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THE RELATIONSHIP BETWEEN FAMILY SUPPORT AND STRESS LEVELS IN CHILDREN WITH SYSTEMIC LUPUS ERYTHEMATOSUS (SLE)

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ABSTRACT

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease that not only causes physical symptoms such as malar rash, moon face, joint pain, chronic fatigue and organ damage, but also has psychological effects on children, including stress, anxiety, emotional changes and a reduced quality of life due to the disease and long-term treatment. At Dr M. Djamil General Hospital in Padang, between July–October 2025, 87 children with SLE were recorded. This study aims to analyse the relationship between family support and stress levels in children with the condition. This quantitative study employed a cross-sectional design, with the population comprising all children undergoing treatment at Dr M. Djamil General Hospital, Padang, who met the inclusion criteria, and a sample of 44 respondents selected using purposive sampling. The study was conducted from November 2025 to June 2026 using the DASS-42 questionnaire and a family support questionnaire. Data analysis was performed using univariate and bivariate analyses with the Chi-square test. The results showed that 65.9 per cent of respondents had good family support, with the majority (36.4 per cent) experiencing stress, whilst all those with poor family support (9.1 per cent) experienced stress. Bivariate analysis revealed a significant association between family support and stress levels in children with SLE (p=0.034). Recommendations for hospitals, families and nurses include optimising emotional and informational support as a means of helping to reduce children's stress levels.

INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a systemic rheumatic disease characterized by the excessive production of autoantibodies against autoantigens, resulting in the loss of the ability to distinguish between foreign substances (viruses, bacteria, allergens, etc.) and the body's own tissues(1). Globally, the number of SLE cases is estimated to be around 0.040 million people per year. The highest prevalence is reported in Poland, the United States and Barbados(2). Between 15 and 20 per cent of SLE cases are diagnosed before the age of 16, with an incidence in children of 0.36–2.5 per 100,000 children and a prevalence of 1.89–3.41 per 100,000 children. SLE in children also has a mortality rate 6.5 times higher than that of the general population(3). According to the Ministry of Health, the prevalence of SLE in Indonesia is estimated at 0.5 per cent, with more than 1.3 million people affected, primarily affecting women of reproductive age between 15 and 45 years (4). The prevalence of SLE in West Sumatra can be seen from the number of patients undergoing treatment at Dr M. Djamil General Hospital in Padang, which rose from 349 patients in 2023 to 469 patients in 2024. Physical symptoms commonly experienced by children with SLE include joint pain, extreme fatigue, a butterfly rash, sensitivity to sunlight, fever, weight loss, a 'moon face', kidney disorders such as nephrotic syndrome,

neurological disorders such as headaches, mood disorders, anemia and thrombocytopenia (5)(6). Psychological symptoms that may occur include emotional, social and psychosocial disturbances such as stress, anxiety and depression, which are unavoidable problems (7). The most common emotional problem among adolescent girls is worried (46.67 per cent), followed by depression and anxiety; this is because adolescence is a transitional period (a time of self-identity exploration), so physical limitations can hinder adolescents' psychosocial development (8).

Common symptoms in SLE patients include difficulty sleeping, irritability and difficulty concentrating (7). SLE has two phases: the remission phase and the relapse phase. Prolonged stress weakens the immune system and increases estrogen and prolactin levels, making it difficult for patients to achieve remission (7). Many SLE patients experience psychological distress, such as depression, anxiety and anger, and therefore require support from their family as their closest support network (9). Family support helps to reduce stigma and feelings of isolation, thereby boosting the child's self-confidence (10). Children with SLE require more frequent hospital care and treatment (11). Changes in body image, such as a 'moon face' and fatigue that can limit activities, may lead to self-denial, low self-esteem, negative emotions, anxiety, depression and behavioral disorders, which impact the patient's physical, psychological and social interactions (12). Recurrences of SLE may be associated with non-adherence to treatment—such as failing to attend regular check-ups, not following the prescribed diet, and failing to restrict physical activity—whilst feelings of hopelessness and a lack of self-confidence can trigger stress. Based on these observations, this study aims to analyze the relationship between family support and stress levels in children with Systemic Lupus Erythematosus (SLE).

