Life-style activities in systemic lupus erythematosus

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Abstract

Objective
We evaluated the life-style activities of outpatients with SLE and factors that reduce their social activities.

Methods
Subjects: SLE group = 60 patients, Control 1 = 30 healthy subjects and Control 2 = 30 patients with other autoimmune diseases. The Frenchay Activity Index (FAI), Zung's self-rating depression scale (SDS), and the Japanese version of the Philadelphia Geriatric Center morale scale-revised (MS) were compared between groups. Relation between FAI and age, disease duration, steroid dose, SDS, and MS were examined in the SLE group, Control 1, and Control 2.

Results
Total scores by FAI was 28.1 ± 8.0 points in Control 1, whereas it was 26.5 ± 5.8 points in Control 2 and 24.5 ± 7.7 points in the SLE group. While there was no statistical difference between the SLE group and Control 2, the scores were significantly lower in the SLE group than in Control 1 ($P < 0.05$). In SLE patients, age, the duration of the disease, and the steroid dose had no correlation, but MS had a positive correlation ($P < 0.05$) and SDS had a negative correlation ($P < 0.05$). In Control 2, age, the duration of the disease, the steroid dose, MS and SDS had no correlation whereas there was significant negative relation between FAI and SDS in Control 1 ($r = -0.516$, $P<0.005$).

Conclusion
The significant relation between life-style activities and subjective well-being, and depression in SLE suggests that detection and treatment of mental status is important in improving the life-style activities of SLE patients.

Key words
Quality of life, systemic lupus erythematosus, life-style activities.

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Introduction

Among a variety of collagen diseases that cause multiple organ failure, systemic lupus erythematosus (SLE) frequently occurs in young females and causes long-term suffering. Conventional SLE treatments focus on autoantibody detection, which is useful in diagnosis and is an indicator of organ damage, and on treating damaged organs. In recent years, the mortality rate of patients with SLE has been decreasing (1), so attention has been drawn to their quality of life (QOL). Although there are various reports on the QOL of patients with SLE (2-9), the daily-life activities of outpatients with SLE have not yet been studied. Therefore, we evaluated the daily-life activities of outpatients with SLE and factors that reduce their social activities.

Subjects

The subjects comprised 30 subjects (Control 1) who visited private clinic for check-up, SLE patients and the patients with autoimmune diseases other than SLE (Control 2) who visited the Third Department of Internal Medicine, Wakayama Medical University and from whom consent was obtained. The patients were consecutively recruited. Sixty subjects satisfied the criteria for SLE by the American College of Rheumatology (10) and 30 subjects as Control 2 subjects met the criteria for autoimmune diseases other than SLE. All subjects were female. Autoimmune diseases other than SLE were: polymyositis, 5 cases; mixed connective tissue disease, 5; scleroderma, 2; primary Sjögren's syndrome, 4; adult onset Still's disease, 4; Beçhet's disease, 1; Wegener's granulomatosis, 1; overlap syndrome of polymyositis and scleroderma, 1; polymyalgia rheumatica, 2; antiphospholipid antibody, 1; and autoimmune hepatitis, 4.

Methods

1. Comparison between SLE and control groups

The Frenchay Activity Index (FAI) (11, 12 for life-style activities, Zung's self-rating depression scale (SDS) (13) for depression evaluation, and the Japanese version of the Philadelphia Geriatric Center morale scale-revised (MS) (14) for subjective well-being evaluation were examined in the SLE and control groups. Then the results were compared between 3 groups. FAI is composed of 2 parts that ask about the conditions during the last 3 and 6 months. The questions regarding the last 3 months are composed of 10 items: preparation of meals, washing dishes, laundry, cleaning and tidying, exertion, shopping, going outdoors, outdoor walking, hobbies, and the use of transportation. Patients scored each item using 4 different points from 0 (not performed) to 3 (almost every day). The questions about the last 6 months were on: traveling, gardening, house and car care, reading, and working. Compared with the questions regarding the last 3 months, the questions regarding the last 6 months concentrated more on social activities. Patients scored each item using 4 different points as follows: traveling, 0 for "none" to 3 for "at least every week"; gardening and house and car care, 0 for "none" to 3 for "always performed when necessary"; reading, 0 for "none" to 3 for "twice or more in 1 month"; working, 0 for "no working" to 3 for "30 hours or longer per week."

