

Original Article

Contribution of occupational therapy to the organization of the routine of women submitted to surgical treatment for breast cancer: a focus on Instrumental Activities of Daily Living (IADL)¹

Contribuição da terapia ocupacional para a organização da rotina de mulheres submetidas a tratamento cirúrgico para câncer de mama: um enfoque nas Atividades Instrumentais de Vida Diária (AIVD)

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How to cite: Camargo, M. J. G., Santos, C. R. A. A., Ferreira, J. N. F., & Abonante, K. S. F. B. (2022). Contribution of occupational therapy to the organization of the routine of women submitted to surgical treatment for breast cancer: a focus on Instrumental Activities of Daily Living (IADL). *Cadernos Brasileiros de Terapia Ocupacional*, 30, e3328. <https://doi.org/10.1590/2526-8910.ctoAO255033282>

Abstract

Introduction: Modified radical mastectomy and quadrantectomy are the main surgical treatments for breast cancer; however, they can cause physical, mental, social and occupational disorders to the patient and her support network.

Objective: To analyze the effect of preoperative occupational therapeutic guidance on the support network of women undergoing breast cancer surgery aiming to organize their postoperative routine with a focus on Instrumental Activities of Daily Living (IADL). **Method:** This is a qualitative, descriptive-exploratory, longitudinal study conducted with 14 women diagnosed with breast cancer and referred to elective surgery, consisting of personalized guidance to their support network. Data were collected at two moments: pre- and post-operatively (30 days after surgery) through recorded semi-structured interviews via videoconference, and explored by content analysis. **Results:** The main guidance provided to family members consisted of strategies for adaptation, grading, and delegating of the activities most significant to the participants. The findings were divided into the following categories: Family as a support network and the recovery process; Care

¹All ethical procedures in force were complied with and approved by the Human Research Ethics Committee under opinion no. 26691819.9.0000.0098.

Received on May 15, 2022; 1st Revision on May 18, 2022; 2nd Revision on Aug 2, 2022; Accepted on Aug 8, 2022.



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challenges; Resuming IADL performance; Assurance of physical and emotional integrity; The occupational therapist as a support network. The participants highlighted the relevance of the study and their desire for broad Occupational Therapy assistance coverage. **Conclusion:** The findings suggest the efficacy of interventions aimed at the routine organization of women who have undergone mastectomy based on the instrumentalization of their support network for collaborative care.

Keywords: Breast Cancer, Social Support Networks, Daily Activities, Oncology.

Resumo

Introdução: Mastectomia radical modificada e quadrantectomia são os principais tratamentos cirúrgicos para o câncer de mama; no entanto, podem ocasionar distúrbios físicos, mentais, sociais e ocupacionais à paciente e sua rede de apoio. **Objetivo:** Analisar o efeito de orientações terapêuticas ocupacionais pré-cirúrgicas na rede de apoio de mulheres submetidas à cirurgia para tratamento de câncer de mama para organizar sua rotina pós-cirúrgica com foco nas Atividades Instrumentais de Vida Diária (AIVD). **Método:** Trata-se de um estudo qualitativo, descritivo-exploratório e longitudinal realizado com 14 mulheres diagnosticadas com câncer de mama e indicadas à cirurgia eletiva, consistindo em orientações personalizadas a sua rede de apoio. Os dados foram coletados em dois momentos: pré- e pós-cirúrgico (após 30 dias) por meio de entrevista semiestruturada via videoconferência gravada e explorados por análise de conteúdo. **Resultados:** As principais orientações fornecidas aos familiares incluíam estratégias para adaptação, graduação e delegação das atividades mais significativas para as participantes. Os achados da pesquisa foram divididos nas seguintes categorias: Família como rede de apoio e o processo de recuperação; Desafios do cuidado; Retorno ao desempenho das AIVD; Segurança da integridade física e emocional; e O terapeuta ocupacional como rede de apoio. As participantes destacaram a relevância do estudo e anseio por ampla cobertura assistencial da terapia ocupacional. **Conclusão:** Os achados sugerem eficácia nas intervenções voltadas à organização da rotina de mulheres mastectomizadas a partir da instrumentalização da rede de apoio para o cuidado colaborativo.

Palavras-chave: Câncer de Mama, Redes de Apoio Social, Atividades Cotidianas, Oncologia.

Introduction

Cancer is the main public health problem worldwide, and one of the four main causes of death before the age of 70. In most countries, breast cancer is the most prevalent and lethal type of cancer among women (Brasil, 2020). In Brazil, the estimated incidence of breast cancer for 2022 is 66,280 new cases (Prolla et al., 2015; Almeida et al., 2015). Silva (2009) stated that the causes of breast cancer are multifactorial and interrelated with the lifestyle and genetics of each woman.

Pereira et al. (2019) pointed out that the main surgical approaches used to remove this type of neoplasm are quadrantectomy, which consists of partial removal of the

breast, and modified radical mastectomy, which is the total removal of the breast affected by cancer.

Nevertheless, although these treatments are essential, they generate serious anguish, uncertainties, insecurity, and limitations in women who undergo them, impoverishing their everyday lives in the face of a routine characterized by impersonal activities organized according to their clinical needs, thus directly affecting the performance of their roles and occupations (Nascimento et al., 2015; Fangel & Cardoso, 2018).

