

# Comparative Study for Pattern of Social Support among Systemic Lupus Erythematosus Patients' at Out-patient Clinics, Assiut University Hospital

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**Abstract** People with Systemic Lupus Erythematosus need for social support more than others due to Systemic Lupus Erythematosus' often caused severe and unpredictable symptoms; also can be affected multiple system. **The study aimed** to determine the pattern of Social support among Systemic Lupus Erythematosus patients; also to identify the risk factors among Systemic Lupus Erythematosus patients at out-patient clinics, Assiut university hospital. **Patients and methods:** The study was conducted in Rheumatology clinic at Assiut university hospital. The total sample size was (104); total coverage technique used in this study. **Tools:** Two tools were used, first tool: A structured interview questionnaire sheet which included two parts; demographic data and questions regarding risk factors and the second tool; it included Social Support Assessment scale. **Results:** more than half (55.8%) of patients had high level of social support after disease compared to 39.4% of them had moderate and high level of social support before disease also, Sunlight exposure was the most risk factors among Systemic Lupus Erythematosus patients. **Conclusion:** there was statistically significant differences between total score of social support before and after disease (P value=0.001\*). **Recommendation:** Health education about rheumatologic services for community to early detection, diagnosis and treatment.

**Keywords:** Pattern- Social support, Systemic Lupus Erythematosus

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## 1. Introduction

Systemic lupus Erythematosus (SLE) is one of several chronic conditions that may result in long-term disability. It is more common than other disorders, such as leukemia, multiple sclerosis, cystic fibrosis, and muscular dystrophy. SLE affected all people but it is more common in young or middle aged. It is also more common in black and Asian people than in white people. It affects mostly women, with an incidence about nine times higher than in men [1,2].

SLE referred to a chronic inflammatory autoimmune disorder of the connective tissue, primarily affecting the skin, joints, blood, and kidneys. In this disorder, antibodies are formed within the body that attack healthy body systems, causing inflammation and structural changes. Normally the body's immune system helps protect against infection but in SLE, the immune system does not work well and creates auto antibodies that spell

healthy cells and tissue. The word lupus means "wolf" in Latin, while erythematosus means "redness." The disease is named for the representative red rash that seems on the face and is look like a wolf's face [1].

The strict cause of SLE remains a unknown, but possible causes may be interrelated and include immunologic dysfunction, genetic factors, hormones, and environmental influences as ultraviolet light exposure, and infections, Also; Some drugs are known to cause a variant of lupus, known as drug-induced lupus these include sulphur-containing drugs, tetracycline and non-steroidal anti-inflammatory drugs [2].

People with SLE have symptoms that can range from mild to severe, and may come and go over time. Also; Symptoms can vary widely from one patient to another or within a given patient over the course of disease [3]. SLE manifestations include varying symptom features that comprise renal, dermatologic, neurological, and hematological involvement [4]. The most common symptoms include; Severe tiredness/fatigue, weight loss, fevers, skin changes (including a red 'butterfly' rash across the cheeks and

nose, or other exposed areas and scaly rashes that can appear on areas not exposed to sunlight), Painful, stiff or swollen joints (arthritis), poor circulation in the fingers and toes which causes them to become pale (Raynaud's). Lupus can cause periods of illness ('flares') and periods of feeling comparatively well with no/fewer symptoms or signs of disease ('remission'). It is not infectious and cannot be caught from another person [5,6].

There is no single investigation for SLE. The diagnosis is usually depending on symptoms and a number of special blood tests which measure auto antibodies and levels of inflammation. There are numerous types of drugs available in management of symptoms. These drugs include nonsteroidal anti-inflammatory drugs, corticosteroids, antimalarials, biologics, and immunosuppressives drugs [5].

SLE may influence family life, work, sexual & social activities, finances, and day-to-day living. Being diagnosed with a chronic illness may result in a wide range of reactions, including anxiety, fear, shock, denial, negative self-esteem and body image, and self-blame. Feelings of isolation, grief, stress, guilt, anger, loss of control, decreased confidence, depression, hopelessness or helplessness, irritability, and suicidal ideations are also common in those with a chronic illness such as lupus [7].

