

Factors Affecting Adherence of Medication for Patients with Systemic Lupus Erythematosus

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Abstract

Background: Systemic Lupus Erythematosus (SLE) is a multisystem, autoimmune disease, it affect all organ systems or tissues, involvement of the skin, joints, central nervous system, and kidneys are among the most frequent manifestations. SLE is a chronic disease, the patients are generally treated with long-term regimens or even life-long immunomodulatory or immunosuppressive medications. Adhering to medications can be a challenge for patients with SLE. **Objectives:** This study aimed to identify the factors affecting adherence of medication for patients with systemic lupus erythematosus. **Setting:** The study was conducted at the Blood Disease and Immunology inpatient Department of Alexandria Main University Hospital and the affiliated Outpatient Clinic. **Subjects:** This study comprised a convenience sample of 60 adult patients of both sexes and diagnosed with systemic lupus erythematosus. **Tools:** three tools were used Tool I: Patient's Sociodemographic Characteristics , clinical data & Patient's Knowledge Structured Interview Schedule .Tool II Korean Version of the Hill-Bone Medication Adherence Subscale (HBMA-K) ,and tool III : Factors Affecting SLE patients' Adherence to medications checklist. **Results:** The study result revealed that more than half of studied patients had fair knowledge level regarding SLE. More than half of studied patients had low adherence to SLE medication, finally the patient related factors were the most factors affecting the adherence level on other hand Condition-related factors rated the lowest factors affecting the adherence level . **Conclusion:** this study revealed that more than half of the studied patient with SLE were low level adherence to their medications, and more than half of them had poor knowledge related to SLE disease. In addition to it was found that patient related factors are most factors affect medications adherence for SLE. **Recommendations** Develop and apply an educational sessions in order to improve patients knowledge regarding the SLE disease and consequence of non adherence with medication. provide communication between the healthcare provider and the patient, as well as simpler prescription regimens, to enhance medication adherence.

Keywords: Systemic lupus Erythematosus SLE, Adherence of Medication, Factors Affecting on Adherence .

Introduction

Systemic lupus erythematosus (SLE) is an autoimmune disease that affects the connective tissue in different organs. It is a long-term illness that causes organ dysfunction (Rose;2022). SLE can cause a wide range of symptoms, including joint pain, rash, photosensitivity, and fatigue, as well as irreversible organ damage, hospitalization, and death. It has been linked to significant morbidity and mortality, as well as significant negative effects on patients' perceptions of health and daily activities (Baligar et al ;2018) .

Patient adherence to therapy guidelines, as well as early diagnosis and treatment of SLE,

are critical for improving patient outcomes. In SLE, however, poor adherence to drug therapy has been linked to an increased risk of flares, morbidity, hospitalizations, and a poor renal outcome. As a result, it's critical to comprehend the prevalence and factors linked to medication nonadherence in these patients, as this will likely aid in the development of specific interventions to improve adherence and outcomes. (Mendoza-Pinto et al ;2021) .

Unfortunately, there is currently no cure for SLE. Treatment of SLE is frequently complicated, requiring long-term pharmacological medication. Treatment plans aim to achieve illness remission or low disease activity, as well as to prevent disease flare-ups,

stop tissue damage, decrease complications, and improve quality of life. (Golder, & Tsang-A-Sjoe,2020). Antimalarial agents (AMA), glucocorticoids (GCs), and traditional synthetic or biologic disease-modifying anti-rheumatic medications are commonly used to treat SLE. Adherence to medications can be difficult for patients with chronic diseases; . Patients with SLE are reported to be non-adherent to treatment in 43-75 % of cases. (Mehat et al ;2017) .

Systemic lupus erythematosus is associated with several factors that may make these patients at especially high risk for treatment nonadherence, including cognitive and psychological manifestations, frequently complex treatment regimens, fluctuating symptoms, and a disproportionate prevalence of disease among people of lower socioeconomic status. The seriousness of SLE can range from mild to life-threatening. People with SLE patients who receive proper medical care, preventive care, and education can improve their function and quality of life dramatically. (Shi et al ,2020) .

Medication adherence and drug effectiveness are two important factors of therapeutic success. As a result, drug adherence is critical for achieving desired clinical outcomes (Kvarnstrom et al., 2021). Medication adherence is described as “the degree or extent of conformity to the instructions regarding day-to-day treatment by the health care provider concerning the timing, dosage, and frequency (Pina et al , 2021). Patients who adhere to their treatment plan have better illness management, higher remission rates, improved physical function, slower disease progression, and a lower likelihood of escalation to more aggressive treatment. (Kvarnstrom, Airaksinen, & Liira 2018) . Non-adherence to prescriptions reduces drug efficacy, delays symptom recovery, allows disease progression, and requires the inclusion of new interventions and medications to maintain optimal symptom control, which increases the risk of pharmacological interactions and adverse effects. (Minhas et al., 2021).

Medication adherence is a multifaceted issue that is influenced by a number of factors.

Factors associated with medication adherence are classified by the World Health Organization into five categories: social and economic factors (e.g. medication cost), healthcare team and system-related factors (e.g. lack of knowledge and training of healthcare providers), disease-related factors (e.g. disease-related disability), therapy-related factors (e.g. medication regimen complexity), and patient-related factors (e.g. perceptions and expectations of the patient) (Sae-Lim et al,2021)

Nurses are critical in providing advice and education in combination with the teach-back method, proposing and implementing a feasible medication regimen (e.g., dose simplification, medication schedules, and involving informal caregivers in medication management), assisting with medication intake, motivating patients to change their medication intake behaviour, and providing medication-taking reminders (e.g., written or phone reminders and (automatic) pill dispensers). (Walker et al ,2014).

