, the highest rates were found in Western Europe (96/100,000) and the lowest rates were reported in Central Africa and East Asia (27/100,000) (American Cancer Society, 2014). Breast cancer survival rates also vary across the world, ranging from 80% in North America and in developed countries, to 60% in middle-income countries, and to less than 40% in developing countries. In the United States of America, 231,840 new cases of breast cancer and 40,730 deaths were expected in 2015 (Naz et al., 2016).

In Brazil, strategies for coping with breast cancer are among the public policy priorities for 2017, as the country estimates that there will be 57,960 new cases of the disease, i.e., 56.2 cases per 100,000 women in that year. Breast cancer is the most common cancer in women in the South (74.30/100,000), Southeast (68.8/100,000), Midwest (55.87/100,000) and Northeast (38.74/100,000) regions of the country when non-melanoma skin cancer is not considered. In the North region, it is the second most common type of cancer (22.26/100,000) (INCA, 2015).

In the State of Ceará, located in Northeastern Brazil, the National Cancer Institute (Instituto Nacional do Câncer – INCA) estimated 2,160 new cases of breast cancer in 2016, with a crude rate of 46.30 cases per 100,000 women, which is also valid for the year 2017. These data make the city of Fortaleza a place of great concern that requires the development of actions focused on ED and rehabilitation of this type of cancer (INCA, 2015).

Breast cancer may have a good prognosis if diagnosed early and treated properly; however, its mortality rates

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remain high in Brazil – most likely because the disease continues to be diagnosed in advanced stages.

Cancer staging and severity, particularly in breast cancer, is also affected by the problem-solving capacity of primary health care services. This is because problem-solving care allows diagnosing the disease at an early stage (Sharma et al., 2012). The strategy of seeking an early diagnosis contributes to reducing negative outcomes, which points to the importance of sensitizing women and health professionals to this issue (Thuler, 2012).

In women's lives, factors such as discipline, the will to be healthy, emotional balance, and trust in the professional, in the technique chosen for treatment and in the health services can influence the search for care in a timely manner. On the other hand, the discovery of breast cancer has a devastating effect on women, who may delay or even not adhere to the treatment, which may lead to mastectomy or even death.

Thus, knowing the meanings attributed by mastectomized women to the diagnosis and experience of breast cancer can open up new ways of supporting them and encouraging the early detection of the disease.

Given that, the present study aimed to discovering the meanings, attributed by mastectomized women, to the delay in the early detection of breast cancer.

Materials and Methods

This is a qualitative study that used the Symbolic Interactionism framework to access mastectomized women's subjective interpretations (Minayo, 2010) of situations of delay in diagnosis and in decision making regarding the treatment of breast cancer.

Participants were 26 women diagnosed with breast cancer, with no proven metastasis, who had undergone unilateral or bilateral mastectomy six months prior to the study. The participants were selected from a reference oncology outpatient clinic located in the city of Fortaleza, Ceará, Northeastern Brazil. The city is divided into six administrative regions and all the women lived in Region III. To preserve their identities, the participants' statements are identified by the letter 'W' followed by numbers 1 through 26 according to the order in which they were interviewed.

The city of Fortaleza has 21 Oncology services, but only seven are provided by Brazil's National Health Care System, also known as the Unified Health System (Sistema Único de Saúde – SUS) – five hospitals and two outpatient clinics. The outpatient clinic where the present research took place performs an average of 1400 consultations per month and at least 200 surgeries in women, 60% of which are mastectomies (Instituto do Cancer do Ceará, 2016).

Data were collected from December 2015 to January 2016 through participant observation and semi-structured interviews with an average length of 40 minutes. The set of questions addressed the meaning attributed by women to the detection and diagnosis of breast cancer. The themes and analyses emerged concomitantly while data were being collected. Four key categories emerged: "Fear as a protective dimension"; 'Neglect of self-care'; 'Denial and redefinition of life'; and 'Lack of access to information

and delay in care: reinterpreting the meanings'.

