MULHER E A DESCOBERTA DO CÂNCER DE MAMA: TRILHANDO CAMINHOS NO SISTEMA ÚNICO DE SAÚDE

WOMEN AND BREAST CANCER DISCOVERY: PATHING WAYS IN THE UNIFIED HEALTH SYSTEM

LA MUJER Y EL DESCUBRIMIENTO DEL CÁNCER DE MAMA: VIAJANDO POR CAMINOS EN EL SISTEMA ÚNICO DE SALUD

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RESUMO
Objetivo: compreender como mulheres detectaram o câncer de mama, desvelando o tempo entre o diagnóstico e início do tratamento. **Método:** estudo do tipo exploratório, descritivo, com abordagem qualitativa, com dez mulheres mastectomizadas. A coleta de dados realizou-se por meio de entrevistas com roteiro, contendo questões semiestruturadas. Para análise dos dados utilizou-se a análise de conteúdo. **Resultados:** sete participantes detectaram alterações na mama por meio do autoexame, levando-as a investigação diagnóstica. Quatro entrevistadas iniciaram o tratamento em até 60 dias e as outras seis extrapolaram o tempo preconizado, portanto, o tempo entre diagnóstico e início do tratamento variou de dois a oito meses. **Conclusão:** salienta-se a necessidade de maiores investimentos no setor saúde, fortalecendo ações para rastreamento, detecção precoce do câncer de mama e início do tratamento no prazo de 60 dias, contribuindo para reduzir a mortalidade e os riscos de morbidade ocasionados pelos tratamentos, interferindo também no emocional das mulheres.
Descritores: Neoplasias da mama; Assistência integral à saúde; Autoexame de mama; Detecção precoce de câncer; Sistema Único de Saúde.

ABSTRACT
Objective: To understand how women detected breast cancer, unveiling the time between diagnosis and treatment initiation. **Method:** an exploratory, descriptive study with a qualitative approach, with ten mastectomized women. Data collection was performed through interviews with script, containing semi-structured questions. For data analysis we used content analysis. **Results:** seven participants detected breast changes through self-examination, leading them to diagnostic investigation. Four respondents started treatment within 60 days and the other six extrapolated the recommended time, so the time between diagnosis and initiation of treatment ranged from two to eight months. **Conclusion:** stresses the need for greater investments in the health sector, strengthening actions for screening, early detection of breast cancer and initiation of treatment within 60 days, contributing to reduce mortality and morbidity risks caused by treatments, interfering also in the emotional of women.
Descriptors: Breast neoplasms; Comprehensive health care; Breast self-examination; Early detection of cancer; Unified Health System.

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RESUMEN

Objetivo: comprender cómo las mujeres detectaron el cáncer de mama, revelando el tiempo entre el diagnóstico y el inicio del tratamiento. **Método:** estudio exploratorio descriptivo con enfoque cualitativo, con diez mujeres mastectomizadas. La recolección de datos se realizó a través de entrevistas con guiones, que contienen preguntas semiestructuradas. Para el análisis de datos se utilizó el análisis de contenido. **Resultados:** siete participantes detectaron cambios en los senos a través del autoexamen, lo que los llevó a una investigación diagnóstica. Cuatro encuestadas comenzaron el tratamiento dentro de los 60 días y los otros seis extrapolaron el tiempo recomendado, por lo que el tiempo entre el diagnóstico y el inicio del tratamiento varió de dos a ocho meses. **Conclusión:** se destaca la necesidad de mayores inversiones en el sector de la salud, fortaleciendo las acciones de detección, detección temprana del cáncer de mama e inicio del tratamiento dentro de los 60 días, lo que contribuye a reducir los riesgos de mortalidad y morbilidad causados por los tratamientos, interfiriendo también en lo emocional de las mujeres.
Descriptores: Neoplasias de la mama; Atención integral de salud; Autoexamen de mamas; Detección precoz del cáncer; Sistema Único de Salud.

