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PERIOD PREVALENCE OF DEPRESSION, LEVELS OF DEPRESSION AND PERCEIVED ILLNESS STIGMA IN PATIENTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS

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Abstract: **Back ground:** *SLE being a chronic and systemic disease affects not only the physical well-being but also the psychological well-being. The patients felt stigmatized of their disfigurement, lack of socialization, impaired sexuality and poor body image by their friends, spouse and family members and developed a sense of isolation. Depression is commonly under diagnosed in patients with SLE.*

Objective: *To assess period prevalence of depression, levels of depression and perceived illness stigma among patients with SLE.*

Design: *Descriptive design.* **Methodology:** *The study was conducted in the selected rheumatology, medical wards and outpatient services of CMC, Vellore. 94 patients were selected using total enumeration sampling. Data was collected using self-administered questionnaires (BDI –II and SSCI).*

Results: *The period prevalence of depression was found to be 72.3%. Majority (33%) of them had severe depression, 24.5% had moderate depression and 14.9% had mild depression. 42.6% of the patients reported perceived illness stigma. There was a correlation between depression and perceived illness stigma (r= 0.568). There was a significant association between depression and marital status (p=0.033) and also it was shown that there was a significant association between frequency of hospitalization with depression (p=0.008) and perceived illness stigma (p= 0.012).* ***Conclusion***: *A formal assessment of depression and perceived illness stigma among these patients are very important for nurses in preventing under diagnosis and under recognition of psychological problems associated with SLE.*

Key words: *Depression, Period prevalence of depression, Perceived illness stigma, Systemic Lupus Erythematosus.*

Systemic Lupus Erythematosus (SLE) is a chronic multisystem inflammatory disorder that occurs when the body produces antibodies against its own cells. The resulting antigen and antibody complexes damage the connective tissues. It affects several organs like skin, joints, kidneys and serous membranes. SLE is an incurable and multi causal disease as well as a disease of exacerbations and remissions. Although the syndrome's origin is a mystery, increasing evidence suggests that immunologic, hormonal, genetic and possibly viral factors may contribute to its onset (Dubois, 2007).

The global distribution of SLE is relatively homogenous. The reported prevalence of SLE in the general population is 20 to 150 cases per 100,000. Due to improved detection of mild disease, the incidence nearly tripled in the 40 years of the 20th century. The prevalence of SLE in USA is 12.5 per 100,000 population. In Asia, the prevalence of SLE is 3 per 100,000 population. In India it is found to be 3.2 per 100,000 population (Pons-estel., 2010). In CMC, Vellore, 500 to 580 SLE patients visit the Rheumatology department per year, 68 to75 patients visit per month and 15 to 20 patients get admitted in the wards each month.

SLE is found to have a marked female predominance, with a 9:1 female to male ratio (Petri et al., 2008). The peak age at onset is between 20 and 30 years (Malaviya, and Sharma, 2005).

The mortality rate in SLE is found to be threefold higher than for the general population due to disease-related morbidity like cardiovascular disease, renal impairment, obesity, hypertension, and diabetes (Julian et al 2011); however, a study done by Mahmoud, 2013, shows that there is significant improvement in the survival rate over the last five decades, from 50% to 85%. It is also found that survivors of this chronic disease experience varied unpredicted physical symptoms owing to the chronicity as well as acute flare-ups of the disease along with the complications related to the treatment.

Patients with these unpredicted physical symptoms also found to experience a high degree of psychological symptoms like anxiety, depression, mood disorders, of which depression is an important and debilitating co-morbidity among patients with SLE (Ward et al., 2002).

There is a broad range of prevalence rates of depression in patients with SLE ranging from 17% to 75%. Evidence shows that clinically significant symptoms and lifetime incidence of major depressive disorder occur in approximately 50% of the patients with SLE (Nery et al., 2008).

SLE is also found to be affecting patient's self-esteem because of their disfigurement, lack of socialization, impaired sexuality and poor body image; hence patients feel stigmatized by their friends, spouse and other family members and develop a sense of isolation (Sultano, 2013).

RESEARCH DESIGN:

A descriptive study design was adopted to assess the period prevalence of depression, levels of depression and perceived illness stigma among patients with SLE.

SETTING OF THE STUDY:

The Christian Medical College, Vellore is a 2695 bedded multi-speciality, tertiary care teaching hospital. The study was conducted in the Clinical immunology and Rheumatology outpatient department, Lupus Vasculitis clinic, Rheumatology, general and private wards of Christian Medical College, Vellore.

The Out-patient services of these departments functions on every Monday and Thursday in the main building, the lupus vasculitis clinic on every Wednesday at 1pm to 5pm in Private Consultant Facility (PCF).

POPULATION:

The population chosen are all female patients who were diagnosed to have SLE.

SAMPLE:

All female patients diagnosed with SLE who either attended the clinical immunology and rheumatology OPD, vasculitis clinic, or those who are admitted in general medical and private wards under Rheumatology department, who fulfilled the inclusion criteria during the study period in Christian Medical College and Hospital, Vellore

SAMPLING TECHNIQUE

Total enumeration sampling technique was used.

SAMPLE SIZE:

The required sample size to find the prevalence of about 25% with 7.5% precision and 95% confidence interval was calculated to be 92 SLE patients. The sample size was calculated using the formula.

$n=4*p*q/d^2$

n = sample size,p = prevalence,d = precision,q = 100 - prevalence

CRITERIA FOR SAMPLE SELECTION:

Inclusion criteria:

- Female patients who have been diagnosed with SLE.
- Patients diagnosed with SLE for a minimum period of 6 months Patients who can read and write Tamil/English /Hindi /Bengali /Malayalam.

  patients who are 18 years of age or above

Exclusion Criteria:

- Patients who are not willing to participate in the study.
- Patients who are critically ill.

DATA COLLECTION INSTRUMENT:

The instruments used for the study are as follows

Part – 1 Patient profile.

Part – 2 Beck's Depression Inventory – II (BDI-II).

Part – 3 Stigma Scale for Chronic Illness (SSCI).

Part – 1 Patient profile:

This included the socio-demographic variables and clinical variables which include age, religion, education, occupation, monthly income, marital status, number of children, type of family, type of residence, duration of illness, number of hospital admissions, co-morbidity, SLEDAI score and organ damage.

Part – 2 Beck's Depression Inventory – II (BDI-II):

Beck's Depression Inventory – II is a standard instrument prepared by Dr. Aaron T. Beck. The BDI-II was a 1996 revision of the BDI, developed in response to the American Psychiatric Association's publication of the diagnostic and statistical manual of mental disorders, fourth edition. It consists of 21 questions built on 2 subscales. It consists of a rating scale with a score of 0 to 3.

Part – 3 Stigma Scale for Chronic Illness (SSCI):

The SSCI is a 24-item self-report questionnaire built on 2 subscales to measure self/internalized stigma and enacted stigma. It quantifies the degree and impact of stigma in patients with chronic illnesses.

SCORING AND INTERPRETATION

1. Demographic and Clinical variables

It consists of the socio-demographic and clinical variables and no scoring was allotted for this data.

2. Beck's Depression Inventory– II (BDI-II):

This questionnaire consisted of 21 questions, each answer being scored on a scale value of 0 to 3.

The BDI-II consisted of 2 subscales.