The information was analyzed on the basis of symbolic interactionism with a focus on the way women see and define themselves. These aspects are closely related to the social definitions with which they are confronted in life, whether through social interaction or through the interpretation of the subjective and objective reality they experience. This premise was used with the participants of the present study because it enabled them to interpret and express the meaning of breast cancer in their lives based on the redefinition of experiences. The "meaning" is herein understood to be a socially and culturally constituted production (Blumer, 1969).

Data collection was finished after data saturation was achieved, that is, the point at which the diversity of ideas collected through the interviews or observations no longer presented new information (Minayo, 2010).

The present research is in compliance with Resolution No. 466/12 of the National Health Council (Conselho Nacional de Saúde – CNS), which provides for the ethical precepts of research involving human beings (Brasil, 2012). The study was approved by the Research Ethics Committee of the University of Fortaleza (UNIFOR) under Approval No. 618.818.

Results

The central theme of this study deals with the meanings attributed by mastectomized women to the delay in the early detection of breast cancer. Fear of the disease, the multiple roles taken by women in modern society, denial of breast changes, lack of information about the issue and lack of professionals to encourage women's involvement in health care were the factors pointed out by the participants as reasons for delaying care. These factors were probably determinants of disease evolution.

Time is a relevant factor in breast cancer management. Cancer staging is a significant prognostic indicator (Trufelli et al., 2008). Staging is the process of determining the location of the tumor and its classification according to size, extent of involvement and presence of metastases. Depending on the classification, the clinical treatment may not be efficient and therefore radical mastectomy is required. The stage of disease at diagnosis also influences patient survival (Torres, 2008).

Several intrinsic and extrinsic factors affecting the patient can determine mutilations and deaths related to breast cancer staging. Thus, among the many determinants of breast cancer outcomes, women's non-adherence to early detection and treatment of breast cancer deserves special attention from health care providers and professionals. In this sense, scarcity of materials, geographical and cultural barriers, difficulties in accessing specialized services, logistical problems affecting the treatment plan, and poor or no professional-patient relationship, among other factors, are conditions that may lead the woman to delay the discovery of this neoplasm and the initiation of its treatment (Trufelli et al., 2008).

Fear as a protective dimension

Emotions or feelings about the possibility of "having"

the disease are associated with fear of death and may influence non-adherence to therapy. At the time of cancer diagnosis, a protective dimension rises against the awareness of the finite condition of life in its material dimension. This disease is still referred to as a "bad" or "fatal" disease nowadays (Tejeda et al., 2013).

The diagnosis of cancer is still seen as a major threat to life. Such stigma generates different emotional responses, and the adoption of a different medical nomenclature does not change expectations regarding its fatality (Angerami-Camon, 2013). The ways culture has built up this representation of the disease over time, coupled with past experiences of suffering, emerge as barriers to women's adherence to treatment, i.e., in addition to the individual experience, a family history of the disease can also influence the way women feel about a cancer diagnosis:

Because my mother had it (breast cancer)... Poor woman! She did not want to hear it was cancer [...]. The worst thing about it was that she had it in one breast first and then in the other. She suffered a lot! What if I got it too? It is scary! (W7)

I know someone who had cancer, but it was not breast cancer. She underwent treatment. She kept vomiting; she lost her hair [...]. I am afraid of going through this, and I know that although it is a different type of cancer, it is cancer. It can also happen to us. (W7)

Given that patient adherence is a behavioral phenomenon, non-adherence – as an impediment to the achievement of goals related to diagnosis and interventions – can be a source of treatment frustration (Trufelli et al., 2008). In this context, other people's negative experiences may influence the "fear factor" and hence lead to the delay in the diagnosis and adherence to treatment:

[...] I am afraid of getting that examination that presses the breast and hurts. I am afraid of going through surgery, I am afraid of removing my breast, I am afraid of dying [...] I am afraid of not having the chance to raise my children. (W18)

Being diagnosed with such a stigmatized disease generates many doubts and becomes life-threatening. Faced with that, women try to avoid exposure to the fragility resulting from fear by developing an unconscious mechanism of passive resistance, which may lead to flight or self-sabotage behaviors:

I used to undergo regular exams, but I was afraid to go get the results. If I could not go there on the appointed day, I would not go any later. But it was all about the fear of knowing the result. The will to go there got stuck in my head, but I kept making up some cleaning I had to do and which I could not miss. It was an excuse! In fact, I was just running away. Everyone is afraid to know, right? I think that is the way it is. (W9)

A review study on the feelings and behaviors of women diagnosed with breast cancer conducted by Regis and Simões (2005) found that fear followed by denial are common among these women, particularly because of the ideas of danger, threat and suffering associated with the disease. The authors report that these feelings are associated with the stigma that the cancer carries, which

leads to disbelief in the possibilities of treatment and cure.

