

Effect of Pre-discharge Guidelines on Women's Knowledge and Self- Care Practices Regarding Arm Lymphedema Prevention Post mastectomy

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Abstract: Background: Arm lymphedema is a serious complication post-mastectomy. Lymphedema prevention is essential for long-term survival after breast cancer. So, education is needed to increase patients' awareness of lymphedema and self-care practices for lymphedema prevention after mastectomy. **Objectives:** The aim of this study was to assess and evaluate the effect of pre-discharge educational guidelines on women's knowledge and self-care practices regarding arm lymphedema prevention post-mastectomy. **The design** of this study was a quasi-experimental research design. **Setting:** The study was conducted at 6, 9 and 10 surgical units and the outpatient clinics for breast cancer in Ain Shams University hospitals, Cairo, Egypt. **The Subjects:** Purposive sample of 50 patients were included in the study. Patients for this study were adult women and diagnosed with breast cancer and undergoing mastectomy. **Instruments:** Patient's assessment and clinical data sheet ; Lymphedema patient's knowledge questionnaire sheet ; Measure of arm symptoms survey- Version 3 (MASS) ; Upper limb functioning scale ; Self-care assessment questionnaire. **Results:** All of the studied patients had inadequate knowledge about arm lymphedema and self care practice regarding prevention of arm lymphedema before pre-discharge educational guidelines intervention, which improved after guidelines intervention to reach to the majority of the studied patients had adequate level with a significant differences between pre- and post- guidelines intervention. Also, the majority of the studied patients had adequate self care practices post- guidelines intervention and during the follow up period. Also arm morbidity minimized during the follow up period. **Conclusion:** It was concluded that pre-discharge educational guidelines improved women's knowledge and self- care practices, regarding arm lymphedema prevention post mastectomy , Also arm morbidity minimized during the follow up period. **Recommendation:** The study should be replicated on large sample and different hospitals and community setting in order to generalize the results.

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1. Introduction

Breast cancer (BC) is the most common malignancy and the second most common cause of cancer death after lung cancer in women worldwide. In Egypt, out of 9,587 female cancers cases registered in the last 10 years by the Alexandria Cancer Registry, 33.0% of them were breast cancer (Yager and Davidson, 2006). In addition over 1 million (1,437,180) new cases diagnosed annually, resulting in 565,650 annual deaths from cancer are projected to occur in the United States in 2008 (Jemal *et al.*, 2008).

Breast cancer is the most commonly diagnosed cancer in women and accounts for approximately 15% of all cancer deaths in women in the United States. In 2005, an estimated 211,000 women will receive a diagnosis of breast cancer, and an estimated 40,000 will die of the disease (American Cancer Society, 2005). Vaidya *et al.*, (2007) reported that, modern treatment of breast cancer in most developed countries is based on a

multimodality approach combining surgery, radiotherapy, chemotherapy or hormonal therapy. Although these treatments have improved patient outcomes, they have been associated with substantial adverse effects.

Furthermore, Brown (2005) mentioned that, secondary lymphedema (LE) most frequently seen or developed after lymph node dissection, breast surgery and / or radiation therapy. lymphedema is a chronic condition in which interruptions or obstructions of lymphatic vessels lead to the accumulation of lymph fluid in the interstitial spaces, resulting in persistent swelling in the affected areas, such as arm, hand, wrist, neck, shoulder, or thoracic regions. The swelling often causes a wide range of discomfort and disability.

Lymphedema is a common problem for patients diagnosed with breast cancer, with an estimated 6 – 35% developing it sometime after breast cancer treatment. In 2007, it is estimated that 178,480 women will be diagnosed with breast cancer,

and 88% of these women will survive at least 5 years. The reported incidence of lymphedema varies with the length of follow-up, the measurement techniques, and other patient and treatment-related factors (**Jemal et al., 2007**). It can range from mild to severe, and can be a chronic condition that affects patients' quality of life for years after cancer surgery (**Brown, 2004**).

Lymphedema is a common, debilitating complication of the surgical removal or radiation treatment of lymph nodes during breast cancer treatment. The occurrence of lymphedema after breast cancer treatment varies greatly, from 5% to 60% (**Poage et al., 2008**), depending on the predisposing factors and on the diagnostic criteria. In 3-year prospective studies, 20.7% (**Clark et al., 2005**) and 32% (**Paskett et al., 2007**) of the women studied were found to have lymphedema after breast cancer treatment. Of the 42% of women experiencing lymphedema, 80% of cases had occurred in the first 2 years after treatment (**Norman et al., 2009**). Also, 45.5% of lymphedema cases were found to occur within 6 months of axillary dissection for breast cancer (**Lee et al., 2006**). Women may experience lymphedema at any time in their lives after breast cancer treatment.

Lymphedema is a serious complication from breast cancer surgery and radiation therapy. Development of lymphedema can be divided into 2 phases that are latent phase and clinically manifest phase. Clinically manifest phase is defined as more than 1.5 to 2 cm of the normal size in the affected extremity. Circumferential measurement is the most common diagnostic method to be used (**Voogd, et al., 2003 ; Armer et al., 2008**).

Lymphedema after breast cancer treatment cannot be over looked since it causes not only symptoms of pain, numbness, stiffness, and limitations in the range of motion (**Park, 2005 ; Lee, 2006**) but has major effects on emotional and psychological health, social life and interpersonal relationships, functional status, and quality of life (**Ahmed et al., 2008**).

Since after cancer treatment, maintaining optimal function is one of the quality of life goals in the treatment of cancer patients, lymphedema prevention is essential for long-term survival after breast cancer. So, researches are needed on education to increase patient awareness of lymphedema, to determine the efficacy of self-care strategies, and to develop practical guidelines that women can apply in their daily lives, as well as improve patterns of self-care practices for lymphedema prevention in women after breast cancer treatment (**Fu et al., 2010**).

Women's education regarding early prevention and self-care should be overemphasized in

clinical nursing practices. Risk factors of lymphedema, the triggering or exacerbating conditions for lymphedema that women are exposed to in daily life, to what extent they are able to adhere to preventive guidelines, and their symptom should be identified. Lymphedema risk reduction practices have been disseminated through education for patients with breast cancer. Also, Primary aims from women's education are to maintain function of the arm by maintaining range of motion in the shoulder, prevention/control of edema (swelling) and encouraging the use of the affected hand from the earliest stage (**Meneses & McNees, 2007**).

