Journal of Multidisciplinary Healthcare

Dovepress
Taylor & Francis Group

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PERSPECTIVES

Establishment of a Multidisciplinary Pediatric Lupus Care Clinic at a Tertiary Center

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Abstract: Childhood-onset systemic lupus erythematosus (cSLE) is a complex autoimmune disease marked by higher disease severity, multi-organ involvement, and a greater risk of kidney damage compared to adult-onset SLE. Recognizing the challenges associated with treating cSLE, especially in patients with lupus nephritis, Boston Children's Hospital established a multidisciplinary pediatric lupus clinic. This clinic integrates rheumatology, nephrology, nursing, and social work services to provide comprehensive, coordinated care. The team-based model facilitates shared decision-making, personalized treatment plans, and proactive management of social determinants of health. The average SLEDAI-2K score improved in this lupus clinic patient population. Clinic follow-up rates were 100% and patient ER visits and inpatient admissions of this high-risk patient population were low (15% and 4%). Despite challenges related to team formation, practice standardization, and financial sustainability, the clinic has demonstrated success in improving care delivery. Future goals include expanding trainee involvement, piloting quality improvement measures, and using the clinic as a model for broader cSLE care. This approach offers a promising framework for equitable, high-quality care for pediatric lupus patients.

Keywords: pediatric lupus, childhood onset SLE, childhood-onset systemic lupus erythematosus, lupus nephritis, multidisciplinary care

Introduction

Childhood-onset systemic lupus erythematous (cSLE) is a life-long autoimmune disorder characterized by higher disease severity and multisystem involvement as compared to adult-onset disease.[1] This is commonly due to the higher prevalence of lupus nephritis in the cSLE population, which increases disease burden, accrual of organ damage, treatment-related toxicities, and the risk of end-stage kidney disease (ESKD). Lupus nephritis develops in approximately 40–70% of children with cSLE, occurring within the first two years of cSLE diagnosis in over 90% of patients.[1–4] In addition to the disease severity, disparities exist in disease prevalence, morbidity, and mortality-related disease outcomes.[5–7] Childhood-onset SLE requires a thorough, multidisciplinary management approach that addresses the patient's growth, psychological needs, and the unpredictable progression of the disease and its complications.[8]

Despite the need for multiple specialists such as pediatric rheumatologists, nephrologists, dermatologists, psychiatrists, nurses, and social workers to care for children and adolescents with SLE, there are few reported pediatric multidisciplinary lupus clinics. In the adult populations, a few studies have suggested improved outcomes, such as reduced time to a renal biopsy for patients who receive care in multidisciplinary lupus clinics.[9–11] In pediatric lupus, a recent study shows that focus on quality metrics can improve outcomes, and a multidisciplinary care model facilitates equitable care delivery.[12] While there are no other studies on multidisciplinary clinics on pediatric lupus, there has been

Received: 21 May 2025
Accepted: 23 September 2025
Published: 9 October 2025

multidisciplinary clinic models in other chronic diseases of childhood such as atopic dermatitis that improves disease severity and quality of life for patients.[13,14]

Based on these observations and reported data, there is a clear need for comprehensive, integrated multidisciplinary care for youth living with lupus. With this in mind, the study's objective was to create a multidisciplinary lupus clinic for pediatric lupus patients with nephritis. Our second objective was to discuss the structure and workflow of our team, highlight challenges inherent in multidisciplinary care, and share initial quality improvement and disease outcome measures.

Materials and Methods

Building a Multidisciplinary Team

The study was approved by Boston Children's Hospital Institutional Review Board (IRB-P00000433) The initial phase consisted of identifying physicians, nurses, and social workers in each relevant specialty interested in pediatric lupus care. The process also involved obtaining leadership support from division chiefs and practice managers and securing hospital resources, including funding and a physical clinical space. Multiple meetings occurred to identify appropriate patients and schedule their visits, delineate a workflow before and after clinic, and develop a comprehensive follow-up plan.

Our Lupus Nephritis Clinic multidisciplinary team includes a pediatric rheumatologist, a pediatric nephrologist, a rheumatology nurse, a social worker, and two research coordinators.