Social support can have a positive impact on physical and psychosocial well-being of SLE patients. Also; the absence of social support can be cause deterioration of physical and mental health among the individuals. Social support defines as "interactions with family members, friends, peers, and health professionals that communicate information, esteem, practical aid, or emotional help". Social support may improve coping and that these interactions helped to promote health and decrease stressors. It is can be gained from various sources, including a spouse, other family members, friends, neighbors and community members [8,9,10].

Nurses have a significant role in supporting SEL patients'. The role of the nurse covers a wide range, including education, guidance and support. It is enables the people to gain health knowledge and influence their lifestyle and attitude [11]. Nurses offering advice about the use of sun protection, a balanced diet, smoking cessation, adequate exercise and rest, and the use of heat or cold therapy (depending on joint symptoms) to manage disease activity [12].

### 1.1. Significant of Disease

SLE is an autoimmune disorder associated with significant mortality and morbidity. It is currently estimated that 10% to 15% of those diagnosed with lupus were die as a result of the disease [13]. According to the Centers for Disease Control and Prevention, lupus was identified as the underlying cause of death for an average of 1,034 deaths annually from 2010 to 2014 [14].

It is prevalent worldwide but the proportion of patients with SLE varies between different ethnic groups; there are an estimated 1.5 million people in United State living with SLE [15]. In study conducted at Egypt, Assiut by Goma et al., [16] who found that SLE represents 14.3% (182 out of 939) patients among Rheumatic patients at Assiut Hospital.

Social support is considering one of the greatest factors in improving the physical health and well-being of

everyone, from childhood to elderly. Previous studies reported that the presence of social support significantly influence the individual's ability to cope with any disease. It is helping them to forget the negative aspects and contemplate positively about their lives. Not only does social support help improve a person's well-being but also; affects the immune system as well; therefore, the objective of this study was to determine pattern of social support among Patients with SLE.

### 1.2. Aim of Study

- To determine the pattern of Social support among Systemic Lupus Erythematosus patients.
- To identify the risk factors among Systemic Lupus Erythematosus patients.

### 1.3. Research questions

- Is there a difference between social support before and after diseases?
- What is the most common risk factor for SLE?

## 2. Patients and Methods

### 2.1. Research Design

Descriptive cross sectional research design was used in this study.

### 2.2. Setting

The study was conducted in Rheumatology clinic at Assiut university hospital; this clinic serves patients from all areas at Assiut Governorate and it is work a day/week for Systemic Lupus Erythematosus patients.

### 2.3. Sampling

Purposive sample of (104) adult patients male and female, their age ranged from 18 to more than 30 years diagnosed with SLE and agree to participate in the study. Total coverage technique used in this study

### 2.4. Tools of Data Collection

#### Tool I:- A structured interview questionnaire sheet

It was based on review of pertinent literature to elicit information from the patients; it included two parts.

- *Part one: demographic data;* sex, age, residence, level of education, occupation, marital status, and duration of disease.
- *Part two: questions regarding risk factors;* it included sunlight exposure, smoking, family history & degree of relation, exposure to any infection, vitamin D deficiency and drugs that causes disease.

#### Tool II:- Social Support Assessment scale;

This scale measured by multidimensional scale of perceived social support (MSPSS) Developed by Zimet et al., [17]. It consisted of 12 items to measure perceived adequacy of social support from family, friends and

significant other. Responses are scored on 7 point ranging from (1) very strongly disagree to (7) very strongly agree.

The scale was translated into Arabic language and checked for its content validity According the opinions of jury, the scale responses categories were modified to be formed into 5 point format ranging from (1) strongly disagree to (5) strongly agree by Abd-Elzahar, [18].

The scoring system calculated by: strongly disagree (1), disagree (2), Neutral (3), agree (4), and strongly agree (5); the total score is ranged from 5-60. Low acuity=12-28, Moderate acuity =29-44 and High acuity =45-60.