Nursing care for lymphedema prevention would not be successful without the careful assessment of distress symptoms and related factors, as well as self-care education tailored to each individual. This aiming to bridge the gap by taking into account aspects of women's daily reality in relation to current recommendations for preventive measures and self-care guidelines for lymphedema prevention. Patients are interested in learning how to prevent lymphedema because it is one of the more feared side effects following completion of treatment (**Hayes et al., 2005 ; Helyer et al., 2009**).

Nurses play a vital role when interfacing with breast cancer survivors and should engage in prevention, treatment, and patients' education. Prevention of lymphedema is a very important role for the medical-surgical nurse (**Jane et al., 2006**). Also, **Fleissig et al., (2006)** mentioned that, the community health nurse has an important role in preventing, and control of arm lymphedema in breast cancer survivors after mastectomy and / or axillary lymph node radiation therapy. Nurses list risk-reduction practices, and provide an educational program for patients with lymphedema following treatment of breast cancer as well as following the guidelines, and recommendations in preventing, and assessment of problems to keep patients functioning optimally.

Nurses play a major role in the rehabilitation of the patients with cancer. They frequently provide case-management and patient education services and facilitate support for these groups. Discharge plan involves the activities that facilitate a patient's movement from one health care setting to another, or to home. It is a multidisciplinary process involving physicians, nurses, social workers, and possibly other health professionals; its goal is to enhance continuity of care. It begins on admission. Discharge planning begins at the initial evaluation with patient and family education on the goals, treatment plan, prognosis and expected outcomes with therapy. The discharge plan is individualized for each patient and

will include education for lymphedema prevention (Fu *et al.*, 2010).

Clearly, the prevention of lymphedema is much more effective than treating the problem after it occurs. The National Lymphedema Network (NLN) published a position statement that lists risk-reduction practices, such as proper skin care (avoiding injury, reducing infection risks), appropriate activity levels, avoidance of constrictive clothing, use of compression garments, avoidance of temperature extremes, and other suggestions (Mak *et al.*, 2007)

Significance of the study:

Secondary lymphedema post-mastectomy is associated with adverse physical and psychosocial consequences among women with breast cancer (BC). Secondary lymphedema is arguably the most problematic and dreaded complication of breast cancer treatment. Although the incidence is generally accepted at approximately 30%, reported rates vary greatly, ranging between 2% and 83%. Lymphedema may present immediately or years after treatment, although the majority of cases occur during the first 18 months (Clark *et al.*, 2005). Benoit *et al.*, 2007 and Mak *et al.*, 2008 reported that, the incidence of lymphedema after treatment of breast cancer varies widely depending upon the extent of axillary surgery, and the use of radiotherapy. It is ranged from 38.3% to 83.0% within 1 year of treatment for breast cancer with breast-conserving surgery and radiation therapy. So, Prevention is the best tool against arm lymphedema. Breast cancer represents 10% of all cancers diagnosed worldwide annually and constituted 22% of all new cancers in women in 2008, making it by far the most common cancer in women. The rate of increasing incidence is higher in developing countries (Porter, 2008). In the Eastern Mediterranean region, breast cancer is by far the most common cancer even when considering men and women together, with 2 time more cases (N=57 000 new cases per year) than lung cancer (N=25 000) or bladder cancer (N=25 500) (Ferlay *et al.*, 2002). Breast cancer is the most important cancer, with women in an increasing numbers in incidence developing countries. It is by far the commonest cancer among Egyptian women and represents 37% of all female cancers. (Aboserea *et al.*, 2011).

The impact of lymphedema on breast cancer survivors includes physical, functional, occupational, psychosocial, cognitive, lifestyle, and financial dimensions, which wholly exert intense influence on the women's quality of life (Beaulac *et al.*, 2002 ; Swenson *et al.*, 2009). In addition, inadequate self-care practices remain a significant problem facing health care providers in all settings and populations. Based on the previous researches, it was noted that

inadequate self-care practices poses a threat to satisfactory outcome. It was emphasized on the impact of adequate self-care practices on the patient's morbidity and mortality and on increasing the costs of medical treatment as cost of medication, cost of laboratory tests and cost in time and effort of the care providers in addition to the frustration for both the patients and the care providers. In contrast, other studies reported that the patients who had adequate self-care practices had better outcomes, live longer, enjoy a higher quality of life, and suffer fewer symptoms and complications.

Aim the study:

The aim of this study was to assess and evaluate the effect of pre-discharge educational guidelines on women's knowledge and self-care practices regarding arm lymphedema prevention post mastectomy through the following:

1. Assessment of women's knowledge and self-care practices pre intervention.
2. Planning and implementation of pre-discharge educational guidelines.
3. Evaluation of the effect of pre-discharge educational guidelines on women's knowledge and self-care practices regarding arm lymphedema prevention post-intervention.
4. Evaluation of the effect of pre-discharge educational guidelines on arm morbidity during the follow up period post guidelines intervention.

Research hypothesis:

It was hypothesized that:

- 1- Pre-discharge education guidelines will improve women's knowledge and self-care practices regarding arm lymphedema prevention post-intervention.
- 2- Arm morbidity will be minimized during the follow up period post guidelines intervention.

2. Patients and Methods:

Research Design:

A quasi-experimental research design has been utilized in this study.

Research setting:

The study was conducted at 6, 9 and 10 surgical units and the outpatient clinics for breast cancer in Ain Shams University hospitals, Cairo, Egypt.

Subjects:

Purposive sample of patients were included in the study. Patients for this study were adult women and diagnosed with breast cancer and undergoing mastectomy. Patients were excluded if they had a previous history of BC, or prior injury or surgery of the affected upper limb. The sample size was estimated with STATA 10 program. The estimated required sample size was 50 patients, to achieve

power of study $=1-\beta = 0.95$ and Alpha $\alpha = 0.01$ (sig. 99%).