Among the occupations most affected by the surgical treatment of breast cancer are the Instrumental Activities of Daily Living (IADL), which support daily activities at home and in the community, and which often require more complex interactions than those required, for instance, in self-care (Associação Americana de Terapia Ocupacional, 2015; Ribeiro et al., 2019).

Accordingly, Dias et al. (2017) pointed out that, in the postoperative context, performance of IADL such as household chores is hindered because of possible physical complications, such as lymphedema, pain, reduced range of motion and muscle strength in the limb ipsilateral to the surgery, as well as of the emotional disturbance caused by fears and anxiety arising from treatment. Moreover, Ribeiro et al. (2019) stated that 74% of cancer patients treated by occupational therapy report deficits in performing IADL.

The patient and her family face the crucial challenge of organizing themselves to perform activities that were previously carried out with full energy, vitality and pleasure, representing an aspect that needs to be addressed even before the surgery and that involves the patient, their family, caregivers and friends, as well as the technical team, in a process of mutual accountability in relation to the disposition and definition of these tasks, which were previously developed, in part, under the supervision and assistance of this woman (Dias et al., 2017).

In the face of so many challenges presented to these women and their families to face cancer, during the time of this study, the context of the COVID-19 pandemic is added to this struggle, which, according to Correia et al. (2020), haunted the world population, generating fear and insecurity caused by lack of knowledge about the behavior of the disease, which has a high dissemination capacity and great socioeconomic impact, and can be lethal in its complications.

Therefore, this study is justified because it produces knowledge about strategies that can be used by occupational therapists to minimize the occupational impacts resulting from surgical treatment, in relation to IADL, from previous guidance to the support network. This study aimed to analyze the effect of preoperative occupational therapeutic guidance on the support network for the organization of the postoperative routine of women undergoing breast cancer surgery focusing on IADL.

Methodology

This is a qualitative, longitudinal study with an exploratory and descriptive design consisting of the analysis of remote occupational therapy interventions supported by teleconsultation, according to resolution no. 516/2020 of the Federal Council of Physical Therapy and Occupational Therapy (COFFITO), conducted during the preoperative phase with participants who underwent surgical treatment for breast cancer.

To define the study sample size, we adopted the principle of theoretical saturation of data explored through content analysis, which according to Bardin (2016), consists of systematic and objective procedures to analyze communication and infer what was said in the interviews or perceived by the researchers, using the steps of pre-analysis, material exploration and treatment of results to define categories and subcategories.

The study focused on the occupational therapeutic approach to the IADL that were significant to the participants, who considered they needed assistance from family members and/or caregivers to carry them out during the postoperative period.

The intervention was conducted through personalized occupational therapy guidance to family members and/or caregivers three days before the surgical procedure for total or partial, unilateral or bilateral, removal of the participants' breasts. These guidance addressed the demands presented by these women regarding IADL, and sought to make family members and/or caregivers aware of the subjective importance of these activities for the participants, guiding the first on how the tasks that compose these activities could be performed postoperatively with a view to organizing of the routine.

The guidance carried out considered the knowledge about activity analysis, as proposed by Lamport et al. (2001), in addition to strategies for grading and adapting to doing, added to considerations regarding the contexts, standards, intrinsic motivations, and performance skills of each participant, according to the Associação Americana de Terapia Ocupacional (2015). The participants were not evaluated, but focally interviewed.

The following inclusion criteria were adopted: a) women with breast cancer referred to radical mastectomy or quadrantectomy, with or without concomitant axillary lymphadenectomy; b) agreement with all project stages previously presented to participants; c) mandatory indication of at least one family member or caregiver, with acceptance of the informed consent form and adherence to the research purposes.

Exclusion criteria: a) hospital readmissions not resulting from the specific surgery; b) change of caregivers during the 30-day postoperative period; c) postponement of the surgical procedure for more than 30 days, after the intervention; d) lack of accessibility to the Internet; e) barriers to using the technology platform.

The following professionals participated in the study: three occupational therapy undergraduates, a supervising professor of the Occupational Therapy Course at the Federal University of Paraná (UFPA) and two collaborators from the co-participating institution, and a nurse and a surgeon working in the breast surgical oncology sector of Erasto Gaertner Hospital, which is a center specialized in the treatment of oncological diseases in Curitiba, state of Paraná, Brazil, where the research was carried out. The project was approved by the Research Ethics Committee of the aforementioned Institution under protocol no. 26691819.9.0000.0098, and was conducted between March 2020 and March 2021.

