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ACHIEVING BETTER QUALITY OF LIFE THROUGH THE PROVISION OF SUPPLEMENTS, MEDICAL AIDS, AND COUNSELLING OF SLE PEDIATRIC PATIENTS AT RSSA MALANG

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ABSTRACT

Introduction: Systemic lupus erythematosus (SLE) in children can interfere with their growth and social functioning and the treatment process is often hampered by low compliance and the unmet secondary needs of the patient. The aim of this community service activity is to improve the quality of life of patients by fulfilling their secondary needs and providing free consultation and education.

Methods: This community service was carried out by educating and provide free consultation for 38 SLE pediatric patients accompanied by their parents directly at RSSA, monthly for 6 months, and we emphasise topics on management and healthy lifestyle for SLE patients. We also make this opportunity as a means of monitoring patient's condition which includes disease activity through SLEDAI Score, clinical symptoms, and psychosocial support, and we complete it by providing vitamin D supplements, sunblock, and wheelchairs.

Results: All the subjects in this community service were 100% girls and 50% of them had active SLE status with various clinical manifestations. 79% of patients never took vitamin D supplements and all patients did not use sunblock. There were 3 patients with neurological disorders who needed a wheelchair. We provide their secondary needs to maximize the standard therapy we have been doing. After 6 months, there was a decrease in the number of patients who missed monthly controls, and a decrease in patients SLEDAI Score indicating that their lupus activity was appropriately controlled.

Conclusion: Although rarely considered, the fulfillment of secondary needs in SLE patients such as vitamin D, sunblock, and wheelchairs for patients with mobility problems is very meaningful to them, which can optimize the main therapy given and make patients routinely attend monthly controls, because they find it helpful in terms of mobility. In addition, they do not need to buy vitamin D and sunblock themselves.

KEYWORDS

children; lupus; quality of life

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1. INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease with clinical symptoms involving various organ systems. SLE generally affects pubertal age until before menopause, but the incidence of SLE in children is still high (Guritno et al.,

2021). Poorly, the disease is progressive with more severe disease activity, complications, higher morbidity and mortality rates in children than in adults. The incidence of SLE with onset in children ranges from 0.36 to 2.5 per 100,000 children per year (Nazri et al., 2018). SLE in children not only worsens

physical health, but also affects the child's growth and social functioning that cause a decrease in the quality of life of their patients. SLE treatment is a long-term and even lifelong treatment. The patient's condition may worsen due to low compliance. The etiology of SLE is said to be multifactorial, including genetic risk factors, epigenetic mechanisms, as well as environmental triggers. SLE is characterized by the production of antibodies that attack the body itself, namely antinuclear antibodies (ANA), anti-phospholipid antibodies, anti-Smith, and anti-ribonucleoprotein. These autoantibodies then lead to overproduction of proinflammatory cytokines and cause dysregulation of the innate and adaptive immune systems (Nosal et al., 2022).

Patients with SLE often have vitamin D deficiency and insufficiency. The main risk factor for this is the occurrence of photosensitivity in the (Yap et al., 2015). UV-B exposure triggers photosensitivity, dermatologic abnormalities, and even systemic flares. For this reason, SLE patients are recommended to avoid excessive exposure of sunlight and apply sunblock when they are doing outside activities. The use of sunblock in patients with photosensitive traits can have an effect on the improvement of the patient's condition (Corbin et al., 2023). However, this causes their vitamin D levels to be lowered, as the main source of vitamin D is from sunlight through the conversion of 7-dehydroxycholesterol in the skin to previtamin D3 (Raymond-Lezman & Riskin, n.d.). In addition, individuals with darker skin pigmentation are more prone to vitamin D deficiency, due to the presence of melanin, which protects the skin from the effects of UV irradiation, resulting in decreased vitamin D synthesis (Bonilla et al., 2014).

Meanwhile, vitamin D is one of the steroid hormone precursors that is said to have a role as an immunomodulator both innate and adaptive. The active metabolites of vitamin D play a role in the process of regulation and differentiation of immune cells as well as the production of several cytokines

(Sassi et al., 2018). Vitamin D deficiency is also associated with increased disease activity and severity of SLE. Many studies have shown that vitamin D supplementation can reduce disease activity and improve quality of life (Arshad et al., 2021).

