

Community Engagement Program *Odapus* (People with Lupus) 'My Lupus' Support Group Based in Wedomartani

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Abstract Lupus is one of the autoimmune rheumatic diseases that require long-term treatment, can potentially be life-threatening, but is still unknown to the general public. However, there are various problems encountered by *odapus* (*orang dengan lupus* = people with lupus) and their companions during treatments. This program is established to create a support group for *odapus*, their companions, and associated medical professionals by organizing counseling and focus group discussion (FGD) during March until November 2018 in Wedomartani, as well as providing information regarding Lupus and its problems on www.jogjalupuscare.com and Lupus bulletin. Simultaneously, several studies were conducted to evaluate psychological factors of lupus survivors. Pre-test and post-test scores were used as evaluations of counseling and FGD, the results were analyzed using paired t-test or Wilcoxon test, whereas the research used Pearson or Spearman correlation test. The pre-test score increased from 86.81 to 100. There was a significant relationship between disease activity and depression scores, quality of life and insomnia scores, as well as anxiety and depression levels with the quality of life ($p < 0.05$). There was no correlation between disease activity and anxiety scores. Education and counseling are some of the main pillars in lupus treatment, while psychological factors faced by *odapus* during treatments cannot be ignored.

1. INTRODUCTION

Systemic lupus erythematosus (SLE), or lupus, is an autoimmune inflammatory disease that can involve multiple organs including skin, nervous system, kidney, hematology system, lung, and many others with various manifestations and levels of severity starting from mild to life-threatening. Incidence is 5,1 per 100.000 persons with nine-fold higher prevalence in females than males. Morbidity and mortality are high with five, ten, and twenty-year survival rates are 93-97%, 70-85%, and

53-64% respectively. The mortality rate is five times higher than the healthy population. Lupus often affects young and productive people (Perhimpunan Reumatologi Indonesia, 2011).

Various disease courses and high mortality rates due to this disease make it important to manage this disease very appropriately and comprehensively. Treatment and medication in lupus may take a long time or even become life-long to reach and maintain remission as well as to prevent disease flare (Perhimpunan Reumatologi Indonesia, 2011). There

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are several points in managing lupus, such as 1) education and counseling, 2) rehabilitation program, and 3) medication. These three points should be done together and simultaneously. Education and counseling are very important because they can support the success of the other two points (Perhimpunan Reumatologi Indonesia, 2011).

The objectives of this community program are to develop a support group that involves lupus patients (*odapus*), patients' spouses, and health care workers who will have appropriate knowledge and attitude so that they can overcome various problems the *odapus* often have and help to reach the goal of treatment done in hospital or clinic.

2. PROBLEMS

There are some issues faced by *odapus* while undergoing treatment, such as lack of knowledge about lupus itself, healthy diet, a tendency to develop anxiety and depression, skin, cosmetic, hair fall, even reproduction problems, and also long-term fatigue. In a previous study at Dr. Sardjito General Hospital Yogyakarta rheumatology clinic, among 30 subjects, 100% of *odapus* had depression in various levels (30% minimal, 40% mild, 20% moderate, and 10% severe depression) and 33% had anxiety (23% mild, 7% moderate, and 3% severe). *Odapus* would get a lot of advantages by developing and being supported by a support group to deal with problems and achieve therapy success (Maria, Paramaiswari, & Sofia, 2018; Dorsey, Andresen, & Moore, 2004; Mazzoni & Cicignani, 2011; Raesfeld, 2017).

3. METHOD

3.1 Problem solving

The *Odapus* Community Engagement Program involves the *odapus* who lives in the Wedomartani area, from March to November 2018. Various activities were carried out to support the program, such as counseling, focus group discussion, website development, lupus bulletin, and numerous researches to assess the psychological factors among people affected with lupus.

3.1.1 Counseling

Counseling was given to *odapus* and their companions regarding lupus and its problems, skin health, healthy diet, fitness exercises, coping strategies, and social support. The counseling was carried out 4 times. The first was held on March 17, 2018 at the residents' homes in Wedomartani Sub-district, the second was on May 12 at the Ambarukmo Hotel Pavilion, the third was on July 7 at the Grand Cokro Hotel Lobby, and lastly on November 11 at the Hi-lab Laboratory Lobby. An

open discussion was held at the end of each session to accommodate questions and other matters that have not been conveyed to *odapus* and their companions. A pre-test and post-test were conducted to evaluate the understanding and knowledge of the counseling participants. The counseling covers the following points:

1. Explanation about lupus and its causes
2. Types of lupus and the nature of each type
3. Problems related to physical health: the benefits of exercise, especially concerning long-term use of corticosteroids such as osteoporosis; rest; diet education; use of assistive devices; skincare (avoiding sun and ultraviolet exposure, wearing sunscreen, umbrellas or hats), contraception, and attempts to avoid and treat infections
4. Introduction of topics with psychological aspects: self-understanding, ways to deal with prolonged fatigue, emotional stress, psychological trauma, problems related to family and work, overcoming pain
5. Use of drugs such as type, dose, and duration of administration, whether or not vitamin and mineral supplementation is needed
6. Description of where the patient can get precise and accurate information about lupus, support group, lupus foundations, and many others

3.1.2 Focus group discussion

Focus group discussion (FGD) is a qualitative approach to understanding the problem. This FGD was held on 11 November 2018 and took place in the Hi-lab Laboratory Lobby. *Odapus* and their companions were divided into small groups of 8-12 people together with a moderator/facilitator and observer/note-taker. The discussion began with an introduction from the facilitator about common problems encountered by *odapus* and their companions, followed by opinions/brainstorming on these issues from each participant as well as the suggestions that can be made to solve them. It could be from reading material/literature and also from the personal experiences of *odapus* and their companions.

3.1.3 Website development

Searching for information through the internet and internet search engines is one of the simplest, quickest, and cheapest methods. However, the quality of internet searches is limited by a large amount of information and sometimes without specific references, so that *odapus* and their companions need an accurate and reliable information portal. Since 2018, the website www.jogjalupuscare.com has provided articles written by health professionals, such as doctors, psychologists, nurses, nutritionists, physiotherapists, as well as *odapus*, to share literature-based and personal

experience in their attempts to overcome lupus. There is a section for doctor's questions and answers, lupus registries, information on where to seek treatment, information for the public and medical professional on lupus-related symposiums or conferences.

3.1.4 Development of a Lupus Bulletin

The lupus bulletin will enclose numerous articles written by health professionals such as doctors, nurses, nutritionists, physiotherapists, and *odapus*. The published articles provide various features about lupus and things that can be done to solve the problems encountered by *odapus* and his companions. The bulletin will be distributed to *odapus* at the lupus-themed events.

3.1.5 Research

Several studies were conducted on the *odapus* population in Wedomartani from March to November 2018, particularly to assess the relationship of psychological factors with lupus disease activity. The study was performed on 30 participants with SLE based on the 1997 ACR criteria who were willing to participate in the study. *Odapus* who were hospitalized or had cerebral lupus were excluded from the study. Descriptive-analytic research was carried out using a cross-sectional method.

The studies which have been performed include:

1. The Relationship between Disease Activity and Depression and Anxiety Score in Systemic Lupus Erythematosus Patients (Maria, Paramaiswari, & Sofia, 2018)
2. The Relationship between Anxiety Level and Quality of Life in Systemic Lupus Erythematosus (Prabowo, Paramaiswari, & Sofia, 2018)
3. The Relationship between Depression Level and Quality of Life in Systemic Lupus Erythematosus (SLE) Patients (Khairina, Paramaiswari, & Sofia, 2018)
4. The Relationship between Disease Activity and Quality of Life in Systemic Lupus Erythematosus Patients (Theresia, Paramaiswari, & Sofia, 2018)
5. The Relationship between Disease Activity and Insomnia Score in Systemic Lupus Erythematosus Patients (Zagoto, Paramaiswari, & Sofia, 2018)

Research on the relationship of disease activity was measured using the Mexican Systemic Lupus Erythematosus Disease Activity (MEX-SLEDAI), while the depression score was measured using the Patient Health Questionnaire-9 (PHQ-9). Anxiety scores were assessed using the General Anxiety Disorder-7 (GAD-7) and Quality of Life using the SLE-Quality of Life (SLE-QOL) score. Lastly, the insomnia score used the Insomnia Severity Index (ISI) measurement tool.

3.2 How to analyze results

Data analysis will be performed using SPSS 20.0. The pre-test and post-test results from the counseling program were analyzed using a paired t-test or Wilcoxon test if the parametric test criteria were not met. A p-value <0.05 was considered statistically significant. The research data was analyzed using the Pearson and Spearman correlation test (if it did not meet the criteria of the parametric test) to determine the strength of the relationship between independent and dependent variables. The p-value <0.05 was considered statistically significant with r correlation <0.3 indicating a weak relationship, 0.3-0.49 showing a moderate relationship, 0.50-0.69 showing a strong relationship, while > 0.7 showing a very strong relationship.