METHOD

This study employed a quantitative design using a cross-sectional approach. The study was conducted at Dr M. Djamil General Hospital, Padang, from November 2025 to June 2026. The study population comprised all pediatric patients with SLE receiving treatment at Dr M. Djamil General Hospital, Padang, at the time of the study. A purposive sampling technique was employed based on inclusion and exclusion criteria, with a sample size of 44 respondents. Data collection was carried out through interviews, medical record documentation, journals, the completion of questionnaires and reports supporting the study. The research instrument comprised a family support questionnaire adapted from Anggraeni, consisting of 16 questions categorized as poor family support (0–5), adequate (6–11) and good (12–16). It had passed the validity test with r values of 0.78–0.943 (>0.444) (13). Stress levels were measured using the Depression, Anxiety and Stress Scales (DASS-42) questionnaire, adapted from Yasmin, comprising a total of 14 questions; each item on the DASS-42 subscales was scored on a scale of 0–3. The questionnaire was subsequently modified and classified into two stress level categories: 'not stressed' (score 0–14) and 'stressed' (score ≥15–34). The data were analyzed using univariate

analysis to describe the frequency distribution of respondent characteristics, family support and stress levels in children with SLE. Bivariate analysis was used to assess the relationship between family support and stress levels in children with SLE, employing the Chi-square test with a 95 per cent confidence level.

RESULT DAN DISCUSSION

The study sample comprised 44 children with SLE. The results showed that almost all respondents were female, totalling 41 (93.2 per cent) The respondents in this study were grouped into three categories: 4 children (9.1%) aged under 12 years, 16 adolescents (36.4%) in early adolescence (12–16 years), and 24 adolescents (54.5%) in late adolescence (17–19 years).

1. Family Support

Table 1. Frequency Distribution of Respondents Based on Family Support for Children with SLE

Family Support	*f*	%
Insufficient	4	9.1
Fair	11	25.0
Good	29	65.9
Total	**44**	**100**

Table 1 shows that the majority (65.9%) of respondents received family support rated as 'good'. Family support was categorised into four groups; for each component of family support, the majority of respondents also fell into the 'good' category, namely emotional support (81.25%) and appreciative support (82.57%). Instrumental support (84.54 per cent) and informational support (81.25 per cent). The most dominant component of family support was instrumental support (84.54 per cent).

2. Stress Levels

Table 2. Frequency Distribution of Respondents Based on stress Levels in Children with SLE

Stress Level	*f*	%
No Stress	14	31.8
Stress	30	68.2
Total	**44**	**100**

Table 2 shows that 30 respondents (68.2 per cent) experienced stress. Fourteen respondents (31.8%) did not experience stress. Stress among children was categorised into four groups: mild stress in 10 children (22.7%), moderate stress in 12 children (27.3%), severe stress in 4 children (9.1%) and very severe stress in 4 children (9.1%).

3. The Relationship Between Family Support and Stress Levels

Table 3. Relationship between Family Support and Stress Levels in Children with SLE

Family Support	Stress Level						p-Value
	No Stress		Stress		Total		
	f	%	f	%	f	%	
Less	0	0.00	4	9.1	4	9.1	
Enough	1	2.3	10	22.7	11	25	**0.034**
Good	13	29.5	16	36.4	29	65.9	
Total	**14**	**31.8**	**30**	**68.2**	**44**	**100**	

