Prevention and Care of Lymphedema after Breast Cancer: Understanding and Adherence to Physiotherapeutic Guidelines

http://dx.doi.org/10.32635/2176-9745.RBC.2019v65n1.273

Prevenção e Cuidado do Linfedema após Câncer de Mama: Entendimento e Adesão às Orientações Fisioterapêuticas

Prevención y Cuidado del Linfedema después del Cáncer de Mama: Comprensión y Adhesión a las Orientaciones Fisioterapéuticas

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Abstract

Introduction: Lymphedema is the most common complication after breast cancer surgery. Early physiotherapeutic intervention is essential to improve quality of life and prevent such sequelae, but preventive guidelines can generate a feeling of incapacity and limitation. **Objective:** To identify the level of understanding and adherence of patients to physiotherapeutic guidelines in the prevention and care of lymphedema. **Method:** Descriptive, qualitative research, performed at Hospital de Cancer III the National Cancer Institute José Alencar Gomes da Silva (INCA). Fourteen patients were submitted to surgical treatment for breast cancer, and semi-structured interviews were performed. **Results:** The patients interviewed reported that they received guidance from the physiotherapy team and understood the importance of the recommendations. The main feelings aroused when asked about adherence to preventive care were worry, fear and panic, as well as the phantom of lymphedema. The interviewees recognized that soon after the surgery, they adhered more to preventive care, but that with the passage of time, this routine of care became more complicated, especially in front of their domestic commitments. **Conclusion:** We can see that these women coexist with a great fear of developing lymphedema, but they have a strong need to resume their domestic tasks. It was remarkable in the speeches how much the physiotherapeutic orientations generate anguish, sadness and sense of uselessness in these women. Physiotherapy should be attentive to the way it presents the preventive guidelines for lymphedema, and should always seek adaptation and never prohibition, in order to bring understanding and promote cooperation, sharing with women the responsibility for their self-care.

Key words: Breast Neoplasms; Lymphedema; Physical Therapy Modalities; Disease Prevention.

Resumo

Introdução: O linfedema é a complicação mais frequente após a cirurgia do câncer de mama. A intervenção fisioterapêutica precoce é fundamental para melhorar a qualidade de vida e prevenir tal sequela, porém as orientações preventivas podem gerar um sentimento de incapacidade e limitação. **Objetivo:** Identificar o nível de compreensão e a adesão das pacientes às orientações fisioterapêuticas na prevenção e cuidado do linfedema. **Método:** Pesquisa descritiva, qualitativa, realizada no Hospital do Câncer III do Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA). Foram incluídas 14 pacientes, submetidas a tratamento cirúrgico para o câncer de mama, sendo realizadas entrevistas semiestruturadas. **Resultados**: As pacientes entrevistadas relataram que receberam orientações da equipe de fisioterapia e compreenderam a importância das recomendações. Os principais sentimentos despertados, ao serem questionadas sobre a adesão aos cuidados preventivos, foram a preocupação, o medo e o pânico, além do fantasma do linfedema. As entrevistadas reconheceram que, logo após a cirurgia, aderiram mais aos cuidados preventivos, mas que com o passar do tempo, essa rotina de cuidados tornou-se mais complicada, especialmente diante de seus compromissos domésticos. **Conclusão:** Pôde-se perceber que essas mulheres convivem com um grande medo de desenvolver o linfedema, porém têm a forte necessidade de retomar suas tarefas domésticas. Foi marcante nas falas o quanto as orientações fisioterapêuticas geram angústia, tristeza e sensação de inutilidade nessas mulheres. A fisioterapia deve estar atenta à maneira como apresenta as orientações preventivas de linfedema, devendo buscar sempre a adaptação e nunca a proibição, de forma a trazer compreensão e promover a cooperação, compartilhando com as mulheres a responsabilidade por seu autocuidado.