INTRODUCTION

Breast cancer is the disease that most affects women in Brazil and worldwide, its mortality rates have increased considerably in recent decades, representing the leading cause of cancer death in the female population.[1-2] Over the past twenty years, only developed countries have shown reduced mortality from breast cancer, as they are usually diagnosed at localized stages.[3] Scholars "attribute cancer control programs, especially early detection and treatment, as the main determinants of this reduction.".[3:5] In underdeveloped countries, breast cancer is usually diagnosed at an advanced stage, reducing prognosis, increasing treatment-related morbidity and compromising patients' quality of life.[3]

In this sense, strategies have been implemented in Brazil to reduce cancer incidence, mortality and morbidity through programs that address primary prevention, in order to reduce or eliminate risk factors,

early detection, treatment, rehabilitation and palliative care. Among the early detection strategies for breast cancer are screening actions, which relate to identification in asymptomatic and early diagnosed people, i.e. identification of suspicious signs and symptoms in primary care (PC) for risk classification and referral for diagnostic investigation in other care levels.[3]

The Ministry of Health (MH) established Ordinance No. 876/2013, which provides for the first care to symptomatic users of malignant neoplasia, diagnosis and initiation of treatment within 60 days. Recommends that the care flow begins in the PC, where suspicious cases will be identified, referred to the secondary level for examination and diagnosis, and for treatment in the tertiary level referral cancer units.[4]

However, research conducted with women diagnosed with breast cancer shows

that the time interval from symptom to treatment is longer than recommended by the MH, especially the waiting time for specialized medical consultation at the secondary level of health care, suggesting weakness in the implementation of the care line and difficulties in articulating the different levels of the Health Care Network. They also state that time and quality of health care are factors that influence the morbidity and mortality rates of the disease, demonstrating the effectiveness of health centers and the resoluteness of public policies.[5-6]

In this context, the question arose: How did women detect breast cancer and how long did it take between diagnosis and initiation of treatment?

This study is justified by the opportunity to know the health care for women who experienced breast cancer, in the perception of the users of the Unified Health System (UHS), allowing to reflect and analyze the planning of the care network and health services for faster care, flow and quality of care, to facilitate diagnosis and initiation of treatment within 60 days, as established by the MH.

Thus, the aim of this study is to understand how women detected breast cancer, unveiling the time between diagnosis and treatment initiation.

METHOD

This study is an excerpt from an exploratory, descriptive and qualitative approach, from a broad research project of the Nursing course at the Federal University of Fronteira Sul (UFFS).

The research was conducted in the city of Chapecó - Santa Catarina (SC), in which ten mastectomized women participated, according to data saturation, selected according to the inclusion and exclusion criteria. Only women who underwent mastectomy between 2012 and 2018 were included to facilitate contact and identification. As exclusion criteria, we opted for mastectomized women who were not UHS users. To identify and contact these women, they had the help of the Community Health Agents (CHA) of the municipality.

Data was collected in the first semester of 2018 through pre-scheduled interviews at the participants' homes to establish an appropriate and quiet time. Therefore, a script containing semi-structured questions about how they detected breast cancer, the time between the onset of the first symptoms until the mastectomy was performed. Before starting the interviews, the Free and Informed Consent Term (FICT) was made available to the participants. The interviews were recorded and later transcribed.

To maintain the anonymity of the participants, we chose to use children's story heroine codenames, considering that to overcome breast cancer and all the difficulties encountered during the stages of the disease, these women fought bravely, becoming the heroines of their own life stories.

Content analysis was the method of choice for organizing and analyzing data.[7] Thus, the first moment consisted of pre-analysis, when fluctuating reading of the data extracted in the interviews was performed, building a table with the collected data, choosing thus the documents for the constitution of the data taken into account to be submitted to the analytical procedures. Afterwards, the analysis material was explored in three stages: the organization of the units, the definition of the counting rules and the definition of the categories. Thus, two categories emerged: Women and the discovery of breast cancer; Time does not stop: the challenges of achieving rights in UHS, which will be presented and discussed below.

This study was approved and approved by the Research Ethics Committee of the Federal University of Fronteira Sul (UFFS), under the opinion number 2.634.165, and Certificate of Presentation for Ethical Appreciation (CAAE) number 86982318.5.0000.5564, following the Resolution of the National Health Council No. 466/12, which regulates research involving human beings.