SDS composed of 20 items. The possible range of the scale is 20 points from 80 points. An SDS score of 40 or more is associated with a high tendency towards depression. MS composed of 17 items. A subject answers it "Yes" or "No." The possible range of the scale is from 0 points to 17 points. If the score is high, subjective well-being is high.

2. Factors affecting life-style activities in the 3 groups

To elucidate the factors affecting lifestyle activities, the relation between FAI and age, the results of SDS, and the Morale scale-revised were examined in the Control 1 group, and the relation between FAI and age, the duration of the disease, disease activities, daily steroid dose (mg), the results of SDS, and the Morale scale-revised were examined in the Control 2 group and the SLE group.

For statistical analysis, the Mann-Whitney's U test and the Spearman's rank correlation were employed.
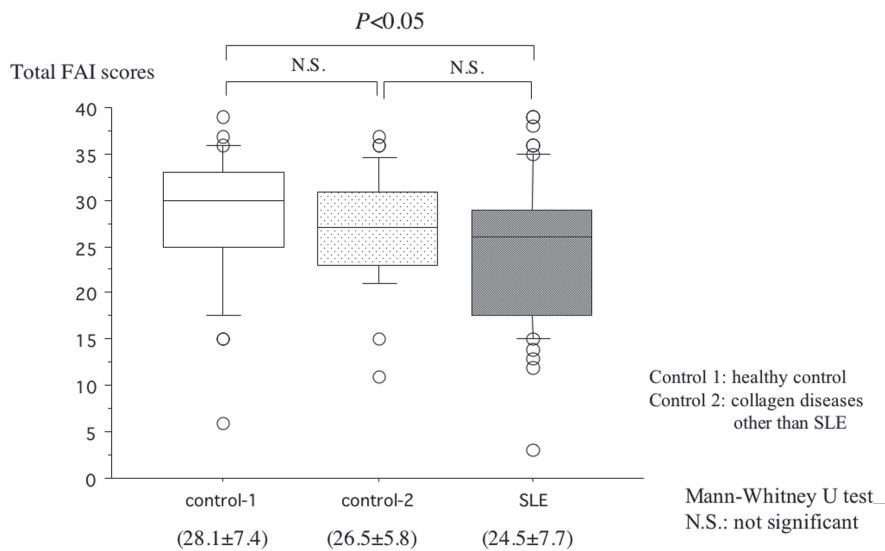
Fig. 1. Total scores by FAI was 28.1±8.0 points in the Control 1 group, whereas it was 26.5±5.8 points in the Control 2 group and 24.5±7.7 points in the SLE group. While there was no statistical difference between the SLE group and the Control 2 group, the scores were significantly lower in the SLE group than in the Control 1 group (P<0.05).
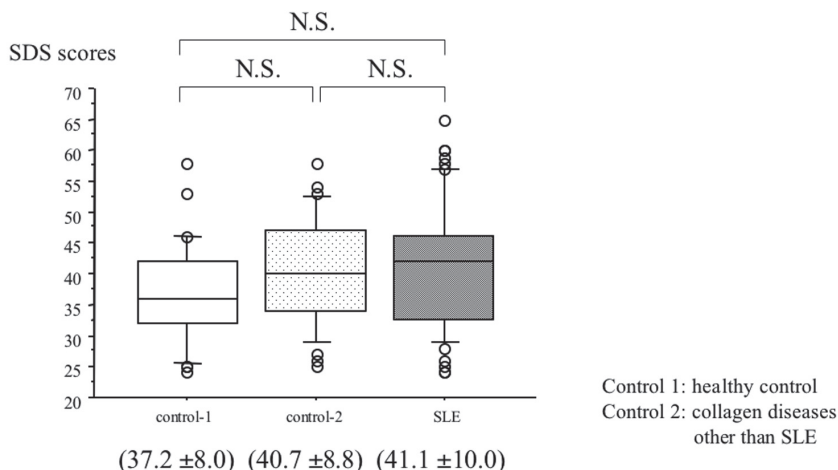
Fig. 2. Scores by SDS was 37.2±8.0 points in the Control 1 group, whereas it was 40.7 ± 8.8 points in the Control 2 group and 41.1±10.0 points in the SLE group. There was no statistical difference between the 3 groups.

