Original article

Young people and their families' perspectives of living with juvenile systemic lupus erythematosus: an exploratory qualitative study

Abstract

Background Juvenile systemic lupus erythematosus is a rare autoimmune condition with wide-ranging physical, psychological and social impacts on children and young people (CYP) and their families. This study explored the perspectives and experiences of young people with juvenile systemic lupus erythematosus and their families.

Methods An exploratory qualitative study using interpretive description methodology was conducted. Six young people aged nine to fourteen years, all female, and ten family members (five mothers, three fathers and two siblings) were recruited purposively from a tertiary paediatric rheumatology service in Auckland, Aotearoa New Zealand. Semi-structured family group interviews were audio-recorded, transcribed verbatim and analysed thematically.

Findings Five themes were developed from the perspectives of CYP and their families: getting the right diagnosis; coming to terms with the diagnosis; managing medications; challenges and disruptions; and finding support in family and the healthcare team. CYP and families described lengthy and emotionally draining diagnostic journeys marked by repeated misdiagnosis and delayed recognition. Following diagnosis, families navigated significant emotional adjustment alongside the complexity of medication management. CYP experienced disruptions to schooling, social participation and daily life, including stigma related to visible symptoms. Family relationships, specialist healthcare teams and educational support through the Northern Health School were identified as key sources of support.

Discussion The findings emphasise the complex challenges that extend beyond medical management. Family support and coordinated healthcare relationships were key protective factors.

Conclusion The study highlights the importance of family-centered, culturally responsive care, timely diagnosis, nursing support to enhance adherence and integrated healthcare and education strategies to reduce psychosocial disruption.

Keywords adolescent, child, family, qualitative research, systemic lupus erythematosus, medication adherence

For referencing Blamires J, Foster M, Concannon A. Young people and their families' perspectives of living with juvenile systemic lupus erythematosus: an exploratory qualitative study. Journal of Children and Young People's Health. 2026;7(2):4-12.

DOI https://doi.org/10.33235/jcyph.7.2.4-12

Submitted 4 February 2026, Accepted 19 May 2026

Julie Blamires*[1]
RN DHSc
ORCID: 0000-0002-8515-1769
Email julie.blamires@aut.ac.nz

Mandie Foster[1,2]
RN, PG Dip/Cert, PhD
ORCID: 0000-0002-3100-0885

Anthony Concannon[3]
MBCHB, FRACP
ORCID: 0000-0001-7733-2677

[1] School of Nursing, Auckland University of Technology, Auckland, New Zealand

[2] School of Nursing and Midwifery, Edith Cowan University, Perth, Australia

[3]Health New Zealand Te Whatu Ora Counties Auckland, Paediatric Rheumatology Auckland, New Zealand

**Corresponding author*

Introduction

Systemic lupus erythematosus (SLE) is a chronic complex autoimmune disease affecting multiple organ systems including skin, muscles, joints and internal organs such as lungs, heart, and kidneys.[1] Due to the multi-system involvement, symptoms are varied and include malar and discoid rash, arthralgia, fatigue, pain, weight loss and fever, with disease characterised by periods of flare and remission.[2] Both the reduced life expectancy and high morbidity of this complex lifelong disease are related to disease activity, as well as the therapies used to treat it.[3] Juvenile SLE (jSLE) is rare, with global incidence estimated at 0.36 to 2.5 per 100,000 children and prevalence ranging from 1.89 to 34.1 per 100,000, with significant variation across ethnic groups.[4] In New Zealand (NZ), annual incidence is similar to United States of America rates.[5]

Like adult onset SLE, jSLE does not affect populations equally.[1] Higher prevalence rates are reported among racial

and ethnic minorities[6]; there are known ethnic disparities in terms of outcomes, co-morbidities and severity of disease.[1-3,7] In NZ, Māori and Pacific Island CYP have a higher incidence of jSLE, with a higher frequency of lupus nephritis and severe renal lesions compared to European children.[5] Māori and Pacific Island children with lupus nephritis are more likely to experience poor outcomes including end-stage renal failure and death compared to all other ethnic groups in NZ.[8]

jSLE is more aggressive in CYP than adults, with greater disease activity, organ involvement and mortality.[1,9] The physical and psychosocial changes that occur with maturity, the increased likelihood of requiring more intensive drug therapy, and necessity to have parents and caregivers involved in management of the disease contributes to the complexity of managing jSLE.[10,11] When jSLE develops at a young age it has more time to develop long-term complications, and multi-system co-morbidities that equate to an unpredictable and challenging clinical course for the person and family.[3]

Beyond its physical manifestations, jSLE is associated with significant psychological and social burden including bullying and mental health risks.[10] CYP with jSLE experience fatigue, pain and visible symptoms that disrupt schooling, peer relationships and daily activities, alongside elevated rates of anxiety and depressive symptoms compared with healthy peers.[12,13] CYP with jSLE reported anxiety (22/60, 37%), depression (18/60, 30%), high levels of catastrophising pain (13/60, 22%) and fatigue (24/60, 65%) with pain, fatigue and anxiety negatively impacting health-related quality of life, school attendance, social participation and overall wellbeing.[14]

In a recent review, CYP living with jSLE reported challenges with their symptoms (fatigue, pain, depression), medicines (burden, adherence) and side effects (steroids, Cushingoid features), complicated life (school, quality of life, self-esteem) and different ways of coping (relationships).[10] Family members were seen as invaluable sources of support in providing psychosocial, emotional and practical support to CYP.[10] These relational and psychosocial dimensions of living with jSLE extend well beyond medication management and have significant implications for the wellbeing of the whole family.

