

The Relationship Between Family Support and Stress Levels of People with Lupus at the Kupu Parahita Indonesia Foundation

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ABSTRACT

Introduction: Family life will inevitably change when a family member is diagnosed with lupus. Due to the necessity of sharing responsibilities, reassigning chores, and remaining flexible, many people with lupus experience stress. Maintaining as much normality in the home as possible after receiving a lupus diagnosis depends on family support. The objective of this study is to determine the relationship between family support and stress levels in people with lupus at the Kupu Parahita Indonesia Foundation

Methods: The research was conducted on 92 people with lupus at the Kupu Parahita Indonesia Foundation, a lupus support group in Malang Indonesia, using a cross-sectional approach, with data collected in a single meeting. A questionnaire was used to collect data on family support and stress levels, which were then correlated using the Spearman rank correlation test with CI=95% and $\alpha=0.05$.

Results: The majority of people with lupus at the Kupu Parahita Indonesia Foundation received good family support and experienced mild stress. The correlation between family support and stress levels was significant at $p=0.000$, indicating that the better family support provided to people with lupus, the lower the level of stress experienced by people with lupus, and vice versa, the lower family support provided to people with lupus, the higher the level of stress experienced by people with lupus.

Conclusion: There was a relationship between family support and stress levels of people with lupus at the Kupu Parahita Indonesia Foundation. Future studies should involve family members and visit the respondent's house to learn more about the family support given to people with lupus in order to explore family support and stress levels.

Keywords: Family support, Kupu Parahita Indonesia Foundation, Lupus, People with lupus, Stress levels.

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INTRODUCTION

Systemic Lupus Erythematosus (SLE) or lupus is a chronic autoimmune disease that affects the organ systems and usually results in circulating autoantibodies against several cell components, causing widespread inflammation, complex deposition, and organs damage (1,2). SLE symptoms include joint pain and swelling, muscle pain, unidentified fever, facial redness, chest pain when taking a deep breath, hair loss, pale or purple fingers, sensitivity to sunlight, and skin edema in the feet and around the face, gland swelling, mouth ulcers, and tiredness (3-5). This disease has periods of fluctuating remissions and exacerbations and causes morbidity and mortality if not properly treated (6). Physical stress, emotional stress, sunlight, irregular eating, lack of sleep, and hormonal changes are the factors that contribute to SLE exacerbation (7,8).

Syamsi Dhuha Foundation, a lupus support group in Bandung Indonesia, reported that the global prevalence of SLE in 2017 was around 5 million people, with 100,000 new cases reported each year. In Asia, the average number of SLE cases per 100,000 people was 1 to 25 (9). The exact number of people with lupus in Indonesia was unknown, but according to the Ministry of Health in 2017, it was estimated to be 1.5 million. Data from a lupus support group in Malang Indonesia, the Kupu Parahita Indonesia Foundation, showed that Malang had approximately 350 people with lupus in 2017 spread throughout the city and its surroundings (5).

Due to physical changes – like butterfly rash, hobble, hair loss, etc. – people with lupus often feel inferior when it comes to socializing and were more withdrawn from their neighbours, coworkers, and loved ones (10). Furthermore, because of the stress experienced by people with lupus, communication and interaction with others was reduced (4). Stress is a situation in which reality do not match expectation caused by physical demands on the body, environmental, and social conditions that have the potential to harm a person (5). Williams discovered that 5.48% of people with lupus experienced severe stress at the age of 49 years. According to educational data, people with lupus who are currently in college (a bachelor's

degree) has a mild stress level and a high school graduate has a severe stress level. According to household income data, 46.2% of those earning less than \$30,000.00 experienced severe stress (11).