Results

1. Comparison between SLE and control groups

In the SLE, the Control 1 and the Control 2 group, the age distribution was 18-66, 26-58 and 20-66 years old, respectively, and there was no difference in this factor between the 3 groups. In the SLE and Control 2 group, the disease duration was 1-25 and 1-28 years, and the steroid dose was 0-20 and 0-14 mg/day, respectively, and there was no difference in these factors between the 2 groups. In the SLE group, the disease activity index score (SLEDAI) (15) was 0-12 points (3.1 ± 2.4 points), and the damage index score (16) was 0-5 points (0.8 ± 1.2 points).

Total score by FAI was 28.1 ± 8.0 points in the Control 1 group, whereas it was 26.5 ± 5.8 points in the Control 2 group and 24.5 ± 7.7 points in the SLE group (Fig. 1). While there was no statistical difference between the SLE group and the Control 2 group, the scores were significantly lower in the SLE group than in the Control 1 group ($P < 0.05$). Scores by SDS was 37.2 ± 8.0 points in the Control 1 group, whereas it was 40.7 ± 8.8 points in the Control 2 group and 41.1 ±10.0 points in the SLE group (Fig. 2). There was no statistical difference between the 3 groups. Scores by MS were 11.0 ± 3.4 points in the Con-
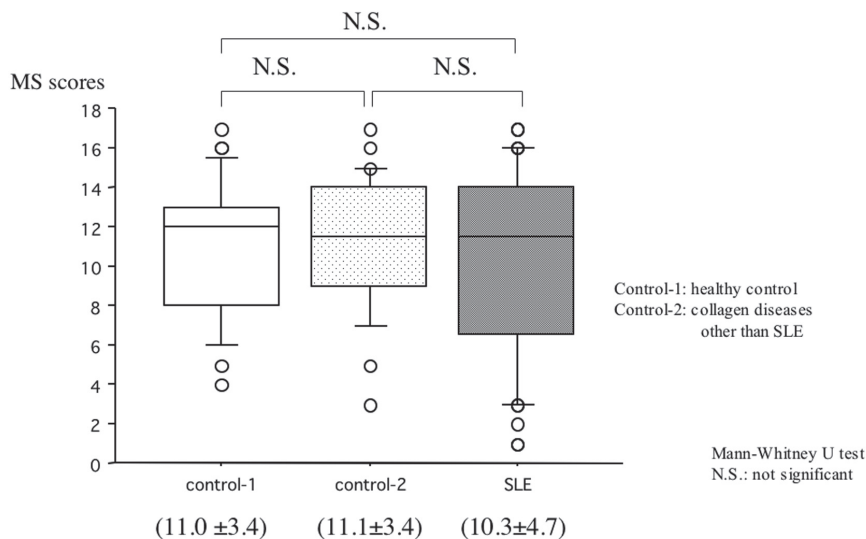
trol 1 group, whereas it was 11.1 ± 3.4 points in the Control 2 group and 10.3 ± 4.7 points in the SLE group (Fig. 3). There was no statistical difference between the 3 groups. There was no significant relation between the daily dose of steroid and SDS, and MS in the control 2 group and the SLE group. There was also no significant relation between age and SDS, and MS in the 3 groups.

