

Women Perception of their Functionality and Quality of Life after Mastectomy

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Percepção das Mulheres sobre sua Funcionalidade e Qualidade de Vida após Mastectomia

Percepción de las Mujeres sobre su Funcionalidad y Calidad de Vida después Mastectomía

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Abstract

Introduction: In Brazil, the breast cancer diagnosis usually occurs an advanced stage, culminating in more aggressive treatments that lead to greater functional and psychological sequelae that interfere negatively in the quality of life. **Objective:** This study aimed to understand and describe the patients' perception about the impact of cancer treatment and the contribution of physiotherapy to recover their quality of life and functionality. **Method:** It's a qualitative study with twenty-nine women, underwent modified radical mastectomy and who presented a restriction of the range of motion of the upper limb. The patients underwent ten physiotherapeutic sessions and, in the end, they were submitted to semi-structured interviews, which were categorized in relation to the effects of oncological treatment, post-surgical limitations, concept of quality of life and impact of physical therapy on return to daily activities of daily living. **Results:** After the treatment, the patients reported functional, emotional and self-esteem improvement, allowing their social reinsertion and return activities of daily living. **Conclusion:** Through the reports, it was possible to conclude that the rehabilitation promoted positive results in the quality of life and functionality and we could have a broader perception about the impact of the illness and oncological treatment in the daily life of these women, thus subsidizing ways to improve the physiotherapeutic care to this population.

Key words: Breast Neoplasms; Mastectomy, Modified Radical; Physical Therapy Modalities; Quality of Life; Rehabilitation.

Resumo

Introdução: No Brasil, o diagnóstico do câncer de mama ocorre geralmente em fase avançada, culminando com tratamentos mais agressivos que levam a maiores sequelas funcionais e psicológicas, que interferem negativamente na qualidade de vida. **Objetivo:** Compreender e descrever a percepção das pacientes sobre o impacto do tratamento oncológico e a contribuição da fisioterapia na recuperação da sua qualidade de vida e funcionalidade. **Método:** Trata-se de um estudo qualitativo no qual foram incluídas 29 mulheres submetidas à mastectomia radical modificada, que apresentaram restrição da amplitude de movimento de membro superior. As pacientes realizaram dez atendimentos fisioterapêuticos e, ao final, foram submetidas a entrevistas semiestruturadas, categorizadas em relação aos efeitos do tratamento oncológico, limitações pós-cirúrgicas, conceito de qualidade de vida e impacto do tratamento fisioterapêutico no retorno às atividades de vida diária. **Resultados:** Após o tratamento, as pacientes relataram melhora da capacidade funcional, emocional e autoestima, possibilitando sua re inserção social e retorno às atividades de vida diária. **Conclusão:** Por meio dos relatos, foi possível concluir que a reabilitação promoveu resultados positivos na qualidade de vida e funcionalidade e ter uma percepção mais ampla sobre o impacto do adoecimento e do tratamento oncológico no cotidiano dessas mulheres, subsidiando assim caminhos para o aperfeiçoamento do cuidado fisioterapêutico a essa população. **Palavras-chave:** Neoplasias da Mama; Mastectomia Radical Modificada; Modalidades de Fisioterapia; Qualidade de Vida; Reabilitação.

Resumen

Introducción: En Brasil, el diagnóstico del cancro de mama ocurre generalmente, en fase avanzada, culminando con tratamientos más agresivos que llevan a mayores secuelas funcionales y psicológicas que interfieren negativamente en la calidad de vida. **Objetivo:** Comprender y describir la percepción de las pacientes sobre el impacto del tratamiento oncológico y la contribución de la fisioterapia en la mejora de su calidad de vida y funcionalidad. **Método:** Se trata de un estudio cualitativo en el que se incluyeron 29 mujeres, sometidas a la mastectomía radical modificada, que presentaron restricción de la amplitud de movimiento de miembro superior. Las pacientes realizaron diez atendimientos fisioterapêuticos y, al final, fueron sometidas a entrevistas semiestruturadas, categorizadas en relación a los efectos del tratamiento oncológico, limitaciones postquirúrgicas, concepto de calidad de vida e impacto del tratamiento fisioterapêutico en el retorno a las actividades de vida diaria. **Resultados:** Después del tratamiento, las pacientes reportaron mejoría de la capacidad funcional, emocional y autoestima, possibilitando su re inserción social, retorno a las actividades de vida diaria. **Conclusión:** Por medio de los relatos, fue posible concluir que la rehabilitación tuvo resultados positivos en la calidad de vida y funcionalidad y tener una percepción más amplia sobre el impacto de la enfermedad y del tratamiento oncológico en el cotidiano de esas mujeres, subsidiando así caminos para perfeccionar el cuidado fisioterapêutico a esta población. **Palabras clave:** Neoplasias de la Mama; Mastectomía Radical Modificada; Modalidades de Fisioterapia; Calidad de Vida; Reabilitación.