**Reliability of the tool:** reliability was assessed by using cronbach's test to measure internal consistency; it was  $r=0.871$ .

## 2.5. Methodology

### I-Preparatory phase and administrative design

- An official approval letter was obtained from the Dean of Faculty of Nursing, Assiut University to the director of outpatient clinic at Main Assiut university hospital. This letter includes a permission to conduct the study and explain the aim and nature of the study.

- **Pilot study**

A pilot study was conducted before starting data collection on 10 patients in the selected setting to evaluate the applicability and clarity of the tool and estimate the time required to fill the sheet. Some modifications were done to the tool, so these patients were excluded from the study sample.

### II-Data Collection:

#### Ethical Consideration:

The research proposal was approved from ethical committee in the Faculty of Nursing at Assiut University. There was no risk for study subject during application of research, the study followed the common ethical principles in clinical research, oral consent was obtained from the patients after explaining the nature and purpose of the study, confidentiality and anonymity was assured and study patients have the right to refuse to participate or withdraw from the study.

#### Field Work:

The researchers met with the patients in the Rheumatology clinic at Assiut university hospital, explained the purpose and nature of the study, and asked for participation. The researchers started a face to face individual's interview with patients. Each interview took about 20-30 minutes. About (3 to 4) sheets were finished (one day/week). Data was collected in the period from the first of October 2017 until the end of March 2018.

## 2.6. Statistical Analysis

Date entry and data analysis were done using SPSS version 19 (Statistical Package for Social Science). Data were presented as number, percentage, mean, standard deviation. Chi-square test was used to compare between qualitative variables. Wilcoxon Signed Rank Test was done to compare quantitative variables between before and after disease. P-value considered statistically significant when  $P < 0.05$ .

## 3. Results

**Table 1:** Illustrates that the majority of patients (91.3%) were female and 42.3% of them aged up to 30 years. As regards residence the table clears that 75% of patients were from rural area and the highest percentage of the patients (49.0%) had secondary level of education. Also; 60.6% & 55.8% were married and housewife respectively.

**Figure 1:** Clarifies that 45.2% of patients had disease up to 2 years compared to only (16.3%) of them had disease from 6 months to less than one year.

**Table 2:** Shows that 55.8% followed by 25.0% of patients exposed to sunlight and passive smoking respectively; while only (8.7%) of them had family history of disease and vitamin D deficiency and only (4.8%) were exposed to infection.

**Table 3:** Reveals that there was statistically significant differences in items of social support related to family, friends and significant other before and after disease whereas found that mean score increased after disease..

**Table 4:** Shows that there was statistically significant differences between total score of social support before and after disease ( $P$  value=0.001\*) with mean  $\pm$  SD 40.50  $\pm$  12.52 and 46.21  $\pm$  12.36 respectively.

**Figure 2:** Presents 55.8% of patients had high level of social support after disease compared to 39.4% of them had moderate and high level of social support before disease. Also there was statistically significant differences between social support before and after disease ( $P$  value=0.002\*).

**Table 1. Distribution of demographic characteristics among Systemic Lupus Erythematosus patients' at out-patient clinics, Assiut university hospital**

Demographic characteristics	No. (n= 104)	%
<b>Sex:</b>		
Male	9	8.7
Female	95	91.3
<b>Age: (years)</b>		
< 25	35	33.7
25-30	25	24.0
> 30	44	42.3
Mean $\pm$ SD (Range)	28.83 $\pm$ 8.82 (15.0 - 57.0)	
<b>Residence:</b>		
Rural	78	75.0
Urban	26	25.0
<b>Level of education:</b>		
Illiterate	12	11.5
Basic education	36	34.6
Secondary	51	49.0
University	5	4.8
<b>Occupation:</b>		
Employee	20	19.2
Skilled worker	11	10.6
Housewife	58	55.8
Not working	15	14.4
<b>Marital status:</b>		
Single	39	37.5
Married	63	60.6
Divorce	2	1.9

