Is Quality of Life of Lupus Better than Systemic Sclerosis?

Laniyati Hamijoyo[1,2], Nadia Gita Ghassani[2], Bernard Santoso Suryajaya[2], Ignatius Irawan Hidayat[2], Valentine Natasya Moenadi[2], Sasfia Candrianita[2], Sumartini Dewi[1,2]

[1] Rheumatology Division, Internal Medicine Department, Faculty of Medicine Universitas Padjadjaran /Hasan Sadikin General Hospital, Bandung Indonesia.
[2] Lupus Study Group, Immunology Study Center, Faculty of Medicine Universitas Padjadjaran, Bandung Indonesia.

Corresponding author:
Laniyati Hamijoyo,
hamijoyo@yahoo.com

Abstract

Background Patients with systemic lupus erythematosus (SLE) and systemic sclerosis (SSc), have to cope with lifelong disease manifestation and impaired physical function. Limited physical activities along the disease will affect their quality of life (QoL). The QoL is recognized as an important factor of treatment strategy. This study aims to compare the quality of life of patient with SLE and SSc.
Method This study was a cross-sectional study and conducted in rheumatology outpatient clinic of Hasan Sadikin Hospital Bandung, Indonesia from January 2015 until March 2017. The respondents were patients diagnosed as SLE and SSc who regularly visit rheumatology outpatient clinic. Respondents were asked to complete the Short Form-36 (SF-36). Baseline characteristics, including age, gender, and duration of disease, were collected during the visit. The Mann-Whitney U test was used to analyze the comparison.
Result There were 242 patients who completed the SF-36 questionnaires, consisted of 193 SLE patients and 49 SSc patients. SLE patients were slightly younger and had a longer duration of disease compared to SSc. The SF-36 Physical Component Summary (PCS) score was significantly higher on SLE patients (40.6 vs 40.4, p = 0.0001), but the mean of Mental Component Summary (MCS) score was similar among both diseases. **Conclusion** Physical functioning aspect on quality of life is better in SLE patients compared to SSc patients. However, mental aspect for both diseases are relatively similar.

Keywords : systemic lupus erythematosus, systemic sclerosis, quality of life.

Introduction

Rheumatic diseases encompass a diverse group of over 100 autoimmune and chronic degenerative conditions that are linked with persistent, recurrent, or even lifelong pain and impaired physical function.[1] Musculoskeletal conditions provoke more functional limitations in the adult population in most developed nations than any other group of disorders. They are the major cause of years of living with disability all around the world and economies.[1] The burden of rheumatic diseases is overwhelming and continuously expanding that coping with them will affect a wide spectrum of physical and psychological functions,[2] which eventually impair quality of life.

Quality of life (QoL) is a subjective, diverse concept of well-being correlated with a number of factors, such as severity and duration of illness, use of medications, and stress events.[3] The subjective perception of QoL is now considered of great importance to assess the outcomes in a chronic disease, and has become central to evaluate the effectiveness of treatments as well.[3] With no exception, this also occurs in systemic lupus erythematosus (SLE) and systemic sclerosis (SSc). They are multiorgan diseases that have a heterogeneous physiologic and biologic changes, unpredictable disease course, and many comorbidities which can decrease patients' physical activity, which eventually affecting the health-related QoL.

There are many studies evaluating QoL of SLE and SSc individually.[2-6] However, there are only a few studies comparing their findings between both of them.[6, 7] This study aims to compare the quality of life on SLE and SSc patients.

Method

This study was a cross-sectional study and conducted in rheumatology outpatient clinic of Hasan Sadikin Hospital Bandung, Indonesia from January 2015 until March 2017. The respondents were patients diagnosed as SLE and SSc who undergo routine follow-up at rheumatology outpatient clinic. Respondents were asked to complete the Short Form-36 (SF-36), which is a comprehensive, general health survey with physical and mental health components.[8] It consisted of 8 domains: physical functioning, physical role functioning, bodily pain, general health, vitality, social role functioning, emotional role functioning, and mental health. SF-36 has been validated as a quality-of-life measure in SLE, SSc, and many other rheumatic diseases.[9, 10]

The inclusion criteria were 1) respondents who were at least 18 years old, and 2) fully completed the SF-36 questionnaire. Respondents with other chronic and severe comorbid diseases, such as malignancy, diabetes mellitus, and heart failure, would be dismissed as an exclusion criteria, as those described above may significantly be accounted

for the impaired health-related QoL of the patients. Baseline characteristics, including age, gender and duration of disease, were also collected during the visit. The Mann-Whitney U test was used to analyse the comparison. This study also has been approved by Hasan Sadikin General Hospital Ethics and Research Committee.