Other affected physical health conditions may also cause some of the patients to be unable to walk normally. This happens to some of our patients who need to be carried by their parents when they visit RSSA. Lack of money is one of the reasons why they cannot afford a wheelchair. Therefore, we hope to alleviate the pain and improve the quality of life of patients and their families by providing some stuff, not only wheelchairs, but also vitamin D, sunblock, and monthly free consultation which are indeed supporting the patient's recovery.

2. MATERIAL AND METHODS

This community service was held regularly and continuously every month from May 2023 to November 2023. The subjects were 38 SLE patients who were accompanied by their parents, and who were in full attendance every month. By necessity, we had to exclude some patients who were absent from one or more of the scheduled appointments. In addition to pediatricians, this community service programme also involves residents and other medical personnels. The various activities that we carried out are as follows:

Collecting data and conducting interviews on SLE patients

At the beginning of the activity, we collected the medical records of 38 pediatric patients with SLE including sex, age, nutritional status, clinical manifestation, SLEDAI scores, vitamin D status through ELISA method, and conducted direct interviews about the patient's daily lives.

1. SLEDAI (Systemic Lupus Erythematosus Disease Activity Index) scores is a scoring system used to

assess the severity of SLE in the past ten days that contains clinical and laboratory parameters.

2. Serum vitamin D levels obtained using the Enzyme-Linked Immunosorbent Assay (ELISA) method are required to determine the vitamin D status of patients. Here are the steps: Blood collected from the patient was centrifuged converted into serum by centrifugation (3000 rpm, 5 min, 4°C). Measurements was carried out using the ELISA (DBC, London, Ontario Canada). Vitamin D levels are then grouped into three categories: normal (> 50 nmol/L), insufficient (20-50 nmol/L), and deficiency (<20 nmol/L).
3. Through the interview, we wanted to gain information on the patient's level of compliance in conducting monthly controls, taking medications, and daily habits. We found that many patients did not consume vitamin D and did not apply sunblock during outdoor activities through those interviews. Apparently, there are also some patients who do not perform routine controls due to mobilisation constraints. There are two main reasons for this. The first reason was the location of the patient's house which is far from the hospital. The second reason was that the patients was unable to walk due to their body condition affected by SLE, so they had to be carried by their parents because they did not have a wheelchair.

Providing items to support SLE main therapy

After knowing the patient's daily needs and habits, we provide daily requirements such as vitamin D supplements, sunblock, and wheelchairs with the hope that it can support the standard treatment management that we strive together.

Monthly monitoring and counselling

We gave vitamin D and sunblock to be used for one month, and the patient was instructed to come in the following month to get the necessities to be used the next month. It was given to both hospitalised and outpatients. This was done for 6 consecutive months. Hence, monitoring the patients on a monthly basis

becomes easier as the they were more enthusiastic and compliant about doing regular controls. The percentage of patients who attended monthly control increased to almost 100%. During this monthly monitoring, we provide free face-to-face counseling and education with SLE pediatric patients and their parents at the Department of Pediatrics at Dr. Saiful Anwar Hospital Malang. Some of the topics we covered were:

1. Symptoms of lupus

Each child is likely to experience a variety of symptoms that may be different. These symptoms must be controlled to avoid the risk of complications and further organ damage.

2. Treatment of lupus

We explained that the goal of lupus treatment is to control the symptoms. We also talked about how to manage side effects that may arise from the treatment. We emphasised the importance of taking medication as prescribed and not stopping medication without consultation.

3. Living a healthy lifestyle

We always remind patients to eat more fruits, vegetables, whole grains, nuts, fish, or chicken breast to reduce the consumption of saturated fat. We also prohibit patients from eating processed foods such as chicken nuggets and other snacks with high sugar and salt content. Staying hydrated is a must. Doing regular light exercise to avoid joint stiffness but not fatigue is also important, but outdoor activities between 10am to 4pm are allowed after the patient has applied sunblock, hat, and sunglasses. As for the parents, we encourage them to provide emotional support and help their children manage anxiety and depression.