Much of the existing research in jSLE has focused on disease activity, treatment targets, medication adherence, and health literacy, with considerably less attention given to the broader psychosocial, relational and lived experience dimensions of living with the condition.[13,15] In NZ, growing up with jSLE as a CYP can deeply affect not just the individual but the entire family and community.[16] The complexities of diagnosis, treatment and daily life with a chronic and unpredictable condition are navigated collectively, especially in Māori and Pasifika contexts where family/whānau-based decision-making and support are central.[17,18] Research that includes the whole family is essential to truly understand the holistic lived realities of managing jSLE. Without including family voices, research risks overlooking key factors that shape a child's health journey and misses opportunities to develop more responsive, meaningful and culturally grounded support and interventions.[17,19] Yet empirical evidence capturing family members' own perspectives and experiences of living with jSLE remains limited. The aim of this study was to investigate the perspectives and experiences of CYP and their families living with jSLE.

Materials and methods

Study Design

This exploratory qualitative study used interpretive description (ID) methodology[20] and followed Consolidated Criteria for Reporting Qualitative Research (COREQ) and Child Centred Research Checklist (CCRC) guidelines. [21,22] ID was selected as a qualitative methodology explicitly designed for applied health research, positioned within a naturalistic epistemological framework that moves beyond description to generate clinically meaningful interpretation.[20] Its practice-oriented focus, producing knowledge directly applicable to practice improvement, made it particularly well-suited to exploring the experiences of CYP and families living with a complex chronic condition.[20]

Participants

A purposive sampling strategy recruited families of young people diagnosed with jSLE who were actively engaged with the paediatric rheumatology service in Auckland, New Zealand. Families were informed via clinic flyers and direct healthcare provider invitation, then contacted by the research team to confirm eligibility. Direct healthcare provider invitations were nurse specialists and allied health staff from the rheumatology service who were not members of the research team. To mitigate potential power imbalance, families were reminded that participation was voluntary and would not affect their care; consent was obtained by a researcher independent of their clinical team. Inclusion criteria were: (1) a young person aged 9–18 years with jSLE as defined by American College of Rheumatology (ACR) classification criteria; and (2) the young person and family were able to converse in English. Participants self-defined their family group composition, with interviews scheduled at mutually convenient times and locations. Informed consent and assent were obtained from all participants (section 2.5).

Data collection

Semi-structured family group interviews explored CYP and family perspectives cohesively, eliciting shared experiences and meanings.[23] Unlike focus groups, family interviews involve already-connected participants sharing daily experiences, allowing both collective and individual expression.[23] Two researchers co-facilitated interviews in participants' homes (35–60 minutes), using a literature-based interview guide.[10] Participants received an information sheet outlining researchers' backgrounds and study aims prior to interview, and researchers introduced themselves at commencement of each interview. To prevent parental overshadowing, interviewers directed opening questions to CYP first, used age-appropriate language, explicitly invited CYP views when parents dominated, and monitored non-verbal cues per CCRC guidelines.[22,24] All interviews were audio-recorded and transcribed verbatim, with transcripts reviewed for accuracy and de-identified.

Data analysis

Analysis followed an iterative, interpretive approach consistent

with ID methodology, guided by its four quality principles: epistemological integrity, representative credibility, analytic logic and interpretive authority.[20] The lead researcher (JB) undertook prolonged data immersion, reviewing transcripts against audio recordings alongside observational field notes. Line-by-line coding identified meaningful statements and preliminary themes, with each family examined individually before comparative analysis explored cross-family patterns. Analysis was primarily inductive, though deductive reasoning informed the process given the literature-based interview guide and the team's clinical and research expertise. Mind maps and reflective memos supported iterative movement between data and emerging interpretations, maintaining a practice-oriented focus throughout. [20]

The research team brought complementary perspectives: JB and MF as paediatric nurse researchers with qualitative expertise (MF having no prior jSLE involvement, providing analytical distance) and AC as a paediatric rheumatologist providing disease-specific context. No prior relationship existed between researchers and participants prior to the study. The lead researcher maintained reflexive memos throughout to identify assumptions arising from clinical backgrounds and familiarity with the research setting. Constant comparative analysis[25] refined preliminary themes into coherent overarching themes capturing both collective and nuanced dimensions of family experience. Reflexive memoing and iterative co-author discussions ensured the final narrative remained data-grounded while offering a higher-level interpretive account of experiences and perspectives of CYP and families living with jSLE.

Ethical considerations

University Ethics Committee approval (#21/355) was obtained pre-recruitment. Informed consent/assent was secured from families and young people. COREQ and CCRC guidelines were followed.[22] Confidentiality was maintained throughout, with identifying details removed.

Results

Six CYP (9 to 14yrs) and ten family members (five mothers, three fathers and two siblings) participated in this study (Table 1). CYP had been living with jSLE for between 1–5 years at time of interview, with age at diagnosis ranging from 1–13 years.