Study tools:

The following tools were used to collect data related to this study:

Tool I : Patient's assessment and clinical data sheet: The sheet was designed by the researchers to gather information related to patient's age, education, marital status, number of children and residence, also covered data related to side of surgery, type of surgery and others treatment modalities. . This tool was revised by a group of three expertise in Medical Surgical Nursing and two expertise in Community Health Nursing at faculty of Nursing, at Ain Shams University for the content validity. No modifications were done.

Tool II: Patient's knowledge interview questionnaire sheet: It was used to assess patient's knowledge about arm lymphedema (such as; definition, causes, risk factors, signs & symptoms and complications) and self care practices regarding prevention of arm lymphedema post-mastectomy (such as; arm exercise, indoor arm care, outdoor arm care, diet, precautions with medical intervention, and when to visit doctors without call). It was written in Arabic language and developed by the researchers based on the related literature (**Lewis et al., 2007; Lemon & Burke, 2008; Dewit, 2009; Osborn et al., 2010**). This tool was revised by a group of three expertise in Medical Surgical Nursing and two expertise in Community Health Nursing at faculty of Nursing, at Ain Shams University for the content validity. Based on the opinion of a panel of expertise some modifications were done, and then the final forms were developed. It was composed of 30 questions. The Score one was given for each correct answer and zero for incorrect answer. For each area of knowledge, the scores of the items were summed-up and the total score divided by the number of the items. These scores were converted into a percent score. The total women's knowledge was considered adequate if the percent score was 60% and more, and inadequate if less than 60%.

Tool III: Measure of arm symptoms survey-Version 3 (MASS): This tool was developed by (**Swenson et al., 2009**) and also had acceptable validity and reliability. This tool was divided into two parts. **Part I:** it was used to assess the potential risk factors for arm lymphedema as DM, HTN, smoking, past shoulder injury, exercises, medical procedures as (Bp, IV), arm /hand injury, radiation, reconstructive surgery, etc. **Part II:** it was used to assess the severity of arm symptoms using 5 point likert scale of "not at all" to "very much" including pain, swelling, range of motion and heaviness.

Tool IV: Upper limb functioning scale:

The scale is developed by **Weon et al., 2011** also had acceptable reliability and validity. This scale was used to assess the overall upper limb functioning. It was evaluated with two questions regarding the degree of usage and the strength of the arm on the affected side. To assess the degree of usage of the arm, participants were asked to indicate "To what extent do you use the affected arm in daily life?" using a score from 0 (rarely use) to 10 (use to the same extent as before treatment). A higher score meant better functioning of the affected arm. The degree of strength was described on a scale ranging from 0 (noticeably much weaker) to 10 (same as before treatment) by asking "What do you think of the strength of the affected arm now compared to prior to treatment?" Thus a higher score meant more strength in the affected arm after cancer treatment.

Tool V: Self-Care Assessment questionnaire

It was used to assess maintenance a self-care practices. It was adopted from (**Yekta et al., 2011**). A group of expertise reviewed the questionnaire for face and content validity. The scale rates maintenance a self-care practices in terms of frequency as the following: 5 = Frequently, 4 = Occasionally, 3 = Rarely, 2 = Never and 1 = It never occurred to me. The total score of questionnaire was 100. The level of self-care practice was classified into poor (<49), moderate (50 to 74), and good (>75) considering to the total score of questionnaire.

Educational Guidelines:

Educational guidelines was designed by the researchers to improve the patients' knowledge and self-care practices regarding arm lymphedema prevention post-mastectomy and minimizing arm morbidity. Educational guidelines was designed by the researchers based on the related literature based on the related literature (**Daniels, et al., 2007; Lemon & Burke, 2008; Smeltzer, et al., 2010 ; Ignnataviev and Workman, 2010 ; Lewis et al., 2011**). It was written in Arabic language. Knowledge about arm lymphedema included (such as; definition, causes, risk factors, signs and symptoms, complications) and self care practices regarding arm lymphedema prevention post-mastectomy and minimizing arm morbidity (such as; arm exercise, indoor arm care, outdoor arm care, precautions with medical intervention, and nutrition) . The guidelines was revised by a group of three expertise in Medical Surgical Nursing and two expertise in Community Health Nursing at faculty of Nursing and two expertise in oncology medicine at faculty of Medicine, at Ain Shams University for the content validity. Based on the opinion of a panel of expertise some modifications were done, and then the final forms were developed.

Pilot study:

The pilot study commenced once ethical approval had been obtained. A pilot study was carried out by 10% of patients (5 patients) to test the clarity, applicability, objectivity and feasibility of the tools to conduct the study. No Changes or modifications were done. The patients included in the pilot study were included in the study.

Procedure:

The current study was carried out on three phases, preparatory phase, implementation phase and evaluation phase.

Phase I: Preparatory phase:

Human rights and ethical permission were obtained to conduct the study. The researchers developed the educational guidelines regarding knowledge about arm lymphedema and self care practices regarding prevention of arm lymphedema post-mastectomy. Also, media was prepared by the researchers which included the guidelines handout and audiovisual materials as video. Guidelines were revised by a group of five experts in medical surgical nursing department of faculty of nursing and two professional surgical consultant experts from faculty of medicine at Ain Shams University for the content validity. Based on the opinion of a panel of expertise some modifications were done, and then the final form was developed.

Phase II:**Implementation phase:**

Data for the current study were collected through the period from February 2012 to August 2012. Before conducting the study, an exploratory visit was done in surgical units in order to estimate the rate of admission and suitable time for collecting data according to each unit. Besides, personal communication was done with nurses and physician to explain the purpose of the study and gain their best possible cooperation. The Patients in the surgical units who met the study criteria were included in the study after explaining the purpose of the study and obtaining consent. Pre intervention, patient's assessment & clinical data sheet, Lymphedema patient's knowledge interview questionnaire sheet, Measure of arm symptoms survey and upper limb functioning scale were fulfilled before surgery to obtain baseline data for comparison after surgery in the presence of the researchers who were available 2 days per week alternatively at morning or afternoon shifts in different study settings. Then implementation of the guidelines was given at the previously mentioned study settings for each patient separately based on her needs. An instructional media was used. Each patient took three sessions. The duration of each session took approximately 1 to 1.5 hours. Methods of teaching used were modified

lectures, demonstration and re-demonstration. All of the studied patients in all study settings were cooperative with the researchers. The researchers telephone Number were given to studied patients and patient telephone number were taken to ensure contact and meeting them during follow up visits in out patients clinics to complete data collection during follow up period. The studied patients were interested in the topic. While, post-operative and before discharge, upper arm symptoms and functioning were also assessed.

