Quality of Life SLE Patients in India

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***Abstract*—Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disorder with multisystem involvement that significantly affects patients' quality of life (QoL). In India, SLE predominantly affects young women, leading to long-term physical, psychological, and social consequences. [1] Clinical indicators alone often fail to reflect the real-life challenges faced by patients. Disease-specific patient-reported outcome measures such as the Lupus Quality of Life (LupusQoL) questionnaire have therefore gained importance in assessing the multidimensional impact of SLE on daily living.[2] Enhancing quality of life should remain a central objective in the comprehensive management of SLE patients in India.**

Objective:To explore the quality of life among SLE patients in India using disease-specific assessment tools, particularly the Lupus Quality of Life (LupusQoL) questionnaire, and to highlight the multidimensional factors influencing QoL.

Methods:A narrative review approach was used, synthesizing findings from Indian and international studies focusing on patient-reported outcome measures (PROMs), especially LupusQoL. Relevant literature was analyzed to identify domains of impairment and contributing socio-cultural and clinical factors.

Conclusion:SLE significantly compromises physical, emotional, and social well-being in Indian patients. The LupusQoL tool provides a comprehensive and culturally adaptable method to assess QoL. Integrating QoL evaluation into routine clinical practice is essential for holistic management and improved long-term outcomes.

***Index Terms*—SLE – Systemic Lupus Erythematosus, QoL – Quality of Life, PROMs – Patient-Reported Outcome Measures, LupusQoL – Lupus Quality of Life Questionnaire**

I. INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a chronic, inflammatory autoimmune disease characterized by periods of remission and relapse, affecting multiple organ systems including the skin, joints, kidneys, cardiovascular system, and central nervous system. In India, SLE commonly affects women in their reproductive and economically productive years, thereby imposing a substantial personal and societal burden.[1]

Quality of life (QoL) assessment has emerged as a critical outcome measure in chronic diseases such as SLE, where cure is not possible and long-term management is required. Generic QoL instruments may not adequately capture lupus-specific concerns such as fatigue, body image disturbances, emotional stress, and disease unpredictability. The LupusQoL questionnaire offers a disease-specific, patient-centered approach to evaluating the impact of SLE on daily functioning and well-being.[2].

II. SYSTEMIC LUPUS ERYTHEMATOSUS IN THE INDIAN CONTEXT

The prevalence, severity, and outcomes of SLE in India vary widely due to differences in genetic background, environmental factors, healthcare accessibility, and socio-economic conditions. Delayed diagnosis remains common because of limited awareness and restricted access to specialized rheumatology services. As a result, severe disease manifestations such as lupus nephritis and neuropsychiatric lupus are frequently encountered, contributing to increased morbidity and impaired quality of life.[1]

Socio-cultural factors, including gender roles, family expectations, stigma associated with chronic illness, and dependency on caregivers, further influence disease coping and adaptation among Indian patients. In addition, the financial burden associated with long-term treatment and recurrent hospital visits significantly affects patients' quality of life, often leading to catastrophic health expenditure.[4]

III. CONCEPT OF QUALITY OF LIFE IN SLE

Quality of life is a multidimensional concept encompassing physical health, psychological state, social relationships, and level of independence. In SLE, QoL is often compromised even during clinical remission due to persistent symptoms such as fatigue, pain, and emotional distress[3].

Patient-reported outcome measures (PROMs) are increasingly recognized as essential components of disease assessment, as they capture patients' subjective perceptions of health status, which may not correlate directly with clinician-assessed disease activity indices. The World Health Organization emphasizes the importance of such subjective assessments in understanding overall health and well-being.[5]

IV. LUPUS QUALITY OF LIFE (LUPUSQOL) TOOL

The LupusQoL questionnaire is a disease-specific QoL assessment tool developed for patients with SLE. It consists of 34 items covering eight domains:

1. Physical Health
2. Pain
3. Planning
4. Intimate Relationships
5. Burden to Others
6. Emotional Health
7. Body Image
8. Fatigue

Each domain reflects an area of life commonly affected by SLE. Scores range from 0 to 100, with higher scores indicating better quality of life. The LupusQoL has been validated in various languages, including Hindi, making it suitable for use among Indian SLE patients[2].

V. QUALITY OF LIFE DOMAINS IN INDIAN SLE PATIENTS

Physical Health and Pain

Indian studies using LupusQoL have shown that physical health and pain are among the most affected domains. Chronic joint pain, muscle weakness, and fatigue significantly limit daily activities and occupational functioning. These symptoms often persist even during periods of low disease activity[3].

Fatigue

Fatigue is one of the most disabling symptoms reported by SLE patients and has a strong negative impact on overall QoL. LupusQoL assessments consistently demonstrate low scores in the fatigue domain, indicating its profound effect on patients' daily functioning and emotional well-being[3].

Emotional Health

Emotional distress, including anxiety, depression, and fear of disease flares, is commonly observed among Indian SLE patients. The unpredictable course of the disease and concerns about long-term prognosis contribute to poor emotional health scores on the LupusQoL scale.

Body Image and Intimate Relationships

Skin manifestations, hair loss, weight changes due to steroid therapy, and visible disease symptoms adversely affect body image. These concerns, along with fatigue and pain, negatively influence intimate relationships, particularly among young women[4].

Planning and Burden to Others

The planning domain reflects patients' ability to make future plans, which is often impaired due to uncertainty about disease flares. Many patients also report feelings of being a burden to their family, especially in the Indian cultural context where dependence on caregivers is common.

Factors Influencing Quality of Life

Multiple factors influence QoL in SLE patients, including disease duration, severity, organ involvement, treatment side effects, socio-economic status, educational level, and social support. Psychological factors such as depression and anxiety have been shown to be stronger predictors of poor QoL than disease activity alone[3].

VI. NURSING AND CLINICAL IMPLICATIONS

Assessment of quality of life using the LupusQoL tool enables healthcare professionals to identify hidden patient concerns that may not be evident through routine clinical evaluation. Nurses play a crucial role in holistic care by providing patient education, psychological support, fatigue management strategies, and counseling services. Incorporating QoL

assessment into routine clinical practice can improve patient-centered care and treatment outcomes[4].

VII. CONCLUSION

Systemic Lupus Erythematosus significantly impairs the quality of life of patients in India across multiple physical, emotional, and social domains. The LupusQoL tool provides a comprehensive and culturally relevant method for assessing patient-reported outcomes. Findings from LupusQoL-based assessments highlight the need for holistic management approaches that address not only disease activity but also fatigue, emotional health, body image, and social support. Integrating quality of life evaluation into routine care is essential for improving long-term outcomes and overall well-being of SLE patients in India.

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