

# AN OVERVIEW OF KNOWLEDGE LEVEL REGARDING THE SYSTEMIC LUPUS ERYTHEMATOSUS (SLE) IN PEOPLE WITH LUPUS (ODAPUS)

Farah Azwinda<sup>1</sup>, Lilik Djuari<sup>2</sup>, Gatot Soegiarto<sup>3</sup>

<sup>1</sup>Faculty of Medicine, Universitas Airlangga, Surabaya, Indonesia

<sup>2</sup>Department of Public Health, Universitas Airlangga, Surabaya, Indonesia

<sup>3</sup>Department of Internal Medicine, Dr. Soetomo General Hospital, Surabaya, Indonesia

Correspondence Address: Farah Azwinda

E-mail: farahazwinda@gmail.com

## ABSTRACT

**Introduction:** Systemic Lupus Erythematosus (SLE) is lay disease in Indonesia. People with lupus must undergo lifelong treatment because the manifestations vary with high mortality rate. The aim of this study is to measure the level of knowledge of ODAPUS about SLE. **Methods:** This study was an observational descriptive with a cross-sectional approach. One hundred respondents were selected consecutively according to inclusion criteria from SLE patients who attended outpatients of Rheumatology Polyclinic in RSUD (Regional Public Hospital) Dr. Soetomo Surabaya from September 2019 to January 2020. The variable was knowledge level of ODAPUS about SLE and ODAPUS characteristics. Data analysis used descriptive statistical analysis. Data were obtained using LKQ-R questionnaires. **Result:** The result showed that majority of respondents are female (95%), aged 17-25 years (34%), had Senior High School (SHS) as their highest educational background (60%), do not work (53%), got the information about SLE only from health services (71%), and had lack knowledge about SLE (68%). There is no difference between knowledge about SLE in gender (p-value 0.123), a significant relationship between knowledge and educational background (p-value 0.005), and differences in the level of knowledge in group of information sources (p-value 0,000). **Conclusion:** In conclusion, most of the SLE patients have lack of knowledge about SLE, especially those who have SHS educational background and only depend on the health service as the source of information. Special interventions are needed as health promotion, especially in childbearing age women who likely suffer from the disease.

**Keywords:** Knowledge, Systemic Lupus Erythematosus (SLE), people with lupus, ODAPUS, LKQ-R questionnaires.

## INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease. This disease often occur the complex interaction disorder between the apoptosis clearance process, the increase of innate and adaptive immune responses, the immunity complex, and the inflammation process in the soft tissue, which is the climax of the autoimmune process (Fava and Petri, 2019). The clinical manifestations and severity of this disease vary according to the organ affected (Vaillant, McClellan and Varacallo, 2018). SLE can be stated as a still common disease, especially in Indonesia. Many people assume that SLE is a rare disease. The prevalence of SLE is different in every country. The difference in prevalence and incident varies related to

gender, age, ethnicity, and time. It is stated that the highest prevalence occurs in America, which is 241 patients out of 100,000 people (Rees et al., 2017). In Indonesia, the prevalence of this disease is still low, which is 0.5% of the total population, but the number of new cases continues to increase (Infodatin Kemenkes, 2017). However, the increase of cases is not followed by an increase in information and knowledge about the disease. This is due to the lack of information, education, and socialization about lupus with easy language, which is easily understood by the people (Fatmawati, 2018). Based on the study conducted by Kalim et al., from 1,250,000 people in Indonesia who have lupus, just a few of them have realized that they have lupus (Infodatin Kemenkes, 2017).

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ODAPUS should be well-educated about disease pathology, some conditions when this disease attacks certain organs, and the importance of treatment and adherence monitoring. (Vaillant, McClellan and Varacallo, 2018). The knowledge level of lupus patients can influence the patients' adherence to have treatment. The low level of patients' knowledge about their disease will cause a lack of adherence to have treatment (Sheba *et al.*, 2018). There's a research that states SLE patients with severe disease status have a significant relationship with a decrease in quality of life and have an impact on their mental health. Patients also tend to experience depression and anxiety about their illness (Shen *et al.*, 2013). Those conditions will impact other health conditions, such as complications that could have been prevented. This condition can cause an increase the mortality rate of SLE if not handled properly.

