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▪ **Basic Research**

**Self-Care Program for Patients with Leprosy Grade 2 in Abu Zaabal  
Leprosy Colony**

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**ABSTRACT**

**Background:** Leprosy, is a chronic infectious illness caused by Mycobacterium leprae which, also known as Hansen's disease, which consider a major health problem globally and in Egypt. **Aim:** The study aimed to enhance self-care program for patients with leprosy grade 2 in Abu Zaabal Leprosy Colony. **Study design:** To perform this study a quasi-experimental design was used. **Subject:** A purposive sample composed of 85 patients with age ranged from 25: 60 years and diagnosed as G2Ds. **Setting:** This study was conducted at Abu Zaabal Leprosy Colony. **Tools:** It was composed of two-tools. First tool: An interviewing questionnaire to assess socio-demographic characteristics of patients, their knowledge, practices, and health problems. Second tool: An observational checklist: to assess patients' independence level of daily living activities. **Results:** The findings of this study revealed that 76.5% of the study participants had unsatisfactory knowledge about leprosy before program implementation and improved to 92.9% post program and 84.7% at follow up as well the practices were inadequate before program and enhanced for 94.1% post program and 89.4% at follow up with significant statistical relations between patients' knowledge/practices and their independence level, social, and psychological health problems as well as their age, gender, and educational level, through program implementation phases ( $P < .0001$ ). **Conclusion:** The self-care program had improved patients' knowledge and practices related to leprosy, which affected in a positive impact on restoring their health and improving their independence level. **Recommendation:** The study recommended that, publication, and dissemination of self-care program in all leprosy colony and any health care services to raise awareness about leprosy and its prevention.

**Keywords:** Self-care, patients with leprosy, independence level, grade 2

## 1. Introduction

Leprosy, or Hansen's disease, is a chronic infectious disease caused by *Mycobacterium leprae* (*M lepra*).<sup>(1)</sup> *M. leprae* reproduces slowly, and the illness typically takes 5 years to develop. The time it takes for symptoms to manifest can range from a year to twenty years or longer. In order to be infected with the disease, one must have continual, close contact with a person who has untreated leprosy for a number of months.<sup>(2, 3)</sup>

The mode of transmission of leprosy is droplets infection, from the nose and mouth, throughout close and frequent contact with untreated cases. Children are at a higher risk of getting leprosy than adults. Untreated leprosy cases can cause advanced, progressive, and permanent damage to the skin, limbs, nerves, and eyes.<sup>(4)</sup>

Leprosy affects the skin, a mucous membrane of the upper respiratory tract, peripheral nerves, and eyes, causing polyneuropathy and associated long-term consequences, which including irreversible eyes deformities and grad-2 of disability associated with significant stigma and deterioration of the quality of life for patients.<sup>(5, 6)</sup>

Based on the World Health Organization's epidemiological report, *Mondale de la Sante*. According to 2017.<sup>(7)</sup> Global Leprosy Update, there were more than 210 000 new cases of leprosy worldwide and almost 200 000 people registered for leprosy treatment. 238 of the new cases included children; 60% of them had multibacillary teeth, 38% of them were female, and 7% had obvious abnormalities or grade 2 impairments. at the very end of 2017. Additionally, it is believed that more than three million people worldwide experience difficulties associated with leprosy.<sup>(8-9)</sup>

This disease is most prevalent among people residence in some communities characterized by poorness and illiteracy neighborhoods.<sup>(10)</sup> Existing research on leprosy reveals that poor living conditions may increase risk, while stigma and anxieties surrounding the disease may cause incompliance of treatment, G2 disabilities, and declines in personal economic productivity, which would perpetuate poverty.<sup>(11)</sup>

Unfortunately, this infection can cause severe damage to the nerves, eyes, skin, and nasal mucosa. The nerves are damaged by the causative bacteria (*M leprae*), which lead to swollen beneath the skin, which could lead to ulcers and burns. Due to skin inflammation, the affected skin often changes color, becoming either more light or dark, extremely dry, or flaky, feelingless, or crimson due to skin inflammation.<sup>(12)</sup>

In addition to hands and feet paralyzed and disfunction of them. Reabsorption of toes and fingers which lead to shortening of them. Beside the most common complications of untreated severe Hansen's disease such as chronic non-healing ulcers in the feet on its bottom sides, loss of eyebrows, nose disfigurement, and blindness as grade 2 disability. <sup>(13)</sup>

According to the World Health Organization (WHO), a leprosy patient's level of disability ranges from 0 to 2. Grade 0 implies no impairment, Grade 1 indicates a loss of sensation in the hand, eyes, or foot, and Grade 2 indicates a visible impairment. <sup>(14)</sup> Failures in the diagnosis and treatment of the disease may also contribute to the development of stigmatizing leprosy-associated grade-2 disabilities (G2Ds). According to estimates, 7% of the more than 200,000 new cases of leprosy had G2Ds by the time of diagnosis. <sup>(15)</sup> As one of the psychological and social issues that a leprosy sufferer is exposed to, the stigma and anxieties surrounding leprosy may result in treatment delays, G2Ds, and reductions in personal economic productivity. <sup>(16)</sup>

Although care and therapy are sometimes available, this disease can be prevented and cured for a modest cost. If leprosy is not identified early, it frequently results in infirmities that limit people's ability to perform their customary tasks and lower their social position. stigmatization, social isolation, and discrimination towards those affected. <sup>(17)</sup>