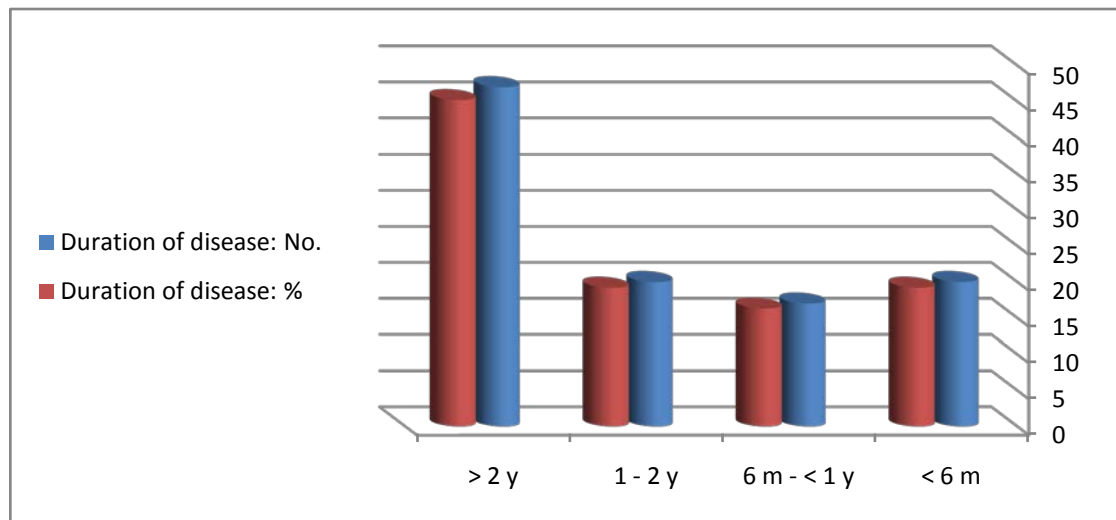


Figure 1. Duration of disease among Systemic Lupus Erythematosus patients' at out-patient clinics, Assiut university hospital, No. (104)

Table 2. Distribution of risk factors among Systemic Lupus Erythematosus patients' at out-patient clinics, Assiut university hospital

Risk factors	No. (n= 104)	%
<b>Sunlight exposure:</b>		
Yes	58	55.8
No	46	44.2
<b>Smoking (active or passive)</b>		
Yes	26	25.0
No	78	75.0
<b>Family history:</b>		
Yes	9	8.7
No	95	91.3
<b>Degree of relation (no. 9):</b>		
First degree	5	55.6
Second degree	4	44.4
<b>Exposure of any type of infection:</b>		
Yes	5	4.8
No	99	95.2
<b>Vitamin D deficiency:</b>		
Yes	9	8.7
No	95	91.3

Notes: There wasn't any patient had history of taking drugs that consider risk factors of disease.

Table 3. Social support among Systemic Lupus Erythematosus patients' at out-patient clinics, Assiut university hospital, No. (104)

