

## Factors that Affect the Quality of Life of Systemic Lupus Erythematosus Patients Treated at Rsup Dr. Hasan Sadikin Bandung

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**Abstract:** The prevalence of SLE is increasing every year. On a global scale, SLE affects 4-250 per 100.000 people and mainly affects productive women. The goal of therapy is to get good QoLSLE. QoL is dependent on SLE itself, such as disease activity, disease damage and disease severity. QoL is also dependent on the drugs used for therapy, which have many side effects. Social-psychology, related to the perception of *Odapus*, knowledge and social support. So that the reason why the factors related to QoL was important and the increased of QoL was reached. This study was designed using analytic observational cross-sectional method. The data obtained regarding factors influencing QoL are analyzed by using univariate and bivariate methods. Based on the generic questionnaire (SF-36), QoL of *Odapus* treated at RSHS, showed QoL based on physical health: 22.7% good and 77.3% poor; and based on mental health: 40% good and 60% poor; while based on SLEQoL, the QoL of *Odapus* was 52% good and 48% poor. Based on those aspects that are measured (36 aspects of the SF-36; 40 aspects on SLEQoL), *Odapus* perception is not in line with the QoL values obtained. According to the SF-36 aspects, *Odapus* perception showed good conditions are about  $74.9 \pm 13.9\%$ , through SLEQoL  $80.7 \pm 13.7\%$ . From those external factors examined, compliance of the patient significantly affected the QoL based on physical health ( $p = 0.026$ ) and mental health ( $p = 0.007$ ) and the type of therapy significantly affects mental health ( $p = 0.028$ ).

**Keywords:** Systemic lupus erythematosus, quality of life, SF - 36, SLEQoL, external factors.

### Introduction

Bertsias et al reported that Systemic Lupus Erythematosus (SLE) is a type of autoimmune disease marked by the spread of inflammation and affects one or more organs or body systems.<sup>1</sup> This disease is related to the deposition of the immune complex, which causes tissue damage. SLE generally influences young women with the peak of age incident around 15-45 years or during productive age.<sup>2,3,4</sup>

On a global scale, the prevalence of SLE reached 4-250 per 100.000. Statistics have shown that SLE more often affects woman (9:1) of African, American, Chinese, and Japanese descent. Data from 1988-1990 show that the incidence of SLE was about 37.7 per 10.000 nursing cases and has been increasing in the last two decades.<sup>2,4</sup>

The main goal of management therapy of SLE is to increase the QoL.<sup>5-11</sup> QoL aspects of *Odapus* consist of physical and mental health which is influenced by the disease activity, disease damage and disease severity<sup>8,9</sup>. Besides that, QoL is also influenced by the medication taken. Management therapy for *Odapus* not only prevents the disease's progressivity by treating the symptoms, but can also cause many side effects, even to the point of aggravating the condition of the patient.<sup>9,12,13,14,15</sup>

This study aims to discover the external factors that are related to the QoL of *Odapus*. QoL is generally determined using the SF-36 Questionnaire and specifically using the SLEQoL Questionnaire.<sup>13-16</sup> The use of these two questionnaires is expected to assess aspects that are more adequate to be able to give an overview of the QoL of *Odapus*.<sup>3,14,16</sup> However, literature analysis conducted on QoL mention that there are other external aspects that affect QoL aside from the aspects mentioned in the questionnaires.<sup>15</sup> The result of this study is expected to discover the external aspects that affect the QoL of *Odapus*.<sup>17-20</sup>

## Methods

### Study Design

This study was designed using analytic observational cross-sectional method.

### Patients

This study was conducted at the rheumatology outpatient and Fresia 2 hospitalization clinic at Hasan Sadikin General Hospital, Bandung, between the period of March and May 2014. The patients recruited in the study were patients diagnosed with SLE based on the American College of Rheumatology (ACR) criteria and approved with informed consent. New patients with SLE who have not had lupus treatment, pregnant or breastfeeding patients, patients with consciousness disorders, patients with severe visual impairment, and patients with hearing disorders were excluded from the study. This study used the consecutive sampling method, where all the data collected by observed the inclusion and exclusion criteria included as a subject in the study until the minimum number of required subjects was fulfilled.

### Measurement

The QoL assessed by two questionnaire, *i.e* SF-36 as generic questionnaire; and SLEQoL as specific questionnaire. The questionnaires were interviewed to the patients as the respondent.