The ability of people, families, and communities to "promote health, prevent disease, maintain health, and live with illness and disability with or without the support of a healthcare provider" is how the World Health Organization (WHO) defines self-care. <sup>(18)</sup> Self-care programs are health care interventions that patients conduct on their own, without the help of any professionals. These services could be based on medical advice given by experts. The goal of the self-care approach is to help patients prevent or manage their basic medical and social issues with reduced reliance on hospital resources by using affordable, accessible, and sustainable tools in their homes and communities. <sup>(19)</sup>

### **1.1. Significant of the study**

Although Egypt has achieved the WHO goal of eliminating leprosy since 1994 at the national level, with the prevalence rate dropping from 0.17 per 10,000 in 2010 to 0.075 per 10,000 in 2016, there are still a few areas which have not yet achieved elimination; between 300 and 900 new cases/year have been reported in Egypt. <sup>(20, 21)</sup>

Self-care for people with leprosy has benefits for improving the quality of life in terms of physical, psychosocial, and socioeconomic needs. Thus, it leads them to seek

prevention and prophylaxis measures with actions that reduce physical disability and enhance independence level. <sup>(22)</sup>

### **1.2. The aim of this study**

The aim of this study was to enhance self-care program for patients with leprosy grade 2 in Abu Zaabal Leprosy Colony.

### **1.3. Research hypothesis:**

The self-care program will enhance patients' knowledge and practices related to leprosy, which will have a positive impact on restoring their health and improving their level of independence.

## **2. Subjects and Methods**

### **2.1. Research design:**

A quasi-experimental design was used with pre, post, and follow-up tests in order to achieve the aim of the study.

### **2.2. Setting:**

The study was conducted at outpatient clinics in Abu Zaabal Leprosy Colony as this hospital is specialized in leprosy treatment and the only one covers all leprosy patients surrounding this area of Cairo Governorate, and other patients coming from all over the Egyptian Governorates.

### **2.3. Subjects:**

A purposive sample was selected; the total number of patients with leprosy attending the outpatient clinic at the previously selected setting in the last year was (580). The total number of the represented sample was calculated by sample size equation with estimated proportion= 0.3, desired precision of estimate =0.05, and confidence level 0.95. Which are 85 patients and had been selected according to the criteria till the sample reaches the pre-determined number.

The inclusive criteria are patients with leprosy and their age ranged from 25: 60 years and diagnosed as G2Ds.

### **2.4. Tools of data collection:**

The data was collected using the two following tools:

**2.4.1. First tool:** An Interviewing questionnaire, which was designed by the researchers after reviewing the related literature and consulting the experts, written in Arabic language

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in all the related parts and used through pre, post and follow-up post implementation of the self-care program, which included the following parts:

**Part 1:** Socio demographic characteristics of patients: It consisted of nine open and closed ended questions such as age, gender, educational level, occupation, marital status, family size and monthly income, residence, and household crowding index.

The crowding index was calculated by using the following equation: 
$$\frac{\text{Number of family members}}{\text{Number of house rooms}}$$

There are three categories of crowding index as follow: Not crowded  $\leq 1.0$  person per room, Crowded  $>1.0 \leq 1.5$  people per room, and severely crowded  $>1.5$  people per room. The Family Crowding Index (F.C.I) formula adopted from adopted from Torshizian and Grimes.<sup>(23)</sup>

**Part 2:** This part assesses patients' knowledge about leprosy disease. It consisted of eight main questions as meaning of leprosy, causative agent, mode of transmission, incubation period, symptoms, complications, treatment, and preventive measures of leprosy.

**Scoring system:**

The score ranged from zero to one, correct = 1 & incorrect = 0. The total score for all sup items related to knowledge was 32 items summed up and categorized into two levels as unsatisfactory if less than 60%, and satisfactory if more than or equal 60%.

**Part 3:** This part to assess patients' practices as reported which consisted of 30 questions classified as follow: 10 questions about skin care, 10 questions about wound dressing and artificial prosthesis, 3 questions towards the administer of prescribed medications, 2 questions about follow up, and 5 questions regarding appropriate nutrition.

**Scoring system:**

The total number of reported practices by patients related to leprosy disorders is scored as follows: (1) for done, and (0) for not done. Each item's total score was added up, and the result was given as a percentage score. The overall practices were divided into two levels: adequate if the score was higher than 60%, and inadequate if the score was lower.

**Part4:** Assessing health problems for patients with leprosy G2Ds. This part consisted of three sections as follows:

- a) Physical health problems assessment which is composed of 20 closed questions as optic problems, nasal problems, loss of sensation, ulcerous condition, skin patches, upper limbs (hands), and lower limbs (Feet).
- b) Psychological health problems which consisted of 6 closed questions as feeling of sadness and depression, fear, and anger, feeling a lack of self-acceptance, unsatisfied of body image, suffering of negative emotions, and suicide trying.

- c) Social problems consisted of 6 closed ended questions such as: social stigma, social discrimination, social isolation, lack of community services, avoidance of visiting relatives, and the effect of marital relationship.

**Scoring system of health problems:** The total level of health problems score for leprosy patients was calculated as follows; one score for the answer “yes” and zero for “no,” according to their complaint, and categorized into two levels like suffered of health problems if total marks of score  $\geq 60\%$  and not suffered if score  $<60\%$ .

**2.4.2. Second Tool:** An observational checklist: This tool assesses patients' independence level of daily living activities for patients with leprosy G2Ds. It consisted of twelve closed ended questions; it was scored by Likert scale ranged from 0:2 score. 0 score for dependent, one score for slightly dependent while two score for independent.