The significance of the study:

The consequences of adherence problems in SLE have not been thoroughly investigated. Existing studies suggest that poor adherence is linked to a poor SLE prognosis in terms of service consumption and that there is a link between medication adherence and increased emergency hospitalizations among SLE patients. Thus, identifying the factors that influence treatment adherence allows for the development of strategies to improve adherence and avoid problems caused by non-adherence .(Dey et al 2021), Hence, the goal of this study was to figure out what factors influence medication adherence in SLE patients.

Aim of the study

Identify factors affecting adherence of medication for patients with systemic lupus erythematosus

Research question:

What are the factors affecting adherence of medication for patients with systemic lupus erythematosus?

Materials and Method

I- Materials

Research design:

A descriptive research design was utilized to accomplish the aim of the present study

Setting:

The study was conducted at the blood disease and immunology inpatient department of Alexandria Main University Hospital and the affiliated Outpatient Clinic .

Subjects:

A convenience sample of 60 adult patients of both sexes admitted to above mentioned setting and diagnosed with systemic lupus erythematosus.

The study sample was estimated based on the Epi-info -7 program using the following parameters:

- 1- Population size: 150 patients
- 2- Expected frequency: 50%
- 3- Acceptable error: 10%
- 4- Confidence coefficient: 95%
- 5- Minimum sample size: 60

The patients, who participated in this study, were chosen based on the following criteria:

1. Adult patients diagnosed with systemic lupus erythematosus since one year. aged from 20 to 60 years.
2. Able to communicate verbally
3. Patients willing to participate in the study.

Tools of the study :

Three tools were used to collect the necessary data

Tool I: Socio-Demographic, Clinical Data, and Patient's Knowledge Structured Interview Schedule:

This tool was developed by the researcher after reviewing relevant literature(Alhazami et al ;2020; Lavielle et al 2018) , and. It consisted of three parts:

Part I: Patient's Sociodemographic

Characteristics: this part included data related to; age, sex, educational level, marital status residence area, income,treatment payment system and occupation.

Part II: Patients' Clinical Data: This part included data such as; medical history, how disease discovered , duration of disease, names of prescribed medications , sources

of health teaching,and previous hospitalization.

Part III: SLE Patient's Knowledge Structured Interview Schedule

This tool was developed by the researcher, after reviewing related literature (Pirri et al ;2021, Moustafa et al ;2020& Fairley et al ;2020) , to assess patient's knowledge about SLE disease.

It included questions about definition ,causes, signs and symptoms, ,diagnostic studies, specific laboratory investigations , management modalities for SLE and complications.

Also this tool included questions related Knowledge about SLE medications as name, route, dose, frequency, actions, side effects, problems of non-adherence, types of medications, number of medications taken per day, patient's actions if side effects occur, what to do if you forget a dose?

Scoring System:

The patients' knowledge answers were scored on a 3 points Likert Scale; a score of (2) point was given to "correct and complete answer "while score (1) point was given to "correct and incomplete answer" and score (0) was given to "wrong answer or do not know". This score were converted to percent.

Patients who had knowledge score less than 50 % were categorized as having "poor knowledge level", while those who had knowledge score 50 to less than 75% were categorized as having "fair knowledge", while those who had knowledge score 75% and more were categorized as having "good knowledge level".

Tool II: Korean Version of the Hill-Bone Medication Adherence Subscale (HBMA-K):

This subscale was adapted by the researcher from the original Hill-Bone Compliance Scale which was developed by Kim, et al (2000) , for reviewing patient's medication-taking behavior and barriers to adherence .It consist from 9 items Each item can be answered on a 4-point Likert-scale (1 = none of the time, 2 = some of the time, 3 = most of the time, and 4 = all the time).

▪ A total score of each item was calculated; it was summed up into number and then transferred into percent score. Patients' adherences were evaluated as the following:

- ✓ Scoring of less than 50% will be considered as "low adherence".
- ✓ Scoring of 50% to 75% will be considered as "moderate adherence"
- ✓ Scoring more than 75% will be considered as "high adherence"

Tool III : Factors Affecting SLE patients' Adherence to medications checklist

This tool was developed by the researcher, after reviewing related literature (Sae-Lim et al., 2021, Kvarnstrom et al., 2021 & Bae et al., 2016; Behnood-Rod et al., 2016) ,to identify the factors affecting SLE patients' adherence to medications. It was composed of 52 items in form of statements grouped into 5 dimensions namely Educational , social and economic dimensions that consisted from 12 statement ,health care system dimensions that included 10 substatment , -Condition-Related dimensions that consisted from 4 statement, Therapy related dimensions that contained 8 statement, Patient related dimensions in the form of two main factor physical factors contained 5 statement and Psychological and behavioral factors contained 13 statement.

The tool covered 52 statements with "Yes" or "No" answer. It was represented statistically as number and percent .