Phase 3: Evaluation phase:

During the evaluation phase, the effect of pre-discharge educational guidelines was evaluated on: (1)- women's knowledge about lymphedema and self care practices regarding prevention of arm lymphedema post-mastectomy by comparing results pre-discharge, 1 month & 3 months post- discharge; (2)- women's maintenance level of self care practices by comparing results at 1 month & 3 months post-discharge was evaluated. (3)- women's upper arm symptoms and functioning by comparing results pre-discharge, at 1 month & 3 months post- discharge.

Administrative design and ethical consideration:

An official permission was obtained from the Director of Ain Shams University Hospital and the heads of the outpatient clinic in which the study was conducted. Meeting and discussions were held between the researchers and administrative personnel to make them aware about the aims and objectives, as well as to get better cooperation during the implementation phase. It was important to have their full support, especially to find out some sort of motivation to stimulate patients to participate positively in the study. The aim of the research was explained to the participants. Verbal consent was obtained from each patient to participate in the study, after clarifying the procedures of the study. Participants were informed about their right to refuse participation and to withdraw at any time without any consequences. Confidentiality of data was ensured.

Data analysis:

Data entry and analysis were done using the Statistical Package for Social Science (SPSS) version 10. Data were presented in the tables and charts using actual numbers and percentages. Appropriate statistical methods were applied (percentage, chi-square (X²), and *t*- test. Regarding *P* value, it was considered that: non-significant (NS) if $P > 0.05$, Significant (S) if $P < 0.05$, and Highly Significant (HS) if $P < 0.01$.

3. Results:

Table (1), shows that about one third (34%) of the studied patients were less than 45years old , with a mean of age was (48.3±5.8). Regarding level of education, more than one quarter (28%) and one

fifth of them of were illiterate and read & write respectively. Also more than two thirds of them (68 %,) resident in urban areas. As regard marital status and number of children, it was found that about three quarter (74 %) and near two third (64%) were married and had more than three children respectively. In addition, none of them didn't receive any education regarding lymphedema prevention.

Table 1: Distribution of the Studied Patients According to Socio-Demographic related Characteristics (N = 50).

Items	Socio-Demographic related Characteristics (N = 50).	
	No	%
Age (years) :		
35-	17	34
45-	23	46
55-	10	20
Range	(35 - 58)	
Mean X ± SD	48.3 ± 5.8	
Education		
Illiterate	19	28
Read & write	10	20
Primary education	9	18
Secondary education	12	24
Residence :		
Rural	16	32
Urban	34	68
Marital status:		
Married	37	74
Widow	8	16
Divorced	5	10
Number of children		
1-3	18	36
> 3	32	64
Lymphedema prevention education:		
Received	0	0
Not received	50	100

Figure 1: Shows that about one quarter (26%) of the studied patients mentioned that physicians were a source of knowledge to them regarding arm lymphedema and the minority (10%) of them mentioned that nurses were a source of knowledge to them regarding arm lymphedema. While, more than half (64%) of them mentioned that there was no one was a source of knowledge to them regarding arm lymphedema.

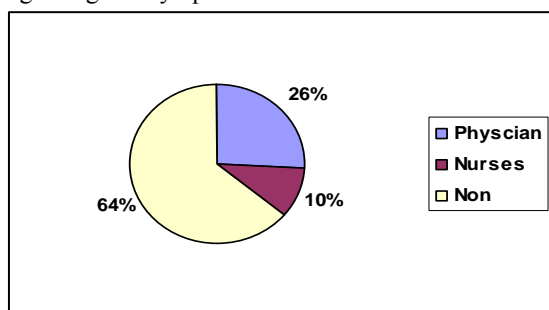


Fig. 1: Sources of Knowledge about Arm Lymphedema among The Studied Patients. (N = 50).

Table (2) shows clinical data characteristics of the studied patients. Regarding side of surgery, more than half (62%) of them were undergoing mastectomy of right breast. Concerning type of surgery and other type of treatment post mastectomy, about three quarter (76%) of them had modified radical mastectomy and 60% & 68% of them received radiotherapy and chemotherapy respectively. However, regarding risk factors of lymphedema post discharge, 16% and 20% of them were diabetic and hypertensive respectively. Also, 16% and 4% of them were obese and had wound infection.

Table 2: Distribution of the Studied Patients According to clinical data Characteristics (N=50).

Items	Clinical data characteristics (N = 50).	
	No	%
Side of surgery		
Right breast	31	62
Left breast	19	38
Type of surgery		
Modified radical mastectomy	38	76
Reconstructive	12	24
Other type of treatment post mastectomy:		
Radiotherapy	30	60
Chemotherapy	34	68
Hormonal	7	14
Risk factors of lymphedema post discharge:		
1. DM	8	16
2. HTN	10	20
3. Smoking	3	4
4. Obesity	8	16
5. Type of the affected arm:		
- Dominant	45	90
- Non dominant	5	10
6. Infections	2	4
7. Hand/Arm injury	3	6
8. Medical procedure (I.V., BLP)	0	0
9. Lift more than 10 pounds	0	0
10. obesity and infection	2	4

Table (3) shows levels of knowledge of the studied patients regarding arm lymphedema characteristics pre- & post discharge guidelines implementation. It illustrates that none of them had adequate knowledge pre- intervention. However, post-intervention, the majority (90%, 84%, 86%, 88%, 80%) of them had adequate knowledge about definition, types, causes & risk factors, signs & symptoms, and complications respectively with a statistically highly significant differences between pre- & post- guidelines intervention regarding all items ($P < 0.001$). Also, none of them had adequate total knowledge pre- intervention, but, the majority (88%) of them had adequate knowledge & post-

guidelines intervention respectively with a highly statistically significant differences between them ($P < 0.001$).