4. RESULT AND DISCUSSION

4.1 Subject characteristics

There were 44 *odapus* who participated in counseling and focus group discussions (FGD), consisting of 29 (65.9%) women and 15 (34.1%) men (Table 1). The population included participants from 10-49 years old, with 50% of the population were 30-39 years old, 34.1% were 20-29 years old, 11.4% were 40-49 years old, and 4.5% were 10-19 years old. Most of the participant were senior high school dan university graduates (40.9% and 43.2%, respectively).

Table 1. Subject characteristics

Subject characteristic	n	%
Number of subjects		
Sex		
Male	15	34.1%
Female	29	65.9%
Age:		
10-19 years old	2	4.5%
20-29 years old	15	34.1%
30-39 years old	22	50%
40-49 years old	5	11.4%
Latest education		
Primary school	3	6.8%
Junior high school	4	9.1%
Senior high school	18	40.9%
University	19	43.2%

(Maria, Paramaiswari, & Sofia, 2018)

4.2 Knowledge of lupus

The average *odapus* pretest score improved from 86.81 to 100 after counseling and FGD ($p = 0.00$) (Table 2). In the pre-test, the least correct answers were found in question 10 (34%), question 13 (64%), and question 17 (80%). All participants were able to answer the question correctly in the first, third, eighth, ninth, and eighteenth questions. There is an increase in scores

from all question items, where all post-test questions can be answered correctly (100%).

Table 2. Pre-test and post-test results

Question	Pre-test N=44 Correct answer= n(%)	Post-test N=44 Correct answer= n(%)	p-value
Question 1	44 (100)	44 (100)	
Question 2	41(93)	44 (100)	
Question 3	44 (100)	44 (100)	
Question 4	38(86)	44 (100)	
Question 5	38(86)	44 (100)	
Question 6	43(98)	44 (100)	
Question 7	36(82)	44 (100)	
Question 8	44(100)	44 (100)	
Question 9	44(100)	44 (100)	
Question 10	15(34)	44 (100)	
Question 11	37(84)	44 (100)	
Question 12	43(98)	44 (100)	
Question 13	28(64)	44 (100)	
Question 14	43(98)	44 (100)	
Question 15	43(98)	44 (100)	
Question 16	43(98)	44 (100)	
Question 17	35(80)	44 (100)	
Question 18	44(100)	44 (100)	
Question 19	41(93)	44 (100)	
Question 20	42(95)	44 (100)	
Mean score	86.8	100	0.00

The www.jogjalupuscare.com website has been developed and operated since 2018. The website consists of a home page with links to each sub-category, as well as brief reviews of new articles and columns of works, events and agendas (Figure 1-4).



Figure 1. www.jogjalupuscare.com home website

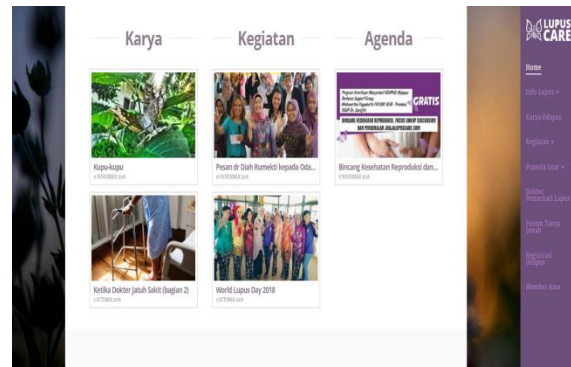


Figure 2. Links to *odapus'* work, activities and agenda on the www.jogjalupuscare.com website

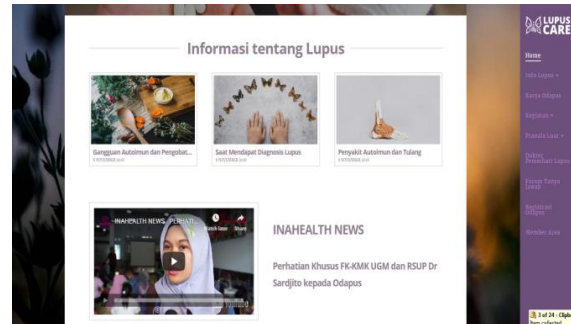


Figure 3. Lupus information page on the www.jogjalupuscare.com homepage

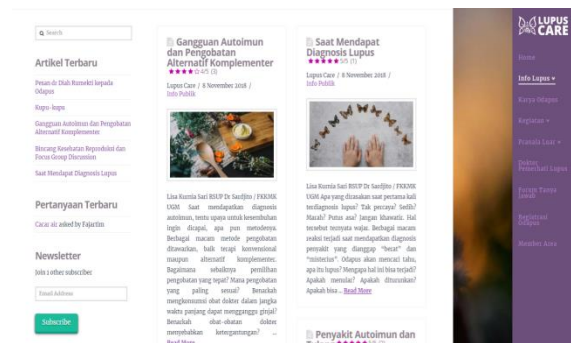


Figure 4. Lupus educational article page for medical community, people with HIV/AIDS and companions.