FAI scores during the last 3 months in the Control 1 group and the Control 2 group were 2.5 ± 0.9 and 2.8 ± 0.6 points for preparation of meals and 2.5 ± 1.0 and 2.9 ± 0.3 points for washing dishes, and the scores were significantly lower in the Control 1 group than in the Control 2 group ($P < 0.05$). The scores for laundry in the Control 1 group, the Control 2 group and the SLE group were 2.4 ± 0.9, 2.9 ± 1.1 and 2.4 ± 1.1 points, and the scores were significantly higher in the Control 2 group than in the Control 1 group ($P = 0.001$) and the SLE group ($P < 0.05$). The scores for cleaning and tidying in the Control 1 group and the Control 2 group were 2.0 ± 0.8 and 2.3 ± 1.0 points, and the scores were significantly lower in the Control 1 group than in the Control 2 group ($P < 0.05$). The scores for shopping in the Control 2 group and the SLE group were 2.4 ± 0.8 and 2.1 ± 0.7 points, and the scores were significantly lower in the SLE group than in the Control 2 group ($P < 0.05$). The scores for going outdoors in the Control 1 group and the SLE group were 2.8 ± 0.7 and 2.2 ± 1.0 points, and the scores were significantly lower in the SLE group than in the Control 1 group ($P < 0.002$) (Fig. 4).

FAI scores during the last 6 months in the Control 1 group, the Control 2 group and the SLE group were 0.7 ± 0.5, 0.3 ± 0.5 and 0.2 ± 0.4 points for traveling and 2.5 ± 0.9, 0.9 ± 1.1 and 1.0 ± 1.2 points for working, and the scores were significantly higher in the Control 1 group than in the Control 2 group and in the SLE group (P < 0.001) (Fig. 5). In the other items, there was no statistical difference between the 3 groups.

2. Factors affecting life-style activities
In terms of the factors affecting the daily life-style activities of Control 1

MS scores

control-1   control-2   SLE

(11.0 ±3.4)   (11.1±3.4)   (10.3±4.7)

Fig. 3. Scores by MS were 11.0 ± 3.4 points in the Control 1 group, whereas it was 11.1 ± 3.4 points in the Control 2 group and 10.3 ± 4.7 points in the SLE group. There was no statistical difference between the 3 groups.
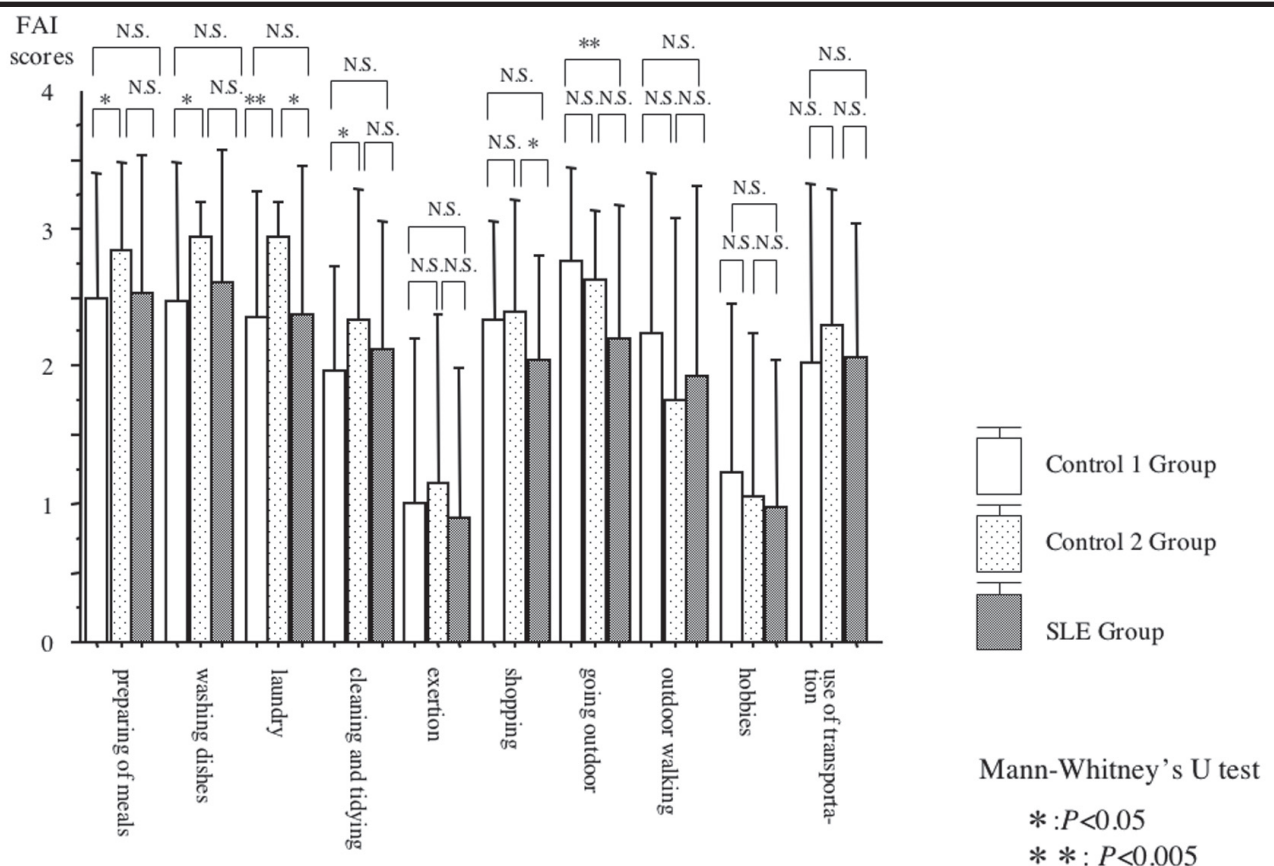
the steroid dose, MS and SDS had no correlation.