Table (4) shows levels of knowledge of the studied patients regarding items of self-care practice for arm lymphedema prevention pre- & post discharge guidelines implementation. It illustrates that none of them had adequate knowledge pre-intervention regarding arm exercise, indoor arm care, when to call doctors and nutrition. However, the majority (90%, 92%, 88%, 94%) of them had adequate knowledge with a statistically highly significant differences between pre- & post-guidelines intervention regarding all items respectively ($p < 0.001$). Also, none of them had adequate total knowledge pre- intervention, but, the majority (86%) of them had adequate knowledge post- guidelines intervention regarding self-care practice with a statistically highly significant differences between them($p < 0.001$).

Table (5) shows difference between maintenance levels of self- care practice 1month & 3months post discharge. It illustrates that the entire study patients showed good maintenance level of self care practices regarding precaution with medical intervention 1month & 3months post discharge. Also, It illustrates that the majority (94%, 92% & 94%) of

them showed good maintenance level of self care practices regarding indoor arm care , outdoor arm care and total self-care practice 1month post discharge respectively with a slight decrease to (84%, 86% & 84%) 3months post discharge respectively. However, 70% & 62% of them showed good maintenance level of self care practices regarding arm exercises and nutrition 1month post discharge respectively with a slight decrease to (54% & 52%) 3months post discharge respectively. Also, there was no statistically significant difference between maintenance levels of all items of self- care practices 1month & 3months post discharge ($p > 0.05$).

Figure (2) shows levels of total knowledge of the studied patients regarding of arm lymphedema characteristics and self-care practice for arm lymphedema prevention pre-, post-immediately and 3months post-discharge guidelines implementation. It illustrates that none of them had adequate knowledge pre- intervention. However, the majority (88%, 86%) of them had adequate knowledge regarding them respectively post-immediately guidelines implementation. Also the majority (80%, 82%) of them had adequate knowledge regarding them respectively 3 months post- guidelines implementation with a statistically highly significant differences between them ($p < 0.001$).

Table 3: Difference between Level of Knowledge of The Studied Patients Regarding Arm Lymphedema Characteristics pre- & post guidelines implementation (N = 50).

Items of Knowledge	(N = 50).			
	Pre- guidelines		Post- guidelines	
	No	%	No	%
1- Definition :				
Adequate	0	0	45	90
Inadequate	50	100	5	10
	$\chi^2 = 81.8$; $P = 0.000^{**}$			
2- Types				
Adequate	0	0	42	84
Inadequate	50	100	8	16
	$\chi^2 = 72.4$; $P = 0.000^{**}$			
3- Causes & Risk factors :				
Adequate	0	0	43	86
Inadequate	50	100	7	14
	$\chi^2 = 75.4$; $P = 0.000^{**}$			
4- Signs and Symptoms:				
Adequate	0	0	46	88
Inadequate	50	100	4	12
	$\chi^2 = 85.2$; $P = 0.000^{**}$			
5- Complications				
Adequate	0	0	40	80
Inadequate	50	100	10	20
	$\chi^2 = 66.7$; $P = 0.000^{**}$			
Total level of knowledge				
Adequate	0	0	44	88
Inadequate	50	100	6	12
	$\chi^2 = 78.6$; $P = 0.000^{**}$			

Chi-squared Test. (χ^2) *Significant($P < 0.05$). **Highly significant($P < 0.001$).

Table 4: Difference between Level of Knowledge of The Studied patients Regarding Items of Self-Care Practice for Arm Lymphedema Prevention pre- & post guidelines implementation (N = 50).

Items of Knowledge of Self-Care Practice	(N = 40).			
	Pre- guidelines		Post- guidelines	
	No	%	No	%
1- Arm Exercises:				
Adequate	0	0	45	90
Inadequate	50	100	5	10
	$\chi^2 = 81.8$; P = 0.000**			
2- Indoor Arm care post discharge:				
Adequate	0	0	46	92
Inadequate	50	100	4	8
	$\chi^2 = 72.4$; P = 0.000**			
3- Outdoor Arm care post discharge				
Adequate	1	2	44	88
Inadequate	49	98	6	12
	$\chi^2 = 74.7$; P = 0.000**			
4- Precaution with medical intervention				
Adequate	2	4	46	92
Inadequate	48	96	4	8
	$\chi^2 = 77.6$; P = 0.000**			
5- when to visit doctors without call				
Adequate	0	0	44	88
Inadequate	50	100	6	12
	$\chi^2 = 78.6$; P = 0.000**			
6- Nutrition				
Adequate	0	0	47	94
Inadequate	50	100	3	6
	$\chi^2 = 88.7$; P = 0.000**			
Total level of knowledge of Self-Care Practice				
Adequate	0	0	43	86
Inadequate	50	100	7	14
	$\chi^2 = 75.4$; P = 0.000**			

Chi-squared Test. (χ^2) *Significant(P < 0.05). **Highly significant(P < 0.001).

Table 5: Effect of discharge guidelines on maintenance of self- care practice 1month & 3months post discharge (N = 50).

Items	Self- Care Practice Maintenance			
	1month Post-discharge		3 months Post-discharge	
	No	%	No	%
1- Arm Exercises:				
Poor	5	10	8	16
Moderate	10	20	15	30
Good	35	70	27	54
	$\chi^2 = 2.7$ P = 0.256 NS			
2- Indoor Arm care				
Poor	0	0	0	0
Moderate	3	6	8	16
Good	47	94	42	84
	$\chi^2 = 1.6$ P = 0.201 NS			
3- Outdoor Arm care				
Poor	0	0	0	0
Moderate	4	8	7	14
Good	46	92	43	86
	$\chi^2 = 0.4$ P = 0.523 NS			
4- Precaution with medical intervention				
Poor	0	0	0	0
Moderate	0	0	0	0
Good	50	100	50	100
	Equal values			
5- Nutrition				
Poor	6	12	10	20
Moderate	13	26	14	28
Good	31	62	26	52
	$\chi^2 = 1.5$; P = 0.478 NS			
Total				
Poor	0	0	2	4
Moderate	4	8	6	12
Good	47	94	42	84
	$\chi^2 = 2.7$; P = 0.263 NS			