Until this time, there is no research about this topic in Surabaya. This study aims to measure the knowledge level of people with lupus (ODAPUS) about SLE. The results of the study are expected to increase ODAPUS awareness about their disease. Moreover, the results of the study can be used as an attempt to increase community participation, especially ODAPUS in the prevention and control of SLE disease, also as the evaluation material for the health workers in giving health promotion and education for ODAPUS effectively and efficiently. Thus, in the future, it can help the government to determine what program can be applied as a health promotion attempt regarding the SLE disease in Indonesia.

## METHODS

This study, according to the data collection technique, was observational research. The researcher conducted observation in outpatients of Rheumatology Polyclinic in RSUD (Regional Public Hospital) Dr. Soetomo Surabaya using the

LKQ-R (Lupus Knowledge Questionnaire-Revised) as an instrument, which has been modified. This study was an observational descriptive with a cross-sectional approach. The researcher collected the data when patients came to the Rheumatology Polyclinic of RSUD Dr. Soetomo Surabaya from September 2019 to January 2020.

The population of the study was all outpatients or people with lupus (ODAPUS) in RSUD Dr. Soetomo. Meanwhile, the samples of the study were outpatients or people with lupus (ODAPUS) in Rheumatology Polyclinic of RSUD Dr. Soetomo Surabaya, which were selected according to the inclusion and exclusion criteria sequentially. The inclusion criteria of the samples were men or women more than 12 years old, can read and write, also willing to be a respondent by signing an informed consent sheet. Meanwhile, the exclusion criteria of the samples were a not cooperative respondent (have mental and physical disorders, limitation in speaking, unstable disease conditions) and work as health workers. The number of samples in this study was 100 respondents, which was obtained from the calculation using a consecutive sampling technique with the infinite population.

Variables in this study were the knowledge level of people with lupus (ODAPUS) about the SLE and ODAPUS characteristics. Variables of ODAPUS characteristics consisted of several sub-variables, which were age, gender, educational level, occupation, and source of information.

The questionnaire of knowledge about the Systemic Lupus Erythematosus (SLE) used as the data collection instrument was LKQ-R (Lupus Knowledge Questionnaire-Revised) modified, then a validity and reliability test was conducted. The validity and reliability test was conducted on people with lupus (ODAPUS), who were not a sample in this study. After conducting a validity and reliability test, it was obtained the results of

validity ( $r > 0.648$ ) and reliability (Cronbach's alpha = 0.706).

The questionnaires consisted of 22 questions: definition, epidemiology, etiology, diagnosis, indication and symptoms, and myths about SLE. The questionnaires consisted of two questions about the definition, epidemiology and etiology, respectively. On the topics that discussed diagnosis and myth regarding SLE, there were five questions, respectively. Moreover, there were six questions for discussion topics regarding the indication and symptoms of SLE disease. Respondents were asked to answer every question with correct and wrong choices (Guttman scale). After that, it was given a score of 1 for the correct answer and 0 for the wrong answer. Then, calculation was conducted and then grouped into three categories of knowledge level; good, moderate, and lack. The researcher chose to use the theory by Arikunto, which stated that the knowledge level is divided into three levels based on the percentage value. It is stated in a good knowledge level if the score is  $\geq 76-100\%$ , in the moderate knowledge level if the score is  $60-75\%$ , and in the lack knowledge level if the score is  $< 60\%$  (Arikunto, 2012).

The data collection was conducted in the Rheumatology Polyclinic of RSUD Dr. Soetomo, where the respondents got the explanation regarding this study and filling the agreement form first to participate in this study. After respondents signed the agreement form, the respondents were asked to complete the personal data as determined by the researcher, and then the respondents were asked to fulfill the prepared questionnaire. Respondents fulfilled the questionnaire completely, consciously, and without coercion. The data were processed using SPSS IBM 20 and then presented descriptively. Data of the study were processed by cross-tabulation. The researcher added Mann Whitney's test for the gender, Spearman rho test for the educational level, and the Kruskal-Wallis test continued the post hoc

for the source of information to strengthen the research. This study has obtained a passing statement of ethics from the Ethics Commission of RSUD Dr. Soetomo No: 1350/KEPK/VII/2019, and monitoring and evaluation have been done during the research.