### Statistical analysis

Data was obtained from research regarding QoL from the score of a generic questionnaire, SF-36, and a specific questionnaire, SLEQoL. Additional data was also obtained from medical records and interviews regarding the patient's drug history, presented as external factors that influenced the QoL observed during the study. Those external factors include the compliance of *Odapus* towards treatment, payment status, types of medication used, duration of therapy, activity of the disease, occupational status, and marital status. The data obtained was then processed univariately and bivariately.

## Results And Discussion

Determination of the QoL using a generic questionnaire, SF-36, is the result of evaluation towards aspects of physical and mental health included in the 36 internal aspects of the questionnaire.<sup>16</sup> The aspect of physical health is obtained from the evaluation of physical functions, functional constraints due to physical problems, pain and perception of awareness in general; while the aspect of mental health is obtained from the evaluation of social functions, functional constraints due to emotional problems, mental health and the vitality of the *Odapus*.<sup>14,15</sup> Whereas the determination of QoL using the specific questionnaire, SLEQoL, is obtained from the evaluation of 40 internal aspects of the questionnaire, such as physical functions, activities, syndromes of disease, therapy, mood, and self-image.<sup>2,14,16</sup>

**Table 1 QoL Profile of *Odapus* Treated at RSHS**

Questionnaire	Parameter	QoL			
		Good		Poor	
		n	%	n	%
SF-36	Physical Health	17	22.3	58	77.3
	Mental Health	30	40	45	60

SLEQOL	39	52	36	48
n=75				

From the 75 subjects in this study – all of them women – a QoL profile of *Odapus* treated at RSHS was obtained and can be seen in Table 1. Data on Table 1 shows that the QoL of *Odapus* being treated at RSHS is generally poor, shown by the amount of *Odapus* with low physical and mental health at 77.33% and 60% respectively. With the specific questionnaire SLE, which has more responsive aspects with SLE, a QoL score of 52% good and 48% poor was obtained, which statistically is not too different.

This shows that the general QoL score (SF-36) is worse than that obtained from the specific questionnaire (SLEQoL). Most studies that analyze the relationship between health and the QoL of *Odapus* use a generic questionnaire like SF-36. The advantage of using a generic questionnaire like this is that the QoL of SLE can be compared with related conditions or with a normal population. However, this generic questionnaire is not specifically for SLE only. The difference of QoL scores obtained from the SF-36 with that of the SLEQoL is caused by the difference in the aspects that are evaluated in each questionnaire.<sup>2,14,15,16</sup>

The SF-36 questionnaire consists of 36 aspects and scores QoL in general based on physical health (physical functions, functional constraints due to physical problems, pain and perception of awareness in general) and mental health (social functions, functional constraints due to emotional problems, mental health and the vitality of the *Odapus*).<sup>2,16</sup> The SLEQoL questionnaire consists of 40 aspects which are considered more responsive towards SLE (physical functions, activities, therapy, symptoms of disease, mood, and self-image).<sup>2,16</sup>

If the perception of *Odapus* is analyzed using the 36 aspects of SF-36 and the 40 aspects of SLEQoL, the results show  $74.9 \pm 13.9\%$  positive perception using the SF-36 and  $80.7 \pm 13.7\%$  positive perception using the SLEQoL. The data is displayed in Table 2. Data on Table 2 shows that the perception of *Odapus* towards each aspect evaluated in the two questionnaires is generally positive. However, the QoL scores of both questionnaires are poor. This indicates that there is inconsistency between the perception felt by the *Odapus* towards each of the internal aspects evaluated using the QoL obtained, thus it is still necessary to review the two questionnaires in order to utilize it in the determination of the QoL of *Odapus*.<sup>10,14,15,17,18,19,20</sup>

**Table 2 Analysis of Perception of *Odapus* towards Aspects of the SF-36 and SLEQoL Questionnaires**

Aspects (Internal)	Positive Perception (%)	
	SF-36	SLEQoL
Standard Deviation (SD)	<b><math>74.9 \pm 13.9</math></b>	<b><math>80.7 \pm 13.7</math></b>

