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Advancing the standard of care for lupus in Sri Lanka

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ABSTRACT

Systemic Lupus Erythematosus (SLE) is an autoimmune disease with a female preponderance, predominantly affecting those of reproductive age. Among Asians, disease severity is intermediate between that of Caucasians and African Americans, with the latter having the most severe disease phenotype. Compared with other rheumatological diseases, the introduction of new, effective medications for the management of SLE lags far behind. Despite this, large-scale, high-quality research over the past few decades has added extensive new knowledge on how to manage lupus effectively to reduce mortality and morbidity, using available medications, close disease monitoring, and more proactive patient involvement in care decisions. As a country with excellent performance on healthcare indicators in the region, it is imperative to explore ways to improve disease-related outcomes for patients with SLE. Here, we discuss how we can achieve that utilising the limited resources at our disposal.

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Introduction

Systemic lupus erythematosus (SLE) is a chronic multisystem autoimmune disease with a wide spectrum of clinical manifestations. Since its first description in the early eighteenth century, understanding of its pathogenesis and management has evolved considerably. Early descriptions portrayed lupus as a frequently fatal condition. The introduction of glucocorticoids in the 1950s dramatically improved survival, and subsequent decades saw the development of a wide range of immunosuppressive therapies.[1]

In recent decades, the focus of lupus management has shifted from merely controlling disease activity to preventing irreversible organ damage, minimising treatment-related toxicity, and improving long-term quality of life. Concepts such as treat-to-target strategies, steroid minimisation, and multidisciplinary care now form the cornerstone of modern lupus management.[2]

SLE predominantly affects women of reproductive age, with a female-to-male ratio of approximately 9:1.[3] The disease can involve multiple organ systems, and renal and neurological manifestations contribute significantly to morbidity and mortality. Despite advances in global management, significant challenges remain in delivering optimal lupus care in resource-limited settings. Addressing these challenges is essential to achieving higher standards of care in Sri Lanka.

The burden of lupus in Sri Lanka

Timely diagnosis and appropriate treatment of SLE remain challenging in Sri Lanka due to a combination of healthcare system, socioeconomic, and disease-related factors.

The clinical presentation of lupus is often variable and non-specific. In tropical settings such as Sri Lanka, where infectious diseases are common, several infections may mimic lupus manifestations.[4] Available local data suggest that South Asian patients may experience more severe disease and higher rates of major organ involvement than Caucasian populations.[5] In particular, lupus nephritis appears to be more common in this population.

Access to immunological investigations remains limited in the state healthcare sector, which provides more than 80% of healthcare services in Sri Lanka. Peripheral hospitals often lack facilities for tests such as anti-double-stranded DNA antibodies and complement levels. This poses challenges not only for diagnosis but also for monitoring disease activity.

Another barrier is the lack of well-defined referral pathways. Patients are often referred late to rheumatology or nephrology services, even when specialist care is required. In addition, limited awareness of autoimmune diseases among patients and healthcare providers may contribute to delayed recognition and treatment interruptions.

The socioeconomic impact of poorly controlled lupus is substantial. As the disease predominantly affects young adults, it leads to lost productivity and reproductive health challenges. Long-term treatment and monitoring place an additional burden on the healthcare system.

Key message: *Earlier recognition and coordinated care, with active patient participation in management decisions, can significantly reduce morbidity and prevent organ damage.*

Early recognition and diagnosis

Early symptoms of lupus are often non-specific. For example, local studies have reported hair loss as one of the most frequent initial complaints among Sri Lankan patients.[6] However, this symptom is also common among otherwise healthy young women. Clinicians must therefore interpret symptoms within the broader clinical context rather than relying on isolated findings.

Maintaining a high index of suspicion in patients presenting with multisystem disease is crucial. Early identification enables prompt initiation of therapy and prevention of irreversible organ damage.

Table 1
Clinical considerations in early recognition and diagnosis of SLE.

