Adherence to Medication and Factors Contributing to Non-Adherence among Systemic Lupus Erythematosus (SLE) Patients in Outpatient Department at Kolkata

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Abstract: *<u>Background</u>: Systemic lupus erythematosus is a chronic autoimmune disease that requires long term medication. Poor adherence to medication can lead to adverse outcomes, including frequent hospitalizations which further leads to increased health care cost. Due to the chronic nature of this disease, non-adherence to medication regimen has significant morbidity, mortality and considerable adverse effects among patients. In a view, the study was aimed to evaluate medication adherence of the patients periodically and to identify contributing factors related to non-adherence among SLE patient attending out-patient department of selected hospital, Kolkata. <u>Material and Methods</u>: A descriptive survey research design was adopted to find out assessment of adherence to medication and factors related to non-adherence to medication among patients with SLE attending out-patient department of selected hospital, Kolkata. The conceptual framework was based on Rosen stock's Becker and Mauman's Health belief Model. The non-probability purposive sampling technique was used to select 104 respondents. An un-structured interview schedule for demographic characteristics, standardized Morisky Medication Adherence Scale 8-item to assess adherence level and structured interview schedule for factors contributing to non-adherence was used to collect the data. The descriptive statistics were used to analyze the data based on objectives of the study. <u>Result</u>: The study findings showed that 73.07% respondents had poor adherence,26.92% respondents had medium adherence while no respondents had good adherence to medication. With mean percentage of 88%, factors related to medicines stands out as the most important contributing factor of non-adherence. The most common reason were feeling fatigue to take medicine regularly (74.03%), believe on bad luck or karma (61.53%), unavailability of free medicines (82.69%), too many medicines per day (82.69%), could not come to hospital alone(77.88%), cost of medication(83.65%), distance between home and hospital(88.46%) which were cited as most contributing reason for non-adherence of respondents. The analysis showed that there was statistically significant association between adherence to medication with occupation, duration of illness (in years), duration of taking medicines (in years) at 0.05 level of significance. <u>Conclusion</u>: The study had important implication in various field of nursing education, administration and research which paves the way for further research. The study was concluded with the recommendation to find out the effect of interventional protocol to enhance medication adherence among SLE patients.*

Keywords: Medication adherence, non-adherence factors, Systemic lupus erythematosus (SLE), healthcare outcomes

1. Introduction

Systemic lupus erythematosus (SLE) is a chronic multi system autoimmune disease characterized by relapsing and remitting episodes. [1] In this disease, antibodies are produced that act against the body cells by circulating in the bloodstream and depositing in various tissues.[2] SLE manifests in a wide variety of symptoms such as joint pain ,rash, photosensitivity ,fatigue, irreversible organ damage, hospitalization and even death.[1] Involvement of different body systems causes many problems and disabilities for patients leading to dependence and difficulty in meeting health care needs.[2] In recent study, Indian journal of Rheumatology in 2020, reported that the prevalence of SLE is 6.5-1.78 per 100000 globally and in India reported that prevalence 3.2 per 10000 population.[3]

SLE symptoms vary considerably across patients.[4] Most of the medication options available generally suppress immune system activity in order to alleviate symptoms with a focus on minimizing disease activity.[1] Additionally, many of the medications have potential significant side effects, such as allergic reactions, mood disorders, infertility, liver damage and risk of serious infections.[1]

Medicine adherence is a critical challenge in the management for SLE patients. Adherence is defined as the extent to which a patient taking medications, proper diet and executing lifestyle with agreed recommendations from the health care provider.[5] Early diagnosis and treatment is most important and patients adherence to therapy recommendations are crucial for the improvement of patients outcomes.[6]

However, studies has shown that due to its chronic nature, patients do not adhere medicines regularly. The constant changing treatment regimens and the wide variety of potential side effect are barriers to patients.[1] Medical non-adherence defined as the level at which a patient do not follow the doctor's recommendations, is a persistent issue among individuals with SLE.[7] Non-adherence is an issue both with medication and with other forms of clinical participation (e.g., individuals missing appointments).[8,9] Non-adherence to medication regimen hinders the effective management of the disease and leads to negative health outcomes, worsening of the disease, hospitalization, and even death among SLE patients .[10]

As reported by the WHO, patient adherence to long term therapies is alarmingly low in both developed and developing

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countries.[11] The impact of poor adherence on the effectiveness of chronic disease treatment is severe both in terms of poor health outcomes and increased health care costs .[11] Low adherence impacts the quality of life of patients and affecting their ability to function in society.[11] Furthermore, it increases the costs associated with the required medical interventions , rates of hospitalization and increased visits to physician. [12]

Thus, it is important to understand the level of adherence to medication and factors related to non-adherence among SLE patients and as this is likely help to contribute to develop target intervention to improve the adherence and outcomes of the patients.

