Desafios enfrentados por mulheres mastectomizadas e o impacto das orientações pós-operatórias

Challenges faced by mastectomized women and the impact of post-operative guidelines

Retos a los que se enfrentan las mujeres mastectomizadas y el impacto de la orientación postoperatoria

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How to cite: Júnior JJF, Luna MES, Freitas MVO, Carvalho RMF, Firmo RC. Challenges faced by mastectomized women and the impact of post-operative guidelines. REVISA. 2025; 14(2): 1569-81. Doi: https://doi.org/10.36239/revisa.v14.n2.p1569a1581

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Received: 12/01/2025
Approved: 22/03/2025

RESUMO

Objetivo: Analisar a percepção de pacientes mastectomizadas sobre os desafios enfrentados no pós-operatório, considerando as complicações pós-cirúrgicas e as orientações recebidas no pós-operatório imediato. **Método:** Trata-se de um estudo qualitativo com mulheres mastectomizadas, utilizando-se entrevistas semiestruturadas com falas gravadas, transcritas e posteriormente analisadas através da Análise de Conteúdo de Bardin. R**esultados:** Foram realizadas 38 entrevistas, sendo identificados três temas: orientações, recuperação e formato de orientação. Foram destacados 11 tipos de incômodos pós-operatórios no total de 61 queixas e 21,05% das participantes referiram não receber nenhum tipo de orientação pós-operatória. **Conclusões:** A dor, o edema em membro superior e as limitações das atividades de vida diária são os incômodos mais frequentemente relatados. Tornou-se evidente que as orientações desempenham um papel fundamental na qualidade de vida dessas mulheres.
Descritores: Cuidados pós-operatórios; Mastectomia radical; Linfedema pós-mastectomia; Fisioterapia.

ABSTRACT

Objective: To analyze the perception of mastectomized patients regarding the challenges faced in the post-operative period, considering post-surgical complications and the guidelines received in the immediate post-operative phase. **Method:** This is a qualitative study with mastectomized women, using semi-structured interviews with recorded speeches, transcribed and subsequently analyzed through Bardin's Content Analysis. **Results:** A total of 38 interviews were conducted, identifying three themes: guidance, recovery, and the format of guidance. Eleven types of postoperative discomforts were highlighted out of a total of 61 complaints, and 21.05% of participants reported not receiving any type of postoperative guidance. **Conclusions:** Pain, upper limb swelling, and limitations in daily life activities are the most frequently reported discomforts. It became evident that guidance plays a fundamental role in the quality of life of these women.
Descriptors: Post-operative care; Radical mastectomy; Post-mastectomy lymphedema; Physiotherapy.

RESUMEN

Objetivo: Analizar la percepción de pacientes mastectomizadas sobre los desafíos enfrentados en el postoperatorio, considerando las complicaciones posquirúrgicas y las orientaciones recibidas en el postoperatorio inmediato. **Método:** Se trata de un estudio cualitativo con mujeres mastectomizadas, mediante entrevistas semiestructuradas con discursos grabados, transcritos y posteriormente analizados mediante el Análisis de Contenido de Bardin. **Resultados:** Se realizaron 38 entrevistas, identificando tres temas: orientación, recuperación y formato de orientación. Se destacaron 11 tipos de molestias postoperatorias en un total de 61 quejas y el 21,05% de los participantes refirieron no recibir ningún tipo de orientación postoperatoria. **Conclusiones:** El dolor, el edema en el miembro superior y las limitaciones en las actividades de la vida diaria son las molestias más frecuentemente reportadas. Se hizo evidente que las pautas juegan un papel fundamental en la calidad de vida de estas mujeres.
Descriptores: Cuidados posoperatorios; Mastectomía radical; Linfedema postmastectomía; Fisioterapia.

