

Effect of Educational Nursing Program on knowledge and Quality of Life of Women with Post Mastectomy Lymphedema

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Abstract

Background: Post mastectomy lymphedema is a chronic disease that negatively affects physical, social, psychological and emotional well-being. So patient education regarding lymphedema is crucial to enhance knowledge and quality of life of post mastectomy women. **Study Aim:** To evaluate effect of educational nursing program on knowledge and quality of life of women with post mastectomy lymphedema. **Research design:** A quasi-experimental design with a pre–posttest approach was utilized. **Subjects:** A convenient sample of forty women with post-mastectomy lymphedema participated in this study. **Setting:** The study was conducted in the breast, oncology outpatient clinics and Rheumatology and rehabilitation unit at Assiut University Hospital. **Tools:** Tool (I) Women's Structured Interview Questionnaire, including three sections: Women's demographic data, Women's medical history and Pre/Post Knowledge Assessment Questionnaire. Tool (II): Lymphedema Quality of Life Questionnaire-Arm. **Results:** The mean age of the women was 47.67±6.45 years, regarding women's total knowledge, 92.5% had unsatisfactory scores before the program. In contrast, 85.0% and 65.0% achieved satisfactory scores immediately and three months after program implementation, respectively. Moreover, total quality of life means score was improved post implementation of program (77.98±7.31 versus 47.75±9.934, respectively; $p<0.001^{**}$), with higher scores indicating worse quality of life according to Lymphedema Quality of Life Questionnaire-Arm. **Conclusion:** Implementing educational nursing program significantly enhanced knowledge and quality of life in women with post-mastectomy lymphedema. **Recommendation:** Create a multidisciplinary lymphedema outpatient clinic staffed by a physician, physiotherapist, social worker, and lymphedema specialist nurse to provide integrated care through diagnosis, treatment, education, and ongoing follow-up.

Keywords: Educational Nursing Program, lymphedema, mastectomy & Quality of life

Introduction:

Improvements in breast cancer screening and treatment has translated into higher survival rates. Unfortunately, also increased prevalence of serious side effects, like post-mastectomy lymphedema (Ramirez-Parada et al., 2023). An estimated 10 million women worldwide have breast cancer-related lymphedema (BCRL), with 3-5 million in the United States (Sobh et al., 2023). Post-mastectomy lymphedema is a chronic tissue swelling from protein-rich fluid buildup due to disrupted lymphatic drainage (Skjødt et al., 2023). It causes physical symptoms like heaviness, pain, numbness, while also affecting social, psychological, and emotional well-being, contributing to poor quality of life (QoL) (Sun et al., 2024).

Non-surgical interventions are pivotal for managing lymphedema, with complete decongestive therapy (CDT) represents the gold standard. CDT is a comprehensive program, combining manual lymphatic drainage (MLD) massage, compression bandaging, compression garments, exercises, and

meticulous skin care (Sun et al., 2024). It consists of two phases: Phase I, the intensive phase, lasts two to four weeks and aims to decrease limb volume and alleviate symptoms. Phase II, the maintenance phase, an individualized program executed daily at home, designed to sustain self-care management and limit complications (Rafn et al., 2024).

Nurses contribute significantly in management of post mastectomy lymphedema through educating the patients about lymphedema self-care behaviors which are important to control lymphedema symptoms, decrease lymphedema stages and prevent further progression of the disease (Wang and Du, 2024). Lymphedema self-care involves maintaining risk-reduction behaviors, exercising, weight control, good nutrition, healthy lifestyle behaviors, caring and proper fit of compression garments, self-lymph drainage, skin care and preventing or managing infections (Mohammed, 2023).

Significance of the study:

Lymphedema is a prevalent and debilitating complication post mastectomy, affecting one in three

patients after axillary lymph node dissection (Skjødt et al., 2023). In Egypt, cases ranges between 20% to 30% (Abed El-Rahman & Abdelkader, 2023). It adversely impacts physical, Psychological, social, and emotional functioning, contributing to poor quality of life. Educating women on lymphedema is a critical nursing role to manage symptoms, restore functioning, and promote quality of life.