Result

There were 242 patients who completed the SF-36 questionnaires. One hundred and ninety-three of them were SLE patients and forty-nine were SSc patients (see Table 1). The proportion of female patients was similar across two groups, which was more than 95%. Patients with SLE were slightly younger, with a mean age of 34.9 year, and had a longer duration of disease, with a median of 60 months. The highest proportion was found on the 21-30 years old age group on SLE patients (34.1%), meanwhile on SSc patients the 31-40 years old age group was the highest proportion (36.7%).

The mean of physical component summary (PCS) score was significantly higher on SLE patients compared to SSc patients, which was about 40.6 vs 40.4 with p = 0.0001 (see Table 2). Meanwhile, the mean of mental component summary (MCS) score was similar among SLE and SSc patients (p=0.103). Almost all domains of SF-36 scores on SLE patients were significantly better than SSc patients ($p < 0.05$, see Figure 1), except for vitality (VT) and mental health (MH).

However, there were not any significant differences (p-value > 0.005) between PCS and MCS scores among limited and diffuse types of SSc (see Table 3).

Table 1. Demographics SLE and SSc Patients

Characteristics	SLE* (n = 193)	SSc ** (n = 49)
Sex: Female (%)	185 (95.8)	47 (95.9)
Age: years (Mean)	34.9	39.7
Age group		
≤ 20 (%)	7 (3.6)	2 (4.1)
21-30 (%)	66 (34.1)	8 (16.3)
31-40 (%)	64 (33.1)	18 (36.7)
41-50 (%)	42 (21.8)	15 (30.6)
≥ 51(%)	18 (9.3)	6 (12.2)
Duration: months (Median (range))	60 (47-145)	36 (47-145)

* Systemic Lupus Erythematosus
** Systemic Sclerosis

Table 2. Comparison of Quality of Life SLE and SSc Patients

Variables	SLE† (n=193)	SSc‡ (n=49)	*P value*
PCS§ (*mean*)	40.6	40.4	0.0001*
MCS¶ (*mean*)	42.2	42.2	0.103*

*p-value analysis was done by Mann-Whitney U Test.
†Systemic lupus erythematosus
‡Systemic sclerosis
§Physical Component Summary
¶ Mental Component Summary

Table 3. Comparison of Quality of Life between Limited and Diffuse SSc

Outcome measure	Limited (n=28)	Diffuse (n=21)	p-value
Mean PCS†	40.9	39.8	0.64
Mean MCS‡	41.3	43.4	0.54

†Physical Component Summary
‡Mental Component Summary

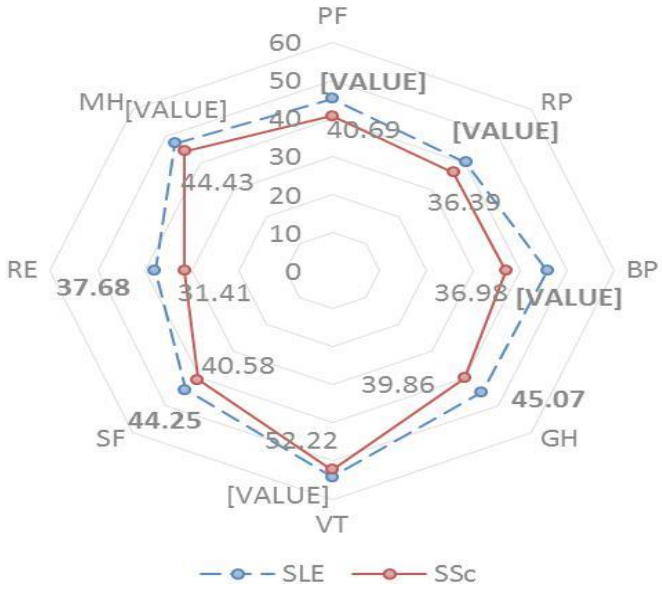

Figure 1. Web Diagram of 8 components of Quality of Life

Physical Functioning (PF), Physical Role Functioning (RP), Bodily Pain (BP), General Health Perception (GH), Vitality (VT), Social Role Functioning (SF), Emotional Role Functioning (RE), and Mental Health (MH), Systemic Lupus Erythematosus (SLE), Systemic Sclerosis (SSc).
Bold: SLE patients have significantly better score than SSc patients on this domain

Discussion

Patients with autoimmune rheumatic diseases share the same factors which probably influence their quality of life, such as chronic inflammation, pain, physical disability, anxiety and depression. It appears that overcoming rheumatic diseases affects an extensive spectrum of physical and psychological functions.[2] Health-related QoL (HRQOL) of patients with SLE was significantly worse in all scales domains at an earlier age in comparison to both healthy individual and patients of some other common chronic diseases, such as hypertension, diabetes, and myocardial infarction.[4,5,7] Similar with SLE patients, all the SF-36 subscale scores of SSc patients were lower than those in general population.[3]