The study methodology can be described as follows: a) Initially, the participants' contacts were forwarded by the Institution's collaborators (surgeon and nurse), adopting as only criterion the need for the surgical procedure to occur during the study period. b) After that, the undergraduates made the first telephone contacts to identify whether the participants met the established inclusion criteria and wished to participate in the study, when they would be fully informed about it. c) Upon acceptance of the invitation by the participant, a recorded videoconference was set between them one week prior to the surgery, when the informed consent form was presented and signed. Then an initial

focused interview, following a semi-structured script based on the Associação Americana de Terapia Ocupacional (2015), was conducted to identify the IADL that the participants most needed occupational therapeutic guidance. Next, a new remote meeting was scheduled, this time with the participation of the family members listed by the patients as their main caregivers in the recovery period. The semi-structured interview script was guided by questions related to the everyday routine of the participants, and included: caring for other people and animals, managing communications, commuting, financial management, managing and maintaining health, establishing and managing the household, preparing meals and cleaning, religious and spiritual activities and expression, safety and emergency maintenance, and going shopping. d) After the first meeting with the participants, the undergraduates and the supervising professor evaluated and discussed the case through a videoconference and defined the occupational therapeutic guidance items that would be sent and explained to the family members using Google Docs. e) When the analysis of the IADL reported by the participants was completed, virtual meetings with the family members and the undergraduates were scheduled to transmit the appropriate guidance. f) One month after surgery, a new meeting was held via videoconference for the final interview with the participant, when the following open questions to assess the intervention were asked: Did you receive the family support you expected during the postoperative period? How has the routine organization contributed to your recovery process? How could this period have been without the assistance to organize the proposed routine? How did you perceive the organization of your family members during your recovery? Were your family members more distant or closer to you? Were your preferences respected? How was your participation in the IADL during the postoperative period? g) Subsequently, the material obtained was systematically transcribed and interpreted by content analysis. All the aforementioned stages of the study were audio and image recorded using the StreamYard platform. .

Results and Discussion

Fourteen (14) women aged 32 to 66 years, residing in the state of Paraná, Brazil, with average monthly family income of BRL 1,599.57 (~USD 302.00), participated in this study, according to the data presented in Figure 1 in the QR-Code format.



Figure 1. Socioeconomic and clinical characteristics of the participants. Source: Prepared by the authors (2022).

To carry out the occupational therapeutic guidance, it was necessary to know which activities were considered significant by the participants in their recovery process. The activities mentioned by the participants are presented in the Table 1.

Table 1. Occupations considered as priority by the participants.

Participants	Instrumental Activities of Daily Living (IADL)
P.1, P.5, P.6, P.10, and P.11	Cooking and cleaning; Household management.
P.2	Caring for other people.
P.3 and P.9	Cooking and cleaning.
P.4, P.12, and P.14	Household management.
P.7	Commuting.
P.8 and P.13	All IADV.

Source: Prepared by the authors (2022).

Initially, the researchers provided the caregivers with general guidance aiming to sensitize them to care for the participants. This guidance included preventing overburden, appreciating significant activities, understanding of the individualized recovery process, respecting body image and emotional instability, being attentive to postoperative physical limitations, and keeping affective bonds, occupational roles and sense of belonging.

The occupational therapeutic guidance carried out with the caregivers (Figure 2) were designed so that they could become aware of the occupational participation of the participants and recognize the importance of both supervising and partially or fully performing a given task, thus building new ways of caring.



Figure 2. Occupational therapeutic guidance for caregivers. Source: Prepared by the authors (2022).

From the final interviews and the exhaustive reading of the collected material, the researchers organized the results found according to the delimited objectives, as shown in Table 2.

Family as a support network and the recovery process

Cancer patients have their routine interrupted by the consequences of invasive therapeutic procedures that can limit or prevent the performance of their occupations in the short and long term, which can interfere with the quality and continuity of their

Table 2. Analysis categories and subcategories.

Category	Sub-category
Family as a support network and the recovery process	Instrumentalizing the family; delegating tasks and grading doing.
Care challenges	Participant’s autonomy and independence; adapting contexts and environments to the surgical process demands.
Resuming IADL performance	
Assurance of physical and emotional integrity	
The occupational therapist as a support network	

Source: Prepared by the authors (2022).

treatment and decrease their survival time when they do not have a support network (Ribeiro et al., 2019).

All participants in this study pointed to their family members as their main support network, which according to Vargas et al. (2020) can be understood as a set of meaningful interconnected bonds, based on mutual help, that includes people who interact regularly at a given time.

The support received from family members during the critical period of recovery - the first 30 days after surgery, surprised the participants and caused feelings of gratitude and security that seemed to inhibit their guilt for not being able to perform essential daily tasks, as evidenced in the following excerpts:

They’re helping me. It has been a good experience, because it helped in many situations, both postoperatively and now. Now I’m doing things, but if it wasn’t for their help, I don’t think recovery would be so important (P.1).

My family has helped a lot. If not for them, I don’t think I would have made it. I didn’t expect all this help, from my mother, my sister, my daughter. They have and are still helping me a lot to this day. In the beginning, they all supported me in caring for my son in everything! (P.2).

These reports corroborate the study by Alecrim et al. (2020), who state that the family plays a crucial role in motivating and encouraging the participant not to give up the treatment, since all the necessary support to face the symptoms arising from the pathology and therapies will come first from within the family field.

Discussing the importance of family support for breast cancer treatment, Furlan et al. (2012) and Vargas et al. (2020) consider the relationship between social support and breast cancer fundamental for the recovery of these women, since the support network is considered a protective factor for their health, as it has direct effects on their well-being, because when these women receive social support, they perceive themselves as important and respond to challenges by adopting positive behaviors, such as maintaining actions that promote their health and being protagonists of their care, enabling their restructuring, psychosocial adjustment and adaptation to the new routines.