Study Aims:

1. Assess the level of women's knowledge regarding post mastectomy lymphedema.
2. Design and implement educational nursing program for women with post mastectomy lymphedema.
3. Evaluate effect of educational nursing program on knowledge and quality of life of women with post mastectomy lymphedema.

Hypotheses:

- H1:** Implementation of educational nursing program will enhance knowledge among women with post-mastectomy lymphedema.
- H2:** Implementation of educational nursing program will improve quality of life for women with post mastectomy lymphedema.

Patients and Methods

Research design:

A quasi-experimental design with a pre–posttest approach was employed for this study.

Setting: The study was carried out in the breast, oncology outpatient clinics and Rheumatology and rehabilitation unit at Assiut University Hospital.

Subjects and sample size: Convenient sample of forty women with post-mastectomy lymphedema participated in this study. Sample size calculations using EPI info7, based on approximately 250 women were attained to the aforementioned setting during 2021-2022(Assiut University Hospitals records, 2022). with a confidence level 95% and confidence limit 5%, the calculated sample size was 151. The educational program applied to 25% of this sample, increase to 40 to avoid dropout and refuse.

Inclusion criteria:

Participants selected for study met the following criteria: women diagnosed with post-mastectomy lymphedema, no other disabling conditions impeding program implementation, hadn't received educational programs about post-mastectomy lymphedema, and agree to participate.

Tools of the study:

Tool I: Women's Structured Interview Questionnaire: Developed by the researcher based on reviewing the related literatures (Elia and Maruccia, 2024; PALABIYIK E., 2023; Tatar K., 2023; El-Araby et al., 2020). To assess demographic data, medical history and knowledge regarding post mastectomy lymphedema. **It included three sections:**

Section (1): Women's demographic data: encompassing age, marital status, educational level, occupation, and residence.

Section (2): Women's medical history: including affected (dominant) side, lymphedema location and stages, and any chronic diseases.

Section (3): Pre/Post Knowledge Assessment Questionnaire: It utilized by the researcher to evaluate women's knowledge of post-mastectomy lymphedema through nineteen multiple-choice questions covering definition, causes, signs and symptoms, risk factors, timing of occurrence, stages, potential complications, signs of infection (cellulites) and conservative treatment of post mastectomy lymphedema. Additionally, the questionnaire covers the phases of complete decongestive therapy, skin care precautions to minimize lymphedema symptoms, and balanced nutrition. It also addresses the definition, contraindications, and key considerations of manual lymphatic drainage massage. Furthermore, it includes the wearing schedules for compression garments, the duration of compression bandage wear, proper washing instructions, and signs indicating the need for garment replacement (El-Araby et al., 2020).

Scoring system:

Responses were scored as "one" for each correct answer and "zero" for incorrect answers or unknown; the total score was calculated by adding up the scores for each item and then transformed into a percentage. A percentage score of 60% or higher was considered satisfactory knowledge, while below 60% was considered unsatisfactory (Mahmoud & Ammar., 2019).

Tool II: Lymphedema Quality of Life Questionnaire-Arm (LYMQOL-Arm):

Developed by (Keeley et al., 2010) to assess the impact of arm lymphedema on patient's quality of life. It comprises 21 questions across four domains: Function 1 (a-h), 2,3, Appearance 4,5,6,7,8 Symptoms 9,10,11,12,13,14 and Emotion 15,16,17,18,19,20. The final question (question 21) addresses overall quality of life. Responses are evaluated on a four-point Likert scale: 1 (not at all), 2 (a little), 3 (quite a bit), and 4 (a lot), with higher scores indicating a worse QoL. In contrast, question 21 asks patients to rate their general QoL on a scale from 0 (poor) to 10 (excellent), with higher scores indicating better QoL. The LYMQOL-Arm scale demonstrated ease of administration and high internal consistency, with a Cronbach's alpha of 0.90 confirming its reliability (Keeley et al., 2010).