Palavras-chave: Neoplasias da Mama; Linfedema; Modalidades de Fisioterapia; Prevenção de Doenças.

Resumen

Introducción: El linfedema es la complicación más frecuente después de la cirugía del cáncer de mama. La intervención fisioterapéutica precoz es fundamental para mejorar la calidad de vida y prevenir tal secuela, sin embargo, las orientaciones preventivas pueden generar un sentimiento de incapacidad y limitación. **Objetivo:** Identificar el nivel de comprensión y adhesión de las pacientes a las orientaciones fisioterapéuticas en la prevención y cuidado del linfedema. **Método:** Investigación descriptiva, cualitativa, realizada en el Hospital del Cáncer III del Instituto Nacional de Cáncer José Alencar Gomes da Silva (INCA). Se incluyeron 14 pacientes, sometidos a tratamiento quirúrgico para el cáncer de mama, realizándose entrevistas semiestructuradas. **Resultados:** Las pacientes entrevistadas relataron que recibieron orientaciones del equipo de fisioterapia y comprendieron la importancia de las recomendaciones. Los principales sentimientos despertados al ser cuestionados sobre la adhesión a los cuidados preventivos fueron la preocupación, el miedo y el pánico, además del fantasma del linfedema. Las entrevistadas reconocieron que luego de la cirugía, se adhirieron más a los cuidados preventivos, pero que, con el paso del tiempo, esa rutina de cuidados se volvió más complicada, especialmente ante sus compromisos domésticos. **Conclusión:** Se puede percibir que esas mujeres conviven con un gran miedo a desarrollar el linfedema, pero tienen la fuerte necesidad de reanudar sus tareas domésticas. Fue marcante en las conversaciones cuanto las orientaciones fisioterapéuticas generan angustia, tristeza y sensación de inutilidad en esas mujeres. La fisioterapia debe estar atenta a la manera como presenta las orientaciones preventivas de linfedema, debiendo buscar siempre la adaptación y nunca la prohibición, para traer comprensión y promover la cooperación, compartiendo con las mujeres la responsabilidad por su autocuidado.

Palabras clave: Neoplasias de la Mama; Linfedema; Modalidades de Fisioterapia; Prevención de Enfermedades.

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INTRODUCTION

Lymphedema is the most feared complication by the patients submitted to axillary lymphadenectomy for breast cancer treatment. It manifests by the accumulation of water, proteins and cellular products in the extracellular space as result of insufficiency of the lymphatic system in the conduction of the lymph due to the obstruction of its flow [1,2].

Various lymphedema risk factors have been reported in literature, including radiotherapy in chain drainage, extensive axillary surgery, obesity, subclinical edema, infusion of chemotherapy in the ipsilateral member of breast cancer, infection and seroma [3-6]. A recent meta-analysis demonstrated that approximately one in every five survivals of breast cancer will develop lymphedema with median commencement from 14 to 18 months post-surgery[7].

In a study conducted at "Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA)" in 2012 with 1,054 women submitted to axillary lymphedema, its incidence was of 17% in two years and 30% in five years[8]. Macedo et al.[9] performed a cohort observational study with 933 women (683 women submitted to sentinel lymph node; 144 biopsies of the sentinel lymph node followed by axillary lymphadenectomy and 106 submitted to axillary lymphadenectomy) and concluded that the biopsy of the sentinel lymph node is an independent protection factor for complications when compared to axillary emptying. Ribeiro Pereira et al.[10] conducted a 10-year prospective observational study in a hospital cohort with 965 women submitted to breast cancer surgical treatment and, after this period, it was observed an incidence of 41.1% of lymphedema.

Lymphedema may impact directly the quality of life of the patients with physical, emotional consequences and interfering in their daily life, therefore the preventive guidance provided by the multiprofessional team is very important [11].