1. *The Affective subscale* - It contains 8 items: 1.Pessimism, 2.Past failures, 3.Guilty feelings, 4.Punishment feelings, 5.Self-dislike, 6.Self-criticalness, 7.Suicidal thoughts or wishes and 8.Worthlessness.

2. *The Somatic subscale* - It contains 13 items: 1.Sadness, 2.Loss of pleasure, 3.Crying, 4.Agitation, 5.Loss of interest, 6.Indecisiveness, 7.Loss of energy, 8.Change in sleep patterns, 9.Irritability, 10.Change in appetite, 11.Concentration difficulties, 12.Tiredness or fatigue and 13.Loss of interest in sex.

Scoring Technique:

0-13 - No depression

14-19 - Mild depression

20-28 - Moderate depression

29-63 - Severe depression

Part – 3 Stigma Scale for Chronic Illness (SSCI):

The Stigma scale for chronic illness (SSCI) consists of 2 subscales the self/internalized stigma and enacted stigma. Thirteen items are measured in "self/internalized stigma," about, the subject feels a sense of shame or anxiety about their condition (SSCI-I).Eleven items are measured in "enacted stigma", about instances of actual discrimination (SSCI-E). The scoring is based on the overall mean scores and they are interpreted as follows.

Perceived illness stigma > 48.3

a. Self stigma > 30.4

b. Enacted stigma > 18

VALIDITY AND RELIABILITY:

The beck's depression inventory - II and Stigma scale for chronic illness were standardized tools with a good reliability and validity. Beck's depression Inventory-II has an excellent internal consistency of average alpha-coefficient = 0.82. Stigma scale for chronic illness also has good internal consistency of average alpha-coefficient = 0.81. The instruments were translated into Tamil, Malayalam, Hindi and Bengali language and back-translated into English.

PILOT STUDY:

Pilot study was conducted on 10 patients who fulfilled the inclusion criteria for a period of 1 week. Pilot study helped to assess the feasibility of the study. The results were insignificant due to a small sample size. No modifications were made in the methodology as it was found to be feasible.

DATA COLLECTION PROCEDURE:

Data was collected for a period of six weeks from 02.06.2014 to 13.07.2014. Patients with SLE who fulfilled the inclusion criteria were chosen. The data was collected from morning 7:30 am till 5 pm.

DATA COLLECTION SCHEDULE (6 WEEKS)

Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**
7:30am-5pm	**7:30am-5pm**	**7:30am-5pm**	**7:30am-5pm**	**7:30am-5pm**	**7:30am-1pm**

The process of data collection was as follows

1. Patients with SLE were chosen with the help of medical records in the outpatient department and in the wards they were chosen with the help of charge nurse.

2. Patients were identified according to the inclusion criteria from both the outpatient unit and the wards

3. Female patients diagnosed with SLE for a minimum of 6 months were chosen

4. A good rapport was established with the patient

5. The purpose of the study was explained in a language understandable to them and they were given an information sheet regarding the purpose, choice of participation, benefits, risks and privacy.

6. A written consent was obtained from the patient after explaining about the study.

7. Guidelines were given to the patient on how to respond. The questionnaire was explained to them in a simple language understandable to them and explained that there was no right or wrong answer and only one response had to be answered

8. They were given 30 minutes to answer each questionnaire and if any doubts arise they were requested to ask the researcher.

9. The level of depression was assessed using the Beck's depression inventory - II and perceived illness stigma using the Stigma scale for chronic illness.

DATA ANALYSIS PLAN: Descriptive and inferential statistics were used to analyse the data using the statistical Package for Social Sciences (SPSS) version 17 computer programme.

The descriptive statistics were used to describe the distribution of the demographic and clinical variable, period prevalence of depression, levels of depression and perceived illness stigma among patients with SLE.

- Period prevalence was calculated as the proportion of the total number of depressed patients to the total number of patients in that period of time.

- Chi-square was used to find the association between depression and perceived illness stigma with demographic and clinical variables.

- Pearson correlation was used to find the relationship between depression and perceived illness stigma.

ETHICAL CONSIDERATION

The study was conducted after the approval from the College Of Nursing Research Committee. Permission was obtained from the Nursing Superintendent and the Head of clinical immunology and rheumatology department, Christian Medical College, Vellore. Information was given on the rights of each patient and it will not affect the care rendered to them by the institution anyway. Patients were explained about the purpose and need of the study, and were assured that their confidentiality will be maintained throughout the study. Informed consent was obtained from the patients before collecting the data and confidentiality was maintained.

RESULTS

This chapter deals with the results of the study. A descriptive study to assess the period prevalence of depression, level of depression and perceived illness stigma among patients with Systemic Lupus Erythematosus was done. This study was conducted among 94 patients with SLE. The data was collected by using self-administered questionnaire. The data was analysed using SPSS version 17. The results of the study are presented under the following sections.

SECTION – A:

Distribution of patients with SLE according to the demographic and clinical variables.

SECTION – B:

Period prevalence of depression among patients with SLE.

SECTION –C:

Distribution of patients with SLE according to their levels of depression.

SECTION – D:

Distribution of patients with SLE according to their Perceived illness stigma.

SECTION – E:

Distribution of patients according to the association of depression and perceived illness stigma among patients with SLE with demographic and clinical variables.

SECTION – F:

Relationship between depression and perceived illness stigma among patients with SLE.

SECTION – A

Table 2.

Distribution of patients with SLE according to demographic variables (N =94)

Demographic variable	Frequency (n)	Percentage (%)
Age (years)		
18 – 30	57	60.64
31 – 40	24	25.53
41 – 50	10	10.64
> 50	3	3.19
Religion		
Hindu	56	59.57
Muslim	24	25.53
Christian	11	11.70
Others	3	3.19
Education		
Primary	4	4.26
Secondary	31	32.98
Higher secondary	19	20.21
PG/technical/professional	40	42.55
Occupation		

Unemployed	67	71.28
Professional	1	1.06
Unskilled	4	4.26
Student	22	23.40

Demographic variable	**Frequency (n)**	**Percentage (%)**
Monthly income		
Nil	80	85.10
< Rs.1000	4	4.26
Rs.1001-5000	3	3.19
Rs.5001-10000	7	7.45
> Rs.10000	0	0
Marital status		
Single	30	31.91
Married	63	67.02
Divorced	0	0
Widow	1	1.06
Separated	0	0
No. of children		

Not applicable	30	31.91
No child	22	23.40
1-2 children	32	34.04
>2 children	10	10.64
Type of family		
Nuclear	87	92.55
Joint	7	7.45
Type of residence		
Urban	72	76.60
Rural	22	23.40

Table 2. Illustrates that most of the patients with SLE are between the age group of 18 – 30 years (60.64%). Majority of them were Hindus 56 (59.57%). Nearly 40 (42.55%) of them had professional level of education. 67 (71%) of them were unemployed, 80 (85.10%) of them were not earning. Most of them were married (67.02%), 32 (34.04%) of them had 1-2 children, 87 (92.55%) of them were from nuclear family and 72 (76.60%) of them were from urban area.