Analysis of the data generated five overarching themes, grounded in the perspectives of CYP, and their families living with jSLE. The complexity of living with jSLE in NZ is reflected across these themes, which move beyond the medical aspects to highlight psychosocial and relational dimensions. Direct quotations from participants illustrate these themes, ensuring voices of CYP and families remain central to data interpretation. Where quotations are attributed to family members, the relationship to the CYP is specified. Sibling perspectives are incorporated where data allowed, though their contributions were limited in scope across interviews.

Getting the right diagnosis

Both CYP and their families highlighted how the diagnostic process was lengthy, emotionally draining and initially included misdiagnosis and incorrect treatments for the symptoms they were experiencing. Repeat visits to General

Table 1. Demographic characteristics of participants

Pseudonym	Gender	Age	Ethnicity	Household composition	Age at diagnosis	Medications
Talia	F	12yrs	Tongan	7	1yr	Hydroxychloroquine, Azathioprine, Iron
Talia's mother	F		Tongan			
Manaia	F	11yrs	Thai	5	9yrs	Methotrexate, Loratadine, Amitriptyline, Folic Acid
Manaia's mother	F		Thai			
Penny	F	11yrs	Tongan	6	10yrs	Hydroxychloroquine, Paracetamol PRN
Penny's father	M		Tongan			
Penny's brother	M		Tongan			
Lea	F	11yrs	Samoan/ Japanese	4	9yrs	Hydroxychloroquine, Mycophenolate mofetil, Lisinopril
Lea's mother	F		Japanese			
Lea's father	M		Samoan			
Sonya	F	9yrs	Tongan	8	8yrs	Methotrexate, Prednisone, Folic Acid
Sonya's mother	F		Tongan			
Sonya's father	M		Tongan			
Sonya's sister	F		Tongan			
Adita	F	14yrs	Indian	8	13yrs	Hydroxychloroquine, Methotrexate, Mycophenolate mofetil
Adita's mother	F		Indian			

F Female; M Male

Practitioners, Accident and Emergency's and hospitals were part of all participants journey before receiving the correct diagnosis. However, CYP and parents described this journey from different vantage points.

CYP recalled the onset of symptoms-rash, joint pain, mouth ulcers and fatigue, that prompted them to seek help. Parents, by contrast emphasised frustration at these symptoms being dismissed, overlooked or rationalised during the early stages, delaying recognition of lupus. Fatigue emerged as one of the most prominent and disruptive symptoms for CYP, particularly during disease onset and flare. Prior to diagnosis, CYP often attempted to normalise their loss of energy, attributing it to poor sleep or everyday activities.

> *"Oh, I felt tired all the time. Right around like, maybe two hours after waking up my fatigue would kick in, and it would go on until I go to bed. And then it affected everything I did during the day at school. Going out and playing sports and doing normal things I would usually do. I would push through the day and then come back home and sleep — I thought it was just that I didn't sleep at night." (Talia)*

Manaia similarly attempted to rationalise her symptoms until their persistence forced reconsideration,

> *"My ankle was sore, and we thought it was just from running around at school. But the soreness didn't go away for weeks." (Manaia)*

Parents and siblings also observed changes in the young person that was difficult to explain. Talia's mother described extreme fatigue, pallor and reduced appetite, alongside a facial rash that remained unidentified in primary care. Penny's brother similarly noticed changes in his sister,

> *"She seemed to be tired all the time, like more dopey than usual … just didn't know what was wrong with her ... but she just wasn't acting like herself." (Penny's brother)*

Despite families raising concerns, symptoms were frequently attributed to other conditions, such as viral illness, herpes, eczema, insect bites or allergies, prolonging the diagnostic journey. Frustration with repeated consultations without resolution was a common thread.

> *"We went to the GP five times, and they kept saying it was an insect bite or an allergic reaction to something. Took us a month and a half, almost two months — that's why everything got worse. Nobody ever picked up anything or saw how this thing grew on the face, on the body, she started limping ... there should be some things that need to be looked at." (Penny's father).*

Lea's mother described turning to online research when clinicians were unable to identify the cause, intensifying anxiety and catastrophic fears.

> *"The GP suspected it was a virus and told us to wait a couple of days. But I had a gut feeling it wasn't quite right. I started googling. And I thought, 'Oh, she might have leukaemia.' I was pretty sure she had it." (Lea's mother).*

Parents expressed considerable frustration that their CYP were prescribed treatments that were ineffective and accompanied by limited explanation, leaving them feeling unheard as their child's condition worsened. Several parents described fearing their young person had cancer based on observed symptoms, with Sonya's mother stating, "*I thought she had leukaemia and felt like it was the end of the world*." Although deeply distressing, these fears intensified parents' determination to advocate for their CYP. The emotional strain of seeking answers was substantial, with a hospital admission often described as the turning point in reaching a lupus diagnosis. Across families, the phrase *'at least we finally knew'* captured a shared sense of relief following prolonged diagnostic uncertainty.

Coming to terms with the diagnosis

Although CYP and their family members felt initial relief after a diagnostic journey, this was short-lived, as they realised that lupus would be a difficult condition to live with, due to its multisystem nature, invisible symptoms and lack of cure. Parents described struggling to grasp the disease's complexity, its unpredictability, and the impact on their CYP's life. For some, the diagnosis brought shock and despair as they tried to understand how their previously healthy CYP had developed such a challenging condition.