Methods

1. An official letter was obtained from the administrative office & Ethical Committee of the Faculty of Nursing, Alexandria University.
2. A written approval was obtained from the hospital administrator and head of blood disease and immunology department, after explanation of the study aim.
3. Tool I, II, III was developed by the researchers after reviewing related literature.
4. Tool II it was adopted from Korean Version of the Hill-Bone Medication Adherence Subscale
5. Tools were tested for content validity, completeness and clarity of items by five faculty staff of Medical –Surgical Nursing in Alexandria University and Comments and suggestions of jury were considered and the tools were modified accordingly .
6. The reliability of the tools was measured by Cronbach's alpha test tool I=0.95 and tool II=0.80, III= 0.76 indicating reliable tools.
7. Pilot study was carried out on 6 patients that representing 10% of total studied subjects with SLE to ascertain the clarity, feasibility and applicability of the developed tools, then the necessary modifications were done. Patients included in the pilot study were excluded from the total number of study subjects.
8. Data were collected during the morning shift on Sunday, Tuesday and Thursday from each week at the Outpatient Clinic .
9. The patients were interviewed individually for 20-30 minutes after explaining the purpose of the study
10. Data were collected throughout a period of two months from the beginning of August 2021 to the end of september 2021.

11. Ethical Considerations:

- Informed consent was obtained from each study subject after explanation of the aim of the study.
- The anonymity and confidentiality of patients' responses were assured.
- The participants were informed that their participation was not obligatory and they had the right to refuse the participation in the study.
- The patients were informed that they have the right to withdraw from the study at any time.

Limitation of the study

- Variety of follow-up sitting (In patient department and Outpatientclinics)
- Unsuitable environment, as interview were held in the out patient clinics where there were too much noise, lack of privacy and intrusion of strangers patient

Statistical Analysis:

- After the data were collected, they were coded and transferred into special design formats, so as to be suitable for computer feeding. Following data entry, checking and verification processes were carried out to avoid errors during data entry. Data was computed and statistically analyzed using the Statistical Package for Social Sciences "SPSS" software version 20.
- 1- Count (numbers) and percentage, used for describing and summarizing qualitative data.

- 2- Mean, median and standard deviation, used for describing and summarizing quantitative data.
- 3- Minimum- Maximum used for presenting non parametric quantitative data.
- 4- Significance of the obtained results was judged at the 5% level.
- 5- Cronbach's alpha reliability test: It was used to measure the reliability of the developed tools.

The used tests were

- 1 - **Student t-test:** For normally distributed quantitative variables, to compare between two studied groups
- 2 - **F-test (ANOVA):** For normally distributed quantitative variables, to compare between more than two groups
- 3 - **Pearson coefficient:** To correlate between two normally distributed quantitative variables

Results

Table (1) Shows the distribution of studied patients according to their socio-demographic characteristics. The age of the studied patients ranged from 20.0 to 59.0 years with a mean age of 49.15 ± 6.02 and Min-Max age 20-49 years old. The majority of studied patients (93.3%) were female and 75.0% of them were married. The table also shows that about 48.3% of the studied patients were illiterate. Regarding to treatment payment system about 70.0% of the studied patients on state expense, about 73.3 % of the studied patients from urban area, the majority of studied patient 86.7% discovered SLE disease by suffering from symptom.

Table (2) Distribution of studied patients according to level of adherence with SLE medication, this table illustrated that around two fifth 41.7% of the studied patient had Some of the time adherence when asked about how often do you forget taking the SLE medications?, while more than half 51.7% of the studied patient had Some of the time adherence when asked about how often do you decide not to take SLE medications?, about 78.3% of the studied patient had all of the time adherence regarding question of how often do you forget to get prescriptions filled?, while 60.0% of the studied patient had Some of the time adherence when asked about how often do you run out of SLE medications? regarding question of how often do you omit or

skip your SLE medications ? 63.3% of the studied patient answer most of the time adherence. about 61.7% of the studied patient had all of the time adherence when asked about how often do you miss taking SLE medications when he feel better?, while 55.0% of the studied patient had Some of the time adherence when asked about how often do you miss taking SLE medications when he feel sick? regarding question of how often do you miss taking when he is not caring of dose (careless)? 81.7% of the studied patient answer most of the time adherence , while 53.3% of the studied patient answer most of the time adherence when asked about how often do you take alternative SLE medications?

Regarding the educational, social and economic factors, the study finding revealed that three quarters (76.7%) of the studied patients couldn't read and understand the medical guidelines for treatment and the majority (83.3%) of them reported that family members were helping them to take medications regularly. Also, this table revealed that nearly three quarters (76.7%) of the studied patients were having difficulty in transportation to go to the hospital and the health care institutions were far away from their home. **Table (3)**

Regarding treatment schedule, the majority (80%) of the studied patients were having a full day treatment schedule, while (70%) of them didn't have health insurance. Concerning medications cost, two third (68.3%) of the studied patients reported that the medications were sometimes too expensive to buy. Also, it was found that all of the studied patients (100%) sometimes didn't have a desire to take medications because of some thoughts as the drug affects the kidneys and liver, while (83.3%) of the studied patients didn't increasing, decreasing or stopping the dose without doctor advice.

Regarding the health care system factors, it was found that the majority (88.3%) of the studied patients reported that the doctor didn't show them all the available medications for SLE and more than half (78.3%) of them reported that the doctor explained to them how to use the medications, the importance of their use, side effects, and how to deal with them, also two-third (76.7%) of the studied patients reported that the doctor was allowing them to ask questions and

answer them while only (13.3%) of the studied patients reported that the doctor and nurse motivate them to take their medications regularly, while the majority (88.3%) of them said that the doctor's instructions on how to use the medications were unclear.