Table 3. *Distribution of patients with SLE according to clinical variable (N =94)*

Clinical variable	**Frequency (n)**	**Percentage (%)**
Duration of illness		
3months to 6 months	5	5.3
6 months to 1 year	16	17.0
1 – 2 years	15	16.0
> 2years	58	61.7
No. of hospital admission		
Nil	8	8.5
Once	44	46.8
Twice	17	18.1
> twice	25	26.6
Co- morbidity		
Nil	69	73.4
Diabetes	5	5.3
Major infections	2	2.1
Others	6	6.4

Hypertension	10	10.6
More than one	2	2.1
SLEDAI		
0	27	28.7
2	1	1.1
3	21	22.3
5	1	1.1
6	1	1.1
8	21	22.3
12	3	3.2
16	10	10.6
18	1	1.1
21	1	1.1
24	2	2.1
32	4	4.3
42	1	1.1

5.	**Organ damage**		
	Ocular	18	19.1
	Neuropsychiatry	1	1.1
	Renal	15	16.0
	Pulmonary	1	1.1
	Peripheral vascular	2	2.1
	Musculo skeletal	2	2.1
	Skin	21	22.3
	Nil	13	13.8
	> 1	21	22.3

Table 3. shows that 58 (61.7%) of the patients have been living with SLE for more than 2 years. Majority of them had no co-morbidity 69 (73.4%). Nearly 44 (46.8%) of them got admitted in hospital once. 27 (28.7%) of them had SLEDAI score of 0. 21. (22.3%) of the patients had skin damage and 21 (22.3%) had more than one organ damage.

SECTION – B

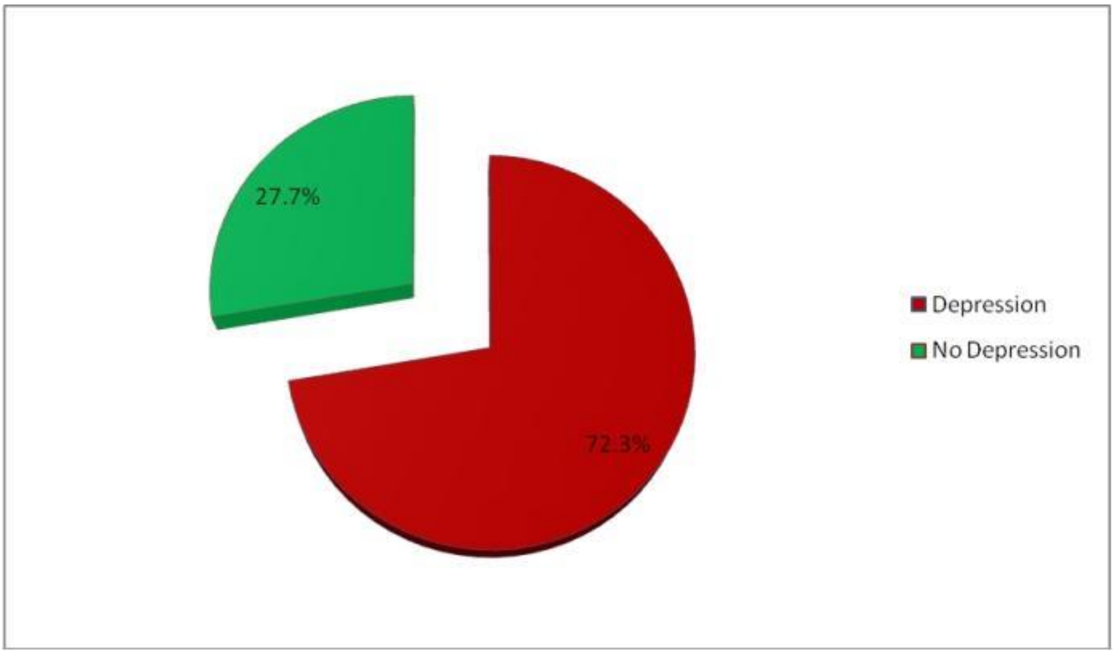

Figure 2. Period prevalence of depression (N =94)

Figure 2. Shows that the period prevalence of depression among patients with SLE was 72.3%. Out of 94 patients 68 (72.3%) of them were depressed.

SECTION – C

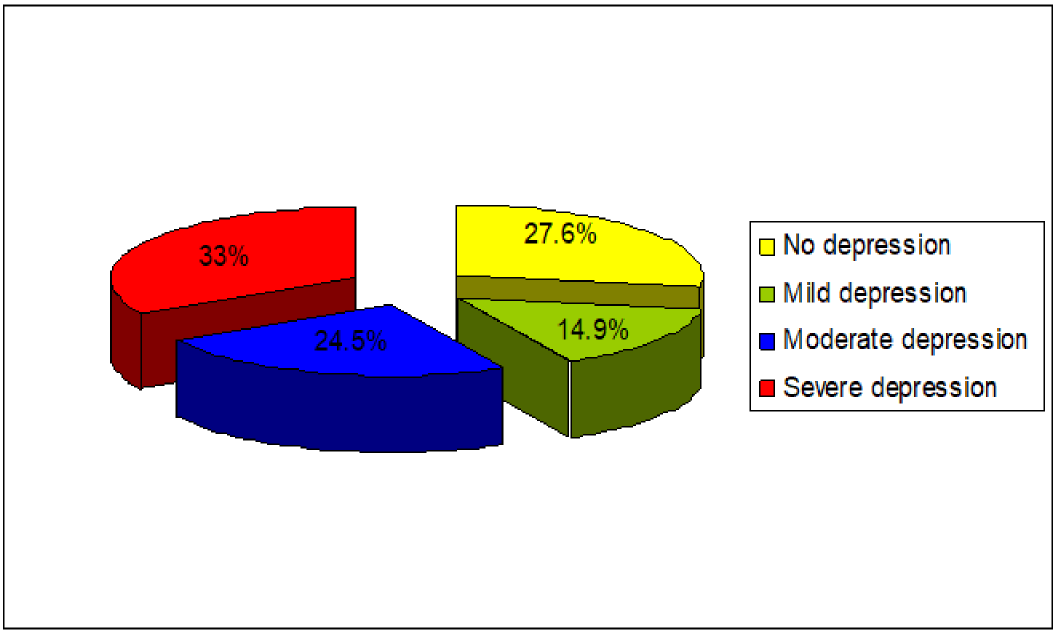

Figure 3. Distribution of patients with SLE according to their level of depression

Figure 3. Shows that among 94 patients 26 (27.6%) of them had no depression, 14 (14.9%) of them had mild depression, 23 (24.5%) of them had moderate depression and 31 (33.0%) of them had severe depression.