Physical aspect of quality of life

This study showed that SLE patients had better physical components of QoL compared to SSc. This finding is similar to that reported in previous studies.[6,7] The SF-36 score for PCS was lower in systemic sclerosis compared to SLE patients but not significantly (31.8 ±13.2 vs 39.0 ± 13.0).[7] This might be

due to several reasons. First, SSc patients have greater physical disability than those with SLE. Earlier studies had measured physical disability among SSc and SLE patients using the disability section of the Health Assessment Questionnaire (HAQ) scores. In patients with systemic lupus erythematosus, the score was 0.66.[11] Meanwhile, the disability index of patients with systemic sclerosis was found to be 0.92, which was higher than those with systemic lupus erythematosus. Disability subsequently has a significant influence on psychosocial adjustment and may influence the QoL of these patients.[6] However, disability has largely been attributed to major internal organ involvement, Raynaud's Phenomenon, or limitation in range of motion resulted from skin tightening, in patient with SSc, especially the diffuse type.[7] Therefore, one may assume that the QoL as assessed by the SF-36 appeared to be related to the burden of clinical manifestation, such as the number of clinical involvements, the functional disability, and the pain.[3]

The other contributing factors that may support the finding in this study is the prognosis of SSc itself that is poorer than SLE. The survival rates of SLE were 94% and 89% respectively at 5 and 10 years[12], meanwhile survival rates of SSc were only 74.9% at 5 years and 62.5% at 10 years.[13] The lack of knowledge regarding the disease in conjunction with the facts that there are no definitive cure for both diseases make the appropriate pain management and any other treatments to slow down the progression of diseases are crucial in improving the physical health to increase QoL on both diseases. The implementation of effective treatment and the better knowledge of SLE within society may cause the better survival rate and lead to improvement of quality of life.

However, as survival of both sufferers improves, the burden placed upon SLE and SSc patients has also increased. The economic burden of SLE is twofold greater than normal population, encompassing both the cost of treatment itself and the productivity losses caused by the disease.[14] Eventually, the increasing burden of diseases will lead to the worsening of QoL. Disease activity along with poor mental and physical health, were repeatedly reported to be related to disease status, and it is therefore logical that their worsening would be associated with the increasing disease burden, such as costs.[14] As there is currently no definitive therapy for both diseases, treatments that are able to improve the disease flares and delay its progression are necessary in order to reduce the burden and improving QoL.[14] Therefore, it is important to quantify costs, especially in an unpredictable and chronic autoimmune diseases.[14]

The result of this study is in contrast with the study from Austria.[15] They stated that patients with SLE had lower mean scores than SSc patients for QoL in all 8 domains, except for bodily pain and emotional role. Differences of total number of patients and respective ratio of localized and diffuse types of SSc could explain the different findings on this study.

Mental aspect of quality of life

The MCS on both groups were not significantly different. This might be due to the stigmatization of rash in SLE, tightening of the skin in SSc, the unpredictable course of the disease, fatigue, environmental factors such as sun exposure and cold weather in both SLE and SSc, and lastly, the reduced life expectancy on both diseases that are influencing both of the diseases' QoL.[15] This might also explain why the comparison of mental health score of SF-36 on this study was not significantly different.

Limited vs diffuse systemic sclerosis

This study found that there were not any significant differences on quality of life in SSc patients based on their type of SSc. This is in contrast with other studies which stated that SSc patients with diffuse type had lower SF-36 scores or had greater disability index than the limited type; thus, representing the lower quality of life that SSc with diffuse type have.[3,6,7] They stated that patients with diffuse type suffered more disability than the limited type because of the extension of the diffuse type, which eventually resulted in more impaired QoL. Although these findings may be due to the fact that Johnson, *et. al.* in their study collected a greater proportion of diffuse type subjects than the limited type, which influenced their PCS score and physical functioning on the SF-36.

The importance of this study is to add knowledge about the impact of SLE and SSc on patients' HRQOL. Healthcare providers should begin to focus on quality of life outcomes of SLE and SSc diseases by incorporating self-administered questionnaire, such as SF-36, in their evaluation of treatment. Clinical practice should accentuate an interdisciplinary approach to SSc patients involving doctors, physical and occupational therapists, psychologists, social workers, and spiritual leaders.[15] Since the physical ability of SLE and SSc patients are impaired, it might also affect their activities of daily living, as well as social and professional skills. Therefore, the refinement of QoL may also eventually improve the lives of their caretakers, community resources, and society.