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INTRODUCTION

Breast cancer is the leading tumor affecting women in Brazil and in the world. It represents an important health public issue in our country, it is the main cause of death in the female population¹.

The therapeutic approach for breast cancer considers the staging of the diseases and the individual, clinical and psychological aspects². In Brazil, advanced stages and more mutilating treatments are observed, resulting in major functional, emotional and social sequelae, increasing disabilities and incidence of complications³⁻⁴.

Among the complications of oncologic treatment, studies demonstrated that the restriction of the range of motion, weakening of the muscle strength, the incidence of pain and the presence of lymphedema may negatively impact the patients' life quality. According to the literature, the extension of axillary approach, the presence of co-morbidities, labor activity and early age contribute significantly for the functionality restrictions of the upper ipsilateral limb of the tumor^{5,6}.

The treatment of breast cancer may also provoke important modifications in the woman body with negative impacts in her self-image, sexuality, femininity and social and affective relations⁷.

In face of the severe impacts of the breast cancer treatment on the life quality and functionality of the woman, the multi-professional team have to be aware to comprehend her necessities and promote an early and proper support⁸. The physiotherapy has a key role in this process, acting along the whole line of cancer care, preventing, minimizing and rehabilitating the complications of the oncologic treatment⁹. The early physiotherapeutic approach to breast cancer is effective to improve the functionality and life quality of the women and must be a routine in the post-operation care¹⁰.

The quality of life is defined by the World Health Organization (WHO)¹¹ as "the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." Through its evaluation, it is possible to understand the perception of the patient about the impact of the disease in its life and predict the influence of the treatments on its condition¹². It is a multi-dimensional and subjective concept that can only be evaluated by the own individual^{13,14}. It is relevant, therefore, to listen to what these women have to say to understand her actual necessities and specificities, enlarging our sensitiveness towards this theme to improve the care provided to this population.

Consequently, this study will attempt to understand under the point of view of the patients, the impact of

the oncologic treatment in their lives and to what extent the physiotherapy may contribute for the improvement of their quality of life and functionality after the breast cancer surgical procedure.

METHOD

It is a descriptive, qualitative approach trial. It were used semi-structured interviews to collect data, with a script containing general selected topics and elaborated to be applied to all the interviewees as proposed by Moraes¹⁵. The objective is to build up a social-demographic profile of this population.

Women with breast cancer diagnosis submitted to radical mastectomy with axillary lymphadenectomy who presented restriction of the range of motion of upper limbs as a result of the surgery and referred for weekly follow-up in the outpatient unit of physiotherapy of "Hospital do Câncer III (HCIII)" of "Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA)", from July '2016 to October 10, 2017 were included.

It were excluded women with locoregional relapse and/or remote metastasis, submitted to breast reconstruction or bilateral surgical treatment and those with background of previous disease in the upper ipsilateral limb prior to surgery.

The patients were followed-up during ten sessions in group, each session took 1 hour, once a week, with global stretching techniques, active free and active-assisted kinesiotherapy; cervical relaxation and home specific guidelines with the objective of reclaiming the range motion of the upper limb and pain relief⁹. The patients were invited to participate of the interviews that addressed life quality and functionality-related issues after the treatment received at the end of the tenth physiotherapy session.

