

High Prevalence of Unemployment in Patients with Systemic Lupus Erythematosus: Association with Organ Damage and Health-Related Quality of Life

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ABSTRACT. *Objective.* To evaluate employment status in relation to organ damage, demographic factors, and health-related quality of life (HRQOL) in patients with systemic lupus erythematosus (SLE).

Methods. One hundred forty-seven patients with SLE, aged 18 to 64 years, were included. Examination of self-reported HRQOL was performed using the Medical Outcome Study Short Form-36 (SF-36). Demographic factors, disease characteristics, and HRQOL were compared between patients with and without paid employment using nonparametric tests.

Results. In 147 patients with SLE (mean age 38.4 ± 11 yrs, mean disease duration 6.3 ± 6.5 yrs), we found a high rate of unemployment (59%), whereas 93% of patients had previously worked. In patients who had stopped or reduced working, 75% attributed their withdrawal from work at least in part to disease-related factors. Unemployed patients had a significantly higher median age at disease onset, a higher frequency of neuropsychiatric organ damage and diabetes mellitus, and lower HRQOL than employed patients.

Conclusion. We found a high rate of unemployment (59%) in patients with SLE. Higher age at disease onset, neuropsychiatric organ damage, diabetes mellitus, and reduced HRQOL were associated with unemployment in patients with SLE. Our findings highlight the need to develop strategies to reduce work loss in patients with SLE, for both individual and socioeconomic reasons. (First Release Mar 15 2008; J Rheumatol 2008;35:1053–7)

Key Indexing Terms:

SYSTEMIC LUPUS ERYTHEMATOSUS
ORGAN DAMAGE

WORKING STATUS
QUALITY OF LIFE

Systemic lupus erythematosus (SLE) is a chronic disease, often characterized by multisystem involvement, cognitive impairment^{1,2}, and fatigue, predominantly affecting young and middle-aged women. Many patients with SLE experience functional limitations and a reduced quality of life^{3–7}, and this may lead to loss of employment. Withdrawal from the workforce may lead to lowered self-esteem, reduced income, and social isolation. Moreover, work loss has been recognized as the most important factor for disease-related costs in patients with rheumatic diseases⁸.

In 2 early studies^{9,10}, normal employment rates were reported in patients with SLE. However, a high rate of unemployment in patients with lupus has been demonstrated in more recent studies, reporting complete withdrawal from

work in 19%–52% of patients within 12 years of disease onset^{2,5,11–16}. Demographic, socioeconomic, and disease-related factors have been investigated in relationship to working status in patients with SLE, with somewhat conflicting results^{2,11,13–16}. The majority of the studies on working status in patients with SLE in the USA^{2,11,14,16} were performed in predominantly non-Caucasian patients^{2,11,14}. The results of these studies may not be generalized to lupus cohorts with a significantly different racial and socioeconomic background. In contrast to the primarily private healthcare system in the USA, most Western European countries have a primarily publicly funded healthcare system, implying equal access to healthcare for all patients, irrespective of income. Studies on working status have been performed in European patients with SLE^{5,10,13,15}. However, 3 of these studies^{5,10,15} comprised patients beyond working age, and the fourth¹³ did not examine working status in relation to disease characteristics and health-related quality of life (HRQOL).

We evaluated working status in patients with SLE of working age, and assessed the relationship between demographic factors, disease characteristics, and HRQOL and working status in this group.

MATERIALS AND METHODS

Patients. One hundred forty-seven consecutive patients, aged 18 to 64 years,

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Accepted for publication November 29, 2007.

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who fulfilled American College of Rheumatology (ACR) revised criteria for the classification for SLE¹⁷ were included in the study. All patients regularly attended the outpatient rheumatology clinic of the VU University Medical Center, the Slotervaart Hospital, or the Jan van Breemen Institute, Amsterdam. These institutions provide primary, secondary, and tertiary care for patients with SLE. All patients provided informed consent for their participation. The local ethics committee approved the study.

