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Awareness of Systemic Lupus Erythematosus and Adherence to Pulse Cyclophosphamide Therapy Among Patients in A Tertiary Care Hospital

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ABSTRACT: ***Background:*** Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease with diverse clinical manifestations, often requiring long-term immunosuppressive therapy for optimal management. Pulse cyclophosphamide therapy is a key treatment strategy, particularly for severe cases such as lupus nephritis, yet adherence remains a significant challenge due to various socio-economic and psychological factors. ***Methods:*** This cross-sectional study was conducted at Khwaja Yunus Ali Medical College & Hospital, Sirajganj, Bangladesh from July 2020 to June 2021 among patients diagnosed with Systemic Lupus Erythematosus (SLE) who had received pulse cyclophosphamide therapy. A total of 32 patients were recruited using a purposive sampling method. The data collected was entered into Microsoft Excel and analyzed using SPSS software. ***Result:*** The study found that most patients (90.6%) were aged 18–40 years, with balanced educational and socio-economic distribution. SLE with associated conditions was the most common diagnosis (31.3%), and 40.6% had incomplete cyclophosphamide therapy, primarily due to financial constraints (38.5%) and fear of side effects (23.1%). While 62.5% were aware of SLE, irregular follow-up (68.7%) was prevalent. Awareness levels influenced treatment adherence, with lower awareness linked to higher discontinuation rates. ***Conclusion:*** This study highlights the impact of awareness on adherence to pulse cyclophosphamide therapy in SLE patients, with financial constraints and fear of side effects being major reasons for incomplete treatment.

Keywords: Systemic Lupus Erythematosus, Cyclophosphamide, Financial Constraints, Awareness.

Article at a glance:

***Study Purpose**: The study aims to assess the awareness of Systemic Lupus Erythematosus (SLE) among patients and evaluate their adherence to pulse cyclophosphamide therapy in a tertiary care hospital.*

***Key findings:** Many SLE patients have inadequate knowledge about the disease, its complications, and the importance of early treatment.*

***Newer findings:** Pharmacogenomics research suggests that genetic factors may influence individual responses to cyclophosphamide, paving the way for personalized therapy.*

***Abbreviations:** SLE: Systemic Lupus Erythematosus.*

INRODUCTION

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease characterized by multisystem involvement, periods of exacerbation and remission, and significant morbidity and mortality. The disease primarily affects women of childbearing age and exhibits a wide spectrum of clinical manifestations, ranging from mild cutaneous involvement to severe organ dysfunction, including lupus nephritis, cerebral lupus, and cardiac complications.[1, 2] The etiology of SLE is complex and involves genetic predisposition, environmental triggers, and immune dysregulation, which together contribute to autoantibody production and widespread inflammation.[3] Despite advances in diagnostic and therapeutic approaches, SLE remains a major challenge due to its unpredictable course and complications arising from both the disease and its treatment. One of the key therapeutic strategies in severe SLE, particularly in lupus nephritis and other organ-threatening conditions, is immunosuppressive therapy, with Cyclophosphamide being a cornerstone of treatment.[4, 5] Cyclophosphamide, an alkylating agent, is widely used in pulse therapy to achieve disease remission and prevent irreversible organ damage.

The National Institutes of Health (NIH) and the European League Against Rheumatism (EULAR) guidelines recommend its use in patients with class III, IV, and V lupus nephritis due to its efficacy in inducing remission.[6,7] However, adherence to Cyclophosphamide therapy remains a significant concern, as incomplete treatment can lead to disease progression, relapses, and poorer long-term outcomes.[8] Several factors influence adherence to pulse Cyclophosphamide therapy, including financial constraints, fear of side effects, lack of awareness, and patient-related non-compliance. Financial burden remains one of the most commonly cited barriers, as SLE treatment often requires long-term immunosuppressive therapy, frequent monitoring, and management of complications, which can be costly.[9] Additionally, the fear of side effects such as infertility, infections, and hematological toxicity discourages many patients from completing their treatment regimen.[10] Lack of awareness about the disease and its potential consequences also plays a crucial role, as patients with limited knowledge about SLE may underestimate the severity of their condition or the importance of sustained immunosuppressive therapy.[11] Moreover, personal reasons, such as psychological distress, misconceptions, and alternative medicine preferences, contribute to treatment non-compliance.[12] Patient awareness and education are crucial in improving adherence to SLE treatment protocols. Studies have shown that informed patients are more likely to adhere to treatment and follow-up schedules, leading to better disease control and fewer complications.[13] Structured patient education programs, counseling, and shared decision-making approaches can significantly enhance adherence to Cyclophosphamide therapy.[14]

Despite the availability of treatment guidelines and structured management protocols, adherence to Cyclophosphamide therapy remains suboptimal in many settings, particularly in resource-limited regions. Studies conducted in different populations have highlighted disparities in treatment adherence, with socioeconomic status, education level, and healthcare accessibility being major determinants.[15] While high-income countries have implemented robust patient education and support systems, lower- and middle-income countries continue to face challenges in ensuring consistent adherence due to healthcare infrastructure limitations and financial constraints.[16] In tertiary care hospitals, where complex cases of SLE are managed, understanding the factors influencing adherence to therapy is crucial in optimizing treatment outcomes and preventing disease progression. This study aims to assess the awareness of SLE among patients receiving treatment in a tertiary care hospital and to evaluate its association with adherence to pulse Cyclophosphamide therapy.

