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On social participation: ways, senses and meanings of occupying oneself for post-mastectomy women

Sobre a participação social: formas, sentidos e significados de ocupar-se para mulheres pós mastectomia

Sobre la participación social: formas, sentidos y significados de ocuparse para las mujeres después de la mastectomía

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Objective: to understand how the occupations of women who underwent mastectomy surgery are presented. **Methods:** research with a qualitative and descriptive approach, using open interviews with women undergoing mastectomy surgery, carried out between late 2019 and early 2020. Data were interpreted using Bardin's content analysis. Results: three categories were constructed: The way of occupying oneself after mastectomy surgery, The meaning of occupying oneself after mastectomy surgery, and The meaning of occupying oneself after mastectomy surgery. Distance and adaptation needs were verified in some occupations, while gains were verified in others, such as being closer to the home environment, which provided satisfaction and discoveries in the occupational field, as well as in the quality of life. **Conclusion:** the mastectomy influenced the active participation in meaningful occupations, affecting the quality of life and

Descriptors: Mastectomy; Activities of daily living; Occupational Therapy.

Objetivo: compreender como se apresentam as ocupações de mulheres que passaram pela cirurgia de mastectomia. Método: pesquisa de abordagem qualitativa e descritiva, com o uso de entrevistas abertas com mulheres submetidas à cirurgia de mastectomia, realizada entre final de 2019 e início de 2020. Os dados foram interpretados pela análise de conteúdo de Bardin. **Resultados:** três categorias foram construídas: A forma do ocupar-se após a cirurgia de mastectomia, O sentido do ocupar após a cirurgia de mastectomia e O significado do ocupar após a cirurgia de mastectomia. Foi verificado o afastamento e as necessidades de adaptações em algumas ocupações, ao mesmo tempo em que verificou-se ganhos em outras, como estar mais próximo ao ambiente domiciliar, o que proporcionou satisfação e descobertas no âmbito ocupacional, bem como na qualidade de viver. Conclusão: a mastectomia influenciou na participação ativa em ocupações significativas, repercutindo na qualidade do viver e da participação social.

Descritores: Mastectomia; Atividades cotidianas; Terapia Ocupacional.

Objetivo: comprender cómo se presentan las ocupaciones de las mujeres operadas de mastectomía. **Método**: investigación de abordaje cualitativo y descriptivo, con el uso de entrevistas abiertas con mujeres sometidas a cirugía de mastectomía, realizada entre finales de 2019 e inicios de 2020. Los datos se interpretaron mediante el análisis de contenido de Bardin. Resultados: se construyeron tres categorías: La forma de ocuparse después de la cirugía de mastectomía, El sentido de ocuparse después de la cirugía de mastectomía y El significado de ocuparse después de la cirugía de mastectomía. Se verificó el alejamiento y las necesidades de adaptaciones en algunas ocupaciones, mientras que se verificaron ganancias en otras, como estar más cerca del ambiente doméstico, lo que proporcionó satisfacciones y descubrimientos en el campo ocupacional, así como en la calidad de vida. **Conclusión**: La mastectomía influyó en la participación activa en ocupaciones significativas, repercutiendo en la calidad de vida y la participación social.

Descriptores: Mastectomía; Actividades cotidianas; Terapia Ocupacional.

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INTRODUCTION

ancer is a general term that comprises a set of more than one hundred diseases, which manifest through a disorderly growth of cancer cells, in which, instead of dying, they multiply in an exaggerated way¹. Among the main types, breast cancer stands out, and it occurs when the cells of the mammary lobes, milk-producing cells or the ducts through which the milk is drained can cause one or more mutations in the genetic material of cells².

According to the Brazilian National Cancer Institute (INCA), it is estimated that in each year of the 2020-2022 period, 66,280 new cases of breast cancer will be reported in Brazil. This corresponds to an estimated risk of 61.61 new cases per 100,000 women³, which represents an important impact on the Brazilian population. The main signs and symptoms of breast cancer are: lump in the breast and/or armpit, breast pain and changes in the skin that covers the breast, such as prominences or retractions with an appearance similar to an orange peel. Breast cancers are mainly located in the upper external quadrant, and, generally, the lesions are painless, stationary and with irregular edges, accompanied by skin changes when in an advanced stage².