Data collection and clinical measures. Data collection was performed between August 2001 and September 2005 and comprised chart review, questionnaires completed by the patient, and a structured interview and clinical examination by 2 rheumatologists (IEMB, FT). Data collected at the time of study inclusion were age, race, body mass index, tobacco intake, exercise status, age at diagnosis of SLE, disease duration, working status in the past (never or ever had paid employment), current working status (having paid employment or not), loss of work or reduction of the number of hours working weekly, and self-reported reason for withdrawal from work or reduction of the number of hours working weekly (SLE itself, other reasons only, both SLE and other reasons). Exercise was defined by a minimum of 3 × 40 minutes of aerobic exercise weekly. Patients were asked to fill in a validated Dutch translation¹⁸ of the Medical Outcome Study Short Form-36 (SF-36) health questionnaire¹⁹. The SF-36 is an instrument measuring HRQOL, organized into 8 multi-item scales covering the dimensions physical functioning, physical role functioning, social functioning, emotional role functioning, mental health, vitality, bodily pain, and general health. An additional item pertains to health change. The scales may vary from 0 to 100, higher scores indicating better health status. In addition, a visual analog scale (VAS) for patient's global assessment of general well-being over the past 4 weeks (0–10; higher values indicating better well-being) and a VAS for doctor's global assessment of disease activity over the past 4 weeks (0–10; higher values indicating more disease activity) were completed. Disease activity at study inclusion was scored using the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI)²⁰ and the European Consensus Lupus Activity Measure (ECLAM)²¹. Accumulated organ damage was assessed with the Systemic Lupus International Collaborating Clinics (SLICC)/ACR damage index (DI)²².

Statistical analysis. Subjects were stratified into 2 groups based on self-reported current working status (performing paid work or not). Demographic factors, clinical characteristics, and the domains of the SF-36 in patients with SLE with and without current paid employment were compared using the nonparametric Mann-Whitney test. A 2-sided p value ≤ 0.05 was considered statistically significant. The software used was the Statistical Package for the Social Sciences for Windows, version 13.0 (SPSS Inc., Chicago, IL, USA).

RESULTS

Demographic and clinical features. Among 147 patients included, 136 (93%) were female. The majority of patients were Caucasian (68%). The ethnic backgrounds of the remaining 32% of patients were Asiatic (9%), Black African (9%), Mediterranean (5%), and other (9%). The mean (\pm SD) age at study entry was 38.4 ± 10.9 years and the mean disease duration was 6.3 ± 6.5 years, with a median disease duration of 4.0 years (range 0–25 yrs). Organ damage was observed in 76 patients (52%), as evidenced by a DI score greater than zero. The mean (\pm SD) DI score was 1.2 ± 1.7 . Organ damage had occurred most frequently in the renal system (31 patients; 21%), the musculoskeletal system (24 patients; 16%), and the neuropsychiatric system (21 patients; 14%).

Self-reported working status. The majority of the 147 patients reported previous paid employment (137 patients; 93%). At the time of inclusion, however, 86 of the 147 patients (59%; 95% CI 51%–67%) reported themselves as being without paid

employment. Gender-specific unemployment rates were 59% (81/137 patients) in female patients and 45% (5/11) in male patients. In the subgroup of 61 (41%) patients currently working, 18 patients had fulltime employment whereas 43 patients were working part-time.

Reasons for withdrawal from paid work. We found 118 patients (80%) had stopped working or had reduced the number of hours working weekly. The reasons reported for this decision were: SLE itself as the only reason in 65 patients (55%), other reasons only in 29 patients (25%), and both SLE and other reasons in 24 patients (20%). Thus, 75% of all patients attributed their withdrawal from paid work or reduction of the number of working hours at least in part to SLE.

In the subgroup of 86 patients who were unemployed at the time of inclusion, 7/86 (8%) reported no paid employment in the past. The reasons for stopping work reported by the remaining 79 unemployed patients who had performed paid work in the past were: SLE itself as the only reason in 47 patients (59%), other reasons only in 16 patients (20%), and both SLE and other reasons in 16 patients (20%).

Of the 137 patients with previous paid employment, 39 (28%) had reduced the number of hours working weekly. The reasons reported for this decision were: SLE itself as the only reason in 18 patients (46%), other reasons only in 13 patients (33%), and both SLE and other reasons in 8 patients (20%).

Demographic and clinical variables according to working status. As shown in Table 1, patients without paid employment had a significantly higher median age at disease onset than working patients. Further, the median patient's global assessment of well-being was significantly lower in unemployed patients. Overall, the total organ damage index tended to be higher for unemployed patients relative to patients with paid employment ($p = 0.057$). With respect to subitems of the organ damage index, neuropsychiatric organ involvement, premature gonadal failure, and diabetes mellitus were significantly more frequent in unemployed patients.

