

Knowledge of women undergoing mastectomy regarding lymphedema

Conhecimento de mulheres mastectomizadas sobre linfedema

Conocimientos de mujeres mastectomizadas sobre linfedema

**Fernanda Cristina Rosa
Alves¹**

ORCID: 0000-0003-1331-8889

**Fernando Conceição de
Lima¹**

ORCID: 0000-0002-9418-3711

**Bruna Camila Blans
Moreira¹**

ORCID: 0000-0002-9036-5286

**Tatiana Menezes Noronha
Panzetti¹**

ORCID: 0000-0001-7560-4595

**Antônio Jorge Silva Corrêa
Júnior²**

ORCID: 0000-0003-1665-1521

Mary Elizabeth de Santana¹

ORCID: 0000-0002-3629-8932

Abstract

Objective: Assess knowledge held by women who have undergone mastectomy concerning lymphedema. **Methods:** Descriptive qualitative study conducted with women in the intermediate postoperative period following mastectomy at an oncology hospital in Northern Brazil. Data were collected through semi-structured interviews. Analysis followed Bardin's content analysis principles combined with IRaMuTeQ software. **Results:** A total of twenty women participated, aged between 36 and 75 years, with mean education level, predominantly mixed race, most having undergone chemotherapy and presenting Systemic Arterial Hypertension. IRaMuTeQ generated a dendrogram encompassing five classes. Semantic content from classes 1, 2, and 5 was subdivided into the class "Communication: nursing professionals' care guidelines regarding lymphedema," while semantic content from classes 3 and 4 originated the order of classes 2 and 3 described subsequently as: "Understanding among women who underwent mastectomy regarding lymphedema" and "Surgical experience of women who underwent mastectomy: reflections and consequences." **Conclusion:** Knowledge held by women who underwent mastectomy regarding lymphedema and the guidance received during postoperative care varies according to understanding. Guidance received mainly focused on general postoperative care following mastectomy. Improvement opportunities are suggested for communication that promotes self-care aimed at prevention.

Descriptors: Lymphedema; Breast Neoplasms; Women; Knowledge; Mastectomy.

¹Universidade do Estado do Pará.
Belém, Pará, Brasil.

²Universidade de São Paulo.
Ribeirão Preto, São Paulo, Brasil.

Corresponding author:
Fernanda Cristina Rosa Alves
E-mail:
fernandacrosaalves@gmail.com

What is already known on this?

Mastectomy surgery constitutes one of the primary factors contributing to lymphedema development. Lymphedema is characterized by interstitial fluid accumulation and represents a significant health issue.

What this study adds?

There exists a lack of emphasis on lymphedema prevention alongside limited understanding of the condition. Enhancements in information dissemination promoting self-care aimed at prevention are suggested.



How to cite this article: Alves FCR, Lima FC, Moreira BCB, Panzetti TMN, Corrêa Júnior AJ, Santana ME. Knowledge of women undergoing mastectomy regarding lymphedema. UFPI. [internet] 2025 [Cited: ano mês abreviado dia];14:e6301. DOI: 10.26694/reufpi.v14i1.6301

Resumo

Objetivo: Avaliar o conhecimento de mulheres mastectomizadas sobre o linfedema. **Métodos:** Estudo descritivo, qualitativo, realizado com mulheres em pós-operatório mediato de mastectomia em um hospital oncológico no Norte do Brasil. Os dados foram produzidos por meio de entrevistas semiestruturadas. Analisaram-se os dados sobre os preceitos da análise de conteúdo de Bardin associado ao software IRaMuTeQ. **Resultados:** Participaram 20 mulheres, com idade entre 36 e 75 anos, média escolaridade, com predominância de mulheres pardas, sendo que a maioria passou por quimioterapia e apresentava Hipertensão Arterial Sistêmica. O IRaMuTeQ originou um dendograma com cinco classes. O conteúdo semântico das classes 1, 2 e 5, foi subpartilhado na classe "Comunicação: orientações de cuidados dos profissionais de enfermagem sobre linfedema"; enquanto o conteúdo semântico das classes 3 e 4 deu origem à ordem das classes 2 e 3 descritas, respectivamente, a seguir: "Entendimento das mulheres mastectomizadas sobre linfedema"; "Experiência cirúrgica de mulheres mastectomizadas: reflexões e consequências". **Conclusão:** O conhecimento das mulheres mastectomizadas sobre linfedema e as orientações recebidas no pós-operatório variam conforme o entendimento. As orientações recebidas estavam mais direcionadas ao cuidado pós-mastectomia em geral. Sugere-se um espaço para melhorias na transmissão de informações que promovam o autocuidado direcionado à prevenção.

Descritores: Linfedema; Neoplasias da Mama; Mulheres; Conhecimento; Mastectomia.