This multidisciplinary team model relies on joint decision making between the two physician providers with team-based facilitation of the treatment plan, rather than on a single provider from a single discipline.

Identifying the Target Population

Due to resource limitations, our clinic cannot serve every child with lupus in our catchment area. Therefore, we chose cSLE patients with nephritis who are generally more complex with regard to the need for multiple immunomodulatory therapies and/or with a history of barriers to care, including non-adherence to treatment and clinic visits. When the internal flow of the clinic was established, we worked within the hospital to raise awareness about the Multidisciplinary Lupus Clinic. We educated referring providers about the clinic. We reviewed the qualifying criteria and the process for referral to the Multidisciplinary Lupus Clinic with both the rheumatology and nephrology groups at division-wide meetings. In addition, we sent emails to the rheumatology and nephrology providers to inform them of the clinic and qualifying criteria to reinforce this teaching. Our goal was to recruit all eligible new SLE patients with nephritis as well as consider the transfer of some existing patients who met our qualifying criteria.

Establishing a Clinical Workflow

The function and workflow of our team is shown in Figure 1. We have a robust system of population management with a process for pre-visit planning. Prior to a Multidisciplinary Lupus Clinic visit, the dedicated Lupus Clinic Registered Nurse screens the patient list for the upcoming day to ensure that all necessary orders have been placed, including laboratory, disease-activity screens (SLEDAI-2K), screening studies (echocardiogram, pulmonary function tests), and vaccinations. If there are studies that are due or overdue, these are scheduled as well. At the clinic visit, each patient occupies one clinic room, and each team member evaluates the patient in sequence (rheumatology first, followed by nephrology, followed by RN and social worker). All providers develop an individualized, comprehensive treatment plan with the patient and their family. At the end of the visit, the nurse is responsible for helping to coordinate the treatment plan, which often includes ensuring correct prescriptions being sent, and follow-up appointments being scheduled.

Each family meets with the social worker to address health-related social needs, including ongoing educational, transportation, food or housing needs and if any additional resources would facilitate care. Social work interventions include providing letters for schools, assistance with days off from work, and support for meals and transportation.

In addition to the clinical function of the multidisciplinary team, several research coordinators assist in managing ongoing research studies and grant applications. As an academic teaching hospital, fellows from both nephrology and rheumatology participate in the clinic, which allows them to advance expertise in their chosen field as well as gain