SECTION – D

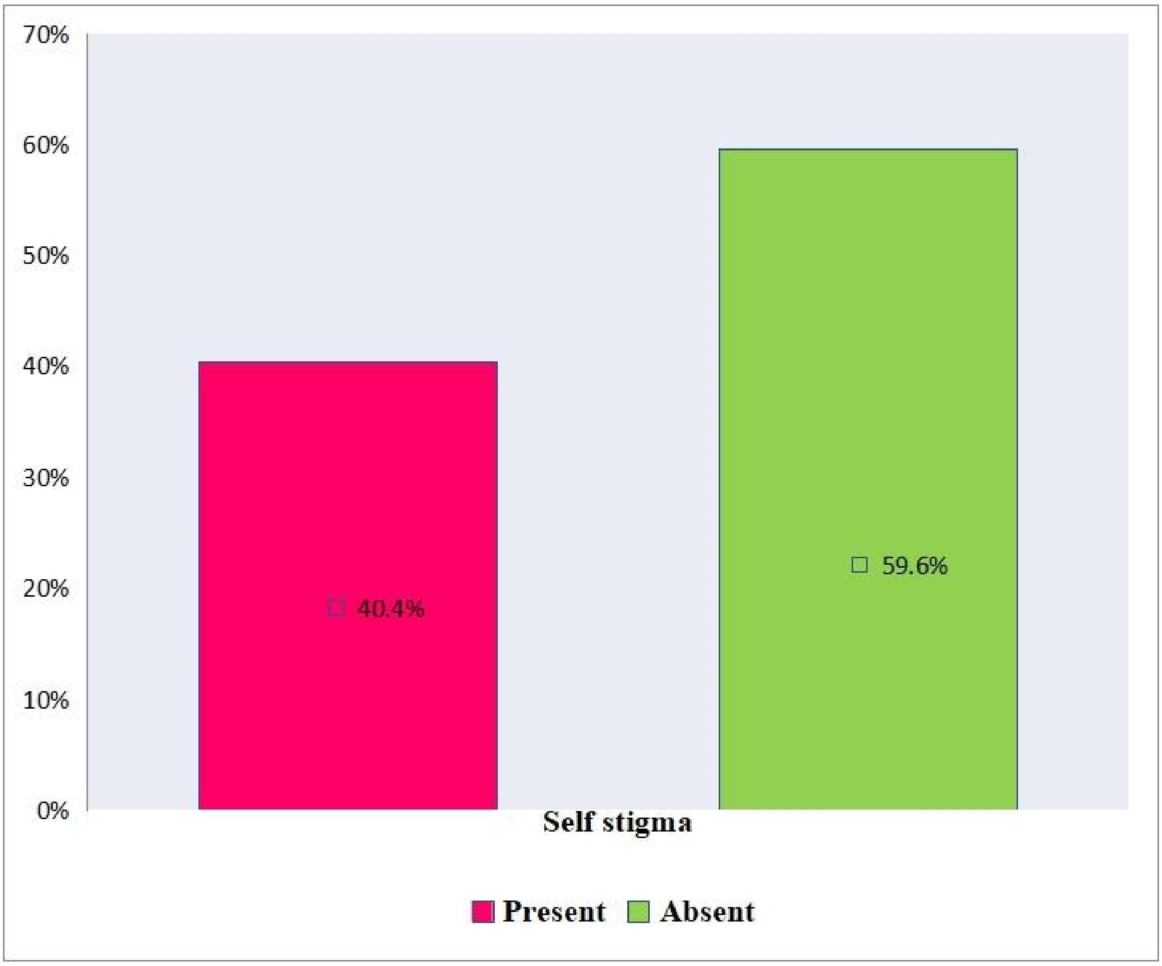

Figure 4. Distribution of patients with SLE according to their perceived illness self stigma

Figure 4. Shows that 40.4% of the patients with SLE have perceived illness self stigma.

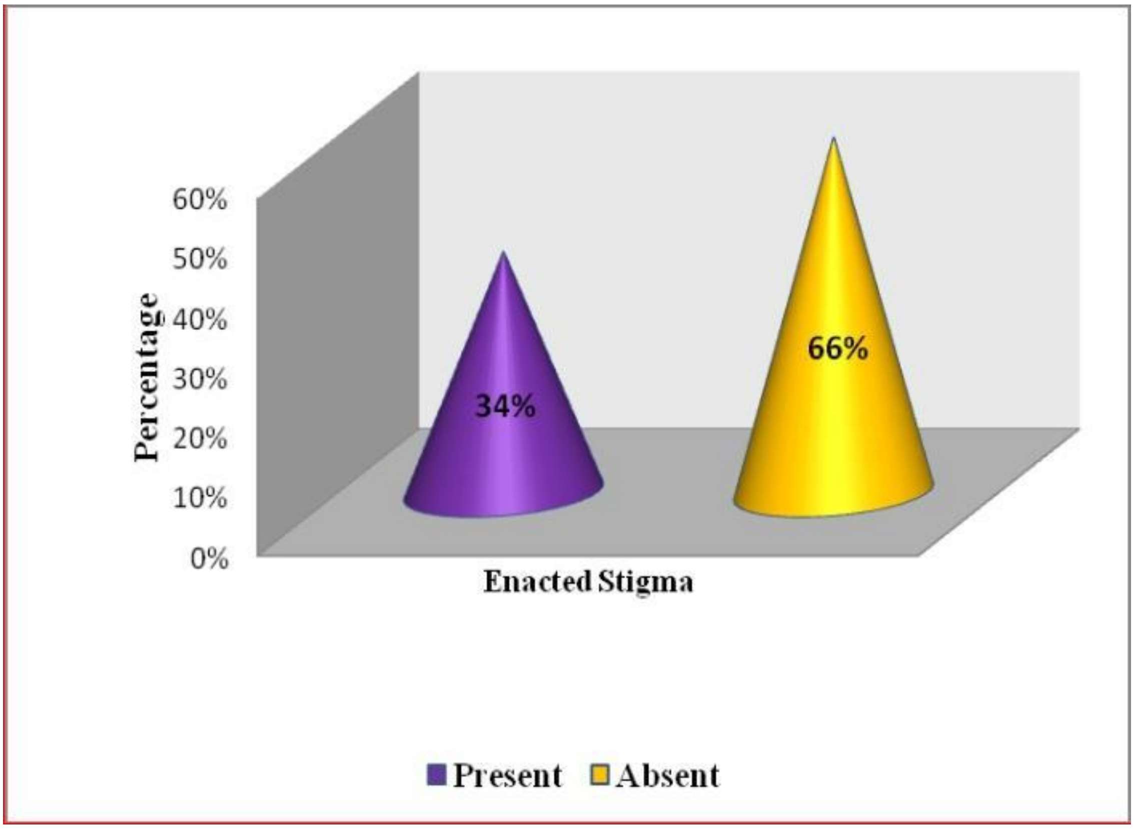

Figure 5. Distribution of patients with SLE according to their perceived illness enacted stigma

Figure 5. Shows that 34% of the patients with SLE have perceived illness enacted stigma.