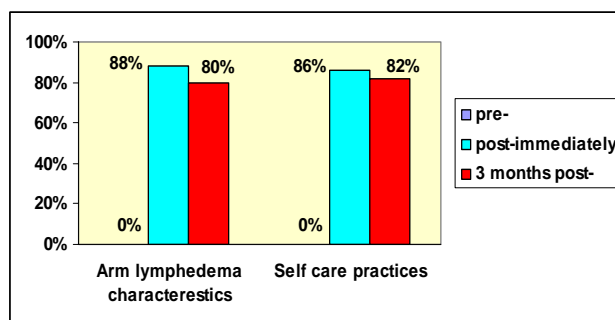


Fig. 2: Difference between Total Level of Knowledge of The Studied Patients Regarding Arm Lymphedema and Self-Care Practice pre-, immediately post- & 3 months post- guidelines implementation (N = 50).

Table (6) reveals that all of the studied patients hadn't pain, heaviness, limited range of motion and swelling as upper limb symptoms pre-operative. Also, all of the studied patients had high range and mean regarding the degree of the usage and strength of the affected side as upper limb function pre-operative.

Table (7) shows the difference between upper limb symptoms pre-discharge, 1 month and 3 months post-discharge. More than two third (68%, 78%, 76%, 72%) of the studied patients had moderate pain, moderate heaviness, moderate stiffness and no swelling pre-discharge respectively. However, at 1 month post-discharge, 24%, 26%, 44% and 90% had moderate pain, moderate heaviness, moderate stiffness and no swelling respectively. While, at 3 months post-discharge, the majority (80%, 84%, 88%, 96%) had no pain, no heaviness, no stiffness and no swelling respectively. Also, there was a statistically significant difference between upper limb

symptoms pre-discharge and 3 months post-discharge.

Table (8) shows difference between upper limb functioning of the studied patients pre-discharge, 1 month and 3 months post-discharge. It illustrates low mean score regarding the degree of usage and strength of the affected side (2.98 ± 0.96) and (3.12 ± 0.23) pre-discharge respectively. Also, It illustrates low mean score regarding the degree of usage and strength of the affected side (3.78 ± 0.76) and (4.26 ± 0.99) at 1 month post-discharge respectively. However, the improvement regarding the degree of usage and strength of the affected side with mean score (6.8 ± 0.76) and (6.84 ± 0.74) respectively at 3 months post-discharge. Also, there was a highly statistically significant difference ($p < 0.001$) between upper limb functioning of the studied patients pre-discharge, 1 month and 3 months post-discharge

Table 6: Distribution of Upper limb symptoms & functioning of The Studied Patients pre-operative (N = 50)

Items	Upper limb pre-operative (N = 50).	
	No.	%
Upper limb symptoms pre-operative		
Pain	0	0
Heaviness	0	0
Limited range of motion	0	0
Swelling	0	0
Upper limb function pre-operative		
The degree of usage of the affected side		
Range	9 – 10	
Mean X ± SD	9.68 ± 0.47	
The degree of strength of the affected side		
Range	9 – 10	
Mean X ± SD	9.92 ± 0.27	

Table 7: Difference between Upper limb symptoms of The Studied Patients Pre-discharge, 1 month and 3 month Post-discharge (N = 50).

Items	Upper limb symptoms					
	Pre-discharge		1months Post-discharge		3 months Post-discharge	
	No	%	No	%	No	%
Pain						
No	0	0	8	16	40	80
Mild	16	32	30	60	10	20
Moderate	34	68	12	24	0	0
	$\chi^2=106.1; P = 0.000^{**}$					
Heaviness						
No	0	0	6	12	42	84
Mild	11	22	31	61	8	16
Moderate	39	78	13	26	0	0
	$\chi^2=139.4; P = 0.000^{**}$					
Stifness(limited range of motion)						
No	0	0	0	0	44	88
Mild	12	24	28	56	6	12
Moderate	38	76	22	44	0	0
	$\chi^2 = 141.3; P = 0.000^{**}$					
Swelling						
No	36	72	45	90	48	96
Mild	14	18	5	10	2	4
Moderate	0	0	0	0	0	0
	$\chi^2 = 13.0; P = 0.002^{**}$					

Table 8: Difference between Upper limb functioning of The Studied Patients 1 month Post-discharge and 3 month Post-discharge (N = 50).

Items	Upper limb functioning		
	pre-discharge	1 month Post-discharge	3 months Post-discharge
The degree of usage of the affected side			
Range	2 - 4	3 - 5	6 - 8
Mean X \pm SD	2.98 \pm 0.96	3.78 \pm 0.76	6.8 \pm 0.76
	t = 19.9 ; P = 0.000 ^{**}		
The degree of strength of the affected side			
Range	3 - 4	3 - 6	6 - 8
Mean X \pm SD	3.12 \pm 0.23	4.26 \pm 0.99	6.84 \pm 0.74
	t = 14.8 ; p = 0.000 ^{**}		

4. Discussion

Breast cancer is the most important cancer, with women in an increasing numbers in incidence developing countries. It is by far the commonest cancer among Egyptian women and represents 37% of all female cancers. Lymphedema is a common, debilitating complication of the surgical removal or radiation treatment of lymph nodes during breast cancer treatment. The occurrence of lymphedema after breast cancer treatment varies greatly, from 5% to 60% depending on the predisposing factors and on the diagnostic criteria (Poage *et al.*, 2008).

This quasi-experimental study design was used to assess and evaluate the effect of pre-discharge educational guidelines on women's knowledge and self-care practices regarding arm lymphedema prevention post mastectomy. This study was hypothesized that: 1- Pre-discharge education guidelines will improve women's knowledge and self-care practices regarding arm lymphedema prevention post-intervention., and 2- Arm morbidity

will be minimized during the follow up period post guidelines intervention.

A discussion of the findings of this study will be divided into three parts: Part I: Socio-demographic characteristics and clinical data characteristics of the studied patients, Part II: The studied patients knowledge and self-care practices regarding prevention of arm lymphedema post mastectomy, Part III: Arm morbidity during the follow up period post guidelines intervention.

