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RESEARCH

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SELF-CARE AND BREAST CANCER PREVENTION: PERCEPTIONS OF WOMEN WITH MOTOR DISABILITIES

Autocuidado e prevenção de câncer de mama: percepções de mulheres com deficiência motora
Prevención del cáncer de auto cuidado y mama: percepciones de mujeres con discapacidad motor

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ABSTRACT

Objective: to know the perception of women with motor disabilities regarding self-care and breast cancer prevention. **Method:** descriptive study with a qualitative approach, carried out with 11 women from an association of people with disabilities in Agreste Pernambuco, Brazil between February and April 2020. For data collection, an interview script was used and the reports were recorded, which were transcribed, validated and analyzed through the methodological framework of content analysis. **Results:** from the analysis of the reports, the following thematic categories emerged: Self-care initiatives in the prevention of breast cancer; Physical disability and difficulties in breast cancer prevention and knowledge as a barrier to self-care in breast cancer prevention. **Conclusion:** breaking down barriers related to understanding disability and nursing care are essential for strengthening women's autonomy and empowerment.

DESCRIPTORS: Breast neoplasms; Health education; People with disabilities; Nursing.

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RESUMO

Objetivo: conhecer a percepção das mulheres com deficiência motora quanto ao autocuidado e prevenção do câncer de mama. **Método:** estudo descritivo com abordagem qualitativa, realizado com 11 mulheres de uma associação de pessoas com deficiência no Agreste Pernambucano entre fevereiro e abril de 2020. Para coleta dos dados foi utilizado roteiro de entrevista e gravação dos relatos que foram transcritos, validados e analisados através do referencial metodológico da análise de conteúdo. **Resultados:** a partir da análise dos relatos emergiram as seguintes categorias temáticas: Iniciativas de autocuidado na prevenção do câncer de mama; A deficiência física e as dificuldades para prevenção do câncer de mama e o conhecimento como barreira para o autocuidado na prevenção do câncer de mama. **Conclusão:** a quebra de barreiras relacionadas a compreensão da deficiência e o cuidado de enfermagem são essenciais para fortalecimento da autonomia e empoderamento da mulher.

DESCRIPTORIOS: Neoplasias da mama; Educação em saúde; Pessoas com deficiência; Enfermagem.

RESUMEN

Objetivo: conocer la percepción de mujeres con discapacidad motriz respecto al autocuidado y la prevención del cáncer de mama. **Método:** estudio descriptivo con abordaje cualitativo, realizado con 11 mujeres de una asociación de personas con discapacidad de Agreste Pernambucano entre febrero y abril de 2020. Para la recolección de datos se utilizó un guión de entrevista y se grabaron los relatos, que fueron transcritos, validados y analizado a través del marco metodológico del análisis de contenido. **Resultados:** del análisis de los informes surgieron las siguientes categorías temáticas: Iniciativas de autocuidado en la prevención del cáncer de mama; La discapacidad física y las dificultades en la prevención del cáncer de mama y el conocimiento como barrera para el autocuidado en la prevención del cáncer de mama. **Conclusión:** derribar las barreras relacionadas con la comprensión de la discapacidad y el cuidado de enfermería son fundamentales para fortalecer la autonomía y el empoderamiento de las mujeres.

DESCRIPTORIOS: Neoplasias de mama; Educación para la salud; Personas con discapacidad; Enfermería.