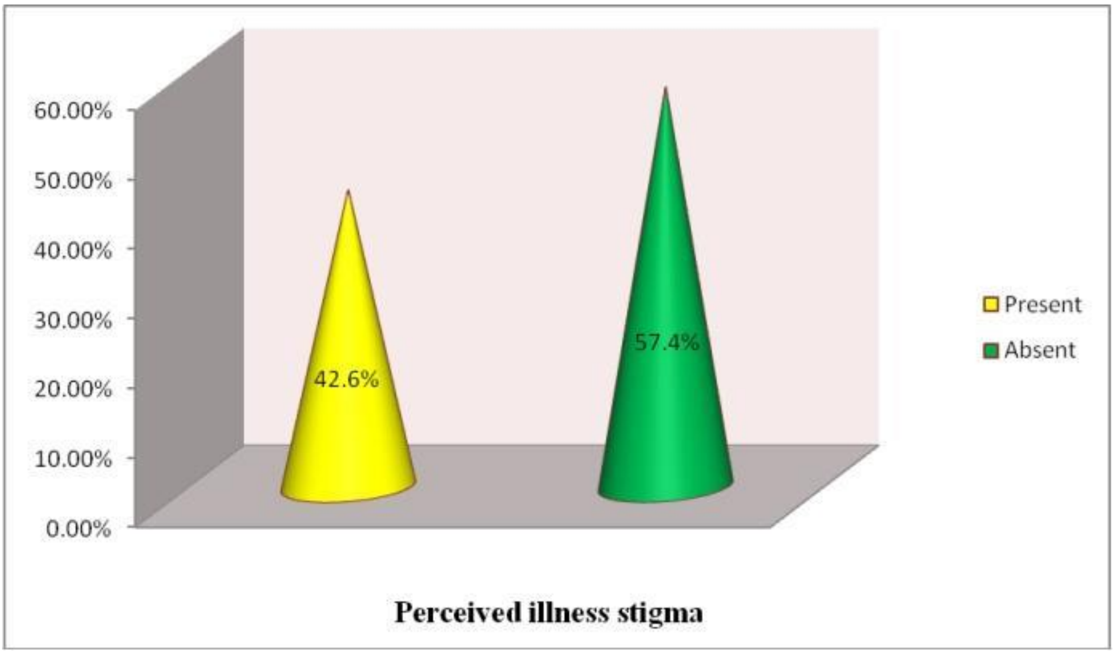

Figure 6. Distribution of patients with SLE according to their Perceived illness stigma

Figure 6.shows that 42.6% of the patients with SLE have perceived illness stigma

SECTION -E

Table 4: Association of depression among patients with SLE with their selected demographic variables (N=94).

Demographic variables	Depression								Chi-square χ^2	p value
	Minimal		Mild		Moderate		Severe			
	n	%	n	%	n	%	n	%		
Age (years)										
18 – 30	20	35.1	8	14.0	9	15.8	20	35.1		
31 - > 50	6	16.2	6	16.6	14	37.8	11	29.7	7.613	0.055
Religion										
Hindu	16	28.6	6	10.7	21	37.5	10	26.3		
									2.614	

Christian/ Muslim/ others	10	26.3	13	23.2	8	21.1	10	26.3		0.455
Education										
Primary/ secondary/ higher sec	11	20.4	11	20.4	12	22.2	11	27.5	5.889	0.117
Pg/technical/ professional	15	37.5	3	7.5	20	37.0	11	27.5		
Occupation										
Unemployed	15	22.7	10	15.2	17	25.8	24	36.4	2.879	0.411
Professional/ unskilled/ student	11	39.	4	14.3	6	21.4	7	25		

Demographic variable	Depression								Chi-square	P value
	Minimal		Mild		Moderate		Severe		χ^2	
	n	%	n	%	n	%	n	%		
Monthly income										
Nil	19	23.8	13	16.3	20	25.0	28	35.0	4.359	0.225
< 1000 - >10000	7	50	1	7.1	3	21.4	3	21.4		

Marital status										
Single	14	46.7	4	13.3	4	13.3	8	26.7	8.592	0.033*
Married	12	18.8	10	15.6	19	29.7	23	35.9		
No. of children										
No child	4	17.4	1	4.3	6	26.1	12	52.2	6.199	0.102
1/>1 child	8	20.5	9	23.1	12	30.8	10	25.6		
Type of family										
Nuclear	26	27.7	13	13.8	20	21.3	28	29.8	3.363	0.339
Joint	0	0	1	1.1	3	3.2	3	3.2		
Type of residence										
Urban	20	21.3	13	13.8	15	15.9	24	25.5	3.739	0.291
Rural	6	6.4	1	1.1	8	8.5	7	7.4		

Table 4 shows that there is significant association between levels of depression and marital status (p = 0.03). No significant association was observed between levels of depression and age, religion, education, occupation, monthly income, no. of children, type of family and type of residence.

Table 5: Association of depression with clinical variable (N=94)

Clinical variable	Depression								Chi-square χ^2	p value
	Minimal		Mild		Moderate		Severe			
	n	%	n	%	n	%	n	%		
Duration of illness										
< 2 yrs	10	27.8	7	19.4	5	13.9	14	38.9	0.538	0.463
> 2 yrs	16	27.6	7	12.1	18	31	17	29.3		
No. of hospitalisation										
Nil/once	18	34.6	12	23.1	9	17.3	13	25	11.954	0.008*
> once	8	19.0	2	4.8	14	33.3	18	42.9		
Co –morbidity										.
Nil	16	23.2	13	18.8	16	23.2	25	36.2	6.211	0.102
With co-morbidity	10	40.0	1	4	10	40.0	6	24.0		

SLEDAI										
< 12	22	23.4	13	13.82	18	19.14	22	23.40	3.387	0.336
≥ 12	4	4.26	1	1.06	5	5.32	9	9.57		
Organ damage										
Ocular	3	16.7	3	16.7	4	22.2	8	44.4	18.661	0.770
Neuropsychiatry	0	-	1	100	0	-	0	-		
Renal	6	40.0	1	6.7	5	33.3	3	20.0		
Pulmonary	0	-	0	-	0	-	1	100		
Peripheral vascular	1	50	0	-	0	-	1	50		
Musculo skeletal	0	-	0	-	1	50	1	50		
Skin	6	28.6	2	9.5	6	28.6	7	33.3		
Nil	5	38.5	3	23.1	3	23.1	2	15.4		
> 1	5	23.8	4	19.0	4	19.	8	38.1		

Table 5 shows that there is significant association between levels of depression and number of hospital admission ($p < 0.01$). No significant association was observed between levels of depression and duration of illness, co morbidity, SLEDAI score and organ damage.

SECTION- F

Table 6. Association of self stigma with demographic variables (N = 94)

S.No	**Demographic variables**	**Self stigma**				**Chi – square** χ^2	**P value**
		Absent		Present			
		n	%	n	%		
Age (years)							
18 – 30		32	56.1	25	43.9	0.709	0.519
31 - > 50		24	64.9	13	35.1		
Religion							
Hindu		33	58.9	23	40.0	0.24	1.00
Christian/muslim/others		23	60.5	15	39.5		
Education							
Primary/secondary/higher sec		33	58.9	24	44.4	0.851	0.40
Pg/technical/professional		23	60.5	14	35.0		
Occupation							
Unemployed		38	57.6	28	42.4	0.368	0.64

Professional/ unskilled/ student	18	64.3	10	35.7		
Monthly income						
Nil	46	57.5	34	42.5	0.960	0.389
< 1000 - >10000	10	71.4	4	28.6		

Demographic variables	**Self stigma**				**Chi – square**	**P value**
	Absent		**Present**			
	n	**%**	**n**	**%**	χ^2	
Marital status						
Single	19	63.3	11	36.7	0.259	0.658
Married	37	57.8	27	42.2		
No. of children						
No child	12	52.2	11	47.8	0.856	0.426
1 - > 2 children	25	64.1	11	35.9		

Type of family						
Nuclear	54	62.1	33	37.9	3.019	0.115
Joint	2	28.6	5	71.4		
Type of residence						
Urban	43	59.7	29	40.3	0.003	1.000
Rural	13	18.1	9	40.9		

Table 6 shows that there is no significant association between self stigma and demographic variable. ($p > 0.05$).

