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EARLY DETECTION AND COUNSELLING OF ANXIETY DISORDERS IN CHILDREN WITH SYSTEMIC LUPUS ERYTHEMATOSUS

Desy Wulandari*^{}, Wisnu Barlianto, and Susanto Nugroho

Department of Pediatric, Saiful Anwar Hospital, Faculty of Medicine, Universitas Brawijaya, Malang, Indonesia

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CONTACT

Desy Wulandari

desywulandari@ub.ac.id

Department of Pediatric, Saiful Anwar Hospital, Faculty of Medicine, Universitas Brawijaya, Malang, Indonesia

ABSTRACT

Introduction: Paediatric Systemic Lupus Erythematosus (pSLE) is a chronic autoimmune disease that affects the quality of life of patients. Anxiety is a mental health problem that is rarely addressed in Indonesia. There are still many instances of children and adolescents with anxiety due to the duration of therapy, the severity of the disease, psychological conditions, and support from the environment and family. Therefore, the detection of anxiety disorders in children and adolescents really needs to be improved. This community service activity aims to provide counselling on anxiety detection in children with SLE.

Methods: This community service has been carried out in June 2024 at Polyclinic of Dr Saiful Anwar Hospital Malang. The counselling about SLE, mental health, and the relationship between the two was done directly to the paediatric and adolescent patients with SLE and the evaluation was done through questionnaires using the Screen for Child Anxiety and Related Emotional Disorders (SCARED).

Results: After the delivery of content related to SLE and mental health as well as the completion of questionnaires, from this activity there were 12.5% of children and adolescents from 32 patients with systemic lupus erythematosus disease who experienced anxiety disorders so that further evaluation and intervention were needed.

Conclusion: Although the number of patients who did not experience anxiety was more than patients who experienced anxiety in this community service activity, psychological support to maintain optimal mental health is needed besides primary treatment for paediatric and adolescent patients with chronic illnesses.

KEYWORDS

anxiety; children; lupus; SCARED; SLE

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1. INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a complex, multisystem autoimmune disease with variable clinical symptoms that can affect multiple organ systems with a disease course of remission and relapse (Guritno et al., 2021; Smith et al., 2022). The prevalence of SLE in children and adolescents is quite variable, but can be as high as 5 per 100,000 children. However, this figure will depend on the population and the method of diagnosis used. The onset of the

disease is common during adolescence, especially adolescent girls, with a ratio of girls to boys of about 3:1 (Charras et al., 2021). The occurrence of multi-organ inflammation in SLE patients has the potential to affect various body systems including the joints, skin, kidneys and other vital organs. In addition, patients will also often experience fatigue, limiting their physical activity. In addition to the adverse effects on physical health, SLE can also trigger anxiety and depression which are part of mental health. This

anxiety is usually caused by uncertainty and the various effects they feel in their daily lives (Putera et al., 2020).

Problems with SLE include frequent school absences, low therapy compliance, changes in physical shape, anxiety, and other psychological symptoms (Tang et al., 2021; Narupan et al., 2022). These problems of SLE patients if not addressed will increase morbidity and mortality, where poor physical and mental health has long-term consequences that affect their quality of life (Tang et al., 2021). Anxiety and high levels of stress are psychological disorders that are often experienced by patients. This can worsen their physical and mental symptoms (Putera et al., 2020). Some of the causes of anxiety and stress include patients feeling unable to control their physical symptoms, worries about their future, and concerns about the impact of lupus on social relationships and education (Blamires et al., 2023). Early detection of anxiety in pSLE is very important. Some of the main reasons are due to the high prevalence of psychological disorders in patients with chronic diseases and the adverse impact of anxiety on quality of life (Neufeld et al., 2024). Moreover, this is the first time we have collected data on the mental health of patients.

The impact of anxiety in SLE pediatrics patients varies, ranging from insomnia, mood changes, to depression. The worst thing is that anxiety and stress will affect the patient's quality of life, causing limitations for them to carry out social interactions (Vara et al., 2022). Medical personnel play a role in helping children and parents to overcome the problems of their illness, explore and develop the potential of children optimally. Therefore, it is very important to provide education or counselling and early detection of anxiety in children and adolescents with SLE to optimise their growth and development.

2. MATERIAL AND METHODS

This activity was conducted on 32 patients pSLE at the Pediatrics Polyclinic of Dr Saiful Anwar Hospital Malang. The aim of this activity is to increase participants understanding of the recognition of anxiety in children with Systemic Lupus Erythematosus. With a good understanding, it is hoped that parents can recognise anxiety symptoms in children. The SCARED questionnaires were completed by the patients after they received a direct presentation by a paediatrician consultant allergist and immunologist regarding SLE and its relationship with the patient's mental health. Although the content was very scientific, the presentation was done using language that is easily understood by the general public. This is an initiative to make the material more easily understood by paediatric or adolescent patients, and also by parents of patients who have diverse backgrounds.