Stress can have either immediate or long-term consequences (12,13). People with lupus are advised to avoid stress and try to live their lives normally, because physical and emotional stress can cause relapse and harm their physical health (11). People with lupus require support from their families in addition to avoiding stress (5). Family support can be defined as the family's behavior, attitudes, and acceptance of its members, as manifested by mutual love and support. Family support for those with lupus includes maintaining open lines of communication, demonstrating empathy, refraining from passing judgment, spending time with family members, sharing information, preparing items they may need, providing feedback on one's spirit, going with a patient to see a doctor, and remembering to take medications on schedule (14,15). Family support plays a significant role when people with lupus experience stress (11).

A preliminary study on October 8, 2017, conducted by author using direct interview, revealed that five samples of people with lupus from the Kupu Parahita Indonesia Foundation in Malang were diagnosed in 2004, 2010, 2011, 2013, and 2016. They ranged in age from 19 to 45 years. SLE is more common in productive ages because it is caused by an abnormally metabolized estrogen hormone (3). The five samples frequently experienced stress in the previous month. The causes of perceived stress were typically simple things like a lack of attention, experiencing unhappiness, being exposed to sunlight, or feeling tired. When stressed and unable to carry out daily activities, the disease was more likely to flare up. When the disease flared up, people with lupus were unable to perform daily tasks and had to rely on their families for assistance. When people with lupus were diagnosed with SLE, their family's affection increased compared to before they became ill. Families also provided the necessary facilities, such as medical expenses and transportation to and from the hospital for treatment. When they forget to take their medication, their family reminds them on a regular basis. They provided solutions when

families were having difficulty resolving problems. The five samples stated that they have complete family support, but they still experience stress 4-5 times per week. This preliminary study results in line with William's research in 2015, that although 92.7% of 41 people with lupus received support from their families, they still experienced stress (11). Therefore, the purpose of this study was to investigate the family support and stress levels of people with lupus at the Kupu Parahita Indonesia Foundation, as well as the relationship between these two variables.

METHODS

This was a cross-sectional study that was conducted between March and April 2018 on people with lupus who joined the Kupu Parahita Indonesia Foundation, a support group in Malang, East Java, Indonesia. The location of this study was in the Rheumatology Division of the Saiful Anwar Hospital Malang Internal Medicine Polyclinic. The study included 120 people with lupus with the inclusion criterion of living with family, experiencing stress (level mild to severe), and being willing to participate as respondents that selected using a purposive sampling technique. The sample to be used was calculated using the Slovin formula and obtained a sample of 92 people with lupus. This research was accepted by the Health Research Ethical Commission Faculty of Medicine Universitas Brawijaya and informed consent was obtained. This study was conducted in Indonesian.

The family support questionnaire was based on Friedman's 1998 theory of family support, as modified by Kusuma in 2011 ($r = 0.375-0.720$ and Cronbach's Alpha value of 0.888). This questionnaire measures four components: emotional support, reward support, instrumental support, and information support. The measurement results are then classified into three categories: less (16-31), sufficient (32-47), and good (48-64) (16).

The stress level questionnaire was based on the Depression, Anxiety, Stress Scale (DASS-42) with Cronbach's Alpha value of 0.9483. This questionnaire assesses physical and emotional stress, and the results are divided into four categories: no stress (0-13), mild stress (14-27),

moderate stress (28-41), and severe stress (48-56) (5).

Data Analysis

The Statistical Package for the Social Sciences, Version 17 (SPSS 17) for Windows program was used to analyze the data. Descriptive statistics were employed to present the characteristics of sociodemographic variables of the participants and main study variables. Categorical variables were summarized in frequency, percentage, and tables. Because the data on family support and stress levels were nonparametric, it was analyzed using the Spearman rank correlation test. The confidence intervals were set at 95% and the level of significance at $p=0.05$.

RESULTS

Table 1 shows that 79.4% of respondents were between the ages of 18 and 40. The majority of respondents (46.7%) work as housewives. The respondents' most recent education was senior high school, which accounted for 45.7% of the total. Respondents in the study were mostly married (63%), and some had suffered from SLE for more than two years (82.5%).