**Scoring system:**

The score of patients' independency level calculated post summed up all items' scores and converted into percentage which categorized into three level as follow, the patient was considered dependent if score  $< 60\%$ , slightly dependent if score  $60: <75\%$  and independent if score.  $\geq 75\%$ .

## 2.5. Validity and Reliability

Five experts evaluated the tools' validity; three of them were professors from Ain Shams University's faculty of nursing, faculty of community health nursing, and college of medicine, faculty of dermatology, who checked the instruments for content accuracy. The Cronbach alpha coefficient test and Pearson correlation were used to create the reliability test of the translated version, and they both demonstrated good construct validity and internal consistency (0.877).

## 2.6. Pilot study

Before beginning data collecting, a pilot study was carried out, and a sample of 8 leprosy patients was randomly selected. It was done to gauge the amount of time needed to complete the tools and to assess the questions' clarity, application, and relevance. The pilot sample was used in the study since, in light of the findings of the pilot study, no adjustments are required.

## 2.7. Operational design:

### 2.7.1. Field work:

To conduct the research in their facility, approval from the various authorities in charge of Abu Zaabal Leprosy Colony was requested. The Dean of the Nursing Faculty at Ain Shams University wrote an official letter in order to secure their consent and

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participation, outlining the purpose of the study and the time frame for publishing the findings in order to profit from research findings and enhance patient health.

Preparation of data collection tools was conducted over a period of one month beginning from end of May 2020 to end of June 2020, after being revised from experts to evaluate their validity.

The researchers applied the self-care program for five months, from the beginning of August 2021 to the end of March 2022; data collection was done in one month for the pretest and one month for the implementation of the self-care program for study patients; the post test was implemented right away after the self-care program had finished; and another three months for conducting the follow-up test through an outpatient clinic, three days per week (Saturdays, Mondays, and Tuesdays). The researchers completed the observational checklist in 15 minutes and took about 30 minutes to complete the questionnaire, which involved 5–6 patients per day. For each of the patients who were illiterate or impaired, written consent or a recorded voice was recorded. The self-care program was applied in five sessions of 5 hours; for giving theoretical part and for practices related to care of patients with leprosy Grad 2 disability.

### **2.7.2. Self-care Program Development Phases:**

**Phase 1; Phases of preparation and assessment:** In this phase the researchers designed the tools for data collection after revising the recent local and international related literature. This phase was aimed at enhancing the patients' knowledge and practices toward care of leprosy through determining their needs about technique of wound care and prevention of leprosy. Researchers developed the program sessions according to the educational needs, assessment of patients, and guided by related literature.

**Phase 2; Planning phase:** In this phase the researchers set the general and specific objectives of self-care program session.

**The general objective of self-care program:** acquire the patients with leprosy knowledge and practices regarding to self-care of skin ulcer and their prosthesis if found and help them to prevent transmission of infection to others and decrease the complications which lead to enhance the independency level. At the end of self-care of leprosy sessions, the patients will be able to:

#### **The objectives of theoretical sessions.**

- ✓ Identify the meaning of leprosy

- ✓ Identify the causative agent of leprosy
- ✓ Determine the factors contributing to leprosy
- ✓ Explain the mode of transmission,
- ✓ Identify the incubation period
- ✓ Explain the symptoms
- ✓ Discuss the complications, and treatment of leprosy disease.
- ✓ Recognize the preventive measures of leprosy

**The objectives of practical sessions**

- ✓ Conduct skin care
- ✓ Redemonstrate procedure of wound dressing
- ✓ Implement self-care of artificial prosthesis
- ✓ Conduct administration of prescribed medications correctly
- ✓ Adheres to the medical follow-up schedule
- ✓ Apply appropriate nutrition

**Phase 3; Implementation of the program:**

The work started by meeting the study group of patients at dermatology clinic. Assessment and data collection phase started by researchers introducing themselves to the patients and showing the formal letters issued from the health center. Then, the researchers gave them a brief idea about the study and its aim. Data was collected using the constructed tools by interviewing techniques. The self-care sessions content has been sequenced through five sessions (each session took about one hour). Evaluation of the effects of self-care program on patients with leprosy and conducting it elapsed immediately after finishing of program sessions.

Each session started with a summary about what was given through the previous session and stated the objectives of the new one, taking into consideration using simple and clear Arabic language. All patients received the program as face to face, using effective different media of conveying information as posters, power point presentation by using laptop or tablet and real objects to demonstrate wound dressing and ulcer care. A booklet was constructed for patients as an educational reference after program implementation. Its aim was to provide accurate information about the care of leprosy disease.

**Phase 4: Evaluation phase:**

By using the same pre-program tools, the self-care program's impact on patients with leprosy's knowledge and practices level with regard to self-care for their skin, wound dressing, prosthetic care, as well as leprosy prevention measures, was assessed immediately

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following the program's completion and again three months later.

### **2.7.3. Ethical Considerations:**

The Nursing Research Ethical Committee connected to the nursing faculty at Ain Shams University gave its approval to the study. After a formal letter from the Dean of the Faculty of Nursing at Ain Shames University was issued, the requisite consent from the administrative authority of the Abu Zaabal Leprosy Colony was granted. Each patient was given a thorough explanation of the study's objectives before providing their informed consent to participate in the current trial. The privacy of participant patients was completely respected, and confidentiality of the collected personal data was completely upheld. They were given a brief explanation of the self-care program and advised that they could voluntarily withdraw from the study at any moment without providing a reason.