HRQOL according to working status. HRQOL characteristics in the subgroups of patients with SLE with and without paid employment are shown in Table 2. The patients without paid employment had a significantly lower HRQOL, as ascertained by the SF-36 summary measures for physical and social functioning, mental health, pain, vitality, general health perception, and role limitations due to physical and to emotional problems. Health change was not significantly different between patients with and those without paid employment.

DISCUSSION

The main finding from our study is the high frequency of unemployment in a large group of Dutch patients with SLE, despite mild organ damage and access to primarily publicly funded healthcare and education systems. Dropout from work was, in 75% of cases, at least partially attributed to disease-related factors. In addition, we observed a significant associa-

Table 1. Demographic and clinical variables in 147 patients with SLE according to working status. Except where indicated otherwise, values are the median (range).

Variable	Working, n = 61	Not Working, n = 86	p
Demographic			
Female, %	90	94	NS
Caucasian, %	72	65	NS
Age at study entry, yrs	35.0 (21–63)	39.0 (18–64)	0.004
Body mass index, kg/m ²	23.3 (17.6–35.4)	23.9 (15.4–50)	NS
Current smoker, %	21	23	NS
Exercise ≥ 3 times weekly, %	21	30	NS
Clinical variables			
Age at disease onset, yrs	26.0 (11–51)	34.5 (11–64)	0.003
Disease duration, yrs	4.0 (0–24)	4.25 (0–25)	NS
Patient assessment of general well-being (0–10 cm VAS)	7.0 (1–10)	5.0 (0–10)	< 0.001
Physician global assessment of disease activity (0–10 cm VAS)	3.0 (0–7)	2.0 (0–8)	NS
SLEDAI score	4.0 (0–15)	4.0 (0–20)	NS
ECLAM score	2.5 (0–8)	2.5 (0–10)	NS
SLICC/ACR damage index total score	0.0 (0–6)	1.0 (0–9)	0.057
SLICC/ACR damage index total score ≥ 1, %	44	57	NS
Ocular damage, %	10	9	NS
Neuropsychiatric damage, %	2	23	< 0.001
Renal damage, %	18	23	NS
Pulmonary damage, %	5	8	NS
Cardiovascular damage, %	7	6	NS
Peripheral vascular damage, %	2	5	NS
Gastrointestinal damage, %	0	2	NS
Musculoskeletal damage, %	13	19	NS
Skin damage, %	3	7	NS
Premature gonadal failure, %	2	12	0.024
Diabetes mellitus, %	0	7	0.036
Malignancy, %	3	6	NS

VAS: visual analog scale; SLEDAI: Systemic Lupus Erythematosus Disease Activity Index (range 0–105); ECLAM: European Consensus Lupus Activity Measurement (range 0–10); SLICC/ACR: Systemic Lupus International Collaborating Clinics/American College of Rheumatology; NS: not significant.

Table 2. Health-related quality of life in patients with SLE according to working status. Values are median (range).

Short Form-36 Domains	Working, n = 61	Not Working, n = 86	p
Physical function	85.0 (0–100)	55.0 (0–100)	< 0.0001
Social function	75.0 (25–100)	62.5 (0–100)	< 0.0001
Role function physical	75.0 (0–100)	0.0 (0–100)	< 0.0001
Role function emotional	100.0 (0–100)	66.6 (0–100)	0.001
Mental health	76.0 (24–100)	68.0 (8–100)	0.002
Vitality	60.0 (5–90)	37.5 (5–100)	< 0.0001
Pain	67.3 (10–100)	55.1 (0–100)	< 0.0001
General health	50.0 (5–90)	30.0 (5–100)	< 0.0001
Health change	50.0 (0–100)	50.0 (0–100)	NS

NS: not significant.

tion among unemployment and demographic factors, disease-related characteristics, and a reduced quality of life.