In addition to the majority (86.7%) of the studied patients reported that the health institution they're following didn't hold educational courses about the importance of medications adherence, while more than three-quarter (80%) of them said that the doctor was prescribed more than one medications to be taken at the same time. Also, three quarters (75%) of the studied patients were skipping some visits because of the long time waiting in the clinic, and the majority (80%) of them reported that the doctor who examined them at the first time did not follow them at every visit.

Regarding the condition related factors, the study finding revealed that the majority (88.3. %) of the studied patients were thinking that the SLE is a chronic disease and can't be cured. Regarding symptoms around two third (68.3%) of the studied patients were having symptoms that affect daily life activities, and (90%) of the studied patients symptoms increase to them despite taking their medications, while the vast majority (93.3 %) of the studied patients were having psychological problems as depression because of taking medications.

Also, Table (3) Showed distribution of the studied patients according to factors associated with their medications adherence. **Regarding the therapy-related factors**, the table revealed that the majority (88.3%) of the studied patients were taking many numbers of medications and its dose per day. While (78.3%) of them didn't affected by injection route. Also, more than two-third (76.7%) of the studied patients reported that the treatment period was long so they can't take their medications regularly. Concerning the doctor frequently changes the medications regimen it was found that the majority (86.7) of the studied patient reported no. regarding the positive effect of medications, more than two-third (88.3%) of studied patients reported that the action of medications was taking a long time to start, While the majority (88.3%) of them the medications caused unwanted side effects to them, also more

than two-third (80%) of them the medications were affecting their daily life activities

Regarding patient-related factors, it included two subcategories; physical factors and psychological & behavioral factors. **Concerning physical factors**, the study finding revealed that (13.3%) of the studied patients had vision problems, while the majority (93.3%, 93.3%) of them didn't have hearing problems and memory problems respectively, and more than two-thirds (81.7%) of them didn't have movement problems, and the majority (88.3) of them didn't have swallowing problems.

Concerning psychological and behavioral factors, the table revealed that the two third (70%) of the studied patients had information about SLE disease, while three quarters (76.7%) of them didn't knew the severity of the disease and its complications, and the majority (81.7) of the studied patients knew the need for the medications. In addition to only (31.7%) of the studied patients were expecting that the treatment was beneficial and had a positive result for the disease, while the majority (76.7%) of them knew the importance of taking the medications regularly. Also, more than half (86.7%) of the studied patients had the self-confidence to be committed to the follow-up schedule and taking the treatment regularly.

Regarding dependence on motivation, the table showed that the majority (81.7%) of the studied patients didn't depend on the motivation of others to taking medications, while (85%) of them had a fear of unwanted side effects. Also, (11.7%) of the studied patients had fear of dependence on treatment and not to dispense with it, and the majority (83.3%) of them didn't feel stigmatized by the disease, in addition to (23.3%) of the studied patients were feel stress, anger, and anxiety when taking treatment, while the majority (93.3%) of them didn't use substance abuse.

Table (4): revealed that the patient related factors rated the highest factors with high main score (21.85 ± 2.00) . While Condition-related factors rated the lowest factors with low main score (4.56 ± 1.51).

Table (1): Frequency distribution of studied patients according to their socio-demographic characteristic

Sociodemographic		N	%
▪ Sex	Male	4	6.7
	Female	56	93.3
▪ Age Min. – Max. Mean ± SD.	20.00 –49.00		
	49.15± 6.02		
▪ Marital status	Single	2	3.3
	Married	45	75.0
	Widow	8	13.3
	Divorced	5	8.3
▪ level of education	Illiterate	29	48.3
	read and write	16	26.7
	primary education	10	16.7
	Preparatory education	3	5.0
	secondary education	2	3.3
▪ Residence area	rural	16	26.7
	urban	44	73.3
▪ Treatment payment system	Health Insurance	8	13.3
	State Expense	42	70.0
	Patient Expense	10	16.7
▪ How disease discovered (SLE)	Discovered by periodic check up	3	5.0
	Discovered by suffering from symptoms	52	86.7
	Accidental discovered	5	8.3