Educational nursing program for post mastectomy lymphedema women:

The researcher created this program based on literature reviews (Elia & Maruccia., 2024), (Abd Elsalam et al.,2022), (Cansiz et al., 2022) & (El-Araby et al., 2020), to provides essential knowledge

and self-care practices regarding post mastectomy lymphedema through a straightforward Arabic booklet with colorful illustrations to accommodate varying educational levels. It includes topics such as the anatomy and physiology of the lymphatic system, definition, causes, signs and symptoms, stages, complications of post mastectomy lymphedema, It also covers practices for infection prevention, hand and arm care, healthy nutrition, recognizing when to consult a physician, proper use and care of compression bandages and garments, upper extremity lymphedema exercises, and manual lymphatic drainage massage techniques.

Administrative design and ethical considerations:

Research permission was granted from the ethical committee with IRB no: (1120230624) on May 29, 2023 at the Faculty of Nursing, Assiut University, An official letter from the Dean of the Faculty of Nursing was sent to the directors of the outpatient clinics at Assiut University Hospital, requesting the permission for data collection. Informed consent was obtained after explaining the study's purpose, risks, and procedures. Confidentiality and anonymity were strictly maintained. Women could withdraw at any point, regardless of the reason.

Content validity and reliability:

Content validity was done by a panel of five experts; three in medical-surgical nursing (two professors and one assistant professor from Assiut University) and two medical consultants from Assiut University Hospital. they reviewed the tools for clarity, relevance, comprehensiveness, and applicability. Based on their feedback, minor modifications were made. Reliability was tested using Cronbach's alpha, yielding coefficients of 0.79 and 0.90 for tools I and II, respectively.

Pilot study: A pilot study was undertaken on 10% of the sample to evaluate the applicability, clarity, feasibility of the study tools and to estimate the duration required to finish them. Based on the data, necessary modifications were made, including deleting, adding, or rephrasing statements. The pilot study participants were not included in the final study.

Procedure: Data collection and the educational program were conducted over ten months, from July 2023 to April 2024. Prior to commencing the study, formal approval was secured from the administrative authorities of the chosen settings. Data collection tools were prepared after reviewing of national and international literature (Elia & Maruccia., 2024), (Abd Elsalam et al.,2022), (Cansız et al., 2022) & (El-Araby et al., 2020). The researcher outlined the educational program subjects, designed the educational program, prepared content, and developed it into a booklet. Expert opinions were sought to ensure the booklet's validity.

Once acquiring the official permission, the researcher started data collection by visiting the outpatient clinics three days a week (Sunday, Tuesday and Thursday) from 9.00 AM to 2.00 PM. the researcher introduced herself, explained study's objectives, and conducted face-to-face interviews with women meeting the inclusion criteria in quiet, well-lit, and well-furnished areas of the clinics.

Pre-test data were completed using tool I (sections 1 & 2) for demographic and medical history and tools I (section 3) and II for assessing knowledge and quality of life, taking 45-60 minutes. The data were analyzed to determine teaching needs and developed a program plan, including session frequency, educational methods and teaching aids. An appointment schedule was then set to begin the program sessions.

Based on the baseline assessment, the program was implemented in five sessions: two theoretical presented through lectures, group discussion, educational booklet, power point and three practical presented through demonstrations, re-demonstrations, real materials, and video illustrations. The session lasting 45 to 60 minutes and were held individually or in small groups of 2-3 women. Each session began with summary of the previous session and outlining the current session's goals. To enhance engagement, the researcher encouraged questions and used motivational techniques.

The first session provided an orientation to the program, outlining its importance and purposes. It covered theoretical knowledge on post-mastectomy lymphedema, including the lymphatic system's anatomy and physiology, definition, causes, signs and symptoms, risk factors, stages, and complications.

The second session concerned with knowledge regarding infection prevention (cellulites), hand and arm care, healthy nutrition, and when to contact a physician.

The third session covered manual lymphatic drainage massage, including its definition, physiological effects, contraindications, and key considerations when performing it. The researcher demonstrated the technique, supervised by a physiotherapist and a lymphedema specialist nurse, for 20-30 minutes, three times a week, over 2-4 weeks. Women were then trained in a simplified self-MLD technique that can apply by themselves throughout their life.