Sub-categories that can be accessed include: 1) lupus information, containing several different lupus-related articles, its problems and treatments for medical professional, *odapus* companions, and *odapus* itself; 2) *odapus* works, comprising *odapus'* numerous works and writings; 3) events, including information on the activities of *odapus*, seminars/symposiums, and activities schedule/calendar; 4) external links to various supportive sites, such as various domestic and international organizations, rheumatology associations, health services, and BPJS; 5) doctors who observe lupus; 6) forums for questions and answers; 7) *odapus* registration; and 8) area of membership. There is also a link to the practice of doctors who have a special interest in treating lupus patients and information about contacting the website administrator via our contact link.

4.3. The relationship between disease activity and depression and anxiety score in patients with SLE

The study on the relationship of disease activity (measured using MEX-SLEDAI) with depression score (PHQ-9) and anxiety (GAD-7) in systemic lupus erythematosus patients at RSUP DR Sardjito Yogyakarta involving 30 patients with SLE showed that depression occurred in 100% of lupus patients, specifically 30% had minimal depression, 40% mild depression, 20% moderate depression, and 10% major depression. The incidence of anxiety was found to be 33.33% of patients with lupus, where 23.33% had mild anxiety, 6.67 % moderate anxiety, and 3.33% severe anxiety.

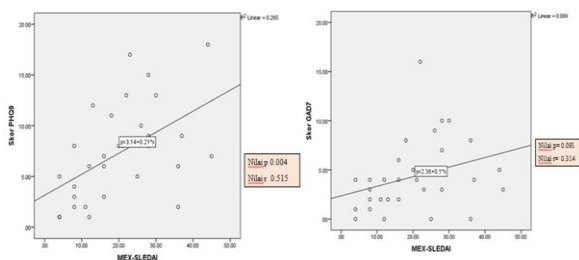


Figure 5. Scatter plot of correlation between MEX-SLEDAI with PHQ-9 and GAD-7

The correlation test result between disease activity and depression score was $p = 0.004$ and $r = 0.515$, while the correlation test result between disease activity and anxiety scores was found to be $p = 0.091$ and $r = 0.314$ (Figure 5). A significant correlation was found between disease activity and depression scores with moderate correlation strength, whereas there was no correlation between disease activity and anxiety scores (Maria, Paramaiswari, & Sofia, 2018).

4.4 Relationship between the level of anxiety and quality of life in patients with SLE

The study on the relationship between anxiety level (GAD-7) and quality of life (SLE-QOL) in SLE patients at RSUP DR Sardjito Yogyakarta involving 30 patients with SLE showed a significant correlation ($p = 0.000019$) with a strong correlation strength ($r = 0.697$) between GAD-7 and SLE-QOL (Figure 6) (Prabowo, Paramaiswari, & Sofia, 2018).

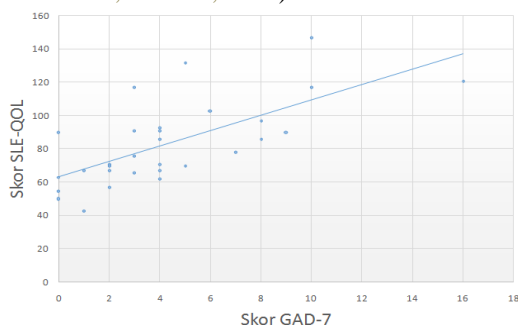


Figure 6. Scatter plot of correlation between GAD-7 and SLE-QOL

4.5 The relationship between the depression level and the quality of life in patients with SLE

The study on the relationship between depression level (PHQ-9) and quality of life (SLE-QOL) in SLE patients at RSUP DR Sardjito Yogyakarta, including 30 SLE patients, showed a significant correlation ($p=0.009$) with a strong correlation ($r=0.783$) between PHQ-9 and SLE-QOL (Figure 7) (Khairina, Paramaiswari, & Sofia, 2018).