Mastectomy (from the Greek, *mastós*, breast, and *ektomia*, to remove) is the name given to breast surgery first performed by Halsted in 1882, and consists of one of the surgical treatments for breast cancer⁴. In addition to the pain and discomfort resulting from the disease and its treatment, psychic, social and economic changes may occur. Also, questions may arise about the previous and future life of the disease, which may affect the way of life and behavior in relation to one's own health⁵. The performance of the mastectomy brings repercussions that can be experienced in a traumatic way by women, being considered a mutilation⁶. It is also noteworthy the possibility of experiencing mourning and shame in dealing with one's own body, which can make it difficult to return to one's occupational life⁷. In this sense, it is understood that these situations can lead to repercussions on day-to-day occupations.

Occupations are defined as activities in which people engage to occupy their time, in a meaningful way⁸. In 2020, the American Association of Occupational Therapy released the fourth edition of its guiding document called the Structure of Occupational Therapy Practice - Domain and Process. In this document, social participation is understood as activities that involve interaction in the social sphere with other people, including involvement with family, friends, colleagues and community members⁸.

Within the scope of Occupation Science, its focus of analysis is not limited to a specific action itself, but also to the social actors who participate in these occupations in social, cultural and historical contexts of their lived world. One of the perspectives of Occupational Science is

concerned with how people live and learn in everyday life, understanding the importance of the relationship between occupation, participation and health⁹.

For one of the lines of analysis of the Science of Occupation, understanding the forms, senses and meanings of occupations is a path that makes it possible to learn a reality experienced by people. The occupational form is characterized according to the identity, history and sense of belonging of each person¹⁰. According to Sy et al11: "(...) the occupational form refers to the observable aspects of 'what', 'how', 'where' and 'who' is performing a certain occupation." In addition, occupations have a meaning, that is, people are busy looking for something they want to achieve. The meaning, in turn, is characterized as the result of achievement and satisfaction in occupying oneself. Thus, meaning is constructed through cultural influences and personal history¹¹.

This study is based on the assumption that the changes resulting from the mastectomy affect the performance of occupations and influence the forms, senses and meanings, or even that women with breast cancer may develop changes in their occupational repertoire as a result of the process of onset of a disease.

Occupational therapists have sought to study people's occupations to understand how people engage and participate in the community, seeking to understand the occupations they are involved in, what their meanings are, how they use time, whether the social context facilitates or hinders people's engagement in different occupations, thus having a vision of how people construct their daily life¹². Thus, this study aims to understand how the occupations of women who underwent mastectomy surgery are presented.

METHODS

This is a research with a qualitative and descriptive approach, carried out between November 2019 and February 2020, in the Project entitled: *Ações de cuidado integral à saúde de pacientes mastectomizadas do Estado do Pará: abordagens interdisciplinares entre a Fisioterapia e Terapia Ocupacional* (Comprehensive health care actions for mastectomized patients in the State of Pará: interdisciplinary approaches between Physical Therapy and Occupational Therapy) and occurred in the body practices room at the Faculty of Physical Therapy and Occupational Therapy at the Universidade Federal do Pará (UFPA).

The inclusion criteria adopted were: women over 18 years old, who underwent mastectomy surgery due to breast cancer.

Data collection took place through an interview that consisted of two stages, the first referring to the socio-demographic information of each participant (name initials, age, address,

contacts, how long ago the surgery was performed, type of surgery, how many surgeries, time attending the sector and others).

The second stage consisted of questions about the occupations. The first question was "Describe to me what your occupations were like before the mastectomy". The second question was "Tell me what you do on a routine day in your current life". The idea of these two questions was to identify and understand the list of occupations performed before and after mastectomy surgery. In both questions, we sought to know the occupational form before and after the mastectomy.

The third question asked "What is the purpose of these occupations?". In order to understand the purposes attributed to their occupations. The fourth question was "What do these occupations mean to you today?" in order to understand the meaning of current occupations. The interview was developed based on a similar study¹³, in which questions involving knowledge and understanding of occupations were also applied.