ORIGINAL

Introduction

Breast cancer is the most common malignant neoplasm worldwide, accounting for 11.7% of all cancer cases. In Brazil, it is the leading cause of cancer mortality among women. In 2020, there were 17,825 deaths due to female breast cancer, equivalent to a risk of 16.47 deaths per 100,000 women. The National Cancer Institute José Alencar Gomes da Silva (INCA) estimates that for the 2023-2025 triennium there will be 73,610 new cases, which represents an estimated risk of 66.54 cases per 100,000 women.[1]

Breast neoplasia is the result of damage to the genetic code, of chemical, physical, or biological origin, that accumulates over a lifetime. Early diagnosis upon the onset of the disease is important for determining the patient's survival, which is essential for the decision-making process regarding surgical and adjuvant treatment. Treatment varies from case to case, but often involves the surgery known as mastectomy, chemotherapy, radiotherapy, and hormone therapy.[2]

Among the surgeries performed as an intervention for breast cancer are mastectomies, which can be radical or modified, and conservative surgeries, also known as quadrantectomy, lumpectomy, and sectorectomy, in which only a part of the breast is removed, aiming for the complete removal of the tumor, with a safety margin and preserving the remaining breast tissue.[3]

The modifications of surgical techniques were carried out through methods that preserved the pectoralis major muscle (Patey and Dyson) or both pectorals (Madden), which began to be referred to as modified radical mastectomy, leading to conservative surgeries, resulting in the replacement of radical techniques with less mutilating procedures that ensure better aesthetic, functional, and psychological outcomes.[4]

These surgical techniques can still be accompanied by axillary lymphatic drainage (lymphadenectomy), increasing the risk of upper limb lymphedema, which is a chronic, progressive disease that is usually incurable. Its repercussions extend to physical and mental dysfunctions, changes in self-esteem, and feelings of depression, insecurity, harmful changes to intimacy, work, and social relationships that can lead to life-threatening conditions.[5]

The post-operative (PO) consequences of these interventions can affect work and activities of daily living (ADL), potentially leading to pain, muscle strength restriction, fatigue, and limitations in the movements of the upper limb (UL) on the same side as the surgery.[6] Considering the area of surgical intervention, the procedure can also cause changes related to sensitivity, as the resection of the intercostobrachial sensory nerve is common in these procedures, resulting in reduced muscle strength of the affected limb, as well as a likely trauma to the long thoracic motor nerve, which is near the intercostobrachial nerve, especially when there is metastatic compromise of the lymph nodes.[7]

A study conducted in Rio Grande do Sul on the epidemiological profile of 150 mastectomized women from different regions of the Taquari Valley showed that women with lower education levels have the greatest complications in treatment. The way information reaches the patients, how they will absorb it and later use it in their daily lives is extremely important

for care, especially when the service is focused on patients with different levels of education and socioeconomic status.[8]

The present study aims to analyze the perception of mastectomized patients regarding the challenges faced in the postoperative period, considering the postoperative complications and the functional guidelines received in the immediate postoperative phase.

Method

This is a qualitative study conducted from December 2022 to June 2023 with the participation of female patients aged 18 years or older, who have undergone mastectomy and are treated at the Women's Health Physical Therapy Clinic of the Professor Fernando Figueira Integral Medicine Institute (IMIP), excluding patients with a diagnosis of significant cognitive decline that would impair their understanding of questions. The number of participants was defined according to the number of patients treated at the Clinic during a three-month period (February to April).

Two data collection methods were used: the first was a sociodemographic questionnaire with separate sections for personal data, biological characteristics, sociodemographic information such as income, education, and marital status, and lifestyle habits, in order to understand the sociodemographic profile of the women participating in the research. The second method was a semi-structured interview with questions regarding complaints, difficulties, and postoperative guidance.

The speeches were transcribed simultaneously and the testimonies were recorded on a voice recorder from Samsung Electronics Co., Ltd. for a thorough listening of the interviews later. The data obtained from the interview were analyzed by the researchers through Bardin's Thematic Content Analysis.[9] Through transcription and reading of the speeches, relevant points were marked, identifying units of analysis taken from the responses, structuring the analysis with the identification of themes and categories. In order to preserve the anonymity of the patients, their identities were replaced by the letter M accompanied by the number of their form.