Overcoming fear is a skill that can be developed since childhood through health education actions in schools and through health promotion actions in health care services and in the community.

Discussion

Denial and redefinition of life

Saying the name of the disease is avoided by some people so that "such evil" is not attracted. This can be observed in the following statement:

"[...] we do not want to find the thing, we do not want to touch our breast and find that evil. Search and you will find. I never even talk about it." (W2)

The self-perception of a breast change is possibly the first time a woman becomes aware that the body can suffer and that life is threatened. In this sense, denying the disease is another mechanism that influnces the adherence to discovery and treatment. Many women get scared when they notice any anatomical and/or physiological changes to the breast and therefore delay their visit to the health service.

For people with cancer, the period of shock and denial is often prolonged due to uncertainties regarding the treatment of the disease. Authors, such as Kubler-Ross (2008) and Simonetti (2004), who have written about terminal illnesses and the awareness of human finitude, reveal that the diagnosis of stigmatized diseases like cancer is always accompanied by feelings of denial. Such perception of the disease leads the person to deny his or her symptoms and diagnosis as a way to cope with it.

I do not have cancer! My problem is not cancer; it was just a lump full of mass. But then it kept growing, growing [...]. It was not 'the thing', it was just a small lump that grew, but it was benign. After a dark discharge appeared, the doctor suspected and requested its removal. I had to have my entire breast removed, but I knew it was not cancer. (W2)

The aforementioned statements demonstrate a redefinition of the risks posed by the disease, which leads to its denial. According to Barros et al., (2012), denial consists in stating that something does not exist or is not true. Denial of disease is herein understood as a subjective factor that can influence the waiting time for diagnosis and treatment. Blumer (1969) mentions that the human individual has to cope with the situations in which he is called on to act, ascertaining the meaning of the actions of others and mapping out his own line of action in the light of such interpretation; therefore, he has to construct his own action.

As regards such phenomenon, it seems that at the first moment of the diagnosis the woman avoids the assumption that she is ill and begins to "draw" herself from the real world into the ideal world – denial of cancer. When the signs and symptoms of the disease are experienced, the woman moves on to a second phase in which she refuses to accept all or most of the implications of what is being communicated to her. Finally, the period of denial of disease gives way to acceptance and the woman acquires a new internal model of the world (Santos and Chubaci, 2011).

When studying the dimensions of psychological involvement, Simonetti (2004) clarifies that the phase of denial is transient and necessary to protect cognition. It serves the purpose of preserving the self, i.e., it reduces the deleterious effects of the relationship that the person (in that case, the woman who is ill) establishes with her body and her mind. It turns out that the woman gets to formulate her own concepts based on her experiences, which allow her to share, interact and act towards a new condition in which she has to cope with breast cancer.

Denial of disease can be seen in many ways: an initial retreat that will allow the patient to recover and think better about a line of action; a way of minimizing the severity of the disease; belief in the possibility of diagnostic errors, among others.

Simonetti (2004) explains that there is something magical embedded in the mechanism of denial. For that author, denial occurs not because of lack of information, but because of lack of psychological conditions, which should not be understood as a defect, but as a characteristic at that particular moment (Simonetti, 2004).

Denial represents a natural feeling of rejection of the idea of being ill, and the time it takes to accept the unwanted condition will depend on the subjectivity of each person. Support provided by the family and healthcare professionals may help the woman regain self-esteem and prevent her from delaying treatment decisions.