2. Materials and Method

Research Approach: Quantitative research approach

Research Design: Descriptive survey research design

Setting of the study: Final study was conducted at out-patient department of SSKM Hospital, Kolkata in the month of February 2022 to March 2022.

Population: The Population of the study comprised of all patients with systemic lupus erythematosus (SLE).

Sample: In this study, the samples were patients with SLE attending out-patient department of SSKM hospital, Kolkata and who met inclusion and exclusion criteria.

Sampling technique: Non probability purposive sampling technique was adopted.

Table 1: Data collection tools and techniques

The following data collection tools are developed in order to obtain necessary information.

Tool No.	Variables to be measured	Tools	Techniques
I	Demographic characteristics	Un-structured interview schedule	Interviewing
II	Adherence to medication	Standardized Morisky Medication Adherence Scale 8-item(MMAS-8)	Interviewing
III	Factors related to non-adherence	Structured interview schedule	Interviewing

3. Results

Section I
Finding related to demographic characteristics of the respondents

Table 2: Distribution of demographic characteristics of respondents according to their age (in years) and gender, n=104

Sample characteristics	Frequency(f)	Percentage (%)
Age (in years)		
<30	61	58.65
30-45	38	36.53
>45	5	4.8
Gender		
Male	14	13.46
Female	90	86.53

The data presented in the above table 2 depict that maximum number of respondents 58.65% belonged to the age group of below 30 years.

The data also indicate that most of the respondents 86.53% were female.
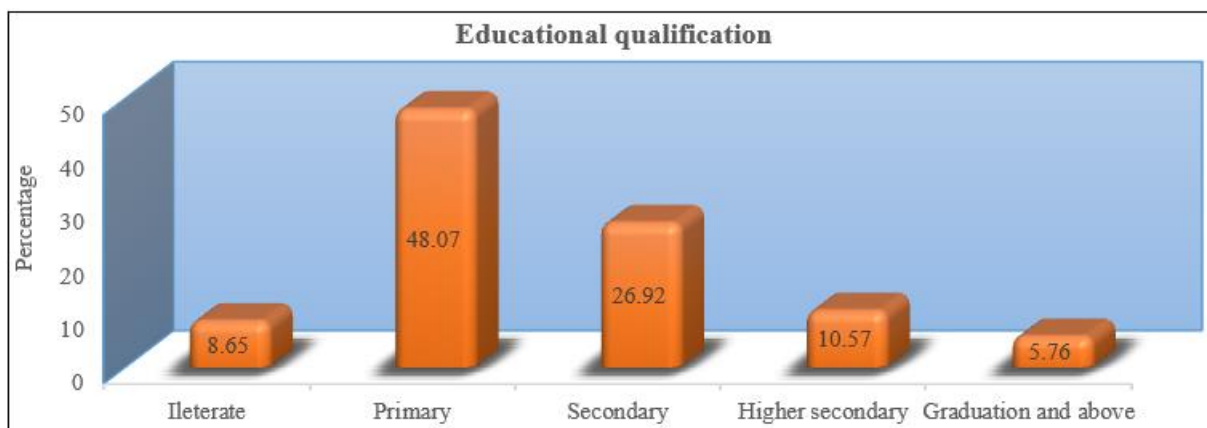n=104

Figure 4: Distribution of respondents according to educational qualification

Data presented in figure 4 depicts that 48.07% respondents were educated up to primary level followed by 26.92% respondents who were educated up to secondary level, 10.57 % respondents were educated up to higher secondary, 5.76% were educated up to graduation and above and 8.65% respondents were illiterate.