## RESULTS

### The Respondents' Demographic Characteristics

**Table 1.** The distribution of respondents' demographic characteristics in Rheumatology Polyclinic of RSUD Dr. Soetomo Surabaya from September 2019 - January 2020

The Respondents' Demographic Characteristics	n	%
<b>Gender</b>		
Women	95	95
Men	5	5
<b>Age</b>		
Early adolescence (12-16 y.o)	1	1
Late adolescence (17-25 y.o)	34	34
Early adulthood (26-35 y.o)	26	26
Early middle age (36-46 y.o)	26	26
Late middle age (46-55 y.o)	10	10
Late adulthood (56-65 y.o)	3	3
<b>Educational Level</b>		
Elementary School	7	7
Junior High School	13	13
Senior High School	60	60
College	20	20
<b>Occupation</b>		
Do not have a formal occupation/housewife	53	53
Private employees	18	18
PNS (Government Employee)/ABRI (Indonesian National Armed Forces)/POLRI (Indonesian National Police)	2	2
Students	19	19
Entrepreneur	8	8

<b>The Respondents' Demographic Characteristics</b>	<b>n</b>	<b>%</b>
Source of Information		
Only health services	71	71
Health services and mass media	28	28
Health services, mass media, and families	1	1

Based on the average age and deviation standard in this study, respondents were  $32 \pm 11$  years old. Table 1 shows that ODAPUS, who are the respondents of this study, were mostly 17-25 years old, which were 34 respondents (34%). The majority of respondents were women, 95 respondents (95%) with the last educational level of Senior High School of 60 respondents (60%), and have no formal occupation or a housewife, 53 respondents (53%). As many as 71 respondents (71%) received information about SLE only from health services.

### The Respondents' Knowledge

**Table 2.** The distribution of respondents' knowledge level about SLE

<b>Knowledge Level</b>	<b>n</b>	<b>%</b>
Good ( $\geq 76-100\%$ )	8	8
Moderate (60–75 %)	24	24
Lack ( $< 60\%$ )	68	68

Table 2 presents the distribution of respondents' knowledge levels which are divided into three groups. From 100 respondents obtained, the majority (68%) of respondents' knowledge level was lack. Meanwhile, only a small number of respondents (8%) have a good knowledge level.

The evaluation results of systemic lupus erythematosus (SLE) knowledge regarding the red rashes as one of the lupus' symptoms, were 92 respondents (92%) answered correctly. These results show that questions about the rashes in the SLE patients were the most correctly answered by the respondents. However, in the aspect of knowledge about race/ethnicity and who are most susceptible to lupus, these were

aspects that most respondents did not know. On that topic, 91 respondents (91%) answered incorrectly, and only nine respondents (9%) answered correctly. One respondent obtained the highest score of 95.45 or 21 points, and one person got the lowest one of 13.63 or 3 points.

Cross-tabulation statistical analysis was conducted on the respondents' demographic characteristics and the respondent's knowledge level, as presented in Table 3. The analysis results were used to determine the general overview of the respondents' knowledge level about SLE based on demographic characteristics. Respondents' demographic characteristics include gender, age, educational level, occupation, and source of information about SLE disease.

Based on Table 3 regarding gender characteristics, it was obtained that 63 women respondents (66.3%) have a lack knowledge level, 24 (25.3%) have a moderate knowledge level, and only eight respondents (8.4%) have a good knowledge level. Meanwhile, for the men respondents, there were five respondents (100%) who have a lack of knowledge level. The differences in knowledge level between women and men were tested using Mann Whitney. From the results of the statistic test it can be concluded that there were no differences in knowledge level about SLE between women and men ( $p$ -value = 0.123).