### **2.7.4. Statistical Design:**

The SPSS program version was used to review, code, analysis, and tabulate the data using the number and percentage distribution (20). The arithmetic mean, standard deviation, and t-test were used to present and analyze the quantity data. ANOVA was also used for the analysis of variance. To evaluate the association between variables, qualitative data are provided as numbers and percentages and are then subjected to a chi-square test. Relevance of the findings: P 0.05 indicates significant (S), P 0.05 indicates non-significant (NS). P0.01 qualifies as highly significant (HS).

## **3. Results:**

The study results proved that 38.8 % of the patients with leprosy aged 25 < 35 years while 35.3% their aged 45 to 60 years and 75.6% were male, while 36.5% of them had basic education and 58.8% of them worked as a farmer and 23.5 not worked. Also, the result shows that 97.6% of the study sample had insufficient monthly income, 45.8% of them were married and 88.2% lived in overcrowded households.

**Table (1):** reveals that, patients with leprosy had unsatisfactory knowledge about meaning of leprosy disease, causative agent, incubation period, symptoms of leprosy, and its complications for 60.0%, 61.2%, 82.4%, 76.5%, and 87.1%, of them, respectively. While there is noticed improvement in this level of knowledge post and follow up phases of program intervention. Concerning to mode of transmission, treatment, and preventive measures of leprosy the study sample had unsatisfactory knowledge for 92.9%, 94.1%, and 88.2% respectively, while post program and follow up this level improved to satisfactory knowledge.

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**Figure (1):** illustrated that 76.5% of the studied patients had unsatisfactory knowledge about care of leprosy before program implementation, while there was noticed progress to satisfactory knowledge about leprosy disease. Immediately post program implementation for 92.9% and through follow up for 84.7% of them. There was a statistically significant relation between level of knowledge through program phases with p-value is  $< 0.00001$ .

**Table (2):** regarding to the practices about self-care of leprosy there are 77.6%, 78.8%, and 80.0% of patients had inadequate practices level about care of skin ulcer, wound dressing, and administer of prescribed medications respectively before program intervention and enhanced to adequate level post and follow up the program implementation.

**Figure (2):** illustrated that 29.4% of the studied patients had adequate practices about care of leprosy before program implementation, while there was noticed progress immediately post program implementation for 94.1% and through follow up for 89.4% of them. There was a statistically significant relation between level of practices through program phases with p-value is  $< 0.00001$ .

**Table (3):** reveals that, all of study sample (100%) had Skin patches preprogram while, through follow up it became 85.9% of them. Also, 83.5% and 78.8% of them suffered sadness and dissatisfaction from the body image preprogram while it became 40.0% and 28.2% through follow up. Also 89.4% of patients suffered from social stigma preprogram which improved to 45.9% through follow up.

**Table (4)** The study demonstrated a significant improvement in the level of independence for leprosy patients, as the percentage of independence improved from 11.7% in the pre-program phase to 17.4% during the follow-up phase. Also, the table proves that there was a statistically significant relation between total knowledge of patients with leprosy and their level of practices, independence level, psychological health problems, and social health problems preprogram implementation and follow up phase with p-value is  $< 0.05$ .

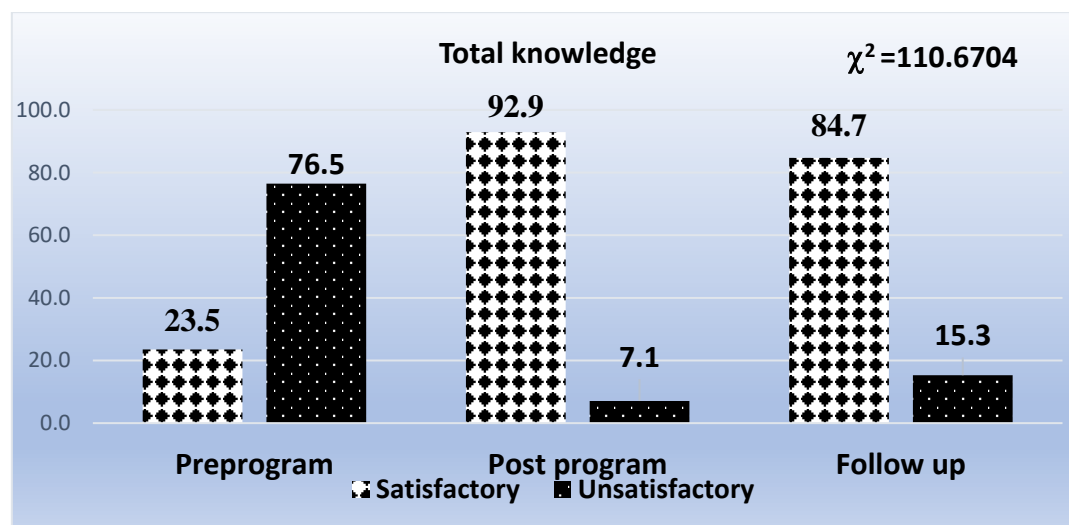
**Table (5)** explains that there was statistically significant difference between health problems of patients with leprosy preprogram implementation such as psychological health problems and social health problems preprogram implementation and follow up phase with p-value =  $< 0.05$ .

**Table (6):** demonstrates that there was a statistically significant relationship between practices and patients' gender and educational level as well as a significant relationship between independence level and age, gender, and age of patients with leprosy. Additionally, a significant relationship between their knowledge and educational attainment was found, with a p-value of 0.05.