Table 7. Association of self stigma with clinical variable. *(N =94)*

Clinical variable	**Self stigma**				**Chi – square χ^2**	**P value**
	Absent		**Present**			
	n	**%**	**n**	**%**		
Duration of illness						
< 2 yrs	22	61.1	14	38.9	0.057	0.832
> 2 yrs	34	58.6	24	41.4		
No. of hospital admission						

Nil/once	37	71.2	15	28.8	6.479	0.828
> once	19	45.2	23	54.8		
Co –morbidity						
No	41	59.4	28	40.6	0.003	1.00
With co - morbidity	15	60.0	10	40.0		
				40.0		
SLEDAI						
< 12	48	64.0	27	36.0	3.018	0.082
≥ 12	8	42.1	11	57.9		
Organ failure						
Ocular	10	55.6	8	44.4		
Neuropsychiatry	1	100	0	-		
Renal	11	73.3	4	26.7		
Pulmonary	0	-	1	100		
					4.322	

Peripheral vascular	1	50	1	50		0.074
Musculo skeletal	0	-	2	100		
Skin	14	66.7	7	33.3		
Nil	11	84.6	2	15.4		
> 1	8	38.1	13	61.9		

Table 7 shows that there is no significant association between self stigma and clinical variable such as duration of illness, no. of hospital admission, co morbidity, SLEDAI score and organ damage ($p > 0.05$).

Table 8. Association of enacted stigma with demographic variable (N= 94)

Demographic variable	**Enacted stigma**				**Chi – square** χ^2	**P value**
	Absent		**Present**			
	n	**%**	**n**	**%**		
Age (years)						
18 – 30	38	66.7	19	33.3	0.32	1.000
31 - > 50	24	64.9	13	35.1		
Religion						
Hindu	37	66.1	19	33.9	0.001	1.000
Christian/muslim/others	25	65.8	13	34.2		

Education						
Primary/secondary/higher sec	32	59.3	22	40.7	2.536	0.128
Pg/technical/professional	30	75.0	10	25.0		
Occupation						
Unemployed	40	60.6	26	39.4	2.826	0.103
Professional/ unskilled/ student	22	78.6	6	21.4		
Monthly income						
Nil	51	63.8	29	36.3	1.166	0.368
< 1000 - >10000	11	78.6	3	21.4		

Demographic variable	**Enacted stigma**				**Chi – square χ^2**	**P value**
	Absent		**Present**			
	n	**%**	**n**	**%**		
Marital status						

Single	22	73.3	8	26.7	1.068	0.356
Married	40	62.5	24	37.5		
No. of children						
No child	15	65.2	8	34.8	0.238	0.788
1 - > 2 children	23	59.0	16	41.0		
Type of family						
Nuclear	59	67.8	28	32.2	1.797	0.224
Joint	3	42.9	4	57.1		
Type of residence						
Urban	47	65.3	25	34.7	0.63	1.000
Rural	2	22.2	7	31.8		

Table 8 shows that there is no significant association between enacted stigma and demographic variables.

Table 9. Association of enacted stigma with clinical variable (*N = 94)*

Clinical variable	**Enacted stigma**				**Chi – square χ^2**	**P value**
	Absent		**Present**			
	n	**%**	**n**	**%**		
Duration of illness						
< 2 yrs	21	58.3	15	41.7	1.510	0.265
> 2 yrs	41	70.7	17	29.3		
No. of hospital admission						
Nil/once	35	67.3	17	32.7	0.094	0.828
> once	27	64.3	15	35.7		
Co –morbidity						
No	47	68.1	22	31.9	0.538	0.471
With co - morbidity	15	60.0	10	40.0		
SLEDAI						
< 12	52	69.3	23	30.7		

					1.883	0.170
> 12	10	52.6	9	47.4		
Organ damage						
Ocular	12	66.7	6	33.3		
Neuropsychiatry	0	-	1	100		
Renal	12	80	3	20		
Pulmonary	0	-	1	100	19.158	0.014 *
Peripheral vascular	1	50	1	50		
Musculo skeletal	0	-	2	100		
Skin	14	66.7	7	33.3		
Nil	13	100	0	-		
> 1	62	66.0	32	34.0		

Table 9 shows that there is significant association between the enacted stigma and organ damage p = (0.014).

Table 10. Association of perceived illness stigma with demographic variable (N =94)

Demographic variable	Perceived illness stigma				Chi – square χ^2	P value
	Absent		Present			
	n	%	n	%		
Age (years)						
18 – 30	32	56.1	25	43.9	0.751	0.832
31 - > 50	22	64.9	15	40.5		
Religion						
Hindu	32	57.1	24	42.9	0.942	1.000
Christian/muslim/others	22	57.9	16	42.1		
Education						
Primary/secondary/higher sec	28	51.9	26	48.1	0.202	0.215
Pg/technical/professional	26	65.0	14	35.0		
Occupation						
Unemployed	35	53.0	31	47.0		

Professional/ unskilled/ student	19	65.0	9	32.1	0.184	0.254
Monthly income						
Nil	44	55.0	36	45.0	0.251	0.381
< 1000 - >10000	10	71.4	4	28.6		

Demographic variable	**Perceived illness stigma**				**Chi – square χ^2**	**P value**
	Absent		**Present**			
	n	%	n	%		
Marital status						
Single	21	70.0	9	30.0	0.092	0.119
Married	33	51.6	31	48.4		
No. of children						
No child	12	52.2	11	47.8	0.899	1.000
1 - > 2 children	21	53.8	18	46.2		
Type of family						
Nuclear	52	59.8	35	40-2		

Joint	2	28.6	5	71.4	0.108	0.131
Type of residence						
Urban	40	55.6	32	44.4	0.450	0.624
Rural	1	11.1	8	36.4		

Table 10 shows that there is no significant association of perceived illness stigma with demographic variable. ($p > 0.05$).

Table 11. Association of perceived illness stigma with clinical variable (N = 94)

Clinical variable	Perceived illness stigma				Chi – square χ^2	P value
	Absent		Present			
	n	%	n	%		
Duration of illness						
< 2 yrs	20	55.6	16	44.4	0.770	0.832
> 2 yrs	34	58.6	24	41.4		
No. of hospital admission						
Nil/once	36	69.2	17	30.8	0.010	0.012*
> once	18	42.9	24	57.1		

Co –morbidity						
No	39	56.5	30	43.5	0.763	0.817
With co - morbidity	15	60.0	10	40.0		
SLEDAI						
< 12	46	61.3	29	38.7	2.293	0.130
> 12	8	42.1	11	57.9		

Clinical variable	**Perceived illness stigma**				**Chi – square χ^2**	**P value**
	Absent		**Present**			
	n	**%**	**n**	**%**		
Organ failure						
Ocular	9	50.0	9	50.0		
Neuropsychiatry	0	-	1	100		
Renal	10	66.7	5	33.3		
Pulmonary	0	-	1	100		
					15.197	0.055

Peripheral vascular	1	50	1	50
Musculo skeletal	0	-	2	100
Skin	15	71.4	6	28.6
Nil	11	84.6	2	15.4
> 1	8	38.1	13	61.9

Table 11. Shows that there is significant association of perceived illness stigma with no. of hospital admission (p=0.012).