Table 3: Distribution of respondents according to their family income per month (in Rupees) and occupation, n=104

Sample characteristics	Frequency (f)	Percentage (%)
Family income per month (in Rupees)		
<5000	14	13.46
5000-10000	72	69.23
>10000	18	17.3
Occupation		
Labour	7	6.73
Housewife	61	58.65
Business	2	1.92
Service	2	1.92
Students	31	29.8
Agricultural worker	1	0.96

Data presented in table 3 shows that 69.23% respondents had family income within Rs.5000-10000. It was revealed that maximum respondents 58.65% were housewife followed by students (29.80%), labour /daily wages (6.73%), business and services (1.96%) and agricultural worker (0.96%).
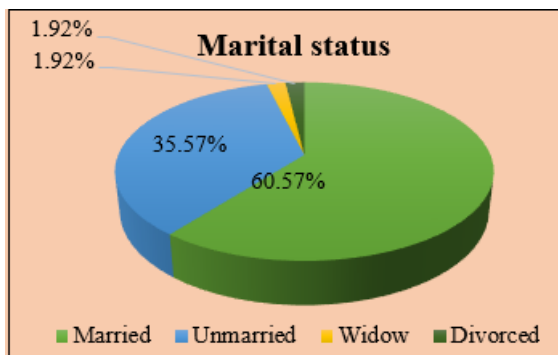

Figure 5: Pie diagram representing percentage distribution of respondents according of their marital status, n=104

Data presented in figure 5 shows out that of the 104 respondents, the majority (60.57%) were married.
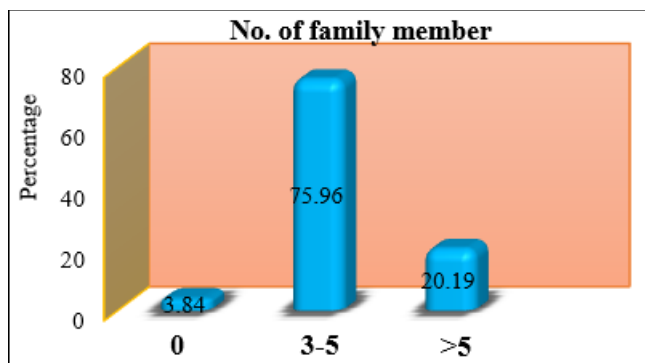

Figure 6: Bar diagram representing percentage distribution of respondents according to their number of family member, n= 104

The figure 5 shows that having 3-5 members in the family was most common as with 75.96% of the respondents. More than 20.19% of the respondents had more than 5 members in the family and only 3.84% had between 0-2 members in their family.

Table 4: Distribution of respondents as per illness and medication profile, n=104

Sample characteristics	Frequency (f)	Percentage (%)
Duration of illness (in years)		
<5	58	55.76
≥ 5	46	44.23
Number of prescribed medicines per day		
<5	20	19.23
≥5	84	80.76
Duration of taking medicines (in years)		
<5	58	55.76
≥ 5	46	44.23

Data presented in table 4 shows that majority (55.76%) of the respondents were suffering from illness for less than 5 years.

The majority (80.76%) of the 104 respondents were taking 5 or more medicines per day.

Majority 55.76% of respondents had been taking medications for less than 5 years.

Table 5: Distribution of respondents according to their history of any co-morbidities, n=104

Sample characteristics	Frequency (f)	Percentage (%)
History of co-morbidities		
Present	59	56.73
Absent	45	43.26

Data presented in table 5 shows that 56.73% respondents had history of Co morbidities and 43.26% respondents had no history of any comorbidities.

Type of co-morbidities (n₁=59)		
Diabetes	2	1.92
Hypertension	16	15.38
Hypothyroidism	22	21.15
Diabetes and hypertension	4	3.84
Diabetes and hypothyroidism	2	1.92
Hypertension and hypothyroidism	10	9.61
Diabetes, hypertension and hypothyroidism	3	2.88

Section II
Findings related to level of adherence to medication among patients with SLE

Table 6: Frequency and percentage distribution of level of adherence to medication among respondents, n=104

Adherence level	Frequency (f)	Percentage (%)
Low or poor adherence (Score < 6)	76	73.07
Medium adherence (Score 6 to < 8)	28	26.92
High or good adherence (Score 8)	-	-

Data presented in table 6 depicts that maximum respondent (73.07%) had low or poor adherence to medication, 26.92 % respondents had medium adherence, while no respondents had high or good adherence to medication based on the scoring of the Morisky medication adherence scale of 8 item (MMAS-8).