The above inconsistency shows that there are external factors affecting the determination of QoL of *Odapus*. Nofitri found that aspects of the quality of life of individuals varies due to the difference in interests of each individual be it in the nomination of the aspects of life quality itself or in its relevance towards the quality of life of the individual.<sup>14</sup> This also explains the varying scores of physical and mental health as well as the SLEQoL score of each individual *Odapus*. Apart from the varying perceptions influencing the score of QoL of each *Odapus*, it is believed that there are still other factors that influence the QoL score of *Odapus*, such as level of compliance, payment status, type of therapy, duration of therapy, activity of the disease, occupational status and marital status.<sup>13,17,18,19,20</sup>

According to Felce and Perry, literature analysis from various studies mention 5 overarching criteria of quality of life that is most often used, i.e. physical wellbeing, material wellbeing, social welfare, activity, and emotional welfare.<sup>13</sup> Physical wellbeing encompasses health, fitness, physical safety and mobility. Material wellbeing encompasses income, privacy, quality of environment, availability of food, transportation, living environment, security, and stability. The criteria of activity encompass hobbies, career, and sports. Welfare encompasses mood, achievement of needs, self-confidence, religion and status. This literature analysis by Felce and Perry showed that there are numerous external factors that influence QoL, which are not included in the two questionnaires usually used to analyze QoL.<sup>13,14,15,17,18,19,20</sup>

From this study, observations of several external factors were obtained, including level of compliance, payment status, type of therapy, duration of therapy, activity of the disease, occupational status and marital status. Those external factors can be seen in Table 3

**Table 3 Profile of External Factors Observed**

<b>Factors</b>	<b>Respondents n (%)</b>
Compliance	
♦ Compliant	31 (41.3)
♦ Non-compliant	44 (58.7)
Payment Status	
♦ BPJS	46 (61.3)
♦ nonBPJS	29 (38.7)
Type of Therapy	
♦ < 2 main medications	20 (26.7)
♦ ≥ 2 main medications	55 (73.3)
Duration of Therapy	
♦ <5 years :	36 (48)
♦ ≥ 5 years :	39 (52)
Activity of Disease	
♦ None (remission)	49 (65.3)
♦ Active	26 (34.7)
Occupational Status	
♦ Active	20 (26.7)
♦ Not Active	55 (77.3)
Marital Status	
♦ Not married	21 (28)
♦ Married	54 (72)

n=75

Table 3 shows that the external factors observed in this study such as level of compliance, payment status, type of therapy, duration of therapy, activity of the disease, occupational status and marital status, are used to observe its role towards the QoL of *Odapus*. Table 4 shows that the external factors affecting physical health in SF-36 are compliance and type of therapy. Table 5 shows that the external factor affecting mental health in SF-36 is compliance towards treatment. Table 6 shows that there are no external factors affecting SLEQoL. From Table 7 it is possible to obtain the probability of having a good QoL. If the *Odapus* is obedient towards the treatment, then the probability of having a good physical health QoL is 77.7%. If the *Odapus* is obedient towards treatment then the probability of obtaining a good mental health QoL is 78.7%. The use of ≥ 2 main medications for SLE can give a physical health QoL probability of 88.6%.

**Table 4 Relationship Between External Factors and Physical Health**

(QoL SF-36)

<b>Factors</b>	<b>QoL</b>		<b>Total</b>	<b>P</b>	<b>OR</b>
	<b>Poor</b>	<b>Good</b>			
<b>Compliance:</b>					
♦ Non-Compliant	38 (50.7)	6 (8)	44 (58.7)	0.026*	3.483
♦ Compliant	20 (26.7)	11 (14.)	31 (41.3)		
<b>Payment Status:</b>				0.419	

♦ NonBPJS	21 (28)	8 (27.6)	29 (38.7)		
♦ BPJS	37 (80,4)	9 (19.6)	46 (61.3)		
<b>Type of Therapy:</b>					
♦ < 2 main medications	19 (25.3)	1 (1.3)	20 (26.7)	0.028*	7.795
♦ ≥ 2 main medications	39 (52)	16 (21.3)	55 (73.3)		
<b>Duration of Therapy:</b>					
♦ < 5 years	28 (37.3)	8 (10.7)	36 (48)	0.93	
♦ ≥ 5 years	30 (40)	9 (12)	39 (52)		
<b>Activity of Disease:</b>					
♦ None	35 (46.7)	14 (18.7)	49 (65.3)	0.094	
♦ Active	23 (30.7)	3 (4)	26 (34.7)		
<b>Occupational Status:</b>					
♦ Not active	41 (54.7)	14 (18,7)	55 (73.3)	0.339	
♦ Active	17 (22.7)	3 (4)	20(26.7)		
<b>Marital Status:</b>					
♦ Not married	15 (20)	6 (8)	21 (28)	0.446	
♦ Married	43 (57.3)	11 (14.7)	54 (72)		