This research was approved by the Research Ethics Committee of IMIP under Opinion number 5.773.225. All participants signed the Informed Consent Term, complying with the regulatory guidelines of Resolution number 466/12 of the National Health Council/MH and its amendments.

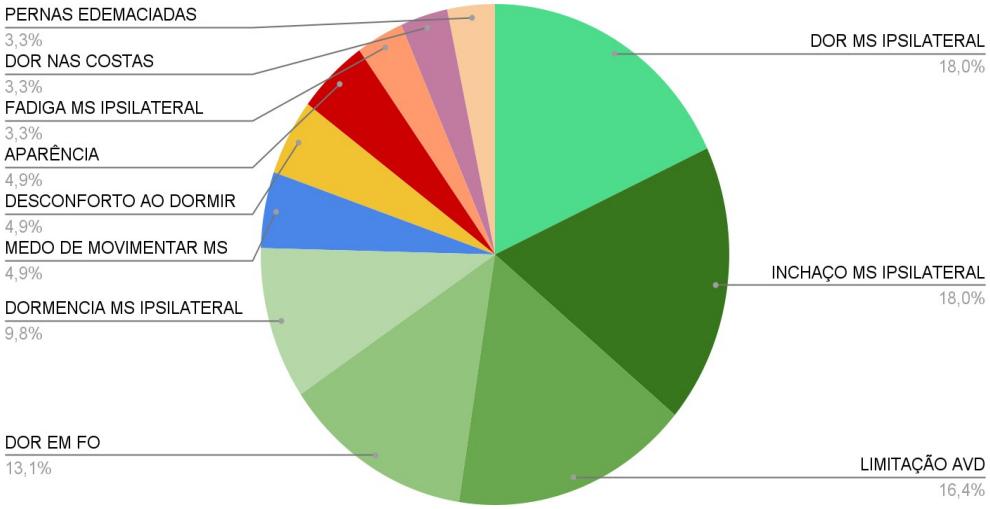
Results

A total of 40 women were approached, of which one did not accept to participate in the research and one did not meet the inclusion criteria, yielding a total sample of 38 women. The mean age of the participants was 53.60 ± 9.61, ranging from 41 to 75 years. The majority of them (55.25%) did not live with a partner, completed high school (36.84%), had a per capita income of up to one minimum wage (76.31%), and underwent radical mastectomy (57.89%). Table I presents the social, economic, and demographic characteristics of the women who participated in the research, collected at the time of the interview.

Table 1 - Sociodemographic profile of mastectomized patients attended at the women's health physiotherapy outpatient clinic of IMIP from February to April 2023.

Variables	f	%
Sex		
Female	38	100
Surgical procedure		
Conservative Surgery/Quadrantectomy	11	28.94
Radical Mastectomy	22	57.89
Modified Mastectomy	05	13.15
Age group		
41-50	18	47.36
51-60	12	31.58
61-70	04	10.52
71-80	04	10.52
Color		
White	06	15.78
Brown	22	57.89
Black	08	21.05
Others	02	5.26
Marital status		
Married	17	44.73
Single	18	47.36
Widowed	03	7.89
Education		
Completed elementary education	03	7.89
Incomplete elementary education	12	31.57
Completed high school	14	36.84
Incomplete high school	01	2.63
Completed university education	07	18.42
Incomplete university education	01	2.63
Origin		
Countryside	17	44.73
Urban area	21	55.26
Habits		
Current alcoholic	15	39.47
Previous alcoholic	08	21.05
Current smoker	04	10.52
Previous smoker	07	18.42
Monthly per capita income (R$)		
Up to half the minimum wage (651.00)	05	13.15
Up to one minimum wage (1,302.00)	29	76.31
Up to two minimum wages (2,604.00)	02	5.26
Up to four minimum wages (5,208)	01	2.63
Up to eight minimum wages (10,416.00)	01	2.63

Figure 1- Main post-surgical discomfort reported by research participants. 2025.



Spontaneous reports of deep depression and suicidal thoughts were noted during the first months after the procedure by 2.63% of the patients, and 5.26% mentioned a loss of intimacy with their partner and embarrassment when undressing in front of another person (partner or relative) in the same environment after the surgery.