The education process was also conducted in an interactive environment, where the audience could ask questions to the presenters both in the middle of the presentation session and in the Q&A (question and answer) session. To maintain the enthusiasm of the audience, there was also a quiz session with prizes for those who could answer questions about SLE and mental health correctly. In addition to paediatricians, this community service activity was also fully supported by other health workers and paediatric residents.

The following is a series of core material presented before the patient fills out the SCARED questionnaire.

a) Introduction of SLE

In this section, the materials presented include an introduction to SLE, manifestations of SLE, early symptoms of SLE, how to diagnose SLE, treatment goals of SLE in paediatric patients, and steps to prevent complications.

b) Mental health

The material discussed in this section is the definition of mental health, the difference between good mental health and mental disorders, symptoms of mental health disorders in children, the impact of mental health on children, risk factors and causes of mental health disorders, strategies in improving mental health, to the role of parents and stakeholders around children in becoming a supporting resource for the creation of good mental health.

c) Mental health disorder and the relationship with SLE

This section covered the impact of SLE on mental health, as well as the importance of psychological support in paediatric patients with SLE.

After the in-person counselling, patients were asked to complete the Screen for Child Anxiety and Associated Emotional Disorders (SCARED) questionnaire which is a test used to objectively assess anxiety levels in children. In the context of children with SLE, completion of this questionnaire is important to identify the psychological impact of their chronic illness. The purpose of completing this questionnaire is to identify symptoms of anxiety that parents or caregivers may not be aware of. In addition, it can also be used to monitor mental health as the SLE disease progresses.

Patients rate how they feel and think, and each statement is scored from 0-2 (0 = not true or rarely true, 1 = probably true or sometimes true, 2 = very true or often true) and the scores are combined into a total score. The child will score a total of 0-82 on SCARED. The answers to the items are summed to get a total score, with a total score ≥ 25 indicating an anxiety disorder (Al-Biltagi & Sarhan, 2016). The results of this questionnaire will be helpful for medical personnel as it will provide information to plan appropriate psychological interventions. The SCARED structure consists of several aspects of anxiety including general anxiety which is the feeling of anxiety experienced by the child on a daily basis, social anxiety which is the child's fear of interacting with others, separation anxiety which measures the child's fear of separation from parents or caregivers, and specific anxiety which assesses the catastrophising of certain situations such as exams.

3. RESULTS

The characteristics of the participants in this community service activity are shown in Table 1. There were 32 participants, most of whom were female (93.75%) with an age range of 8-17 years. The educational background of the patients was quite diverse, including elementary school (6.25%), junior high school (43.8%), and senior high school (31.3%). The number of parents with regular jobs far

Table 1. Characteristics of Participants in Community Service Pediatrics Polyclinic of Dr Saiful Anwar Hospital Malang (n=32)

Participant Characteristics	n	%
Age (year)	13.59 \pm 2.564	
Sex		
Female	30	93.75
Male	2	6.25
Educational background		
Elementary school	8	25
Junior high school	14	43.8
Senior high school	10	31.3
Parental occupation		
Not employed	5	15.63
Having a regular job	27	84.37

Table 2. Anxiety Disorders in Children with Systemic Lupus Erythematosus (n = 32)

Children's Characteristics	n	%
Systemic Lupus Erythematosus		
SCARED Score	15,625±6,424	
No anxiety disorder	28	87,5
With anxiety disorder	4	12,5
SLE Disease Activity		
SLEDAI Score	6,97±5,949	
Remissions	2	6.25
Mild	17	53.125
Moderate	8	25
Severe	5	15.625
Physical Changes		
Moon face	2	6.25
Alopecia	8	25
Malar rash	13	40.625
Striae	2	6.25
Short stature	3	9.375



Figure 1. The paediatrician presenting the topic of anxiety and anxiety disorder



Figure 2. Patient briefing on how to complete the SCARED by the paediatrician

outweighs the number of parents who are not working.

Education on the importance of anxiety disorder detection for children with systemic lupus erythematosus was conducted by paediatricians. Paediatric residents and other health workers helped prepare the venue and gifts for the Q&A session. Questionnaires were completed by patients with SLE. Evaluation of the detection of anxiety disorders in patients was carried out through filling out the Screen for Child Anxiety and Associated Emotional Disorders (SCARED) questionnaire. From the SCARED results on Table 2., it can be seen that there were 12.5% of children with LES disease with a total score ≥ 25 with anxiety disorders.