Table 3 shows that respondents with insufficient family support all experienced stress, totalling 4 respondents (9.1 per cent). Among respondents with adequate family support, the majority experienced stress, totalling 10 respondents (22.7 per cent). Meanwhile, among respondents with good family support, more than half experienced stress, totalling 16 respondents (36.4 per cent). The results of the Chi-Square test showed a p-value of 0.034 ($p < 0.05$); it can therefore be concluded that there is a significant association between family support and stress levels in children with SLE.The research findings show that almost half of the respondents had 'good' family support (65.9 per cent), whilst 25 per cent had 'adequate' support and 9.1 per cent had 'insufficient' family support. Jannah's study states that families play a vital role in supporting patients undergoing treatment, particularly during relapses (13) . Another study notes that family support plays a crucial role in helping SLE patients survive. In fact, the presence of family support is an indication that SLE patients are receiving personalised care or assistance (14) .

Family support generally comprises four main components: evaluative support, informational support, instrumental support and emotional support (15) . Based on the results of the study, it was found that 81.25 per cent of respondents received 'good' emotional support, 82.57 per cent received 'good' appreciative support, 84.54 per cent received 'good' instrumental support, and 81.25 per cent received 'good' family support. The research findings indicate that the majority of respondents received the most family support in the area of instrumental support, with 84.54 per cent rated as 'good'. Regarding the statement "my family always supports me during treatment", 93.18 per cent of respondents agreed or strongly agreed. These results indicate that the majority of children with SLE receive support from their families whilst undergoing treatment. The better the instrumental support provided by the family, the better the recovery rate for SLE patients (13) .

This is in line with Rosi's view that instrumental support—such as in caring for the patient, covering treatment costs, and assisting with the patient's daily activities when these are compromised due to fatigue or SLE relapses—also significantly influences the quality of life of SLE patients (9) . Regarding the statement "my family explains things to me whenever I ask about aspects of my illness that are unclear", the results showed that 65 per cent of respondents agreed or strongly agreed. These results indicate that the majority of respondents received informational support from their families, particularly although the percentage was lower compared to some other forms of support. The researcher's assumption is that this situation is related to the parents' educational background. This is consistent with Anisa's research, which found that parents' educational level is linked to their ability to provide support, parenting styles, and the quality of communication within the family. Parents with higher levels of education tend to have better access to information regarding adolescents' development and mental health (16) .

Regarding the component of emotional support, 97.72 per cent of respondents agreed or strongly agreed with the statement "my family continued to love me whilst I was ill". Meanwhile, 70.45 per cent of respondents agreed or strongly agreed with the statement "my family took an interest in my condition whilst I was ill". These results indicate that the majority of respondents felt emotional support from their families in the form of affection, attention and care whilst undergoing treatment. This is in line with Jannah's view that emotional support can boost self-confidence and reduce the psychological stress caused by their illness.

This study shows that the majority of respondents experienced stress, namely 30 respondents (68.2 per cent). The respondents who did not experience stress numbered 14 (31.8 per cent). Jannah's research shows that stress can occur in individuals with chronic illnesses, one of which is SLE(13) . SLE is a chronic autoimmune disease, meaning it is suffered by patients over a long period, potentially for life (11) .

In the questionnaire on stress, regarding the statement "getting angry over trivial matters", 20.45 per cent of respondents answered "very often", 22.72 per cent of respondents answered "very often" to the statement "feeling that I use up a lot of energy due to anxiety", 22.7 per cent answered "very often" to the statement "finding it difficult to rest", and 20.45 per cent also answered "very often" to the statement "feeling easily agitated". These results indicate that a proportion of respondents still very frequently experience symptoms of stress, particularly in the form of energy-sapping anxiety, difficulty resting, getting easily annoyed by trivial matters, and feeling easily agitated. These findings are consistent with Dinda's research, which found that paediatric patients with SLE generally experience difficulty resting, are easily irritated, and struggle to remain calm and concentrate in their daily lives (7).

Research findings indicate that SLE frequently occurs in adolescents aged 17–25, particularly among females (17) . Other research indicates a link between gender and stress levels in adolescents (18) .