INTRODUCTION

Breast cancer is a disease resulting from the multiplication of abnormal cells in the breast, which form a neoplasm with the potential to develop. It fits into a heterogeneous group of diseases by the varied clinical and morphological manifestations, different genetic signatures and consequent differences in therapeutic responses. It is the most common type among women in Brazil and in the world, with an estimated 66,280 new cases for each year of the triennium 2020-2022. Its incidence and mortality tends to grow progressively after the age of 40.¹⁻³

The increase in the number of cases of the disease is justified by the occurrence of risk factors associated with women's lifestyle habits, which are justified by the process of urbanization and changes in lifestyle. Risk factors include advanced age at first pregnancy, low parity and breastfeeding for short periods, alcohol use, being overweight, and physical inactivity after menopause. These factors require interventions related to prevention and health promotion as a means of providing early diagnosis and treatment for a better prognosis and cure of the disease.⁴

Early detection and treatment are generally considered the most effective means of reducing breast cancer mortality. Prevention is related to changes in lifestyle (modifiable habits) and strengthening women's knowledge to access health services. Systematic Review Studies, which fostered the construction of guidelines for early detection of breast cancer in Brazil encourage mammographic screening, which should be adopted through biennial mammography, as a way to establish safe and accurate diagnosis. These actions should be referred to all women in the

age group 50 to 69 years, regardless of any psychological, social, affective, and physical factors.⁴⁻⁵

It is understood that women who present physical, sensory, or behavioral limitations need adaptations for these treatments to be complete and of high quality, reaching the objectives for the control of breast cancer. The importance of actions that promote access to information and expand opportunities for weight control and regular physical activity is also highlighted, since this is related to primary prevention in the control of modifiable risk factors.⁶

Considering the fundamental principles for the functioning of the Unified Health System (SUS), specifically integrality and equity, there is a need to prioritize actions aimed at people with physical disabilities, ensuring equal service to overcome points beyond architectural and access barriers, allowing the disabled woman to be inserted into the continuum of care in health, as proposed in the national policy for the health of people with disabilities, which, among its guidelines, highlights the promotion of quality of life, prevention of disabilities, comprehensive health care, expansion and strengthening of information mechanisms, the organization and operation of services for the care of people with disabilities, and the training of human resources. Such measures enable the strengthening of knowledge, development of attitudes and behaviors that favor autonomy and self-care in facing the risks of getting sick from breast cancer.⁷⁻⁸

Based on the aspects presented, this study aims to know the perception of women with motor disabilities regarding self-care and prevention of breast cancer.

METHODOLOGY

A descriptive study with a qualitative approach carried out from February to April 2020 with women participating in an association of people with disabilities in a city in the interior of Pernambuco. The sample size was defined by the sample saturation technique. Among those selected to make up the sample, there were losses of 6 participants, 4 of whom gave up and 2 due to the absence of a telephone set for the woman's own use, making it impossible to carry out the interview.

We included women over 18 years old, with motor disabilities and association members. Women who had been diagnosed with breast cancer in the period prior to the research were excluded. For data collection a semi-structured interview script was used, divided into two parts: the first related to the participants' sociodemographic data, and the second containing three questions based on the study objective and on the following guiding question: "How does the woman with motor disability perceive her self-care practice in breast cancer prevention?"

To collect the participants' reports, the association's board of directors was asked to schedule a meeting with the women interested in participating in the study to explain the research objectives and to get to know the researchers. On this occasion the identification data and the signatures on the Free and Informed Consent Form were collected, and the days for the interviews were scheduled.

Due to the social isolation defined by the Brazilian Ministry of Health among the several actions for prevention and control of the Coronavirus pandemic (COVID-19), it was not possible to collect the data in person. These adaptations were communicated to the participants and they were given the right to leave the research group without any personal burden by not participating, and the women were told before the interview how it would be conducted and which questions would be addressed.

The answers to the questions were recorded using a cell phone application (tape recorder) and were later transcribed in a reliable way and stored in a database by the researchers. The recorded reports contained the women's records regarding their desire to participate in the research by means of the adaptation factors of the collection carried out in face of the difficulties of social contact established.

For the data analysis, Bardin's content analysis technique was used, which comprises a set of techniques of communication appreciations, in the perspective through objective procedures, thus obtaining the content description. To preserve the names of the women interviewed we selected as "M1, M2, M3." each woman according to the order of the interview.

