

Effect of Educational Instructions Regarding Self Care of Women with Breast Cancer Related Lymphedema

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Abstract: Breast cancer related lymphedema represents a major complication of breast cancer treatment, impacting the quality of life of breast cancer survivors. Patients with lymphedema need to conduct lifelong self-care activities to control the progression of swelling, manage lymphedema-associated symptom burden, and minimize long term negative outcomes. **Aim:** This study aimed to determine the effect of educational instructions regarding self-care of women with breast cancer related lymphedema. **Study design:** A quasi-experimental design was utilized to conduct this study. **Setting:** This study was conducted in the outpatient breast clinic at Oncology and Nuclear Medicine Center, affiliated to Ain Shams University Hospitals. **Subjects:** A purposive sample of 50 women newly diagnosed with breast cancer related lymphedema, post mastectomy, treated with radiotherapy free from any other dysfunctional disabilities that might interfere with self-care and didn't receive any instructions regarding breast cancer related lymphedema. **Data collection tools:** A structured interview questionnaire for women with breast cancer related lymphedema, lymphedema scale, lymphedema functioning, disability and health questionnaire, upper limb functional index and lymphedema self-care practices questionnaire. **Results:** The mean age of the studied women was 47.71 ± 71.16 , and 88% of them had satisfactory level of total knowledge post implementation of self-care educational instructions, also; 92% of them had adequate level of total lymphedema self-care practices post implementation of self-care educational instructions. **Conclusion:** The implementation of educational instructions regarding self-care for women with breast cancer related lymphedema has a statistically significant positive effect on their knowledge and self-care practices. **Recommendation:** Self-care educational instructions should be added to the routine nursing care delivered to those women in all breast cancer treatment units and should be updated periodically in order to enhance their knowledge and self-care practices.

Keywords: Breast cancer, Education, Lymphedema, Self-care, Women.

1. INTRODUCTION

Breast cancer (BC) is the most commonly occurring cancer in women (*World Cancer Research Fund, 2018*). One complication of BC treatments is lymphedema (LE), a chronic health problem, troublesome to both patients and health professionals (*Wanchai, Armer, Stewart & Lasinski, 2016*). LE is defined as the interstitial collection of protein-rich fluid due to disruption of lymphatic flow (*Kayran, Cruz, Tane & Soran, 2017*). LE Classification is divided into two groups according to LE etiology; idiopathic / primary or acquired / secondary LE (*Timby & Simth, 2014*).

Breast cancer related lymphedema (BCRL) represents a major complication of BC treatment, impacting the quality of life (QoL) on BC survivors that develop it. It may lead to symptoms such as pain, fatigue, depression, and eventual deterioration in QoL (*Timothy et al., 2018*), BC is the most common type of cancer in Egypt for women, 34% of Egyptian women suffer from BC (*Emara, 2017*). Women treated for BC are facing a life-time risk of developing LE, its incidence values ranging between 20% and 30% have been considered realistic by several authors (*Stuiver, ten Tusscher &*

McNeely, 2017), also its incidence reported in numerous publications is extremely variable, from 6% to 80% (Cronenwett & Johnston, 2014).

Oncology nurses are essential members of the interdisciplinary team in the management and treatment of LE (McCaulley & Smith, 2014). Nurses play a crucial role in the prevention of complications associated with LE by educating the patient about signs and symptoms of acute inflammatory episodes and LE management (Zuther, 2013).

When caring for patients with LE, nurses should encourage self-care, provide emotional support, offer patient and lay caregiver education, assess symptoms that patients with LE may be experiencing and develop a plan of management (Ridner, 2013). Also, LE awareness and education, along with attention to both cognitive and affective responses to the health threat situation are important patient-centered management strategies (Sherman, Miller, Roussi & Taylor, 2015).

Self-care strategies for patients with BCRL may include compression bandaging, resistive or aerobic exercise, self applied manual lymphatic drainage, intermittent pneumatic compression therapy (IPCT), elevation of the affected extremity, and weight management (Hutchison, 2018).

Patients' education is a dynamic, integrated and multifaceted teaching-learning process in which the nurse and patient work together to change patients' behaviors through their compliance with medical instruction. Health education is an independent function of nursing practice and a primary nursing responsibility. All nursing care is directed toward promoting, maintaining, and restoring health, preventing complications, and helping patients adapt to the residual effect of illness. Many of these nursing activities are accomplished through patients' education (Hinkle & Cheever, 2014).

BCRL self-care generally includes wearing a compression garment and/or self-bandaging, conducting self- Manual Lymphatic Drainage (MLD), and completing skin care and arm exercises. Lifelong self care is required to slow the progression of LE and reduce negative health outcomes. LE self care practices target swelling and skin; however, self-care should also address associated physical and psychosocial symptoms (Ridner et al., 2016).

Significance of the study:

More than one in five of BC patients will develop BCRL, which is one of the most disabling complications after BC and related treatments, it has a significant impact on BC survivors, including declined physical function and increased disability, which negatively affects QoL (Ezzo et al., 2015). It can also lead to difficulty with many activities of daily living (ADLs), a changed view of self, reduced physical activity and lower QoL (Thomas, Quinlan, Kowalski, Spriggs & Hamoline, 2014).

There is an unmet need for education or information about LE after BC treatment, especially in developing countries (Borman, Yaman, Yasrebi & Özdemir, 2017). So, patient education is essential to help those who develop LE resume their usual activities and improve their overall QoL (Gregory & Schiech, 2017). Also, patients with LE need to conduct lifelong self-care activities to control the progression of swelling, manage lymphedema-associated symptom burden, and minimize long term negative outcomes (Ridner, Deng & Rhoten, 2018).

Suboptimal BCRL self-management adherence rates may be directly or indirectly related to the lack of interactive patient-centered programs that provide education and support throughout survivorship. Nurse researchers can be instrumental in conducting patient-centered research that will provide evidence-based alternatives to education and support for chronic treatment related conditions, such as BCRL (Ostby & Armer, Smith & Stewart, 2018).

Aim of the study

This study aimed to determine the effect of educational instructions regarding self care of women with breast cancer related lymphedema through the following:

- 1-Assessing women's knowledge regarding breast cancer related lymphedema.
- 2- Assessing women's self care practices regarding breast cancer related lymphedema.
- 3- Planning and implementing educational instructions on self care for women with breast cancer related lymphedema based on women's knowledge and needs.
- 4- Assessing the effect of educational instructions on self care for women with breast cancer related lymphedema.