Part I:

Regarding age, about one third of the studied sample was less than forty five years old and near half of them was from forty five to less than fifty five. This finding was goes in the same line with Chu *et al.*, (2008) and Beaulac *et al.*, (2008) who discovered that, breast cancer can occur at any age-adjusted breast cancer mortality and morbidity rate between females similar among this group less than 40 years of age.

Regarding level of education, the results of the current results revealed that, more than one

quarter and one fifth of them of was illiterate and read & write respectively. This is congruent with **Ali, 2010** who found that more than one quarter of the study sample was illiterate. Also, the current results revealed that, about three quarter and near two third were married and had more than three children respectively. This comes in agreement with **Abd El Razik, 2010**. This could reflect Egyptian culture which encourage early marriage and lots number of children especially among rural areas.

In addition, the results of the present study showed that, none of the study sample receive education regarding lymphedema prevention and mentioned that there was no one was a source of knowledge to them regarding arm lymphedema. This goes in the same line with **Paskett and Stark, 2008** who found that most physicians reported that they did not routinely counsel women or provide written information on lymphedema prevention to their patients, and the extent to which women's daily living was affected by the condition was not always recognized. These findings have implications for interventions aimed at educating women and providers about lymphedema.

Concerning clinical data characteristics of the studied sample, the result of the present study revealed about three quarter of them had modified radical mastectomy, more than half of them received radiotherapy and about two third of them received chemotherapy. This was supported with the results of **Springer et al., 2010** which revealed that the majority of patients had axillary lymph node dissection and underwent a modified radical mastectomy (MRM). About two third received radiation and more than half received chemotherapy.

However, regarding risk factors of lymphedema, The results of the present study revealed some risk factors which may predispose the studied patients for lymphedema. However, the minority of them were diabetic, hypertensive and obese. Also, only two cases had wound infection. **Swenson, 2007** found when examined predictors of lymphedema following breast cancer surgery that cases and controls did not differ significantly in current age, age at time of surgery, personal history of diabetes or hypertension, smoking history (ever/never), or having a prior medical condition limiting their hand or shoulder movement. Body mass index (BMI) was significantly higher in cases than controls. In addition, **Johansson et al., 2009** focused on examining factors that may influence the development of arm lymphedema following breast cancer treatment and concluded that, women treated for breast cancer with axillary node dissection with or without adjuvant radiotherapy could maintain their level of physical activity and occupational workload

after treatment without an added risk of developing arm lymphedema. On the other hand, a higher BMI before and after operation increases the lymphedema risk.

Part II:

The results of the current study showed that none of the studied patients had adequate total knowledge regarding arm lymphedema characteristics and self-care practice for arm lymphedema prevention pre- intervention. This goes in the same line with **Paskett and Stark (2008)** who found that overall women knew little to nothing about lymphedema before they developed it. After diagnosis, the primary source of information about lymphedema was a doctor or physical therapist. . Most physicians reported that they did not routinely counsel women or provide written information on lymphedema prevention to their patients, and the extent to which women's daily living was affected.

Regarding levels of knowledge of the studied patients regarding items of arm lymphedema characteristics pre- & post discharge guidelines implementation, the current results illustrated that none of them had adequate knowledge pre-intervention . However, post- guidelines intervention, the majority of them had adequate knowledge about definition, types, causes & risk factors, signs & symptoms, and complications with a statistically significant differences between pre- & post-guidelines intervention regarding all items. These results were in accordance with **Anderson et al., (2006)** who explained that, arm lymphedema has received little attention even from health care providers as well as clinicians caring for breast cancer survivors; beside to they had limited knowledge of that condition. After implementing the health education intervention, there was a significant increase and improve in women's knowledge regarding arm lymphedema characteristics and its consequences.

Regarding levels of knowledge of the studied patients regarding items of self-care practice for arm lymphedema prevention, the current results illustrated that none of them had adequate knowledge pre- intervention regarding arm exercise, indoor arm care, when to call doctors and nutrition. However, the majority of them had adequate knowledge regarding them with a statistically significant differences between pre- & post- guidelines intervention regarding all items. These findings were supported by, **Petrek et al., (2007)** and **Bertz et al., (2007)** who emphasized that, appropriate information and education about arm lymphedema among breast cancer survivors for 1-3 months after the end of treatment resulting in increase of their knowledge after intervention by nurses, physicians and other

health care professionals. Also, **Aly et al., 2012** revealed that, after implementing of health education intervention, there were a significant improvement and increase in studied women's among all of them about arm lymphedema post mastectomy and prevention strategies.

The current results revealed that the majority of the study patients showed good maintenance level of self care practices regarding indoor arm care, outdoor arm care and total self-care practice at one month post discharge with a slight decrease at three months post discharge. This might be due to women's understanding of the effect of lymphedema as a problem post mastectomy that will affect quality of life if the women complained it. This is supported with **Gautam et al., 2011** who found that patients' training program post mastectomy led to good adherence to self-care practices as arm care, arm exercise and improved QOL scores.

However more than two third of the study showed good maintenance level of self care practices regarding arm exercises 1 month post discharge which decrease to more than half of them 3 months post discharge. Good maintenance level of self care practices regarding arm exercises decreased 3 months post discharge might be due to the improvement of upper limb function after 3 months post mastectomy. This goes in the same line with recent studies by **Ahmed et al., 2006** and **Schmitz et al., 2009** who reported that eighty and eighty eight percent adherence rates during the first three months after an supervised educational program for women post mastectomy.

Also, the results of the present study illustrated that all of the study patients showed good maintenance level of self care practices regarding precaution with medical intervention at one month and three months post discharge. This is congruent with **Sisman et al., 2012** who found that the patients were informed by a trainer nurse about the precautions they should take to prevent the development of lymphedema showed good maintenance level of self care practices post discharge for at least six months.