Section III Findings related to factors related to non-adherence to medication among patients with SLE

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Table 7: Mean and Mean percentage of factors related to non-adherence to medication among respondents, n=104

Factors related to non-adherence	Mean	Mean%	Rank
Factors related to medicines	3.52	88%	1st
Financial factors	4.38	87.6%	2nd
Personal factors	4.11	68.5%	3rd
Organizational factors	3.59	59.83%	4th
Factors related to support system	2.15	53.82%	5th
Factors related to knowledge and belief	1.85	26.5%	6th

Above table 7 reflects the factors related to non-adherence of medication. With mean percentage of 88%, factors related to medicines stands out as the most important factors contributing to non-adherence to medication.

Table 8: Frequency and percentage distribution of factors of non-adherence to medication among SLE patients related to personal factors, n= 104

Personal factor	Perceived as a factor to non-adherence	
	Frequency	Percentage (%)
Feel fatigue to take medicine regularly	77	74.03
Find it difficult to take medicines at specified time	73	70.19
Have too much work at home/workplace	73	70.19
Need to take leave for follow-up visit	69	66.34
Stops medicines when feeling better	53	50.96
Stop medicines for religious reasons (fasting, Ramadan)	22	21.15

*Multiple responses included

The above table 8 depicts the various personal factors that were identified as reasons for non-adherence. The most common reason under personal factors was feeling of fatigue to take medicine regularly which was expressed by 74.03% of the respondents.

Table 9: Frequency and percentage distribution of factors of non-adherence to medication among SLE patients related to factors of knowledge and belief, n=104

Factors related to knowledge and belief	Perceived as a factor to non- adherence	
	Frequency	Percentage (%)
Believe on bad luck or karma	64	61.53
As improved conditions need not take medication any more	56	53.84
Believe on ayurveda, kabiraj, homeopathy medicines	33	31.73
Think that regular follow-up is not necessary	14	13.46
Can stop taking medicines without doctors advice	9	8.65
Believe that God can cure disease without taking medicines	9	8.65
Think that regular medicines is not necessary for illness	6	5.76

*Multiple responses included

Data presented in table 9 depicts the various factors related to knowledge and belief that were identified as reasons for non-adherence. The most common reason under this factor was believe that it was because of bad luck or karma which was expressed by 61.53% of the respondents.

Table 10: Frequency and percentage distribution of factors of non-adherence to medicines among respondents related to medicine, n=104

Factors related to medicines	Perceived as a factor for non-adherence	
	Frequency	Percentage (%)
Unavailability of free medicines	86	82.69
Too many medicines per day	86	82.69
Unpleasant taste of medicines always present	79	75.96
Physically and mentally exhausted to take medicines	75	72.11

*Multiple responses included

The above table 10 depicts the various medicine related factors that were expressed as important reason for non-adherence. The first among them was unavailability of free medicines which was cited as reason for non-adherence by 82.69% of respondents.

Table 11: Frequency and percentage distribution of factors of non-adherence to medication among respondents related to support system, n=104

Factors related to support system	Perceived as a factor for non-adherence	
	Frequency	Percentage (%)
Can not come to hospital alone to get medicine	81	77.88
Had no one in the family to accompany for follow-up visit	61	58.65
No one to remind to take medicines	48	46.15
Failure of family member to get medicines	21	20.19

*Multiple responses included

Data presented in table 11 presents the various support system related factors that were expressed as important reason for non-adherence. The first among them was could not come to hospital alone to get medicines which was cited as reason for non-adherence by 77.88% of respondents.

Table 12: Frequency and percentage distribution of factors of non-adherence to medication among SLE patient related to financial factors, n=104

Financial factors	Perceived as a factor for non-adherence	
	Frequency	Percentage (%)
Cost of medicines	87	83.65
No financial support from other member in the family	85	81.73
Inability to maintain the family with monthly income	81	77.88
Not able to visit hospital regularly for transportation fare	79	75.96
Not able to visit hospital regularly because of loss of earning on the day	70	67.3

*Multiple responses included

Data presented in table 12 depicts that under financial factors , the cost of medication stands out as the most important reason for non-adherence among 83.65% of respondents .

