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Systemic Lupus Erythematosus Outpatients Medication Knowledge and Quality of Life

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Abstract: According to the Indonesian Lupus Foundation (YLI) in the last decade, the number of people with SLE (Systemic Lupus Erythematosus) has continued to increase every year. This research was undertaken to assess the medication knowledge and quality of life among SLE outpatients who had been counselled by pharmacist. A cross-sectional, non-experimental, descriptive study design was used in this research. A total of 121 respondents from Semarang and Yogyakarta met the criteria. Seventy (57,85%) respondents had previous counseling, while 51 (42,15%) respondents never. Their knowledge score was 32,17 ± 3,52 and the quality of life was 59,23 ± 17,04. There was any correlation between the knowledge score and their quality of life. *P 0,014. Their average age was 31,53 ± 7,77 years. It was positively related with their Quality of life *P 0,031 but not to their knowledge score. The participants' education level and disease duration were not considerably related with QoL and knowledge. Previous counseling by the pharmacists was positively related to their knowledge score, but not to their quality of life (*P 0,034 and 0,793). The conclusion that can be drawn is the SLE outpatients had low knowledge and their quality of life is not good enough. Pharmacists' counseling can improve SLE outpatients' knowledge scores significantly but not their QoL.

Keywords: Knowledge; outpatients; pharmacist counselling; QoL; SLE

1. Introduction

System Lupus Erythematosus (SLE) is an autoimmune, inflammatory, chronic disorder characterized by the participation of the multiorgan system (Barbhaiya & Costenbader, 2014; Gomez *et al.*, 2021). The disease impacts people all over the world, although the incidence and currency vary between countries. In Brazil, the prevalence ranges from 20 to 150 cases per 100,000 persons with the most prevalence were reported, and it appears to be growth more and more. People of Black/African American or Asian origin have a higher risk for SLE than White/Caucasian individuals, and show more serious disease phenotypes (Chen *et al.*, 2022; Carrasco *et al.*, 2013). Some data in Indonesia are obtained from hospitalized patients. In the year 2014, there were 1169 SLE in-patients but in 2016, there were 2166 in-patients diagnosed with SLE, in many hospitals in Indonesia, it was an 85% increased (Kementrian Kesehatan RI, 2016).

There are still few studies that show the knowledge of patients especially in chronic autoimmune cases (such as SLE) whose incidence is increasing nowadays and many people still don't understand all about SLE, cause nowadays SLE is still regarded as an uncommon disease in Indonesia. To characterize the full spectrum of the effects of SLE, Quality of Life is being known as an important aspect and relevant measure of efficacy in a clinical trial. Analyzing the quality of life (QoL) is thus an important measure to examine how much the chronic disease process is influencing the SLE patients. There is a paucity of literature on QoL issues in SLE patients from Asia (Chen *et al.,* 2022).

Pharmaceutical care needs a direct connection between a pharmacist and a patient as an individual. Patient counseling is one of the most important roles that a pharmacist can play. Patient's therapy accomplishes counseling produce an occasion for pharmacists to enhance patient's therapeutic outcomes (Sanii *et al.,* 2016). This study was conducted to know the sociodemographic profile of the SLE outpatients, to evaluate the knowledge about their medication and illness, and also to measure their quality of life. This study evaluate to know its correlation with age, disease duration, level of education, and being given previous counseling or formal information about SLE.

2. Material and Methods

2.1. Ethical approval

This study was approved by the Ethics Committee of the Community Health Faculty Diponegoro University Semarang No 004/EC/FKM/2015 in research to compile and developing Pharmacist counseling Module about SLE (This research article is a part of compiling that Module).

2.2. Materials

This study used questionnaire to measure the SLE outpatients' level of knowledge about SLE that has been validated before (Setiawati *et al.,* 2014). The questionnaire was prepared to measure the level of SLE outpatient knowledge about SLE. The questionnaire consisted of respondents' personal data (also whether the subjects has been given formally information) and 36 questions about understanding, causes and consequences of SLE (15 questions), non-pharmacological therapy (5 questions), SLE pharmacological therapy (9 questions), and drug's side effects (7 questions).

This study used questionnaires on Quality of Life (SF36) which has been validated and widely used all over the world. The SF36 is a generic, 36 item self-report questionnaire. It includes two component scores: the physical and the psychological component summary score. The SF-36 Score, a global measure of health-related quality of life, has been progressively reported in the scientific literature. Some studies using the SF-36 Score were published in reputable journals (Lins & Carvalho, 2016).