Key point	Clinical implication
Recognise common early manifestations	Inflammatory arthritis, photosensitive rash, cytopenias, unexplained proteinuria, serositis
Avoid using classification criteria as diagnostic criteria	The 2019 EULAR/ACR criteria are intended for classification, not diagnosis[1]
Understand the spectrum of disease	Tools such as BILAG-2004 illustrate the full range of disease manifestations
Appropriate interpretation of ANA testing	ANA is sensitive but not specific, and should be interpreted in the clinical context
ANA titres should not be used for monitoring	ANA levels do not correlate with disease activity
Consider differential diagnoses	Infection and malignancy may mimic lupus presentations

Key message: *Maintain a high index of suspicion when evaluating patients with multisystem disease.*

Organ-specific assessment and risk stratification

Organ damage in SLE may remain clinically silent until advanced stages. A comprehensive baseline assessment is therefore essential at diagnosis.

SLE can affect multiple organ systems, including constitutional, neurological, musculoskeletal, mucocutaneous, gastrointestinal, cardiorespiratory, ophthalmological, haematological, and renal. Early identification of major organ involvement—particularly renal and neurological disease—is critical for determining prognosis.

Disease activity assessment tools, such as SLEDAI and BILAG-2004, enable objective monitoring of disease activity.[7] Regular use of these tools enables early detection of disease flares and assessment of treatment response. Persistent abnormalities lasting longer than six months despite treatment may represent irreversible organ damage rather than active disease. The SLICC/ACR Damage Index provides a standardised method for assessing cumulative organ damage and has been shown to correlate with long-term survival.[8]

Key message: *Early organ assessment and regular monitoring of disease activity guide therapy and prevent irreversible damage.*

Treat-to-Target approach in SLE

Treat-to-target strategies have transformed the management of many rheumatological diseases. In lupus, treatment goals are defined as clinical remission or the Lupus Low Disease Activity State (LLDAS).[9]

Achieving these targets requires:

- Early suppression of inflammation
- Prevention of disease flares
- Minimisation of long-term glucocorticoid exposure

Glucocorticoids remain essential for controlling acute disease activity, but long-term dependence should be avoided because of their well-recognised toxicity. In clinical situations where a long-term maintenance dose of steroids cannot be avoided, the current recommendation is to keep the dose of prednisolone $\leq$ 5mg/day[3].

Disease activity scores help guide treatment decisions. The SLEDAI score is simple but requires laboratory markers such as complement levels and anti-dsDNA antibodies. Although more complex, the BILAG-2004 index captures the full spectrum of lupus manifestations and may be more adaptable in resource-limited settings.

Key message: *Long-term outcomes improve when treatment aims for remission or sustained low disease activity.*

Rational use of pharmacotherapy (Table 2)

Hydroxychloroquine remains the cornerstone of lupus therapy. It has been shown to reduce disease flares, organ damage, thrombosis, and mortality.[10]

Key message: *Optimising available therapies while minimising glucocorticoid exposure is central to modern lupus care.*

Management of lupus nephritis

Lupus nephritis is one of the most serious complications of SLE and appears to be more common in South Asian populations.[5] Regular screening with a urine full report and renal function tests is essential for early detection of renal involvement. Even asymptomatic patients may develop significant kidney disease. Renal biopsy remains the gold standard for classifying lupus nephritis and guides treatment decisions.[11]

Management requires close collaboration between rheumatologists and nephrologists. Multidisciplinary clinics can significantly improve patient outcomes and are feasible even in resource-limited settings.

Key message: *Early detection and aggressive management of lupus nephritis improve renal survival.*

Preventing damage and complications

With improved survival in SLE, long-term complications now account for a substantial proportion of morbidity and mortality. Major contributors include infections, cardiovascular disease, osteoporosis, and treatment-related toxicity.[12]

Table 2
Principles of pharmacological management in SLE.

