

RESEARCH ARTICLE (ORIGINAL) 

Experiences of women after mastectomy: rehabilitation nursing care in promoting autonomy

Vivências da mulher mastectomizada: a enfermagem de reabilitação na promoção da autonomia

Experiencias de la mujer sometida a una mastectomía: la enfermería de rehabilitación en la promoción de la autonomía

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Abstract

Background: The woman with mastectomy experiences changes in functionality and at the emotional and social level. Rehabilitation nursing plays an important role in promoting autonomy and independence.

Objectives: Describe the experiences of women with mastectomy at home and identify the importance attributed by women with mastectomy to the rehabilitation nursing intervention.

Methodology: This study is based on a phenomenological qualitative approach. The snowball sampling technique was used to select the 9 participants. A semistructured interview was conducted.

Results: The women experience physical complications and difficulty in performing tasks. They consider the rehabilitation nursing intervention as significant to recovering functionality and accepting body image. They report feelings like fear, outrage, and changes in interpersonal relationships.

Conclusion: A rehabilitation nursing program adapted to each woman and the phase of the adaptation process she is in is fundamental to prevent complications and promote autonomy.

Keywords: breast neoplasms; mastectomy; nursing; rehabilitation; autonomy

Resumo

Enquadramento: A mulher mastectomizada vivencia alterações ao nível da funcionalidade, e ao nível emocional e social. O enfermeiro de reabilitação desempenha uma função importante na promoção da autonomia e independência.

Objetivos: Descrever as vivências da mulher mastectomizada em contexto domiciliário e identificar a importância atribuída pela mulher mastectomizada à intervenção do enfermeiro de reabilitação.

Metodologia: Assenta numa abordagem qualitativa fenomenológica. Recorreu-se ao método por redes/bola de neve para a seleção de 9 participantes. Realizada uma entrevista semiestruturada.

Resultados: As mulheres experienciam vivências relacionadas com complicações físicas e dificuldades na execução das tarefas. Atribuem significado ao enfermeiro de reabilitação na recuperação da funcionalidade, e na aceitação da imagem corporal. Relatam sentimentos como medo, revolta e alteração nas relações interpessoais.

Conclusão: Um programa de enfermagem de reabilitação adequado a cada mulher e à fase do processo de adaptação em que se encontra é fundamental para prevenir complicações e promover a autonomia.

Palavras-chave: neoplasias da mama; mastectomia; enfermagem; reabilitação; autonomia

Resumen

Marco contextual: La mujer que se ha sometido a una mastectomía experimenta cambios a nivel de la funcionalidad, así como a nivel emocional y social. El enfermero de rehabilitación desempeña una función importante en la promoción de la autonomía y la independencia.

Objetivos: Describir las experiencias de la mujer sometida a una mastectomía en el contexto domiciliario e identificar la importancia que la mujer atribuye a la intervención del enfermero de rehabilitación.

Metodología: Se basa en el enfoque cualitativo fenomenológico. Se recurrió al método por redes/bola de nieve para seleccionar 9 participantes. Se realizó una entrevista semiestructurada.

Resultados: Las mujeres vivieron experiencias relacionadas con complicaciones físicas y dificultades en la ejecución de las tareas. Atribuyen significado al enfermero de rehabilitación en la recuperación de la funcionalidad y la aceptación de la imagen corporal. Señalaron sentimientos como miedo, enfado y cambio en las relaciones interpersonales.

Conclusión: Un programa de enfermería de rehabilitación adecuado para cada mujer y para la fase del proceso de adaptación en la que se encuentra es fundamental para prevenir complicaciones y promover la autonomía.

Palabras clave: neoplasias de la mama; mastectomía; enfermería; rehabilitación; autonomía

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Introduction

Breast cancer is the most common type of cancer in women in the world (World Health Organization [WHO], 2019). The high incidence and the implications of the mastectomy in a woman's life raise several questions that lead to reflecting on the importance of this theme and how the rehabilitation nursing intervention can have an impact on the autonomy and independence of these women.

The mastectomy can result in physical and psychological complications, so the participation of women in a rehabilitation nursing program contributes effectively to the rehabilitation process and the prevention and treatment of these complications. In order to ensure the continuity of care, it is necessary that the discharge and rehabilitation of these women are planned by the inter/multidisciplinary team which the rehabilitation nurse is part of, so that they can be educated and trained in how to take care of themselves, as well as in the physical exercises and care that prevent and lead to the steady recovery of functional capacity (Camões, Gomes, & Pinto, 2015).