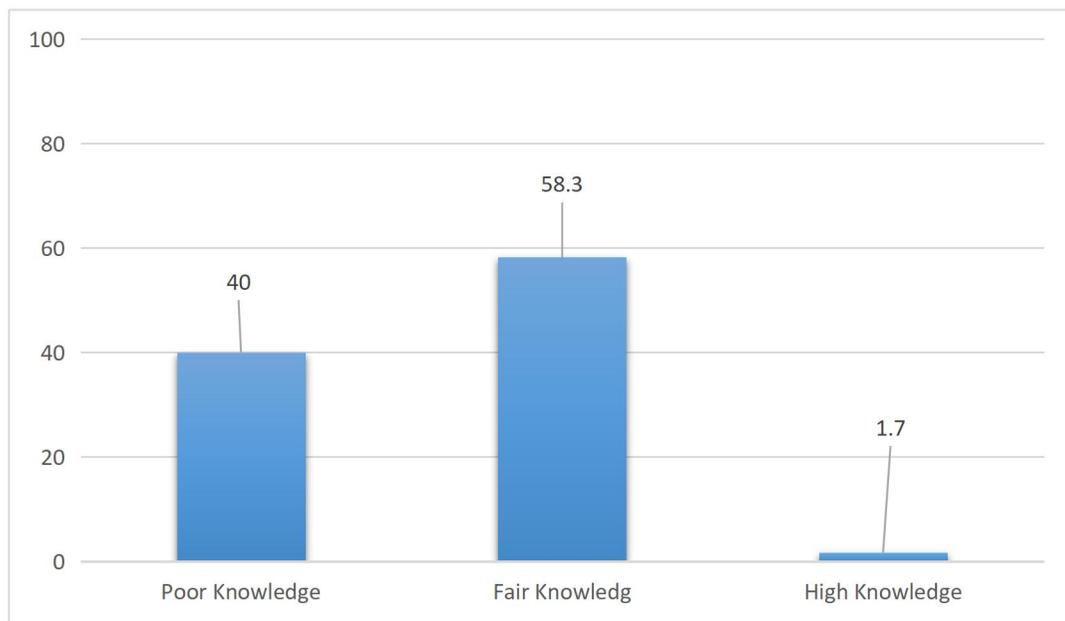


Figure (1): Show distribution of the studied patients according to total knowledge regarding SLE

Table(2): Distribution of studied patients according to level of adherence with SLE medication

Adherence items	Category	N	%
How Often Do You Forget Taking The SLE Medications	All of the time	5	8.3
	Most of the time	20	33.3
	Some of the time	25	41.7
	None of the time	10	16.7
How Often Do You Decide Not To Take SLE Medications	All of the time	11	18.3
	Most of the time	31	51.7
	Some of the time	18	30.0
How Often Do You Forget To Get Prescriptions filled	All of the time	47	78.3
	Most of the time	12	20.0
	Some of the time	1	1.7
How Often Do You Run Out Of SLE Medications	All of the time	7	11.7
	Most of the time	36	60.0
	Some of the time	17	28.3
How Often Do You Omit Or Skip Your SLE Medications	All of the time	5	8.3
	Most of the time	38	63.3
	Some of the time	17	28.3
How Often Do You Miss Taking SLE Medications When He Feel Better	All of the time	37	61.7
	Most of the time	17	28.3
	Some of the time	5	8.3
	None of the time	1	1.7
How Often Do You Miss Taking SLE Medications When He Feel Sick	All of the time	9	15.0
	Most of the time	10	16.7
	Some of the time	33	55.0
	None of the time	8	13.3
How Often Do You Miss Taking When He Is Not Caring Of Dose(Careless)	All of the time	6	10.0
	Most of the time	49	81.7
	Some of the time	5	8.3
How Often Do You Take Alternative Else's SLE Medications	All of the time	23	38.3
	Most of the time	32	53.3
	Some of the time	5	8.3

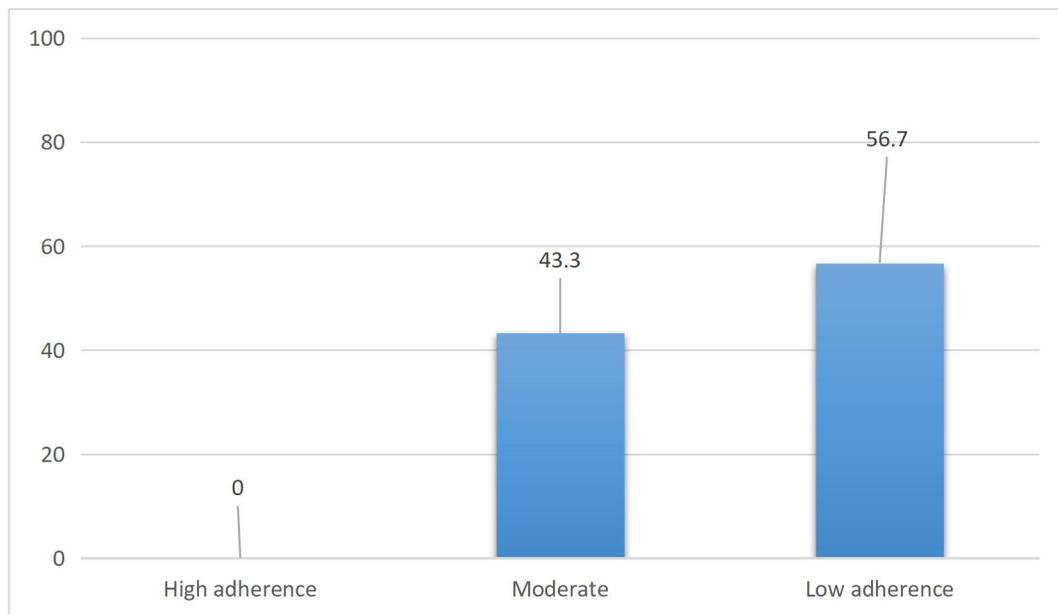


Figure (2): Show distribution of the studied patients according to total adherence with SLE medication.

Table (3): Shows distribution of the studied patients according to factors associated with their medications adherence .