Research hypothesis

The current study hypothesized that: Implementation of educational instructions regarding self care of women with breast cancer related lymphedema will improve their knowledge and self care practices.

2. SUBJECTS AND METHODS

I- Technical Design

▪ Research design

A quasi experimental design was utilized to achieve the aim of the present study.

▪ Research setting

The study was conducted in the outpatient breast clinic at Oncology and Nuclear Medicine Center affiliated to Ain Shams University Hospitals, it was on the ground floor and it consisted of two rooms, one room contained a bed, an office, three chairs and a bathroom and the another room contained two offices, a bed with curtain, six chairs and weight and height measurement scales. The outpatient breast clinic received women daily except Friday and radiotherapy sessions were taken in 3 days Saturday, Monday and Wednesday.

▪ Subjects

A purposive sample of 50 women with BCRL was recruited in this study. The sample size calculation done based on power analysis, as about 400 women in the year (2014-2015) admitted to the previously mentioned setting. The test result was as follows:

Type I error with significant level (α) = 0.5

Type II error by power test (1-B) = 90%

The minimum sample were (50) cases.

▪ Inclusion criteria

The subjects included in the present study were selected according to the following criteria: women newly diagnosed with breast cancer related lymphedema, post mastectomy, treated with radiotherapy, free from any other dysfunctional disabilities that might interfere with self-care and didn't receive any educational instructions about breast cancer related lymphedema and agreed to participate in the study.

▪ Tools for data collection

The study data was collected through the following five tools:

1- A Structured Interview Questionnaire for Women with breast cancer related lymphedema:

This tool was developed by the researcher in Arabic language based on reviewing the related literatures (**American Cancer Society (2015)**, **Timby & Simth (2014)**, **Cashman et al., (2013)** and **Irish Cancer Society (2013)**). It was used to assess women's knowledge regarding BC, BCRL and self-care regarding LE. It included three parts:

First part: Socio-demographic characteristics of the women with BCRL. It consisted of 8 questions regarding age, marital status, educational level, occupation, monthly income, treatment costs, residence, and smoking habits.

Second part: Medical health history of the women with breast cancer related lymphedema. It included the followings:

- **Present history** (It consisted of 11 closed ended and MCQ questions regarding weight, height, body mass index, chief complaint, medical diagnosis, breast cancer stage, time since breast cancer diagnosis, time since mastectomy, time since starting RT sessions, dominant hand, LE location).

- **Past history** (It consisted of 4 MCQ and closed ended questions regarding chronic diseases, previous hospitalization, other surgery and medications not related to the disease).

- **Family history** (It consisted of 2 yes or no questions regarding family history suffering from the same disease or other oncology disease).

Third part: It was used to assess women's knowledge regarding BC, BCRL and LE self-care, pre and post implementation of educational instructions. It included 3 sections as follow:

Section 1: BC information (4 items) including definition, risk factors, diagnostic measures and treatment.

Section 2: BCRL information (8 items) including definition, causes, signs and symptoms, sites, when occurred, stages, complications and treatment.

Section 3: LE self-care information (8 items) including general practices to reduce BCRL, pain control and exercises, hand and arm care, healthy nutrition, safe drugs intake, psychological stress, sexual relation and depression.

Scoring system for the women's knowledge

Regarding scoring of women's knowledge assessment, this tool consisted of 96 statements, which were grouped into 3 sections. The responses were either "yes" or "no", the correct answer was "one score" while the wrong one was "zero". The scores of each statement for every section were summed up giving a total score for every section, then the total score for all the knowledge questionnaire were calculated.

Women's knowledge was categorized according to statistical analysis into satisfactory and unsatisfactory, as follows:

- $\geq 70\%$ was considered satisfactory.
- $< 70\%$ was considered unsatisfactory.

2- Lymphedema Scale:

This tool was adopted from **International Society of Lymphology, (2013)**, and was used to assess arm lymphedema staging for women with breast cancer related lymphedema, pre and post implementation of the educational instructions. In this tool LE was staged into 5 stages (stage 0, stage 1, stage 2, stage 3 and stage 4), each stage had specific criteria.

3- Lymphedema Functioning,

Disability and Health Questionnaire:

This tool was adapted from **Coremans, Christiaens, Devoogdt, Kampen & Geraerts (2011)**, and then translated into Arabic language after its modification, and was used to assess the level of LE effects on functional state, activities and participation of women with BCRL pre and post implementation of the educational instructions. It included 2 parts as follow;

Part I: Impairments in function including physical domain (7 items) and psychological domain (4 items).

Part II: Activity limitations and participation restrictions including household domain (3 items), mobility domain (4 items) and life/social domains (6 Items).

Scoring system

The responses for the previous 24 items were on a scale ranged from 1 to 10:

- < 4 (there was weak effect).
- 4 to 6 (there was moderate effect).
- 7 to 9 (there was strong effect).
- > 9 (there was very strong effect)

The scores of the items in each part were summed up and the total scores were divided by the number of items in each subgroup, also, the total level of LE effect scale was calculated.

4. Upper Limb Functional Index (ULFX): this tool was used to assess function of the affected arm on self-care practices after BCRL pre and post implementation of the educational instructions. It included 23 items. This tool was adapted from **Philip et al., (2006)**, and then translated into Arabic language after its modification.

Scoring system

The responses for the previous 23 items were yes or no, (yes = 1 and no = 0). The scores of the items were summed up and the total scores were divided by the number of items. The total levels of upper limb index were categorized according to statistical analysis into high active and low active, as follows:

- $\geq 70\%$ was considered high functional ability.
- $< 70\%$ was considered low functional ability.

5. Lymphedema Self Care Practices Questionnaire: This tool was used to assess women self-care practices after BCRL pre and post the educational instructions. It was developed by the researcher in Arabic language based on reviewing the related literatures (**Donmez & Kapucu, (2016), American Cancer Society (2015), Regional Cancer Care (2014), Lewis, Dirksen, Heitkemper & Bucher (2014), and Cashman et al., (2013)**). It included 10 parts; self-care practices including general practices to reduce BCRL (7 items), skin care (10 items), skin wound care (8 items), control of pain (4 items), healthy nutrition (7 items), safe drug use (3 items), use of compression bandages (4 Items) general exercises (7 Items) sexual relation (8 Items) controlling of psychological pressures (9 Items).