2.3. Methods

Non-experimental and a cross sectional study design was used in this research. Purposive samples were used to choose the subject, who met the criteria (had been diagnosed for more than 6 months, got routine therapy and agreed to be the subject of this research). Patients were notified of the objectives of the study and verbal consent obtained. Respondents were asked to fill out a questionnaire (informed concern form, agreement form, and 36 questions) as a measure of their knowledge, and SF36 questionnaire as a measure of their quality of life. Questionnaire, which was the instrument used for collecting information, was designed to obtain demographic data such as age, year of diagnosed, and level of education. This study was carried out in Middle Java: Semarang and Yogyakarta city. Data demography patients were shown descriptively and the other data was analyzed using SPSS 23. The inclusion criteria: patients have been diagnosed SLE from physician, according to the American College of Rheumatology (ACR) for more than 6 months, got routine therapy and agreed to be the subjectof this research (fulfilled all the questionnaires).

The filled questionnaires were analyzed as per the study objectives using Microsoft Excel. The SPSS version 23.0 was used to carry out the descriptive statistics. From the knowledge questionnaires, right answers were scored 1 and wrong answers were scored 0, and then we summarize the right answers as their level of knowledge, according to literature are shown in table 1 (Riwidikdo, 2013).

Table 1. Scoring analysis were analyzed as per the study objectives using Microsoft Excel. The SPSS version 23.0 was used to carry out the descriptive statistics.

Category	Calculation	Result
Excellent	Score > mean +1,5 SD	> 35,95 = 36
Good	Mean + 0,5 SD < score> mean +1,5 SD	33,93 < x > 35,95 = 34; 35
Enough	Mean - 0,5 SD < score > mean + 0,5 SD	30,91 < x > 33,93 = 31; 32; 33
Less	Mean – 1,5 SD < score> mean-0,5 SD	26,39 < x > 30,91 = 27; 28; 29; 30
Poor	Score < mean - 0,5 SD	< 26,39 = 25; 26

The SF 36 is the most valid generic health-related QoL questionnaire used in SLE (Kasitanon *et al.,* 2013). To measure QoL in cancer patients, we can use EORTC QLQ-C30 (Permata *et al.,*2023). Bearing in mind that QoL is best measured by the SLE'patients himself/herself and not his or her physician or nurse or other people (Slevin *et al.,* 1988; Khanna *et al*, 2004), the questionnaire was administered to the patients. Domain scores were calculated according to the SF36 guidelines. The more the score is representing better QoL. We divided the QoL score into 2 groups, 60 or more as a GOOD category and less than 60 as a BAD category

Disease duration was described as the time from when diagnosis of SLE was made by a physician. Predictive factors in this research included age, level of education, disease duration and previous counseling. We determined if there is any correlation of SLE outpatients' level of knowledge and their quality of life, with their age, level of education, disease durations and ever being counseled before. Interrelation between variables was analyzed statistically using the cross-tabulation (Chi square) method implemented in SPSS v23. A $P < 0.05$ was considered significant.

3. Results and Discussion

One hundred and thirty-six SLE outpatients were approached and accepted to participate in the study, only 121 participants completed the data and fulfilled the questionnaires, giving a response rate of 88,97%. Among them,1,65 % (n=2) were males and 98,35 % (n=119) were females. The study doesn't compare the knowledge and the quality of life between them, because the male amount was so little and not comparable.

Table 2. Demographic characteristic of survey respondents (n=121). Description: BF = before 5 years, AF = 5 years and more.

Variables	N	%	Range	Mean ± SD
Gender				
Male	2	1,65		
Female	119	98.35		
Age (years)	121		16-56	31,53 ± 7,77
< 30	52	42,97		
30 – 40	46	38,02		
> 40	23	19,01		
Disease duration (years)	121	0,5-33	0,5-33	5,80 ± 5,0
< 5 (BF)	66	54,55		
≥ 5 (AF)	55	45,45		
Education				
Below high school	5	4,13		
High school	50	41,32		
Graduate	66	54,55		

The prevalence of SLE is consistently reported to be higher in females than in males, with a ratio of approximately 10:1 (Waldheim, 2013). Although SLE can affect both men and women at any age, 90% of individuals diagnosed with the disease are female, and 80% of all patients with systemic lupus progress it between ages 15 and 45 (Grundy, 2006) Another study found that about 80–90% of all systemic lupus erythematosus cases are women in the age of 20 to 40 years (with mean age at diagnosis: 29 years) (Olesińska & Saletra, 2018). The average age was 31,53 ± 7,77 years, the youngest is 16 years old and the oldest is 56 years old. This was largely similar to other studies, cause SLE is dominant in women in productive age (Shahin, 2011). In this study, the SLE patients' disease duration is 5,80 ± 5,0 years. The shortest has been diagnosed only six months before the research, the longest has been diagnosed for 33 years by the clinician. This shown that SLE is a chronic disease, which stated in many studies (Chen *et al.*, 2022). The demographic data of the respondents are shown in table 2.