The percentage of patients with SLE reporting unemployment at the time of the study was 59%, and this frequency is much higher than the 36% unemployment rate (26% in men, 46% in women) in the general Dutch population aged 15 to 64

years²³. The rate of unemployment found in our population of patients with SLE (59%; 95% CI 51%–67%) was in the upper range of frequencies reported in previous studies in patients with SLE (19%–52%)^{2,5,11–16}. This finding might be explained in part by differences in inclusion criteria between studies. Our study included all patients with SLE of working age, irrespective of working status at disease onset, while some other studies excluded patients who were not working at the time of diagnosis^{11,14}. Another explanation for the higher rate of unemployment in our study population might be the availability of publicly funded work disability and unemployment pensions in The Netherlands. In general, disability payments are higher in European countries than in Canada and the United States, and these payments are relatively easily accessible in The Netherlands²⁴. Unemployed patients might experience less necessity to return to work because of the higher compensation for loss of income. This hypothesis is in agreement with results of studies in patients with rheumatoid arthritis, demonstrating higher work disability rates in European countries than in the United States²⁴.

Patients with SLE without paid employment had signifi-

cantly more frequent neuropsychiatric organ damage than employed patients. This finding is consistent with a recent study demonstrating a strong association between neurocognitive impairment and formal work disability in patients with SLE². As a consequence of the high frequency of neurocognitive impairment reported in 20%–55% of patients with SLE^{1,2}, this is a matter of concern. A longitudinal study is needed to determine whether neuropsychiatric organ damage and neurocognitive dysfunction are predictors of work loss in patients with SLE.

In contrast to the study of Bertoli, *et al*¹¹, diabetes mellitus was more frequent in unemployed patients with SLE than in employed patients in our study. However, this finding has to be interpreted cautiously because of the small number of patients with diabetes mellitus in our study population.

Surprisingly, premature menopause had occurred more frequently in unemployed patients than in patients with paid employment in our study. This cannot be explained by more frequent use of cyclophosphamide in the subgroup of unemployed patients, since the frequency of cyclophosphamide use in the past for severe disease complications was not statistically significantly different between the subgroups of lupus patients with and without paid employment (data not shown).

The association between higher age at study inclusion and unemployment in our study is fairly consistent with previous findings in patients with SLE^{11,16}. In addition, our study demonstrated a significant association between higher age at disease onset and unemployment. As far as we know, this factor has not been investigated in previous studies in SLE. A limited ability to change working situation in case of disease onset in older patients might be an explanation for this finding.

Several studies^{3,4,6,7} have described a reduced quality of life in patients with SLE in comparison to the general population. In our study, the subgroup of patients with SLE without paid employment had a significantly decreased quality of life, as shown by significantly lower scores in almost all subdomains of the SF-36 and a lower patient general well-being score, compared to those patients who performed paid work. This finding is in agreement with a recent study demonstrating a reduced quality of life in SLE patients with work disability when compared to nondisabled patients². These results suggest an association between work loss and a reduction of general well-being in SLE patients, which should be investigated further in longitudinal studies.

Median disease activity scores were not significantly different between working and nonworking patients at the time of study. However, this does not rule out that disease activity influenced the decision to stop work or reduce the number of working hours in the past.

The generalizability of the results of studies on risk factors for work loss in SLE is restricted by differences in socioeconomic backgrounds and healthcare systems between countries, and by differences in ethnic background and disease

characteristics between study populations. The limitations of our study are the lack of assessment of education level and work-related factors, and the lack of information on working status at the time of disease onset and formal work disability in patients reporting unemployment. A longitudinal study on working status in relationship to demographic factors, disease characteristics, including assessment of cumulative disease activity, and HRQOL in patients with SLE is needed to identify modifiable risk factors for work loss in this patient group.

We found a high rate of unemployment in a group of lupus patients with limited organ damage. The majority of patients reported SLE itself as the only reason for withdrawal from paid work. Unemployed patients with SLE were characterized by a reduced health-related quality of life, higher age, higher age at disease onset, and a higher frequency of neuropsychiatric organ damage and possibly of diabetes mellitus. As a consequence of the high prevalence of unemployment in patients with SLE and the associated impaired quality of life and high disease-related costs, the development of strategies to reduce work loss in patients with SLE is necessary, both for individual and for socioeconomic reasons.