The fourth session on compression therapy included two phases: Phase I, applying arm compression bandages for 2-4 weeks, guided by the researcher. Phase II, where the researcher instructed the women on using compression garment. The session also covered washing methods, wearing schedules, and signs for garments replacement.

The fifth session centered on upper extremity lymphedema exercises with guidance from a

physiotherapist. Women were instructed to wear bandages during exercises. Information was provided in a booklet for future reference.

Follow-up visits for post-testing were scheduled by mobile phone. Evaluation was performed through a post-test administered immediately and three months post program to evaluate women's knowledge using the same pre-test tools (section 3 of tool I). Quality of life was assessed pre and three months post program using tool II. Evaluations were conducted at the outpatient clinics or via telephone.

Statistical design:

Data entry was done using SPSS software (version 26.0). The researcher analyzed and coded the data, presenting results as frequencies and percentages for categorical variables and means and standard deviations for continuous variables. Chi-square and Fisher's exact tests compared categorical variables, while t-tests and ANOVA compared continuous variables. Pearson correlation assessed associations between scores, with statistical significance set at $p < 0.05$.

Results:

Table (1): Demographic Data Distribution of the Studied Women (n=40)

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Variables	n=40	%
Age		
30-<40	8	20.0
40-<50	21	52.5
50-60	11	27.5
Mean \pm SD	47.67 \pm 6.45	
Marital status		
Single	8	20.0
Married	32	80.0
Education level		
Illiterate	7	17.5
Read and write	14	35.0
Intermediate education	11	27.5
High education	8	20.0
Occupation		
House wife/not working	23	57.5
Working	17	42.5
Residences		
Urban	16	40.0
Rural	24	60.0

Table (2): Medical History Distribution of Studied Women (n=40)

Variables	No	%
Affected(dominant) side		
Right	28	70.0
Left	12	30.0
Lymphedema location		
Arm	23	57.5
Arm and hand	14	35.0
Arm and breast	3	7.5
Lymphedema stages		
Stage (0)	3	7.5
Stage (I)	16	40.0
Stage (II)	19	47.5
Stage (III)	2	5.0
Chronic diseases		
Hypertension	11	27.5
Diabetes mellitus	4	10.0
Bronchial asthma	2	5.0
None	23	57.5

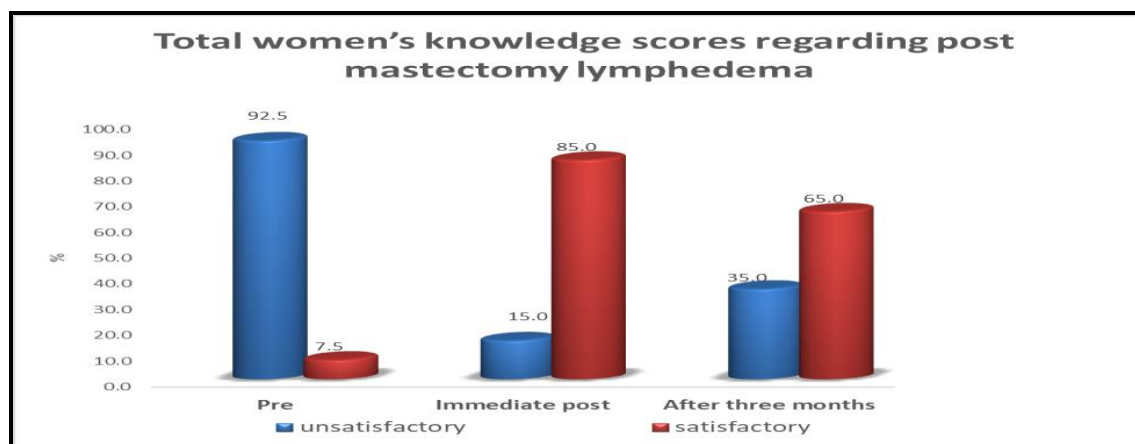


Figure (1): Total Knowledge Score Levels of Studied Women Before, Immediately After, and Three Months Post Educational Program Implementation (n=40)