3. RESULTS

Patient characteristics can be seen in Table 1. Vitamin D levels were obtained using the ELISA method. Of the 38 patients involved in this community service, 15.8% had vitamin D deficiency, 10.5% had vitamin D

Table 1. Characteristic of SLE Patients Allergy-Immunology Division, Pediatric Departement, Saiful Anwar Hospital Malang

Variables	n=38 (%)
Sex, n (%)	
Female	100
Male	0
Age, median (range), year	(median=11)
5-9 years old	18.42
10-18 years old	81.57
Nutritional status, n (%)	
Well nourished	44.73
Undernourished	28.94
Severe malnutrition	7.89
Overweight	5.26
Obese	13.15
Clinical Manifestation	
Malar Rash	28.94
Disoid Rash	5.26
Photosensitivity	18.42
Oral Ulcer	9.52
Non-Erosive Arthritis	26.31
Pleuritis/Pericarditis	2.63
Renal Disorder	10.52
Neurological Disorder	7.89
Hematological Disorder	10.52
Positive dsDNA	28.94
Positive ANA	31.57
SLEDAI score	
Active Disease	50
Inactive Disease	50
Vitamin D 25-OH	
Deficiency	15.78
Insufficiency	10.52
Sufficiency	73.68
Vitamin D consumption	
Took vitamin D	21.05
Never took vitamin D	78.94
Sunblock Application	
Applying sunblock	0
Not applying sunblock	100

Table 2. The prevalence of SLEDAI components in 38 pediatric patients

SLEDAI score	n=38 (%)
Seizure	2.63
Psychosis	0
Organic Brain Syndrome	2.63
Visual Disturbance	0
Cranial Nerve Disorder	0
Lupus Headache	0
CVA	0
Vasculitis	0
Arthritis	21.05
Myositis	0
Urinary Casts	2.63
Hematuria	13.15
Proteinuria	10.52
Pyuria	5.26
New Rash	23.68
Alopecia	5.26
Mucosal Ulcers	5.26
Pleurisy	0
Pericarditis	2.63
Low Complement	0
Increased DNA binding	26.31
Fever	18.42
Thrombocytopenia	0

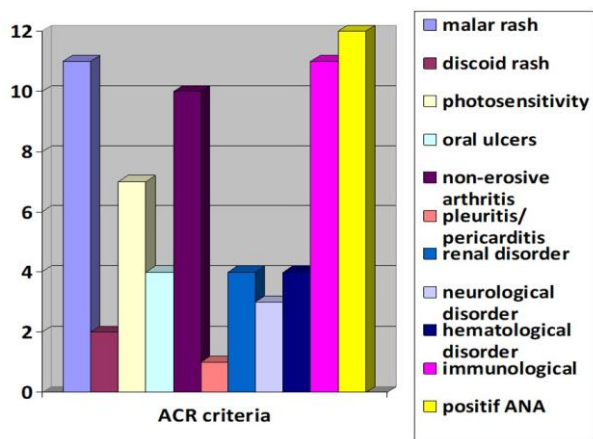


Figure 1. Clinical Manifestation of SLE Paediatric Patients by ACR criteria

In addition, almost 50% of the patients had good nutritional status. However, patients had various clinical manifestations, three of which had neurological disorders and required wheelchair assistance. The number of patients by clinical manifestation based on (American College of Rheumatology) ACR criteria can be seen in Figure 1. The type of clinical manifestation, ANA positive, was the most common in 12 children, followed by malar rash and positive ds DNA with 11 children of each. Moreover, patients with active SLE were exactly 50% of the total participants. We obtained this based on the SLEDAI score measurement. The prevalence of SLEDAI components among the 38 patients can be seen in Table 2. The component of sledai that experienced by many patients, as many as 26.31% or 10 children, was Increased DNA binding. Furthermore, 23.68% of patients had new rash, and 21.05% had arthritis. However, there were no patients with Psychosis, Visual Disturbance, Cranial Nerve Disorder, Lupus Headache, CVA, Vasculitis, Myositis, Pleurisy, Low Complement, and Thrombocytopenia. Based on our interview results, 21% of patients had taken vitamin D supplements, while 79% had not. Furthermore, all patients did not apply sunblock.

After we complemented the monthly monitoring process with the provision of their secondary needs, patients became disciplined to make monthly checks



Figure 2. Providing education about SLE to paediatric patients accompanied by their parents.

to RSSA. This makes it easier for us to conduct routine checks and know the patient's progress more intensely. The number of patients who do not present at the time of control is also greatly reduced. Patients with high adherence to treatment tend to have a better quality of life as their condition is better monitored and controlled by their doctors.

4. DISCUSSION

This community service activity was intended to reinforce and provide moral and material support to lupus suffers and their families by giving free treatment support. Patients frequently overlook the benefits of taking vitamin D supplements and utilizing sunblock. The majority of patients only consider on taking medicines after they experience a relapse. Some of them are also negligent and undisciplined when doing monthly controls. Talking about vitamin D is closely related to talking about the nutritional status of patients. Among the participants in this community service, there were 17 patients who classified as having good nutrition. However, only a small number of them had previously taken vitamin D.