The Cross Sectional design in this study, as well as the relatively small sample, may limit the generalization of the results. However, despite the sample size, several significances were found. On the other hand, because of the sample size, further significances may have been undetected.

Of all the respondents, the mean knowledge score was 32,17 ± 2,52 (enough category), Two (1,65%) respondents got the lowest score, namely 25, and 11 (9,09%) respondents got the highest score, 36. The mean of their quality of life score were 59,23 ± 17,04 (bad category). There was a correlation between the knowledge score and the quality of life, with *P 0,014. The higher the knowledge scores, the better the Quality of life. The level of the subjects' knowledge about SLE can be seen in Figure 1.

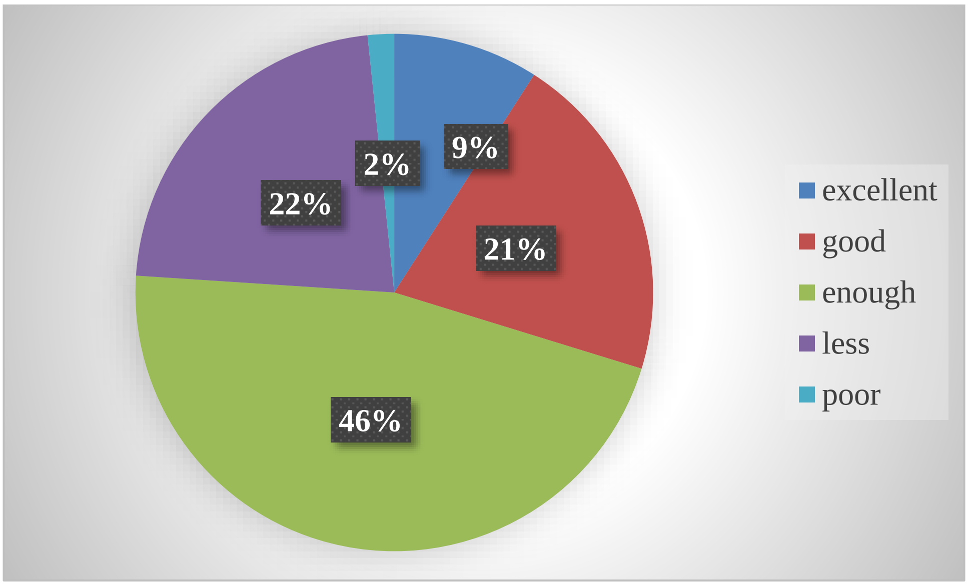

Figure 1. The knowledge level about SLE of samples were used to choose the subject, who met the criteria (n=121).

The association between the age of patients, level of education, disease duration and ever being counseled before with knowledge and Quality of Life score was analyzed and the results were summarized in Table 3. There was no serious interrelation between the age of the patients and their knowledge P > 0,05. However, there was a relationship between age and patients' quality of life, *P 0,031. The level of education of the SLE outpatients did not have any correlation with their knowledge score and quality of life. This result, different from other research (Alkatheri & Albekairy, 2013) which found the significant interrelation between the level of education and the patient knowledge.

Many studies showed enhancements in patient knowledge of their medication as a result of pharmacist counselling interventions (Schmitt *et al.*, 2011). The need for pharmacist's counseling, is needed by patients, especially for SLE patients whose disease is not yet well known and the treatment varies greatly. Our data demonstrated that Indonesian SLE outpatients' knowledge was not satisfied and had relatively poor quality of life.

The mean of the disease duration was 5,80 ± 5,0 year, to study the influence of disease duration, the study population was divided into two groups based upon the median disease duration: those with a disease duration below 5 years were 66 patients (54,55%) and equal or more than 5 years were 55 patients (45,45%). There was no such a relationship between the disease duration of the patients with their knowledge (P 0,061) and Quality of life (P 0,054).