Scoring system

The responses for the previous 67 items were scaled either "yes" or "no", the yes answer has got "one score" while the no answer has got "zero".

The total score for all the post lymphedema self-care practices questionnaire were calculated. The parts and total questionnaire were categorized according to statistical analysis into adequate or inadequate, as follows:

- $\geq 70\%$ was considered adequate.
- $< 70\%$ was considered inadequate

Educational Instructions Booklet Regarding Self Care of Women with Breast Cancer Related Lymphedema

The educational booklet contained information about BC, BCRL, self-care instructions, controlling of psychological pressures, finally instructions regarding hand and arm exercises and self MLD.

II. Administrative design

An official letter was issued from the faculty of nursing, Ain Shams University to the medical and nursing directors of Oncology Center and Nuclear Medicine affiliated to Ain Shams University Hospitals explaining the purpose of the study and requesting the permission for data collection from the study group.

III. Operational design

It includes preparatory phase, tools validity and reliability, pilot study and field work.

A. Preparatory phase

This phase was carried out through the following steps:

- 1- Developing the data collection tools after reviewing the recent related literatures in periodicals, midline research and other resources.
- 2- Outlining all areas to be included in the educational instructions and educational booklet through extensive review of the literature and other available resources
- 3- Designing the educational instructions, preparation of its content and developing the educational booklet.
- 4- Obtaining experts opinion to ensure booklet's validity.

B. Tools validity and reliability

Validity was tested through a jury of (7) experts; (5) medical surgical nursing experts (2) professors and (3) assistant professors at faculty of nursing, Ain Shams University and (2) medical consultants of the Oncology Departments at Ain Shams University Hospitals. The experts reviewed the tools for clarity, relevance, comprehensiveness, simplicity and appropriateness; minor modifications were done.

Testing reliability of the proposed tools was done statistically by Cronbach alpha test. The first tool (Structured interview questionnaire for women with BCRL) was reliable at 0.795, the second tool (Lymphedema scale) was reliable at 0.728, the third tool (Lymphedema functioning, disability and health questionnaire) was reliable at 0.789, the fourth tool (Upper limb functional index) was reliable at 0.728 and the fifth tool (Lymphedema self-care practices questionnaire) was reliable at 0.829.

Ethical consideration

The ethical research consideration in the study included the following:

- The research approval obtained from the ethical committee in faculty of nursing, Ain Shams University before starting the study.
- The researcher clarified the objectives and aim of the study to women before obtaining their consent to participate in the study.
- The researcher assured maintaining anonymity and confidentiality of subjected data.
- Women were informed that they can choose either to participate or withdraw from the study at any time.
- Values, cultures and benefits were respected.

C. Pilot study

A pilot study was conducted on 10% of the study subjects (5 women with BCRL) in order to test the applicability of the study tools, the clarity of the study tools, as well as estimating the average time needed to complete the tools. Accordingly, necessary modifications were made for the final development of the study tools. Women selected for the pilot study were excluded from the study subjects.

D. Field work

The collection of data and application of educational instructions lasted over a period of twelve months; starting at October 2016 and ending in October 2017, through the following phases:

Assessment and planning phase

- The researcher visited the outpatient breast clinic three days on Saturday, Monday and Wednesday during morning shifts (9.00 am to 2.00 pm).
- The women who fulfilled the inclusion criteria were selected.
- The researcher obtained the women's oral consent for participating in this study after explaining the aim of the study.
- Filling in the previously mentioned tools was done by the researcher before implementation of the educational instructions.
- These tools were completed within an average time 60 minutes.
- Lymphedema stages were determined through the tool used for this (Lymphedema scale), also through physical examination and self-reported symptoms and bilateral upper extremities circumference measurements.
- Arm circumference measurements were performed from bone protrusions (ulnar styloid, olecranon, metacarpophalangeal joint), as well as with equal spacing (5 cm) from the anatomical point of the arm, such as the antecubital fossa, to axillary. LE was clinically diagnosed when a 2 cm difference or more in arm circumference at least one anatomic point measured between the affected and nonaffected limbs. Arm measurements were made on a weekly basis using non elastic tape (Can, Eksioğlu, Bahtiyarca & Çakc, 2016).
- All informations collected through data collection tools were interpreted for identifying individualized teaching needs.
- The researcher set up teaching plan covering all objectives. These objectives were categorized into general and specific objectives.

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- The instructions resources and facilities were allocated (printed material and location of session that best serve the learners).
- The researcher determined the timetable of sessions, teaching methods, media used and learner's activities.
- After data collection, the appointment for starting instructions sessions was detected and scheduled with the women for the following weeks.

Implementation phase

- The teaching sessions were conducted in the rooms at outpatient breast clinic. The rooms were conditioned, quiet, had adequate lighting, well ventilated and furnished, and had adequate spacing in the place for implementing educational instructions activities.
- Total number of the sessions of educational instructions was 8 sessions. Each session of them consumed one and half hour/ day for 3 days per week.
- These sessions were conducted for small group; each group number didn't exceed five women. The booklet was given for every woman.
- Implementation of educational instructions lasted over a period of 6 months for all women.
- Each session started by greeting the women, assessing women motivation for learning, getting feedback about what was given through the previous session and present the objectives of the new topic using simple language to suit the educational level of the women.
- At the beginning of the first session an orientation of educational instructions and its purpose took place. The importance and benefit of educational instructions were explained to the women to motivate them to follow instructions.
- The researcher emphasized the importance of adherence to each step of educational instructions, and the rationale for and the benefit of engaging in each new behavior was explained. The researcher encouraged women to express their readiness for changing the behavior.
- Motivation, problem solving, and reinforcement techniques were used to enhance active participation of the women in the educational sessions.
- The first teaching session included BC information. The second teaching session included BCRL information. The third teaching session included applying compression bandages. The fourth teaching session included self-care instructions regarding general practices to reduce BCRL, skin care, and arm care in cases of presence of wound. The fifth teaching session included self-care instructions regarding healthy nutrition, controlling of pain, performing exercises and sexual relations. The sixth teaching session included self-care instructions regarding controlling of psychological pressures. The seventh teaching session included instructions regarding hand and arm exercises. The eighth teaching session included instructions regarding self MLD.
- The educational instructions regarding hand and arm exercises and self MLD were conducted under the instruction of physiotherapists and after reviewing of the related literatures.
- Compression bandaging, exercises, meticulous skin care and self-care practices were divided into two phases: reduction (Phase I) and maintenance (Phase II).
- In Phase I, its main goals were teaching self-care practices and reducing the size of the limb, decreasing symptoms improving the skin condition. This phase depended mainly on the researcher. Daily self-care educational instructions were performed on up to 3 days per week (up to 4 weeks). This phase had lasted for 4 weeks.
- All women acquired instructions about self MLD for 20-30 minutes per day, exercises for 30 minutes per day/3 times weekly, daily compression therapy with a short stretch bandage, daily skin care and self-care practices. No drugs were used for LE.