Neglegt of self-care

In modern culture, women are still valued for their maternal role and are hence viewed as responsible for "taking care of everything and everyone". In modern society, women delay the search for care and need to resist their body's needs, especially when they push aside their most required roles: mother, wife, homemaker, and often family provider or co-provider. In this context, in addition to household chores and home management, they also pursue work outside the home, which makes it even more difficult for them to make time for themselves:

[...] The doctor requested some exams that I only got to do later on because I was doing some work at the company [...], because I work! Then I got to do them later on. (W10)

Gouvea et al., (2014) consider the act of delaying a common feature of human nature. In addition, the authors state that there are many things in daily life that encourage such a behavior:

I had even noticed some sort of 'gland' in my breast. But my mother was a little sick and I had to take care of her. Then I left it until later. Time went by and I did not even notice. Fear, right? I do not know! I left until later and later, until I could no longer hide it [...]. When I went there, it was too late. (W6)

Thus, in addition to cultural influence, the elements involved in that behavior – which each woman manifests in a single way – may sometimes be affected by motivational factors, i.e., that behavior may involve factors over which the woman has no control:

The doctor told me I should have sought medical care earlier. He does not know what life is like for us. I had to schedule an appointment and it is not easy to do so in the health center [...]. There is also the difficulty to get here. I had to come here many times on foot, at dawn, in the rain, under the hot sun [...]. (W13)

Thus, it is thought that women may be putting health care aside while giving priority to domestic activities, family, children, and work.

In fact, the social roles of being a "mother", a "successful woman" and a "good housewife" are used by women as subterfuges. Resisting receiving the diagnosis of a disease and having to care for oneself emerge as worrying cultural traits.

In an empirical analysis, as the doctor makes the diagnosis technically on the basis of the clinic, the woman's imagination suddenly leads her to think about her role as a mother and the missions she needs to fulfill:

I did not expect that. I was not ready to face it [the cancer]. You have a lot of dreams; you plan a lot of things. You do not think of such a thing, you do not imagine it can be cancer. Then you receive the news and that is it, life seems to end there! It is distressing. You cannot get to sleep! [Tears and prolonged silence]. (W12)

People are not generally ready for the diagnosis of cancer. Therefore, the medical discourse should not focus on the disease itself; rather, it should focus on the person, his/her roles in society and his/her support network (Usta and Farver, 2005).

In this context, the encounter for the receipt of the diagnosis is of the utmost importance as it can determine the way the patient will cope with the problem, i.e., such encounter may or may not favor the immediate search for care. Therefore, health professionals should be prepared to tell the 'news', which should be free from stigma and based on scientific knowledge. In addition, professionals should transmit confidence and provide support in a humanized way when informing about the treatment.

Lack of access to information and delay in care: reinterpreting the meanings

A study by Hamasaki and Kerbauy (2001), whose objective was to check whether people delay medical examinations or general health care and the reasons for doing so, found that some of the factors associated with such behavior are: economic factors, lack of information on disease prevention and detection, forgetfulness, and other priorities. These factors are responsible for the delay in the diagnosis and hence the initiation of the treatment, which can affect the breast cancer staging process.

With regard to this issue, Kubler-Ross (2008) mentions that the woman takes the time necessary to think about the meanings of the disease in her life. In the meantime, she keeps selecting the steps to follow and going over possible actions for seeking professional help. There is also a chance she will not seek medical care for thinking she might be walking into a place where the control of the situation is no longer possible.

People construct images of objects according to the stimuli experienced and the meaningful symbols related to these objects. Depending on the woman's expectations about the best way to live her daily life, she will create mechanisms of resistance and protection based on what she interprets as a threat (Carvalho, 2010). In the case of breast cancer, the way women have established the symbols and the meanings through their interaction with other women, health professionals and society in general may lead them to remain "silent". This might prevent them from seeking the diagnosis so as not to discover they are 'ill'.

An analysis of Brazilian women's access to breast health care services conducted by Gonçalves (2013) points out that the most delayed procedure is the first consultation, particularly due to lack of cohesive practices and language. The author reports that such inefficiency is mainly caused by lack of information, especially about service resources and routines. Lack of information is, therefore, another determinant of non-adherence to early detection of breast cancer.