Resumen

Objetivo: Evaluar el conocimiento de mujeres mastectomizadas sobre linfedema. **Métodos:** Estudio descriptivo y cualitativo realizado con mujeres en el período posoperatorio inmediato posterior a una mastectomía en un hospital oncológico en el Norte de Brasil. Los datos se recopilaban mediante entrevistas semiestructuradas. El análisis de datos se llevó a cabo sobre la base de los preceptos del análisis de contenido de Bardin combinados con el software IRaMuTeQ. **Resultados:** Participaron veinte mujeres, con edades comprendidas entre 36 y 75 años, elevado nivel de educación y predominio de raza mestiza, advirtiéndose que la mayoría se había sometido a quimioterapia y presentaba Hipertensión Arterial Sistémica. El software IRaMuTeQ generó un dendograma con cinco clases. El contenido semántico de las clases 1, 2 y 5 se subdividió en la clase "Comunicación: orientación para el cuidado del linfedema por parte de los profesionales de enfermería"; mientras que el contenido semántico de las clases 3 y 4 dio lugar al orden de las clases 2 y 3 descritas, respectivamente, a continuación: "Comprensión de las mujeres mastectomizadas sobre linfedema"; "Experiencia quirúrgica de la mujer mastectomizada: reflexiones y consecuencias". **Conclusión:** El conocimiento de las mujeres mastectomizadas sobre linfedema y las orientaciones recibidas en el posoperatorio varían según la comprensión. Las recomendaciones recibidas estaban más orientadas al cuidado postmastectomía en general. Se sugiere un espacio para mejoras en la transmisión de información que promueva el autocuidado orientado a la prevención.

Descriptores: Linfedema; Neoplasias de la Mama; Mujeres; Conocimiento; Mastectomía.

INTRODUCTION

Breast cancer (BC) originates from genetic alterations in mammary glands that render cells "defective", resulting in their rapid and disordered growth.⁽¹⁾ In 2020, BC ranked as the most prevalent neoplasm globally among women, second only to malignant skin tumors, with 2.3 million women diagnosed.⁽²⁾

In Brazil, BC incidence stands at 43.74 cases per 100,000 women, representing the highest occurrence among the female population; notably, Pará State recorded an estimated 22.56 new cases per 100,000 women in 2023.⁽²⁾ Concerning treatment, nearly 90% of diagnosed patients may undergo breast-conserving surgery, referred to as quadrantectomy, involving tumor and adjacent tissue excision, or a mastectomy, entailing complete removal of breast tissue.⁽³⁾ Mastectomy surgery constitutes a principal factor fostering lymphedema development.⁽⁴⁾ Moreover, lymphedema is identified by interstitial fluid accumulation, manifesting as "swelling".⁽⁵⁾

Hence, this condition is chronic, characterized by enduring "swelling", reduced mobility, pain, stiffness, and paresthesia within the upper limb.⁽⁶⁾ In this context, lymphedema signifies a critical health challenge, given its potential to provoke skin lesions and infections, impair limb function, and impact psychological well-being by directly affecting patient body image.⁽⁷⁾

Additionally, women undergoing or preparing for mastectomy frequently lack information on lymphedema and required preventive measures.⁽⁸⁾ Therefore, dissemination of knowledge regarding lymphedema, risk factors, and prevention is imperative for post-mastectomy women.⁽⁶⁾

Subsequently, such information supports enhancement of life quality for patients experiencing lymphedema related to BC.⁽⁴⁾ Furthermore, nursing assumes a crucial role in providing instructions related to self-care for the ipsilateral limb, aiming at lymphedema prevention before and after mastectomy surgery.⁽⁸⁾

This study is warranted due to the essential role that women's knowledge concerning lymphedema plays in postoperative prevention; insufficient information negatively influences adherence to behaviors that mitigate lymphedema risk.^(6,9) Accordingly, the objective is to evaluate understanding among women who have undergone mastectomy regarding lymphedema.

METHODS

This descriptive study employed a qualitative approach to explore participants' interpretations and meanings⁽¹⁰⁾, conducted at a reference oncology hospital in Northern Brazil, situated in a municipality within Pará State. The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist from the Enhancing the Quality and Transparency of Health Research (EQUATOR) network. The methodological guidance adopted was content analysis.⁽¹¹⁾

Participants comprised women in the intermediate postoperative phase following mastectomy surgery enrolled in the oncology service of the cited hospital, specifically the mastology clinic, selected according to the following criteria: women diagnosed with BC from the Northern Region who underwent unilateral or bilateral mastectomy, aged 18 years or older in the intermediate postoperative period. A total of sixteen women were excluded for not meeting these criteria, cognitive impairments affecting reading, comprehension, or speech, or reporting pain and discomfort at the time of approach, resulting in a final sample of 20 participants.