Instrumentalizing the family

The fight against breast cancer brings changes to family relationships, requiring ability to (re)adapt to new needs, as it is the family members who will provide the main support and help to the woman before, during and after the surgical intervention. Therefore, special attention should be given to family relationships during care, as they are important determinants of the health/disease process (Faria et al., 2016).

According to Sanchez et al. (2010), Gariglio (2012) and Faria et al. (2016), understanding the essentiality of family engagement in the recovery process of cancer patients illustrates the need to organize their routine based on guidance provided to their families. This guidance has the function of forming a structure for the division of tasks and assistance to the IADL performed by these women, who would be unable to perform them partially or totally during the recovery period, and these are the activities that most demand help after breast surgery because of their greater complexity.

Ribeiro et al. (2019) state that 74% of cancer patients treated by occupational therapy report deficits in performing IADL. In this study, each participant listed the IADL they considered to be a priority in their routine and for which they thought they needed help after breast surgery. Based on these data, the researchers developed personalized guidance for the family members on how they could organize themselves, according to their availability, to perform the IADL, avoiding overburden and letting the women participate in the decisions, respecting their preferences, in order to minimize disruption to their routine. This included adapting environments to facilitate the performance of some tasks - such as leaving routinely used utensils and accessories at shoulder height, grading activities that the participant could perform, avoiding fatigue and stress, as well as providing guidance on tasks that only the caregivers could perform for a certain time.

To this end, Marchi et al. (2016) affirm that it is necessary that the caregiver be instrumentalized to care for the family member, know and understand the purpose of the treatment, and be aware of the importance of their involvement in this process.

The following reports exemplify the successful engagement of family members in understanding the limitations inherent in this type of surgery and the need to respect the preferences and autonomy of the participants, including them in the decision-making process, which provided confidence in how, what, and who should do each task. Factors that provided lightness to face such a critical period, both for the women and for their family members.

They've managed it they cooperated. They really surprised me. I could've coped with it, do things the way I could. But then it was very good that they had the right guidance, divided the sectors and services. They did as you told them to. Without your help, it would be nearly impossible, because I had no idea of how I would do it. I realized that they were happy to do everything right, the way I wanted, they didn't feel obligated, they did everything of their own free will... as I said, it's working to this day (P.1).

I've always been very confident about my things, but when you're there, with a big cut like that, there's a lot of insecurity. So their firmness... because they had good guidance, they both knew what to do. So, they were prepared for anything (P.12).

In addition to the confidence demonstrated by family members, the structuring of the routine, based on the proposed instrumentalization, contributed not only to carry out the IADL, but also to bring out feelings of well-being and satisfaction, both in the participants - because they knew they could count on a support network, and in the family members - because they knew that they were acting assertively to promote the care and adherence of these women to the treatment.

Delegating tasks and grading doing

Participating in occupations can be a protective factor for women's health, generating benefits that go beyond the physical, mental and social aspects, being able to provide satisfaction and well-being (Virgínia, 2011).

According to Wilcock (2006), well-being refers to a person's perception of their own health, and is associated with concepts such as self-esteem, happiness, belonging, and self-growth.

Virgínia (2011) claims that feelings of well-being often stem from things people do that provide a sense of purpose, vitality, or wholeness. However, when the performance of some activities is compromised, performing them can have harmful effects on health, and it is thus essential to make some (re)arrangements in the family structure to ensure that significant and essential activities are carried out, and for this, adaptation and graduation techniques and even task delegation can be used to guarantee the integrity of people's physical and mental health.

According to the guidance provided by the researchers to the family members, this study emphasizes that, despite some limitations, the women could grade some tasks to remain active in their routines. However, other tasks should be performed only by the caregivers for a certain time, with delegation of those considered harmful to surgical recovery.

The following reports show how these family arrangements are indispensable to guarantee the well-being of the participants and the continuity of their treatment, thus favoring their better recovery. These conditions are possible only when the participant has a properly oriented social support network.

The girl did almost everything, what I could do, lightly, I did, but she did all the heavy work. I chopped the vegetables, washed them, she did the rest. I never stayed next to the stove, at least for a fortnight, then I started dealing with the stove (P.3).

At first, my son washed the dishes and dried them, too. Now I wash them and he dries them and puts them away. They cooked, washed the dishes, hung clothes... my husband did the work of ten people here. He used to put the clothes in the washing machine, hang them up, stretch them out, turn them inside out, which I couldn't do. He used to wash the dishes, clean the stove. Last Saturday, he mopped the house and washed the bathroom. My husband would sometimes make dinner. He used to do the laundry on Saturdays because he had to work on weekdays (P.11).

These reports, in addition to demonstrating the commitment and engagement of family members in the care of these women, brought reflections about the overburden imposed on caregivers, since they become responsible for tasks that did not use to be part

of their routine, but still have their own responsibilities, obligations, and routine activities. Borges et al. (2017) point out that patients and caregivers have an interdependent relationship regarding quality of life. The better the patient's quality of life, the smaller the impact on the caregiver's life. In view of this, it is extremely important that family members and patients be instrumentalized to offer and receive care in order to reduce this burden and, consequently, improve the quality of life for both.