Several clinical singularities associated with SLE are nutritionally related, perhaps as an etiologic factor or as a clinical impact. Nevertheless, dietary intake has the capacity to be a major risk element in SLE. Dietary patterns can alter various metabolism, including the gut microbiota (Tedeschi et al., 2020).

SLE not only reflects metabolic alterations but also deficiency of vitamins and minerals superposed by clinical manifestations that lead to increased morbidity and mortality. Researchers have investigated that nutrition is a possible influence in SLE, thus they have recommended complementary medicine using consumption patterns in the last two decades (Islam et al., 2020). There are several dietary parameters that must be considered, including calorie restriction, polyunsaturated fatty acids (PUFA), proteins, fibers, vitamins such as vitamin D, polyphenols, isoflavones, minerals, amino acids and other nutrients (Constantin et al., 2019). Many studies have found that the more adequate level of vitamin D will be accompanied by a lower SLEDAI score (Guan et al., 2019). It is well known that calcitriol widely recognized for stimulating the innate immune response and regulating T and B cell responses. For this reason, a lower level of vitamin D may raise the risks of evolving not only SLE but also different autoimmune diseases (Constantin et al., 2019).

On the other hand, applying sunblock is highly beneficial for lupus patients due to their increased sensitivity to ultraviolet light. Sunblock helps protect the skin from UV radiation, which can trigger lupus flares and worsen the symptoms. According to lupus experts, it is recommended that people with the disease apply a sunblock with at least 30 SPF and broad-spectrum protection against both UVA and UVB radiation (Corbin et al., 2023). This is particularly crucial because even a few minutes of sun exposure without protection can provoke a lupus flare-up (Suebsarakam & Mairiang, 2023). Sunblocks, particularly those containing physical blockers such as titanium dioxide or zinc oxide, effectively prevent the sun's damaging UV rays from reaching the skin, providing an extra layer of defense for lupus sufferers (Smijs & Pavel, 2011). In addition to preventing lupus flares, sunblock also reduces the risk of skin damage and skin cancer in lupus patients. Given that UV

exposure can exacerbate lupus related skin problems, such as rashes, it is critical for individuals with lupus to be diligent about sun protection. Lupus patients can better control their illness and reduce the impact of UV radiation on their skin by applying sunblock on a regular basis and following other sun-safe practices, such as wearing sun-protective clothes and avoiding the sun during peak hours.

SLE has a wide spectrum of clinical manifestations. In addition to vitamin D supplements and sunblock, we provide wheelchairs to patients with limited movement caused by neurological disorder (Figure 2). This has proven to make it easier for them to carry out their activities and requires them to return on a monthly control. By checking in on a regular basis, we can monitor the patient easily and maximize their treatment, thereby improving their quality of life.

5. CONCLUSION

This community service activity was carried out in accordance with the target . which is to improve the patient's quality of life through the fulfilment of secondary needs so as to make the patient able to routinely carry out monthly monitoring. We did this so that their SLE can be better controlled through SLE management support. Conducting education and monitoring complemented by fulfilling the secondary needs of SLE patients can increase the level of patient compliance in conducting controls, so pharmacological therapies such as hydroxychloroquine, corticosteroids, and immunosuppressant drugs as well as non-pharmacological therapies such as counselling or education on coexistence management with SLE can be given regularly and improving the quality of life of patients can be easier to achieve. The continuity of community service with many positive impacts like this needs to be realized in the following year, even interdisciplinary collaboration can be carried out to expand the reach of respondents so that more people can benefits.