Data collection occurred from August to October 2024 through individual interviews using a semi-structured script, conducted by a trained undergraduate student and a nursing master's student, with a mean duration of 30 minutes. The interview script was divided into three sections: (1) participants' socioeconomic data, (2) health-related questions, and (3) open questions about lymphedema, including: "What do you understand about lymphedema (arm swelling) following mastectomy?"; "What guidance did you receive from nurses regarding lymphedema (arm swelling)?"; "What knowledge do you have about risk factors for lymphedema (arm swelling) after mastectomy (breast removal surgery)?"; "What information do you have regarding prevention and treatment measures for lymphedema (arm swelling) after mastectomy (breast removal surgery)?" Interviews were audio-recorded in a private room equipped with a table, chairs, and air conditioning, ensuring privacy.

Non-probabilistic convenience sampling was employed to approach women in the intermediate postoperative period hospitalized in the mastology clinic, without interfering with staff routines or participants' daily activities. The project was presented to nurses in the clinic treating BC patients. Participant selection relied on contact with clinical nurses and managers who informed investigators of surgery dates. Additionally, the interview location provided explanations regarding the study's purpose, interview procedures, and importance of participation.

Interview collection was terminated upon reaching saturation, characterized by a point where responses no longer provided new information and content became repetitive without significant additions to the studied phenomenon.⁽¹²⁾ Socioeconomic data were organized in Microsoft Office Excel 2016 after tabulation.

Content analysis followed Bardin's three-stage process: pre-analysis, material exploration, and inference and interpretation, validated by a team of three nurse researchers experienced in qualitative study.⁽¹³⁾ Audio recordings were transcribed immediately, forming the textual corpus, initiating pre-analysis. Content analysis identified semantic and linguistic group affinities. This method facilitated fragmentation of the textual unit, focusing on secondary cores integrated into communication with participants, which were reorganized into categories of similar ideas. During material exploration, IRaMuTeQ software version 0.7 alpha 2 was used for lexical statistical analysis based on lexicometry.⁽¹⁴⁾ Interpretation relied on Reinert's method of descending hierarchical classification (DHC) of text segments (TS). In the inference and interpretation stage, classes generated by IRaMuTeQ were described through DHC and compared with literature and theoretical materials.

Data collection proceeded after signing the Free and Informed Consent Form (FICF). Participant confidentiality was safeguarded through alphanumeric codifiers P01, P02, P03, etc., where "P" denotes participant, arranged sequentially by interview order. Participants were informed of their right to withdraw at any time and to have collected data permanently deleted.

The study received approval from the Ethics Research Committee (ERC) of Magalhães Barata Nursing School (Opinion No. 6,926,401) and Ophir Loyola Hospital (Opinion No. 7,002,908).

RESULTS

The socioeconomic profile of participants demonstrated that women's mean age ranged from 36 to 75 years. Furthermore, seven (35%) were single, six (30%) married, three (15%) living in stable unions, three (15%) widowed, and one (5%) divorced. In relation to education level, eight (40%) of participants had

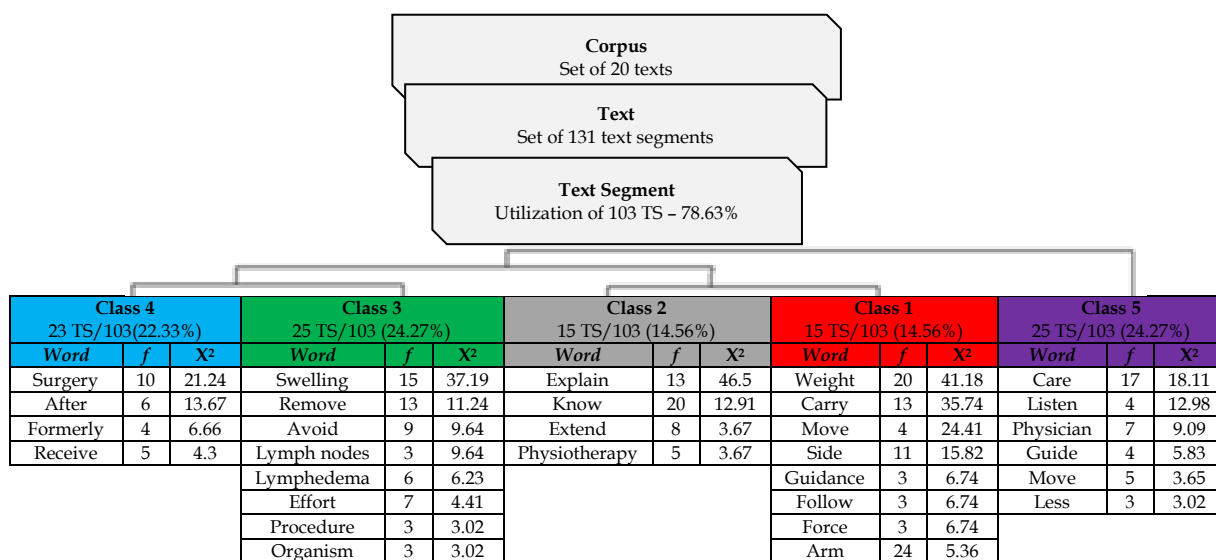
completed secondary education, five (25%) incomplete primary education, four (20%) incomplete higher education, two (10%) completed primary education, and one (5%) completed higher education.