The interviews were recorded and transcribed in full. All transcripts were read individually by two researchers and subsequently re-read to ensure inclusion of all relevant material. After transcription, data analysis was performed through content analysis, covering a set of strategies, in search of the meanings contained in documents, material collected through interviews, or observation notes taken in field diaries¹⁴. For each theme analyzed in the research, categories were created by approaching the affinity of the theme, for better reading and understanding of the results in question.

This research is part of the project entitled: "Como se apresentam as ocupações de mulheres no pós-operatório de mastectomía" (How are the occupations of women in the post-mastectomy period presented), from the Occupational Therapy Course at UFPA and funded by the Institutional Program of Scholarships for Scientific Initiation and Technological Development and Innovation (PIBIC) and the Research Doctor Support Program (PRODOUTOR) at UFPA.

It was approved by the Ethics and Research Committee of the Institute of Health Sciences at UFPA, with CAEE No. 16711019.5.0000.0018 and opinion No. 3,677,894. The participants were informed by the researchers about the objectives and reliability of the data. All ethical aspects were respected in compliance with the Resolution of the National Health Council (CNS) on research involving human beings No. 466/1215. Participants in this research were called by fictitious random names to preserve identity.

RESULTS

Twelve women aged between 40 and 70 years who underwent mastectomy surgery participated in this research. Ages ranged from 44 to 70 years. As for marital status, five were single, six married and one divorced. With regard to religion, of the 12 participants, 10 claimed to belong to the Catholic religion, while one reported following the spiritist doctrine and the other was Evangelical. With regard to their profession, nine participants reported that they were housewives, two were retired and one was unemployed (Table 1).

Chart 1. Women with mastectomies according to sociodemographic data. Belém/PA, 2020.

No.	Participant	Age	Marital status	Occupation
1	Acacia	58	Single	Homemaker
2	Amaryllis	47	Married	Homemaker
3	Azalea	58	Divorced	Retired
4	Camellia	60	Single	Retired
5	Carnation	65	Single	Homemaker
6	Sunflower	59	Married	Homemaker
7	Iris	51	Married	Manicurist/Homemaker
8	Jasmine	70	Married	Homemaker
9	Lily	51	Single	Homemaker
10	Daisy	56	Married	Homemaker
11	Orchid	53	Married	Homemaker
12	Rose	44	Single	Unemployed

After analyzing the interviews, three categories were constructed: *The way of occupying oneself after mastectomy surgery, The meaning of occupying oneself after mastectomy surgery,* and *The meaning of occupying oneself after mastectomy surgery.*

The way of occupying oneself after mastectomy surgery

The participants described what occupations they perform and what their routine was like. In Iris's report, it is clear that the day-to-day life before the surgery was hectic, however, after the mastectomy there was an important change in the way in which she took care of social participation, restricting her occupations to the environment of her own home . These restrictions were related to the repercussions, needs and guidelines for treatment after surgery:

Before I didn't stop, at home I did my things; walked all over the street, because I also sold catalogs on the streets, going after customers and solving family problems [...]. I was a very active person [...]. Today, I just lie down, watch television, sort out some things, take my medicines, read, check my phone, check Facebook, these things. I lie down more, rest, because I feel a lot of pain in my arm and breast, and I can't even walk, I walk and my arm hurts. (Iris)

In Azaleia's description, it was observed that, after the mastectomy surgery, there were limitations that led to the removal of some occupations such as caring for family members and weekend trips. In addition to the repercussions of the surgery, the participant evidenced a limitation due to the family members' fear of not allowing them to engage in some occupations:

Before, everything was normal, I woke up early, went to work, got home at 2 pm, had lunch. Sometimes I had lunch at work, sometimes at home, I live close to work. In the afternoon, I took care of my grandson and that was it. On the weekends, I went for a walk, I went to Castanhal [municipality in the state of Pará], there was a time when I walked, did water aerobics, and stopped. I did things at home, I did everything myself, I cleaned the house, I cooked [...] today, my daughter doesn't let me do much. (Azalea)

As for Carnation, regarding taking care of social participation, the most latent limitation was not being able to attend church. Currently, Carnation dedicates her time to taking care of herself as a result of the necessary treatments after the mastectomy:

I used to go to church more often, [...], we went out a lot with friends. My life was pretty busy. Then, after I got sick, my life stopped. Now that I am able to walk, I am very weak. Currently, the activity I do the most is going, [...], to the medical appointments [...]. I live to go to the doctor, starting in March, I'll be alone at home, my husband works all day and my two children go to college [...] then I won't have anyone to stay with me. Usually someone from the church comes to the house, but not many at all. (Carnation)

Also noteworthy was the fact that there were changes that, from the perspective of the participants, brought benefits to their lives. It is noticed in Camellia's report that the mastectomy brought the opportunity to meet new people and to get involved in new relationships and experiences, which can foster personal appreciation and the importance of groups:

After the mastectomy, I was able to reframe my experiences. Today, I participate in several support groups for women who underwent surgery, as I have already had surgery for some time, I share my experiences with those who are going through it for the first time. I am invited to participate in lectures and I am always involved in movements that value women. (Camellia)

The meaning of occupying oneself after mastectomy surgery

Regarding the meaning of engaging in social participation, it was found that changes occurred due to the process of adapting to the new context of life. It was identified that the moment post-surgery provided an opportunity to approach the family and also allowed the process of selection and organization of some occupations that provided more satisfaction, pleasure, as well as favored quality of life:

Today, I can participate more in activities in my family, before I did a lot in my community and I didn't work so hard at home. (Amaryllis)

In this same line of observation, many participants reported that they tried their best to do what they used to do, but that today they prefer to perform their occupations at home, in the presence of their children and grandchildren. In general, it was found that changes in social participation resulting from the mastectomy revealed that, despite the occupational losses experienced after breast surgery, some benefits were observed, such as appreciation of some occupations that were previously experienced in an unsatisfactory way in the context of an intense routine.

It was observed that the mastectomy contributed to the fact that social participation, understood from an occupational perspective, was restricted to domestic life. Despite the record of changes and occupational losses, in some cases, it was reported as something positive, as the family can get closer, as observed in Amaryllis's report, although, due to the occupational routine of the other family members, this conviviality at home, at other times, has generated moments of loneliness.

As for the meaning of occupation, the participants reported that dealing with the impact of the mastectomy and the disease process can interfere with the meaning of occupations among family members, friends, neighbors and communities:

[...] I was a very active person, cooking, sweeping the house, washing clothes, doing housework. I wake up in the morning, I drink my coffee, I watch the news, I watch the two morning news. My son goes out so I'm alone, so I like to do things alone, if there are dishes, I wash them, without scouring the pan, I clean the stove, I take and fill the bottles slowly and leave them in the fridge, I take the food out of freezer, tidy up the area, tidy up my son's room. Then I make my lunch, when it's 1pm I go to bed, it's my time to rest. (Sunflower)

Currently nothing! I just stay at home, taking care of my father and housework, it's limited now, right?! I do it, but I have this swelling problem in my arm, so I'm taking it easy to not have it anymore, wash the dishes, sweep the house, clean, I do it, but with limitations. (Daisy)

The meaning of occupying oneself after mastectomy surgery

It was observed that the mastectomy contributed to the fact that social participation, understood from an occupational perspective, was restricted to domestic life. Despite the record of changes and occupational losses, in some cases, it was reported as something positive, as the family can get closer, even though, due to the occupational routine of the other family members, this interaction at home, at other times, has generated moments of solitude.

The feeling generated by the contact with other people, the knowledge of new places, the need and opportunity to leave the house more often, the increase in the intensity of family relationships. Such repercussions provided the elaboration of new occupational meanings:

It gave me greater pleasure to be more involved with my family, it gave me freedom to do something, today I feel truly useful and with the possibility of using my time well. (Azalea)

The recurring changes in their occupations were configured as a gain for bringing a new discovery in acquiring more possibilities to engage in occupations. And with regard to social participation, the mastectomy favored the strengthening of the family bond, intensifying the dimension of the meaning of loss, as the loss of the breast transcended the individual scope, directly affecting the social relationships in which these women participated.