The answers were organized into thematic categories defined from the nucleus of meaning of the women's reports, which were obtained from the critical and exhaustive reading of the text corpus from the transcription of the interviews, and were named: 1 – Initiatives of self-care in the prevention of breast cancer; 2 – The physical disability and the difficulties to prevent

breast cancer; 3 – Knowledge as a barrier to self-care in the prevention of breast cancer.

For adequacy of the necessary components in the construction and description of qualitative research, we used the methodological guide of the Consolidated Criteria for Reporting Qualitative Research (COREQ), a tool which enables greater methodological rigor and the approach of fundamental aspects which must be considered in the preparation of the study, reverberating in credibility and consolidation of the exposed data.⁹

The research is in accordance with the principles of the National Health Council Resolutions (CNS) No. 466/2012 and No. 510/2016. It was approved by the Research Ethics Committee (CEP) of the Tabosa de Almeida University Center (ASCES-UNITA), filed under CAAE No. 25451219.7.0000.5203, Opinion Number: 3.745.071, on December 04, 2019.

RESULTS

The qualitative analysis was used with the objective of interpreting the data collected, then recording and organizing them to create some categories. Thus, the disabled women who participated in the research were in the age range of 30 to 69 years, considering the types of color and race (white and brown), and for better identification of the sample the marital status of the participants varied between (single, married, widowed and divorced), and finally encompassing the family issues it was observed the affiliation of the participants, where all claimed to have children.

With this, the axis of the semi-structured interview was through the guiding question that referred to how the woman with motor disability perceives her practice of self-care in the prevention of breast cancer. From the analysis, categories emerged that are related to the objectives of this study. Some excerpts from the participants' narratives will be cited, exemplifying the content of the categories.

CATEGORY 1 – SELF-CARE INITIATIVES IN BREAST CANCER PREVENTION.

This category expresses how women perceive their self-care actions for breast cancer prevention. What strategies they use in their daily lives to promote self-care is also related to women who believe that self-care is only developed through exams, consultations, and health education information from health professionals.

I do the self-examination, right? In the shower, you examine yourself, in front of the mirror, you examine yourself. If you find any bumps, anything strange, different in your breasts, "there" you look. This is how I do it, I examine myself when I'm in the shower, in the bathroom, in front of the mirror, I always examine my breasts.

In my day to day life I lead a normal life, sometimes I do a touch exam and I also like to have a healthy diet. (M4)

Doing the mammogram, these routine exams that we have to do, at least once a year. (M7)

[...] This question of eating, I hardly eat any junk food, only if I really feel like it and I also do exercises – I am an athlete. I do exercises there in the Association and I also do the gym there, this is every day from Monday to Friday, that I move, I do the exercises. (M10)

CATEGORY 2 – THE PHYSICAL DISABILITY AND THE DIFFICULTIES TO PREVENT BREAST CANCER

The participants' perceptions emerged regarding the physical disability and the difficulties presented for the prevention of breast cancer. Such limitations are perceived in the daily life of women and are related to their physical, social and labor conditions, in the care of children and family, in social interactions and in the condition of autonomy for health care practices (independent or dependent). It can be seen that the physical disability is not a factor that prevents women from establishing preventive measures against breast cancer, but the difficulties of access and reception in the health services keep them away from the care measures, as shown in the following reports:

The difficulty is locomotion, but I take a shower "only", I do most things alone, "there" to do the touch that I think is a prevention my disability does not hinder. (M2)

No, it does not prevent me from doing things no, I do my normal exercises, so I can do practically everything, the fact of being in a wheelchair does not prevent anything, and also when I go to do my exams, I go easily too. (M10)

Yes, it does, it makes it difficult, you know? Not having access, accessibility in the places where you can go, I can't "only" go there, you know? I have to depend on people, everything becomes difficult, you know? It is very difficult. We would need an adequate place for women with this kind of disability, if there was accessibility, right? So that "we can" go to a place with a bed that is accessible to do the breast exam because it is very difficult. Here in the city it is very complicated, very difficult. (M3)

My physical disability does not hinder me in any way from taking care of myself, going out to do the exams, do the touch exam, it does not hinder me.