The prevention of lymphedema is based in guidelines to reduce the risk of this complication throughout life. This strategy has been applied to minimize the stress of the lymphatic system of the upper member at risk (upper ipsilateral member to breast cancer), hoping to prevent the lymphatic overbearing caused by the exit of water and nutrients from the interior of the blood capillary into the cellular interstice[7]. The multidisciplinary team is in charge of working conjointly for the full approach of this patient and early detection of this complication. The physiotherapist should be attentive and intervene along the whole line of care to the patient at risk of developing lymphedema.

Among the preventive guidance of lymphedema, it can be mentioned: avoid heat exposure of the ipsilateral member to the surgery, restrain any overload, do not make rapid and repetitive movements with this member[6], avoid using moisturizers and repellents, prevent trauma and burning to the member, avoid wearing compression garments during airplane trips, not measure blood pressure and not having injections applied in the ipsilateral member to surgery[12,13].

Another physiotherapeutic recommendation for lymphedema prevention is the exertion of myolymphokinetic exercises with the upper limbs. These exercises must be initiated earlier and done slowly, without resistance and few repetitions. Muscular contraction promoted during the exercises unchains a type of mechanic pumping, increasing the lymphatic angiomotricity and use of collateral lymphatic vessels [14-17].

The "Serviço de Fisioterapia do Hospital do Câncer III (HCIII)/INCA" (Physiotherapy Service of HCII/INCA) has a stablished routine which determines that every breast cancer patient submitted to axillary surgery (biopsy of the sentinel lymph node or axillary lymphedema) should be followed up by physiotherapy since post-operation until one year after the surgery, attempting to prevent postoperative complications and promotion of the quality of life[12,18].

Along the years, oncologic treatments and surgical techniques are evolving rapidly and doubts have arisen about the actual necessity, effectiveness and intensity of the preventive care as guided to the patients submitted to breast cancer surgical treatment. Have we provided too much guidance? Are we excessively restrictive? Are we saying too much "no's"? As much as surgeries evolve, we should also attempt to improve our conducts to offer better outcomes to our patients.

Therefore, this work had the objective to identify the level of understanding and adherence of the patients to the physiotherapeutic guidance for lymphedema prevention and care. It was also attempted to understand what are the adherence-related factors or non-adherence to care, to have an improved comprehension of what these patients think and, from then on, to match the preventive physiotherapeutic guidance to the current context, promoting as much independence and as less restrictions as possible to these patients.

METHOD

It is a descriptive, qualitative approach research conducted in HCIII/INCA. It were included women with breast cancer diagnosis submitted to breast surgical treatment and with some axillary approach (axillary

lymphedema or biopsy of the sentinel lymph node) followed up at this institution in any phase of the oncologic treatment. It were excluded patients with less than six months of surgery, under 18 years old, who presented local or remote metastasis and those with problems of comprehension to respond the questions.

From July to November 2017, data were collected. The eligible patients were selected through active search in the institutional system of visits appointment, approached by the investigator after the routine visits at the Mastology and Oncology outpatient units and invited to participate. After the medical visit in a private environment, a skilled and trained health professional informed the patients about the study, objective, risks, benefits and they signed the Informed Consent Form (ICF).

After accepting to participate, it were conducted semistructured interviews according to a tailored script for this research with the following questions: Were you informed about postoperatory preventive physiotherapeutic guidance? Have you understood the reason of the guidance? Do you follow the guidance? If not, why? Which guidance do you follow and which ones you don't? Do you think this guidance is important? Why? What do you think can affect your adherence? Do you think that, as times passes, you adhered less or more to the guidance? The interviews lasted 40 minutes in average.

It was decided to use the principle of theoretical saturation of the data to define the size of the sample for this research. According to this process, data collection is interrupted when it is concluded that the elements drawn are sufficient to support the interpretations[19,20]. Pursuant to this proposal, at the end of the enrollment 14 patients were invited to participate of the semistructured interviews.