> *"It's not easy her having this disease … Lupus is complicated and the medications have side effects too. This is not a good lot…" (Sonya's father)*

Lea's mother described the shock of coming to understand the long-term implications of the diagnosis,

> *"After a while I realised it actually ended up being worse than I thought ... I was like maybe it would have been better with leukaemia because it seems like there have been a lot of advances in treatment and people have actually improved. But you hear about the fact that there's no real treatment for lupus — they're just trying to subdue the symptoms." (Lea's mother)*

Parents varied in emotional responses and coping approaches. Some described feelings of sadness, anxiety and constant worry, while others were determined to learn as much as possible, exploring alternative treatments and taking proactive steps to support their young person's health. However, even proactive information-seeking could be distressing. Lea's parents described how their attempts to connect with others through online support groups proved unhelpful.

> *"I also joined this support group of lupus patients on Facebook and it's mostly adults and they, they talk about how hard their lives are … it sounded so sad and miserable." (Lea's mother and father).*

The lack of a definitive cure and reliance on symptom management deepened parents' concerns, and feelings of hopelessness. A particularly strong theme across parent accounts was grief about their CYP being '*so young with this disease'* and the unjustness of a young person needing to take medications for life. Manaia's mother articulated this sentiment: "*Why should she have this, when even aunties and grandparents don't have to take medicines every day, but she does. She is too young for this*." The sense that a

serious chronic illness violated expectations of a healthy, carefree young person's life represented a significant source of parental distress.

Despite challenges, all parents articulated having an important role in looking after their young person by ensuring healthy food, adequate rest and medication adherence. For some, maintaining hope was essential.

> *"Hope that one day Sonya will get out from there. And become normal ... I'm hoping that one day Sonya will get away from medication and be good, but I don't know." (Sonya's mother)*

Sonya's sister also reflected on the impact of medications on her sibling,

> *"The worst part about if for her I think is she takes a lot of pills now and I know she doesn't like it, especially the one that makes her feel sick." (Sonya's sister)*

Across families, coming to terms with the diagnosis was described as an ongoing and evolving process.

Managing medications

Both CYP and parents identified medication management as central to daily life, however, their perspectives on adherence, side effects and risks revealed important differences in understanding and decision-making. For example, Penny described independently reducing or stopping medications because of intolerable side effects and adopted a pragmatic, symptom-based approach where she resumed medication only when experiencing symptoms:

> *"I just stopped it myself … I take it sometimes when my legs start hurting, but it doesn't really hurt … I haven't felt the lupus come back." (Penny)*

Whereas Penny's father's understanding differed markedly:

> *"Oh, she's taking it, sometimes, but slowed down a bit lately and then maybe our next appointment we'll see how we go and then maybe start again" (Penny's father)*

Both Penny and her father expressed knowledge about risks ('*we know she could get ill again*'), yet this didn't translate into consistent adherence. For Penny, relief from side effects outweighed risk of disease flare, a trade-off she deemed '*worth it*'.

Side effects presented challenges for other families too. Manaia's mother described an early medication adjustment,

> *"As soon as she took it for the first couple of months, they had to take it off because it was too much for her ... she had blurry vision." (Manaia's mother)*

Sonya's family also described using traditional medicines sent from family in Tonga alongside prescribed medications, reflecting culturally embedded approaches to health and healing.

In contrast, other CYP articulated clearer connections between medication adherence and disease control. Talia described how remembering past symptoms motivated her adherence, "*When I get tired, I remember the fatigue I had last year, and then I remember to take it. That's motivating*." Similarly, Adita explained that "*medicines make sure it doesn't get worse, like before we left the hospital*". These CYP's accounts demonstrate how their experience of severe symptoms strengthened their understanding of medication necessity and supported adherence.

Parents also varied in their own understanding and management of medication regimens. Several found complex dosing schedules confusing, particularly medications requiring weekly dosing or tapering schedules. Lea's father recounted giving the wrong combination of medications for an extended period due to misunderstanding the schedule:

> *"I said, man I'm still confusing myself with these medications. She was supposed to take only the pink one for two weeks and all these times we are giving her the pink one and the white one." (Lea's father)*

Parental observation also played a role in monitoring medication effectiveness and disease activity. Sonya's father described watching for subtle physical signs in his daughter.

> *"She doesn't say 'I'm sore.' But I can tell something's not right by the way she walks." (Sonya's father)*

Access to specialist nursing support was identified as crucial for navigating medication complexity. Sonya explained how her nurse provided essential guidance, "*X [nurse] always helps us with understanding the medicines and we can ask questions*". Yet this reliance on specialist expertise also created vulnerability. Lea's mother described the anxiety that arose when she couldn't access specialist support, particularly given her lack of confidence in other healthcare providers' knowledge of lupus treatments:

> *"I started panicking ... I couldn't get hold of the rheumatologist, or the nurse and I just knew the pharmacist, or our GP wouldn't know about the medications." (Lea's mother)*

Despite these challenges, most families had developed a positive relationship with their medication regimens. When treatment became effective and integrated into daily routines, CYP like Adita came to view medications as enablers rather than restrictions.

> *"Everything is just normal now; I just need medicine that's all ... cause like I think, the lupus is in the background now 'cause the medicine controls it." (Adita)*

Challenges and disruptions

Living with lupus brought daily challenges regarding sun exposure management. Both CYP and parents described practical difficulties of sun protection. Parents described challenges encouraging CYP to keep hats on, wear sunblock and the financial costs of sunscreen. Young people expressed frustrations in wearing sunscreen. Penny's father captured the seemingly impossible nature of this requirement in NZ's climate:

> *"avoiding the sun is hard. We live in New Zealand. How can you avoid the sun? I feel sorry for her." (Penny's father)*

The physical effects of lupus on skin also had social consequences for some CYP. Lea's mother described how visible skin changes affected her daughter's confidence.