Rehabilitation nursing has a prominent role in the effective treatment, prevention, and management of complications that may compromise functionality and affect the woman's quality of life. Here the nurse is the link between the experiences of women and their adaptation process.

Thus, the objectives of this study are defined as follows: describe the experiences of women with mastectomies at home and identify the importance attributed to the rehabilitation nursing intervention by women with mastectomies.

Background

According to the World Health Organization, up to 2020, more than 1.2 million women will be diagnosed with breast cancer per year worldwide (WHO, 2019).

In Portugal, 6000 new cases of breast cancer are diagnosed per year, which is equivalent to the diagnosis of 11 new cases of this disease per day (Liga Portuguesa Contra o Cancro [LPCC], 2019).

According to the National Comprehensive Cancer Network (NCCN, 2011), breast cancer is divided into in situ carcinoma, which consists of the carcinoma located within a limited area of the breast and is considered *non-invasive*, and *invasive carcinoma*, which invades adjacent structures, occurring metastazation. Breast cancer is divided into five stages that take into account the following indicators: tumor size, number of affected ganglia, and presence of metastases. There are several treatment options, such as surgery, chemotherapy, radiotherapy, hormone therapy, and targeted therapies.

It is necessary to introduce an early rehabilitation program because it is possible to obtain satisfactory results at the level of the increase in the amplitude of joint movement, the reduction in the volume of the edema of the limb on the same side of the mastectomy, and, consequently, the reduction of pain and functional incapacity (Táboas et al., 2013).

There are three phases inherent in the rehabilitation nursing

process: Preoperative phase whose objective is to know previous changes, check risk factors for the postoperative period, which contributes to the functional improvement of the limb on the same side of the mastectomy (Silva, Koetz, Sehnem, & Grave, 2014); Postoperative phase, in which in the immediate postoperative period involves a series of procedures such as positioning in bed on the opposite side of the mastectomy, relaxation and stretching exercises for pain and muscle contraction relief, and active assisted exercises of low amplitude (Camões et al., 2015); Chronic phase, which aims at the continuity of care to ensure the woman's quality of life, as regards the development of activities of daily living (ADL).

The rehabilitation nursing intervention is reflected in the independence and autonomy of the person to take care of herself and also in gains in health for the women with mastectomies. This intervention is carried out for the prevention of complications secondary to surgery, the empowerment of women in performing ADL, and in the recovery and/or maintenance of functional capabilities (Camões et al., 2015).

Autonomy and independence, although not synonymous, are frequently associated. The definition of autonomy is the ability to control, be responsible for the actions and decision-making in accordance with the person's environment (WHO, 2002). Still according to WHO, independence relates to the ability to perform ADL, that is, to live in the community without help.

The rehabilitation of women with mastectomies should aim for an intervention that promotes independence and autonomy through the definition of strategies that help in the process of adaptation, contributing to the physical, psychological, and social well-being of the woman.

Research questions

What are the experiences of women with mastectomies?
What is the importance attributed to the rehabilitation nursing intervention in the promotion of autonomy?

Methodology

A phenomenological research study of qualitative nature was conducted. The phenomenology is a qualitative method that emerged from philosophy and psychology. The authors Polit, Beck, and Hungler (2004, p. 207) stated that "phenomenologists investigate subjective phenomena in the belief that critical truths are grounded in people's life experiences".

The participants included in the study were selected in accordance with the specific knowledge they hold about the phenomenon, with the particularity of sharing this knowledge (Streubert & Carpenter, 2002).

This research study was based on the socio-professional contact with a woman with mastectomy, who referred to other women with mastectomies living the same experiences. The sample selection was carried out through the snowball sampling method. The intentional sample consists

of nine participants, being defined when the saturation of data was achieved.

The choice of the context in which the collection of data took place considered the objectives outlined for this study, requiring the approach to be made at the participants' homes. Thus, the interview took place at the participants' homes, providing a greater involvement of the woman who experiences the phenomenon.

Considering the research issues and objectives, the data collection method was the semistructured interview, based on an interview script, which included the themes for analysis. An opinion was requested to the Ethics Committee of the Health Sciences Research Unit: Nursing of the Nursing School of Coimbra, which was favorable (Opinion no. P27:2-03/2015).

The participants were informed of the study and its contributions to nursing, society, and women with mastectomies. They were given the document of informed consent for signing and requested authorization to proceed with the audio recording of the reports. The following inclusion criteria were considered: female gender; consent to their collaboration in the study; be oriented; having undergone intervention due to diagnosis of breast carcinoma; having undergone mastectomy more than a year ago; being at home. As regards the exclusion criteria, the non-fulfillment of any of the inclusion criteria was the only one.