All the interviews were audio-recorded and later transcribed to ensure the faithful expression of the patients' perceptions about their preventive care or attention to breast cancer post-treatment lymphedema. It was utilized the Technical Analysis proposed by Bardin[21] to analyze these information. In the Content Analysis, the speech of the individual corresponds to its expression as a subject. The analysis considers the presence of words and expressions that repeat along the text, attempting to categorize these findings later[19]. For Bardin[21], the Analysis of Content is "a set of techniques of analysis of communication that aims to obtain indicators that ensures the inference of knowledge related to the conditions when these messages were produced" through systematic and objective procedures of description of the messages content.

The Institutional Review Board of INCA, CAAE number 68894017.6.0000.5274, dated July 1, 2017 approved the research in compliance with Ordinance 466/12 of "Conselho Nacional de Saúde – CNS (National Health Council), which disposes about Guidelines and ruling Norms of researches involving human beings.

RESULTS AND DISCUSSION

The average age of the population included in the study was 55.3 years. The majority claimed they were Caucasian (71.4%), completed High School (71.4%), 50% did not live with spouse and 50% were married and had home activities as main occupation (71.4%).

About the treatment, 92.8% were submitted to mastectomy, 64.2% underwent axillary lymphadenectomy and 35.7%, biopsy of the sentinel lymph node. The average time between surgery and interview was 4.07, ranging from one to 14 years.

Through the analysis of the narratives, it were elaborated three thematic categories that represent ideas, words and core expressions, considering the subject of understanding and adherence to therapeutic care (Table 1).

The names of the patients were replaced by the letter M and a number, for the sake of anonymity.

Table 1. Analysis of Content – Categories

Thematic Categories
Awareness and importance of guidances
Anguish and limitations
Living with guidances along the time

Awareness and importance of guidance

The patients interviewed reported they were dully advised and understood the actual relevance of these guidances in what concerns the recommendations provided by HCIII physiotherapy team.

> I think it is important to follow these guidances, because if I don't, I am the one who is going to suffer, I will feel pain, my arm will swell, it is me that gets it all, so I am a stickler and I still want to live for a long time. M11

> I was given physiotherapy guidance when I was hospitalized and understood why I had to do this. If I push hard, the arm will swell and it will be prejudicial for me, correct?! M13

> Think it is important to do these exercises. Is for my well-being, right?! So far, I do the exercises. M4

> At the physiotherapy, they explained in detail and I understood clearly that it could have lymphedema. I

> followed thoroughly what they guided me to do and I was well, thanks the Lord. M2

The physiotherapeutic intervention should happen early for better adherence to the preventive guidances and understanding the importance to care along life, with as less restrictions as possible to the patients. The "Service of Physiotherapy" of HCIII/INCA, through routines of follow up, promotes primary prevention (guidelines to reduce exposure to risk factors), secondary (early diagnosis) and tertiary (treatment) of lymphedema[12].

Anguish and limitations

The main feelings aroused in these women, when asked about the adherence to the preventive care, are worry, fear and panic. After the surgery, they are always haunted by lymphedema. This constant fear appears to be what reminds them of continuing the preventive care.

> I fear my arm will swell, because in INCA I see horrible things, when I see, I'm more aware and take more care. I fear it swells and looks like this awful thing, it doesn't reduce anymore. M11

> I know someone who had her arm swollen, I am terrified that my arm swells. It is disagreeable that arm swollen, I am not pretty, you know, it will be tougher with the arm swelled and the arm should weigh. M7

> Sometimes, I avoid doing anything with the arm, because I am in panic if it swells, I'm terrified of the arm swelling and have to wear gloves, no way I want this. M12

> I am sad seeing women here in the hospital with that arm swollen, with those bands and the big worry is that it doesn't come down to normal anymore. M7

The guidances to reduce the risk of lymphedema are common in the assistance to postoperative breast cancer patients, but there is no consensus in the scientific literature about its actual necessity[2,22,23] Because of the paucity of data that prove the effectiveness of lymphedema preventive care, the benefit of these guidelines should be pondered, because the strict adherence to these measures may contribute to increase the stress and anxiety and unnecessarily escalate the concern about its actual condition [24].