According to **Table 2**, the majority of respondents (72.8%) received family support in the good category and experienced stress in the mild category. The results of statistical tests using Spearman Rank, the correlation value between family support and stress levels was significant ($p=0.000$), indicating that the two variables are related. The magnitude of the correlation strength between the two variables was -0.541 , indicating a negative relationship. It means that the better the family support, the less stress people with lupus experience, and vice versa, the lower family support provided to people with lupus, the higher the level of stress experienced by people with lupus.

DISCUSSION

SLE Family Support at the Kupu Parahita Indonesia Foundation

According to the findings of this study, almost all people with lupus have good family support. There were 23.9% respondents who fell into the sufficient category. Only 3.3% respondents have family support in the lower category. The findings of this study are similar

Table 1 Characteristics of Respondents (n=92)

Variable	Frequency (n)	Percentage (%)
Age (years)		
12 - 18	1	1.1
18 - 40	73	79.4
40 - 55	18	19.5
Employment		
Lecturer	1	1.1
Teacher	1	1.1
Housewife	43	46.7
College student	10	10.9
High school student	8	8.7
Farmer	1	1.1
Government employee	2	18.8
Unemployed	5	5.4
Entrepreneur	21	22.8
Last education		
Elementary school	16	17.4
Junior high school	23	24
Senior high school	42	45.7
Diploma	2	2.2
Bachelor's Degree	7	7.6
Master's Degree	1	1.1
Doctoral Degree	1	1.1
Marital status		
Not married yet	30	32.6
Married	58	63
Widow	4	4.3
Duration of SLE (months)		
2 - 6	1	1.1
7 -12	13	14.2
13 - 24	2	2.2
> 24	76	82.5

Table 2: Distribution of Family Support, Stress Levels, and Their Correlation (n = 92)

Family support	Stress levels						P-value	r
	mild		moderate		severe			
	n	%	n	%	n	%		
Less	0	0	0	0	3	3.3	0.000	-0.541
Sufficient	0	0	22	23.9	0	0		
Good	67	72.8	0	0	0	0		

to those of Desmisagli (2012), who found that 76.7% respondents supported the good category, 20% respondents supported the sufficient category, and 3.3% respondents supported the bad category (17). Family support is important for everyone when they are experiencing problems, particularly health

problems, and it is used as a preventative measure to reduce life pressure (18). This is supported by Yosep's assertion that the role of the family in caring for patients has a significant impact on the respondents' recovery, one of which is participation in all treatments (19).

In this study, the majority of people with lupus experienced lupus for more than two years, giving them and their family adequate time to adapt it and respond accordingly. Family life will unavoidably change during that period as everyone adjusts to living with lupus rather than leading a healthy lifestyle. Families can help people with lupus in a number of ways, including by going with them to health services, staying with them throughout therapy sessions, giving them their full attention, assisting in meeting their needs while they are receiving treatment, and helping to find and provide the information they need (20, 21).

Another factor influencing family support in this study was family involvement in the Kupu Parahita Indonesia Foundation's activities. Every year, the lupus support group, the Kupu Parahita Indonesia Foundation, hosts an event to boost the spirits and life expectancy of people with lupus and their families or companions. At least the majority of respondents and their families have taken part in activities at the Kupu Parahita Indonesia Foundation and received intensive assistance with lupus education. Furthermore, by joining a support group, people with lupus can meet new families who will help them cope with their illness.

Stress Level of People with Lupus at the Kupu Parahita Indonesia Foundation

According to the findings of the study, the majority of people with lupus (72.8%) experienced mild stress. There are 23.9% respondents who experienced moderate stress and 3.3% respondents experienced stress in the severe category. This was consistent with the findings of Bruner et al. that 52.8% of respondents experienced mild stress, 33.3% experienced moderate stress, and 13.9% experienced severe stress (22). Baron and Byrne define stress as a physical or psychological condition that can jeopardize a person's physical or emotional health (23). Stress can have both positive and negative effects. Stress has a positive impact in that it encourages people to continue doing things, raises awareness, and can result in useful new experiences. Stress has a negative impact by causing feelings of insecurity, withdrawal, being easily discouraged, and being unable to accept the situation (24).