In terms of the factors affecting the daily life-style activities of SLE patients, age, the duration of the disease, and the steroid dose had no correlation, but MS had a positive correlation (r = 0.44, $P < 0.05$) and SDS had a negative correlation (r = -0.50, $P < 0.05$, Fig. 7). There was no significant relation between the daily dose of steroid and SDS, and MS in the Control 2 group and the SLE group.

Discussion

The FAI was developed for evaluating the higher level functions that stroke patients need in order to live in the community. In recent years, it has also been used for evaluating the life-style of community-dwelling elderly people. Wade *et al.* (12) reported that the FAI is an evaluation method for higher levels of independence, i.e., social survival,
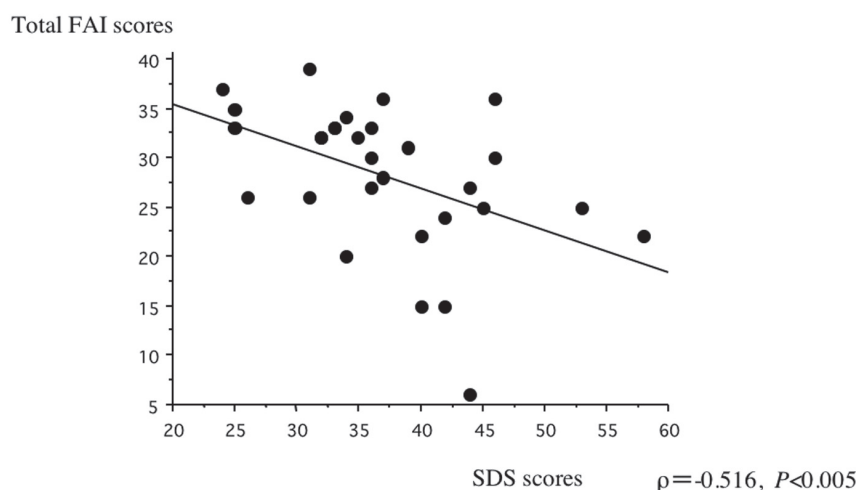
group, age had no correlation, but SDS had a negative correlation (r= -0.516, $P < 0.005$, Fig. 6).