I don't think my disability prevents me (M1)

No, it does not. (M9)

CATEGORY 3 – LACK OF KNOWLEDGE AS A BARRIER TO SELF-CARE IN BREAST CANCER PREVENTION.

It was evidenced, through the reports, a lack of knowledge about self-care measures for breast cancer prevention. It highlights the importance of knowledge for autonomous health

care measures and based on scientific assumptions, provided to women through contact with health professionals and health education actions.

I have never done a breast exam. (M3)

I used to do the exam annually, but I haven't done it for 2 years now. (M4)

Nothing, because I don't even know what to do. (M5)

But I don't know what to do to prevent breast cancer. (M6)

[So there is no different basis, I take care normally, I do nothing.

I myself learned on TV, right? And the last time I went to do the exam with my fingers, so I lift my arms and do the exam myself, the touch exam. (M1)

DISCUSSION

Strengthening the knowledge of the female population on breast cancer prevention is an extremely fundamental strategy. It is understood that it is limited when associated with the level of education, because it acts as a possible barrier when it comes to access to information.⁸ The control of this disease depends essentially on actions aimed at women's health education, especially in the measures of promotion, prevention, and early diagnosis. Such measures should strengthen the search for health services, motivating access, reducing the questions related to their efficiency and strengthening the strategies and programs for guidance and stimulation.¹⁰

Women's broad access to clear, consistent, and culturally appropriate information should be an initiative of health services at all levels, especially in Primary Health Care (PHC). It is known that prevention for breast cancer can be primary (linked to lifestyle changes) and secondary (based on Clinical Breast Examination (CBE) measures and screening through biannual mammography).¹¹⁻¹²

Based on the women's previous knowledge about self-care and prevention measures, a great emphasis was observed on the reference to the performance of breast self-examination (BMA). Its reference is possibly related to the reflection of the campaigns (digital media, social networks, and other means of communication) where this method is widely encouraged as a way to motivate women to know their own body and seek health services.¹³ On the other hand, there are references to reduced or absent access to information, generating a reduction in the initiative of self-care practices aimed at disease prevention.

The term self-care involves the ability to take care of oneself. When related to the context of care in breast cancer prevention, it is understood that its effectiveness aims to provide autonomy for this care to be performed individually with the objective of maintaining breast health.¹⁴⁻¹⁵

In agreement with this concept and relating the assistance of health professionals with emphasis on the role of nurses, this

assistance needs to be based on integral care, founded on the sociocultural aspect, understanding the popular knowledge and contextualizing the beliefs and independent self-care practices.¹⁶ Numerous changes occur in the structure and customs related to self-care. This statement is evidenced when the study participants refer to different initiatives of self-care, which can be related to the preparation and consumption of food, the regular practice of physical exercises, and the search for health professionals to support and guide the development of health-seeking behaviors. A study shows that the news published in the media (newspaper/magazine/television) and the health education actions carried out by nursing professionals are the main sources of information about breast cancer prevention.¹⁷

However, the process of caring goes far beyond the use of technology, the production of new drugs, or even medical-hospital equipment and accurate diagnoses. It is much more than caring for a "part of the body that is not functioning well, or that has been injured" as oriented by the biomedical paradigm.¹⁶

The care provided by nursing in support of autonomous health-seeking behavior is based on the theoretical and historical assumptions of the profession. Nursing care is practiced through simple actions such as listening, welcoming anguish, offering a word of comfort, and providing support in moments of difficulty faced by women. This assumption is reinforced in the statements and testimonies of problems faced in the process of access to care and the orientation measures for the prevention of the disease, especially regarding being a woman with a physical disability which, in the participants' view, aggravates this problem even more.