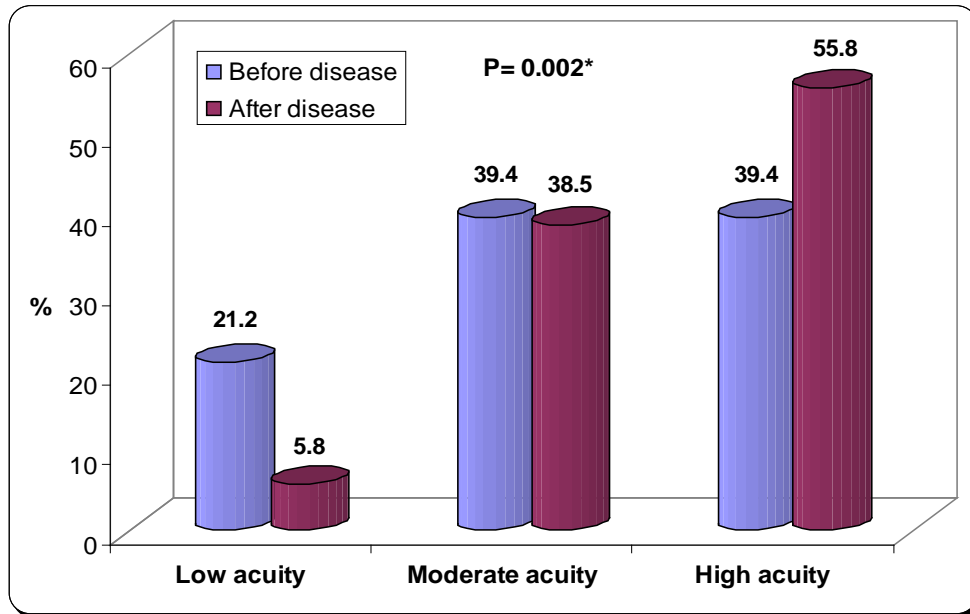
Social support	Before disease	After disease	P-value
	Mean $\pm$ SD	Mean $\pm$ SD	
There is a special person who is around when I am in need.	3.58 $\pm$ 1.38	4.05 $\pm$ 1.19	0.004*
There is a special person with whom I can share my joys and sorrows.	3.56 $\pm$ 1.36	4.09 $\pm$ 1.14	0.000*
My family really tries to help me.	3.49 $\pm$ 1.37	4.11 $\pm$ 1.12	0.000*
I get the emotional help and support I need from my family.	3.64 $\pm$ 1.29	4.18 $\pm$ 1.04	0.000*
I have a special person who is a real source of comfort to me.	3.45 $\pm$ 1.50	4.02 $\pm$ 1.22	0.000*
My friends really try to help me.	2.98 $\pm$ 1.56	3.28 $\pm$ 1.62	0.072
I can count on my friends when things go wrong.	2.96 $\pm$ 1.54	3.30 $\pm$ 1.61	0.013*
I can talk about my problems with my family.	3.60 $\pm$ 1.33	4.11 $\pm$ 1.06	0.000*
I have friends with whom I can share my joys and sorrows.	2.91 $\pm$ 1.51	3.37 $\pm$ 1.57	0.001*
There is a special person in my life who cares about my feelings.	3.70 $\pm$ 1.28	4.12 $\pm$ 1.12	0.003*
My family is willing to help me make decisions.	3.62 $\pm$ 1.28	4.16 $\pm$ 1.00	0.000*
I can talk about my problems with my friends.	3.01 $\pm$ 1.51	3.43 $\pm$ 1.56	0.001*

Wilcoxon Signed Ranks Test, \* Statistical significant difference (P < 0.05).

**Table 4.** Mean score of social support scale before and after disease among Systemic Lupus Erythematosus patients' at out-patient clinics, Assiut university hospital, No. (104)

Social support scale	Before disease	After disease	P-value
Mean $\pm$ SD	40.50 $\pm$ 12.52	46.21 $\pm$ 12.36	0.001*
Range	18.0 – 60.0	18.0 – 60.0	

Wilcoxon Signed Ranks Test, \* Statistical significant difference ( $P < 0.05$ ).

**Figure 2.** Relation between social support before and after disease among Systemic Lupus Erythematosus patients' at out-patient clinics, Assiut university hospital, No. (104) (Chi-square test , \* Statistical significant difference ( $P < 0.05$ ))

## 4. Discussion

SLE is a disease that includes a broad spectrum of clinical, immunological manifestations and affected multiple systems. The findings of previous studies highlight the complexity of support within and across individuals. Social support is considered a modifiable factor that can influence health appraisals and well-being [19,20].

The present study found that the majority of patients were female; this result agrees with Zheng et al, [21] & Drenkard et al, [22] who reported that the majority of patients were female, Also; this finding supported by Crosslin & Wiginton, [23] and Schwartzman-Morris *et al.*, [24] who stated that "SLE is a disease that overwhelmingly affects women, with a ratio of approximately nine women for every one man". These differences attributed to differences in sex hormones, biological features, societal gender norms, parental influence or other factors.