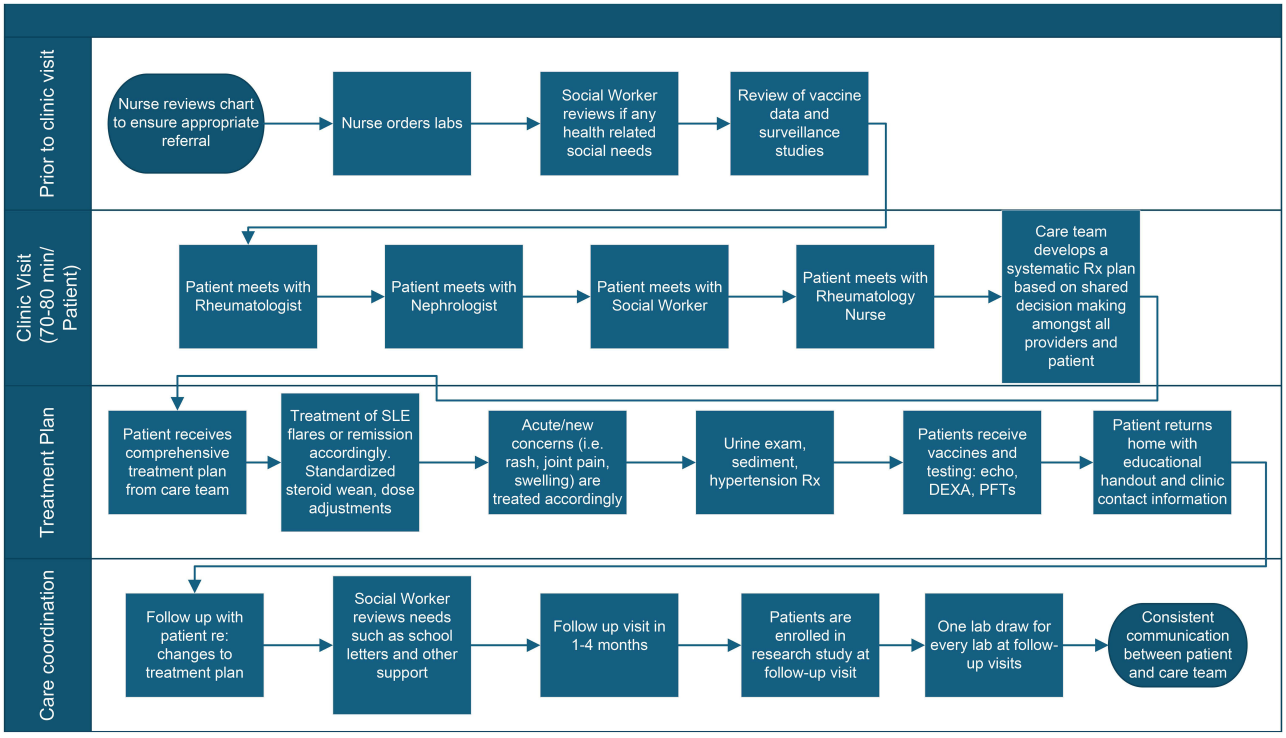

Figure 1 Workflow of multidisciplinary lupus clinic showing the stepwise approach to every patient in the clinic.

experience in collaborative and multidisciplinary care. The collaborative teamwork of our clinic allows expert delivery of integrated clinical care and advancement of science through research and education.

Results

We provide our clinic on a monthly basis and see patients every 2–6 months based on their disease activity levels and social needs. We currently follow 24 lupus patients with lupus nephritis and multi-organ involvement (>2 organs involved). The average age for our lupus clinic patients is 18.08, female to male distribution is 22/2. Ethnical distribution is 33% Black, 58% Hispanic, 12.5% Asian while 1 patient is of Black and Hispanic ethnicity. 54% of the patients have public medical insurance and 33% of the patients and their families cannot speak English (Table 1).

Table 1 Baseline Characteristics of Multidisciplinary Lupus Clinic Patients. 100% of the Patients Followed up in the Clinic in a Timely Manner. 16% of the Patients Visited Emergency Department (ED), While 4% of the Patients Got Admitted with Lupus Flare

Number of patients, n	24
Mean age of patients, years	18.08 years
Female/Male, n	22/2
Black, n (%)	8 (33%)
Hispanic, n (%)	14 (58%)
Asian, n (%)	3 (12.5%)

(*Continued*)

https://doi.org/10.2147/JMDH.S541836

Table 1 (Continued).

Public insurance, n (%)	13 (54%)
Non-English speaking, n (%)	8 (33%)
Multi-organ involvement, n (%)	24 (100%)
Clinic follow up rate, n (%)	24 (100%)
ED visit rate, n (%)	4 (16%)
Inpatient admission rate, n (%)	1 (4%)

Between January 2024 and January 2025, 100% (24/24) of lupus clinic patients were scheduled and seen for a follow-up appointment within the providers' recommended time frame (from 2–6 months) (Table 1). In the same time frame of 1 year, 16.7% (4/24) of lupus clinic patients presented to Emergency Department (ED). Hospital admission rates for the same 1-year period were 4.17% (1/24) for lupus clinic patients (Table 1). As such, ED visits and hospitalizations are not always avoidable as these patients are socially complex and have multi-organ and kidney involvement. There is a downtrend in the average SLEDAI-2K (Systemic Lupus Erythematosus Disease Activity Index) score for the lupus clinic patient population (Figure 2). Our structure proved successful in providing timely patient-centric care.