> *"The rash on her cheeks made her very shy. She didn't want her photos taken anymore." (Lea's mother)*

Manaia described concealing here skin from others to avoid unwanted attention.

> *"Even now, I cover myself up with long sleeves and pants because I don't want people to see my skin." (Manaia)*

CYP identified missing school as the most distressing disruption. Having jSLE disrupted daily routines, school attendance, and family life due to symptoms or medical appointments. Frequent absences from fatigue, pain or appointments led to feelings of disconnection. *"Sometimes I was too tired to go to school. Sometimes when I did go, I was too tired to pay attention." (Manaia)*

Manaia's mother confirmed the extent of these absences.

> *"She only goes to school about half the time each term. On some days, I have to pick her up early because she's too tired or in pain." (Manaia's mother)*

Talia similarly expressed disappointment about missing important school events, *"I missed my prizegiving, and I was winning a prize too, so that kinda sucked."*

Talia's mother also described the impact of hospitalisation on her daughter's school participation.

> *"It's hard when she has to miss school. And then she was up for an award at school and was in Middlemore Hospital and she can't make it." (Talia's Mother)*

Finding support in family and the healthcare team

CYP and their families identified family, healthcare providers and educational support as central to managing life with jSLE. Northern Health School* provided vital resources and support to help navigate school absences and enable reintegration back to school. CYP and families valued how Northern Health School allowed them to maintain educational progress during periods of illness. CYP described returning to regular schools part-time with Northern Health School support. Adita articulated the importance of this continuity:

> *"It's so good, it allows people who have been in hospital to keep on track. Because that's one of the biggest things when you're sick is that you miss school and missing school is kind of hard 'cause it's hard to keep up in high school." (Adita)*

Families and CYP valued their specialist rheumatology team's support, advice, and confidence in having the *'right doctor now'.*

> *"Yeah, and if anything, um suspicious, anything that we want to talk you can ring directly to the doctor." (Penny's father)*

*The Northern Health School (NHS) is a publicly funded specialist school in Aotearoa New Zealand that provides education for children and young people with significant health needs who are unable to attend their regular school due to illness.

Talia's mother highlighted that the healthcare team's interest extended beyond medical management and that they felt a strong sense of wrap-around support.

> *"The team, the doctors they care about her. They ask about what Talia is doing at school at home. That's great for me. It's not just about the lupus." (Talia's mother)*

The value of having specialist paediatric hospital care was also acknowledged by families. Lea's mother described feeling well supported.

> *"I feel lucky that we have Starship, especially during lockdown. Even when things were really hard, they looked after us very well." (Lea's mother)*

Adita's mother similarly reflected on the care provided by nursing staff and the sense that they were cared for holistically.

> *"The nurses were like angels. One even massaged her feet when they were sore." (Adita's mother)*

Family support was described as fundamental across all families. Adita described family as her most important source of support:

> *"Probably like my family and the hospital and stuff. When I got sick, all my family would visit me and call me. And the hospital staff too, they were really nice." (Adita)*

Parents described rallying around their young person and drawing on both immediate and extended family networks. Talia's mother described her commitment:

> *"I support her 100 percent — because I know her. Sometimes I just cry because she got the lupus, so I try to make courage. It's hard for me, I got to accept the situation and keep her healthy." (Talia's Mother)*

Adita's mother described how extended family shared caregiving responsibilities:

> *"Our extended family supports us. My sister and I work together to take care of Adita, balancing our schedules to make sure she's looked after." (Adita's mother)*

Some families also reflected on how the diagnosis had deepened their appreciation of family relationships. Lea's father reflected:

> *"We bond more with Lea and have more conversations; It's like a blessing and a curse." (Lea's Father)*

Discussion

While the experiences of adults living with SLE has been researched,[26,27] the experiences of CYP and their families navigating jSLE remain less studied. This study addressed that gap by including the perspectives of both CYP and family members in NZ. The findings highlight the distinct perspectives that family members bring, including the emotional burden of the diagnostic journey, the complexity of medication management and the central role of family in supporting CYP to cope and adapt. These findings highlight the importance of a family-centred approach to jSLE care and research.[17,19]

Families described substantial emotional and practical challenges surrounding diagnosis. All reported difficulties obtaining a correct lupus diagnosis, with multiple consultations, misdiagnoses and prolonged delays contributing to frustration and anxiety. This 'diagnostic delay' is consistent with international evidence. A large registry study of jSLE patients (n=598) reported early presentation (<1 month) in 44%, moderate delay (3–12 months) in 23%, and severe delay (≥1 year) in 9%.[28] Similarly, Costagliola et al, [29] reported a median time of six months from symptom onset to diagnosis, extending to 54 months in children presenting with isolated haematological abnormalities.

Diagnostic delay is likely multifactorial, reflecting heterogeneous initial presentations, absence of cardinal lupus features, and the lack of a single reliable biomarker.[30] Although lupus-specific manifestations may reduce diagnostic delay,[31] the pathognomonic malar rash was present in only 38% of NZ CYP at jSLE diagnosis.[5] Given the rarity of jSLE and its variable presentation, increased clinical awareness remains critical to support timely recognition and referral.