In the characteristics of age, most respondents in this study were in late adolescence, which was 17-25 years old. Then, it was followed by early adulthood which was, 26-35 years old and early middle age, which was 36-46 years old. When viewed from the respondents' knowledge level about SLE, most respondents in the late adolescence have a lack of knowledge level. In which the group of lack knowledge level was dominated by the respondents of childbearing age. It was also obtained that four of eight respondents in the good knowledge level were in early adulthood.

Based on the educational level, most respondents in this study had Senior High School background education. Meanwhile, only seven respondents had Elementary School background education. When reviewed based on the knowledge level, most lack knowledge level was dominated by the respondents who had Senior High School background education. Meanwhile, four from eight respondents who had good knowledge level had college background education. The relationship between knowledge level about SLE and the respondents' educational level was examined using Spearman's rho. Based on the results of the statistic test, it can be concluded that there is a significant relationship between the knowledge level about SLE and the respondents' educational level ( $p\text{-value} = 0.005$ ).

When viewed from the respondents' occupation characteristics, most respondents in this study did not have a formal occupation or as a housewife. In which the respondents included in that group mostly had a lack of knowledge level and became the biggest contributor in the group of lack knowledge level.

In the respondents' source of information characteristics, most respondents got the information about SLE only from the health services. Only few respondents looked for other additional sources of information, either from media or families. Respondents who chose the source of information only from health workers, the majority of them had a lack of knowledge level. Meanwhile, when viewed based on the good knowledge level, all respondents who had good knowledge levels were from the group who chose the source of information from the health personnel and media. The differences in knowledge level about SLE based on the group of respondents' source of information were examined using the Kruskal-Wallis test. The results of the statistical test concluded that there is a difference in knowledge level in the group of respondents' source of information. Then, the post hoc statistic test was conducted to see which group was different. The results of the test stated that there is a difference in knowledge level between health personnel's source of information and health service and media ( $p\text{-value} = 0.000$ ).

**Table 3.** The survey results in the respondents' knowledge level about SLE according to the respondents' demographic characteristics.

The Respondents' Demographic Characteristics	Knowledge Level						Total		P Value
	Good		Moderate		Lack		n	%	
	n	%	n	%	n	%			
Gender									0.123
Women	63	66.3	24	25.3	8	8.4	95	100	
Men	5	100	0	0	0	0	5	100	
Age									
Early adolescence (12-16 y.o)	1	100	0	0	0	0	1	100	
Late adolescence (17-25 y.o)	27	79.4	5	14.7	2	5.9	34	100	
Early adulthood (26-35 y.o)	14	53.8	8	30.8	4	15.4	26	100	
Early middle age (36-46 y.o)	18	69.2	7	26.9	1	3.8	26	100	
Late middle age (46-55 y.o)	5	50	4	40	1	10	10	100	
Late adulthood (56-65 y.o)	3	100	0	0	0	0	3	100	
Educational Level									0.005
Elementary School	6	85.7	0	0	1	14.3	7	100	

The Respondents' Demographic Characteristics	Knowledge Level						Total		P Value	
	Good		Moderate		Lack		n	%		
	n	%	n	%	n	%				
Junior High School	11	84.6	2	15.4	0	0	13	100	0.000	
Senior High School	42	70	15	25	3	5	60	100		
College	9	45	7	35	4	20	20	100		
Occupation										
Do not have a formal occupation/housewife	35	66.0	15	28.3	3	5.7	53	100		
Private employees	11	61.1	4	22.2	3	16.7	18	100		
PNS (Government Employee)/ABRI (Indonesian National Armed Forces)/POLRI (Indonesian National Police)	0	0	1	50	1	50	2	100		
Students	15	78.9	3	15.8	1	5.3	19	100		
Entrepreneur	7	87.5	1	12.5	0	0	8	100		
Source of Information										
Only health services	58	81.7	13	18.3	0	0	71	100		
Health services and mass media	9	32.1	11	39.3	8	28.6	28	100		
Health services. mass media, and families	1	100	0	0	0	0	1	100		