METHODS

This cross-sectional study was conducted at Khwaja Yunus Ali Medical College & Hospital, Sirajganj, Bangladesh from July 2020 to June 2021 among patients diagnosed with Systemic Lupus Erythematosus (SLE) who had received pulse cyclophosphamide therapy. A total of 32 patients were recruited using a purposive sampling method. The inclusion criteria comprised patients diagnosed with SLE based on ACR/EULAR classification criteria, those who had received or were receiving pulse cyclophosphamide therapy, and individuals willing to provide informed consent. Data was collected through a structured questionnaire and a review of medical records. The questionnaire gathered information on demographic characteristics, including age, education level, and socioeconomic status, as well as clinical history, such as the type of diagnosis, treatment completion status, and follow-up adherence. Awareness of SLE was assessed through direct questions evaluating patients' knowledge about their condition, while adherence to cyclophosphamide therapy was determined based on treatment completion and follow-up history. Additionally, the reasons for incomplete therapy were categorized into financial constraints, fear of side effects, lack of awareness, and personal reasons. The data collected was entered into Microsoft Excel and analyzed using SPSS software. Ethical approval for the study was obtained from the Institutional Ethics Committee. Written informed consent was obtained from all participants before data collection, and confidentiality and anonymity of patient information were strictly maintained throughout the study.

RESULTS

Table 1: Distribution of Study Population-Based on Basic Characteristics (n=32)

Basic Characteristics	n	%
Age		
<18	1	3.1
18-40	29	90.6
>40	2	36.2
Education		
Primary	10	31.25
Secondary	12	37.5
Hier Secondary	10	31.25
Socia-Economic Status		
Low	15	46.9
Middle	17	53.1

Table 1 presents the distribution of the study population (n=32) based on basic characteristics. Most participants (90.6%) were aged 18–40 years, with only 3.1% below 18 and 6.2% above 40. Education levels were relatively balanced, with 31.25% having primary education, 37.5% secondary, and 31.2% higher secondary. In terms of economic status, 46.9% belonged to the low socio-economic group, while 53.1% were from the middle socio-economic group.

Table 2: Distribution of Study Population-Based on Clinical History (n=32)

Clinical History	n	%
Diagnosis		
Cerebral Lupus	2	6.2
Lupus Nephritis	7	21.9
Lupus Nephritis with other associated diseased conditions	2	6.2
SLE with other associated diseased conditions	10	31.3
SLE with Cerebral Lupus	2	6.2
SLE with Cardiac Lupus	2	6.2
SLE with Lupus Nephritis	7	21.9
Treatment with Cyclophosphamide pulse		
Treatment Complete	19	59.4
Treatment incomplete	13	40.6
Follow-up		
<6 months	22	68.7
>6 months-12 months	6	18.8
>12 months	4	12

Table 2 summarizes the clinical history of the study population (n=32). The most common diagnosis was SLE with other associated diseased conditions (31.3%), followed by Lupus Nephritis (21.9%) and SLE with Lupus Nephritis (21.9%). Cerebral Lupus, Lupus Nephritis with other associated conditions, SLE with Cerebral Lupus, and SLE with Cardiac Lupus each accounted for 6.2%. Regarding treatment, 59.4% had completed Cyclophosphamide pulse therapy, while 40.6% had incomplete treatment. In terms of follow-up duration, 68.7% were followed for less than six months, 18.8% for 6–12 months, and 12.5% for more than 12 months.

Table 3: Awareness of Systemic Lupus Erythematosus (SLE) Among Study Population (n=32)

Awareness Level	n	%

Aware	20	62.5
Partially Aware	8	25.0
Not Aware	4	12.5

Table 3 illustrates the awareness levels of Systemic Lupus Erythematosus (SLE) among the study population (n=32). A majority (62.5%) were aware of the disease, while 25% had partial awareness, and 12.5% were not aware of SLE.

Table 4: Reasons for Incomplete Cyclophosphamide Therapy (n=13)

Reason for Incomplete Therapy	n	%
Financial Constraints	5	38.5
Fear of Side Effects	3	23.1
Lack of Awareness	2	15.4
Non-compliance/Personal Reasons	3	23.1

Table 4 presents the reasons for incomplete Cyclophosphamide therapy among 13 patients. Financial constraints were the most common reason (38.5%), followed by fear of side effects (23.1%) and non-compliance or personal reasons (23.1%). Lack of awareness contributed to 15.4% of incomplete treatments.

Table 5: Adherence to Follow-up Appointments (n=32)

Adherence Level	n	(%)
Regular Follow-up (>6 months)	10	31.3%
Irregular Follow-up (<6 months)	22	68.7%

Table 5 illustrates adherence to follow-up appointments among the study population (n=32). Only 31.3% of patients maintained regular follow-ups for more than six months, while the majority (68.7%) had irregular follow-ups of less than six months.