SECTION – G

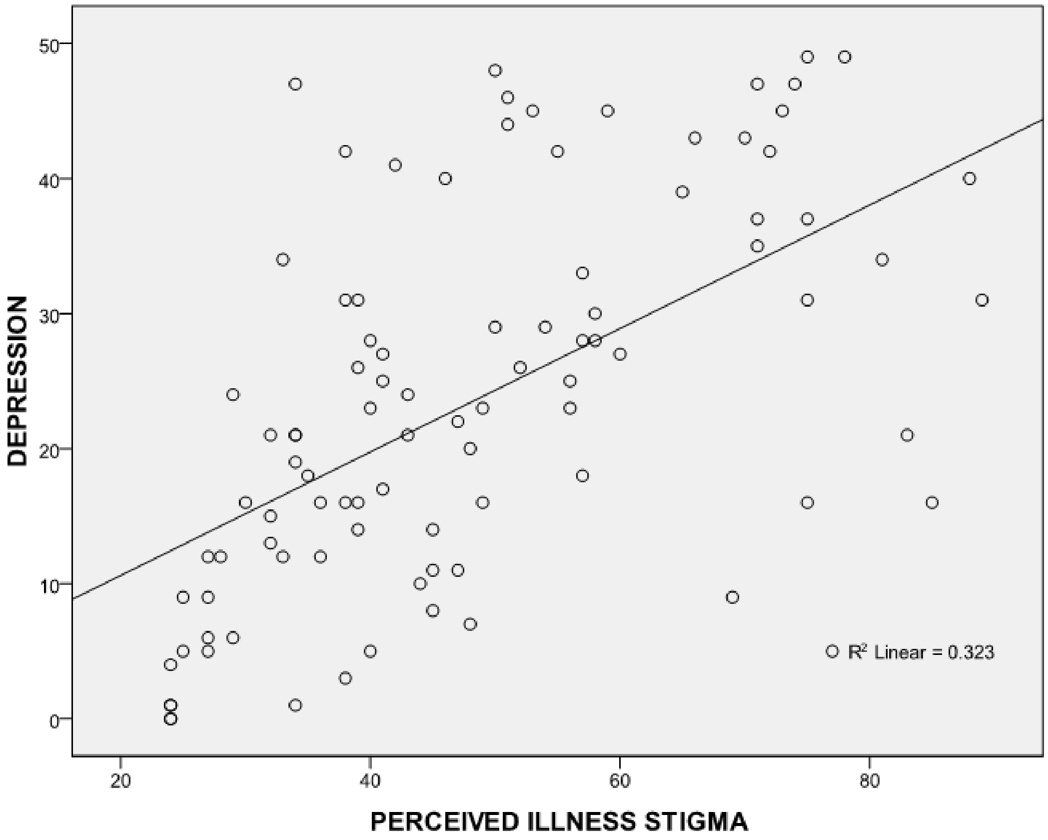

Figure 7. Relationship between depression and perceived illness stigma among patients with SLE.

This scatter plot shows that there is significant relationship (r = 0.569) between depression and perceived illness stigma among patients with SLE. It infers that if depression increases among patients with SLE, perceived illness stigma also get increased. (P < 0.001)*

DISCUSSION

Distribution of socio-demographic variables:

The socio-demographic variables assessed were age, religion, education, occupation, monthly income, and marital status, number of children, type of family and type of residence.

From the study it revealed that a higher percentage of patients (women) (60.64%) with SLE belonged to the age group of 18 - 30 years ,which is similar to the findings of the study by Janwityanujit, Totemchokchyakarn, Verasertnlyom, Vanlchapuntu, & Vatanasuk, (2011) where SLE was more prevalent among the age group of 20-30 years. As active immunity is high among the younger population, autoimmune disease is highly prevalent among them.

The study findings also revealed that a majority (59.57%) of the patients were Hindus by faith. The distribution of Christians and Muslims were 25.53% and 11.70% respectively and a very few percentage (3.19%) of them belonged to other religions.This could be attributed to the Indian background where there is a higher Hindu population.

From the present study, it is clear that a majority of patients (42.55%) had completed their University graduation and most of them (32.98%) had completed secondary education. This indicates that high education plays an important role in creating awareness and health seeking behaviour among these patients.

In the current study, it was found that students and unskilled workers were 23.4% and 4.26% respectively. 71.28% of them were unemployed, which is supported by the findings of Drenkard et al., (2014) where the risk of unemployment in those patients affected with SLE was almost 4-fold higher than the general population. The most important factor that increased the risk of unemployment was due to severe disease activity and organ damage. During the interviews, patients expressed that, it was due to severity of the disease they were not able to work and it was done among the female patients where stigma with the physical appearance caused them to stay at home rather than to get employed.

The present study findings show that the monthly income of 7.45% of the patients ranged from Rs.5001 to 10,000 and for 4.26% of the patients, it was less than Rs.1000.

The findings of the current study revealed that a majority (67.02%) of the patients were married, while 31.91% were single. With regard to age most of them belong to the age group of 18-30 years (60.64%), 31-40 years (25.53%) This could be because of the higher prevalence of SLE among women within the reproductive age group.

In this study 63 women were married; with regard to the number of children 22 women did not have a child. Majority (92.55%) of the patients belonged to a nuclear family and 7.45% of them were from joint family.

From the study it was clear that a majority (76.6%) of them were from urban area while 23.4% of them were from rural area which was congruent with the study findings of Barnabe et al., (2012) where they found that the prevalence of SLE among urban dwellers was higher ($p = 0.001$). In this study it is more evident that most of them belong to the urban population because in our country access to health care system is easier for an urban dweller than patients from the rural community.

Distribution of Clinical variables:

The clinical variables analysed in this study include duration of illness, number of hospital admissions, SLEDAI score, presence of co-morbidities and organ damage.

With regard to the duration of illness revealed that majority of the patients (61.7%) had a disease lasting more than 2 years. This suggests the nature of the disease chronicity. The current study showed that a majority of the patients (73.4%) had no other co-morbidities while 10.6% of the patients had Hypertension. In contrast to these findings, a study done by Molina et al., (2007) on co- morbidities in SLE showed that the prevalence rate of co- morbidities among SLE patients' was 79.1% out of which 33.7% had hypertension.

In the current study, it was also revealed that, a nearly half of the patients (46.8%) with SLE had hospitalised at least once, while 8.5% of them had never been hospitalised. The findings of this study was nearly congruent to the findings of the study done by Asiri et al., (2011) who identified that 54% of SLE patients were hospitalised during their disease course and explored that the major causes for admissions were SLE flare-ups and recurrent infections. There was also a high rate of re-admission within a 2 year period. The major causes for re-admissions were infections and unresolved SLE flare-ups.

The present study also revealed that a majority (28.7%) of the patients had a SLEDAI score of 0 which revealed that most of the patient's did not have active flares. 22.3% of the patients had SLEDAI score of 3 and 8 which indicates mild to moderate flare. In the study the flares were due to irregular follow up and discontinuation of prescribed medications which is in line with the study done by Costedoat et al., (2006) where poor compliance with treatment caused the increase in flares.

Skin and more than one organ damage were equally seen in majority of the patients (22.3%) which is similar to the study done by Rivest et al (2000), where most of the patients (12.5%) in their study had skin damage. The organ damage can be because of high use of corticosteroids which is supported by a study done by Mae Thamer (2009) where low doses of the drug resulted in less risk of organ damage.