On the other hand, some women reported that, after the mastectomy, they presented changes related to the occurrence of feelings such as shame in dealing with their own amputated body:

I look in the mirror and I don't recognize myself, having to leave the house like that makes me ashamed, I don't feel like a woman due to the lack of my breasts. (Acacia)

In addition, the participants emphasized the insecurity in dealing with the prejudice of other people:

Today, leaving home is synonymous with sadness and doubts, I don't know how people will react when they see me, many look with pity. (Orchid)

Cancer betrays us, you know, when people saw me without hair, thinner, they looked at me in astonishment, some were even afraid to get close to me thinking that my disease was contagious. (Rose)

It is possible to observe in these reports some impacts of the mastectomy and the repercussion of the oncological treatment in the actions of leaving home and occupying oneself in their social relationships.

The highlighted reports identified from an occupational perspective drew attention to the impact of mastectomy on the forms, senses and meanings of occupations, mainly with regard to the social participation of the participants.

In a report by the participants, it was also possible to observe another meaning when dealing with social participation after mastectomy. Before the surgery, leaving home was not a significant occupation, despite this, there was a strengthening of bonds with the people who participated in their daily lives:

I've always been a bit of a homebody, I don't have many friends, with the surgery, I didn't feel much about leaving home, the people who were important to me were at home, so we were able to get closer and I could feel their care for me. (Amaryllis)

DISCUSSION

The mastectomy surgery, due to the physical, emotional and occupational limitations resulting from this process, had repercussions on engagement in the occupation of social participation. However, it was observed that the form, sense and meaning of occupying oneself attributed to this occupation differ among the participants.

It is observed that the understanding of social participation is broad and encompasses several social actors¹⁶. This occupation consists of the interrelation of occupations to support the desired involvement in community and family activities, as well as those involving peers and friends¹⁷.

From an occupational therapeutic perspective, social participation is understood as people's verbal or non-verbal interactions, and with or without involvement in an activity¹⁸. In addition, social participation is classified based on the active engagement of people in occupations. For the International Classification of Functioning, Disability and Health (ICF), social participation is configured as involvement in a life situation and participation restrictions are the problems experienced by the individual in the various situations involving daily life¹⁹.

Women in the post-mastectomy surgery have changes in their occupations with difficulties in resuming their occupational lives. Feelings of impotence, frustration, anxiety, depression and the very fear of the disease may arise, which, consequently, can compromise their daily lives and harm their socio-family relationships^{18.} Involvement in occupations can generate negative reactions that can prevent the expression of their interests.

Restricted occupational participation occurs due to physical and social limitations, as in the case of situations in which family members prevent occupation, or even in the involvement in day-to-day occupations that are significant and motivating for those who exercise it 20 . The absence or reduction of involvement in social participation of women undergoing breast cancer surgery is mostly related to the requirement for a new occupational sense that comes from feelings such as: frustration, discouragement, shame and devaluation of the self-image of one's own body 18 .

Also, the treatment of breast cancer generates social impact, and, consequently, in dayto-day occupations. The return to activities includes a new way of dealing with physical and occupational restrictions, so that assistance to women focused on their social participation has been understood as an essential focus²¹.

The physiological changes resulting from the mastectomy generate pain, muscle weakness and joint dysfunctions in the shoulder, which can limit their engagement in social activities²². The illness process causes restrictions on social participation, which can limit participation in occupations of family life. When offering services to this public, it is necessary to identify support networks and encourage them, to help in coping with stressful situations during the treatment period, in addition to promoting health recovery, acting, above all, in improving the emotional aspects affected by illness²³.

The process of coping with a significant loss can affect different areas of life, whether emotional, behavioral, social and occupational, as it impels an occupational reorganization aimed at changes in everyday life in which there is no longer what was lost²⁴. In the case of the participants in this research, the loss was the breast itself. This grieving process in the face of breast loss begins with the diagnosis, surgery and extends to the postoperative period, since women can face situations in their daily lives in which they perceive themselves without their breasts, which affects choices, habits, routines and social participation within the family²⁵.

Understanding the care given by family members to mastectomized women becomes a challenge, above all, because this process involves interpersonal and family relationships that are influenced by the meaning that both the woman and the family attribute to the process. The presence of a caregiver is as important as the performance of technical procedures, but it is important that this care works satisfactorily in situations of overprotection and favors the patient's family and social dynamics²⁶.