- Phase I should lead directly into Phase II, which involved individualized self-management or caregiver for the long term maintenance of phase I reductions. During Phase II, the maintenance of care transferred to the women, who were encouraged to continue lifetime regular checkups.
- The self-care instructions consisted of independent application of bandages, home exercises, skin care and self-care practices.
- Phase II maintenance was monitored and adjusted periodically, just as with treatment for any other chronic medical condition. This phase had lasted for 4 weeks.
- Periodic monitoring of Phase II self-care educational instructions was conducted via phone or internet for giving the women's reassurance to complete the educational instructions.

Evaluation phase

The evaluation phase emphasized on determining the effect of the educational instructions on knowledge and self-care for women with BCRL through pre/post assessment using the previously mentioned tools, concerning knowledge, was assessed pre and immediately after implementation of the educational instructions and self-care was assessed pre and three months after implementation of the educational instructions and comparing the collected data before and after application of educational instructions.

IV. Statistical Design

The data were collected, coded and entered a suitable excel sheet. Data were analyzed using the statistical package for social sciences, version 20.0 (SPSS). The statistical analysis was done using percentage (%), mean, standard deviation; Chi-Square (χ^2) was used in order to compare proportions between two qualitative parameters. The observed differences and association were considered as follows:

- Non-significant (NS) $P > 0.05$
- Significant (S) $P \leq 0.05$
- Highly Significant (HS) $P \leq 0.01$

Limitations of the study

1. The literacy and a lack of reading skills limited the ability of some women to access and use written information. So, the researcher depended on assistive person or caregiver to provide this information for them.
2. The researcher contact with three women who accepted to participate in the study was missed and two of women couldn't apply the educational instructions more than 3 times. So, the researcher replaced them with another five women.

3. RESULTS

Table 1. reveals that, 46% of the study sample were between age 40 to less than 50 years with mean 47.71 ± 71.16 ; also, 86% of them were married. Regarding to educational level, 38% of them had intermediate education. In relation to occupation; it was found that, 62 % of them were housewives, and 18% of them were worked in governmental work; meanwhile, 14% of them were worked in private work; also, 6% of them were retired. As regard to monthly income and treatment costs the result showed that, 84% of them had insufficient monthly income, and 78% had free/ government treatment costs. In relation to residence, 72% of them were from urban. Lastly as regard to smoking, 8% of the studied group were smokers, but 84% of them had smokers in their family education.

Table 2. clarifies that, the studied women present history, concerning to body mass index, it was observed that, their mean body mass index was 27.61 ± 5.52 . As regard to the chief complaint, the results showed that, 100% of them had swelling and heaviness in arm. Regarding to medical diagnosis, the results revealed that, 56% of them had right breast cancer, also; 58% of them had stage III breast cancer. Meanwhile, 66% of them were diagnosed with breast cancer since less than one year; also, the time since mastectomy was more than six months in 84% of them, while 42% of them started radiotherapy sessions since 4 weeks. In relation to dominant hand, 88% of them were right dominant hand. Lastly as regard to lymphedema location 62% of studied women had arm lymphedema.

Table 3. illustrates that, there was highly statistically significant difference between studied women's total knowledge pre and post implementation of self-care educational instructions, at ($P < 0.001$), as shown the knowledge level was improved.

Table 4. shows that, the stages were receded and moved back and there was a highly statistically significant difference between studied women's lymphedema stages pre and post implementation of self-care educational instructions at, ($P < 0.001$).

Table 5. illustrates that, there was a highly statistically significant difference between studied women pre and post implementation of self-care educational instructions regarding to their level of lymphedema effect at ($P < 0.001$).

Table 6. reveals that, 20% of the studied women had high functional ability of the upper limb pre implementation of educational instructions, while 92% of them had high functional ability of the upper limb post implementation with highly significant difference between them at ($P < 0.001$).

Table 7. shows that, there were highly statistically significant differences between the studied women's total level of post lymphedema self-care practices pre and post implementation of educational instructions at ($P < 0.001$).

Table 1: Number and percentage distribution of socio-demographic characteristics of the studied women (n=50).

Socio-demographic data	No.	%
Age (years)		
30-<40	11	22
40-<50	23	46
≥50	16	32
Mean±SD	47.71±7.16	
Marital status		
Single	1	2
Married	43	86
Divorced	4	8
Widow	2	4
Educational level		
Can't read & write	12	24
Read and write	10	20
Intermediate e education	19	38
High education	9	18
Occupation		
Governmental work	9	18
Private work	7	14
Housewife	31	62
On retirement	3	6
Monthly income		
Sufficient	8	16
Insufficient	42	84
Treatment costs		
Free/ Government	39	78
Private	11	22
Residence		
Urban	36	72
Rural	14	28
Smoking		
No	46	92
Yes	4	8
Family Smoking		
No	8	16
Yes	42	84

Table 2: Number and percentage distribution of present history of disease among the studied women (n= 50).

Present history	No.	%
Body mass index		
Normal (18 to 24.9)	12	24
Overweight (25 to 29.9)	24	48
Obese (≥30)	14	28
Mean ± SD	27.61±5.52	
Chief complaint		
Severe pain in arm	26	52
Swelling in arm	50	100
Heaviness in arm	50	100
Decrease of movement in arm and shoulder	38	76
Medical diagnosis		
Left breast cancer	22	44
Right breast cancer	28	56
Breast cancer stage		
Stage I	0	0
Stage II	4	8
Stage III	29	58
Stage IV	17	34
Time since breast cancer diagnosis		
<1 year	33	66
>1 year	17	34
Time since mastectomy		
<6 months	8	16
>6 months	42	84
Mean ± SD	6.14±2.45	
Time since starting radiotherapy sessions		
2 weeks	5	10
3 weeks	8	16
4 weeks	21	42
5 weeks	16	32
Mean ± SD	3.5±1.4	
Dominant hand		
Left	6	12
Right	44	88
Lymphedema location		
Arm	31	62
Arm and hand	17	34
Arm and breast	2	4

Table 3: Studied women's level of total knowledge pre and post implementation of self-care educational instructions (n= 50).