In study conducted by Sliem et al., [25] who found that the mean age of studied sample was  $28.6 \pm 6.6$  and age ranged from 16 to 42 years these result similar to the current study which showed that mean age of patients were  $28.83 \pm 8.82$  with range (15.0 - 57.0) while disagrees with Morales et al, [26] who found that mean age of sample were  $40.3 \pm 11$  (19.0 - 73.0).

**According to level of education;** nearly half of patients had secondary level. This finding not in line with Gooden, [27] who mentioned that nearly half had university education.

**As regards to occupation;** more than half of patients were housewife; this result in the same line with Gooden, [27] who mentioned that about two thirds of patients were housewife.

**In regard to marital status** the current study indicated that about three fifths of patients were married, this result agrees with Morrison, [20] who mention that about three fifths of sample was married. On the other hand this result incompatible with study carried by Drenkard et al, [22] who found that about one third of the sample were married..

**As regard to disease duration** the present study observed that more than two fifths of patients had disease up to two years; this result consistent with Sliem et al., [25] and Morales et al, [26] who found that The mean disease duration was  $5.6 \pm 3.4$  years and  $8.8 \pm 6.4$  years respectively.

Johns Hopkins Lupus Center [28] reported that nearly half of patients with Systematic Cutaneous Lupus Erythematosus also have SLE. This condition is often induced by ultraviolet light exposure, this finding supported the result of the present study which found that more than half of the participant exposed to sunlight.

**The findings of present study** found that one quarter of patients had exposed to smoking either active or passive. This may be attributed to SLE is autoimmune disease; the smoking is considering from the most factors can be affected on the immune system and causes the disease. Also this finding supported by Sison, [29] who stated that Cigarette smoke is greatest significant source of environmental exposure to toxic chemicals and reactive molecular species, so it is a risk factor for increasing morbidity.

**In referral to family history;** the present study found that 8.7% of patients had family history of disease this finding congruence with study carried by Sullivan, [15] who reported that 6.6% of sample had family history of disease.



**The current study showed that** only (8.7%) of patients had vitamin D deficiency this finding compatible with finding of Bonakdar et al, [30] who found that relationship between vitamin D deficiency and systemic lupus erythematosus.

**The current study revealed that** there was statistically significant differences in items of social support related to family, friends and significant other before and after disease whereas found that mean score increased after disease. These changes in family role may be attributed to their emotions toward relatives with disease whereas the family contributes the patients in all stages of disease as diagnosis, treatment, any complications, etc. Also; norms and culture of society effect on personality and attitude of family relations.

These findings similar with study conducted by Williams et al, [19] who found that the majority of sample having social support from the family. In addition Brooks et al, [31] stated that the most common sources of social support were family members. These individuals may play a key role in integrated chronic care management because the family members are the first contact with patients. So, they are joining aspects of social support and interdisciplinary plans for care.

Also; this interpretation supported by study conducted by Vélez-Bermúdez, [6] who said that the patients reported sometimes in addition to their own self-care behaviors, requiring outside assistance to help manage their condition, such as receiving the help from friends and family. Also; Patients who reported that friends and family helped them by allowing them to rest, making their work-load lighter, being available for emotional support, and validating their concerns.

**According to total score of social support before and after disease the present study indicated that** there was statistically significant differences between total score of social support before and after disease ; more than half of patients had high level of social support after disease compared to nearly two fifths of them had moderate and high level of social support before disease. Also; the finding of the current study cleared that the mean  $\pm$  SD of social support  $40.50 \pm 12.52$  and  $46.21 \pm 12.36$  respectively. These findings disagree with Morrison, [20] who stated that the total score of social support among studied sample after disease was  $31.81 \pm 8.86$ .

## 5. Conclusion

**The present study concluded that** more than half of patients had high level of social support after disease compared to nearly two fifths of them had moderate and high level of social support before disease; So there was statistically significant differences between total score of social support before and after disease.

## 6. Recommendation

- Health education about rheumatologic services for community to early detection, diagnosis and treatment.
- Health education programs for families who have patient with systematic lupus erythematosus to

provide them with appropriate support and advice about how to maintain wellbeing and active lives.

- Further studies should be conduct in the point of social support and affect of it on the health status.

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