**Table (1) Percentage distribution of study sample according to their knowledge about self-care of leprosy throughout the program phases (n = 85).**

Items	Pre-program		Post-program		Follow up	
	Satisfactory	unsatisfactory	Satisfactory	unsatisfactory	Satisfactory	unsatisfactory
	%	%	%	%	%	%
Meaning of leprosy	40.0	60.0	92.9	7.1	94.1	5.9
Causative agent	38.8	61.2	94.1	5.9	90.6	9.4
Mode of transmission	7.1	92.9	91.8	8.2	88.2	11.8
incubation period	17.6	82.4	87.1	10.6	85.9	14.1
Symptoms of leprosy	23.5	76.5	92.9	7.1	91.8	8.2
Complications	12.9	87.1	71.8	28.2	69.4	30.6
Treatment	5.9	94.1	90.6	9.4	87.1	12.9
Preventive measures of leprosy	11.8	88.2	94.1	5.9	89.4	10.6

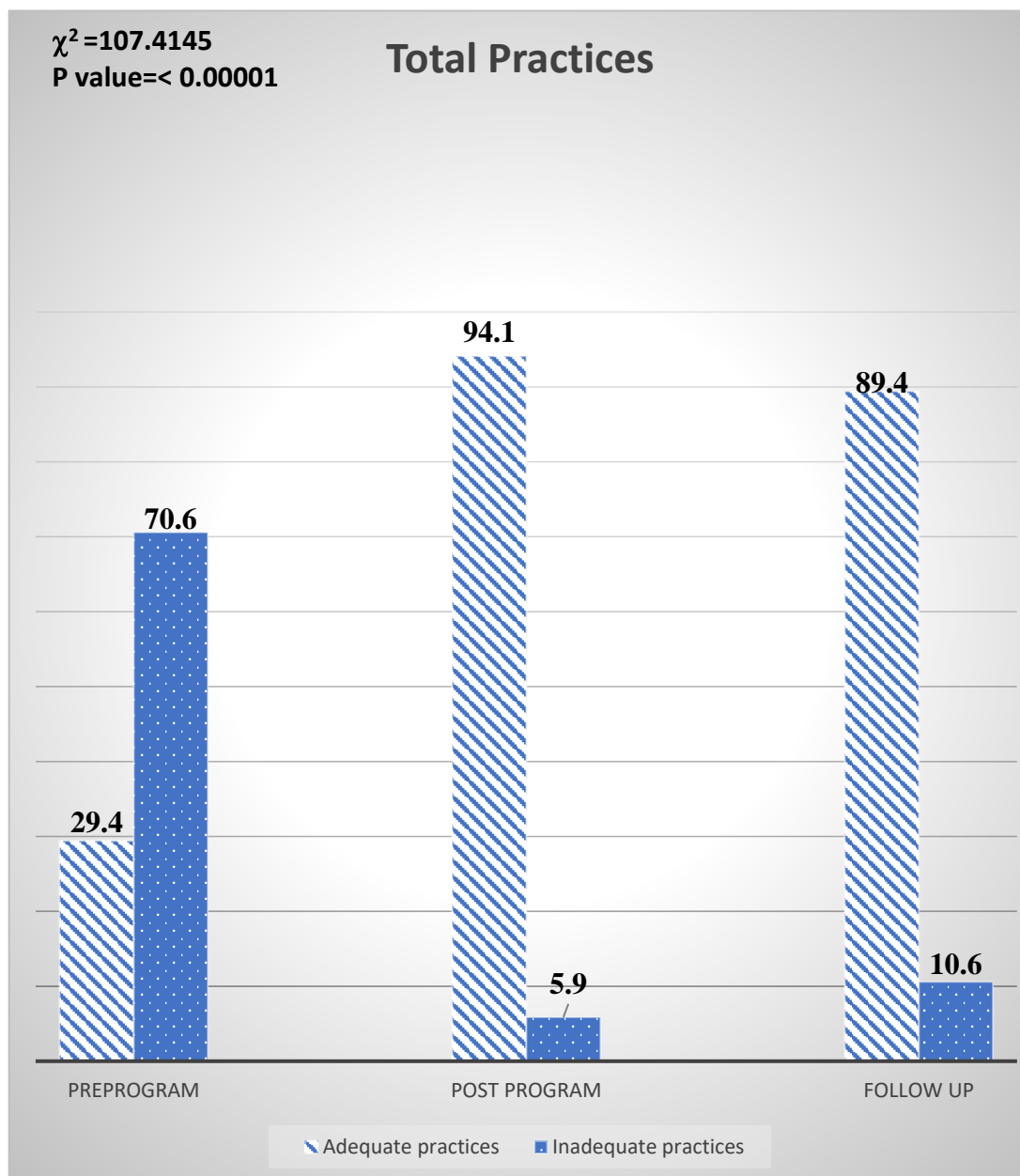
**Figure (1): Distribution of patients' total knowledge regarding leprosy diseases. (n=200)**



**Table (2) Percentage distribution of study sample according to their practices about self-care of leprosy throughout the program phases (n = 85).**

Items	Pre-program		Post-program		Follow up	
	Adequate	Inadequate	Adequate	Inadequate	Adequate	Inadequate
	%	%	%	%	%	%
Care of skin ulcer	22.4	77.6	89.4	10.6	85.9	14.1
Wound dressing	21.2	78.8	88.2	11.8	85.9	14.1
Care of prostheses	29.4	70.6	92.9	7.1	81.2	18.8
Administer of prescribed medications	20.0	80.0	85.9	14.1	80.0	20.0
Medical follow up	37.6	62.4	83.5	16.5	78.8	21.2
Appropriate nutrition.	48.2	51.8	81.2	18.8	82.4	17.6