Factors	Yes		No	
	No.	%	No.	%
Educational, Social and Economic Factors				
- Medical terminologies, the doctor uses during treatment prescription, are not understood	52	86.7	8	13.3
- You have the ability to read and understand the medical guidelines for treatment	14	23.3	46	76.7
-The doctor gives instructions and advice on treatment to the family members, but not to you	15	25	45	75
- Family members help you to take medication regularly	50	83.3	10	16.7
- There is a difficulty in transportation to go to the health institution to follow up	46	76.7	14	23.3
- The treatment schedule on the day is full so you forget some of them	48	80	12	20
-The pharmacy is in a place that is some time too difficult for you to reach to buy medication	9	15	51	85
- Health care institutions are far away from home	53	88.3	7	11.7
- You have health insurance to get the medication	18	30	42	70
- The medication is sometimes too expensive to buy	41	68.3	19	31.7
- You have no desire to take medications because of some thoughts such as: the drug affects the kidneys and liver	60	100	0	0
- You Increase, decrease or stop the dose without the doctor's advice	10	15.7	50	83.3
Health Care System Factors				
- The doctor shows to you all the available medication for SLE treatment and see your opinion before the prescription	7	11.7	53	88.3
- The doctor explain to you how to use the medications , the importance of its use , side effects and how to deal with it	47	78.3	13	21.7
- The doctor gives you the opportunity to ask questions and answer it	46	76.7	14	23.3
- Your doctor and nurse motivate you to take your medication regularly	8	13.3	52	86.7
- The health institution you're following holds educational courses about the importance of medication adherence	8	13.3	52	86.7
- The doctor's instructions on how to use medication are unclear and understandable	53	88.3	7	11.7
- More than one medication is prescribed by the doctor to be taken at the same time	48	80	12	20
- The doctor is sometimes absent on the follow-up days.	4	6.7	56	93.3
- You sometimes skip Some visits because of the long time waiting in the clinic	45	75	15	25
- The first-time doctor who examined you is following you at every visit	12	20	48	80
Condition-Related Factors				
- You think that this disease is chronic and can't be cured	53	88.3	7	11.7
- You have no symptoms that affect daily life activities such as joints pain so you don't take medication	41	68.3	19	31.7
- Symptoms increase despite taking medication	54	90	6	10
- Taking medication will cause you psychological problems such as depression	56	93.3	4	6.7

Table(3):cont.

Factors	Yes		No	
	No.	%	No.	%
Therapy Related Factors				
- The number of medications and their dose is so many per day.	53	88.3	7	11.7
- Treatment requires injection which makes it difficult to sustain it	47	78.3	13	21.7
- The treatment period is long so you can't take it regularly	46	76.7	14	23.3
- The doctor frequently change the medication regimen	8	13.3	52	86.7
- The positive effect of medication such as pain relief takes a long time to occur after taking the medicine	53	88.3	7	11.7
- Taking medication regularly is a stigma in society	8	13.3	52	86.7
- The drug causes unwanted side effects	53	88.3	2	3.3
- Taking medication regularly affects daily life activities such as feeling fatigued	48	80	12	20
Patient Related Factors				
Physical factors				
- Having vision problems makes you unable to read the instructions for using the medicine	8	13.3	52	86.7
- Having hearing problems that make it difficult to communicate with your doctor	4	6.7	56	93.3
- Having memory problems that make you forget some doses or take overdoses	4	6.7	56	93.3
- You have problems with movement or you have a severe muscle relaxation that makes you unable to take medicine or bring it from the pharmacy	11	18.3	49	81.7
- You have trouble swallowing. (You cannot swallow large tablets or large capsules)	7	11.7	53	88.3
Psychological and behavioral factors				
- You have information about the disease	42	70	18	30
- Know the severity of the disease and its complications	14	23.3	46	76.7
- Know what the reasons for the need to the drug	49	81.7	11	18.3
- Expect that treatment is not beneficial and doesn't have a positive result for the disease	19	31.7	41	68.3
- You are aware of the importance of taking the treatment regularly	46	76.7	14	23.3
- You have self- confidence to be committed to the follow-up schedule and having the treatment regularly.	52	86.7	8	13.3
- Depends on the motivation of others to take treatment	11	18.3	49	81.7
- You have a fear of unwanted side effects	51	85	9	15
- Fear of dependence on treatment and not to dispense with it	7	11.7	53	88.3
- Feeling stigmatized by the disease	10	16.7	50	83.3
- Your doctor or nurse will frustrate you (such as the disease is chronic illness and treatment only treats the symptoms)	42	70	18	30
- Feel stress, anger and anxiety when taking treatment	14	23.3	46	76.7
- Substance abuse make you dispensed on treatment	4	6.7	56	93.3

Table (4): Shows rank order of factors associated with medications adherence among patients with SLE.

Rank	Factors associated with Medications Adherence	Min. – Max.	Mean ± SD.
1-	Therapy related factors	9– 14.00	11.21 ± 1.23
2-	Condition-related factors	2 – 7.00	4.56 ± 1.51
3-	Educational, social and economic factors	12 – 19.00	15.20 ± 1.89
4-	Patient related factors	19 – 33.00	21.85 ± 2.00
5-	Health care system factors	10.0 – 15.00	12.38 ± 1.89

Discussion

The medication regimen of the chronic diseases demands long term drugs administration and following up. It is well known that the treatment failure caused by poor medication adherence leads to frequent re-hospitalizations, poor outcomes of the disease and increased healthcare costs (Chehab et al 2018). According to the World Health Organization (WHO), non-adherence to the medical regimen consists a major clinical problem in the management of patients with SLE. Rates of nonadherence with any medication treatment is consider one of the major health problems that require specific attention (Kotuniuk & Chojdak-Lukasiewicz, 2022).

Therapeutic success depends on both drug efficacy and medication adherence. Therefore, medication adherence is essential for desired clinical outcomes. Several interacting factors can influence patients' adherence behavior including disease-related factors, patient-related factors, health professional/health service-related factors, therapy-related factors and social and economic related factors (Zhang et al., 2019 & Xie et al 2018). Therefor this study was carried out to identify factors associated with medication adherence among SLE patients.