Some women affected by breast cancer can give new meaning to engaging in social participation and can improve family and social ties instead of isolating themselves, seeking to share with those around them the experiences triggered by the diagnosis and treatment²⁷, such as it is perceptible in the reports of those surveyed, who gave new meaning to the process they experienced, sharing experiences with other women.

In addition, faced with a process in which changes in participation are necessary, the person undergoes changes in the way of thinking, feeling and carrying out their occupations. Such alterations modify the sense and significance of occupational participation, making it necessary to the reconstruction or adaptation of occupational habits and routines that may or may not favor engagement²⁸.

The form and meaning of involvement in social participation stood out in the reports after the mastectomy surgery, in which the changes occurred due to the occupational change

process, which in itself provided the opportunity to approach the family and also allowed the selection process and organization of activities that provided more satisfaction, and also favored the quality of life. Many participants reported that they tried their best to do what they used to do, but that nowadays they prefer to do the tasks at home, in the presence of their children and grandchildren.

The services that provide assistance to these patients must pay attention not only to their physical characteristics and needs, but also to their occupational demands, with a view to providing services in a broader, more adequate and efficient way, especially after surgery. The participants' reports revealed that occupations changed after the mastectomy surgery, leading to different situations that generated impacts on daily life²⁹.

Occupations are configured as a structuring and organizing aspect of everyday life that provides motivation for life and is closely related to subjective experience. Occupational identity is part of each person's personal identity and is built in the involvement of daily occupations, being influenced by the environment and circumstances that surround human beings³⁰ and is expressed by various aspects of human nature in interaction with the context, being developed throughout a person's life course and as crucial means by which a person achieves meaning and purpose in life²⁹.

Engaging in occupations of a social nature, including involvement in community, family activities and those involving peers and friends, can act as a protective agent against the risk of stress-induced illnesses, which are considered one of the factors that most affect how people adapt to adverse situations²⁸.

There is individuality attributed to occupational meaning. Meanings are interpreted and generate consequences in the way and in the sense of engaging in occupations. It was possible to verify that the stimulus for social participation is present in debates and interventions around health care; autonomy, well-being and independence; exercise of citizenship and access to social rights. This is because the participation process is essential for maintaining the health of each individual and the community, in addition, participation meets the assumptions of health promotion and favors the empowerment of the individual 17,18,20 .

Empowerment favors the development of skills to control one's own health and exercise one's participation autonomously, which can have a direct effect on subjective well-being, in addition to promoting health recovery, acting, above all, in improving the emotional aspects affected due to illness¹⁸.

The impacts resulting from post-mastectomy surgery on social participation had repercussions on changes in the form, sense and meaning of occupations. Difficulties in

engaging in social participation allowed the emergence of negative feelings of dissatisfaction and discomfort, due to not occupying themselves in the way they were used to.

The changes occurred due to the occupational adaptation process, which made it possible to get closer to the family and also allowed for the process of selecting and organizing occupations that provided more satisfaction and quality of life. These occupational changes, according to the reports, were related in many cases to the prejudice experienced after the mastectomy, in addition to feelings of pity that were reflected by many of the groups that were part of it.

In Occupational Therapy, social participation is seen as a fundamental occupation to promote occupations and people's involvement in society. In the case of women undergoing mastectomy surgery, encouraging social participation provides access to and involvement in everyday activities and citizenship, such as: study, work, leisure and cultural practices, political activities, among others; as well as the establishment of social relationships, whether within the family, friends or affective relationships. It is believed that promoting social participation is necessary, in order to enable the strengthening of social support networks, in addition to directing a better quality of life.

CONCLUSION

The mastectomy influenced the active participation in meaningful occupations, affecting the quality of life and social participation of the study participants.

The research provided the participating women with a space to express the repercussions of the mastectomy on their occupations and to share the difficulties and occupational potential that could be experienced after the surgery.

As for the limitations of the study, the qualitative methodology stands out, as it does not allow comparison with other groups, as well as generalizations regarding the findings. Finally, it is suggested that new studies that address the occupations of women who have experienced mastectomy can be carried out, as they are still incipient and scarce.

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