This suggests that age and gender are factors influencing stress levels in adolescents. From these findings, it is evident that there are factors influencing stress levels in children with SLE: gender is influenced by biological and hormonal factors, whilst age is influenced by the child's stage of psychological and emotional development.

In addition to gender, age also influences stress levels in children with SLE. The results of this study showed that the majority of respondents fell into the late adolescent category (17–19 years), totalling 24 individuals (54.5 per cent). A study in Surabaya indicated that the age distribution of paediatric SLE patients was highest in the 12–18-year-old age group (19) . Erikson's psychosocial theory states that adolescence is characterised by the 'identity versus identity confusion' stage. During this stage of identity formation, stress may arise as part of the journey towards self-discovery (20). The 12–18 age range marks the transition from school-age to adolescence. At this stage, adolescents begin to focus on their appearance, sense of self and personal potential (21) . The physical changes they experience during adolescence can make them feel self-conscious and uncomfortable.

The results of this study indicate that although the majority of children with SLE fall into the 'not stressed' category, there are still some who experience moderate to severe stress. According to the researchers' hypothesis, these differences in stress levels are influenced by age; as children get older, their ability to understand their health condition, physical changes and treatment increases . This is consistent with Bagus's study, which showed that the majority of adolescents aged 15–18 have normal stress levels, although respondents experiencing mild to very severe stress were still found among those aged 16–17 (22) . The study indicated that as adolescents get older, the levels of stress they experience decrease because their knowledge, experience and ability to respond to stressors improve (22) .

Family support plays a vital role in accompanying treatment, providing access to healthcare, offering love and attention, making time to listen to concerns, praising efforts towards treatment, and explaining health issues to the child so that they feel loved, valued and accepted. Family support can reduce the stress experienced by SLE patients, thereby lowering the risk of relapse (13) . Based on this study, family support in the areas of emotional support and informational support falls into the 'good' category; however, it has the lowest percentage (81.6%) compared to other forms of support. This indicates that children with SLE may not yet be receiving optimal emotional attention from their immediate environment.

Psychological factors such as stress, anxiety and depression are key components that influence an individual's mental and physiological health. These three factors are interrelated and can significantly affect an individual's physical health, creating a complex relationship between mental and physical health outcomes (23) . This study found that informational support was in the 'good' category at 81.25 per cent. Another study showed that 60 per cent of SLE patients had informational support in the 'good' category and required such support to gain knowledge and assistance from their families regarding

their condition as a means of preventing relapses (24) .

CONCLUSION

More than half (65.9%) of the child respondents at Dr M. Djamil General Hospital in Padang received 'good' family support, whilst more than half (68.2%) of the child respondents at Dr M. Djamil General Hospital in Padang experienced stress. The results of the chi-square test showed a significant association between family support and stress levels in children with systemic lupus erythematosus (SLE) at Dr M. Djamil General Hospital, Padang, with a p-value of 0.034. It is hoped that the findings of this study will encourage hospitals to develop information, communication and education (ICE) techniques, taking into account the family's stage of development, in order to improve knowledge regarding the importance of the family's role in preventing SLE relapses influenced by stress factors in children with SLE. Education should involve family members so that they understand how to reduce relapses in children with SLE, and how to accompany and support patients, thereby fostering a sense of care and warmth that can boost self-confidence. The active role of healthcare professionals can improve the quality of care by providing motivation, knowledge and informational support to children and their families. Informational support can be provided by healthcare professionals, friends, family and the SLE community through the creation of a WhatsApp group as a means of communication and emotional support. It is hoped that future research will further explore the growth and development of families in the care of children with SLE.

AUTHOR CONTRIBUTIONS

Contributions of the study's authors. Zolla Amely Ilda, Tisnawati, and N. Rachmadanur were responsible for designing the research methodology and providing supervision throughout each stage of the study until the manuscript was completed. Meanwhile, Dhea Indah Putri contributed to data collection, data analysis, and the preparation of the research findings and discussion.

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