## DISCUSSIONS

The term "thousand faces disease" given for SLE is not without reason. The symptoms can resemble allergic inflammation to the malfunctioning of various organs in the human body. SLE is an autoimmune disease that can affect many organs, including skin, joints, central nervous system, and kidney (Kaul *et al.*, 2016). In Indonesia, the increase of ODAPUS is not accompanied by the increase in information about SLE for ODAPUS or society. The lack of information using easier language contributes to increasing lupus patients (Azmi, 2017). Thus, ODAPUS often ignores the symptoms of this disease. This condition is a result of the ODAPUS' lack of awareness toward their disease, which eventually impacts the delays of treatment and diagnosis. If the patient is diagnosed late, there can be a deterioration in the patient's condition because early diagnosis is important to have the appropriate

treatment to prevent more severe and widespread disease manifestations (Kaul *et al.*, 2016). This situation is very regrettable because the lack of education and socialization, either directly or through various media, can cause unfavorable conditions for ODAPUS.

The knowledge level of each ODAPUS varies; some have good knowledge, and some have moderate knowledge, but some have lack of knowledge. Based on the results of the study on 100 respondents, it was obtained that most of ODAPUS had a lack of knowledge level about SLE disease, which was 68 respondents (68%), and only eight respondents (8%) had good knowledge level. Those results are in line with research by Komalig *et al.* (2008) which stated that the knowledge of SLE patients about their disease is still low (41.1%). However, the results of the study are not in line with research by Sari (2016), which stated that all respondents in their study have a good knowledge level (100%). It can be

explained that there is a possibility in Sari's research that the respondents get better socialization from the health service than respondents of this study.

Someone's knowledge can be influenced by several factors, such as age, experiences, education, information/mass media, social, culture, economic, and environment. The differences in these factors can exactly also create different individual knowledge (Budiman, 2013). Society is expected, especially people with lupus (ODAPUS), to gain information from other reliable media sources to improve and expand knowledge about their disease. The government is also expected to provide facilities in delivering information regarding SLE that is easy to be accessed and understood.

### **Gender**

Most respondents were women, which is in accordance with the theory by Pons-Estel et al. SLE disease often occurs in women than men with a ratio close to 9:1 (Pons-Estel, Ugarte-Gil and Alarcón, 2017). SLE mostly affects women because of several roles of hormones: hormones on estrogen, androgens, prolactin, and gonadotropin-releasing hormone. The mechanism that works is associated with the differences in the metabolism of these hormones. There is a role for the activity of hormone estrogen effect on the hydroxylation process. Besides that, there is a condition where there is a decrease in the level of an androgen hormone, hyperprolactinemia, and differences in the expression of G protein signaling in GnRH (Tedeschi, Bermas and Costenbader, 2013). Although SLE disease attacks many women, the men patients tend to have the manifestation of more severe disease, consequently the level of disease activities is higher (Pons-Estel, Ugarte-Gil and Alarcón, 2017). The results of another study also show the same results, which are obtained from 34 female SLE patients (87.2%) and five male patients (12.8%) (Ghafirah, 2018).

Based on the results of the statistic test, it was obtained p-value (0.123) >  $\alpha$  ( $\alpha = 0.05$ ), which shows that there is no difference of knowledge level about SLE between women and men of ODAPUS in RSUD Dr. Soetomo. According to the research, this is because the respondents are in the same hospitals. Moreover, there is no difference in the provision of special interventions that differentiate the patients' gender when having treatment until provision of education by the health workers, either doctors or nurses, to the patients. Thus, the information received about SLE disease is the same, and the services provided also do not differentiate between women or men patients. This in line with the theory by Lynn, Wilberg-Neidhardt and Margraf-Stiksrud (2005) who stated that there is no substantial and significant difference in gender in general knowledge. In knowledge management, it can be stated that gender relations are not explicitly possible to have a deeper understanding (Peter and Selvi, 2020).