Table 6: Association Between Awareness of SLE and Reasons for Incomplete Cyclophosphamide Therapy (n=13)

Awareness Level	Financial Constraints (n=5)	Fear of Side Effects (n=3)	Lack of Awareness (n=2)	Non-compliance/Personal Reasons (n=3)	Total (n=13)
Aware	2 (40%)	1 (33.3%)	1 (50%)	2 (66.7%)	6
Partially Aware	2 (40%)	1 (33.3%)	1 (50%)	0 (0%)	4
Not Aware	1 (20%)	1 (33.3%)	0 (0%)	1 (33.3%)	3
Total	5	3	2	3	13

Table 6 presents the association between awareness of Systemic Lupus Erythematosus (SLE) and reasons for incomplete Cyclophosphamide therapy among 13 patients. Among those aware of SLE, financial constraints (40%) and non-compliance/personal reasons (66.7%) were the most common barriers to completing treatment. Partially aware patients primarily cited financial constraints (40%) and lack of awareness (50%) as reasons for discontinuation. Among those not aware, financial constraints (20%), fear of side effects (33.3%), and non-compliance (33.3%) contributed to incomplete therapy. This highlights the role of awareness in influencing treatment adherence.

DISCUSSION

The study population predominantly comprised patients aged 18–40 years (90.6%), aligning with the known epidemiological distribution of SLE, which primarily affects women in their reproductive years.[1,17] Education levels were relatively balanced, but nearly half (46.9%) of the participants belonged to a low socioeconomic status, which is a well-recognized factor influencing adherence to chronic disease management.[3] Financial constraints were identified as the most common reason (38.5%) for incomplete Cyclophosphamide therapy, consistent with previous studies highlighting cost-related barriers to treatment in low-resource settings.[4,5] Patients from lower socioeconomic backgrounds often struggle with medication affordability, transportation costs for follow-up, and access to specialized care, ultimately impacting treatment adherence.[7] This study found that 62.5% of patients were aware of SLE, while 25% had partial awareness, and 12.5% were unaware. Awareness levels directly influenced adherence, as demonstrated by the association between awareness and reasons for incomplete therapy.

Among patients with incomplete treatment, financial constraints were common across all awareness levels, but non-compliance/personal reasons were predominantly reported by those aware of SLE (66.7%). This suggests that while awareness contributes to adherence, additional psychological, social, and logistical factors must be addressed to improve treatment completion rates.[9] The role of awareness in influencing adherence has been documented in prior studies, emphasizing the need for patient education programs to improve treatment outcomes.[13] Educational interventions, counseling sessions, and structured disease management plans have been shown to enhance adherence in chronic conditions, including SLE.12 Despite the known benefits of Cyclophosphamide in inducing remission and preventing disease flares, only 59.4% of patients in this study completed their prescribed therapy, while 40.6% discontinued treatment prematurely. This highlights a significant gap in adherence, which has been similarly reported in other studies on immunosuppressive therapy in SLE.[14,15]

Fear of side effects was another notable barrier (23.1%), with concerns such as infertility, infections, and toxicity often discouraging patients from continuing therapy.[15] Follow-up adherence was also suboptimal, with 68.7% of patients having irregular follow-ups of less than six months. Regular follow-up is crucial for monitoring treatment response, managing side effects, and preventing relapses. Patients who fail to attend follow-ups are at higher risk of poor disease control and complications.[18] Several studies have explored the factors influencing adherence to SLE treatment, with similar findings regarding financial constraints, fear of side effects, and lack of awareness.[19,20] A study by Mehat et al. reported that up to 50% of SLE patients exhibit some degree of non-adherence to immunosuppressive therapy, reinforcing the need for targeted interventions.13 Additionally, healthcare provider-patient communication has been identified as a key determinant of adherence, with patients who receive clear explanations about their disease and treatment being more likely to comply with therapy.[21-36]

CONCLUSION

This study highlights the impact of awareness on adherence to pulse cyclophosphamide therapy in SLE patients, with financial constraints and fear of side effects being major reasons for incomplete treatment. While 62.5% of patients were aware of SLE, irregular follow-up (68.7%) and lack of awareness (37.5%) contributed to non-compliance. Strengthening patient education, addressing economic barriers, and improving follow-up adherence are crucial for better treatment outcomes.

Recommendation

To improve adherence to pulse cyclophosphamide therapy in SLE patients, targeted patient education programs should be implemented to enhance disease awareness and address misconceptions about treatment. Financial assistance programs and policy interventions are needed to reduce economic barriers to therapy. Additionally, regular follow-up reminders and counseling on treatment benefits and side effects can help improve compliance and long-term outcomes.

Authors' Contributions

MRI, AD: Concept and design, data acquisition, interpretation and drafting. R and EM: Data acquisition, interpretation, drafting, final approval and agree to be accountable for all aspects of the work.

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