The World Health Organization (WHO) (Organização Mundial da Saúde, 2002) defines quality of life as an individual's perception of their own life in relation to their goals, expectations, standards and concerns, and involves physical, mental, psychological and emotional well-being, in addition to social relationships and other life circumstances.

Accordingly, Monteiro et al. (2010) point out that a person's quality of life is directly related to their perception of their in everyday life, including physical, economic and social aspects, such as the quality of their relationships, well-being, and health.

Hence the importance of keeping participants active in their everyday activities during treatment, grading tasks so that they could be performed by the participants themselves, and delegating only those whose execution could be harmful to their recovery, because, according to Organização Mundial da Saúde (2002), patients undergoing treatment are not passive beings, but agents that produce their health.

Care challenges

In addition to what the family members were instructed as being unsafe to be performed by the participants until a certain time after recovery, and therefore the exclusive responsibility of the family members and/or caregivers, numerous possibilities of active participation of these women were recommended aiming to prevent disruptions to their routine and restrictions on their activities. Despite these recommendations, participants P.5 and P.6 reported little involvement in doing during the first 30 days after surgery.

To be honest, I didn't do anything, as usual. They wouldn't let me do anything. I went from my bed to the sofa, from the sofa to my bed. I didn't do anything that I had to move my arm. I was, indeed, in complete rest. And it has been so until today. I didn't give much importance to doing this or that, because it was more difficult, right? So, I was quiet (P.5).

She wouldn't let me do anything. Sometimes I washed a couple of cups, took the trash from the bathroom, hung my towel on the clothesline, my way, but it was all kind of hidden from her, because she wouldn't let me, she preferred to do everything herself (P.6).

Being an informal caregiver means exercising an occupational role, and usually this person is a family member, a friend, or an acquaintance who is willing to help with the health needs of another person. This role is added to other roles played throughout life and, despite being onerous and having a potentially negative impact on quality of life, it can also be an object of learning and social recognition (Dahdah & Carvalho, 2014).

Participants P.5 and P.6 presented a challenge to occupational therapy practice when they reported the reproduction, by their caregivers, of a care centered on “doing for the other”, stimulating the dependence of the individual being cared. However, it is worth noting that “caring is not doing for the other, but helping and encouraging the person being cared to achieve their autonomy even if in small tasks”; also, “[...] the role of the caregiver is to accompany and help the person to take care of themselves, doing for them only the activities they cannot do by themselves” (Brasil, 2008, p. 7 and 8). This positioning of care centered on the passivity of the other illustrates the way these family members conceive their occupational role as caregivers.

Restriction to occupational participation postoperatively can also be the result of an individualized choice, whereas excessive participation can be established, among other factors, by the participant’s personality and life experiences. Participant P.11, despite the therapeutic recommendations to avoid exposure to intense heat, especially due to axillary lymphadenectomy, abruptly made unsuccessful attempts to cook before the recommended time (15 days).

I am stubborn! After a few days, I tried to cook, then I was with my hand like this near the stove, you know? Then I started feeling that it was hot, and I saw it was getting red, and then it began to leak... I was like that for two days. I'm stubborn, but thank God, now I've decided I'm going to take better care of myself. The stove is an issue, because I like cooking, right? I like the spices. When I was going to insist on it, I remembered what you told me: 'but I can't do that', then I felt a pain, you know, I felt some pain, and then I stopped (P.11).

This report shows the participant’s anxiety in the face of the limitations caused by the surgery, experiencing a detachment from her occupational roles and loss of control over the environment, which led her to impulsively break with the proposed guidance and, consequently, develop an inflammatory process.

Considering this report, Strain (1978, as cited in Botega, 2017) argues that the fear of losing control is part of the psychological stress that, from the discovery of a life-threatening disease, invades patients when they maintain contact with the universe of cancer centers. Since the beginning, these patients need to be actively listened, and this must continue throughout all phases of treatment.

Participant’s autonomy and independence

Occupational therapy practice is associated with social emancipation, when it aims to enable people to exercise their autonomy in everyday life, have the necessary freedom and resources to make constructive choices, and the maximum independence possible to carry out their life purposes (Carvalho, 2012).

Approaching the occupational therapeutic principles of autonomy and independence, participants P.8 and P.14 reported making choices about what they would like to eat and buy, how to cook, in addition to noticing differences in the recovery process compared with previous experiences.

My daughter used to go shopping. She would go to the market and I would tell her what I wanted her to buy, and then my mother or my sister would cook according to

what I wanted to eat. The other time, I didn't even care about it, you know? Not this time, this time I was more demanding. For me, it was much better than the first surgery. The first surgery was more restrictive, I was afraid of many things. But in this second surgery, I was more independent. Knowing that you can be independent and bother other people less was very helpful to me. I felt really good (P.8).

I think that every little tip you gave me, like moving little by little, leave things within reach, knowing that I couldn't exposed myself to heat, but that some things I could do, have helped me a lot. Even, in the case of my boyfriend, hearing that 'you can and should do things alone', so it's knowing that I'm still in charge of myself (P.14).