### **Age**

The majority of respondents in the 17-25 years old (late adolescence) were 34 respondents (34%). Followed by the next group in the 26-35 years old (early adulthood) were 26 respondents (26%), and in the 36-46 years old (early middle age) were 26 respondents (26%). SLE mostly affects women of childbearing age, which is women 15 to 44 years old, where this age range is the most significant risk of developing SLE (Carter, Barr and Clarke, 2016). Besides that, there is a previous study that is in line with this study, which obtained that the majority of the respondents are women SLE patients, 44.4%, and among them are in the 35-45 years old (Sari, 2016).

In the group of 17-25 years old, most respondents had a lack of knowledge level about SLE disease. Besides that, the proportion of respondents with a lack of knowledge level was dominated by the childbearing age. Adolescence or adulthood

age have more comprehension and developed mindset. The individual tends to have active action in seeking knowledge. Thus, in that age range group, the knowledge obtained will be better and more increased (Notoatmodjo, 2012). However, the results of this study show that in childbearing age is obtained the lack of knowledge level about SLE, which should be used as the step to increase the awareness and knowledge in that age group. It is important for the individual (especially women), including the childbearing age, to realize those things and be motivated to improve their knowledge level. Thus, they can be more obedient in the treatment and management program of SLE by the doctor, and also can prevent the progression or deterioration of their disease control level.

### Education

The results of this study show that most respondents' education was Senior High School of 60 respondents (60%). This is in line with the previous study conducted by Sari which also stated that from 36 respondents involved in their study, most of them or 30 respondents have Senior High School as the educational background (Sari, 2016).

It was also obtained that the most respondents who had good knowledge results were dominated by those who have college as the educational background, which was four respondents from eight others, followed by the respondents with Senior High School educational level (3 respondents) and Elementary School (1 respondent). The knowledge level about SLE was less, dominated by respondents with a Senior High School educational background, which was 42 respondents. Based on the results of the statistic was obtained  $p\text{-value} (0.005) < \alpha (\alpha = 0.05)$ , which showed that there is a significant relationship between knowledge level about SLE and the respondents' educational level.

Waldron *et al.* (2011) stated that educational level can influence patients' needs of SLE information, how deep the

information, and their ability to access and process information. The results of the analysis in this study show that 50% of respondents with a good knowledge level have a college educational background. This is something normal and should be like that because the individual formal education can give the basis for thinking and a better understanding regarding the knowledge obtained, including the knowledge about SLE. This flow of thinking will influence the individual in interpreting the information obtained in the future (Waldron *et al.*, 2011).

Education significantly affects someone's knowledge level. The higher someone's knowledge, the easier for someone to accept information from others. This also applies to the opposite, where individuals with a low educational background will be inhibited in receiving information. This study shows that most respondents have a Senior High School educational background (60%). However, formal education not always can be used as the measurement of knowledge. This is because the knowledge is not only from the formal education but also from the informal education, such as experience in society: socialization, and educative information of mass media. Both are one of the forms of primary health prevention (Notoatmodjo, 2010).

### Occupation

Most of the respondents do not have a formal occupation or as a housewife. The number of respondents who did not have a formal occupation or housewives was 53 respondents (53%). In which among them, 35 respondents (66%) had a lack of knowledge level. Moreover, when viewed from the lack of knowledge level, the group that did not have a formal occupation or housewife became the largest contributor. In line with the research conducted by Komalig *et al.* (2008), which stated that, based on the type of occupation, most SLE patients do not have formal occupation (32.2%) while the least are workers/farmers



(1.9%). However, the results of this study are not in line with the research by Sari (2016), which stated that the majority of respondents that are SLE patients are entrepreneurs (33.3%) and private employees (33.3%).

The low economic conditions and educational level, also the lack of health insurance for SLE patients, are all related to unfavorable disease outcomes for patients. Moreover, the treatment of SLE disease is not cheap, either directly or indirectly. Besides that, the treatment cost is influenced by the severity of the disease and organ manifestations (Carter, Barr and Clarke, 2016). The obstacles can cause the patients' conditions to be worse. The research conducted by Feldman *et al.* (2013) stated that SLE is more commonly diagnosed in the individual from a lower socioeconomic population. This condition causes an increase in pressure stigmatization on SLE patients. This stigmatization of the patients occurs because of low education, which significantly affects the patients' self-perception. This stigma can raise concerns and become additional obstacles for SLE or ODAPUS patients to find appropriate medical care.