After data collection, the interviews were transcribed in their entirety. The data obtained were analyzed by the analysis method according to Loureiro (2002; 2006), which is derived mainly from pioneering work, but seeks to preserve the essence of the Husserl's proposal.

As a way to ensure credibility, one last contact was established, via telephone and e-mail, in accordance with the desire expressed by women, validating the transcriptions. To ensure the transferability of the data collection process, intentional sampling was applied to select the participants, according to the inclusion criteria, as well as the detailed description of the reports associated with the meticulous collection of descriptions. As regards reliability, which ensures research accuracy, a thorough data collection was performed based on the interview, including the meticulous transcription of reports. The confirmability was ensured through the contextualization of the current state of knowledge about the mastectomy and accurate description of the path and methodological option.

Results and Discussion

Based on the objectives and the phenomenon studied, and after the transcription of reports, a set of themes and sub-themes emerged, which is divided into two groups: experiences of women with mastectomies at home and experiences of women with mastectomies relating to health care. These are central themes, which are cross-checked with the literature.

The transcribed participants' reports are coded with the letter P (participant) and the number of the order in which the participants were interviewed.

Experiences of women with mastectomies at home

The mastectomy still is the most widely used method for the treatment of breast cancer (Furlan et al., 2013), being unanimously reported physical complications and an impact on reality.

Perceived complications and difficulties

When adapting at home, people face complications such as pain, "and the arm on the side of the mastectomy has limited movement . . . This is what causes me a lot of pain" (P2; June 2015). According to Bani-Hashem et al., cited by Mourão et al. (2013), pain control is directly related to the woman's well-being and quality of life. Other reported complications include lack of breast weight, which leads to change in postural biomechanics, "I felt pain in my spine during the first weeks" (P5; July 2015), a situation that can cause irreversible deformities when is not corrected.

"I had complications one year after, swelling of the arm and shoulder" (P7; September 2015). The changes in lymphatic drainage are referred to by four women, and Táboas et al. (2013) estimates that 20 to 25% of women undergoing surgical intervention for breast cancer will develop lymphedema and restriction of joint range of motion, "I always felt like the arm got stuck, prevented me from the simplest movements . . . The hand would swell, and the arm would get bigger . . ." (P1; June 2015). There are functional limitations that prevent performing or developing certain ADL, such as not being able to carry weight and perform tasks that require strength because they feel pain, "I dropped some soup dishes, and when hanging clothes to dry to extend the machine, I felt the arm tighten" (P1; June 2015); "because I cannot carry weights, I cannot carry children at work" (P9; September 2015).

The feeling of uselessness is evident in women because they cease or diminish the performance of daily tasks, "I have many difficulties with everything that requires efforts . . . in the kitchen I am already very limited (sighs)" (P4; July 2015). These women need to define strategies that help in maintaining everyday life to meet self-care needs, which according to Galvão and Janeiro (2013) encompasses the person's ability to take care of herself and perform necessary actions to maintain, restore, or promote health.

The participants reported asking for the support of a family member or significant person in the process, interrupting the tasks at the onset of pain, and acquiring materials such as appliances that assist in the tasks, "instead of sweeping the floor with the broom, I always use the vacuum cleaner. I climb onto a stool to hand the clothes to dry because it hurts to stretch the arm . . ." (P5; July 2015); "if my husband is not at home, I only do things that I know I can handle" (P3; June 2015).

It is noted that, throughout the process, all these women have the support of one or more elements to overcome the various difficulties and report the husband and/or children as significant persons in the process and, also, the belief in God as part of the support in adapting to this life phase, "my family, my children, because I don't have a husband

anymore, and God are my support, my great support . . . the family support is very important and also God's . . . I prayed a lot and still pray every day . . . I have a lot of faith" (P4; July 2015); "My husband was my great source of hope, always by my side to give me strength, he was my right-hand man" (P8; September 2015).

Perceived feelings

The mastectomy triggers doubts, anxiety, and fear of the future, mainly by the lack of information related to the situation. The ablation of breast changes the woman's social and sexual identity, influencing interpersonal relationships (Natalia, Fangel, Almeida Prado, & Carlo, 2016), "I was afraid for my husband, and I hid myself from him a lot at the beginning . . . Didn't want him to see the scar but I think that this is normal in all women . . ." (P1; June 2015).

After the reading and analysis of reports, it is observed that the predominant feelings among women are mainly the sorrow associated with fear, "I feel sad . . . afraid to see myself in the mirror . . ." (P3; June 2015), the discouragement and outrage, "it affected me a lot, I wasn't counting on this, and suddenly it happens to me and everything falls apart (cries)" (P6; August 2015).