Principle	Clinical considerations
Minimise glucocorticoid exposure	Use the lowest effective dose for the shortest possible duration. Aim for a prednisolone dose of $\leq$ 5mg per day where a maintenance dose cannot be avoided[3]
Appropriate selection of immunosuppressants	Based on organ involvement, disease severity, comorbidities, fertility considerations, and drug availability
Correct dosing	Most drugs require weight-based dosing and adjustment in renal impairment
Hydroxychloroquine as foundation therapy	Recommended for most patients; reduces flares and mortality[10]. To avoid retinal toxicity, the daily dose should not exceed 5mg/kg/day[3]
Timely de-escalation	Consider gradual reduction once sustained remission is achieved
Monitoring for toxicity	Regular monitoring is necessary for safe long-term therapy

Table 3
Key considerations in reproductive health in women with SLE.

Recommendation	Clinical implication
Pre-pregnancy counselling	Multidisciplinary discussion improves outcomes
Disease control before conception	Maintain remission for at least six months pre-conception with non-teratogenic drugs
Use pregnancy-compatible medications	Hydroxychloroquine, azathioprine, cyclosporine, tacrolimus[4]
Close monitoring postpartum	Disease flares are common during the puerperium
Multidisciplinary care	Pregnancy should be managed in specialised centres

Key message: *Planned pregnancy during disease quiescence significantly improves maternal and foetal outcomes.*

Infections remain a leading cause of death among patients with lupus in Sri Lanka. Preventive strategies, including vaccination, infection control measures, and careful adjustment of immunosuppressive therapy, should therefore be emphasised. A study from Sri Lanka reported very low rates of regular vaccination among patients with SLE against hepatitis B, influenza, and pneumococcal pneumonia.[14] Given this is a highly vulnerable group of patients due to disease-related immune dysregulation, iatrogenic immunosuppression, and potential disease-related lung damage, and given that they live in a tropical country with a high infection burden, simple preventive measures such as vaccination should be emphasised.

Long-term glucocorticoid use contributes to osteoporosis and cardiovascular disease. The risk of osteoporosis is further enhanced by the chronic inflammatory state, and avoidance of sun exposure. Bone protection strategies – including weight-bearing exercise, calcium intake, and vitamin D supplementation – should therefore be routinely discussed.

Pregnancy and reproductive health (Table 3)

Multidisciplinary Care

Optimal lupus management requires collaboration between multiple medical specialities, including rheumatology, nephrology, dermatology, obstetrics, cardiology, and ophthalmology. Multidisciplinary clinics or structured case discussions can improve patient outcomes without requiring significant additional resources.

Key message: *Coordinated multidisciplinary care improves outcomes in lupus.*

Raising the standard of lupus care in Sri Lanka

Sri Lanka has achieved impressive health indicators compared with many countries in the region. However, outcomes for chronic rheumatological diseases, such as lupus, are not routinely captured in national healthcare metrics. Given the young age of affected patients and the potential for severe organ involvement, lupus is an important yet under-recognised healthcare challenge.

Improving lupus care requires:

- Earlier referral to specialist services
- Improved access to immunological diagnostics
- Development of locally relevant treatment protocols
- Establishment of a national lupus registry

A pilot project for a national lupus registry has already generated valuable insights into disease patterns across the country and highlights the importance of systematic data collection.[14] With early recognition, treat-to-target strategies, rational pharmacotherapy, and coordinated multidisciplinary care, outcomes for patients with lupus in Sri Lanka can be significantly improved.

Key Practice Points

- Maintain a high index of suspicion for lupus in young women presenting with multisystem disease.
- Do not rely on classification criteria to establish a diagnosis.
- Perform baseline organ assessment at diagnosis to detect silent organ involvement and use disease activity scores where possible to guide treatment decisions.
- Adopt a treat-to-target strategy, aiming for remission or lupus low disease activity state.
- Minimise long-term glucocorticoid exposure whenever possible and ensure universal use of hydroxychloroquine unless contraindicated.
- Screen regularly for lupus nephritis using urinalysis.
- Address infection prevention, cardiovascular risk, and bone health as part of routine care.
- Encourage planned pregnancy during disease quiescence.
- Promote multidisciplinary care and early specialist referral.

Conflicts of interest

The author declares no conflicts of interest.

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