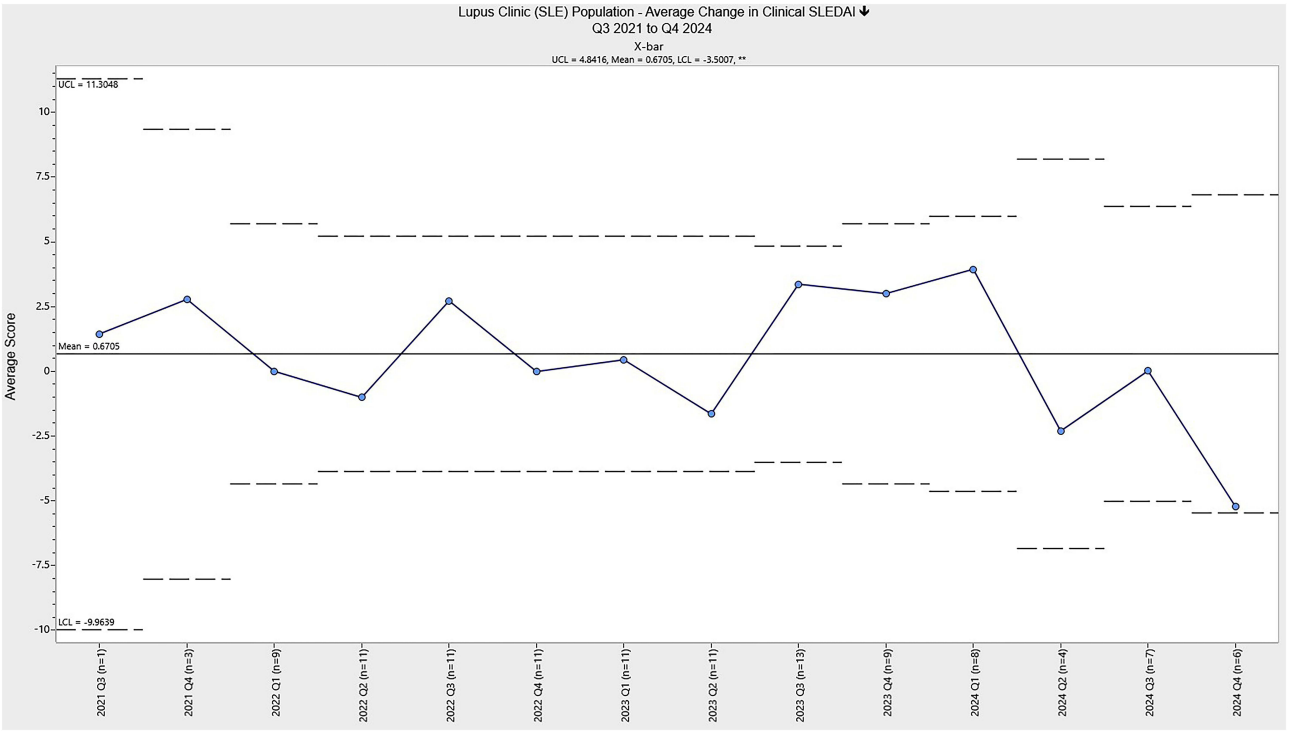

Figure 2 SLEDAI-2K (SLE disease activity index) scores of lupus clinic patient cohort decreased over time.

Discussion

The multidisciplinary care model has proven to be beneficial for both patients and providers. The simultaneous communication between providers and shared decision making for complex patients has led to improvements in care for patients with cSLE and greater job satisfaction for the providers. In addition, this model has led to a broader perspective for providers as expertise from both disciplines is integrated in understanding of patients and the development of treatment plans. Because we provide unified, multidisciplinary care, we have significantly decreased confusing or contradictory messaging and have witnessed a resultant improvement in patient and family adherence to care recommendations.

Our clinic primarily serves patients from underserved communities who often present with more severe disease. Despite these two risk factors for poor outcomes, we observed favorable trends in ER visits, hospital admissions, and SLEDAI-2K scores, underscoring the positive impact of our clinic. While there are many benefits to this clinic so far, we have faced many challenges in establishing multidisciplinary Systemic Lupus Erythematosus care. We would like to discuss our challenges in each step of clinic establishment:

Assembling the Team

Childhood-onset SLE with nephritis is a complicated medical condition, and optimal care for these patients requires considerable time and resources. Recruiting a dedicated pediatric rheumatologist and nephrologist was challenging given the complexity of these patients. Long-term providers with large clinical volumes expressed reservations about assuming the care of these complex and time-consuming patients. Ultimately, providers with a special interest in lupus and nephritis were identified. While this two-provider model requires that both physicians be available to cover this patient population, this potential disadvantage was outweighed by the long-term continuity of care it affords.