These findings corroborate the discussions of Pontes & Polatajko (2016), when they advocate that patient-centered and occupation-based interventions occur through the active participation of patients in determining the goals to be achieved in the therapy, always considering capacity, context, environment, social support, and possible barriers to participation.

Through this study, the participants were able to experience recovery processes that respected their choices, allowing them to receive the care offered by their families integrated with their desires and expectations, when they had the help of researchers who were mediators between the essential demands they presented and the respective therapeutic guidance to their family members. By adhering to the proposed guidance, the family members opened space for the participants to feel confident to decide and ask for help according to their own interests, which often does not happen because of restrictive attitudes imposed by caregivers.

Adapting contexts and environments to the surgical process demands

Adaptive strategies enable people with certain limitations to participate independently in activities they expect, want, and need to perform. Adaptations can be permanent or temporary, depending on the health condition (Crepeau, 2002).

In dialogue with these theoretical assumptions, it is possible to affirm that the guidance provided countless insights to family members and participants as to what could be organized for the benefit of their recovery. In this study, two participants mentioned adjustments to furniture and architectural modifications to overcome the limitations caused by breast surgery. On the one hand, participant P.1 stated that the initiative came from her family members regarding her exposure to intense heat, which prevented her from participating in the possible tasks to be performed in preparing meals and cleaning; on the other hand, participant P.12 reported a personal initiative as to reduce her occupational demands, blocking circulation to one of the rooms in her house and asking for help from others to perform tasks.

I couldn't stay close to the heat, so we modified the kitchen, and put the table away from the stove, they've done all these things for me! They've helped me a lot, haven't they? (P.1).

I locked my bathroom. The one in my bedroom suite. But I wasn't using the shower or anything in this one either. I hired a cleaner... So, it was very clean, I had no problems. I think it was all very smooth, you know? (P.12).

The WHO, through the International Classification of Functioning, Disability and Health (ICF), advocates that human functioning cannot be described merely in the face of the diagnosis of a disorder or disease, but from human multidimensionality, which includes environmental and personal factors, didactically presented as “context” in the classification (Araújo, 2013).

In this context, occupational therapists establish themselves as professionals with skills both to assess contexts and environments and to organize therapeutic plans that maximize people's occupational performance based on the environment where they live (Associação Americana de Terapia Ocupacional, 2015; Bernardo & Raymundo, 2018).

According to Crepeau (2002), adaptation is one of the components of activity analysis that enables occupational therapists to assess the demands of tasks in relation to a person's performance problems, considering the context they are in, thus guided by the paradigmatic triad person-environment-occupation, which allows acquiring, expanding or maintaining the functionality of individuals in their occupations.

Adaptations are justified because they facilitate the adaptive responses of participants to their performance context. Adapting the execution of daily tasks brought security to participation, since the steps of performing an activity were modified, allowing adequate care for body mechanics, especially the range of motion of the ipsilateral upper limb to breast surgery, as well as prevention of accidents, dehiscence, edema, and insecurity in resuming the IADL (Crepeau, 2002; Bregagnol & Dias, 2010).

Resuming IADL performance

Several participants, before their first contact with the study, had not mentioned their fears regarding the execution of the IADL directly to their families, and expressed anxiety when asked about how they conceived the recovery period, when many of them imagined a severe condition of dependence and had not yet sought help from an occupational therapist, when all were unaware of the competences of this profession.

After 30 days of recovery, when asked by the researchers about their participation in the IADL listed as significant, the participants reported what they were being able to perform, confirming the gradual return to these activities. Therefore, it is possible to observe adherence to the guidance provided by the researchers, co-responsibility with the treatment, and satisfaction with performance, as shown in the following statements::

Nowadays, I mop the house, do the dishes, cook, hang and fold the clothes. When I wash the clothes in the washing machine, I take them out with this hand. I hang them, but I'm careful of my arm. I don't push it too hard. But I don't clean the bathroom, my son does it, because it's very difficult, it demands more strength to clean the tiles and the floor. I've even been going out; I feel good. For 25 days now, I've been cooking. I'm still really careful with that arm, I pick up heavy things with the other one (E.11).

I stretch the bedsheets... I don't throw them up, but I stretch them right. When my mother takes the clothes off the lines, I put them away. It's a short clothesline, I also hang the clothes. So, I've already been doing many little things. But my father's always watching me, he comes and says: - What are you doing there? [laughs]. [...] For a week now, my pet has been staying with me, now she stays here in the corner, next to me. Now I'm taking care of her too, I give her water, food, I've been taking care of her (E.13).

These accounts illustrate the claims reported by Dias et al. (2017): organizing oneself in the face of activities that were previously developed with total vitality and pleasure becomes a crucial challenge for the patient as well as for her family, representing a need to be addressed even before the surgery, involving patient, family, and technical team in a process of co-responsibility.

Despite the different surgical approaches, all participants reported that, in the initial recovery period, they were afraid to move the upper limb ipsilateral to the surgery and that they felt pain and reduced range of motion. All participants who underwent axillary lymphadenectomy reported fear regarding this procedure, decreased muscle strength, and discomfort due to the suction drain. This fear influenced the participants' engagement in the resumption of IADL, performing them on average 20 days after surgery, despite the recommendation to resume them only as of the 15th day.