Total Knowledge	Satisfactory		Satisfactory		Chi-square test	
	Pre		Post		x2	p-value
	No.	%	No.	%		
Total Knowledge about Breast Cancer	24	48	40	80	18.196	<0.001
Total knowledge about breast cancer related lymphedema	8	16	42	84	31.441	<0.001
Total knowledge about self-care	12	24	41	82	27.114	<0.001
Satisfactory	6	12	44	88	57.760	<0.001

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Table 4: Number and percentage distribution of studied women regarding their lymphedema stages pre and post implementation of self-care educational instructions (n= 50).

Lymphedema Scale	Pre		Post		Chi-square test	
	No.	%	No.	%	x2	p-value
Stage 0	0	0	39	78	67.805	<0.001
Stage I	30	60	11	22		
Stage II early	20	40	0	0		

Table 5: Number and percentage distribution of studied women regarding to total level of lymphedema effects pre and post implementation of self-care educational instructions (n= 50).

Women's lymphedema effects on physical, psychological, household, mobility and life domains		Pre		Post		Chi-square test	
		No.	%	No.	%	x2	p-value
Total physical domain	Weak	1	2	36	72	44.971	<0.001
	Moderate	38	76	14	28		
	Strong	11	22	0	0		
Total psychological domain	Weak	2	4	41	82	37.196	<0.001
	Moderate	34	68	9	18		
	Strong	15	30	0	0		
Total household domain	Weak	0	0	31	62	52.337	<0.001
	Moderate	17	34	19	38		
	Strong	33	66	0	0		
Total mobility domain	Weak	0	0	30	60	56.194	<0.001
	Moderate	18	36	20	40		
	Strong	32	64	0	0		
Total life domain	Weak	0	0	37	74	67.891	<0.001
	Moderate	37	74	13	26		
	Strong	13	26	0	0		
Total level of lymphedema functioning, disability and health	Weak	0	0	39	78	69.444	<0.001
	Moderate	25	50	11	22		
	Strong	25	50	0	0		

Table 6: Number and percentage distribution of studied women's upper limb function pre and post implementation of self-care educational instructions (n= 50).

Upper limb function		Pre		Post		Chi-square test	
		No.	%	No.	%	x ²	P-value
Stay at home most of the time.	Not affected	14	28	44	88	36.946	<0.001
	Affected	36	72	6	12		
Change position frequently for comfort.	Not affected	21	42	44	88	23.253	<0.001
	Affected	29	58	6	12		
Avoid heavy jobs e.g. cleaning, lifting more than 5kg or 10lbs, gardening etc.	Not affected	1	2	23	46	26.535	<0.001
	Affected	49	98	27	54		
Rest more often.	Not affected	4	8	37	74	45.019	<0.001
	Affected	46	92	13	26		
Get others to do things for me.	Not affected	23	46	41	82	14.063	<0.001
	Affected	27	54	9	18		
Have pain almost all the time.	Not affected	20	40	39	78	14.924	<0.001
	Affected	30	60	11	22		

Have difficulty lifting and carrying (e.g. bags, shopping up to 5kg or 10lbs).	Not affected	0	0	24	48	31.579	<0.001
	Affected	50	100	26	52		
My appetite is now different.	Not affected	1	2	34	68	47.868	<0.001
	Affected	49	98	16	32		
Have difficulty with normal home or family duties and chores.	Not affected	2	4	25	50	26.839	<0.001
	Affected	48	96	25	50		
Sleep less well.	Not affected	4	8	33	66	36.079	<0.001
	Affected	46	92	17	34		
Regular daily activities (work, social contact) are affected.	Not affected	0	0	25	50	33.333	<0.001
	Affected	50	100	25	50		
Being more irritable and / or bad tempered.	Not affected	2	4	35	70	46.718	<0.001
	Affected	48	96	15	30		
Feel weaker and / or stiffer.	Not affected	15	30	43	86	32.184	<0.001
	Affected	35	70	7	14		
Transport independence is affected (driving, public transport).	Not affected	8	16	33	66	25.837	<0.001
	Affected	42	84	17	34		
Difficulty putting my arm into a shirt sleeves or need assistance dressing.	Not affected	13	26	34	68	17.704	<0.001
	Affected	37	74	16	32		
Difficulty writing or using a keyboard and / or "mouse" (n=28)	Not affected	0	0.0	13	46.4	16.930	<0.001
	Affected	28	100.0	15	53.6		

Continue, Table 6: Number and percentage distribution of studied women's upper limb function pre and post implementation of self-care educational instructions (n= 50).

Upper limb function		Pre		Post		Chi-square test	
		No.	%	No.	%	x ²	P-value
Unable to do things at or above shoulder height.	Not affected	0	0	29	58	40.845	<0.001
	Affected	50	100	21	42		
Have difficulty eating and /or using utensils (e.g. knife, fork, spoon, chop sticks).	Not affected	27	54	49	98	26.535	<0.001
	Affected	23	46	1	2		
Difficulty holding and moving dense objects (e.g. mugs, jars, cans).	Not affected	17	34	35	70	12.981	<0.001
	Affected	33	66	15	30		
Tend to drop things and/or have minor accidents more frequently.	Not affected	8	16	40	80	41.026	<0.001
	Affected	42	84	10	20		
Use the other arm more often.	Not affected	0	0	32	64	47.059	<0.001
	Affected	50	100	18	36		
Have difficulty with buttons, keys, coins, taps/faucets, containers or screw-top lids.	Not affected	11	22	31	62	16.420	<0.001
	Affected	39	78	19	38		
Have difficulty opening, holding, pushing or pressing (e.g. triggers, lever, and heavy doors).	Not affected	0	0	10	20	11.111	<0.001
	Affected	50	100	40	80		
Total level of upper limb function	High functional ability	10	20	46	92	52.597	<0.001
	Low functional ability	40	80	4	8		

Table 7: Number and percentage distribution of studied women regarding their post lymphedema self-care practices pre and post implementation of self-care educational instructions (n= 50).