In terms of the factors affecting the daily life-style activities of Control 2 group, age, the duration of the disease,

Fig. 4. The scores for preparation of meal and washing dishes were significantly higher in the Control 2 group than in the Control 1 group ($P < 0.05$). The scores for laundry were significantly higher in the Control 2 group than in the Control 1 group ($P = 0.001$) and the SLE group ($P < 0.05$). The scores for cleaning and were significantly lower in the Control 1 group than in the Control 2 group ($P < 0.05$). The scores for shopping were significantly lower in the SLE group than in the Control 2 group ($P < 0.05$). The scores for going outdoors were significantly lower in the SLE group than in the Control 1 group ($P < 0.002$).
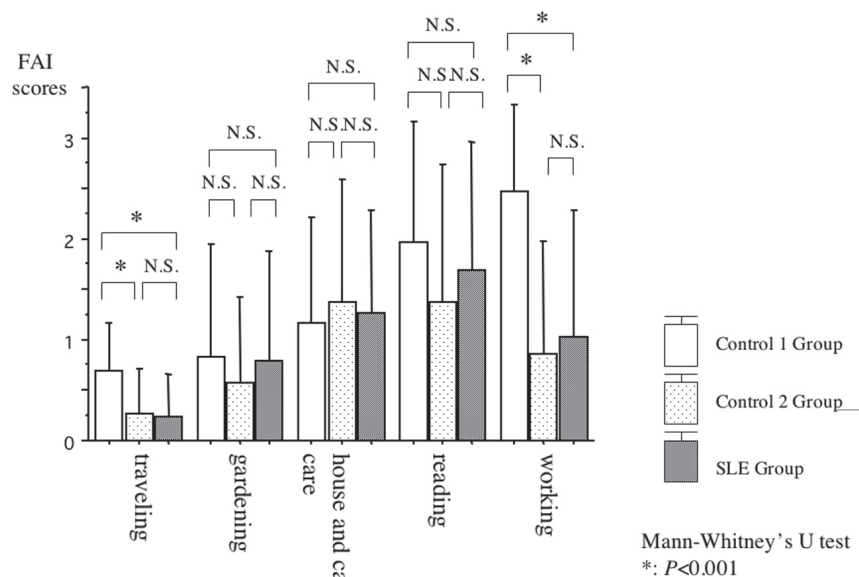
Fig. 5. The scores for traveling and working were significantly higher in the Control 1 group than in the Control 2 group and in the SLE group (P < 0.001).

Fig. 6. In terms of the factors affecting the daily life-style activities of the Control 1 group, age had no correlation, but SDS had a negative correlation (r = -0.516, *P* < 0.005).

rather than the basic activities of daily life (ADL). Most previous studies have used the Quality of Life Scale (6), the Medical Outcomes Study Short Form-36 (4), self-administered questionnaires (2), the SIP and the AIMS (7), to evaluate the QOL of patients with SLE, but no previous studies have used the FAI for this purpose. The FAI provide a more detailed evaluation of the social aspect of the activities of daily life than these other methods, so it is useful in evaluating the QOL of patients with SLE, who participate in community life. For this reason, we used the FAI to evaluate the QOL of patients with SLE and the patients with other autoimmune

diseases. While the questions regarding the last 3 months focused on domestic life, the questions regarding the last 6 months concentrated more on social activities.

The comparison between the SLE group and the Control 1 group revealed that the SLE group had significantly lower scores in the items of "going outdoors" which are among the items relating to the patient's condition over the previous 3 months. The comparison between the SLE group and the Control 2 group revealed that the SLE group had significantly lower scores in the items of "laundry" and "shopping," which are among the items relating to

the patient's condition over the previous 3 months. It has been shown that ultraviolet light plays a role in the development and deterioration of SLE and in the occurrence of skin symptoms such as butterfly rash (17, 18). Our results suggest that patients self-restrict their daily activities, such as "going outdoors," "laundry" and "shopping," which require them to go out in the daytime, therefore exposing them to ultraviolet light. The Japanese usually dry the laundry outdoors during morning than they use a clothes drier or dry cleaner. An additional reason for the SLE group scoring low in "laundry" is that cold exposure may cause Raynaud's phenomenon.