Parents frequently reported initial misdiagnosis in primary care, with children treated for less serious conditions prior to referral. Focus groups with primary health care providers identified limited training in autoimmune disease and difficulties interpreting antinuclear antibody results as contributors to diagnostic delay.[32] Children with jSLE often present with non-specific features, including lymphadenopathy (20%), weight loss (35%), anorexia (25%) and fever (45%), that can mimic infection or malignancy, necessitating additional investigations and potentially prolonging diagnosis.[33] Rather than indiscriminate testing, a staged, pattern-based diagnostic approach is recommended, incorporating targeted serology and urinalysis when symptoms persist or cluster across systems.[34] Early connective tissue disease screening should include antinuclear antibody testing (with extractable nuclear antigens and anti–double-stranded DNA) and urine microscopy with protein–creatinine ratio, in consultation with a paediatric rheumatologist.[34]

Fatigue was commonly reported by our cohort yet remains under-recognised clinically, despite affecting approximately 65% of children with jSLE and being strongly associated with reduced quality of life.[14] Nurses in both primary and secondary settings are well positioned to detect red flag symptom patterns, such as fatigue, joint pain, unexplained rash and malaise, particularly in higher risk populations, and play a crucial role in facilitating timely specialist referral.

Diagnosis initially brought relief after prolonged uncertainty but was soon overshadowed by anxiety, fear and grief. Families felt unprepared for the chronic, unpredictable nature of lupus. These emotional responses mirror those reported in other paediatric autoimmune conditions[35] and highlight significant psychosocial burden associated with jSLE.[10] Jones et al,[14] similarly identified high rates of anxiety (37%) and depressive symptoms (30%) among affected children.

Families described medication management as highly challenging. CYP expressed confusion about dosing, worry about side effects, and uncertainty about medication necessity. Parents balanced encouraging adherence with their child's resistance and fears, constantly negotiating between disease control and normalcy. Families reported difficulty accessing timely guidance for medication problems. These findings mirror evidence showing nonadherence rates up to 65% in jSLE.[11] In NZ nonadherence occurred in 47% of children with lupus nephritis, was more common among Māori and Pacific children, and associated with higher rates of renal failure and mortality.[8] Nurses play a central role in supporting adherence through proactive follow-up, accessible nurse-led helplines and tailored medication education. Nurse practitioners and clinical nurse specialists can regularly assess adherence, discuss barriers in culturally appropriate ways and co-develop strategies supporting safe, consistent medication use. [17]

Challenges identified by CYP and families included managing sun exposure and school attendance. These experiences align with literature showing inconsistent adherence despite education. Sunscreen use among CYP with jSLE (N=100) increased from 79% to 92% following education, though barriers included perceptions of unnecessary use and texture dislike.[36] Similarly, 50% of children and 68% of parents reported illness-related school absences, primarily due to medical appointments or hospitalisations.[37] Families valued Northern Health School[38] which provides teaching to students too unwell to attend regular school, helping maintain normality, academic progress and supporting school reintegration. Such coordinated support across healthcare, education and community services is essential to minimise disruptions to school and daily life.

The trust families placed in healthcare professionals, especially when communication was clear and accessible underscores the value of consistent, relational health care. The ability to directly contact a familiar nurse or other health care team member was identified as a critical support highlighting the importance of designated paediatric nurses who provide consistent touchpoints across inpatient, outpatient, and community settings. This continuity, combined with developmentally appropriate, culturally responsive communication, helps families navigate the complexities of this lifelong condition.

Clinical Implications

The findings of this study have several implications for clinical practice. Early recognition of jSLE symptoms particularly fatigue, joint pain, and skin changes by primary care nurses and GPs is critical to reducing diagnostic delay, especially in higher risk populations.[32,33] Nurses are central to the care and support of people with SLE.[39] Nursing roles supporting medication adherence through accessible nurse-led helplines, proactive follow-up and culturally appropriate education for both CYP and their families are well supported in the literature.[40,41] The emotional burden experienced by families following diagnosis highlights the need for routine psychosocial assessment and support beyond medical management.[13,42] Coordinated care across healthcare, education and community services (including partnership with Northern Health School) is essential to minimising disruption to CYP's daily lives. Finally, the value families placed on consistent, accessible and relational healthcare underscores the importance of designated nursing roles

that provide continuity across inpatient, outpatient and community settings.

Strengths and limitations

This is the first study to report on the lived experience of CYP diagnosed and living with systemic lupus in NZ from a diverse sample of participants. Some of the limitations include a small, purposive sample of families already engaged with rheumatology services, the risk of self-selection bias, a female dominated sample, and absence of Māori participants despite Māori's being at higher risk for severe jSLE, limiting cultural generalisability. The study did not systematically capture socioeconomic status, geographic location, or social support levels, which may have influenced experiences. Clinical data, such as disease activity scores or organ involvement beyond participant disclosure were not collected, limiting ability to correlate experiences with objective measures. Future research should prioritise recruitment of Māori and Pacific families to ensure cultural representation, consider larger purposive samples across multiple sites, and explore the use of mixed methods approaches to correlate lived experiences with clinical measures of disease activity and outcomes.