Additionally, eleven (55%) women self-identified as mixed race, five (25%) as white, and four (20%) as black. Regarding occupation, nine (45%) declared themselves homemakers, six (30%) retired, three (15%) self-employed, one (5%) travel agent, and one (5%) public servant. Ten (50%) reported household income between one and two minimum wages, five (25%) from two to three minimum wages, and five (25%) below one minimum wage. Ten (55%) resided in Belém, three (15%) originated from other municipalities, and six (30%) were from rural regions within Pará State.

Concerning health data, nine (45%) participants denied comorbidities, six (30%) reported only Systemic Arterial Hypertension (SAH), two (10%) declared SAH and Diabetes Mellitus (DM), and three (15%) reported SAH, DM, and an additional associated comorbidity. Moreover, regarding pre-mastectomy treatments, 12 participants (60%) underwent chemotherapy, one (5%) chemotherapy and radiotherapy, and seven (35%) received neither chemotherapy nor radiotherapy before surgery. All 20 participants (100%) held a primary diagnosis of BC.

According to Figure 1, the software processed 20 texts in 131 text segments (TS), with utilization of 103 (78.63% of the corpus). Semantic content from classes 1, 2, and 5 was subdivided into class 1, as the words held similar meanings, demonstrating affinity but distinctiveness. Thus, class 1 was interpreted as: "Communication: nursing professionals' postoperative care guidelines concerning lymphedema", indicating nursing guidance on postoperative mastectomy care. Meanwhile, semantic content from classes 3 and 4 originated classes 2 and 3, respectively, interpreted as: "Understanding among women who underwent mastectomy regarding lymphedema" and "Surgical experience of women who underwent mastectomy: reflections and consequences".

Figure 1. Dendrogram with originated classes. Belém, Pará, Brazil. 2024.



Source: IRaMuTeQ Report, 2024.

Class 1 - Communication: healthcare professionals' care guidelines regarding lymphedema

Lexical analysis of classes 1, 2, and 5 identified the most significant words in Class 1 as "Weight," "Carry," "Move," "Side," and "Guidance"; in Class 2 as "Explain," "Know," "Understand," and "Physiotherapist"; and in Class 5 as "Care," "Listen," "Physician," and "Guide," highlighting the instructions given by nursing professionals to participants about necessary daily care to prevent lymphedema after mastectomy. It was observed that primary precautions focused on avoiding overload of the limb ipsilateral to surgery, as reflected in the following statements:

[...] I received [the information], but I forgot it because I was so nervous that it slipped my mind. (P11)

[...] Do not lift weight, do not lie on that side, they gave me many instructions [...] Rest a lot, do not sleep in a hammock [...] Do exercises. (P02)

[...] Carrying weight and sweeping the house. I think that is it! Not to sleep on that side. (P04)

[...] They said I can move my arm. The only thing I cannot do is lift or carry weight or strain my arm. I can move it any way I want, like combing hair, that just came to mind now. (P11)

[...] She said I must not carry weight and avoid leaning too much; I should lean with the other arm to prevent the problem she mentioned. (P19)

Two women also reported that professionals recommended avoiding certain health procedures on the limb ipsilateral to surgery such as vaccinations and injections due to the risk of lymphedema development.

[...] No blood draws or medication should be done on the surgery side of the arm. (P09)

[...] Never get injections again on the operated arm, right? The mastologist told me not to lean on the right side that was operated on; I should always lean on the left arm. (P20)

Participants indicated that professionals informed them about exercises to prevent lymphedema post-surgery; however, specific types of recommended exercises were not mentioned.

[...] The only restriction the physician mentioned was not to lift weight with the operated arm. Apart from that everything is allowed. It is even good to exercise. (P12)

[...] The important thing is not to strain. Yes, you can stand up. You need to stand to exercise so the arm does not stiffen. Yes, I received this guidance. (P20)

Only one participant reported that the arm should be kept above heart level while resting in bed, as shown below:

[...] Care for the arm is lying down and using a pillow. Having a higher bed; a pillow to keep it elevated at all times. (P20)

Class 2 – Understanding among women who have undergone mastectomy regarding lymphedema

Analysis of Class 3 identified the most frequent words as “Swelling,” “Remove,” “Avoid,” “Lymph nodes,” and “Lymphedema,” highlighting participants’ perception of factors causing lymphedema in their bodies. However, most participants were unable to adequately explain what lymphedema is and what causes it after surgery, as evidenced in the following accounts:

[...] I think it happens because of exertion, and since the lymph nodes that protect and prevent blood clotting or other issues are no longer there due to removal, I believe that is why swelling occurs. (P09)

[...] I believe it happens when lymph nodes that protect the body are removed. If not properly cared for, they become swollen and transform into lymphedema. (P10)

[...] I cannot exactly answer, but I think that this swelling must be inflammation or something wrong in the body because swelling is not normal. (P15)

[...] When they manipulate the armpit and remove lymph nodes, natural lymphatic drainage stops. When the arm swells, it is lymphedema. (P16)

[...] Honestly, I do not really know what it is or if it is dangerous, but my arm is swollen. I cannot say for sure. I think a very swollen arm is not normal. I believe it relates to disease severity. (P20)

Class 3 – Surgical experience: reflections and consequences

Following lexical analysis of Class 4, the most representative words were “Surgery,” “After,” “Formerly,” and “Receive,” indicating reflections by women who underwent mastectomy about the surgery and its consequences after hospital discharge. Surgery was regarded as a “conquered stage,” with emphasis on the importance of mental health during this process.

[...] I could walk. That was the first exercise, just walking. I was not allowed to do other heavy exercises. Actually, I could do weight training but only later, to be able to overcome it. (P01)

[...] Formerly, it was an incredible taboo, you know? That is why women had low spirits. (P05)

[...] She said I had to follow her rule, and I said okay because I was interested in knowing since it was my first surgery, so I was somewhat worried. (P19)

Behavioral changes after breast removal surgery generated concerns, as participants perceived they would no longer be able to perform household chores due to the need to care for the limb ipsilateral to surgery.

[...] I sweep the house, carry weight, exert immense effort, doing things I should not do. (P01)

[...] I believe domestic chores are not good for carrying or pushing weight or making sudden movements. (P15)

[...] I believe I will avoid heavy effort with my arm when at home because I was told I must rest a lot due to the surgery timing. (P19)

DISCUSSION

The socioeconomic profile indicated an age range from 36 to 75 years, with predominance of mean education level: 40% had completed secondary education and 25% had incomplete primary education. Among participants, 55% self-identified as mixed race, while 45% were homemakers, 30% retired, and 15% self-employed. These data resemble findings from a study conducted in Recife with women undergoing outpatient follow-up for breast cancer (BC), whose mean age was 54.53 years; in that group, 44.19% earned up to one minimum wage, and 51.16% self-identified as mixed race, with 41.86% engaged in domestic activities. Both studies highlight a socioeconomically vulnerable profile among women treated for BC.⁽¹⁵⁾

In relation to health data, 45% reported no comorbidities, while 30% had Systemic Arterial Hypertension (SAH) and 10% presented SAH and Diabetes Mellitus (DM). The majority (60%) underwent chemotherapy and 5% received both chemotherapy and radiotherapy, with all holding a primary diagnosis of BC. In comparison, a quantitative retrospective cohort study conducted in São Paulo with women treated in rehabilitation services for lymphedema related to BC reported that 76.6% presented comorbidities such as 43.9% obesity, 48.1% SAH, and 17% DM. Notably, 48.5% underwent neoadjuvant chemotherapy, 74% radiotherapy, and 7.9% axillary lymphadenectomy.⁽¹⁶⁾

Class 1 showed that primary guidance from healthcare professionals regarding lymphedema prevention after mastectomy consisted of avoiding overload of the limb ipsilateral to surgery. Similarly, a qualitative study in Rio de Janeiro with women undergoing breast surgery reported participants were instructed to avoid any exertion with the limb ipsilateral to mastectomy.⁽¹⁷⁾

A study in the eastern Black Sea region noted 72% of participants reported not carrying weight beyond recommended limits with the limb ipsilateral to breast surgery.⁽⁸⁾ Literature indicates it is unclear whether exercise performed by women who underwent mastectomy prevents lymphedema, though exercises contribute to recovery of limb mobility ipsilateral to surgery.⁽¹⁸⁾

Participants also reported receiving guidance to avoid sleeping on the limb ipsilateral to breast surgery. A study in Ceará with healthcare professionals specializing in BC or women's health recommended that postoperative BC patients sleep in a dorsal position, avoiding leaning on the ipsilateral limb.⁽¹⁹⁾

Participants emphasized the importance of avoiding health procedures on the limb ipsilateral to mastectomy, such as vascular access needle puncture. However, a systematic review contraindicates this recommendation for lymphedema prevention due to limited literature evidence and because such practice delays clinical care.⁽²⁰⁾ A scoping review identified that when performed correctly, blood pressure measurement and vascular access puncture are not associated with onset or worsening of lymphedema in women who underwent mastectomy.⁽²¹⁾ Thus, this guidance remains under scientific review and should be individualized for each patient.