The suffering related to the mutilation of a part of the body leads to the reporting of feelings where sadness is dominant (Camões et al., 2015), "When I looked in the mirror, I felt sad . . . I have only one breast, at the beginning it was hard . . . it still is" (P5; July 2015).

Hope is referred to by a participant, "I know that I don't have a breast but I accepted it. It helps a lot to have such a positive personality and to never lose hope (smiles)" (P1; June 2015), a feeling that eventually occurs in any stage of the mastectomy process (Araújo & Fernandes, cited by Lago, Andrade, Nery, Avelino, & Noletto, 2014). These statements are in line with the study of Mourão et al. (2013), which shows that the most frequent feelings in women with mastectomies are sadness, discouragement, poor body image, non-acceptance of the mutilation, and change in sexuality, "I felt sad, discouraged, some days are worse than others, and in the winter I feel much worse (silence)" (P7; September 2015); "there are many things that I can't do at home, which makes me sad because I was very independent (silence)" (P8; September 2015). As regards the changes in body image, women report what they felt regarding the mastectomy process and its impact on body image, "and I just realized my breast was going to be removed in the last days before the surgery (silence)" (P1; June 2015); "psychologically, I still cannot look in the mirror, it bothers me, I prefer not to look, then I think about it . . ." (P3; June 2015).

Rehabilitation process

Rehabilitation plays a crucial role in functionality because women who underwent inpatient and outpatient rehabilitation sessions reported an improvement in joint movements and edema reduction and mentioned benefits in the limb's physical maintenance, leading to an easier performance of ADL: "besides the rehabilitation treatment at the health center, which has helped me a lot to

overcome the physical difficulties . . ." (P1; June 2015); "I don't know but these rehabilitation treatments help me to continue to work . . . These precautions will help me in movement and pain relief" (P2; June 2015). In that relates to rehabilitation at home, only one woman reported having done it, which allows assuming that rehabilitation nursing intervention needs to be developed in his area, "I have a nurse friend who assists me in rehabilitation at home, compression therapy, using a sleeve, and helps me to correct the exercises so I can do them later alone" (P1; June 2015). According to Táboas et al. (2013), it is important to maintain a regular and continuous rehabilitation program, so weekly monitoring at home leads to a greater adherence by woman.

The successful rehabilitation of women with mastectomies is associated with several factors, in particular, the employment factor, which is important to them and where women report feeling more limited due to their current health condition, "my colleagues at work help me a lot in the cleaning of rooms (smiles)" (P1; June 2015); "I go to work in my beauty salon but (silence) . . . I wanted to retire on the grounds of disability" (P2; June 2015). This information corroborates the study by Ferreira (2017), which states that the quality of life of women with mastectomies is associated with several factors, one of them being work.

As regards the scarcity of support, five participants did not indicate psychological and social support in addition to what is provided by the hospital, except those who mentioned the support of rehabilitation nursing, "Thanks to rehabilitation care, I overcame my difficulties at home, I greatly admire all nurses who accompanied me along this journey" (P1; June 2015); "I have no criticisms regarding rehabilitation care, this process helped me a lot . . ." (P2; June 2015). It should be emphasized that one of the participants did not receive any support after discharge, nor had any rehabilitation sessions.

The care inherent to mastectomies considers factors such as skin hydration, sun exposure, and use of compression sleeve, reported by three women, which corroborate the specific recommendations to decrease the risk of complications mentioned by Táboas et al. (2013), how to keep the ipsilateral limb skin clean and dry, moisturize the ipsilateral limb skin with pH-neutral moisturizing cream, and use compression sleeve, "I always use a compression sleeve in the arm every day to protect my arm and help circulation" (P3; June 2015); "I am very careful with the sun" (P4; July 2015).

It is essential to foster in these women the importance of complying with daily measured that decrease the likelihood of developing physical complications after the mastectomy.

Experiences of women with mastectomies relating to health care

In relation to health care, the majority of the participants reported being satisfied and pleased with health professionals, "yes, overall I am satisfied" (P6; August 2015); the health professionals both in inpatient service and now in rehabilitation were amazing" (P8; September 2015);

and also dissatisfied, “I did not feel very cared-for at the hospital. . .” (P2; June 2015).

It is noted that, within the scope of the studied theme, the woman is a significant element in the organization and improvement of care in institutions because the assessment of her satisfaction is an indicator of quality, which must be taken into account in the planning of personalized care (Mendes, Mantovani, Gemito, & Lopes, 2013).