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Table 13: Finding of frequency and percentage distribution of factors related to non-adherence to medication among SLE patients related to organizational factors, n=104

Organizational factors	Perceived as a factor for non-adherence	
	Frequency	Percentage (%)
Distance between home and hospital	92	88.46
Have to wait long time to meet with doctor	90	86.53
Not able to follow all advices given by doctor	78	75.00
Not satisfied with treatment and follow-up session	37	35.57
Health care provider misbehaved during treatment/visit	30	28.84
Health care provider did not explain the treatment	20	19.23

*Multiple responses included

The above table 13 depicts the various organizational factors that were identified as reasons for non-adherence. The most common reason under organizational factors was distance between home and hospital which was expressed by 88.46% of the respondents.

Section IV
Findings related to the association between non-adherence to medication and selected demographic variables.

Table 14: Association between non-adherence to medication and selected demographic characteristics, n=104

Sample characteristics	Adherence score		Chi square
	Below median	At and above median	
Age (in years)			
<30	22	39	0.69
≥30	19	24	
Gender			
Male	07	07	0.76
Female	34	56	

$\chi 2df(1)=3.84$, $p>0.05$

Data presented in table 14 shows there was no significant association between adherence to medication and age (in years) of the respondents, there was no significant association between adherence to medication and gender of the respondents.

Table 15: Association between non-adherence to medication and selected demographic characteristics, n=104

Sample characteristics	Adherence score		Chi square
	Below median	At and above median	
Educational Qualification			
Illiterate	6	3	3.55
Up to Secondary	30	48	
Above Secondary	5	12	
Family income per month (in Rupees)			
Below 5000	6	8	1.24
5000-10000	30	42	
> 10000	5	13	
Occupation			
Housewife	25	36	6.19*
Students	8	23	
Private work/Business	8	4	

$\chi 2df(2)=5.99$, $p<0.05$

Data presented in table 15 depicts that there was no statistically significant association between adherence to medication and educational qualification of the respondents, there was no significant association between adherence to medication and family income per month (in rupees) of the respondents. It also reveals that there was a statistically significant association between adherence to medication and occupation of the respondents (p <0.05).

Table 17: Association between non-adherence to medication and selected demographic characteristics, n=104

Sample characteristics	Adherence score		Chi square
	Below median	At and above median	
Duration of taking medicines (in years)			
<5	15	43	10.09*
≥ 5	26	20	
Duration of illness (in years)			
<5	15	43	10.09*
≥ 5	26	20	
Number of prescribed medicines per day			
<5	8	12	0.003
≥ 5	33	51	

$\chi 2df(1)=3.84$, $p<0.05$

Data presented in table 17 shows there was a statistically significant association between adherence to medication and duration of taking medicines (in years) of the respondents(p<0.05) and a statistically significant association between adherence to medication and duration of illness (in years) of the respondents(p<0.05). It also reveals that there was no significant association between adherence to medication and number of prescribed medicines per day of the respondents.

4. Major Findings of the Study

Findings related to the description of demographic characteristics of the respondents
- Most of the respondents (58.65%) belonged to the age group of below 30 years.
- Majority of the respondents (86.53%) were females.
- Most of the respondents (48.07%) were educated up to primary level.
- Majority of the respondents (69.23%) had monthly family income Rs. 5000-10000.
- Most of the respondents (58.65%) were housewife.
- Majority of the respondents (60.57%) were married.
- Most of the respondents (75.96%) had 3-5 number of family members.
- Majority of the respondents (55.76%) were suffering from less than 5years.
- Most of the respondents (80.76%) took more than 5 prescribed medicines per day.
- Majority of the respondents (55.76%) duration of taking medicines (in years) was less than 5 years.
- Most of the respondents (56.73%) had history of co-morbidities. Among them 21.15% respondents had history of hypothyroidism.

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Findings related to level of adherence to medication among patients with SLE

- The data showed that majority of the respondents (73.07%) had low or poor adherence to medication, 26.92% respondents had medium adherence while no respondents had high or good adherence to medication.