The participants were also categorized according to their level of education into three categories: elementary school (below high school): only 5 patients (4,13 %), high school: 50 patients (41,32%) and graduated: 66 patients (54,55 %). Their knowledge mean were 41,5, 63,75 and 60,39 and their QoL mean were 51,1; 58,13; and 63,92. There was no correlation between level education with their knowledge and Quality of life (P 0,386 and 0,551). There was no such a relationship between the patients' education with their medicine knowledge and Quality of life, P 0,371 and 0,773. The Quality of Life did not have any relationship with disease duration, level of education and ever received previous counseling, P > 0,05.

Finally, 70 patients (57,85 %) of 121 participants had received previous information about SLE as a counseling from the physicians but not from the pharmacist, and the other 51 patients (42,15%) of the patients did not receive previous counseling or they cannot remember, respectively. There was no significant association between the patients ever received previous counselling with their Quality of life,P > 0,05. However, the patients knowledge was found to be significantly associated with ever received previous counselling, P< 0,05.

The quality of life (QoL) is being recognized as an important point of chronic disease. QoL is difficult to measure and there is no consensus on the single best instrument to use. Most researches report a faulty QoL in lupus patients (Wang *et al.,* 2001). Health-related quality of life is an independent territory in the analysis of patients with SLE, and actually the QoL is lower in patients with SLE than in patients with other chronic diseases (Kuriya *et al.,* 2008). Another study also made a conclusion that the quality of life in patients with SLE is lower than in general population and comparable with other chronic diseases (da Hora *et al.,* 2019).

The Qol of SLE patients decreases time after time. Using the SF36, several studies have demonstrated that persons with SLE have a significantly poorer QoL than persons without a chronic illness (Etchegaray-Morales *et al.,* 2017). In this study, the patients' quality of life was evaluated substantially related with age, P 0,031. The other study, stated that age has a negative influence on QoL, especially physical health (Mcelhone *et al.,* 2006). In our study, the disease duration was not associated with quality of life, P 0,054. Another study stated that the effect of disease duration on Quality of life was still unclear, and cause of the confirmed and inveterate of SLE, it will need repeated assessment of health- related quality of life (HRQoL) (Khanna, *et al.*, 2004). There are several studies reporting mutual relationships between subjective symptoms in SLE, like pain, fatigue, anxiety and depression, as well as HRQoL (Pettersson *et al.*, 2012). Another study, like our, found that educational level and disease duration were not associated with HRQOL domains (Etchegaray-Morales *et al.,* 2017). In general, the results from SF-36 are in line with previous studies in other populations showing impaired health-related quality of life in patients with SLE differentiated from controls (Mcelhone *et al.*, 2006).

Table 3. The QoL and knowledge of survey's respondents (n=121). Description: BF = disease duration less than 5 years; AF = disease duration 5 years or more; and PC = previous counseling.

Variable	N	Mean ± SD
QoL	121	59,23 ± 17,04
BF	66	56,86 ± 2,22
AF	55	61,92 ± 2,11
No PC	51	58,89 ± 16,85
Yes PC	70	59,36± 17,38
Knowledge	121	32,17± 2,52
BF	66	33,34 ± 2,11
AF	55	31,99 ± 2,7
No PC	51	31,77± 2,6
Yes PC	70	32,73± 2,32

Fifty-one patients (42,15 %) had previous counseling before but none of them being counselled by pharmacist, they were counselled by physician and the other by survival SLE patients. The rest of the respondents (57,85%) had never been counselled before. There was significantly associated between Previous counseling with knowledge (P 0,039), but not associated to their quality of life (P 0,793). Many researches have shown that counselling achieved by a clinical pharmacist upgrades patients' knowledge of their medications (Ganachari & Almas, 2012). Education and knowledge of patients to appropriate use of medicines and afterward positive therapeutic outcomes and disease control could motivate patients in therapy compliance (Sanii *et al.,* 2016).

4. Conclusion

The most important finding of the present study was many of the SLE outpatients had low knowledge and their quality of life is not good enough. They also need special information about their disease and especially about their therapy. Providing information such as counseling by pharmacist can improve SLE outpatients' knowledge but not their quality of life (QoL). The higher the knowledge scores, the better the Quality of life (P 0,014). Level of education and disease duration did not have any correlation to the QoL in any of the domains.

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Conflict of Interest

As the authors, we have declared there is no conflicts of interest.

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