

## Clinical Perspectives

# Depression and Psychiatric Care Often Overlooked in Pediatric Systemic Lupus Erythematosus

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This Clinical Perspectives manuscript examines depression as a frequently overlooked but clinically consequential comorbidity in pediatric systemic lupus erythematosus (SLE). Depression in youth with SLE contributes to poorer adherence, increased disease activity, and diminished quality of life, yet it is often unrecognized in routine rheumatologic care. Using a representative case illustration and synthesis of current evidence, the paper argues that depression should be treated as an integral component of lupus care rather than a secondary concern. The manuscript outlines practical recommendations for early detection, illness-focused psychotherapy, coordinated pharmacologic management, and family-centered, culturally responsive interventions that can be implemented within pediatric rheumatology and child and adolescent psychiatry settings. The goal is to offer actionable, cost-conscious strategies to advance evidence-informed, equitable mental health care for medically complex youth.

## INTRODUCTION

Pediatric systemic lupus erythematosus (SLE) is a chronic, multisystem autoimmune disease with a high psychiatric burden, particularly depression. Depression and other psychiatric conditions in pediatric SLE are prevalent and profoundly impact disease outcomes, including medication adherence, disease flares, and overall quality of life.<sup>1,2</sup> Current American College of Rheumatology guidelines recommend routine mental health screening with appropriate referrals when indicated for all patients with SLE.<sup>3</sup> However, the absence of standardized, structured pathways for follow-up may limit consistent implementation in clinical practice and may contribute to underrecognition and undertreatment of psychiatric conditions. Recent guidelines from the American College of Rheumatology underscore the urgency for actionable, standardized approaches to mental health screening and early intervention.<sup>4</sup> While many pediatric rheumatologists agree that routine depression and anxiety screenings should be administered, only 2% reported routinely administering screenings with a standardized instrument, with limited time and staffing creating barriers to this implementation.<sup>5</sup>

## BACKGROUND

Patients with SLE may experience neuropsychiatric conditions (ie, mood disorders and cognitive dysfunction) either as comorbidities or disease manifestations, or both.<sup>6</sup> The

prevalence of depression in pediatric and young adult patients (aged 12 to 25) with SLE is significant and appears to increase as patients transition into early adulthood. Specific cohorts of young adults have demonstrated diagnostic rates as high as 47%, with some studies indicating a higher risk of depression in adults with childhood-onset SLE, with up to 59% experiencing depression.<sup>7,8</sup> Cross-sectional studies show significant associations between depression and diminished impact on quality of life in patients with SLE, manifesting as increased fatigue, impaired physical function and cognitive abilities, and social isolation.<sup>1</sup> Neuropsychiatric lupus, a subset of lupus involving the central nervous system, may further blur the distinction between psychological and organic causes of psychiatric symptoms. For example, fatigue may be a primary symptom of a lupus flare, a core diagnostic criterion for major depressive disorder, or a result of neuroinflammatory processes affecting the developing central nervous system.<sup>6</sup> For child and adolescent psychiatrists, this indicates a need to address psychiatric treatment as a key player in treating lupus rather than providing symptom relief.

## CASE ILLUSTRATION

In this fictional case example, a 15-year-old girl with lupus nephritis presents after 2 hospitalizations for SLE within 6 months for flares, despite administration of immunosuppressants. In a questionnaire for mental health screening, she endorses symptoms of major depressive disorder. She



describes passive suicidal ideation alongside beliefs that SLE treatment is inconvenient and that she will not live long enough for it to be helpful. She admits that taking medications in front of her friends is embarrassing and that the medications make her feel nauseous. Her hydroxychloroquine serum levels remain below therapeutic levels despite steadily increasing prescription dosage since SLE diagnosis. Her rheumatologist adjusts her prednisone, which could cause an unpredictable effect on her depression, but her mood has been unaddressed until now.

This scenario, particularly in pediatric patients, demonstrates how undiagnosed or untreated psychiatric conditions, namely depression, can affect adherence to SLE treatments and sustain SLE activity. The key takeaway of this case indicates delivering psychiatric care early after diagnosis, not post flare.

## INTEGRATING PSYCHIATRIC CARE INTO ROUTINE LUPUS CARE

### TRADITIONAL REFERRAL MODEL

Under current guidelines, a rheumatologist may administer routine annual mental health screenings, or when a mental disorder is suspected, which may decrease the number of patients screened.<sup>4</sup> When a patient screens positive for an elevated risk of a psychiatric condition, they might then be referred to an external provider.<sup>5</sup> After screening, patients and their families will need to seek mental health care. However, only 30% of clinicians report high accessibility of onsite psychologists, psychiatrists, and adolescent medicine providers.<sup>5</sup> Under this model, the burden of recognizing depression and other psychiatric disorders falls onto the pediatric rheumatologist, and follow-up care falls onto patients and their families. Given the high reported rates of nonadherence in SLE alongside strong support for mental health training in pediatric rheumatologists, a new standardized care model may be indicated.<sup>1,5</sup> More specifically, the Chronic Care Model creates an outline of goal-oriented care to create more equitable and accessible psychiatric care.<sup>9</sup>

### CHRONIC CARE MODEL

#### INTEGRATED BEHAVIORAL HEALTH AND PRODUCTIVE INTERACTIONS

Warm handoffs can decrease barriers to mental health care, while preexisting relationships between rheumatologists and mental health providers can provide useful context and simplify collaborative decision-making for parents and their patients. The Routine Patient Health Questionnaire, Generalized Anxiety Disorder assessment, and other psychiatric screening tools can flag early mood changes. A positive result can result in immediate action, having same-day behavioral evaluations, or having the clinic schedule follow-up appointments with behavioral specialists.