Only one participant reported receiving guidance on elevating the arm during sleep. In this regard, a descriptive correlational single-group study conducted in the Eastern Black Sea region recommends elevation of the ipsilateral upper limb during dorsal rest to maintain it at heart level.⁽⁸⁾

Class 2 discusses women's understanding of lymphedema and the impact of lymph node removal in lymphadenectomy on condition development, related to interstitial fluid accumulation in the upper limb. Lymphedema is characterized as a chronic inflammation after breast surgery.⁽⁵⁾ Moreover, a predictive retrospective cohort study in Barcelona with women undergoing BC surgery with axillary lymph node dissection indicates the number of lymph nodes removed is a risk factor for lymphedema development, alongside other factors such as postoperative increase in body mass index ⁽⁴⁾

During interviews, some participants did not recall or were unaware of risk factors and care for lymphedema, having failed to absorb guidance from the healthcare team. Lack of adherence to self-management practices is directly associated with misinformation, underscoring healthcare professionals' responsibility to provide necessary guidance.⁽⁹⁾

Regarding this, postoperative care guidance should be conveyed simply to enhance women's adherence to self-care.⁽¹⁹⁾ Hence, health education delivered by nurses is necessary to improve patient quality of life and satisfaction with nursing teams.⁽²²⁾

Class 3 presents reflections and consequences of mastectomy surgery, including a participant's report about the taboo concerning breast removal and its emotional influence on women. Lymphedema associated with breast removal negatively impacts physical and emotional aspects for affected women.⁽²³⁾

Post-mastectomy lymphedema is linked to altered quality of life affecting emotional, functional, and physical well-being, particularly due to aesthetic changes in the limb.^(7,24) Therefore, nurses must provide individualized, humanized care to these vulnerable women through qualified listening and effective communication using accessible language, clarity in explanations, and opportunities for exchange between professional and patient.⁽²³⁾ Additionally, a support network is essential for post-mastectomy women to facilitate improved recovery and treatment.⁽²⁵⁾

Within Class 3, concern arose regarding return to daily activities after surgery due to the necessity of limb rest. A study with women in the postoperative period of mastectomy in a Paraná hospital showed women fear resuming daily tasks, concerned about potential complications in the limb.⁽²⁵⁾

A secondary analysis of a study of women with BC followed for 12 months post-mastectomy in New York revealed that patients developing lymphedema face greater difficulties performing daily activities such as cooking, housecleaning, bathing, dressing, and driving.⁽²⁶⁾ Lymphedema causes pain, reduced limb movement, and in severe cases, stiffness.^(6,8,27)

However, nurses can perform lymphatic drainage massage and progressive exercises to recover limb mobility in patients with lymphedema.⁽²²⁾ Moreover, nursing should encourage women who underwent mastectomy in self-management, empowering patients as protagonists of their care by guiding self-care measures. These include avoiding injections, blood pressure and glucose measurements, cuticle removal, and heat exposure in the ipsilateral upper limb.^(9,19) Additionally, use of compression sleeves, moisturizer, and sunscreen on the limb along with light physical activity is recommended.⁽⁹⁾

A limitation of this study is its methodological nature, as it was conducted in a single healthcare institution, limiting contextual diversity. Another aspect is the scarcity of new studies addressing guidance on limb manipulation to foster discussion.

The results from this research contribute to theoretical and practical nursing care, specifically for women who underwent mastectomy. The study reveals that adequate knowledge and guidance about lymphedema directly impact adherence to preventive measures, promoting more comprehensive care that considers psychosocial factors affecting patients beyond physical care, strengthening development of a more integrated and humanized care approach.

CONCLUSION

Knowledge held by women who have undergone mastectomy regarding lymphedema and the guidance received during postoperative care vary according to their understanding and the importance attributed to self-care in this context. The knowledge derived from received instructions revealed care directed toward general postoperative mastectomy, including recommendations such as avoiding lifting weight with the limb ipsilateral to surgery, not sleeping on the affected limb, and performing light exercises. However, the lack of specific emphasis on lymphedema prevention, together with limited understanding of this condition, indicates room for improvement in information dissemination that promotes self-care aimed at prevention.

Participants' statements reflected doubts and uncertainties about lymphedema following mastectomy, revealing an incomplete comprehension of the condition. In this regard, the importance of

performing exercises with the limb to prevent postoperative stiffness was highlighted, although specific types of exercises were not mentioned. The prohibition of injectable procedures on the limb ipsilateral to mastectomy was emphasized as a topic warranting further clinical research to establish consensus.

Regarding implications for guidance, there is concern about the behavioral changes required, especially related to domestic activities upon return home, due to the need for care of the limb ipsilateral to surgery. Furthermore, the emotional impact of mastectomy due to breast removal was emphasized.