Concerning sociodemographic data, the present study showed that the age of the studied patients ranged from 20 to 59 years old . This results supported by (Dallera ,2013) who reported that the age of 15 to 44 years are at greatest risk of developing SLE ,also stated the immune system defect occurs during the fetal development period, which makes any person with this defect vulnerable to developing SLE disease at any age.

Regarding the gender, the present study revealed that the majority of the studied patients were females. This finding may be related to the fact that the female hormonal changes during menstruation, pregnancy and early menopause , also stressful situation that the women may be exposed to it, may lead to increase secretion of stress hormone which negatively affect immune system (Ysrraelit, & Correale,, 2019) .

Concerning level of education and area of residence , the present study showed that nearly half of the study patients were illiterate and the

majority of the patients were from rural area , these results were supported with (Xie., Yang., Nie., Chen, & Li. ,2018) who reported that one of the possible reasons may be the fact that rural communities usually lack health care services, and poor availability of health care increases the risk of nonadherence ,the higher risk of non-adherence in rural patients is their low level of education. Nonadherence in their study may be associated with lower level of education.

Regarding patients knowledge about SLE, the present study revealed that .More than half of studied patients had fair knowledge level regarding SLE. These findings congruent with (Alrasheed et al., 2018) who reported that the majority of the patients were aware of their own diagnosis, also in this regard (Morenoa et al ,2018) who reported that non-adherence to treatment is usually a clinical problem in patients with SLE so, Increasing the knowledge of predictors of treatment adherence can be meaningful in the clinical setting.

Regarding the adherence level to SLE medications, the current study found that more than half of the studied patients had low dherence to medications,. This result agree with (Alrasheed et al., 2018) who found that Medication non-adherence is highly prevalent among Saudi SLE patients. Routine screening could facilitate the early detection and management medication adherence. **In this regard** (Tan et al 2021) reported that lack of sufficient adherence to medications appears to be a multifactorial problem, Also these findings in line with (Saeedeh et al 2019) who reported that non-adherence to therapy is common in SLE patients and is associated with adverse clinical outcomes and was a high prevalence of drug non-adherence in SLE patients.

Regarding the educational, social and economic factors, the finding of the current study showed that three-quarters of the studied patients couldn't be read and understand the medical guidelines. It could be related to the fact that most of the studied patients were illiterate , and this makes them not aware about their disease and its complications and the importance of its treatment, which is considered an important factor for medication non adherence. This result is supported by (An &Wang 2014) who reported that non adherence in their study was associated

with lower level of education and may be attributed to the fact that patients with lower level of education often have less knowledge of medication and poor comprehension of consequences of nonadherence. Thus, improving the medication knowledge of patients, especially of patients with low education, may help to improve the adherence in patients with SLE

Furthermore, more than half of the studied patients reported that their family members were helping them to take medication regularly. In the fact social support play important role in the life of SLE patients as the patients sometimes suffering from disease flares and can't be bringing their medications by themselves also may forget some doses and family member reminded them ,also these results supported by (**Eslami, et al 2020**) people with social support experienced moderate uncertainty about their illness and were able to better cope with the disease. Subsequently, they were also more likely to follow their treatment and had improved quality of life. Also these findings consistent with (**Moustafa, et al 2020**) who stated that strong family support is vital for the management of chronic conditions. Patients who had little or no family support were noted to be poorly adherent to medications. These findings come in contrast with (**Fernandez-Lazaro et al, 2019**) who mentioned that non-adherence was significantly higher in patients receiving help from their family members.

Moreover the current study findings clarified that nearly two thirds of the studied patients had difficulty in transportation to go to the health institution and the health care institutions were far from their home.in the fact frequent transportation caused a financial burden on patients economic status and patients feel exhausted from long distances to seek medical advice and this makes patients skip follow up which was considered an important part of medication adherence (**Seixas etal 2020,**) . In this regard (**Syed, , Gerber, & Sharp., 2013**) stated that transportation is a basic but necessary step for ongoing health care and medication access, particularly for those with chronic diseases. Chronic disease care requires clinician visits, medication access, and changes to treatment plans in order to provide evidence-based care.

The results of this study revealed that more than half of the studied patients suffer from expensive treatment costs and a full-day treatment schedule. In fact, those factors affect the level of adherence as patients can forget or skip some doses due to the full treatment schedule, also the medication may run out and patients cannot buy it because of its cost. This finding is supported by (**Ismail, Selim, & El-Khashab, 2017**) who mentioned that the medication cost and extensive drug prescription affect adherence level of their studied patients. Also, they mentioned that when the excessive medication prescribed and costs exceed the ability to follow and exceed the financial capacity; the patient not following the treatment recommendation as well.

The current study showed that all of the studied patients sometimes didn't have a desire to take medication because of some thoughts as the drug might affect the kidneys and liver. This belief may be as result of taking medication for long life period and patients may be actually experienced side effects. This finding agree with (**Ismail et al., 2017;**) who stated that culture and lay belief about SLE disease and treatment as medication affect liver were from the most notified factors affecting medication adherence among their studied patients.