Stress can occur in people who have a chronic disease, one of which is SLE. Some of the stress experienced by people with lupus was mild stress, as they believe their illness was a trial that must be accepted sincerely (11). When people with lupus were stressed, they usually prefer to do things they enjoy or tell their families about it to relieve the stress. Several people with lupus experienced severe stress because when they encountered a simple problem, they could not solve it casually, but instead thought deeply, became angry, overreacted, and could not accept their condition sincerely (25). According to the respondents' characteristics, the majority have low stress because they were mature enough to be young adults, do not face much stress at work because they are housewives, have more than two years of experience dealing with lupus, and the need for love and affection was likely fulfilled because they were married and has a very supportive family.

Relationship of Family Support to Stress Levels of People with Lupus

Based on nonparametric statistical tests, the significance value (p) in the Spearman Rank correlation test was 0.000. This means that there was a relationship between family support and stress levels in people with lupus who seek treatment at the Saiful Anwar Hospital Malang and are members of the Kupu Parahita Indonesia Foundation. The correlation coefficient was -0.541, indicating that the relationship between family support and stress levels in people with lupus falls into the moderate correlation category. This was because the level of stress in people with lupus was influenced by factors other than family support. The correlation coefficient results also have a negative sign, indicating that the better the family support, the less stress SLE sufferers experience, and vice versa, the lower family support provided to people with lupus, the higher the level of stress experienced by people with lupus.

This study was similar to the research of Williams et al., in which it was discovered that the majority of respondents received family support, with as many as 92.6% respondents experiencing mild stress (11). According to Friedman, one source of stress management for people with lupus was family support. Good family support for people with lupus can

reduce stress levels, which can reduce mortality and morbidity rates and improve healing (26). All patients with chronic diseases, including SLE, require family support for their health (27). Support can be given in the form of housing aid, time, reminders to take medication regularly, encouragement to practice patience, and seek out information on SLE (28,29,31,32). The presence of family support can reduce the stress felt by people with lupus, preventing the disease from recurring (30,31). Stress is difficult to occur in people with lupus when their family cares for them (11).

Implication

The findings of this study highlight the importance of family support in helping people with lupus cope with their illness. It takes a long time for people with lupus and their families to adjust to their illness, so patience education and a race against time to deal with lupus should be prioritized. Finally, with good family support, people with lupus will experience less stress, allowing lupus exacerbations to be avoided sooner. Nurses should encourage people with lupus to join support groups in their area so that family support can be increased and people with lupus' stress levels can be reduced.

Limitations

Because this is an initial study conducted at the Kupu Parahita Indonesia Foundation as part of a bachelor's degree final project and does not receive funding, the variables studied are very simple. Despite their simplicity, the researchers believe that these findings should be published as an evidence-based care and education for people with lupus.

CONCLUSION

The majority of people with lupus at the Kupu Parahita Indonesia Foundation received good family support, with the tendency of respondents to experienced mild stress when dealing with illness. There was a moderate relationship between family support and stress levels in people with lupus. The more family support people with lupus receive, the less stress they experience in dealing with their illness. The less family support people with

lupus receive, the more stress they experience in dealing with their illness.

Suggestion for Health Service Institutions is expected to be able to facilitate empowerment for families to provide support for people with lupus such as emotional, instrumental, information, and award support, as well as facilitating gatherings held every three months by involving families. In addition, for future research, the researcher recommends that future researchers who want to examine family support with stress levels involve family members and come directly to the respondent's house to learn more about the family support provided to people with lupus.

CONFLICT OF INTEREST

The authors declare there is no conflict of interest.

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