Conclusions

Living with jSLE requires more than symptom management, it demands resilience, adaptation, and support. CYP rely on their own strengths, family relationships, and trusted healthcare connections to navigate the daily challenges of living with a complex chronic condition. These findings have clear implications for practice. Early recognition of jSLE symptoms, accessible and culturally appropriate nursing support, routine psychosocial assessment, and coordinated care across healthcare and education settings are essential to improving outcomes for CYP and their families. Supporting CYP means validating their experiences, empowering families, and prioritising what matters most to them. Future research should prioritise the inclusion of Māori and other under-represented communities to ensure that care approaches are truly culturally responsive and equitable for all New Zealand children living with jSLE.

Author contributions

Julie Blamires: Conceptualisation (lead); data curation (lead); formal analysis; methodology; writing original draft; review and editing. Anthony Concannon: Conceptualisation (supporting); writing – review and editing. Mandie Foster: Data curation (support); writing – review and editing.

Conflict of interest

The authors declare no conflicts of interest.

Funding

This study was partially funded by a AUT Faculty of Health and Environmental Science Contestable Grant.

References

1. Charras A, Smith E, Hedrich CM. Systemic lupus erythematosus in children and young people. *Curr Rheumatol Rep.* 2021;23:20 doi: 10.1007/s11926-021-00985-0
2. Huang X, et al. Differences in the clinical manifestations and mortality of systemic lupus erythematosus onset in children and adults: a systematic review and meta-analysis. *Int Arch Allergy Immunol.* 2021;183:116–126. doi: 10.1159/000518321
3. Ameer MA, et al. An Overview of systemic lupus erythematosus (SLE) pathogenesis, classification, and management. *Cureus.* 2022;14:e30330. doi: 10.7759/cureus.30330
4. Valenzuela-Almada MO, et al. Epidemiology of childhood-onset systemic lupus erythematosus: a population-based study. *Arthritis Care Res (Hoboken).* 2022;74,728–732. doi: 10.1002/acr.24827
5. Concannon A, Rudge S, Yan J, Reed P. The incidence, diagnostic clinical manifestations and severity of juvenile systemic lupus erythematosus in New Zealand Maori and Pacific Island children: The Starship experience (2000–2010). *Lupus.* (2013);22:1156–1161. doi: 10.1177/0961203313503051
6. Maningding E, Dall'Era M, Trupin L, Murphy LB, Yazdany J. Racial and ethnic differences in the prevalence and time to onset of manifestations of systemic lupus erythematosus: The California Lupus Surveillance Project. *Arthritis Care Res. (Hoboken).* 2020;72:622–629. doi: 10.1002/acr.23887
7. Rubinstein TB, Knight AM. Disparities in childhood-onset lupus. *Rheumatic Disease Clinics.* 2020;46:661–672. doi: 10.1016/j.rdc.2020.07.007
8. Concannon A, Wong W, Han DY. The long-term outcome of New Zealand Maori and Pacific Island children diagnosed with childhood onset lupus nephritis. *Lupus.* 2022;31:1671–1678. doi: 10.1177/09612033221128437
9. Vara E, Gilbert M, Ruth NM. Health disparities in outcomes of pediatric systemic lupus erythematosus. *Frontiers in Pediatrics.* 2022;10:879208. doi: 10.3389/fped.2022.879208
10. Blamires J, Foster M, Napier S, Dickinson A. Experiences and perspectives of children and young people living with childhood-onset systemic lupus erythematosus: an integrative review. *Children (Basel).* 2023;10:1006. doi: 10.3390/children10061006
11. Semo-Oz R, et al. Adherence to medication by adolescents and young adults with childhood-onset systemic lupus erythematosus. *Lupus.* 2022;31:1508–1515. doi: 10.1177/09612033221115974
12. Richmond B, et al. The impact of juvenile idiopathic arthritis on psychosocial outcomes: a systematic review and meta-analysis. *J Pediatr Psychol.* 2025;50:1033–1049. doi: 10.1093/jpepsy/jsaf067
13. Treemarcki EB, Danguecan AN Cunningham NR, Knight AM. Mental health in pediatric rheumatology: an opportunity to improve outcomes. *Rheum Dis Clin North Am.* 2022;48:67–90. doi: 10.1016/j.rdc.2021.09.012
14. Jones JT, Cunningham N, Kashikar-Zuck S, Brunne, HI. Pain, fatigue, and psychological impact on health-related quality of life in childhood-onset lupus. *Arthritis Care Res. (Hoboken).* 2016;68:73–80. doi: 10.1002/acr.22650
15. Ciaglia K, Moosa H, Ma Y, Sloan EE. Unmet social needs in pediatric rheumatic disease: a study of disparities. *Pediatric Rheumatology.* 2026;24. doi: 10.1186/s12969-026-01207-6
16. Uzuner S, et al. Caregiver burden and related factors in caregivers of patients with childhood-onset systemic lupus erythematosus. *Clin Rheumatol.* 2021;40:5025–5032.
17. Reweti A. Understanding how whānau-centred initiatives can improve Māori health in Aotearoa New Zealand. *Health Promot Int.* 2023;38(4):daad070. doi: 10.1093/heapro/daad070
18. Firestone R, et al. Identifying and overcoming barriers to healthier lives. *Pacific Health Dialog.* 2018;21;54–66. doi: 10.26635/phd.2018.913
19. Cannon L, Caliendo A, Hersh A. Knight AM. "There's so much to be done": a qualitative study to elucidate research priorities in childhood-onset systemic lupus erythematosus. *Lupus Sci Med.* 2022;9(1):e000659 doi: 10.1136/lupus-2022-000659
20. Thorne S. *Interpretive Description: Qualitative Research for Applied Practice*, 3rd ed. Routledge; 2025.