### **Source of Information**

The results of this study show that the majority of respondents obtained the source of information about SLE disease only from the health service, which was 71 respondents (71%). It is mentioned in theory by Waldron *et al.* (2011) that, when viewed from the needs for early education, patients prefer to be informed about the potential problems that occurred than being naive or do not want to know about the problems. Patients feel helped from the verbal information delivered comprehensively by the doctor. This is what motivates or moves patients to immediately find more information about SLE to medical professionals (Waldron *et al.*, 2011).

In the groups of respondents who obtained sources of information only from the health service, 58 respondents (81.7%) had a lack knowledge level, and the other 13 respondents had a moderate knowledge level. Of all respondents in the good knowledge level, eight respondents obtained information about the SLE disease from the health service and media. Moreover, the results of the statistic test obtained p-value ( $0.000 < \alpha$  ( $\alpha = 0.05$ )), which shows that there is a different knowledge level between health personnel's source of information and health service and media. Notoatmodjo (2012) stated that the individual's knowledge could be influenced by the source of information. The knowledge level is influenced by the individual's exposure to the information received. There are several sources of information that can influence the individual's knowledge, such as printed media: news, book, magazine, also other mass media: radio, television, and the internet.

The health service has many important roles related to the needs of information for patients about their disease. By obtaining appropriate and specific information, the patients will be more understanding and patient regarding their physical conditions, which also affect the risk of SLE disease. Based on Waldron *et al.* (2011), SLE patients who obtain detailed and accurate information from the health service will have a lower level of worry about the disease than the SLE patients who have limited knowledge. Patients who obtain detail and accurate information more can control and avoid several things that can cause remission or recurrence of the disease. Thus, patients need to be mentally better prepared in having treatment for their disease. Also mentioned in the research by Ferenkeh-Koroma (2012) is that currently, the health service must deliver the information needed by the patients to control the symptoms' fluctuation and the treatment for their disease. With adequate support and proper education provision,

patients can be more actively involved in maintaining their condition and quality of life. Thus, the active role of health service is needed, either doctor or nurses as the intermediary for delivering information to the patients. Certainly, education provided will be massive if it is followed by the active role of ODAPUS, such as giving questions related to the SLE disease or confirming information obtained about SLE to the health service, which allows more understand about those topics.

Based on the results of the study, action is needed to give massive education to increase the knowledge of SLE patients. One way is by utilizing several media to distribute information and health socialization for the SLE patients and their family or companions. The utilization of printed media can be done by providing brochures, leaflets, and x-banners regarding SLE in the health service. Moreover, the utilization of social media as the educational step is also very important to be done. One way is by providing information in the educational videos, pictures or animations, articles, and news related to SLE using language that is easy to understand to improve the SLE patients' insight. Providing education can also be done by health socialization methods involving the patients' families. By involving the patients' families, they will be more understanding of and responsible for the treatment given to the patients. From the health socialization, the patients can be actively asked and discuss the SLE disease and their conditions with competent doctors.

## CONCLUSIONS

Most of the SLE patients have a lack of knowledge about SLE, especially those who have Senior High School educational background and only depend on the health service provider as the source of information. There is a significant relationship between the knowledge level about SLE and respondents' educational

level. The health service has an important role in educating patients about their disease. Thus, the particular intervention is needed as the attempt for health promotion, especially for the patient with low educational background and the patients of childbearing age who are most likely having the disease. Many ways can be done to increase the knowledge about SLE disease, such as socialization, regularly seeking information about SLE, having a consultation with an expert that is a doctor, and other health services if problems are found.

It is expected that this study can be used as a guide and inspire further study to determine deeply about the overview of knowledge level in ODAPUS about the SLE disease. Moreover, future researchers can expand the respondents' characteristics that will be studied, expand the research area with a larger number of respondents, and have more varieties of respondents' characteristics.

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