The comparison between the Control 1 group and the Control 2 group revealed that the Control 2 group had significantly higher scores in the items of "preparation of meals," "washing dishes," "laundry" and "cleaning and tidying." This result shows the domestic life of the patients with autoimmune diseases other than SLE is active.

The items "traveling" and "working" which are indices of social activities. The comparison between the 3 groups revealed that the Control 2 group and the SLE group had significantly lower scores in the items of "traveling" and "working." This result shows the social life of the patients with autoimmune diseases is inactive.

An SDS score of 40 or more is associated with a high tendency towards depression. The SLE group and the Control 2 group had high SDS scores, and there were no significant between-group differences. In addition, there were no significant between-group differences in the results of the MS. Therefore, these results suggest that the common factor that all the patients had autoimmune diseases affected the SDS and the MS scores.

The evaluation of factors that affect the life-style activities of patients with SLE revealed that there were no significant correlations between the FAI and each of age, disease duration, disease activity and daily steroid dose. However, there was a negative correlation between the FAI and the SDS and a positive correlation between the FAI

FAI scores / MS scores
$\rho=0.44$, p<0.001

FAI scores / SDS scores
$\rho=-0.50$, P<0.001
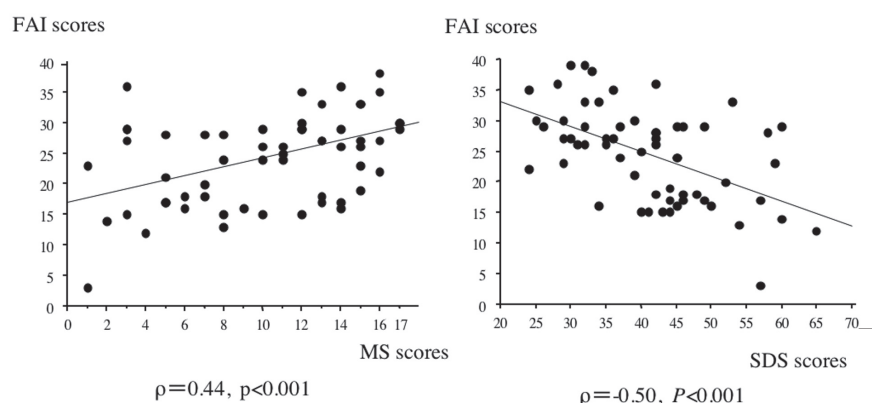
Fig. 7. In terms of the factors affecting the daily life-style activities of SLE patients, age, the duration of the disease, and the steroid dose had no correlation, but MS had a positive correlation ($r = 0.44$, $P < 0.05$) and SDS had a negative correlation ($r = -0.50$, $P < 0.05$).

and the MS, showing that depression is the negative factor that has the effect on the life-style activities of patients with SLE.

The report by Abu-Shakra *et al*. (5) is the only report on the relations between SLE activity and QOL. They used the QOLS to evaluate the QOL of patients with SLE and used the SLEDAI as an indicator of disease activity. They concluded that there was no correlation between the QOLS and the SLEDAI. Similarly, in our study, no correlation was observed between disease activity and life-style activities. The reasons for this may be that all the study subjects were outpatients in whom diseases were well-controlled and disease activity was not very high.

In the patients with SLE, not only the social life but also the domestic life were inactive, and the life style activities were low generally. We consider that in order for patients with SLE to live normally in the community, it is important to evaluate and improve the social aspects of their daily QOL. Because there was a significant relation between life-style activities and subjective well-being, and depression in SLE, it was suggested, in addition to detecting damage to various organs such as the bones, joints, central nervous system and kidneys, detection and treatment of mental status such as depression play an important role in improving the life-style activities of patients with SLE.