CONTRIBUTIONS

Contributed to the conception or design of the study/research: Alves FCR, Lima FC, Santana ME. Contributed to data collection: Alves FCR. Contributed to the analysis and/or interpretation of data: Alves FCR, Lima FC, Santana ME. Contributed to article writing or critical review: Lima FC, Moreira BCB, Panzetti TMN, Júnior Corrêa AJ, Santana ME. Final approval of the version to be published: Lima FC, Moreira BCB, Panzetti TMN, Santana ME.

REFERENCES

1. International Agency for Research on Cancer. Cancer Today. Lyon: IARC; 2020. Available from: <https://gco.iarc.fr/today/home>.
2. Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA), Coordenação de Prevenção e Vigilância. Estimativa 2023-2025: incidência do câncer no Brasil. Rio de Janeiro: INCA; 2022. Available from: <https://www.gov.br/inca/pt-br/assuntos/cancer/numeros/estimativa>.
3. Lovelace DL, McDaniel LR, Golden D. Long-term effects of breast cancer surgery, treatment, and survivor care. *J Midwifery Womens Health* [Internet]. 2019;64(6):713-24. DOI: <https://doi.org/10.1111/jmwh.13012>.
4. Martínez-Jaimez P, Armora Verdú M, Forero CG, Álvarez Salazar S, Fuster Linares P, Monforte-Royo C, et al. Breast cancer-related lymphoedema: Risk factors and prediction model. *J Adv Nurs*. [Internet]. 2021;78(3):765-75. DOI: <https://doi.org/10.1111/jan.15005>.
5. Rupp J, Hadamitzky C, Henkenberens C, Christiansen H, Steinmann D, Bruns F. Frequency and risk factors for arm lymphedema after multimodal breast-conserving treatment of nodal positive breast cancer - a long-term observation. *Radiat Oncol*. [Internet]. 2019;14(1):39. DOI: <https://doi.org/10.1186/s13014-019-1243-y>.
6. Buki LP, Rivera-Ramos ZA, Kanagui-Muñoz M, Heppner PP, Ojeda L, Lehardy EN, et al. "I never heard anything about it": Knowledge and psychosocial needs of Latina breast cancer survivors with lymphedema. *Womens Health (Lond)* [Internet]. 2021;17:17455065211002488. DOI: <https://doi.org/10.1177/17455065211002488>.
7. Paiva A do CPC, Elias EA, Souza ÍE de O, Moreira MC, Melo MCSC de, Amorim TV. Cuidado de enfermagem na perspectiva do mundo da vida da mulher que vivencia linfedema decorrente do tratamento de câncer de mama. *Esc. Anna Nery (Online)* [Internet]. 2020;24(2). DOI: <https://doi.org/10.1590/2177-9465-EAN-2019-0176>.
8. Aydyn A, Gürsoy A. Lymphedema information and prevention practices of women after breast cancer surgery. *Florence Nightingale J Nurs*. [Internet]. 2020;28(3):350-8. DOI: <https://doi.org/10.5152/FNJJN.2020.18082>.
9. Oliveira JMBB, Marques RRT, Valadares JG, Vieira FVM, Lopes MVO, Cavalcante AMRZ. Ineffective self-management of lymphedema in mastectomized women: concept analysis. *Acta Paul. Enferm*. [Internet]. 2024;37. DOI: <https://doi.org/10.37689/acta-ape/2024AR0001432>.