RESULTS AND DISCUSSION
The woman and the discovery of breast cancer

The control of breast cancer is performed in Brazil through attention strategies aimed at early detection, among which stand out the actions of early diagnosis and screening.[3] According to the MH "early detection is a form of secondary prevention and aims to identify cancer in early stages, when the disease may have better prognosis".[3:19]

The female population in each country has a certain standard risk of developing breast cancer. Therefore, mammography is a disease screening action for this population. This test is recommended by the MH every two years for all women aged 50 to 69 with no suspicious symptoms or family history of breast cancer.[3]

Among the participants in this study, seven had regular mammograms. Of these women, two under 50 years of age underwent periodic evaluations, one due to family history of breast cancer and the other due to breast lump. Three participants reported not having mammograms under the age of 50.

Although the mammogram was up-to-date, only two participants detected the

disease through this procedure and one found with ultrasound:

> *I went for a mammogram, [...] found out that I had a lump in my right breast.* (Batgirl)
> *I had the mammogram [...] and I had to urgently order an ultrasound, which had been a problem.* (Wonder woman)
> *A breast ultrasound appeared that had, that was this cancer.* (Phoenix)

Still, two women reported mammography performed in a shorter time than recommended:

> *In October 2013 I had a mammogram and I was calm, I had another mammogram in early May 2014.* (Wonder woman)
> *Two months earlier I had had a mammogram and nothing came up.* (Supergirl)

Mammography has been used as a means of early detection since the mid-twentieth century. It is an essential intervention to reduce breast cancer mortality by identifying asymptomatic and impalpable tumors. However, the effectiveness of screening depends on the quality of the image obtained, adequate equipment, knowledge, practice and dedication of the professionals involved, ease of access, diagnostic confirmation and treatment of confirmed breast cancer cases.[3]

In the analysis of data obtained from the Department of Informatics of the Unified Health System / Breast Cancer Information System, between 2009 and 2012, researchers highlighted the progressive and continuous increase of imaging diagnosis in Brazil and the state of SC. However, the form of detection by palpation still has higher incidence rates than imaging detection. The number of cases of malignant neoplastic lesion identified by imaging was 8,715, while 14,780 with clinical breast examination. In SC 287 cases of breast cancer were discovered by imaging and 332 by breast palpation.[8]

Breast self-examination (BSE) is a technique for periodically observing and palpating the breasts and accessory anatomical structures. Due to its low effectiveness in reducing breast cancer mortality, the MH does not recommend teaching BSE as a screening method. However, the presence of fixed and hard nodules, detected by palpation, are the main signs of disease presentation.[3,5,9]

In this research, seven interviewees discovered breast changes through BSE, following some statements that express how they identified the changes:

> *I found out this way, I felt and felt a lump.* (She Hulk)
> *I found out on my self exam, I felt a little lump.* (Raven)
> *I was taking a shower, when I felt I had a ball, but it didn't hurt.* (Starfire)
> *I always do that touch on my breasts and I found that sweetie on my breast.* (Storm)

Two studies[5,9] point out, respectively, that 100% and 68% of the women investigated detected breast changes through BSE, leading them to diagnostic

investigation. This reality may indicate the unpreparedness of the health system in making early diagnosis and difficulties in adopting efficient conducts that enable better prognosis, since the detection of the disease, through the evaluation of the women themselves, can be an aggravating factor to the advanced stages of the disease.[5]

Factors that may hinder access to early diagnosis are the lack of knowledge about the disease and the low resolution of procedures performed by certain health services, especially regarding the competencies of PC. The Basic Health Units (BHU) constitute the main contact of the user with the health system. Thus, they need to be organized to hold educational meetings on breast cancer, mobilizing and raising awareness of the importance of self-care and self-awareness. In addition to needing professionals prepared to perform the Breast Clinical Examination (BCE), detect suspicious changes, request mammographic examinations for women at risk, receive results and refer those whose result requires further investigation.[10]

In this sense, it is emphasized the need to improve early diagnosis strategies, enabling professionals to perform BCE, facilitate and ensure access to mammography, increasing the numbers of imaging detection, in order to allow diagnostic investigation in timely, optimizing treatment chances, healing

potentials, decreased risk of relapse and breast cancer mortality.[8,11]