References

1. GLADMAN DD, HOCHBERG MC: Epidemiology of systemic lupus erythematosus. *In* LAHITA RG (Ed.): *Systemic Lupus Erythematosus*, 3rd ed. San Diego, Academic Press, 1999: 537-50.
2. GROOTSCHOLTEN C, LIGTENBERG G, DERKSEN RH *et al.:* Health-related quality of life in patients with systemic lupus erythematosus: development and validation of a lupus specific symptom checklist. *Qual life Res* 2003; 12: 635-44.
3. SHAH M, KAVANAUGH A, COYLE Y, ADAMS-HUET B, LIPSKY PE: Effect of a culturally sensitive cholesterol lowering diet program on lipid and lipoproteins, body weight, nutrient intakes, and quality of life in patients with systemic lupus erythematosus. *J Rheumatol* 2002; 29: 2112-8.
4. THUMBOO J, FONG KY, CHAN SP, LEONG KH, FENG PH, THIO ST: A prospective study of factors affecting quality of life in systemic lupus erythematosus. *J Rheumatol* 2000; 27: 1414-20.
5. PEREZ-CUEVAS JB, FORMIGA F, GARCIA-CARRASCO M, RAMOS M, LARA C, ROJAS-RODRIGUEZ J: A quality of life study in women with systemic lupus erythematosus and its relation to disease activity. *An Med Interna* 1999; 16: 457-60.
6. ABU-SHAKRA M, MADER R, LANGEVITZ P *et al.*: Quality of life in systemic lupus erythematosus: a controlled study. *J Rheumatol* 1999; 26: 306-9.
7. LASH AA: Quality of life in systemic lupus erythematosus. *Appl Nurs Res* 1998; 11: 130-7.
8. MAESHIMA E, YAMADA Y, MUNE M, YUKAWA S: Subjective happiness and psychological condition in SLE. *Ryumachi* 1996; 36: 830-6.
9. LAM GKW, PETRI M: Assessment of systemic lupus erythematosus. *Clin Exp Rheumatol* 2005; 23 (Suppl. 39): S120-32.
10. TAN EM, COHEN AS, FRIES JF *et al.*: The 1982 revised criteria for the classification of systemic lupus erythematosus. *Arthritis Rheum* 1982; 25: 1271-7.
11. HOLBOOK M, SKILBECK CE: An activities index for use with stroke patients. *Age and Aging* 1983; 12: 166-70.
12. WADE DT, LEIGH-SMITH J, HEWER BL: Social activities after stroke: measurement and natural history using the Frenchay Activities Index. *Int Rehabil Med* 1985; 7; 176-81.
13. ZUNG WWK: A self-rating depression scale. *Arch Gen Psychiatry* 1965; 12: 63-70.
14. LAWTON MP: The Philadelphia Geriatric Center morale scale: a *revision. J Gerontology* 1975; 30: 85-9.
15. BOMBARDIER C, GLADMAN DD, UROWITZ MB, CARON D, CHANG CH: Derivation of the SLEDAI. *Arthritis Rheum* 1992; 35: 630-40.
16. GLADMAN D, GINZLER E, GOLDSMITH C *et al.*: The development and initial validation of the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index for systemic lupus erythematosus. *Arthritis Rheum* 1996; 39: 363-9.
17. MONGY AB, HESS EV: The role of environment in systemic lupus erythematosus and associated disorders. *In*: WALLACE DJ and HAHN BH (Eds). *Dubois' Lupus Erythematosus*, 5th ed. Baltimore, MD: Williams & Wilkins Press, 1977; pp 31-47
18. MAESHIMA E, LIANG XM, OTANI H, MUNE M, YUKAWA S: Effect of environmental change on oxidative deoxyribonucleic acid (DNA) damage in systemic lupus erythematosus. *Arch Environ Health* 2002; 57: 425-8.