To define the sample size, it was adopted the principle of theoretical saturation of the data. With this method, the enrollment of new participants stops when the data obtained start to present some redundancy or repetition¹⁶. It were included, therefore, 29 women in this study and it were considered enough and consistent the information drawn from their narratives.

It was used the technique of Content Analysis proposed by Bardin¹⁷ for the analysis of the data. According to the author, the speech of the individual is its expression as a subject. She considers the presence of words and expressions that repeat along the text as a base to categorize the findings later¹⁸.

The information collected to describe the profile of these women were included in a database in Excel; it was made a descriptive analysis using the measures of central tendency for the continuous variables and of frequency for the categorical variables.

The Institutional Review Board of HC III/INCA (CAAE: 55344116.0.0000.5274) approved this study, approval report number 1.585.927 dated June 12, 2016 in compliance with demands of resolution 196/96 revised by resolutions 466/12 and 510/16 of CNS – National Health Council (CNS – Conselho Nacional de Saúde). The resolutions dispose about the guidelines and rules of researches with human subjects.

RESULTS AND DISCUSSION

The average age of the women enrolled was 53.65 (±11.42). Most of them did not live with their spouses (65.3%), had more than eight years of education (67.3%), had social security (61.2%), had a job off-house (59.2%) and 40.8% were mainly housekeepers. The majority of the women (87.8%) reported the upper right limb as the dominant and 42.9% of the surgeries were in this same side. Whereas the clinical and tumoral characteristics, 58.7% of all the patients were on clinical stage IIIB, 85.7% underwent neoadjuvant chemotherapy and 93.9% received adjuvant radiotherapy.

After the transcription of the narratives and analysis of the repeated expressions, it was possible to devise thematic categories and subcategories that illustrate the perception of these women about their life quality and functionality after the breast cancer treatment and how they understood the impact of the physiotherapy treatment in their lives and in their daily activities after the disease (Table 1).

To protect the anonymity of the interviewees, their names were coded with the letter M followed by a number.

Table 1. Thematic Categories and subcategories

Thematic Categories	Thematic Subcategories
1. Living with the effects of oncologic treatment and post-surgery limitations	Self-image Job-related difficulties Performance of domestic activities and daily life Psychologic alterations and physical symptoms
2. Concept of life quality	Life situations Social Support
3. Impact of the physiotherapy treatment when returning to daily activities	Functionality Security and independence Socialization

LIVING WITH THE EFFECTS OF THE ONCOLOGIC TREATMENT AND POST-SURGERY COMPLICATIONS

All the women interviewed reported effects and limitations arising from the breast cancer treatment associated to self-image, work, domestic activities and daily life, upper limb motion limitations, psychologic changes, insecurity feelings and disability, among others.

The patients reported difficulties in accepting the loss of the breast, in relation to self-image and decreased self-esteem.

Nobody accepts being mutilated, right? I was born with two breasts, not one. Sometimes I feel sad to look and wonder how I am going to live with this for the rest of my life. M2

Looking at me after the surgery was a huge shock. See me in the mirror was the toughest part, couldn't accept myself. See me without the breast was very traumatic. M23

Took out all the mirrors in the house because I can't accept my breast, can't look at it. M25

After the surgery, they reported changes in the perception as a woman and shame of their own image.

I feel like I'm less feminine. Some parties, in the beginning I didn't go because I wasn't feeling well, people stare, I preferred not to go. M7

Another remarkable topic in the narratives shows to what extent the surgery negatively impacted the affective relations, specially the sexuality.

Beauty still holds me back, now there is this boyfriend and I didn't want because of the beauty and I hadn't the nerve to tell him I had no more breast. I'm ashamed, I barely look at myself in the mirror, my bra and prosthetics sleep with me in my bed because I only take them off to sleep. It actually gets in the way of men and women relations. M9

In relation to the body, I feel totally insecure, in my marriage too, it ruined my relationship somehow, I feel insecure. M10

The trauma of mutilation and distortion of the self-image is a key aspect, because breast is a symbolic part and characteristic of the female image and relates to sexuality and to the function of the woman¹⁹.

The body image is the cognitive perception of the physical appearance²⁰. In mastectomized patients, the body image has changes not only after surgery but also after chemotherapy and radiotherapy²¹.