21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19:349–357. doi: 10.1093/intqhc/mzm042
22. Foster M, Whitehead L, O'Sullivan TA, Hill J, Mörelius E. A child-centred research checklist to improve the design and reporting of paediatric research studies: A descriptive mixed methods study. *Int J Nurs Stud.* 2025;162:104958. doi: 10.1016/j.ijnurstu.2024.104958
23. Eggenberger SK, Nelms TP. Family interviews as a method for family research. *J Adv Nurs.* 2007;58:282–292. doi: 10.1111/j.1365-2648.2007.04238.x
24. Eder D, Fingerson L. Chapter 9: Interviewing children and adolescents, in JF Gubrium, JA Holstein, eds, *Handbook of Interview Research.* SAGE Publications; 2001:181–201.
25. Elliott RA, Pfaff K, Cruz E. Interpretive description for the novice researcher: reflections and recommendations from a doctoral research journey. *Int J Qual Meth* 2025;24. doi: 10.1177/16094069251410039
26. Petrocchi V, Visintini E, De Marchi G, Quartuccio L, Palese A. Patient experiences of systemic lupus erythematosus: findings from a systematic review, meta-summary, and meta-synthesis. *Arthritis Care Res (Hoboken).*2022;74:1813–1821. doi: 10.1002/acr.24639
27. Sutanto B, et al. Experiences and perspectives of adults living with systemic lupus erythematosus: thematic synthesis of qualitative studies. *Arthritis Care Res. (Hoboken).* 2013;65:1752–1765. doi: 10.1002/acr.22032
28. Rubinstein TB, Mowrey WB, Ilowite NT, Wahezi DM. Delays to care in pediatric lupus patients: data from the Childhood Arthritis and Rheumatology Research Alliance Legacy Registry. *Arthritis Care Res. (Hoboken).* 2018;70:420–427. doi: 10.1002/acr.23285
29. Costagliola G, Mosca M, Migliorini P, Consolini R. Pediatric systemic lupus erythematosus: learning from longer follow up to adulthood. *Front Pediatr.* 2018;6:144. doi: 10.3389/fped.2018.00144
30. Bruce IN, et *al.* Lupus spectrum ambiguity has long-term negative implications for patients. *Lupus Sci Med.* 2023;10(1), e000856. doi: 10.1136/lupus-2022-000856
31. Avar-Aydın P, Brunner HI. Revisiting childhood-onset systemic lupus erythematosus. *Turk Arch Pediatr.* 2024;59:336–344. doi: 10.5152/TurkArchPediatr.2024.24097
32. Schlencker A, et al. Improving patient pathways for systemic lupus erythematosus: a multistakeholder pathway optimisation study. *Lupus Sci Med.* 2022;9(1):e000700. doi: 10.1136/lupus-2022-000700
33. Mitchell JL. Understanding the impact of delayed diagnosis and misdiagnosis of systemic lupus erythematosus (SLE). *J Family Med Prim Care.* 2024;13:4819–4823. doi: 10.4103/jfmpc.jfmpc_1177_24
34. Harry O, Yasin S, Brunner H. Childhood-onset systemic lupus erythematosus: a review and update. *J Pediatr.* 2018;196:22–30.e22. doi: 10.1016/j.jpeds.2018.01.045
35. Cardwell FS, et al. A qualitative investigation of the experiences of patients living with antiphospholipid antibodies. *Lupus.* 2024;33:1043–1058. doi: 0.1177/09612033241265545
36. Suebsarakam P, Mairiang D. Accuracy and adequacy of photoprotection in pediatric systemic lupus erythematosus patients, and the effect of education on photoprotection: a prospective study. *Pediatric Rheumatol.* 2023;21:123. doi: 10.1186/s12969-023-00901-z
37. Moorthy LN, Peterson MG, Hassett A, Baratelli M, Lehman TJ. Impact of lupus on school attendance and performance. *Lupus.* 2010;19:620–627. doi: 10.1177/0961203309355810
38. Northern Health School. *School for children with health issues.* Northern Health School; 2025. https://www.nhs.school.nz/
39. Sweeney A-M, Ndosi M. Emerging evidence for nurse-led interventions in patients with systemic lupus erythematosus and systemic sclerosis. *Evid Based Nurs.* 2024;27:104. doi: 10.1136/ebnurs-2023-103827
40. Sun K, et al. Implementation of a clinician-led medication adherence intervention among patients with systemic lupus erythematosus. *J Rheumatol.* 2024;51:884–890. doi: 10.3899/jrheum.2024-0071
41. Wojeck RK, Arcoleo K, Hathaway EC, Somers, TJ. Nurse-led interventions in systemic autoimmune rheumatic diseases: a systematic review. *BMC Nurs.* 2023;22:232. doi: 10.1186/s12912-023-01393-8
42. James S, et al. Mental health screening in pediatric rheumatology: a feasibility study. *Pediatr Rheumatol Online J.* 2025;23:117. doi: 10.1186/s12969-025-01166-4

Supplementary information

Click here to download the supplementary file.