Lymphedema self-care practices		Pre		Post		Chi-square test	
		No.	%	No.	%	x ²	p-value
General self-care to reduce breast cancer related lymphedema	Inadequate	42	84	5	10	54.958	<0.001
	Adequate	8	16	45	90		
Self-care for skin care	Inadequate	44	88	8	16	51.923	<0.001
	Adequate	6	12	42	84		
Self-care of the arm in case of injury or burn	Inadequate	39	78	11	22	31.360	<0.001
	Adequate	11	22	39	78		
Self-care to overcome pain	Inadequate	44	88	11	22	44.000	<0.001
	Adequate	6	12	39	78		
Self-care about the healthy nutrition	Inadequate	33	66	10	20	21.583	<0.001
	Adequate	17	34	40	80		
Self-care about the safe drug use	Inadequate	35	70	4	8	40.395	<0.001
	Adequate	15	30	46	92		
Self-care about use of compression bandage	Inadequate	48	96	10	20	59.278	<0.001
	Adequate	2	4	40	80		
Self-care about general exercise	Inadequate	39	78	9	18	36.058	<0.001
	Adequate	11	22	41	82		
Self-care about Sexual relation (n=44)	Inadequate	38	86.4	14	31.8	28.926	<0.001
	Adequate	6	13.6	30	68.2		
Self-care to control the psychological pressures	Inadequate	41	82	10	20	38.455	<0.001
	Adequate	9	18	40	80		
Total level of lymphedema self-care practices	Inadequate	46	92	4	8	70.560	<0.001
	Adequate	4	8	46	92		

4. DISCUSSION

Breast cancer related lymphedema is a common but underreported complication of BC treatment because few studies have baseline and follow-up measurements or long-term (5 year) follow-up evaluation adequate to record the incidence accurately. Furthermore, LE has negative impact on overall QoL and represents a financial burden for patients, caregivers, and society (Boyages et al., 2016).

Lymphedema requires life-long self-care and management (Cancer Council, 2017). It is essential that patient education plan to be developed collaboratively with input from all the disciplines involved in the patient's care (William, 2018). So, the nurse is positioned to assist the patient in meeting self-care goals, management and challenges of the patient's lifetime risk and unique trajectory of BCRL (Paula, 2015).

The present study has been designed aiming to study the effect of educational instructions on the knowledge and self-care practices of women with BCRL. Also, it has been hypothesized that, educational instructions regarding self-care of women with breast cancer related LE will improve their knowledge and self-care practices.

Regarding socio-demographic characteristics of the studied women, the findings of the current study revealed that, the mean age of study group was 47.71±7.16 years. This finding near to the result of the study conducted in Egypt titled "Upper limb lymphedema related to breast cancer therapy" by Saleh, Rageh, Alhassanin & Megahed (2018) who reported that the mean age of the study subjects was 48.65±8.17 years.

As regards marital status, the current study stated that the majority of subjects were married; this might reflect the load that is experienced by the married women through their roles in caring of their families that result in increasing the stress on their arms which increases LE risk. This finding is similar to the results of a study about "Nurses' performance to meet satisfaction of patients undergoing breast cancer surgery" presented by **Hussein (2017)** who found that the majority of studied women were married.

Concerning level of education, the results of the current study revealed that more than one third of them had middle education. In contrast to the current study, **Aboul-Enien, Ibrahim, Makar, Darwish & Gaber (2018)** in a study about "Health-related quality of life: impact of surgery and treatment modality in breast cancer" who found that, more than one half of studied subjects couldn't read and write.

Regarding occupation, the results of the present study showed that less than two thirds of study subjects were housewives and about one fifth of them were in governmental work. Those women work for a long period, perform heavy physical workload, and carry heavy objects, this might indicate that, the nature of work had been caused mechanical stress on the arm and acted as a risk factor to develop LE for those women. These findings are consistent with the study conducted about "**Management of breast cancer related lymphedema**" by **Donmez & Kapucu (2016)** who stated that occupations requiring excessive use of the extremity increase BCRL risk and aggravate its symptoms.

In relation to the monthly income and treatment costs, the majority of studied women had insufficient monthly income to meet the costs of their lives and treatment fees were paid by government. This result is inconsistent with study conducted in Zagazig University about "Improving quality of life for women with arm lymphedema post mastectomy" presented by **Hagrass, Abd Allah, H+6|assan & EL Sawy, (2012)**; they revealed that the treatment fees were paid by most of their studied women.

Related to the residence area, the results of the current study stated that, more than two thirds of them were from urban areas. This finding agrees with the study about "Assessment of health related knowledge and practices among female patients with lymphedema post mastectomy" by **Hawash (2014)** who reported that the majority of women with BC came from urban areas. This finding isn't consistent with a study of **Abo-Elazm et al., (2018)** who conducted a cross-sectional study titled "Trends in demographics and reproductive factors in breast cancer in Egypt" and found that, slightly more than half of the studied subjects were from rural areas.

Concerning to the smoking habits, the current study stated that the majority of the studied women weren't smokers, but the majority of them had smokers in their families. This could be due to the nature of the studied subjects as they were females and the culture and customs of the Egyptian community who refuses this habit in women.

Regarding to present history of the studied women, the results of the current study revealed that, less than half of them were overweight; while, more than one quarter of them were obese, and their BMI mean was 27.61 ± 5.52 . This result is supported with the study about "Risk factors for interlimb differences among overweight breast cancer Survivors with lymphedema" by **Dean et al., (2016)** who stated that; high body mass index is a risk factor for upper body BCRL onset.

Concerning women's chief complaint, it was found that, there was more than half of the studied women suffered from severe pain in arm, all of them suffered from swelling and heaviness in arm while, more than three quarters of them suffered from decrease of movement in arm and shoulder. These results are consistent with the study about "Symptom reporting in detecting breast cancer related lymphedema" by **Fu et al., (2015)** who stated that, LE symptoms include arm swelling, breast swelling, heaviness, firmness, tightness, stiffness, pain, aching, numbness, burning, stabbing, tingling, arm weakness, and limited movement in shoulder, arm, elbow, wrist/fingers.

Regarding medical diagnosis, the results of this study showed that more than half of them had right BC. This result is near to the result of a study conducted in **Cairo University** titled "Breast cancer in women aging 35 years old and younger" by **Darwish, Helal, Aly El-din, Solaiman & Amin (2017)** who found that, about half of study subjects had left BC.