Among the guidelines that participants received in the postoperative period are: exercises for the upper limb ipsilateral to the surgery, avoiding strain, care with sharp objects, walking, hygiene, absolute rest, adopting specific positions for sleeping, nutrition, bandaging, and not lifting weights. It is worth noting that 21.05% of women did not receive or do not remember any guidelines, and only 2.63% of the patients who received them obtained these guidelines in written form.

As for the professionals who guided the patients, 78.95% mentioned physicians (28.95%), physical therapists (13.15%), and nursing technicians (2.63%). The other women who received guidance (34.21%) reported that they were advised by more than one professional category, including physician, nutritionist, physiotherapist, and nurse.

The Thematic Content Analysis by Bardin was conducted by the researchers based on the transcription and listening to the interviews with the women participants of the study. In order to identify ideas and meanings from the interview, groupings of categories that emerged from the thematic analysis were constructed and organized into three main themes, described in box 1.

Box 1. Themes and Categories derived from the interview for content analysis.2025.

THEMES	CATEGORIES
1. Guidelines	1.1. Healthcare professionals 1.2. Information provided
2. Recovery	2.1. Challenges and discomfort
3. Guidance format	3.1. Perception and acceptance of video proposal

- Category: Healthcare Professionals.
M1. *They (unidentified) said that I had to do exercises, you know, all those things they talk about, they even gave me a little written guidance on diet and some stuff from the nutritionist.*
M2. *The guidance I received was not to lift weights, to get up only from Nurse Teresa's bed and the surgeon physician, just verbally.*
M13. *I even received a WhatsApp message from a physical therapist, teaching me some exercises, but I never did them.*

Category: Information passed on.
M10. *Only take medication when you feel pain and anti-inflammatory medication then come back for a check-up.*
M13. *I was told not to put any weight on that arm (pointing to the right upper limb), and when I had the drain removed, I was supposed to do some exercise, I was supposed to walk. Nine lymph nodes were removed, so I can't take my blood pressure, get vaccinated, nothing.*
M34. *There was no physical therapist, so the physician told me how far I would have to lift my arm and what I couldn't do. It took about three months for the physiotherapy.*

- Category: Challenges and discomfort.

M8. *Pain to this day, do you understand?! It is a sharp pain during surgery, then it starts during surgery, from surgery it goes to the armpit and responds when I am having cramps here (points to the arm ipsilateral to the surgery).*

M23. *On the fourth day (PO) I was already full of fibrosis. The biggest discomfort was the fibrosis, because it causes pain.*

M38. *I feel pain where it was cut, I can't put clothes over my head, I only wear clothes that are worn over the foot or open in the front, if I make an effort it swells (my arm) and it makes me mentally ill. To this day I don't really like looking at myself in the mirror and I don't take my clothes off for anyone, the only one who saw me without clothes was my husband.*

- Category: Perception and acceptance of proposal in video.

M1. *I like it (the proposal), I do like it, and every educational video is good! Look, everything we learn is valid; it would have been good for sure, because it's one thing to talk about it, another thing to see it, right?! There wasn't any video like that there (at the hospital).*

M16. *It would be great! Because we (patients) would be aware of what could happen, right?! After the surgery.*

M23. *I received a video from a physical therapist and it helped me a lot.*

When an educational video format was proposed, 2.63% of women responded that they would be indifferent, justifying that they would seek information on their own before the surgical procedure. Another 2.63% reported being too shy to show their vulnerability to relatives, justifying that this could make it difficult for them to adhere to the proposed format.

Meanwhile, 94.73% of patients expressed that they would feel benefited if they were presented with video material with some guidelines.

Discussion

Despite advancements in surgical approaches over time, invasive interventions in the treatment of breast cancer still present numerous challenges during the postoperative period. According to Pereira et al., the high incidence and challenging prognoses of breast neoplasia highlight the importance of early diagnosis.[10] It is increasingly crucial to comprehensively address the various aspects of healthcare for these women. When analyzing the patients' statements in the present study, three main themes emerged: guidance, recovery, and format of orientation.