The majority of the patients of this study reported excessive anguish and concern with the adherence to preventive care and this can be observed in the narrative of the patients M7, M11 and M12.

Another remarkable point in the narratives is how the preventive therapeutic guidances end up generating in these women a feeling of severe limitation, which leads to sadness, more fear and worthlessness.

> When I was given the guidances for my arm, I felt my life was limited, I think my life now is going to be like this, I have limitations, everything I do that harms me, will be bad for me, so I try to skip away from this. I am a very hyperactive person, can't stand still when she said I was not able to do lots of things any more, I was very sad. M11

> When I was given the guidances, I felt restrained, up to now I feel like this, I feel as an invalid, can't do anything, but I need to do, but I'm afraid. Sometimes, I go to the bathroom and start to cry. M12

> When my arm started to swell, I was very worried, saw some photos and noticed how much my arm swelled, because earlier was not like this, when I see myself in the mirror, I see the difference of the arm size, sometimes I feel bad, because there is a blouse I want to wear and can't, because it marks the arm, it bothers me, I'm barely wearing my blouses, only the loose ones to avoid marking my arm and had even to change my wedding ring from one hand to the other because it doesn't fit any more. M10.

These women have a great concern about returning to their jobs and house tasks. The participants of this study, in their majority, worked at home exclusively, despite, today, women are taking over multiple social roles either as head of the family, keeper, mother and main care-provider[25].

Take care of their houses is essential for the women studied. A key aspect in their narratives is how the preventive guidance limit their lives, creating a feeling of worthlessness, in addition to fear, panic and concern with the possibility of developing lymphedema, as can observed in the description of M11, M7, M12 and M10. Similar result was encountered in the study of Panobianco et al.[26] where women reported these same negative feelings, which made them abandon activities that were agreeable to them.

The possibility of resuming their work after breast cancer is also a quite complicated and harrowing issue for them. Many women need to stop working or change their functions because of the treatment sequelae.

> My family wants me to rest, to live as a useless person in my house, but I don't want this life. I miss weeding the backyard, tend to my plants, do things I liked, but I'm afraid of hurting myself. I fear having my arm with those bands, because I will see myself as a worthless person with these things. M6

> I want to do stuff in the house to see whether I'm able to go out and work, because after I had cancer,

> I lost my job, I cared for a lady who weighted 100 kg and when I got back to the job, my employer said I had no more conditions to work, did not pay my security and I was left with nothing. M6

An important aspect related to the well-being and quality of life of the breast cancer survival is the return to work after diagnosis and treatment. Resuming their jobs can symbolize the return to normality and social reintegration[27]. As the reality of the majority of the patients is of heavy tasks at their jobs, their return is tougher and, many times, they are compelled to reinsert themselves in another type of activity.

The loss of the job may affect profoundly the quality of life, in addition to causing economic damages to the individual. For many women, work off-house represents a personal achievement, further to being a key income source, health insurance and social interactions [28,29].

Some patients eventually let their concern show up when they see the example of other women; and, others, the regret for having failed to follow strictly the preventive guidance.

> I think it is important to do what they guided me to do. Other colleagues that had mastectomy and failed to follow the guidelines ended up with their arms restricted. M2

> I think it is relevant to follow the guidelines, I let it pass for a while and look what happened, I eventually let it slip away. M9

The Vassard et al.[30] study indicated psychological suffering among the women with lymphedema in comparison with those without this complication. Lymphedema is considered a fearing condition because it creates negative feelings as anxiety, depression, low self-esteem and social shunning of the affected women[31].

Living with guidances along time

The interviewee acknowledge that, soon after surgery, they adhere more to the preventive care but, as times passes by, this routine becomes more complicated, especially because of their domestic tasks.