It is very important for us to be informed about breast problems, which does not often happen when we go to the clinic. Because no one knows much about this disease [breast cancer]. I got to know that I had this disease only when the doctor told me to have the surgery. But it did not hurt at all! I guess that I used to think it was nothing because I did not feel anything. Then, guess what? I did not attend the consultations nor underwent the examinations. So, we have many doubts, we have many questions. Maybe there should be someone to explain us, talk to us, so that we could understand it better. Because we do not know about it, we do not understand what they say. In my case, they kept telling me but I thought my problem was not cancer [...], and sometimes, I still think it is not. (W1)

The woman "who does not know" is not the uninformed woman. Actually, she is the woman excluded from the more technical debates about breast health. She is the one whose knowledge is disregarded. For those reasons, she remains voiceless and outside culturally congruent practices from the medical and scientific points of view.

Maybe the health services should provide more information, right? They should awaken in us the concern to make an appointment and tell us where the examination is performed. But we do not know anything about it. We keep being pushed back and forth and nobody says anything. (W8)

Valente and Carvalho (2011) carried out a study with 385 women to analyze their level of knowledge about breast cancer prevention and found that most of them did not know the predisposing factors and attached great importance to the detection or diagnostic practices related to the disease.

Al Otaibi et al., (2017) emphasize the importance of raising women's awareness of breast cancer and early diagnosis and call for continuous awareness campaigns that must be carried out by schools, universities and health services so as to reach the largest number of women. Likewise, Kirubakaran et al., (2017) reinforce the need for more awareness programs to educate women about BC and to promote its early detection.

Sennet (2003) highlights the need to reduce the "tensions" between an individual's external control and autonomy in self-care, i.e., the care should be guaranteed through the promotion of people's knowledge and control over their health-disease process. Ithink the other doctor, in the other health center, should have discovered it some time ago. He is irresponsible because he examines people as if they were nothing. He would not listen to me. He requested exams, but he just looked at the exams and said nothing. He did not even look me in the face. It was his duty to examine me and tell me. Then, when I realized that he was not going to examine me, I decided to tell him what I had, what I felt. But they do not pay attention to us, to what we are saying. (W2)

The reports indicate the need to overcome the exclusive attention given to the disease in order to recognize people's ability to act towards improving their general quality of life and health. It is also important to recognize that with greater participation and autonomy people can prevent or control the onset of the disease.

Changing a person or a group of people in the perspective of autonomy in health care means to provide them with the power to identify their aspirations, satisfy their needs and favorably modify the environment to face illness. In this context, the breasts are no longer speculative organs in terms of cancer diagnosis; rather, they justify preventive practices that take place through the partnership between health professionals and the people of the community.

Blumer (1969) argues that human groups exist in action and must be seen in a continuum of interaction in which some can and should be modified by the context and needs of others. Therefore, the interactions between health professionals and patients have a strong potential for change.

Thus, in the organizational culture that is established, women are far from enjoying the right to pursue this type of partnership and the (co) production of knowledge in their relationship with health professionals.

In conclusion, this study reveals that the meanings attributed by mastectomized women to non-adherence to early detection of breast cancer are associated with lack of information, fear of disease, health professionals who do not encourage women to co-participate in the health care process, denial of disease, and the busy life of women today. All these factors, according to the participants, led to the delay in the search for care.

The results of the present research demonstrate the need to overcome the exclusive attention given to the disease in order to raise health professionals' will to address the person's or community's ability to act towards the improvement of their quality of life and health and also to encourage their greater participation, autonomy and control over these processes. The ways in which services are organized and health professionals behave create a culture that disregards women's capacity to make decisions and act proactively in favor of their health.

The lack of information on breast cancer reported by women point to the need for the provision of resources by public health policies to improve their knowledge about the most relevant dimensions of the breast cancer phenomenon, including early detection and management of cases to avoid disease progression. The provision of information to women can also minimize the fear that dominates them in the discovery of cancer, which may shorten the length of the period of shock and denial of

disease after the diagnosis and avoid stigmatizing beliefs about the prognosis and treatment.

The findings of the present study suggest further studies to address health education actions and the impact of delay in the search for care on disease staging in order to provide women with a more personalized care in which their particular culture and life relations are taken into account.

Finally, the non-inclusion of health care professionals providing care to these mastectomized women in the present study should be highlighted as a research limitation.

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