Some variables tend to have a significant relationship with mastectomy. According to Almeida (2006), who investigated the impact of mastectomy on women's lives, the age of the woman is one of the factors related to complications.[11] In the present study, the mean age of the participants was 53.60 ± 9.61, which represents a higher likelihood of experiencing physical and emotional complications after surgery due to hormonal and physical changes, resulting in additional challenges in recovery. The importance of adequate support and specific guidance for women in this age group is emphasized, aiming to provide a more satisfactory recovery process and assisting in adapting to the physical and emotional changes resulting from mastectomy.

Regarding the socioeconomic status, 89.46% of the patients had a monthly income equal to or less than 1 minimum wage, and only 21.05% reached university education. No comprehensive relationships were identified between socioeconomic status and the challenges faced during the PO period. However, it can be inferred that technological access to quality information and assistance services is directly linked to these factors.

It is important to highlight that this study was conducted in a public service located in the metropolitan area of Recife, in Pernambuco, which is linked to the Unified Health System (SUS). A relevant fact is that 44.73% of the study participants lived in rural areas of the State, which means they depended on private transportation or transportation sponsored by the municipalities of their respective cities to access the outpatient clinic and receive treatment. Therefore, access to health services at the outpatient clinic was also conditioned by these external factors.

One of the themes of the analysis was related to the guidance, as there was a need to provide adequate guidance during the post-operative period to all women undergoing mastectomy. This guidance should cover not only aspects related to hospital care but also consider the different aspects of a woman's personal life.[12] It is important to recognize that the post-surgical context extends beyond the hospital environment, where interactions with the social environment are more restricted and/or controlled. Therefore, it is essential to ensure that the guidance addresses the various challenges and needs faced by the woman in her daily life.

Since surgical procedures can lead to not only a reduction in Range of Motion (ROM) but also postural alterations, stretching exercises for the cervical region and shoulder movements at different amplitudes are highlighted in the

literature to prevent contractures from fibrosis and adhesion.[13] These pieces of evidence contradict the guidance that some patients in the present study received to remain in complete rest. However, it is important to emphasize that excessive movement or improper practice of exercises can result in additional limitations for these patients, considering the reduction in functional capacity caused by the injury, especially in the limb corresponding to the surgery, the increase in edema, and pain in the muscle groups.[14]

Therefore, it is essential that professionals who care for patients with this profile observe functional impairment, whether due to reduced activities or adjuvant interventions, such as radiotherapy and chemotherapy, and provide precise and well-founded guidance on the need for and appropriate duration of rest.[15]

Regarding guidelines on lymphedema, we can highlight 8 main ones: avoid exposing the limb to heat, do not overload the limb ipsilateral to the surgery, do not perform repetitive and rapid movements, use repellents and moisturizers, avoid trauma and burns, use compression garments during airplane travel, do not measure blood pressure manually and do not administer injections in the limb ipsilateral to the surgery.[16] During the 38 interviews, only 4 of them were mentioned. This is an indication that the guidelines need to be better explored by these patients.

Patients who are monitored by a physical therapist experience a faster functional improvement with fewer difficulties.[17] Some patients end up showing feelings of regret and guilt for not adhering to the treatment when advised. This may be directly related to non-adherence to the guidelines, coming from a rural background, distancing them from the main rehabilitation centers, or even because they do not present common symptoms for the type of illness right at the beginning of treatment, only developing them after some time.

Another item of analysis was the process and challenges of patient recovery. Regardless of the surgical technique, whether conservative or radical, problems such as pain, lymphedema, paresthesia, decreased muscle strength, and reduced range of motion of the involved limb are often observed and reported by women who have undergone breast surgery, and deserve attention as they interfere with the quality of life of these women. In this study, it was observed that a large part of the participants referred to pain, edema, and limitation of activities of daily living when invited to discuss the discomforts as a postoperative consequence.