Morone et al.²² noticed in their study that the patients with their self-image less damaged presented better results in rehabilitation and that the body image is the prognosis factor of life quality.

In the narratives it can also be noticed a great insecurity with working activities. Many need to stop working or change her function because of treatment sequelae. This is certainly a very serious matter that impacts the woman life after the treatment for breast cancer; but it is still very little addressed in literature and deserves to be more explored.

After surgery, I feel I'm being treated in a different manner at my job, a feeling that the firm may think I'm not producing any more. A very strong feeling of insecurity and incapacity. I can't and I fail to work as before, today I feel tired, my production and frequency dropped. M15

I worked as a waitress and *bartender* and this helped me a lot, this was my reality and today isn't any more, today I'm only a housewife. M6

The impact over the social life interferes directly in the health status of the population, which while facing a chronic disease that needs continuous monitoring, is more fragilized with the consequences of this treatment²³.

In this study, 59.2% of the women worked off-house, but also kept their domestic activities and caring their children according to our culture, where the woman is the sole responsible for the house.

According to Coelho (apud Frazão²³), the off-house job is the representation of the personal achievement for many women, it is more than her subsistence, it is their independence and autonomy, which makes her worthy as a person.

The social-occupational reality of the majority of the patients is a job with a heavy workload; in the aftermath of the treatment, these women failed to resume work and, most of the times, are compelled to find another activity.

I'm trying to recycle because I'm unable to sew and I need to work. M2

The patients also reported impacts in their economic status during the treatment for different reasons. Some had financial difficulties because of the treatment costs, as transportation and food. Others, when left their formal jobs, lost benefits as transportation and meal voucher. In addition to informal workers who were unable to contribute to the family income, as is the case of the patient M11.

I used to work, I had a street stall and because of the pain in my arm, I had to stop, but I was lucky

because I managed to get a pension. I'm moving on as best as I can, because right now I'm only with my pension and couldn't get back to cook my food to sell. M11

All the interviewees reported difficulties to do their domestic activities and/or daily chores, they had to make adjustments in their routines to resume their tasks.

Sweep, get something from the top shelf, wipe the house. It was very tough for me to do these things. M1

Can't tidy up my house, can't get on a bus, have to wait for an empty bus because I can't hold my body right. M9

I don't do some tasks because I fear my arm will swell up, when I try to put something in the top shelf, it seems it weighs a ton, the rest I do as usual, but I get tired. M15

All the patients of this study were submitted to modified radical mastectomy, a surgical technique with axillary lymphadenectomy. This procedure is quite well described in the literature about the major frequency of morbidities in the upper ipsilateral limb of the surgery²⁴, like the reduction of the range of motion. This limitation directly interferes in the functional capacity and life quality²⁴.

The restriction of the range of motion may be the result of the pain or even of the surgical scar, because many women who underwent surgery avoid the motion of the upper limb fearing the dehiscence of the operative wound²⁵. The fear of moving the limb and the inactivity provoke a gradual impairment of the muscular strength and limited shoulder motion^{19,26,27}.

At this moment of vulnerability, the domestic tasks grants these women a feeling of reconstruction of their daily life²⁸. While facing physical exertion demanding activities, the patients still find themselves partially restrained, not only because of the morbidities arising from surgery, but also of the lymphedema preventive measures^{19,28,29}, fearing the appearance of the upper limb edema which require adjustments for these tasks as can be seen in the narratives of the patients M3, M22 e M5.

I watch myself fearing any accident at home and arm swelling. M3

I end up forcing the other arm. I do what I can and eventually I can't or ask my daughter for help. I'm very fearful of my arm swelling. M22

I got used to tidy up the house little by little, I distribute the tasks through the days of the week. M5

Throughout the interviews, some women report mood changes after the treatment, others, sleep disorders and recurring symptoms that had negative impact during or after the treatment.