These fears are recurrent among women who undergo such procedures, as the pain generates a latent fear that makes them avoid moving the limb, causing inactivity, gradual decrease in muscle strength and, consequently, in the range of motion, directly influencing their occupational performance. Participating in some IADL, such as household chores, gives new meanings to the continuity of life in their routine and improves their quality of life (Fireman et al., 2018).

In view of this, Fangel & Cardoso (2018) recommend that the follow-up of women undergoing breast cancer treatment and their family members be carried out from the moment of diagnosis, primarily so that they can carry out strategies to prevent occupational diseases, but mainly in the immediate postoperative period, when these women directly perceive the mutilating process and the functional limitations that compromise the performance of their IADL in their routine, facilitating the resumption of their activities and promoting security for the expected performance.

Pereira et al. (2020) report that occupational therapy enables expanded support during recovery processes. Accordingly, Aniceto & Bombarda (2020) confirm that the actions that permeate the principles of the expanded practice in the intra- and extra-hospital context – a fundamental part of comprehensive and integrated care – promote co-responsibility when they carry information about what may or may not be harmful to treatment.

Assurance of physical and emotional integrity

One of the greatest fears of women is receiving a diagnosis of breast cancer, which is associated with its impact on their everyday lives, triggering feelings of pain and anxiety that generate concerns and insecurities in various aspects of their lives and those of their families (Fireman et al. 2018).

Fangel & Cardoso (2018) state that, to minimize these feelings, it is possible to use strategies to prevent or reduce these impacts on the physical-functional, social and

emotional aspects of the lives of women undergoing surgical treatment for cancer, when these strategies are analyzed from the perspective of the individual and their uniqueness, in their everyday life, expanding the look to their occupations, routine, and possibilities of coping with the process. This holistic view makes it easier to anticipate the problems or their worsening as they arise.

Understanding that occupational therapists are specialists in finding strategies focused on individuals, the researchers anticipated the demands of the IADL listed by the participants and guided the caregivers, since the preoperative period, so that they could cope with the impacts arising from breast cancer treatment. The result of this early guidance had a strong impact on both the participants and their families.

When asked how they believed this period would be without the guidance received, the participants showed how unprepared they were to face the postoperative period, and how receiving guidance for this moment reassured them and provided the necessary security. Ten of the 14 participants expressed feelings of assurance regarding their physical and emotional integrity for the recovery period, as exemplified in the following reports.

I believe it would have been much more painful, especially in terms of support, I think just the fact of knowing: 'no, she can do it', and even the confidence of knowing: 'a professional of the area said I can do it, carefully, but I can', so it's really a matter of assurance. I think it gave me more confidence to do things, not to be in a cast, not to stand still (P.14).

I think it would have been more difficult, right? When we don't understand anything, I would think that it's a little surgery, right? Like when I had a cesarean section, even before a month I split firewood! I think it would have been more difficult, but with the guidance, it was good, it helped me a lot (P.3).

In addition to the unpreparedness experienced by most women who need to undergo mutilating surgical treatments, Cavalcante et al. (2016) affirm that these treatments, although strictly necessary for the continuity of life, increase psychic fragility because they provide a perception of health deterioration associated with sadness for the moment experienced, nervousness, fear of a possible recurrence of the disease, of threat to life, of family abandonment, and of changes in personal and social relationships and occupational roles.

The following reports evidence this psychic fragility in the face of the predominant unpreparedness in coping with cancer, but go further, as they show the importance of guidance in the preoperative period both for the participants, who allowed to be cared for when necessary, and for their families, who care for participants with respect to their autonomy and independence.

I think it would have been the worst thing in my life. I wouldn't know what to do, I'd be completely lost, I'd be desperate, I think I would even develop depression. If I hadn't had all this guidance, it would have been worse, much worse! (P.6).

I believe it would have taken longer to recover the movements of my arms, you know? I would be lying there for much longer, with fear, which didn't happen this time. Knowing what you could and could not do! So, this time, I made my moves consciously and knowing that it would be better for me, right? (P.8).

I wouldn't have known how to proceed with my household chores, which ones I could do. I'd feel all limited, you know? I wasn't aware that I couldn't be exposed to heat, to hot steam. But it's hard for you to have to limit yourself a lot, right? It's difficult! (P.11)

Surgical treatment of breast cancer can be traumatic if not followed up early by a multidisciplinary team, since the initial expectations are for immediate recovery; however, they do not correspond to the time required for this, in addition to lack of information regarding the capacities and limitations resulting from the treatment. Therefore, integration between patient, social support network and health professional is essential, aiming at the universality of care and reduction of suffering arising from the insecurities involved in cancer treatment (Cavalcante et al., 2016).

The occupational therapist as a support network

Offering humanized and compassionate care, with qualified listening and availability for clarification in health, contributes to establishing a link between the occupational therapist, the patient and their support network, building relationships of trust and enabling effective care. These resources favor adherence to treatment and create, expand, or maintain personal mechanisms for coping with the disease (Santos et al., 2017).