Establishing Joint Practice Norms

Care for patients with complex conditions is often variable, and it was important for us to establish practice norms shared by both the rheumatology and nephrology providers. Currently, we are in the process of adopting lupus care quality measures in our lupus clinic. These include but are not limited to improving vaccination rates, baseline screening with echocardiogram and pulmonary function tests, and obtaining screening labs to assess co-morbidities. The structure of the clinic has allowed us to pilot these joint quality practice measures. Furthermore, over the last decade, the Food and Drug Administration has approved multiple new immunomodulatory agents, and many others are being studied in pediatrics[15] leading to further variability in care. Kidney Disease Improving Global Outcomes (KDIGO) recently published lupus nephritis guidelines with focus on rapid weaning of prednisone,[16] a practice that may not be adopted by rheumatologists. These and other factors have resulted in challenges in integrating new or possibly contradictory practices, hence the clinic has required interaction and joint decision-making between providers, especially when there are differences in approach to care. Minimizing variability and integrating these disparate approaches to generate a single consistent plan is likely of benefit to the patient. Often the patient is aware of differences in practice and appreciates that providers have collaborated with the single aim of maximizing benefit and minimizing medication toxicity and disease burden.

Achieving Financial Sustainability

While we are confident that this work will result in the return on investment of resources, this clinic model is resource-intensive. The multidisciplinary model is built upon dedicated social work and nursing support, which comes with increased costs. The social and nursing needs for this population cannot be understated. First, many patients with cSLE and nephritis in our clinic come from historically marginalized groups (Table 1) and groups with more limited financial resources. These factors are associated with barriers to care such as immigration status, dynamic economic situation of the family, and low health literacy that can be ameliorated by dedicated nursing and social work support. In addition, given the higher overall complexity, fewer patients can be seen in a single clinic session, thus generating less revenue. The clinic visits are usually 60 to 90 minutes total, much longer than typical individual medical visits. Given the financial burden of the clinic, institutional support was essential for implementation. Our institution recognized the need for

coordinated, comprehensive care of patients with a condition that disproportionately affects children belonging to historically marginalized groups and is associated with substantial morbidity. We offset the financial investment by dividing the costs of providing social work and nursing support and the costs of providing the clinical space (two clinic rooms and a provider touch-down room) between the rheumatology and nephrology programs.

Conclusions and Future Directions

In summary, our multidisciplinary lupus clinic allows us to provide high-quality, coordinated medical care through shared clinical appointments and medical decision-making for a severe chronic disease with substantial racial and ethnic health inequities in disease burden, morbidity, and mortality. This structure provides promising results for timely outpatient follow-up care and treatment adherence in this patient population. Finally, because of the highly uniform care provided to this discrete patient population, the specialized multidisciplinary lupus clinic allows for rapid tests of change and inform interventions aiming to achieve optimal health in all children with cSLE.

Given our initial success, we are now working to incorporate pediatric dermatology and psychiatry specialists to widen the scope of the multidisciplinary lupus clinic. We would like to host both rheumatology and nephrology fellows, pediatric residents, and medical students in our clinic, so they can learn how to participate in multidisciplinary care models. The clinic is also helping us pilot new care processes for patients with lupus on a smaller scale before implementing them for all patients with lupus followed in the general rheumatology clinic. We have also participated in formal Lupus Quality Improvement (QI) work with our hospital QI team and are actively working on implementing additional measures to improve outcomes like vaccination rates, and rates of screening and diagnostic studies. These measures are piloted in the Multidisciplinary Lupus Clinic before being applied to the general SLE population in rheumatology clinic.

Acknowledgments

The first and second authors contributed equally to the paper.

Disclosure

The authors declare that they have no conflict of interest.

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