As regards to BC stages, the present study stated that, more than half of the studied women had stage III BC. This result could be due to that the majority of the studied sample were not aware about breast self examination for early detection of cancer at first stage, thus the BC was discovered at stage III. In this case mastectomy usually associated with lymph nodes removal from the axilla area and could result in LE risk.

This result isn't consistent with study conducted in Alexandria University titled "Effect of nursing rehabilitation program on the prevention of lymphedema among post mastectomy women" by **Hawash, Alaa Eldeen, El Shatby, El Moghazy & Hamid (2018)** who mentioned that more than half of studied women were diagnosed with BC at stage II. This result is supported with the study of by **Saleh et al., (2018)** who concluded that, BC patients of stage IIIB who had undergone modified radical mastectomy are at higher risk for developing LE.

In relation to BC diagnosis duration, the current study showed that, about two thirds of studied women were diagnosed as BC patients since less than one year. According to this finding, **Abo-Elazm et al., (2018)** mentioned that, there are significant changes in reproductive and hormonal pattern in Egyptian females diagnosed with BC over the past 25 years and added that these trends should be taken into account when planning for any future national BC screening and prevention plans.

As Regards to LE occurrence, in the results of the present study, LE appeared on the studied women within the first 1 year after mastectomy, as mean time since mastectomy was 6.14 ± 2.45 months, while mean time since starting RT sessions was 3.5 ± 1.4 weeks; which varied from the study in Cairo University about "Risk factors of upper-arm lymphedema after breast cancer treatment" presented by **Safwat, Shaalan, Mokhtar & Hamood (2017)** who reported that most cases of LE in their study appeared within the first 2 years after mastectomy, as the mean time of appearance of upper-arm LE postoperatively was 14.23 ± 13.93 months.

These findings might be due to the variation in diagnosis process and treatment of BC which took different time and the RT machine at the center during some period when collecting the data wasn't work, so there was variation in the time since women took RT sessions. These results are supported by **Zou et al., (2018)**, who conducted prospective cohort study about "The incidence and risk factors of related lymphedema for breast cancer survivors" and concluded that, BCRL is a common complication for BC patients after surgery, it can be fairly diagnosed only one month post-operation and the cumulative incidence of BCRL seems to be increasing over time, especially in the first year after surgery. Also, they added that RT was found to be independent risk factor in the development of it.

Concerning to dominant hand, the results of this study showed that, the majority of them were right dominant hand. This could interpret the high percentages of the studied women were married and housewives and this might expose them to household insecticides and detergents that increase LE risk. This finding is supported a study conducted in Cairo University by **Safwat et al., (2017)** who showed that there was a statistically significant association between tumor in the dominant arm with development of upper arm LE after BC treatment.

As regard to LE location, the current study illustrated that less than two thirds of the studied women had arm LE. This goes in the same line with the finding of the study conducted by **Winch et al., (2015)** about "Sexual concerns of women diagnosed with breast cancer related lymphedema" who reported that a higher percentage of the studied women had arm LE.

Concerning the current study hypothesis stating that "the implementation of educational instructions regarding self-care of women with BCRL will improve their knowledge and self-care practices" the findings of this study proved this hypothesis. The following is the discussion of the results related to this hypothesis.

As regards to allover studied women knowledge, the results of the current study showed that, there were statistically significant differences among studied women pre and post educational instructions regarding their total knowledge about BC, BCRL and LE self-care, with improving the knowledge post implementation compared to pre. This reflects the positive effect of educational instructions on modifying knowledge of those women.

Additionally, these positive effects of educational instructions post implementation might be due to empowerment of the studied women and using of motivation, which helped them to view their illness as something with which they can live, and recognize that they can control their health problems. This result comes in the same line with the study presented by **Hawash et al., (2018)** who reported that after implementing the nursing rehabilitation program, total knowledge improved among the studied women.

The results of current study revealed that, there were statistically significant differences among studied women pre and post educational instructions regarding their knowledge about BCRL. This finding is in congruence with **Johanna & Beckmann (2016)** who stated that, developing and evaluating educational interventions for patient with BCRL focused on the identified knowledge deficits lead to improved patient outcomes.

The result of the current study revealed that, there were statistically significant differences among studied women pre and post educational instructions implementation regarding their knowledge about self-care regarding BCRL. This reflects the positive effect of educational instructions on modifying knowledge of those women. This finding agrees with the result of a study about "Preparing for and coping with breast cancer related lymphedema" conducted by **Radina & Fu (2012)** which revealed that, patient education about self-care is critical for effective self-management.

Regarding to women's LE stages, the result of the current study illustrated that, there was highly statistically significant difference between studied women pre and post implementation of educational instructions regarding their LE stages, as there was decrease in affected arm sizes and LE stages. This might be due to lacking information and/or not following instructions regarding BCRL had significant relation to LE. In addition, the health instructions given to study the studied women using different teaching strategies as lecture, discussion, and colored booklet motivated them to apply the instructions.

This finding supported by the result of study entitled "The effectiveness of reducing affected arm volume by self-care program in patients with breast cancer treatment-related lymphedema" conducted by **Arinaga, Sato, Sato & Kashiwagura (2015)** who concluded that, self-care program may significantly lessen the severity of unilateral BCRL.

In relation to the part of study hypothesis stating that "educational instructions will improve self-care practices of women with BCRL", the results of the study prove this part of hypothesis, as the results of the current study showed that, there was an improvement among studied women pre and post instructions regarding their level of LE effects, their upper limb function and their LE self-care practices.

These could be due to exercises and self MLD that helping in reducing affected arm size and pain which helped in improving self-care of the studied women. This finding agrees with the result of a study about "Exploring patient perception of success and benefit in self-management of breast cancer-related arm lymphedema" presented by **Jeffs et al., (2016)** who stated that, women who participated in their study showed varying degrees of acceptance and adjustment to life with LE and this appears to directly impact their ability to self-manage LE.

Concerning level of LE effects, the present study showed that, highly statistically significant difference between studied women pre and post educational instructions regarding their level of LE effects as the study revealed presence of significant improvement in women's physical, mental, household, mobility and life domains after implementation of educational instructions.