Table (3): Studied Women's Quality of Life (QoL) and Its Domains Before, and Three Months Post Educational Program Implementation (n=40)

LYMQOL-Arm	Max Score	Pre	After three months	T	P.value
		Mean \pm SD	Mean \pm SD		
Function	40	27.73 \pm 3.73	16.4 \pm 3.46	14.06	<0.001**
Appearance	20	14.38 \pm 2.2	9.05 \pm 2.66	9.75	<0.001**
Symptoms	24	18 \pm 2.25	10.83 \pm 3.01	12.06	<0.001**
Emotion	24	17.88 \pm 2.88	11.48 \pm 3.39	9.10	<0.001**
Overall, how would you rate your quality of life at present? (Question 21)	10	4.4 \pm 1.19	7.48 \pm 1.11	-11.93	<0.001**
Total lymphedema Quality of Life	108	77.98 \pm 7.31	47.75 \pm 9.93	15.50	<0.001**

Paired Sample T-test for qualitative data

*Significant level at P value < 0.05,

**Significant level at P value < 0.01

Table (4): Correlation coefficients between women's total (LYMQOL-Arm) scores and total knowledge scores, before and after the educational program (n=40)

Correlation between total (LYMQOL-Arm) and total knowledge scores	Total Lymphedema Quality of Life Questionnaire-Arm (LYMQOL-Arm)			
	Pre		After three months	
	r	P	R	P
Total knowledge scores	0.045	0.782	-.433- ^{**}	0.005

Table (1): Illustrates that; 52.5% of the studied women are aged 40 to less than 50 years, with a mean age of 47.67 \pm 6.45 years. 80.0% are married, 35.0% can read and write, 57.5% are house wives, additionally, 60.0% reside in rural areas.

Table (2): Indicates that; the majority (70%) of the women are right-dominant. more than half (57.5%) have lymphedema in their arm, and 47.5 % have stage II lymphedema. Over half (57.5%) don't have chronic diseases.

Figure (1): Shows that, before the program, 92.5% of women have unsatisfactory total knowledge scores. In contrast, 85.0% and 65.0% achieve satisfactory scores immediately and three months after the program,

respectively, indicating a highly significant improvement ($p < 0.001$).

Table (3): Reveals that, statistically significant differences in all quality of life domains mean scores before and after the program ($p < 0.0001$). The total QoL mean score improve post the program (77.98 \pm 7.31 versus 47.75 \pm 9.934, respectively; $p < 0.001^{**}$), with higher scores indicating worse QoL according to LYMQOL-Arm.

Table (4): Clarifies that, a statistically significant negative correlation between total (LYMQOL-Arm) scores and total knowledge scores post program. As (LYMQOL-Arm) scores decrease, indicating an improvement in quality of life, total knowledge scores increase.

Discussion

The chronic and disabling nature of lymphedema significantly impairs patient's physical and psychosocial well-being. It adversely affecting body image, self-esteem, and causing pain, depression, and anxiety, ultimately lowering quality of life. Nurses play a crucial role in educating patients about lymphedema to manage symptoms and improve quality of life **Rafn et al., (2024)**. Thus, the study aimed to evaluate the efficacy of educational nursing program on knowledge and quality of life for women with post-mastectomy lymphedema.

Regarding demographic data, the mean age of the women was 47.67 ± 6.45 years. Similar to **El-Araby et al., (2020)**, who found that the mean age of the participants was 47.71 ± 7.16 years. While it contradicts the results by **Mohamed et al., (2023)**, who found that the mean values of age (year) was 57.50 ± 6.44 . in our view, Age over 40 years is linked to increase breast cancer risk due to menopause and hormonal changes, which in turn raising lymphedema risk. The study also indicated that, the majority of women were married, aligning with **Kandasoglu & Delialioglu, (2024)**, who found that, most women were married. The researcher suggests that married women bearing family care burdens, which strains their arms and increases risk of lymphedema.