Regarding the health care system factors, the present study portrayed that the majority of the studied patients reported that the doctor's instructions on how to use medication are unclear and understandable . this result supported with (**Barbosa etal 2012**) who reported that limited comprehension of medication instructions significantly increased the risk of nonadherence in patients with SLE, which may reflect poor doctor-patient communication and also, stated that poor communication is an important barrier to adherence in SLE patients so improved communication between the health care provider and the patient is needed, and it may be beneficial to improve the adherence

The present study showed that majority of the studied patients were skipping some visits because of the long time waiting in the clinic. This could be because patients are followed up in government institutions, and these institutions are crowded, and this makes patients skip some visits. this finding is in line with (**Abdul-Sattar, Abou El Magd, 2015**) who stated that most of their

studied patient skip some appointment due to long wait time at the clinic.

Regarding the condition related factors, the study finding revealed that the most of studied patients were thinking that the SLE is a chronic disease and can't be cured and cause psychological problems as depression. The long term therapy needed for SLE restrict the patient to change their life style and make the patients more stressed and liable for psychological problem which can negatively affect adherence level. This is in line with (**Zyoud et al ,2013**) who reported that chronic diseases can often be complex and require that the patient take multiple medications at various times throughout the day for rest of life, this affect on psychological status which considered as sources of non-adherence among patients with rheumatic disorders.

Regarding symptoms the majority of the studied patients were suffering from symptoms that affect daily life activities, have symptoms despite taking their medication. These symptoms may be related to disease activity which indicates that patients are not taking their medications exactly as prescribed by the doctor, over time patients cannot tolerate pain and have to adhere to treatment. This finding is supported by who stated that non-adherence was associated with increase disease activity, also (**Costedoat-Chalumeau,etal 2013**) mentioned that depressive symptoms were significantly associated with nonadherence, this result is in contrast with (**Cannon et al., 2011**) who found that adherence was not associated with improvements in physical function.

Regarding the therapy-related factors, the study finding found that the majority studied patients were taking many numbers of medication and its dose per day. Also, the majority of the studied patients reported that the treatment period was long so they can't take their medications regularly. This result can be justified by (**Fairley , et al 2020**) who stated that SLE is a multi-system, chronic autoimmune disease. patients with SLE disease often require the use of complex medication regimens, thus challenges to medication adherence .

Furthermore the current study revealed that the majority of studied patients suffered from medications side effects which affecting their

daily life activities. The long term therapy of SLE with multiple medications associated with serious side effect on long run and may lead to poor adherence. This result is in line with (**Marengo et al 2012**) who reported that polytherapy is common and considerable and makes them at risk for medication side effects, also it had a negative impact on health-related quality of life.also stated the side effect experienced is another factor associated with nonadherence, SLE patients stopped taking their medicine because it made them feel worse and the patient does not know how to properly cope with the discomfort caused by taking medicines, and to alleviate the discomfort, medication is discontinued. Therefore, improving the coping skills for self-management of treatment, side effects perhaps can reduce medication nonadherence in SLE patients. This view has been confirmed in other chronic conditions..

Also the present study supported with (**Heiman, 2018**) Patients being nonadherent to medication recommendations may be attributed to a number of causes, occurrence of adverse drug reactions and having to take medicines more than once daily

Regarding patient-related factors, **Concerning psychological and behavioral factors**, the present study revealed that the majority of the studied knew the need for the medication, and knew the importance of taking the medication regularly. In fact, if the patients perceived the importance of adherence and the benefit of medication and its positive effect on disease .

In this regard (**Ragab et al ; 2017**) reported that factors such as lack of disease awareness and lack of belief in the efficacy of the medication as significant factors responsible for non-adherence to SLE medication

Furthermore the current study found that more than half of the studied patients had the self-confidence to taking the treatment regularly didn't depend on the motivation of others to taking medication .in the fact the patient may depend on mobile reminder and hold medication with them at all time and in everywhere so their self-confidence to adherer to medication increase and on time didn't need motivation from other as taking medication become daily routine

consequently this improve level of adherence. This is supported by (Abdul-Sattar, Abou El Magd, 2015)) who mentioned that most of their participants had high self-efficacy and using scheduling reminders through devices ,using weekly pill organizers, and leaving pills in familiar places in homes. These participants reported that, over time, the act of taking their medications became natural, often without the need of explicit reminders to take medications.

Moreover the current study showed that the most of studied patients fear of unwanted side effects and fear of dependence on treatment and not to dispense with it, in addition to the majority of the studied patients were feel stress, anger, and anxiety when taking treatment. The long term therapy needed for SLE make the patient more stressed and anxious regarding side effect and from becoming drug dependent those factor negatively affect adherence level. this finding is matched with (Koneru et al., 2014;) who reported that fear of possible adverse effect , fear of dependence and psychosocial stress were the most notified factors affecting on medication adherence.

Based on the present study findings, it was found that the most of studied patients had poor knowledge level related to SLE disease which considers high predictor for non-adherence later on. So the identification of possible factors that affect adherence to treatment allows developing strategies to improve adherence to treatments and avoid problems arising from lack thereof.

Conclusion

In conclusion, this study revealed that more than half of the studied patient with SLE were low level adherence to their medications, and more than half of them had poor knowledge related to SLE disease. In addition to it was found that patient related factors are most factors affect medications adherence for SLE.

Recommendations

Based on the findings of the present study, the following recommendations are suggested:

- Develop and apply an educational sessions in order to improve patients knowledge regarding the SLE disease and consequence of non adherence with medication.

- Colored illustrated booklet should be available and distributed for each patient with SLE about the complication of SLE and medications instructions.
- provide communication between the healthcare provider and the patient, as well as simpler prescription regimens, to enhance medication adherence.

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