Hidding (2014) points out radiotherapy and hormonal therapy as factors leading to pain after breast cancer surgery. In this study, we found limitations regarding the records of adjuvant treatments performed by the sample. Although pain was not assessed in degree and its origin was not investigated, more than half of the women who underwent mastectomy reported pain both in the affected upper limb and at the Surgical Wound (SW).

According to De Groef (2017), pain was a predictor for dysfunctions in UL, where there were 274 women participants in the study, 65% reported experiencing pain. In this study, it was observed in the treatment, carried out at the physiotherapy outpatient clinic, the predominance of kinesiotherapy treatment for UL as an intervention for shoulder limitations generated by surgery and consequently pain reduction. Early kinesiotherapy proves to be

effective in reducing pain intensity, highlighting the importance of the initial approach of physiotherapy.[21]

The emotional state of the patients who underwent the surgical procedure was a marked factor during the interviews. Both the aspects related to the fear of moving the limb affected by the surgery and the aesthetically related aspects were present in the participants' speeches. Regarding these women's self-esteem, it can be associated with social stigmas related to the breast, sensuality, and female aesthetics.[22] When an illness and/or its treatment affects this area, it is essential for the patient's well-being that alternatives and means for a good recovery and reintegration into their activities are presented.

In this emotional context, there is also a very common major villain in the post-operative phase of mastectomy. The fear of developing lymphedema in the ipsilateral upper limb to the surgery can trigger even greater concerns regarding recovery prospects and future influences on lifestyle habits. Approximately, for every five women who survive breast cancer, one will develop lymphedema between 14 and 18 months after the surgery.[23] On the other hand, the expectation of the onset of lymphedema also serves for good adherence to the guidelines and consistency in physiotherapy treatments.

Among the main complaints, 16.4% are related to performing simple domestic activities such as sweeping the yard, washing dishes, organizing groceries in the cupboard, and cooking. There is a significant stigma and a great concern among patients related to returning to Activities of Daily Living (ADLs).[24] Preventive guidelines play a crucial role in adapting to a new lifestyle, but they can also serve as barriers that impose limits on lives, resulting in feelings of fear, uselessness, panic, and worry about the possibility of developing lymphedema when undertaking certain efforts.

The impact of the aforementioned conditions is significantly greater in women's lives, especially when faced without family participation, since the social context of women in today's world requires them to act in multiple roles simultaneously, such as maternal, head of the family and professional.[25] It was observed that more than half of the patients (55.25%) undergoing mastectomy did not live with a partner. Thus, women undergoing the surgical procedure, in addition to the psychological issues they will have to face, will also deal with restrictions in their work activities, directly influencing their family and social dynamics as a whole.

Regarding the analysis of orientation formats, the similarity in responses during interviews was evident when patients were asked about the guidance they received. It is noteworthy that only 2.63% received written instructions, as this is an accessible method for health professionals and yet is underutilized. About 21.05% of women did not receive any type of guidance, although it is not possible to ascertain with certainty whether they actually did not receive it. This may be explained by influences of the postoperative period, such as the presence of residual narcosis, or by the time elapsed since the surgery, which may mean that patients no longer remember the information received.

It is possible to infer that over the years, or even in the first months after surgery, much important information provided by healthcare professionals was forgotten or not adequately absorbed, which may have negatively impacted the recovery of some patients. This is especially relevant considering that not all participants have access to weekly monitoring by a specialized professional.

Conclusion

A series of post-surgical challenges were noted, with pain, edema in the upper limbs, and limitations in Activities of Daily Living being the most frequently mentioned discomforts by mastectomized women. These problems, arising from the postoperative period, have a significant impact on various aspects of the patients' lives and should be considered a relevant health issue. Through the perception of patients undergoing mastectomy, it became evident that guidance plays a fundamental role in the quality of life of these women, further highlighting the importance of an individualized approach tailored to their daily needs. The participants of the study found a scarcity of available assistance resources, both in printed format, such as booklets, and in digital format, such as videos. Therefore, it is necessary to conduct new research that examines the application of different guidance formats to better serve these patients.

Acknowledgements

This study was funded by the authors themselves.

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