**Figure (2): Distribution of patients' total practices about care of leprosy diseases. (n=200)**



**Table (3): Distribution of patients with Leprosy according to physical, psychological, and social health problems through preprogram and follow up phase (n=83).**

Health problems	Preprogram		Follow up	
	NO	%	NO	%
<b>Physical health problems</b>				
1. Optic problems	56	65.9	56	65.9
2. Nasal problems	47	55.3	39	45.9
3. Loss of sensation	35	41.2	34	40.0
4. Ulcerous Condition	53	62.4	34	40.0
5. Skin patches	85	100.0	73	85.9
6. Upper limbs (hands),	64	75.3	64	75.3
7. Lower limbs (Feet).	39	45.9	39	45.9
<b>Psychological health problems</b>				
8. Feel of sadness	71	83.5	34	40.0
9. Feel of depression	47	55.3	25	29.4
10. Fear, and anger,	23	27.1	12	14.1
11. Feel a lack of self-acceptance,	34	40.0	16	18.8
12. Unsatisfied of body image,	67	78.8	24	28.2
13. Suffering of negative emotions, (suicide trying).	6	7.1	2	2.4
<b>Social Health problems</b>				
14. Social stigma	76	89.4	39	45.9
15. Social discrimination	47	55.3	47	55.3
16. Social isolation	35	41.2	23	27.1
17. Lack of community services,	79	92.9	75	88.2
18. Avoid visiting relatives	34	40.0	15	17.6
19. Negative effect on marital relationship	14	16.5	8	9.4

**Table (4) the relation between total knowledge of patients with leprosy and their level of practices, independence level and health problems preprogram implementation and follow up phase (n = 85).**

Items	Pre-program		Follow up		$\chi^2$	P value
	Satisfactor y knowledge	Unsatisfactor y knowledge	Satisfactor y knowledge	Unsatisfactor y knowledge		
	No/%	No/%	No/%	No/%		
<b>Total practices preprogram</b>					94.039	< 0.0001
Adequate	15/ 17.6	10/ 11.7	69/ 81.1	7/ 8.2		
Inadequate	5/ 5.8	55/ 64.7	3/ 3.5	6/ 7.0		
<b>Independence level</b>					21.668	.0013*
Dependent	5/ 5.8	26/ 30.5	25/ 29.4	2/ 2.3		
Slightly dependent	7/ 8.2	37/ 43.5	38/ 44.7	5/ 5.8		
Independent	8/ 9.4	2/ 2.3	11/ 12.9	4/ 4.7		
<b>Health Problems</b>						
Physical health problems	15/ 17.6	42/ 49.4	44/ 51.7	8/ 9.4	1.3569	.7156
Psychologica l health problems	13/ 15.3	46/ 54.1	28/ 32.9	7/ 8.2	14.909	.0018*
Social health problems	16/ 18.8	47/ 55.3	40/ 47.0	5/ 5.8	10.005	.0185*

**Table (5) The differences between independence level/ health problems of patients with leprosy preprogram implementation and follow up phase (n = 85).**

Items	Pre-program		Follow up		$\chi^2$	P value
	No	%	No	%		
<b>Independence level</b>						
Dependent	31	36.5	27	31.8	1.2874	.5253
Slightly dependent	44	51.8	43	50.6		
Independent	10	11.8	15	17.6		
<b>Health Problems</b>						
Physical health problems	57	67.1	52	61.2	0.6392	.4240
Psychological health problems	59	69.4	35	41.2	13.706	.0002**
Social health problems	63	74.1	45	52.9	8.2258	.0041*

**Table (6): The relation between satisfactory knowledge/ adequate practices and age, gender, and educational level of patients with leprosy (n=83).**

Item	Total		Knowledge		Practices		Independence level		
	No	%	Satisfactor y	Unsatisfactor y	Adequat e	Inadequat e	Dependen t	Slightly dependen t	Independen t
<b>Age</b>									
25 <35 years	33	38.8	4/ 4.7	29/ 34.1	7/ 8.2	26/ 30.5	5/ 5.8	26/ 30.5	2/ 2.3
35 <45 year	22	25.9	6/ 7.0	16/ 18.8	8/ 9.4	14/ 16.4	9/ 10.5	10/ 11.7	3/ 3.5
45 ≤ 60 year	30	35.3	10/ 11.7	20/ 23.5	10/ 11.7	20/ 23.5	17/ 20.0	8/ 9.4	5/ 5.8
<b>Chi-square test</b>	$\chi^2$ P value		4.1608 .1248		1.803 .405954		17.6526 .001443		
<b>Gender</b>									
Male	60	70.6	15/17.6	45/ 52.9	8/ 9.4	53/ 62.3	15/ 17.6	41/ 48.2	4/ 4.7
Females	25	29.4	5/ 5.8	20/ 23.5	17/ 20.0	8/ 9.4	16/ 18.8	3/ 3.5	6/ 7.0
<b>Chi-square test</b>	$\chi^2$ P value		0.2452. .620481		25.4018 < .00001		22.6849 000012		
<b>Educational level:</b>									
Read and write Basic education	29	34.1	2/ 2.3	27/ 31.7	4/ 4.7	25/ 29.4	4/ 4.7	23/ 27.0	2/ 2.3
Secondary education	31	36.5	3/ 3.5	28/ 32.9	5/ 5.8	26/ 30.5	10/ 11.7	18/ 21.1	3/ 3.5
University	22	25.9	13/ 15.3	9/ 10.5	14/ 16.4	8/ 9.4	16/ 18.8	2/ 2.3	4/ 4.7
University	3	3.5	2/ 2.3	1/ 1.1	2/ 2.3	1/ 1.1	1/ 1.1	1/ 1.1	1/ 1.1
<b>Chi-square test</b>	$\chi^2$ P value		26.3297 < 0.00001		20.4596 000136		27.258 .00013		