The treatment weakens me, really down, it is a fight with yourself every day, very tiresome. Makes you emotional, luckily I have my family. M5

I turned out more undemonstrative, it seems the others have pity on me, I stay more at home. I was very angry with treatment. M13

It is not only the hair falling, it is everything, you feel down, unable, most become emotional, but prejudice is there, you are different, you are weakened. Sometimes, I am moody, bonkers, slow thinking, my memory got worse. M15

Physical suffering affects the survival because it can inhibit the coping strategies of the patients in treatment⁵. This scenario has a negative impact over the quality of life and directly reaching the health and well-being³⁰.

Breast cancer treatment has a significant influence on the emotional aspects of the woman³¹. There is also the imaginary or actual proximity to death and impairment that creates fear, anguish, shame and discrimination³².

Insomnia, stress, this bothers me much. I'm all alone most of the time, then I cry, have to take tranquilizers. Sometimes I feel I want to die, but soon I regret having thought about that. M22

Cancer diagnosis creates an important emotional stress that may cause sleeping disorders. The most prevalent disorder is insomnia and is related to fear of relapse, depression, chronic fatigue and cognitive changes³³. The prevalence of depression in cancer patients is three times higher than in the population in general and is related to worse life quality³⁴.

Cancer-related fatigue is multi-causal and can be physical, emotional and cognitive, interfering significantly in the functionality and life quality³⁵. It is one of the most important cancer-related treatment symptoms³⁶.

Late diagnosed patients and submitted to axillary resection have two-fold risk of developing post-mastectomy pain that can show in rest or during the motion³⁷.

This symptom negatively impacts the life quality, self-care, job activities, physical and emotional well-being and domestic chores²⁶. It is already well defined in the literature that exercises with the surgery ipsilateral limb help in the prevention of pain and treatment.

I am very fatigued, some days I feel like a truck tripped over me. M15

Nausea and exhaustion are horrible during chemo. The pain in the arm is boring, something pulling me, I feel like I'm tied, if I don't do the exercises two days in a row, I already feel stuck, it seems it is sewn. M20

The radiotherapy was a landmark that impacts negatively the functionality and life quality of these women as the narratives show.

I felt like a heavy weight in the arm after the radiotherapy as if it were numbed again. After the radiotherapy, I thought I was down to zero. M2

My motion worsened a lot with radiotherapy, it was the worst part of the treatment, my skin burned, the pain came back when I moved my arm. M4

The radiotherapy unchains a slow scarring repair, accentuated tissue fibrosis and, consequently, an important restraining of the upper limb function³⁸.

The axillary lymphadenectomy, conjointly with adjuvant radiotherapy, may cause severe morbidities in the upper limb or worsen the existing, interfering in the daily life and quality of life of these women¹⁹.

According to Bezerra et al.³⁹, as the radiation also affects regions of the normal tissue, there are side effects as pain, fatigue, sensitive and cutaneous alterations as radio dermatitis.

For this author, the pain in the upper limb is a symptom present soon after surgery with significant increase of intensity immediately after the radiotherapy treatment, corroborating the findings of Lahoz et al.¹⁹ and Fabro et al.³⁷.

Simultaneously to the worsening of this symptom, the study by Bezerra et al.³⁹, noticed an increase of the functional disability of the upper limb after the radiotherapy, which is clear in the narratives of our patients.

CONCEPT OF QUALITY OF LIFE

The quality of life has a wide, complex and multifactorial concept.¹¹ When asked what means to have quality of life, the interviewee mentioned their thoughts, like conditions of life (house, leisure, health, food, work and income) and social support (family and/or friends).

Be able to go out, work out, stroll, work. M3

It is what I'm having now, take care of my family, do homework with my son. My food is healthier now. M4

Live well, walk around, read, have fun, travel. Do whatever you want when you want. M7

Be healthy, good food, a family. Family is part of this treatment. M9

Have a job, have fun without difficulties, have good health, good living conditions and good relations. M15

Through the narratives, it is understood that various aspects are valued differently by the interviewees and are able to impact their quality of life. After the cancer and the tough treatment, as concluded from the speeches already mentioned, in the end their lives are seriously modified. While evaluating the life quality, it is possible to realize how the disease impacts the patients' lives and the manner through which they perceive this change¹².