Time does not stop: the challenges of achieving rights in the UHS

Cancer is an invasive disease and therefore needs priority care to increase the chances of cure and control. If diagnosed and treated early, breast cancer has a relatively good prognosis, in Brazil the survival rate is 80%.[12-13-14]

According to the MH, suspicion of breast cancer by early detection or physical examination methods should be referred for diagnostic evaluation.[14] The women in this study followed this approach, seeking assistance at the BHU, in order to be examined and referred to other levels of attention for diagnostic confirmation and treatment initiation.

The main forms of treatment are: chemotherapy (chemo), radiotherapy (radio) and surgery, which can be used together. Effective initiation of the first treatment by the user with confirmed malignancy is considered when initiating one of the three forms. The first treatment should be instituted within 60 days from the diagnosis recorded in the user's medical record.[4,13]

The time between diagnosis and start of treatment of women in this study ranged from two to eight months. Most women started treatment with surgical therapy, only She Hulk and Phoenix first had

chemotherapy. In this study, only four women started treatment at the time recommended by the MH. Following are statements from some participants who would start treatment within 60 days:

In July [2014] I discovered a lump in the right breast. In September I had surgery to remove the nodule and in November I started radiotherapies. In December I finished the radiotherapies and beginning of February I started oral chemotherapy. (Batgirl)

In the Women's Network I showed the girl, that I had a lump, she referred me to the doctor of the clinic. It took about 30 days to find out it was cancer, about a fortnight more, for me to operate [...] I think a couple of months later I started chemotherapy. In the midst of chemotherapy I did the radiotherapies. (Scarlett Witch)

It started at the end of the year [2013], I went to do breast ultrasound appeared it was cancer, I did the biopsy and it really was. On February 19th the chemo began, after 8 chemo I had the surgery there by July and then the radios started. (Phoenix)

In contrast, six users extrapolated the time to start treatment in this study. In the following reports, two participants revealed the time between diagnosis and initiation of the therapeutic process:

In July 2011 I discovered the lump in the breast, I had an ultrasound and it appeared that there were three lumps, in August I had a biopsy, I had all the exams and in January 2012 I had the surgery, I had a year of chemotherapy, then I had 28 radio sessions. (Supergirl)

I went to the post and got the request to do the mammogram. [...] I got it and brought it to the post to show the nurse [march 2016]. [...]I consulted with the doctor, she referred me to the woman's clinic [secondary level of care]. I consulted with a doctor and she referred exams. It took time, within those eight months, just exams, to get everything ready and take to the doctor, who operated on me in November 2016. (Storm)

Experiencing confirmation of the cancer diagnosis becomes an experience of

uncertainty, as the delay in access and establishment of therapy causes a mixture of feelings that added to the stigma of cancer, generate fear and despair.[15-16] This statement can be evidenced below:

As a child we always heard that cancer would be synonymous with death and that is very scary when you receive the news, when you have to do the treatment one day seems like a year. (Batgirl)

Comes that anxiety, I need it, I know that if I don't do it tomorrow I can die [the surgery]. (Gamora)

Only we discover the disease we despair, the wait is suffered. (She Hulk)

The anguish of waiting for treatment led to six interviewees resorting to the private health sector for examinations and consultations and two also performed mastectomy in the private sector. When asked about the reason for seeking this sector, the answers were about the waiting time in UHS:

Because I knew it would be time consuming I paid the ultrasound, I paid an appointment. For surgery I paid the exams. (She Hulk)

I paid the biopsy because I wanted to anticipate the procedure. (Batgirl)

To expedite it was made private [the biopsy]. (Phoenix)

Likewise, the two participants who paid for the surgical procedure opted for this modality to reduce the waiting time, as can be seen in the segments below:

In April 2016 the gynecologist ordered an ultrasound, I went to do the ultrasound in June. By August I had a biopsy diagnosis. In September I consulted with the oncologist and he gave me the right diagnosis. In September and October I ran after others [doctors], *how he wanted to do chemo first, start chemo in February, 4 months later, and*

then have surgery. I did the surgery in 3 months because I did it privately. (Raven)