n=75

Note: \*= statistically significant

**Table 5 Relationship Between External Factors and Mental Health (QoL SF-36)**

Factors	QoL		Total	p	OR
	Poor	Good			
<b>Compliance:</b>					
♦ Non-Compliant	32 (42.7)	12 (16)	44 (58.7)	0.007*	3.692
♦ Compliant	13 (17.3)	18 (24)	31 (41.3)		
<b>Payment Status:</b>					
♦ nonBPJS	15 (20)	14 (18.7)	29 (38.7)	0.245	
♦ BPJS	30 (40)	16 (21,3)	46 (61.3)		
<b>Type of Therapy:</b>					
♦ < 2 main medications	13 (17.3)	7 (9.3)	20 (26.7)	0.594	
♦ ≥ 2 main medications	32 (42.7)	23 (30.7)	55 (73.3)		
<b>Duration of Therapy:</b>					
♦ < 5 years	22 (29.3)	14 (18.7)	36 (48)	0.85	
♦ ≥ 5 years	23 (30,7)	16 (21,3)	39 (52)		
<b>Activity of Disease:</b>					
♦ None	29 (38.7)	20 (26.7)	49 (65.3)	0.834	
♦ Active	16 (21.3)	10 (13.3)	26 (34.7)		
<b>Occupational Status:</b>					
♦ Not active	33 (44)	22 (29.3)	55 (73.3)	1	
♦ Active	12 (16)	8 (10.7)	20 (26.7)		
<b>Marital Status:</b>					
♦ Not Married	14 (18.7)	7 (9.3)	21 (28)	0.462	
♦ Married	31 (41.3)	23 (30.7)	54 (72)		

n=75

Note: \*= statistically significant

**Table 6 Relationship Between External Factors and SLEQoL**

Factors	QoL		Total	p	OR
	Poor	Good			
<b>Compliance:</b>					
♦ Non-compliant	23 (30.7)	21 (27.3)	44 (58.7)	0.378	
♦ Compliant	13 (17.3)	18 (24)	31 (41.3)		
<b>Payment Status:</b>					
♦ nonBPJS	10 (13.3)	19 (25.3)	29 (38.7)	0.063	
♦ BPJS	26 (34,7)	20 (26,7)	46 (61,3)		
<b>Type of Therapy:</b>					
♦ < 2main medications	10 (13.3)	10 (13.3)	20 (26.7)	0.834	
♦ ≥ 2 main medications	26 (34.7)	29 (38.7)	55 (73.3)		

<b>Duration of Therapy:</b>				
♦ < 5 years	17 (22.7)	19 (25.3)	36 (48)	0.897
♦ ≥ 5 years	19 (25.3)	20 (26.7)	39 (52)	
<b>Activity of Disease:</b>				
♦ None	22 (29.3)	27 (36)	49 (65.3)	0.46
♦ Active	14 (18,7)	12 (16)	26 (34,7 )	
<b>Occupational Status:</b>				
♦ Not active	23 (30.7)	32 (42.7)	55 (73.3)	0.076
♦ Active	13 (17.3)	7 (9.3)	20 (26.7)	
<b>Marital Status:</b>				
Not married	12 (16)	9 (12)	21 (28)	0.323
♦ Married	24 (32)	30 (40)	54 (72)	

n=75

**Table 7 Probability Based on OR Score**

Factors	P (< 0,05)	OR	Probability (OR/(1+OR))x100%
Compliance	Physical = 0.026	3.483	77.7
	Mental = 0.007	3.692	78.7
Type of Therapy	Physical = 0.028	7.795	88.6

## Conclusion

In general, based on SF-36 the QoL of *Odapus* being treated at RSHS have poor physical and mental health, and based on SLEQoL, the QoL of *Odapus* being treated at RSHS has an average range of 52% good and 48% poor. The QoL score determined based on SF-36 and SLEQoL are not in line with the perceptions of the *Odapus*. Compliance and medicinal therapy are two factors that play an important role in the QoL of each *Odapus*.

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