**Discussion:**

*Mycobacterium leprae* is the chronic infectious disease that causes leprosy, also known as Hansen's disease, which damages the eyes, skin, and peripheral nerves. <sup>(24)</sup> Additionally, without initial therapy, patients will experience some physical limitations that can be categorized as grade I when accompanied by a loss of sensitivity and grade 2 when abnormalities are present. This emphasizes how crucial health professionals are to the treatment and advertece of disability. <sup>(25)</sup>

So, the current study enhanced self-care program for patients with leprosy grade 2 in Abu Zaabal Leprosy Colony and the study hypothesis was that this program will improve patients' knowledge and practices related to leprosy, which will have a positive impact on restoring their health and improving their level of independence.

The current study conducted on eighty-five patients diagnosed with leprosy G2Ds their age ranged from 25: 60 years and less than three quarters of them were males while the rest of sample were females, while more than one third of them had basic education.

The study results demonstrated that one third of patients their aged ranged from 45 to 60 years and three quarters were male, this finding agreed with Kong et al., <sup>(26)</sup> who found that the average age of the participants was  $55.3 \pm 7.1$  years, most were more than 40 years old. While disagreement with Zheng et al., <sup>(27)</sup> who found that the incidence of leprosy was equally in male and females.

From the researchers' point of view, this sample was characterized by low socioeconomic status, which was evidenced through the results of the study on social demographic characteristics, which proved that more than a third of them received basic education, while more than half of them worked as farmers and a quarter of the sample had no work. It also became clear that most of the study sample did not have a sufficient monthly income, besides marriage and the majority of them lived in crowded housing which led to non-compliance with the treatment of leprosy and adequate health care, which consequently led to the development of symptoms and complications to reach an advanced stage of the disease to reach the second grade.

These findings are in line with those of Pescarini <sup>(10)</sup>, who noted that none of the studies in their systematic review were conducted in low-income nations and that the majority of them were carried out in Brazil, India, or Bangladesh. Increased age, worse sanitary and socioeconomic conditions, a lower level of education, and food insecurity are risk factors for leprosy, according to descriptive synthesis. Leprosy was additionally linked to being a man in pooled estimates.

Regarding the level of knowledge about leprosy, the current study presented that more than three quarters of patients had unsatisfactory knowledge about symptoms of leprosy. These findings concur with those of Ventin et al. <sup>(28)</sup>, who conducted a qualitative study on 24 leprosy patients in Pernambuco reference units for Hansen's disease and noted that the majority of interviewees had some level of handicap based on the data. This may have occurred as a result of a delayed diagnosis brought on by a lack of public awareness of Hansen's disease symptoms. On the other hand, Raju <sup>(29)</sup> disagrees with this finding, claiming that the study participants knew a lot about leprosy.

Also, the study result presented that most of study sample had unsatisfactory knowledge about mode of transmission these results agree with Ventin et al., <sup>(28)</sup>, who reported that, the knowledge about the problems with Hansen's disease is also very restricted regarding its signs and symptoms. In addition to, the aspects related to the types of transmission and treatment of the disease are still not well clarified.

This study showed that regarding to the practices about self-care of leprosy there are more than three quarters of patients had inadequate practices level about care of skin ulcer and wound dressing, before program intervention and enhanced to adequate level post and follow up the program implementation. Which is consistent with Cavalcante et al <sup>(30)</sup>. 's report that self-care practices enabled improved interaction in delivering information and encouragement for self-care through follow-up and educational interventions. Given the improvements in the nasal septum (no dryness), lack of alterations in the hands and feet (cracks, sores, or fissures), hydrated, well-groomed upper and lower limbs, and non-evolution to the degree of handicap, it can be said that educational interventions were crucial in this regard (Grade 2).

The current study explained that the majority of study sample suffered from social stigma and unsatisfied body image. Which agree with Oliveira et al., <sup>(31)</sup> Researchers stated that, in their study, patients with Hansen's disease did not adhere to self-care for a variety of reasons, including the disruption of their body image and the stigma associated with social portrayals of their "leprosy," disabled, and deformed bodies.

Findings proved that there was a statistically significant relation between total knowledge of patients with leprosy and their level of independency, but this result was disagreed with Garbin et al., <sup>(32)</sup> who found that the majority of leprosy clients can still conduct their daily routine activities normally. Based on interviews with several leprosy clients, revealed that patients can still conduct daily activities and even do work that they do routinely to make ends meet.

From point of our view, it can be said that leprosy does not interfere with the patients' activities and independence in their daily lives, but what needs to be underlined is that it

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also depends on the severity or level of disability of leprosy and their level of knowledge and effective practices to perform their self-care.