4. DISCUSSION

Physical changes are common in SLE patients. Of our 32 patients, 17 had malar rash, 8 had alopecia, 3 had short stature, and 2 each had moonface and striae. This can be a cause of anxiety. Anxiety and depression are prevalent in SLE patients compared to healthy subjects. Unwittingly, this has a detrimental impact and contributes to increased mortality in SLE. There have been many studies showing a high prevalence of depression in paediatric SLE patients, but few have addressed anxiety, whereas anxiety may be one of the early factors contributing to the development of depression (Knight et al., 2014).

Patients were educated about mental health and mental health disorders before they were asked to

complete the SCARED questionnaire. Prior to the mental health education, the majority of patients and their families thought that mental health was not an important issue that could also affect the patient's physical condition. Negative stigma and misconceptions about mental health are the main causes. Many of them still think that mental health is only related to mental illness, so many people are embarrassed to seek help. As a result, mental health problems do not receive proper treatment.

There are also other prospects that tend to underestimate mental health problems. Lack of knowledge leads to the assumption that mental health problems will not affect physical health, so early symptoms will be ignored until they lead to more serious problems. This is where having a positive social environment that supports good mental health is important. The attention and contribution of parents, doctors, other health workers, close relatives, and even the government are vital and interrelated in creating emotional and social support for paediatric and adolescent patients suffering from SLE and other diseases.

Anxiety symptoms can be a comorbidity of SLE that strikes in childhood (Quilter et al., 2021). Research in Colombia by Hernandez found that 60% of 40 children with SLE with an average age of 14 ± 2 years had indications that led to anxiety and one patient with depressive symptoms (Hernández et al., 2021). Reid found that 14.5% aged 13-19 years experienced anxiety symptoms as measured by SCARED and 7.8% experienced depressive symptoms as measured by the CDI (Children's Depression Inventory) (Reid et al., 2021). Meanwhile, in a study conducted by Donnelly C., on 50 SLE patients aged 11-20 years, 12.1% experienced psychological disorders in the form of anxiety (Donnelly et al., 2018).

Paediatric patients with SLE and their families have serious challenges in various aspects of their lives, including general health, mental health, and quality of life. Mental health functioning in

adolescents with chronic diseases may be associated with increased disease-related disorders. The need for consistent mental health screening measures with clinically validated timelines will increase insight into the frequency and impact of anxiety experienced. Some quality of life indicators such as the presence of pain and fatigue have the strongest correlation with mental health indicators of anxiety and depression (Warchoř-Biedermann et al., 2022). However, the high levels of anxiety and depression they feel can also be due to the uncertainty of the future, where they are unable to predict events related to their illness and the combination of doubt, ambiguity, and confusion that arise during critical or other unexpected conditions (Mazhariazad et al., 2023).

Physical changes and restrictions in physical activity, fear, pain and concerns about diagnostic procedures and the need for regular monthly controls can cause stress and lead to poor academic performance in school. The most common impairments include self-image problems, anxiety and depression. Chronic illnesses that limit physical activity such as SLE have unintended effects on mental health, causing mental and emotional problems for patients and families. Some studies found anxiety (34-37%) and depressive symptoms (6.7-59%) in children with SLE (Quilter et al., 2021). Another study by Jones found that the most common psychosocial problems in adolescents with chronic diseases include fatigue (65%), pain (40%), anxiety (37%), and depressive symptoms (30%) (Jones et al., 2016).

Based on other studies, the long-term and continuous treatment that SLE paediatric patients must undergo has been known to cause 60% of sufferers to experience emotional disturbances, feelings of sadness, guilt, fear, anxiety, anger, and depression. However, the most common psychological problems in SLE patients are anxiety and depression (Dadwal et al., 2023). From these results, long-term monitoring of children with

autoimmune diseases is needed in an effort to prevent relapse and the importance of detection of anxiety disorders as well as psychotherapeutic efforts and support from schools, families and the environment to achieve optimal quality of life.

5. CONCLUSION

Providing education or direct counselling and detection of anxiety disorders in children and adolescent patients with Systemic Lupus Erythematosus disease is useful to know that it is necessary to provide psychological assistance to patients from the start so that the patient's psychological condition is monitored. Along with the large number of paediatric patients with SLE, there is a need for collaboration between stakeholders so that the implementation of community service can reach a wider scope of patients throughout Malang and not only for our patients. Continuous monitoring of patients is needed so that this programme can be carried out in a sustainable manner.

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