> In the beginning, I followed the guidelines, but as time went by, I let it go away. I realized some guidelines are difficult to follow, because I have to do my tasks at home. M8

> I wasn't very thorough with the care to my arm as time went by. M7

> I followed the guidelines early on, because the limitation was much bigger. Today, I slowed down, but I still take care. M2

In a study from Sherman et al.[31] it was observed that the adherence to the guidelines raised 79% of the patients during follow-up until 12 months post-surgery. On the other hand, in this study, the women interviewed reported that the adherence to preventive care diminished as time passed, especially because of the necessity to do their home tasks.

> I do everything a house needs to do. Have to share with my husband, the heavy stuff I don't do. M10

> When I'm going to clean the house, my children say I can't do, but it is not with the arms, is with the legs. M6

> I watch three grandchildren, but I don't carry them with me. Go the market, but I don't carry nothing too heavy. A house needs to be taken care all the time, but I don't push furniture. When pain starts, I stop. M6

> Now, I tell my husband and my kids, I am limited, my life now is limited, things I did before, can't do any more. From now on, I live to myself, I have already brought my kids up. M11

> I noticed, when I went back to work, that the arm gives a sign when I'm typing too much, so I take more care. I try to level the arm of the chair, limit the movement of the hand, but had no problem to resume my job. M2

> I did not abandon the things I used to do, I learned to slow down. M4

> I adapted my routine and I appreciate the information I was given, I always try to follow. M5

> I try to share the house tasks, do everything slowly and clean one room in one day, don't carry weight, don't take the cuticle any more, but I don't do the exercises. Don't have patience, it is boring. M13

> I do everything at home, but when I go the fair or to the market, I carry the cart and avoid dragging heavy bags. I try to use the back lighters of the stove and do the exercises at least three times a week. M14

In the attempt to continue their routine prior to the treatment, they pursue to match their daily tasks and, for this, many count with their family support and change

of habit as it is clear in the former narratives. The family solidarity was evident also in the Panobianco et al.[26], study, who noticed that the patients had a great concern with lymphedema, which reflected in difficulties at work and daily life and the family support was essential for the social reinsertion of these women.

CONCLUSION

The HCII physiotherapy staff provided prevention guidance to all the patients enrolled in this study and they reported they have understood its importance; however, the majority had difficulties to adhere to care.

The main difficulties encountered for non-adherence to the physiotherapy guidance are related to the need to resume home tasks and working activities. Another relevant lesson learned was that the patients adhered more to the preventive measures in the years immediately following the surgery and reduced as post-surgery time progresses.

Through the interviews, it was possible to notice that the therapeutic guidance create negative feelings in the patients. Most of the times the fear to develop lymphedema is more worrying than the oncologic disease itself. It was clear in the patients' narratives to what extent the physiotherapy ends up creating anguish, sadness and uselessness feeling these individuals experience.

The physiotherapy staff should be alert to how lymphedema preventive guidance are transmitted to their patients to create more information and less anguish, pursuing a more subtle, focused and tailored care. The physiotherapist must promote strategies of adaptation and avoid creating a feeling of prohibition, bringing understanding and cooperation, sharing with them the responsibility for their self-care.

It is understood that more studies about this theme need to be conducted, considering the own characteristics of the Brazilian population, in order to grasp which guidance are essentially necessary and avoid anguish and restrain to the patients.

CONTRIBUTIONS

Liz de Oliveira Marchito, Erica Alves Nogueira Fabro, Marianna Brito de Araújo Lou, Rejane Medeiros Costa e Flavia Oliveira Macedo participated of the study conception and planning, data gathering and analysis, wording and critical review and approval of the final version.

DECLARATION OF CONFLICT OF INTERESTS

There are no conflict of interests to declare.

FUNDING SOURCES

None.

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Recebido em 12/11/2018
Aprovado em 18/2/2019