The study revealed that there was statistically significant difference between psychological health problems and social health problems of patients with leprosy preprogram implementation and follow up phase with  $p\text{-value} = < 0.05$ . And this evidenced by Pinheiro,<sup>(33)</sup> who said that this result becomes a threat to physical and psychological integrity and personal image, even more considering that disabilities can appear at any stage of the disease, requiring self-care as soon as possible.

The results of this study concurred with those of a study by Brakel, et al. (34), "Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma, and discrimination," which discovered that patients' work-related disruptions cause both monetary losses and psychological harm. Accordingly, the research "Health Related Quality of Life in Egyptian Leprosy" by El-Rezaei et al., (35), is also in agreement. Patients said that discomfort made it difficult for them to fulfill their everyday tasks and professional responsibilities and hindered their capacity to socialize. They also suggested a connection between pain and stress, depression, and restless nights.

Findings proved that there was statistically significant relation between independence level and age, gender, and educational level of patients with leprosy as well as a significant relation between practices and their gender /educational level. Also, there was a significant relation between knowledge and educational level of them with  $p\text{-value} = < 0.05$ .

These findings are consistent with those made by Girma et al. (36) who claimed that inadequate understanding and perception of the condition can affect the efficacy of self-care practices. In this study, the researchers discovered a correlation between poor self-care behavior and older age, female sex, marital status, lower educational attainment, lower income, and fewer media access.

Scientific studies have reported that educated leprosy patients have good leprosy knowledge and leprosy self-care practice compared to uneducated patients.<sup>(37)</sup>

Hence, leprosy education and self-care programs may need adult literacy programs, combined with more innovative focused approaches to suit various target population that can impact knowledge, and self-care practice better.<sup>(38)</sup>

## **Conclusion**

The study proved that the research hypothesis has been achieved as the self-care program helped most patients with leprosy grad 2 disabilities to increase their knowledge

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about leprosy, the causative agent, incubation period, mode of transmission and preventive measures. As well as practices about care of skin ulcer, wound dressing, care of prostheses of affected patients. This improvement also led to the disappearance of skin patches and ulcers for more than half of the patients, which resulted in an improvement in their social status for them in addition to no feeling of stigma and social isolation anymore. Also, the study demonstrated a significant improvement in the independence level of regarding the daily living activities through the follow-up phase.

### **Recommendations**

The results of this study recommended that:

- Publication and dissemination of self-care programs in all leprosy colonies and any health care services to raise awareness about leprosy and its prevention.
- Further studies should explore more about the psychological and societal aspects of patients with leprosy in Egypt.
- More research in future to help in overcoming some of the existing limitations in this study such as analyzing of the activities performed by the health professionals to offer guidance to the patients and find what are the challenges they face.

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## الملخص العربي

### برنامج الرعاية الذاتية لمرضى الجذام من الدرجة الثانية في مستعمرة أبو زعبل للجذام

يعتبر الجذام ، أو مرض هانسن ، مرض معدي مزمن تسببه المتفطرة الجذامية كما يعتبر مشكلة صحية كبيرة على مستوى العالم وخاصة في مصر. وقد هدفت هذه الدراسة إلى تقييم أثر برنامج الرعاية الصحية الذاتية لمرضى الجذام والتي طبقت في مستعمرة أبو زعبل للجذام. وقد أتبع تصميم دراسة شبه تجريبية. وتم اختيار عينة هادفة مكونة من 85 مريضاً تتراوح أعمارهم بين 25 الي 60 سنة، قد سبق تشخيصهم بالجذام وهم من الفئة الثانية في مرحلة الأعاقة. وقد أجريت هذه الدراسة في مستعمرة أبو زعبل للجذام حيث تقدم الخدمات الطبية والتمريضية لتلك الفئة من كل أنحاء محافظة القاهرة وضواحيها.

وتكونت أدوات البحث من أداتين. الأداة الأولى: ورقة استبيان لإجراء المقابلات لتقييم الخصائص الاجتماعية الديموغرافية للمرضى ، ومعرفتهم ، وممارساتهم ، ومشاكلهم الصحية. اما الأداة الثانية: فهي قائمة الملاحظة، لتقييم مستوى استقلالية المريض في أنشطة الحياة اليومية.

وقد أسفرت نتائج الدراسة عنالآتي: أن 76.5% من المرضى الذين خضعوا للدراسة ليس لديهم معرفة كافية بمرض الجذام قبل تنفيذ البرنامج وتحسنوا إلى 92.9% بعد البرنامج و84.7% خلال المتابعة وكذلك كانتلممارساتهم تجاه العناية بالجروح والقروح وكل مضاعفات المرض غير كافية قبل البرنامج وتعززت لـ 94.1% بعده. و 89.4% خلال المتابعة مما اسفر عن وجودعلاقة ذات دلالة إحصائية بين معارف وممارسات المرضى ومستوى استقلاليتهم ، والمشكلات الصحية والاجتماعية والنفسية ، وكذلك العمر والجنس والمستوى التعليمي لدي المرضى المشاركين بالدراسة خلال مراحل تنفيذ البرنامج ( $P < .0001$ ).

وتلخصت نتائج الدراسة في أنه قد أدى برنامج الرعاية الذاتية إلى تحسين معرفة المرضى وممارساتهم المتعلقة بالجذام ، مما أثر بشكل إيجابي على استعادة صحتهم الجسمانية والنفسية والاجتماعية وتحسين مستوى استقلاليتهم. كما أوصت الدراسة بنشر برنامج الرعاية الذاتية في جميع مستعمرات الجذام وأي خدمات رعاية صحية أخرى معنية بمرضى الجذام للتوعية بالمرض والوقاية منه.