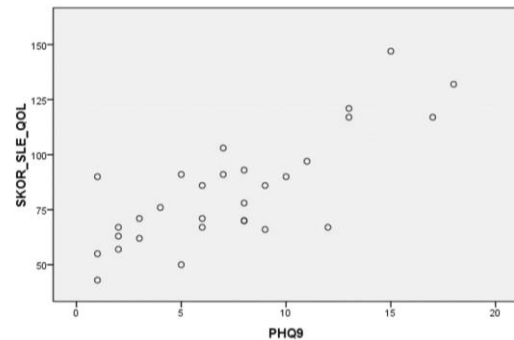


Figure 7. Scatter plot of correlation between PHQ-9 and SLE-QOL

4.6 Relationship between disease activity and quality of life in patients with SLE

The study on the relationship between disease activity (MEX-SLEDAI) and quality of life (SLE-QOL) in RSUP DR Sardjito Yogyakarta among 30 SLE patients showed a significant correlation ($p = 0.017$) with moderate correlation intensity ($r = 0.432$) between MEX-SLEDAI and SLE-QOL (Figure 8) (Theresia, Paramaiswari, & Sofia, 2018).

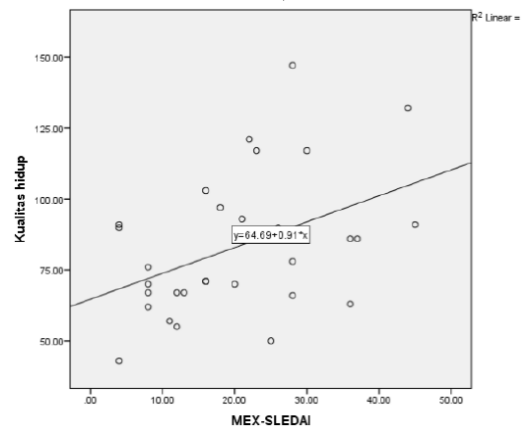


Figure 8. Scatter plot of correlation between MEX-SLEDAI and SLE-QOL

4.7 Relationship between disease activity and insomnia score in SLE Patients

The study on the relationship between disease activity (MEX-SLEDAI) and Insomnia Severity Index (ISI) in SLE patients at RSUP Dr. Sardjito Yogyakarta involving 30 patients with SLE showed a significant correlation ($p = 0.03$) between MEX-SLEDAI and ISI with moderate correlation strength ($r = 0.397$) (Figure 9) (Zagoto, Paramaiswari, & Sofia, 2018).

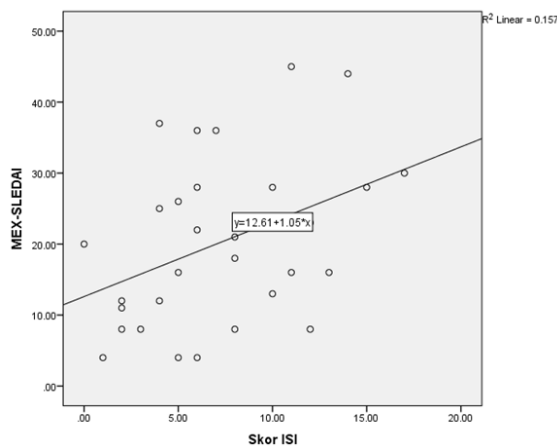


Figure 9. Scatter plot of correlation between MEX-SLEDAI and ISI

5. CONCLUSION

Education and counseling are some of the pillars that will facilitate the success of the rehabilitation program and medical care in the treatment of lupus. It is important since lupus treatment generally takes a long time and *odapus* tend to experience various physical and psychological issues that affect the treatment's effectiveness. Support groups play an important role and are known to assist *odapus* to deal with different lupus-related issues.

The counseling and FGD conducted at the *Odapus*-based Community Engagement Program in Wedomartani have significantly enhanced the knowledge and understanding of *Odapus* and their companions and are expected to support the success of *Odapus* medical and rehabilitation programs. The website www.jogjalupuscare.com and the Lupus Bulletin are expected to be an accurate, affordable, and easily accessible tool for *odapus* and their companions to obtain reliable information containing various writings and works by both health professionals and *odapus*. This media can also play a role as part of the support group system for *odapus* as it also provides space for interaction among *odapus* and their companions through question-and-answer forums and with health professionals such as doctors so that the role of the support group is not limited to face-to-face meetings alone.

The studies conducted showed a significant correlation between disease activity and depression, anxiety levels and quality of life, depression levels and quality of life, disease activity and quality of life, as well as disease activity and insomnia scores. This reveals that instruments for psychological condition evaluation such as PHQ-9 for depression, GAD-7 for anxiety, SLE-QOL for quality of life, and ISI for insomnia may be used as a method to determine *odapus'* psychological problems.

The Support Group-based Community Engagement Program (PKM) in Wedomartani will

improve the knowledge and understanding of *odapus* and their companions constructively and sustainably so that it is hoped to enhance the success of the hospital's lupus treatment.

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CONFLICT OF INTERESTS

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