IMPACT OF THE PHYSIOTHERAPY TREATMENT TO RESUME THE DAILY ACTIVITIES

All the patients reported positive impact of the physiotherapy while doing their daily and domestic activities, they feel more secure and independent to resume their routines and assess as positive the experience of the treatment in group to socialize with persons who went through the same process, to exchange experiences and creation of bonds.

The perception of the quality of life involves several aspects, including the physical, emotional, social and functional well-being¹⁴. A wide range of aspects may affect the perception of the individual, its feelings and behavior associated to its daily functions, but not limited to its health condition and medical interventions⁴⁰, based in the narratives:

Physiotherapy has helped a lot, even to dress, have a shower, wash my head, drive my kids to the school; went back to cook pastries, take care of myself. M4

Couldn't wash my hair, today I manage all by myself. I had a cleaning maid, today, I can tidy my place up. M7

Today, I'm able to raise my arm, put on my clothes, buckle up my bra, my daughter used to do this before, now I'm normal. Taking care of myself again, I cook, clean my house, make the bed. M16

Today, I manage to do my home activities that earlier I failed to do, couldn't do a physical activity because the arm didn't come along and today, I'm doing, I go out, take a bus, before I had limitations. M23

The functional capacity is associated to the ability of an individual in fulfilling its basic activities of daily life independently from other persons⁴¹.

The presence of dysfunctions of the upper limb after breast cancer treatment has a negative impact in the performance of the daily chores⁴² and may lead to the loss of work, family and sexuality related roles⁴³, in addition to interfering in home and personal care management²⁶.

I felt very insecure to get on a bus, always took a cab even with no cash available, today I am able to stand on myself in a bus. I feel safe. I'm on my high heels again, earlier I was afraid of falling and hurting the arm, got my makeup back. I'm meeting my friends again, feel safe to go out, I'm back to myself again. M3

Feel more independent, safer to go around, of course with some restraints, but I know my limits, to what extent my body will be respected. My arm improved visibly and the movement came back. M23

It is a consensus in literature that kinesiotherapy is an essential tool to reclaim the physical function and functionality of these women and should be initiated as early as possible^{10,26,29,44,45}, consistent with the patients' narratives that recovered their functionality, autonomy, safety and independence.

Kinesiotherapy in group was a positive experience for the participants of this study as is clear in the narratives below. The treatment in group provides patients with the broadening of the social support network and reduction of the emotional impact caused by cancer, treatment and complications. Their self-esteem is enhanced, consequently⁴⁶.

I have colleagues of the group we talk in the *whatsapp*, we miss each other, my mood improved a lot, I was down when I went in. M3

I'm extremely shy, I loosened myself up in here, I saw other people, made friends. M5

It helped me a lot, the exercises, the help and contact with other people that went through the same process I did, we managed to exchange many things and make friends. M10

The results of Fangel et al.²⁸ study indicated that there were damages to the psycho-social aspects of the patients, suggesting that cancer treatment predisposes the social isolation and the team should encourage leisure and participative activities.

Living in group formed by people with similar problems grants an experience that can help the participants to break

barriers created by feelings of loneliness and isolation, especially because of the possibility of developing new ways of dealing with breast cancer⁴⁷.

CONCLUSION

Breast cancer treatment has several impacts on the women's lives that directly affect their quality of life and functionality. From the results of this study, physiotherapy was able to contribute specially in resuming the daily life activities and self-care. Furthermore, it helped in their social reinsertion, indicating that the group treatment is a rehabilitation strategy and offers a feeling of support and help.

Despite reporting the improvement of the functional, social, emotional capacity and self-esteem that are directly related to the quality of life, the idea transmitted by women was much more comprehensive, which corroborates the literature about the subjectivity and the multi-factoriality of these ideas, not limited to health conditions.

These results may contribute to the understanding of the challenges faced by patients with breast cancer in a set of full care, granting a wider perspective about the impact of falling ill and oncologic treatment in the daily life of these women.

CONTRIBUTIONS

All the authors participated equally of the study design and planning, data collection, wording and critical revision and approved the final version of the manuscript.

DECLARATION OF CONFLICT OF INTERESTS

No conflicts of interest to declare.

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