I had a mammogram at the beginning of May, May 30, 2014. We removed the mammogram, which requested an urgent ultrasound that had given a problem. I had the ultrasound, and the doctor said, "Go to the post tomorrow because you have a little knot." On Tuesday we went to the health clinic, passed the mastologist who was on duty and they had all the paperwork gathered and went to the health department. We got there, the girl said: if I'm not mistaken, "September 25th there at the hospital with the mastologist the first appointment" [4 months later]. *We remember a mastologist* [private] *He explained everything, analyzed the mammogram, and analyzed the ultrasound. We made the puncture, in two and a half days came that it was evil and that he was already almost 2cm. July 1st 2014 I had the surgery.* (Wonder woman)

The delay in starting treatment is demonstrated by several Brazilian studies.[5-6,9,17] Thus, many users seek the private health sector to expedite diagnosis and / or initiation of treatment. In a study conducted in the city of Goiânia, it was found that less than half of the interviewed women used the assistance flow, in the three levels of health care, exclusively in UHS.[17]

The Federal Constitution of 1988 states that health is everyone's right and the state must guarantee universal and equal access to actions and services.[18] However, the data refer to the reflection on access to the population's right to health. It is noteworthy that among the participants who underwent treatment exclusively by the UHS, two of them started the therapeutic process within the stipulated period of 60 days, demonstrating that the time recommended by the MH is possible. In a BHU in the city of São Paulo, researchers identified that the time between diagnostic

confirmation and the start of various treatment modalities (surgery, chemotherapy and radiotherapy) varied from one to three months.[6]

However, some participants in this study took much longer, asking the question: Why do some users have their rights guaranteed, while others need to wait months for the therapeutic process, increasing the risk of mortality?

The expansion of PC coverage has led to an increase in demand for secondary and tertiary services, and consequently overcrowding these sectors, making access to diagnostic and therapeutic services difficult. Some factors determine access to health services: structure and organization of public services, competent and trained professionals, as well as sociodemographic, economic, behavioral, cultural and psychological conditions of users.[12,17]

Therefore, the implementation of strategies is urgent to relieve these levels of assistance. Strategies include the need for effective dissemination of the signs and symptoms of the disease, availability of mammography and continuing training for professionals. Also, the construction of municipal care flowcharts and protocols prioritizing the early diagnosis of breast cancer, offering women resolute and easily accessible care.[11-12,17]

With regard to cancer care for all, the applicability of the objectives of the

legislations becomes necessary, bringing theory closer to practice, in order to foster cancer care lines. In this sense, it is essential that managers identify the needs of oncology and plan their care network to meet this demand, expanding access to health.[16]

FINAL CONSIDERATIONS

The trajectory of participants with breast cancer began when they detected changes in their bodies. Most have identified breast nodules using BSE, although mammography is recommended as a strategy for cancer screening.

In this walk, the women sought health care, facing the delay in care, scheduling and performing tests to confirm the diagnosis, perform mastectomy and start adjuvant treatment. Although the ideal time to start treatment is 60 days after confirmation of the diagnosis, it was found in this study that only four women were able to start treatment in this period.

Given the waiting, the anxiety of being sick and the fear of death, some participants reported seeking care in the private health sector, in order to expedite the diagnosis and performance of mastectomy. From this perspective, the importance of greater investments by the public sector in actions for screening and early detection of breast cancer, training of health professionals to provide qualified

attention and providing more information on the signs and symptoms of the disease is highlighted, encouraging women to know themselves. Also, managers and health professionals pay attention to the importance of timely treatment, within 60 days as established by the MH, in order to contribute to reducing mortality, reducing the risk of morbidity caused by treatments and their own emotional state, seeing that delayed access and establishment of therapy can lead to fear and despair.

As a limitation for the development of this study is the absence of specific records about women living in the territories, who had breast cancer and used the public system for treatment. A difficulty factor for the initial selection of potential participants, requiring greater participation of CHAs who, with their knowledge of users of their micro areas, helped to locate and contact women.

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