REFERENCES

1. Hay EM, Black D, Huddy A, et al. Psychiatric disorder and cognitive impairment in systemic lupus erythematosus. *Arthritis Rheum* 1992;35:411-6.
2. Utset TO, Fink J, Doninger NA. Prevalence of neurocognitive dysfunction and other clinical manifestations in disabled patients with systemic lupus erythematosus. *J Rheumatol* 2006;33:531-8.
3. Alarcon GS, McGwin G Jr, Uribe A, et al. Systemic lupus erythematosus in a multiethnic lupus cohort (LUMINA). XVII. Predictors of self-reported health-related quality of life early in the disease course. *Arthritis Rheum* 2004;51:465-74.
4. Archenholtz B, Burckhardt CS, Segesten K. Quality of life of women with systemic lupus erythematosus or rheumatoid arthritis: domains of importance and dissatisfaction. *Qual Life Res* 1999;8:411-6.
5. Boomsma MM, Bijl M, Stegeman CA, Kallenberg CG, Hoffman GS, Tervaert JW. Patients' perceptions of the effects of systemic lupus erythematosus on health, function, income, and interpersonal relationships: a comparison with Wegener's granulomatosis. *Arthritis Rheum* 2002;47:196-201.
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. Doria A, Rinaldi S, Ermani M, et al. Health-related quality of life in Italian patients with systemic lupus erythematosus. II. Role of clinical, immunological and psychological determinants. *Rheumatology Oxford* 2004;43:1580-6.
8. Yelin E, Cisternas MG, Pasta DJ, Trupin L, Murphy L, Helmick CG. Medical care expenditures and earnings losses of persons with arthritis and other rheumatic conditions in the United States in 1997: total and incremental estimates. *Arthritis Rheum* 2004;50:2317-26.
9. Stein H, Walters K, Dillon A, Schulzer M. Systemic lupus erythematosus — a medical and social profile. *J Rheumatol* 1986;13:570-6.
10. Sturfelt G, Nived O. Clinical inconsistency, benign course and normal employment rates in unselected systemic lupus erythematosus. *Clin Exp Rheumatol* 1985;3:303-10.

11. Bertoli AM, Fernandez M, Alarcon GS, Vila LM, Reveille JD. Systemic lupus erythematosus in a multiethnic US cohort (LUMINA). XLI. Factors predictive of self-reported work disability. *Ann Rheum Dis* 2007;66:12-7.
12. Clarke AE, Penrod J, St. Pierre Y, et al. Underestimating the value of women: assessing the indirect costs of women with systemic lupus erythematosus. Tri-Nation Study Group. *J Rheumatol* 2000;27:2597-604.
13. Mau W, Listing J, Huscher D, Zeidler H, Zink A. Employment across chronic inflammatory rheumatic diseases and comparison with the general population. *J Rheumatol* 2005;32:721-8.
14. Partridge AJ, Karlson EW, Daltroy LH, et al. Risk factors for early work disability in systemic lupus erythematosus: results from a multicenter study. *Arthritis Rheum* 1997;40:2199-206.
15. Sutcliffe N, Clarke AE, Gordon C, Farewell V, Isenberg DA. The association of socio-economic status, race, psychosocial factors and outcome in patients with systemic lupus erythematosus. *Rheumatology Oxford* 1999;38:1130-7.
16. Yelin E, Trupin L, Katz P, et al. Work dynamics among persons with systemic lupus erythematosus. *Arthritis Rheum* 2007;57:56-63.
17. Hochberg MC. Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythematosus [letter]. *Arthritis Rheum* 1997;40:1725.
18. Aaronson NK, Muller M, Cohen PD, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *J Clin Epidemiol* 1998;51:1055-68.
19. Ware JE Jr, Gandek B. Methods for testing data quality, scaling assumptions, and reliability: the IQOLA Project approach. International Quality of Life Assessment. *J Clin Epidemiol* 1998;51:945-52.
20. Bombardier C, Gladman DD, Urowitz MB, Caron D, Chang CH. Derivation of the SLEDAI. A disease activity index for lupus patients. The Committee on Prognosis Studies in SLE. *Arthritis Rheum* 1992;35:630-40.
21. Vitali C, Bencivelli W, Isenberg DA, et al. Disease activity in systemic lupus erythematosus: report of the Consensus Study Group of the European Workshop for Rheumatology Research. II. Identification of the variables indicative of disease activity and their use in the development of an activity score. The European Consensus Study Group for Disease Activity in SLE. *Clin Exp Rheumatol* 1992;10:541-7.
22. 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.
23. Dutch Bureau for Statistics. Voorburg, The Netherlands; 2003. Internet. Available from: <http://www.cbs.nl/>. Accessed January 25, 2008.
24. Verstappen SM, Bijlsma JW, Verkleij H, et al. Overview of work disability in rheumatoid arthritis patients as observed in cross-sectional and longitudinal surveys. *Arthritis Rheum* 2004; 51:488-97.