10. Silva DCD, Martins Júnior FRF, Silva TMR, Nunes JBC. Características de pesquisas qualitativas: estudo em teses de um programa de pós-graduação em educação. *Educ. Rev.* [Internet]. 2022;38. DOI: <https://doi.org/10.1590/0102-469826895>.
11. Souza VRS, Marziale MHP, Silva GTR, Nascimento PL. Tradução e validação para a língua portuguesa e avaliação do guia COREQ. *Acta Paul. Enferm.* [Internet]. 2021;34. DOI: <https://doi.org/10.37689/acta-ape/2021AO02631>.
12. Moura CO, Silva ÍR, Silva TP, Santos KA, Crespo MCA, Silva MM. Methodological path to reach the degree of saturation in qualitative research: grounded theory. *Rev. Bras. Enferm.* (Online) [Internet]. 2022;75(2). DOI: <https://doi.org/10.1590/0034-7167-2020-1379>.
13. Bardin L. *Análise de conteúdo*. Tradução Luís Antero Reto, Augusto Pinheiro. 1. ed. São Paulo: Edições 70; 2016.
14. Sousa YSO, Gondim SMG, Carias IA, Batista JS, Machado KCM. O uso do software Iramuteq na análise de dados de entrevistas. *Pesqui. Prát. Psicossociais* [Internet]. 2020;15(2):1-19. Available from: https://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1809-89082020000200015.
15. Oliveira MCA, Jordán APW, Ferreira AGC, Barbosa LNF. Characteristics of multidimensional pain in women with breast cancer treated at a referral hospital: a cross-sectional study. *BrJP* [Internet]. 2022;5(4):347-53. DOI: <https://doi.org/10.5935/2595-0118.20220053-en>.
16. Gozzo TO, Aguado G, Tomadon A, Panobianco MS, Prado MAS. Profile of women with lymphedema after breast cancer treatment. *Esc Anna Nery* (Online) [Internet]. 2019;23(4): e20190090. DOI: <https://doi.org/10.1590/2177-9465-EAN-2019-0090>.
17. Marchito LO, Fabro EAN, Macedo FO, Costa RM, Lou MBA. Prevenção e Cuidado do Linfedema após Câncer de Mama: Entendimento e Adesão às Orientações Fisioterapêuticas. *Rev. Bras. Cancerol.* [Internet]. 2019;65(1):e-03273. DOI: <https://doi.org/10.32635/2176-9745.RBC.2019v65n1.273>.
18. Paskett ED, Le-Rademacher J, Oliveri JM, Liu H, Seisler DK, Sloan JA, *et al.* A randomized study to prevent lymphedema in women treated for breast cancer: CALGB 70305 (Alliance). *Cancer* [Internet]. 2021;127(2):291-9. DOI: <https://doi.org/10.1002/cncr.33183>.
19. Santos CPRS dos, Goyanna NF, Corpes EF, Yanez RJV, Mourão Netto JJ, Barbosa RCM, *et al.* Content validity of guidance on self-care in the post-operative period for breast cancer. *Rev. Bras. Enferm.* (Online) [Internet]. 2024;77(4):e20240188. DOI: <https://doi.org/10.1590/0034-7167-2024-0188>.
20. Hadjistyllis M, Soni A, Hunter-Smith DJ, Rozen WM. A systematic review of the complications of skin puncturing procedures in the upper limbs of patients that have undergone procedures on the axilla or breast. *Ann Transl Med* [Internet]. 2024;12(4):70. DOI: <https://doi.org/10.21037/atm-23-1400>.
21. Macêdo MRS, Toscano MLS, Nóbrega WG, Barbosa JV, Chiavone FBT, Martins QCS. Precauções para linfedema em mulheres acometidas por câncer de mama pós esvaziamento axilar: revisão de escopo. *Rev. Enferm. UERJ* (Online) [Internet]. 2020;28: e49435. DOI: <https://doi.org/10.12957/reuerj.2020.49435>.
22. Zhuang Y, Pan Z, Li M, Liu Z, Zhang Y, Huang Q. The effect of evidence-based nursing program of progressive functional exercise of affected limbs on patients with breast cancer-related lymphoedema. *Am J Transl Res.* [Internet]. 2021;13(4):3626-33. Available from: <https://pmc.ncbi.nlm.nih.gov/articles/PMC8129270/>.
23. Rocha CB, Fontenele GMC, Macêdo MS, Carvalho CMS, Fernandes MA, Veras JM de MF, *et al.* Sentimentos de mulheres submetidas à mastectomia total. *Rev. cuid.* (En línea) [Internet]. 2019;10(1). DOI: <http://dx.doi.org/10.15649/cuidarte.v10i1.606>.

24. Gallegos-Alvarado M, Pérez-Sumano S, Ochoa-Estrada MC, Salinas-Torres VM. Improvement of quality of life on breast cancer-related lymphedema patients through a postmastectomy care program in Mexico: a prospective study. *Support Care Cancer* [Internet]. 2024;32(11):713. doi:10.1007/s00520-024-08895-4.
25. Camargo MJG, Santos CRAA, Ferreira JNF, Abonante KSFB. 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). *Cad. Bras. Ter. Ocup* [Internet]. 2022;30. DOI: <https://doi.org/10.1590/2526-8910.ctoAO255033281>.
26. Park JH, Merriman J, Brody A, Fletcher J, Yu G, Ko E, *et al.* Limb volume changes and activities of daily living: A prospective study. *Lymphatic Res Biol.* [Internet]. 2021;19(3):261-8. DOI: <https://doi.org/10.1089/lrb.2020.0077>.
27. Aguilera-Eguía RA, Seron P, Gutiérrez-Arias R, Zaror C. Can resistance exercise prevent breast cancer-related lymphoedema? A systematic review and metanalysis protocol. *BMJ Open* [Internet]. 2024;14(11):e080935. DOI: <https://doi.org/10.1136/bmjopen-2023-080935>.

Conflicts of interest: No
Submission: 2024/12/03
Revised: 2025/03/27
Accepted: 2025/08/13
Publication: 2025/09/10

Editor in Chief or Scientific: José Wicto Pereira Borges
Associate Editor: Államy Danilo Moura e Silva

Authors retain copyright and grant the Revista de Enfermagem da UFPI the right of first publication, with the work simultaneously licensed under the Creative Commons Attribution BY 4.0 License, which allows sharing the work with acknowledgment of authorship and initial publication in this journal.