Findings related to factors related to non-adherence to medication among patients with SLE

- In this study the findings showed that with mean percentage of 88%, factors related to medicines stands out as the most important factors contributing to non-adherence to medication.
- The most common reason under personal factors was feeling of fatigue to take medicine regularly which was expressed by 74.03% of the respondents.
- It was because of bad luck or karma which was expressed by 61.53% of the respondents, was the most common reason under knowledge and belief.
- Unavailability of free medicines and have to take too many medicines per day were cited as most contributing reason for non-adherence by 82.69% of respondents under factors of medicines.
- The most contributing reason under support system was could not come to hospital alone to get medicines which was cited as reason for non-adherence by 77.88% of respondents.
- Under financial factors, the cost of medication stands out as the most important reason for non-adherence with 83.65% of respondents citing that as a reason.
- The most common reason under organizational factors was distance between home and hospital which was expressed by 86.53% of the respondents.

Findings related to the association between non-adherence to medication and selected demographic characteristics

- The chi square value (χ2) showed statistically significant association between adherence to medication and selected demographic variables like occupation, duration of illness (in years), duration of taking medicines (in years) at 0.05 level of significance.

5. Discussion in Relation to Other Studies

Findings related to the level of adherence to medication among patients with SLE.
The findings of this study are consistent with the study conducted by **Moreno PS, Sabio J, Mármol PJ (2018)** which was conducted to assess adherence to treatment in patients with systemic lupus erythematosus in Spain. The results showed that 64% of the respondents with SLE were non-adherent to treatment.[32]

The findings of this study are supported with the study conducted by **Alsowaida N, Alrasheed M, Mayet A (2018)** showed that 62.1% of patients non- adhere to medication regimen.[46]

The findings of this study are also consistent with the study conducted by **Prudente LR, Diniz J S, Ferreira TXAM, Lima DM (2016)** in Brazil showed that medication non-adherence in patients with SLE was 54.1% .[35]

Findings related to factors related to non- adherence to medication among patients with SLE
This findings of this study are consistent with the study conducted by **Ahmed I, Ahmad NS, Ali S, Ali S, George A, Saleem Danish H, et al. (2018)** showed that reasons such as forgetting and feeling fatigue to take medicines were the most important reason of non-adherence to medication regimen. [48]

The study findings are supported with the study conducted by **Emamikia S, Gentline C, Enman Y, Parodis I. (2022)**, the results showed that some patients mentioned that multiple medications and complicated schedules of varying daily doses constituted a reason for impaired adherence documented as a factor contributing to non-adherence. [49]

The study findings are consistent with the study conducted by **Garcia-Gonzalez A, Richardson M, Garcia Popa-Lisseanu M, Cox V, Kallen MA, Janssen N, et .al. (2018)** ,the results showed that no financial support from other member in the family was identified as an important factor to non-adherence by 81.73% .[50]

The findings of the study are supported by a study conducted by **Sae-lim O, Laobandit I, Kitchanwit P (2020)** in Thailand, the results showed that age , reimbursement scheme, pill number, and attitude towards SLE were associated with non-adherence in patients with SLE. [27]

Finding related to association between non-adherence to medication with selected demographic variables
The findings of the study are inconsistent with the study conducted by **Alahmadi JS, Faezi ST, Mahmoudi M (2019),** the results showed that there was no significant relationship between demographic and clinical variables of the patients and adherence to their medication. [2]

The findings of the study are inconsistent with the study conducted **by Moreno** unemployed, living with a partner and alcohol abuse were associated with low treatment adherence. [32]

6. Conclusion

The study highlights the critical need for interventions to address medication adherence among SLE patients. Factors such as medication availability, financial barriers, and personal beliefs significantly influence adherence. Future research should explore interventional strategies to improve adherence and enhance patient outcomes.

7. Limitations

The present study was limited to
- A small number of participants (104) limiting generalization of findings.
- Only selected out-patient department of selected hospital, Kolkata which further limited the generalization of findings.
- The subjectivity of the self report of the respondents further limiting the study findings.

8. Recommendations

On the basis of findings, the following recommendations are offered for future research:

- A similar study can be conducted on larger number of samples to generalize findings and to find strong statistical association.
- A longitudinal study can be conducted to assess the level of adherence to medication among patients with SLE.
- Future study could be done to find out the effect of interventional protocol to enhance the adherence level among patient with SLE.
- A study could be conduct to find out the effect of good communication and effective patients education strategies focused to improve the adherence among SLE patient.

Conflicts of interest: None

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