During the hospital stay, the participants described how significant the educational sessions by nursing professionals were, “they taught me how to climb the wall with the hand . . . and I had a stress ball to squish to practice hand movements. . . arm movements. . .” (P3; June 2015).

It is essential that the woman receives information about the necessary care related to the ipsilateral limb, the exercises to recover the functional capacity of the arm and shoulder, and normal doubts that occur in this experience (Bani-Hashem et al., cited by Mourão et al., 2013), “I always did the recommended exercises that I was taught after the surgery. They gave me some brochures, with the first exercises to do in the first few days . . .” (P9; September 2015); “they spoke of the recommended care: being careful with roses, the thorns, it was even kind of a little scary (smiles) because it was a lot . . . there were many recommendations . . .” (P3; June 2015).

According to Moniz, Fernandes, and Oliveira (2011), the care plan should consider the need for information of women with mastectomies so as to create opportunities for them to ask questions. In this situation, the attention of the nurse is important to the individual nature of women’s information needs, as well as to their learning style. Also, it should be emphasized the importance of the family in the process of care to women, in which the nurse is responsible for creating the connection and family involvement as a partner in care. The family should, in turn, be a recipient of these teachings, so that continuity to the rehabilitation nursing program can be established at home, with a view of the incentive and motivation that can be instilled in women throughout the adaptation process.

The majority of women had rehabilitation nursing sessions, which means that women with mastectomies seek and are referred to the continuity of rehabilitation after discharge, “besides the rehabilitation treatment I do at the health center, I have a friend who assists me in rehabilitation at home” (P1; June 2015).

Nascimento, Oliveira, Oliveira, and Amaral (2012) reported in their study that the introduction of women with mastectomies in a rehabilitation program facilitates the process of knowledge/training in the prevention and treatment of complications that may arise, “I was referred to immediately after the surgery for rehabilitation by the family doctor” (P2; June 2015).

The woman with mastectomy goes through a long process and numerous physical, psychological, and social implications, including compromised self-care. It is essential that nurses, in particular rehabilitation nurses, direct the intervention toward the promotion of independence and autonomy of women (Camões et al., 2015).

It is noted that both the complementary studies select-

ed for this discussion and the meanings that emerged from the reports of the participants demonstrate that the mastectomy causes, in addition to the physical changes, psycho-socio-emotional changes throughout the process to which they are subjected. The reports show that rehabilitation nursing intervention is highly important to the promotion of autonomy and independence.

The study encountered some difficulties and limitations. In the process of result analysis, the applicability of the phenomenological method was a difficulty because it became a new, detailed, and time-consuming task for the researcher. Another limitation occurred at the level of the literature search due to the scarcity of studies using the phenomenological qualitative methodology, mainly developed by nurses. The results and the reflections established allow envisioning new developments, in a constructive dynamic of knowledge. Understandably, there should be greater coordination of rehabilitation care after the discharge of women with mastectomies, in order to ensure continuity of care and personalized monitoring in the adaptation process from a perspective of rehabilitation care in the community.

Conclusion

In Portugal, because breast cancer is one of the most prevalent pathologies in women, there is an urgent need for rehabilitation care according to the exigence of the associated treatments.

The rehabilitation nurse has skills and knowledge about the whole process and can assist in the training of women to develop strategies that prevent complications and support the adaptation to everyday life. It is essential to instill in women the compliance with measures for the prevention of physical complications. Education in the various phases of the rehabilitation process provides the woman and the family the capacity to adopt strategies to face the difficulties of daily life, contributing to functional recovery.

The results of the study show the importance of a rehabilitation nursing program adapted to every woman and every stage of the adaptation process for the continuity of nursing care to prevent complications and promote autonomy and independence.

The rehabilitation nurse intervenes in women with this problem, developing strategies to help in their adaptation process. Here, the nurse includes the family actively to promote a set of elements that facilitate their involvement in the rehabilitation plan at home, for which he/she has the scientific and practical knowledge and skills, promoting the autonomy of women.

The analysis of the rehabilitation nursing intervention in these women is important to research studies. New studies should be developed with a larger number of participants and the identification of other perceptions and meanings attributed by women to this phenomenon, so as to achieve higher levels of understanding about the women with mastectomies and their experiences.

The authors suggest the development of formative activi-

ties directed at nurses who come into contact with women with mastectomies daily to develop an evidence-based practice based regarding the promotion of self-care; the development of research on gains in health resulting from nursing practices developed by rehabilitation nurses in the monitoring of women with mastectomies.

Author contributions

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