Another thing that must be highlighted is that health-related QoL is affected by many other predictors beside the characteristics of the disease itself. Knowledge of these factors is, therefore, important in order to optimize treatment towards a multidisciplinary approach targeting on those related prognostics factors, which will eventually lead to the improvement of patients' health-related QoL and well-being.[2] A subsequent study in the future regarding predictors of quality of life in SLE and SSc patients will be very much helpful to improve each of their QoL.

Limitation of study

Limitation of this study was the unavailability of data regarding each patients' medications. Selection and compliance of medication used by patients may affect the outcomes of the diseases, and therefore, may result in the improvement of QoL. However, all of SLE and SSc patients in this study are still receiving corticosteroids and immunosuppressant or cytostatic agents as their main treatment. Another limitation was the promptness of management on their treatment was not identical in every patient; hence, it will affect the outcome and also the QoL. Lastly, the disease activity and severity of both SLE and SSc were not incorporated in the baseline characteristics of this study, which potentially influence the

QoL of both diseases, further study should be done to evaluate this.

Conclusion

Physical functioning aspect on quality of life is better in SLE patients compared to SSc patients. However, mental aspect for both diseases are relatively similar. Since SSc is not a common disease, there is a lack of awareness on the part of healthcare providers and policy makers.[15] This is unfavorable for the sufferers since their QoL is lower than SLE patients as shown in this study.

Acknowledgement

The authors gratefully acknowledge Asia Pacific Lupus Collaboration (APLC) for providing SF36 form which has been validated in Indonesian language.

References

1. Woolf AD, Pfelger B. Burden of major musculoskeletal conditions. Bull World Health Organ. 2003;81(9):646-656.
2. Anyfanti P, Triantafyllou A, Panagopoulos P, Triantafyllou G, Pyrpasopoulou A, Chatzimichailidou S, et al. Predictors of impaired quality of life in patients with rheumatic diseases. Clin Rheumatol. 2015;35(7):1705-1711.
3. Mura G, Bhat KM, Pisano A, Licci G, Carta M. Psychiatric symptoms and quality of life in systemic sclerosis. Clin Pract Epidemiol Ment Health. 2012;8:30-35.
4. Shen B, Tan W, Feng G, He Y, Liu J, Chen W, et al. The correlations of disease activity, socioeconomic status, quality of life, and depression/ anxiety in Chinese patients with systemic lupus erythematosus. Clin Dev Immunol. 2013; 2013:270878
5. Barnado A, Wheless L, Meyer A, Gilkeson GS, Kamen DL. Quality of life in patients with systemic lupus erythematosus (SLE) compared with related controls within a unique African American population. Lupus. 2012;21(5):563-9.
6. Poole J, Steen V. The Use of the Health Assessment Questionnaire (HAQ) to Determine Physical Disability in Systemic Sclerosis. Arthritis & Rheumatology. 1991;4(1):27-31.
7. Johnson SR, Glaman DD, Schentag CT, Lee P. Quality of life and functional status in systemic sclerosis compared to other rheumatic diseases. J Rheumatol. 2006;33(6):1117-22.
8. McHorney C, Ware J, Raczek A. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Medical care. 1993:247-263.
9. Stoll T, Gordon C, Seifert B, Richardson K, Malik J, Bacon PA, et al. Consistency and validity of patient administered assessment of quality of life by the MOS SF-36; its association with disease activity and damage in patients with systemic lupus erythematosus. J Rheumatol. 1997;24(8):1608-14.
10. Khanna D, Furst DE, Clements PJ, Park GS, Hays RD, Yoon J, et al. Responsiveness of the SF-36 and the Health Assessment Questionnaire Disability Index in a systemic sclerosis clinical trial. J Rheumatol. 2005;32(5):832-40.
11. Hochberg M, Sutton J. Physical disability and psychosocial dysfunction in systemic lupus erythematosus. J Rheumatol. 1988;15:959-64.
12. Wang Z, Wang Y, Zhu R, Tian X, Xu D, Wang Q, et al. Long-term survival and death causes of systemic lupus erythematosus in China: a systemic review of observational studies. Medicine (Baltimore). 2015;94(17):e794.
13. Rubio-Rivas M, Royo C, Simeón CP, Corbella X, Fonollosa V. Mortality and survival in systemic sclerosis: systematic review and meta-analysis. Semin Arthritis Rheum. 2014;44(2):208-19.
14. Meacock R, Dale N, Harrison MJ. The Humanistic and Economic Burden of Systemic Lupus Erythematosus. PharmacoEconomics. 2013;31:49-61.
15. Bretterklieber A, Painsi C, Avian A, Wutte N, Aberer E. Impaired quality of life in patients with systemic sclerosis compared to the general population and chronic dermatoses. BMC Res Notes. 2014;7:594.