6. REFERENCES

- Arshad, A., Mahmood, S. B. Z., Ayaz, A., Al Karim Manji, A., & Ahuja, A. K. (2021). Association of vitamin D deficiency and disease activity in systemic lupus erythematosus patients: Two-year follow-up study. *Archives of Rheumatology*, *36*(1), 101–106. <https://doi.org/10.46497/ArchRheumatol.2021.8178>
- Bonilla, C., Ness, A. R., Wills, A. K., Lawlor, D. A., Lewis, S. J., & Davey Smith, G. (2014). Skin pigmentation, sun exposure and vitamin D levels in children of the Avon Longitudinal Study of Parents and Children. *BMC Public Health*, *14*, 597. <https://doi.org/10.1186/1471-2458-14-597>
- Constantin, M.-M., Nita, I. E., Olteanu, R., Constantin, T., Bucur, S., Matei, C., & Raducan, A. (2019). Significance and impact of dietary factors on systemic lupus erythematosus pathogenesis. *Experimental and Therapeutic Medicine*, *17*(2), 1085–1090. <https://doi.org/10.3892/etm.2018.6986>
- Corbin, D., Christian, L., Rapp, C. M., Liu, L., Rohan, C. A., & Travers, J. B. (2023). New concepts on abnormal UV reactions in systemic lupus erythematosus and a screening tool for assessment of photosensitivity. *Skin Research and Technology*, *29*(3), e13247. <https://doi.org/10.1111/srt.13247>
- Guan, S.-Y., Cai, H.-Y., Wang, P., Lv, T.-T., Liu, L.-N., Mao, Y.-M., Zhao, C.-N., Wu, Q., Dan, Y.-L., Sam, N. B., Wang, D.-G., & Pan, H.-F. (2019). Association between circulating 25-hydroxyvitamin D and systemic lupus erythematosus: A systematic review and meta-analysis. *International Journal of Rheumatic Diseases*, *22*(10), 1803–1813. <https://doi.org/10.1111/1756-185X.13676>
- Guritno, T., Barlianto, W., Wulandari, D., & Amru, W. A. (2021). Effect Nigella sativa extract for balancing immune response in pristane induced lupus mice model. *Journal of Applied Pharmaceutical Science*, *11*(7), 146–152. <https://doi.org/10.7324/JAPS.2021.110716>
- Islam, M. A., Khandker, S. S., Kotyla, P. J., & Hassan, R. (2020). Immunomodulatory Effects of Diet and Nutrients in Systemic Lupus Erythematosus (SLE): A Systematic Review. *Frontiers in Immunology*, *11*, 1477. <https://doi.org/10.3389/fimmu.2020.01477>
- Nazri, S. K. S. M., Wong, K. K., & Hamid, W. Z. W. A. (2018). Pediatric systemic lupus erythematosus. Retrospective analysis of clinico-laboratory parameters and their association with Systemic Lupus Erythematosus Disease Activity Index score. *Saudi Medical Journal*, *39*(6), 627–631. <https://doi.org/10.15537/smj.2018.6.22112>
- Nosal, R. S., Superville, S. S., Amraei, R., & Varacallo, M. (2022). Biochemistry, Antinuclear Antibodies (ANA). In *StatPearls [Internet]*. StatPearls Publishing. <https://www.ncbi.nlm.nih.gov/books/NBK537071/>
- Raymond-Lezman, J. R., & Riskin, S. I. (n.d.). Benefits and Risks of Sun Exposure to Maintain Adequate Vitamin D Levels. *Cureus*, *15*(5), e38578. <https://doi.org/10.7759/cureus.38578>
- Sassi, F., Tamone, C., & D'Amelio, P. (2018). Vitamin D: Nutrient, Hormone, and Immunomodulator. *Nutrients*, *10*(11), 1656. <https://doi.org/10.3390/nu10111656>
- Smijs, T. G., & Pavel, S. (2011). Titanium dioxide and zinc oxide nanoparticles in sunscreens: Focus on their safety and effectiveness. *Nanotechnology, Science and Applications*, *4*, 95–112. <https://doi.org/10.2147/NSA.S19419>
- Suebsarakam, P., & Mairiang, D. (2023). Accuracy and adequacy of photoprotection in pediatric systemic lupus erythematosus patients, and the effect of education on photoprotection: A prospective study. *Pediatric Rheumatology Online Journal*, *21*(1), 123. <https://doi.org/10.1186/s12969-023-00901-z>
- Tedeschi, S. K., Barbhैया, M., Sparks, J. A., Karlson, E. W., Kubzansky, L. D., Roberts, A. L., Willett, W. C., Lu, B., & Costenbader, K. H. (2020). Dietary Patterns and Risk of Systemic Lupus Erythematosus in Women. *Lupus*, *29*(1), 67–73. <https://doi.org/10.1177/0961203319888791>
- Yap, K. S., Northcott, M., Hoi, A. B.-Y., Morand, E., & Nikpour, M. (2015). Association of low vitamin D with high disease activity in an Australian systemic lupus erythematosus cohort. *Lupus Science & Medicine*, *2*(1), e000064. <https://doi.org/10.1136/lupus-2014-000064>