The first objective of the study was to assess the period prevalence of depression among patients with SLE

The period prevalence of depression was assessed using the Beck's depression Inventory-II and was found to be 72.3%. Nancy et al., (2011) reported that the SLE patients are most likely to report feelings of SLE-related depression and anxiety. In 2013 a similar kind of study conducted by Zakeri et al., among SLE patients revealed that 60% of the patients with SLE had depression. A similar study conducted by Nery, Borba, Viana, Hatch, Soares, Bonfá, & Neto, (2008) concluded that the prevalence of mood disorders among patients with SLE was 69%. According to Moussavi, Chatterji, Verdes, Tandon, & Ustun, (2007) the prevalence of depression in patients with chronic diseases is significantly higher than in respondents without chronic diseases ($p<0.0001$). The reason for this increased percentage is not really looked in this study; however it can be of chronicity nature of the disease condition where depression is more common in any individual with any chronic stressor.

Contradictory to the current study findings, Laura, Steven, Chris, Jinoos, Trupin, Lindsey et al., (2011) who conducted a study among 150 patients with SLE reported that only 17% of them were in depression. Yet another study done by Legendre et al., (2005) showed the prevalence of depression among the patients with connective tissue diseases as 43%. Similarly Cohen et al., (2004) reported in their study that 50% of the patients with SLE have depression and emotional distress.

The second objective of the study was to assess the levels of depression among patients with SLE.

On analysing the levels of depression among the patients with SLE, this study showed that 27.6% of them had no depression, 14.9% of them showed symptoms of mild depression, 24.5% moderate depression and 33% showed symptoms of severe depression. Similar findings were also reported by Philip, Lindner, & Lederman, (2009) where they found that there was a high level of depressive symptoms among individuals with lupus.

In Beck's Depression inventory-II with regard to suicidal thoughts among the 94 patients, about 63 of them expressed that they did not have any thoughts of killing themselves. 9 of the participants expressed that they would kill themselves, if they had a chance. It is alarming that all the respondents who opted for this response were in severe depression. There is a statistically significance found between suicidal thoughts and depression with p-value of < 0.001. It is evident in the study done by Xie et al., (2012) revealed that suicidal ideation is more intense in patients with depressive symptoms. Early identification of patients with suicidal thoughts may help to reduce the risk of suicide. Health care professionals should be aware of the social background of patients and provide assistance when necessary. It is important to optimize medical and non-medical therapies to control disease activity.

Hence early detection of depression is essential among patient with SLE.

Similarly Legendre, Allan ore, Ferrand, & Kahan, (2005) in their study found that 26% of the patients who had connective tissue diseases scored above the cut-off usually taken to define moderate-to-severe depression. Banks, & Kerns, (1996) also found that there is a major depressive disorder often found in conjunction with chronic pain, with a prevalence of 30–54%.

The third objective of the study was to assess perceived illness stigma among patients with SLE.

In this study, it was identified that 40 of them with SLE had perceived illness stigma. The study findings revealed that 40.4% had self-related stigma and 34% of them had enacted stigma.

This finding is supported by a study done by Person, Bartholomew, Gyapong, Addiss, & van den Borne, (2009) showed that women affected with diseases that caused disfigurement presented with perceived and internalized stigma experiences, such as being criticized and isolated by the community, health providers, and even by friends and relatives.

Women with SLE felt unattractive, self-conscious, and afraid of rejection, and some postponed parenthood in fear of pregnancy complications and genetic transmission of SLE to their children. SLE is debilitating and patients must accept the unpredictable and pervasive pain, fatigue, multi organ damage, physical limitations, stigmatization, and psychosocial challenges (Sutanto, Grewal, Mcneil, O'Neill, Craig, Jones, & Tong, 2013).

The fourth objective of the study was to determine the relationship between depression and perceived illness stigma among patients with SLE.

In this study the correlation of the mean scores for depression and perceived illness stigma of patients with SLE, revealed that there was a weak positive correlation (r= 0.568, p-value < 0.01) between depression and perceived illness stigma which indicates that as symptoms of depression increase perceived illness stigma also increases. It can also be told as both depression and perceived illness stigma are inter-related.

Extensive scar and specific SLE skin lesions were the reasons for feelings of stigmatization and this resulted in low confidence level among SLE patients (Guarize, Appenzeller, & Costallat, 2007).

Similar to the current study findings Pyne, Kuc, Schroeder, Fortney, Edlund, & Sullivan, (2004) found that symptoms of depression among these patients was associated with significantly higher levels of perceived stigma than those who did not experience depression (p<0.001). Thus, greater depression appears to be a strong predictor of perceived stigma.

Thus, the first hypothesis (HI) is proved that there is a significant association between depression and perceived illness stigma among patients with SLE through the current study.

***The fifth objective of the study was to identify the association of depression and perceived illness stigma with selected socio-demographic and clinical variables*.**

The current study findings revealed that there is a statistically significant association between depression among patients with SLE and marital status with a p-value of 0.033. It was found that 15.6% of the married women had symptoms of mild depression, 29.7% of them had moderate depression and 35.9% of them had severe depression, whereas among those who were single, only 13.3% had mild depression, and moderate depression and 26.7% had severe depression. The reason for high prevalence of depression among married women can be because of disequilibrium in their vital position in a family who has to take a leading part in providing care to the family members and failure to do the expectations of others in a family.

There was no statistically significant association between depression and other demographic variables such as age, religion, education, occupation, monthly income, number of children, type of family and type of residence (p-value > 0.05). Because of this smaller population, the association may not be statistically significant.

It was found in the current study that there was a statistically significant association between depression among patients with SLE with the number of hospital admissions (p-value = 0.008). Hence it was observed that as the frequency of hospital admissions increased, the level of depression among the patients with SLE increased proportionately. Among the patients who had never been hospitalized or those who reported a onetime hospital admission, it was found that 23.1% of them had mild depression, 17.3% of them had moderate depression and 25% of them had severe depression, whereas among those who were admitted more than once 4.8% of them were in mild depression, 33.3% of them were in moderate depression and 42.9% of them were in severe depression.

There was no significant association between depression and other clinical variables such as duration of illness, co-morbidity, SLEDAI score and organ failure.

In contrast to the above study findings Nery, Borba, Hatch, Soares, Bonfá,& Neto, (2007) reported that major depression presented a trend toward having greater severity of SLE disease activity compared with those without major depression (p = 0.056).

Thus the second hypothesis (H2), was proved that there was significant association of depression with selected demographic variable (marital status p = 0.033) and clinical variables (no. of hospital admissions p = 0.008) among patients with SLE in this study.

It was also found that there was a statistically significant association between perceived illness stigma and number of hospital admissions (p = 0.012). It is also inferred that the perceived illness stigma increases with increase in number of hospital admissions. The findings also reported that the increase in number of organ damage increases the enacted stigma (p value = 0.014).

Thus the third hypothesis (H3) was proved that there was significant association between perceived illness stigma and selected demographic and clinical variable in this study.

Conclusion

This study has assessed the prevalence of depression, levels of depression and perceived illness stigma among patients with SLE. The patient’s assessment of depression remains a priority for nurse researchers to play a vital role in helping the patients through stressful and challenging situations to develop a therapeutic relationship. This calls the nurses to address these issues at the appropriate time to prevent under recognition of depression and perceived illness stigma among patients with SLE.

Conclusion

The study shows that there is a higher prevalence of depression among patients who are diagnosed with SLE and also found that most of them had severe depression; they perceive themselves to be stigmatized by self and by others. Appropriate assessments are the most important preventing measure of depression and perceived illness stigma among those patients who are diagnosed with SLE.

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