Therefore, we realize that the welcoming is directly related to the improvement of access because it is a technological tool for intervention, which reflects on the assistance provided, ensuring an improvement in the deliberation of the service. Since the profile of health care for people with disabilities in our country is still disjointed, fragile, and discontinuous as to actions in the public and private spheres, making this statement worrying.¹⁸

Still in this dimension, the importance of health education through group guidance, construction of educational manuals on how to prevent breast cancer by changing the modifiable factors and performing early diagnostic tests within the age range proposed by the Ministry of Health is irrefutable, and there is no doubt that through these actions we can promote the autonomy of women and encourage them to practice self-care.¹⁶

In Brazil and even in other countries in the world, no deficiency is considered to be an impediment to the development of strategies and guidelines for breast cancer screening. This fact is considered a gap in the Brazilian women's health policy, which, among its guidelines, objectives, and strategies, neglects the debate about women with disabilities and their peculiarities.¹⁹ And even with the existence of the National Policy for the Health of Persons with Disabilities, the right to equality for women with disabilities is still not ensured, since it is not enough just to prohibit discrimination through repressive legislation; it is essential

to promote promotional strategies capable of stimulating the inclusion of these socially vulnerable women.²⁰

The use of the term "disabled women", which emanates a biologicist and prejudiced paradigm, places this situation only as an example of the population groups that the policy intends to protect, denouncing the evident invisibility and inequality.¹⁹ It is evident, according to the perception of the participants, the low welcoming and individualized attention to people with disabilities that restrict and hinder the initiatives to seek the health service, and it is up to the professional team to provide quality and humanized care, being of utmost importance to establish a link with the patient, welcoming his needs within the biopsychosocial aspects.²¹

The health services offered must be encouraged to contribute to the improvement of actions aimed at adapting access, since historically the disabled person comes from a social context of struggle and movements for inclusion in society, with the great purpose of health prevention in the face of the scenario of illness. Accessibility, in this context, must be considered in its geographical (spatial distance, structure, and time to get to the service) and social-organizational (adequacy or qualification of health professionals and technological resources used to optimize the professional-user interaction) dimensions.¹⁸

Listening to the user presents itself as a great perspective in the sense of understanding his real needs of access to the health service. It was observed the reference of proposals for intervention in the adaptation, organization, and formatting of services as a means to facilitate the access and the search for actions aimed at the prevention of breast cancer by women; however, no reference was identified about the interaction with the disabled woman in the sense of understanding her personal needs and guiding the health team, especially the nursing team, for such measures.²²

It is understood that the lack of strategy used by some professionals may be the result of an academic training not very inclusive, often failing in the aspect of welcoming and health education.²³ It is up to managers to train professionals to meet the demands of the service and community, especially related to the quality of information transmitted to women, ensuring that the user develops knowledge and capacity for self-care to reduce risk factors, recognize the possible breast changes and have autonomy in seeking service for the prevention of breast cancer.

CONCLUSION

The participants' references provided a reflection on the importance of actions that are based on breaking barriers (physical, knowledge and psycho-affective) so that knowledge is taken as an incentive for self-care in the prevention of breast cancer. The importance of health education practices aimed at prevention in its various aspects was evidenced: behavioral, the search for health services, the reduction of risk factors, the performance of mammography, clinical examination and measures of body knowledge through self-examination.

It is understood that the nursing professional is the protagonist of the actions that will lead to the basis for changes in the services, so that an effective reception occurs, ensuring improved access and allowing better conditions for the prevention of breast cancer. The limitations of the study are considered to be the low number of literary sources on the subject and the resistance of the women in the approach for data collection by telephone. In this sense, it is valid to consider that the study deals with a local reality and presents a limited number of participants, therefore the theme requires more detailed investigations on how the health care of this social segment is carried out.

It is observed as necessary the creation of strategies, policies and specific programs that safeguard and that can guarantee to women with disabilities an assistance based on the principles of universality, equity and integrality foreseen as supports of the SUS, guaranteeing in practice the basic conditions for a humane and inclusive care.

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