The occupational therapist is responsible for knowing and using, in their interventions, updated references of good health practices, such as the guidelines proposed by the National Humanization Policy (PNH) developed by the Ministry of Health (MS) in 2003. Therefore, the construction and application of this study finds a conceptual basis in this theoretical instrument. The researchers, being aware of its recommendations, developed qualified listening to the participants and their families, conducted respectful dialogue attentive to their singularities, and had postures that allowed openness to questions. and doubts related to the research object.

Participants P.2 and P.14 made comments that describe feelings of gratitude for participating in this study, mentioning this reception as crucial at this moment in their lives, as well as in those of their families. They refer to this participation as memorable, reaffirming the commitment of occupational therapy to bring patients closer to humanized health actions based on what makes sense for their lives, making them the protagonists of their histories.

I'd like to thank you so much for what you've done! Because you came and talked to us, to our families, and that has brought us closer every day. I really, really wanted to thank you for your support... Gosh, I'm crying! I will remember what you've done for the rest of my life (P.2).

For me, participating in this study was something precious, because the details made all the difference, knowing my limits, knowing how far I can go. You gave us tips, taught us the best way, so this is very important (P.14).

Experiencing a surgical procedure for breast cancer requires women to organize themselves and rearrange their roles and daily occupational activities. These sudden

changes force them to face new challenges arising from the diagnosis at a time of physical and emotional fragility (Fangel & Cardoso, 2018).

However, feelings of gratitude, when stimulated, increase resilience, physical health and quality of life, and develop positive mental states such as generosity and empathy. People feel loved and cared for, favoring the search for specialized support in situations of emotional discomfort (Pieta & Freitas, 2009).

In addition to gratitude, most participants expressed a desire for broad coverage of occupational therapeutic actions for women undergoing breast cancer treatment in Brazil, as well as recognition of researchers as a part of their support network for performing surgical treatment.

Thank God I have a structured family, and I would like you to take this forward to those who don't, because there are many women who are alone and don't have the support that I do. So, many people face this phase alone... I hear the women's conversations: 'Oh, that was difficult, that was difficult'. So, I would like this to be extended to everyone, so that everyone could have this privileged recovery and, in a way, feel supported. Because in our conversations, you showed concern, interest, so for me, it is important, I believe that if you extended this to more women, it would be very beneficial to their treatment as well, because you play a very important role in this recovery process, 90% of what I did, I did thanks to your guidance (P.8).

Occupational therapists also face some challenges to integrate into the multi-professional team in the care of patients affected by oncological diseases. These insertion difficulties occur because of the little knowledge of physicians and the multi-professional team about the object of study of occupational therapy and its expertise in the care of patients undergoing cancer treatment. There is also poor communication about the theory and practice of the occupational therapy with other health professionals, which can interfere with referral and performance in this context (Ribeiro et al., 2019).

Resolution no. 429/2013 of COFFITO, recognized the specialty of occupational therapy in hospital contexts, predicting the performance of the category in secondary or tertiary hospitals, intra- and extra-hospital care, and Palliative Care. This recognition is a reflection of a practice that has been developed for decades in Brazil, which allows expansion of the occupational therapist's performance in high complexity care (Brasil, 2013).

Final Remarks

This study is an important production in occupational therapy, because it proposes family guidance for the routine organization of women undergoing surgery for breast cancer treatment, thus allowing replication in other contexts of action. The actions developed achieved satisfactory results by enabling responsible involvement in occupations, minimizing routine disruptions, preventing readmissions, and promoting autonomy, independence, and well-being in the face of invasive and mutilating treatment.

In addition to the listed IADL, this study faced other demands mentioned by the participants in need of occupational therapy assistance, such as activities of daily living, work, leisure, rest and sleep, and social participation, but which were not the focus of

this research. Therefore, special attention and efforts from the academic community are needed to promote studies that address the issue and focus on all occupational needs arising from both the diagnosis of breast cancer and its consequences on the surgical treatment of patients and their support network.

The methodology used reflects the profession's commitment to the challenges facing occupational therapeutic actions at the time of the COVID-19 pandemic, which requires restriction of physical contact and jeopardizes the continuity of treatment of numerous diseases, including cancer, intensifying the suffering of thousands of people.

Limitations to this study include its sample size and the fact that it was unable to accommodate, in its developments, participants who had difficulties in using the chosen technological platform and those who did not have access to the Internet.

Throughout the study, the researchers were immersed in atypical and limiting situations regarding its execution as planned. With the advent of the COVID-19 pandemic and its consequences in the hospital context, the scheduling of elective surgeries was impacted, influencing the referrals of cases to researchers and, consequently, reducing the available working time. In addition, the entire proposal outlined previously, which consisted of face-to-face visits to the participants' homes, had to be adapted to the new reality. The favorable position for teleconsultation issued by COFFITO in March 2020, allowed meetings and interventions to be conducted remotely.

The remote modality in occupational therapy is an alternative that requires inclusive and didactic methodologies to be used, enabling the exchange of knowledge with a view to collaborative family care and allowing women the due protagonism they need and hope to have at this moment of their lives.

Acknowledgements

The authors are grateful to Hospital Erasto Gaertner, especially to the professionals of the Gynecology and Breast Surgical Oncology Service, for the support given to this study.

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