Regarding education, occupation, and residence, over one-third of the women could read and write, more than half were house wives , and less than two thirds lived in rural areas, consistent with **Sobh et al., (2023)**, who stated that most both control and study groups were housewives , with more than two-thirds residing in rural areas. In contrast, **Wang & Du, (2024)**, stated that, nearly half were employed, and over one third had graduated from high school. The researcher attributes these findings to the lower socioeconomic status in rural areas, where women are often withdrawn from schools for marriage.

Concerning to affected (dominant) side, lymphedema location and stage, the study found that, most women had arm lymphedema on their dominant right side, with less than half in stage II, congruent with **Abed El-Rahman & Abdelkader, (2023) & Ramirez-Parada et al., (2023)**, who reported that all participants were right dominant hand, had arm lymphedema and fewer than half with stage II lymphedema. In contrast, **Çolak, et al., (2024)** mentioned, over one third had lymphedema in both the arm and hand, with most participants had stage I. The researcher's opinion that, most of the studied women were married housewives, likely overuse their dominant arm in daily tasks and exposure to household detergents, which increasing their risk of lymphedema.

Moreover, the study showed that, more half of the women didn't complain from chronic diseases. This result consistent with **Deveci et al., (2023)**, who revealed that over half of the participants hadn't any other chronic diseases. From the researcher's opinion, the high percentage of women without chronic diseases may enhance their ability to follow the program and manage lymphedema effectively.

The study's findings on women's total knowledge support the hypothesis, demonstrating a significant improvement in total knowledge scores after the program. This aligns with the findings of **Mahrous et al., (2021)** in their study, "Effect of Booklet-Based Education Versus Mobile-Based Education on Women's Arm Lymphedema and Their Knowledge and Practices Regarding Post-Mastectomy Exercise," which reported improved knowledge in both the mobile-based and booklet-based education groups following the educational program.

Additionally, these findings agreed with **El-Araby et al., (2019)**, who concluded that educational instructions significantly improved the knowledge of women with breast cancer-related lymphedema in their study. The researcher believes that high women's knowledge scores immediately after the program were attributed to the researcher's use of motivation, repetition and enhancing active participation. However, a slight decline in scores was noted at three-month follow-up due to natural information retention decline.

As hypothesized, the program led to a significant improvement in quality of life of women with post mastectomy lymphedema. This aligns with the findings of **Kheirkhah et al., (2021)** in their study, "Comparing the Effect of In-Person and Virtual Lymphedema Self-Management Education on the Quality of Life of Women with Breast Cancer: A Randomized Clinical Trial". Their study found that lymphedema self-management education enhanced the quality of life for women with breast cancer, with in-person education proving more effective than virtual delivery in improving QoL. Similarly, **Kavak & Ünver, (2024)**, found that applying 15 sessions of complete decongestive therapy combined with educational interventions for women with post-mastectomy lymphedema significantly enhanced functional capacity and improved their quality of life. As well as, **Anbari et al., (2021)**, who concluded that implementing lymphedema self-care strategies helped breast cancer survivors alleviate breast cancer-related lymphedema symptoms and improve their quality of life.

The researcher attributed poor pre-program QoL to the effects of cancer diagnosis, lymphedema, and limited knowledge and skills in managing the condition, emphasizing the need for tailored

educational programs to enhance knowledge, skills, and QoL. Post-program improvements were credited to lifestyle changes, increased knowledge, and improved lymphedema management skills.

The study revealed a significant negative correlation between women's total LYMQOL-Arm scores and their total knowledge post-program, indicating that as LYMQOL-Arm scores decreased (better QoL), knowledge scores increased. This finding aligns with **Uyar Koylü, et al., (2020)**, who stated that providing women undergoing breast cancer surgery with information about lymphedema development, symptoms, risk factors, and management strategies effectively enhances their quality of life.

According to the researcher, these results can be attributed to the fact that as women's knowledge increases, their engagement in self-care practices improves, leading to a better quality of life. This underscores the effectiveness of the educational program in empowering women by enhancing their knowledge, ultimately improving their quality of life.

Conclusion:

Implementing a lymphedema educational nursing program significantly improved post-mastectomy women's knowledge and quality of life.

Recommendation:

Integration lymphedema educational nursing program into the nursing care routine for all women with breast cancer-related lymphedema and periodically updated it.

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