Universal routine screenings can expand access for rural and low-income populations, such as a self-administered

Patient Health Questionnaire or Generalized Anxiety Disorder assessment with automated results for physicians. This would address some inequities, such as disproportionately underdiagnosed depression and anxiety among African American pediatric patients with SLE.<sup>10</sup> Additional ways to improve screening access can include tools to administer screenings for illiterate or non-English speaking patients. However, this may further burden underresourced clinics and traveling patients, so careful planning is required; this might involve allowing patients to complete screenings remotely and creating urgency-based triage systems, increasing access for patients with transportation issues and decreasing wait times for urgent cases.

#### PSYCHOTHERAPEUTIC INTEGRATION AND DELIVERY SYSTEM DESIGN

Illness-specific cognitive behavioral therapy can help with the unique challenges of chronic unpredictable illness. An adjusted telehealth approach of cognitive behavioral therapy for youth with chronic conditions and their families was shown to increase access to care as well as extend the time between visits.<sup>11</sup> This was done by reframing psychiatric symptoms such as depression, anxiety, and posttraumatic stress disorder as part of disease physiology, which reduces stigma, increases treatment adherence, and directs common goals for families to achieve.

#### PHARMACOLOGICAL THERAPY AND SELF-MANAGEMENT SUPPORT

SLE treatment commonly involves polypharmacy; adherence to a typical pediatric SLE regimen can already pose a challenging deterrent for effective treatment. Additionally, first-line treatments for SLE include corticosteroids, adding further complications as increased corticosteroid dosages are associated with altered emotional health and mental distress.<sup>12</sup> With various medication schedules and timing, instructions for ingestion with meals, and considerations for medication interactions, adding medications for psychiatric treatment can cause additional complexity for both physicians and patients. Carefully coordinating medications can provide convenience and avoid adverse effects and drug interactions.

Incorporating strategies for medication adherence such as scheduled pill boxes can improve both psychiatric and SLE outcomes by avoiding double dosing, missing dosages, or improper dosage time.

#### SOCIAL DETERMINANTS AND DECISION SUPPORT

Families can play a large role in treatment efficacy for pediatric patients. Many social determinants are out of children's control, such as financial stability, access to care, and legal medical decision-making. Parents are essential to medication and treatment adherence, from attending appointments to ensuring medication administration. Educating families and addressing treatment barriers through support groups, group therapy, cognitive behavioral therapy, and individualized educational materials can reduce

stigma while highlighting the importance of medical treatment, including psychiatric treatment. Families can also assist with recognizing early signs of psychiatric distress or abnormal changes in behavior. Chronic illness can profoundly impact family dynamics, causing grief and altering relationships among parents and siblings. With fully informed goal-oriented care, priorities of the patients and their families can be balanced to achieve consensus for treatment.<sup>9</sup>

#### ADDRESSING INEQUITIES

Among pediatric Medicaid patients, African American patients held the highest burden of SLE cases, but they also had the lowest rates of psychiatric diagnosis and treatment.<sup>10</sup> Financial strain was shown to be associated with worse long-term outcomes in patients with SLE into late adulthood, underscoring how psychosocial stressors compound biological risk. Some inequities may be addressed with strategies such as the following:

- integrating community health navigators and case managers to bridge socioeconomic barriers
- employing bilingual screeners and using language interpreters for non-English-speaking families
- incorporating after-hours nurse hotlines to triage for psychiatric and SLE emergencies

#### CLINICAL TRANSLATION AND FUTURE STEPS

The current recommendations for annual mental health screenings are inconsistently and inadequately implemented,<sup>4,5</sup> indicating a clear call for action considering low medication adherence and high depression prevalence in patients with SLE.<sup>1,2</sup> Applying evidence-based models such as the Chronic Care Model can improve early detection, and interventional tools can be minimally invasive and cost effective, alleviating burden on both health care providers and patients. Existing recommendations support screening and referral, but more consistent integration of psychiatric care into routine management may be necessary to improve outcomes. Psychiatric care in pediatric patients with SLE is not contradictory to providing SLE treatment but rather an essential component of it. With careful planning, utilizing tools to address the high prevalence of depression and other psychiatric disorders among pediatric patients with SLE is feasible and can improve outcomes in SLE.

#### PLAIN LANGUAGE SUMMARY

This clinical perspective addresses the under-recognized burden of depression and other psychiatric conditions among youth with systemic lupus erythematosus (SLE) and the critical need to integrate psychiatric care into routine lupus management. Depression affects many pediatric SLE patients and may significantly worsen outcomes by reducing medication adherence, increasing disease activity, and lowering quality of life. Potential interventions show simple, team-based ways physicians can detect psychiatric symptoms earlier, coordinate treatment, and provide culturally aware support while keeping costs and risks low. These strategies may improve care for a vulnerable population and guide better shared decision making.

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#### DISCLOSURE

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#### AUTHOR CONTRIBUTIONS

Conceptualization: Quynh-May Nguyen (Equal). Supervision: Robert J Jaffe (Equal).

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