Part III:

Surgical trauma and/or radiation therapy may lead to upper limb (UL) impairments, functional limitations and disabilities including pain, stiffness, lymphedema, seroma, cording, decreased strength and range of motion (ROM) and decreased activity tolerance (**Kuroi et al., 2006**). Preventative exercise and education are recommended to reduce the incidence of breast cancer-related upper limb symptoms and dysfunction and to enhance quality of life (QOL) (**Gosselink et al., 2003** ; **Demark-Wahnefried et al., 2006**).

Concerning upper limb symptoms, the current study results showed that the symptoms were significant obvious pre-discharge and decreased at 1 month and 3 month post-discharge. Also, there were a statistically significant difference between upper limb symptoms pre-discharge, 1 month and 3 month post-discharge regarding pain, heaviness, stiffness and swelling. This might be due to women's understanding for the problem and good maintenance of self-care practices. This is congruent with **Gautam et al., 2011** who found that the prescribed patients 'training program had positive effect on the participants who reported improvement in their affected upper-limb health (i.e., decreased pain, heaviness, and stiffness) resulting from breast cancer treatments and also led to improved QOL. In addition, **Sisman et al., 2012** added that the patients who were informed by a trainer nurse about the precautions to prevent the development of lymphedema showed an improvement of upper limb symptoms.

In relation to pain as an upper limb symptom post mastectomy, the current study results showed that slightly more than two third of the studied patients had moderate pain pre-discharge which decreased to about one quarter of them at one month post-discharge. However, at three month post-discharge, the majority of them had no pain and only one fifth of them had mild pain. This might be due to complete wound healing and decrease heaviness of upper limb. This goes in the same line with **Springer et al., 2010** who found that over 80% of pain responses by patients at baseline, three-six, and 12 months were at the 0 (no pain) level (on a scale of 0–10), over 60% at one month were at 0. In both cases, distributions showed greater pain at one month. While, **Lauridsen et al., 2005** and **Shamley_ et al., 2007** found that only 30% of the sample reported levels of pain post surgery and postulated perceived pain might be explained as a post-surgical effect. Patients continued to recover, and by three-six months, less than 10% of these patients reported any pain greater than mild. Also, **Thomas-Maclean et al., 2008** found that during the early months after mastectomy, pain and decreased shoulder movements are more common.

In relation to limited range of motion and heaviness as upper limb symptoms post-mastectomy, the current study results showed that about three quarter and more than half of the studied patients had moderate limited range of motion and heaviness of upper limb respectively pre-discharge. This might be due to good maintenance of arm exercise post-guidelines intervention. This is congruent with **Lauridsen et al., 2008** stated that reports of upper limb impairments have been documented in as many

as 76% of patients following breast cancer treatment interventions. Meanwhile, Thomas-Maclean et al., 2008 stated that upper limb impairments reports range from 28% to 50%.

According to the results of the current study, range of motion and heaviness of upper limb improved to more than one third and the minority of them had moderate limited range of motion and heaviness of upper limb respectively at one month post-discharge. However, at three month post-discharge, the majority of them had no limited range of motion and heaviness of upper limb. This goes in the same line with **Robert et al., 2008 and Springer et al., 2010** who found that rehabilitation program had an effective way to improve shoulder mobility and range of motion during the immediate 2- week recovery period following surgery and most women in this cohort undergoing surgery for breast cancer the sum ROM decreased from the 0 visit (baseline) to 1 month ($p < 0.0001$), improved from one month to three-six months ($p < 0.0001$), and further improved from three-six month to 12+ month visits ($p < 0.0001$) and often continue to improve and reach their pre-operative levels by one year post surgery. In addition, **Sisman et al., 2012** added that the patients who were informed by a trainer nurse about the precautions they should take to prevent the development of lymphedema. The patients were also trained for the appropriate exercises and were given written educational material prepared by the researchers showed an improvement of range of motion and heaviness of upper limb.

In relation to upper limb swelling post-mastectomy, the current study results showed, the majority of the studied patients had no swelling at 1 month and 3 month post-discharge. While, only five cases and two cases had mild swelling. This is supported with the study results of **Sisman et al., 2012** revealed that the risk of development and progression of mastectomy-related lymphedema was reduced with education and exercise provided by trained nurses at an early stage. The degree of lymphedema was found lower in the patients that exercised as compared to the patients that did not ($p < 0.05$).

Regarding upper limb functioning, a study by **Box et al., 2002** stated that functional impairment in the first month following surgery should not be surprising. Damaged tissue must heal, and reduced activity levels subsequent to surgery would be expected to result in deficits. This is supported by the results of this study when revealed decrease in the mean of the degree of usage and the degree of strength of the affected side.

In addition, the current study results showed difference between upper limb functioning of the

studied sample 1 month and 3 months post-discharge. It illustrated the improvement regarding the degree of usage and the degree of strength of the affected side with statistically significant difference. This is congruent with (**Courneya et al., 2007 ; Cheema et al., 2008**) who found that strength patient's training helped not only in recovering arm strength but also in recovering bone mineral loss due to cancer treatment. Inactivity of the affected limb may lead to prolonged arm weakness, bone mineral loss and, finally lymphedema.

Springer et al., 2010 added that appropriate intervention and education should be introduced to patients pre-operatively with instruction to begin shortly after breast cancer surgery and it demonstrated excellent return to upper limb function beginning about three-six months after their surgeries.

Finally,

Hopefully, the study results would generate attention and motivation for further investigation into this topic.

5. Conclusion:

The findings of this current study can be concluded as following:

All of the studied patients had inadequate knowledge about arm lymphedema and self care practice regarding prevention of arm lymphedema before pre-discharge educational guidelines intervention, which improved after guideline intervention to reach to the majority of the studied patients had adequate level knowledge with a significant differences between pre- and post-guidelines intervention. Also, the majority of the studied patients had adequate self care practices post-guidelines intervention. In addition, arm morbidity minimized during the follow up period.

Recommendations:

As results of the current research, the following suggestions are proposed:

- 1- Conducting comprehensive health educational programs for women following breast cancer treatment in outpatients' clinics of oncology department units to maintain good adherence to self- care practices for arm lymphedema prevention..
- 2- The study should be replicated on large sample and different hospitals setting in order to generalize the results.
- 3- A home-based program should be done to effectively improve the affected upper-limb symptoms to improve QOL of breast cancer patients.

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