This might be due to the studied women's desire to overcome the disease and their hope in living well to have the ability to care for their families. Moreover, these could be due to the effects of LE self-care instructions, hand and arm exercises and self MLD that helping in reducing arm size and improving upper limb functional ability.

These findings are congruent with the study about "Adherence and quality of life" presented by **Ridner, Deng & Rhoten (2018)** who stated that empowering patients to be able to confidently manage their LE will enhance patient well-being and also added that lack of adherence to self-care could profoundly affect far more than volume, also influencing function, psychological well-being, confidence in body image, and activity levels.

The current study revealed presence of significant improvement in women's physical domain as BCRL-associated symptoms were decreased "heaviness, swelling and hurting". These findings are supported by study conducted by **Arinaga et al., (2015)** who mentioned that there was a significant decrease in severity of arm discomfort regarding associated symptoms of BCRL after patients' self-care adherence.

The results of the current study revealed presence of significant improvement in women's psychological domain after implementation of educational instructions as there was decrease in feeling sad and increase in self-confidence.

These findings are congruent with the study about "How people construct their experience of living with secondary lymphedema in the context of their everyday lives in Australia" by **Meiklejohn, Heesch, Janda & Hayes (2013)** who concluded that, by incorporating self management activities into the everyday routine of life, the psychological burden of treatment is reduced.

The results of the present study illustrated significant improvement in women's household domains after implementation of educational instructions. These indicates that LE self-care education can help women to manage their roles in the life effectively. These findings are supported with the study about "Women's satisfaction with lymphedema prevention information after breast cancer surgery" conducted by **(Hurren & Yates, 2018)** who stated that, tailored information about LE would assist women with BC and improve satisfaction.

The results of the current study showed also significant improvement in women's mobility domains after implementation of educational instructions, as there was an improvement in performing tasks with elevated arm and lift heavy object.

This might be due to the positive effect of self-care education in reducing BCRL associated symptoms and decreasing arm size which could result in improving mobility of the affected arm; also helping those women to perform their needed tasks. These findings are supported with the study titled "Self-care for management of secondary lymphedema" conducted by **(Douglass, Graves & Gordon, 2016)** who stated that empowerment of people with LE to care for themselves with access to supportive professional assistance has the capacity to optimize self-management practices and improve outcomes from limited health resources.

The results of this study revealed also presence of significant improvement in women's life domains after implementation of educational instructions, as there was an improvement in doing the job and social activities. These findings are supported with the study about "The prevalence of lymphedema in women who attended an information and exercise class to reduce the risk of breast cancer-related upper limb lymphedema" done by **Jeffs & Purushotham (2016)** which revealed that, all women found the class beneficial, reporting increased confidence to return to normal life and a wide range of activities/exercise.

As regard to upper limb function, additionally, the result of this study clarified that, there was highly statistically significant difference between studied women pre and post educational instructions regarding their level of upper limb function, as one fifth of the studied women had high functional ability of the upper limb pre implementation of educational instructions; meanwhile, majority of them had high functional ability of the upper limb post the implementation. This might be due to that, all the activities are vital tasks such as home or family duties, household activities, dealing with money and transports they are necessary for usual daily life.

These findings are supported with the study about " Breast cancer related lymphedema: symptoms, diagnosis, risk reduction, and management" conducted by **Fu, (2015)** who revealed that, LE awareness sessions have the potential to empower women to live well and live normally following BC treatment, and provide guidance regarding pacing of exercise and activities.

In relation to LE self-care practices, in the current study, there was highly statistically significant difference between the studied women pre and post educational instructions implementation regarding their level of LE self-care practices as there was an improvement in performing self-care practices to reduce BCRL, skin care, wound care, control of pain, healthy nutrition, safe drug use, use of compression bandages activities exercises, sexual relation and controlling psychological pressures. These indicate the importance of daily performing self-care practices which significantly improves patient outcomes.

These findings are supported with the study titled "Breast cancer treatment-related lymphedema self-care: education, practices, symptoms, and quality of life" conducted by **Ridner, Diertich, & Kidd (2011)** which revealed that, a multidisciplinary approach to LE management, including self-care education and monitoring, is likely needed to improve QoL in this population.

These results were supported by the study titled "Self-reported information sources and perceived knowledge in individuals with lymphedema" conducted by **Armer et al., (2013)** who mentioned that, knowledge impacts ability to carry out self-management activity, and a lack of knowledge about the mechanism of treatment and expected outcomes will inevitably affect perceived benefit of treatment.

On summary, the current study proved the hypothesis that, educational instructions will improve the knowledge and LE self-care practices of studied women. These results are in agreement with the study about "Reducing breast cancer related lymphedema through prospective surveillance monitoring using bioimpedance spectroscopy and patient directed self-interventions" by **Kilgore et al., (2018)** who stated that, self-directed intervention is more convenient for the patient with LE and results in improved compliance. Also, in the study about "The impact of early detection and intervention of breast cancer related lymphedema" conducted by **Shah et al., (2016)** who mentioned that patient education reduces BCRL risk and associated symptoms.

So, the planning and implementing of educational instructions regarding self-care for women with BCRL and providing them with tailored information can decrease reports of pain, increase functional abilities, avoid triggering or worsening of LE, improve self-care practices and also improve their QoL.

5. CONCLUSION

- Application of educational instructions has statistically significant positive effect on knowledge of women with BCRL under study.
- Application of educational instructions has statistically significant positive effect on improving self-care practices of women with BCRL, physical, and psychological status of the women under study. Also enhancing social domain of women under study.

6. RECOMMENDATIONS

- Self-care educational instructions should be added to the routine nursing care delivered to those women in all breast cancer treatment units and should be updated periodically in order to enhance their knowledge and self-care practices.
- Full-day educational programs that provide the latest information about breast cancer related lymphedema and self-care approach to support breast cancer survivors to manage their disease effectively.
- Setup a project that aims to improve women's care by implementing evidence based practice at breast cancer treatment clinics.
- Establish interdisciplinary approach in management of breast cancer related lymphedema at breast cancer treatment clinics.
- Follow up care for women with breast cancer related lymphedema through phone calls, internet and clinical visits by trained oncology nurses at breast cancer clinics should be added to the care of those women.
- Further researches are recommended periodically to be carried out on new approaches in the area of management of patients with breast cancer related lymphedema and evaluate their effect on patients' outcomes.
- Replication of the current study on a larger probability sample is recommended to achieve generalization of the results and wider utilization of the designed instructions.

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