The Impact of Systemic Lupus Erythematosus on Employment

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ABSTRACT. ***Objective***. Our primary objective was to examine work status (e.g., job loss, changes in amount worked) and predictors of job loss in patients with systemic lupus erythematosus (SLE).

Methods. Recently diagnosed SLE patients were enrolled in the Carolina Lupus Study between 1997 and 1999; an age-, sex-, and state-matched control group selected through driver's license registries for the 60-county study area was also enrolled. In 2001, a followup study of both groups was conducted (median 4 yrs since diagnosis). Work history data were obtained in an in-person interview at enrollment and a telephone interview at followup.

Results. Fifty-one patients (26%) and 26 controls (9%) ($p < 0.0001$) who were working the year before diagnosis (or for controls, a corresponding reference year) were no longer working at followup; 92% of patients compared with 40% of controls who were no longer working indicated that they had stopped working because of their health ($p < 0.0001$). College graduates were less likely to quit their jobs due to health compared to non-college graduates (adjusted OR = 0.27, 95% CI 0.09, 0.84). SLE patients with arthritis were 3 times more likely to have left their jobs due to health reasons compared to those who didn't have arthritis (adjusted OR = 3.3, 95% CI 1.2, 8.8); an association was also seen with pleuritis (adjusted OR 2.3, 95% CI 1.1, 4.6).

Conclusion. The burden expressed as work cessation due to health, especially among lesser educated patients and those with arthritis or pleuritis, is significant even early in the disease process. (First Release Oct 1 2009; J Rheumatol 2009;36:2470–5; doi:10.3899/jrheum.080586)

Key Indexing Terms:
JOB LOSS LOST WAGES SYSTEMIC LUPUS ERYTHEMATOSUS
CAROLINA LUPUS STUDY ARTHRITIS PLEURITIS

There have been many large prospective and cross-sectional studies and several recent reviews of work loss and disability among patients with rheumatoid arthritis. Work disability or changes in work status are associated with older age, lower education levels, manual or blue collar jobs, and disease activity or flares, with less consistent findings seen with respect to sex, marital status, and race[1-5].

Because systemic lupus erythematosus (SLE) generally occurs at a younger age than rheumatoid arthritis, the relative impact on employment may be even greater, but limited data regarding employment status and factors predictive of self-reported work loss among patients with SLE are available. Early work loss and disability were reported in a sample of 159 SLE patients drawn from a multicenter study by Partridge, *et al*[6]. These patients were employed at the time of study enrollment, but after a mean followup time of 3.4 years, 40% of the patients were no longer working, and job modification was extensive. In a recent labor force study of German patients of chronic inflammatory rheumatic diseases, overall SLE employment rates were significantly lower than employment rates in the general population (standardized employment ratios = 0.86) and were one of the lowest rates among rheumatic diseases studied[7]. In a 1993 prospective study of cost components, indirect costs (defined as income losses) were responsible for 54% of total costs[8].

The purpose of our study was to estimate the prevalence of illness-related job loss, absenteeism, and amount worked in patients with SLE early in the course of disease, compare these estimates to a control group drawn from the study area, and examine demographic and clinical predictors of job loss among SLE patients.

MATERIALS AND METHODS

Study population and data collection. The Carolina Lupus Study (CLU) is a community-based case-control study of SLE based in North Carolina and South Carolina. The recruitment and data collection methods have been described[9]. In brief, patients were recruited from community-based

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Dr. Campbell's work was supported by the NIH National Research Service Award (grants 1T32-AR050958 and P60-AR049459). Dr. Cooper's work was supported by the Intramural Research Program of the National Institute of Environmental Health Sciences. Dr. Gilkeson's work was supported by the NIH (grants 2R01-AR045476 and P60-AR049459).

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Accepted for publication June 15, 2009.

rheumatologists and university-based rheumatology practices in 60 contiguous counties in the eastern and Piedmont areas of the states, with about 50% coming from each source. Lupus diagnosis was based on the revised American College of Rheumatology classification criteria[10,11], with diagnosis between January 1, 1995 and July 31, 1999. Only patients who were at least 18 years old at study enrollment were eligible. The median time from diagnosis to enrollment in the study was 13 months, and 75% were interviewed within 1.7 years of diagnosis. Controls were identified through driver's license records and frequency matched to patients by age, sex, and state. Ethnicity was not included as a matching variable, but was included as a potential confounding variable in the analysis[12]. In total, 265 patients and 355 controls were enrolled in the study. The study protocol was approved by the review boards at all participating institutions.

The 2001 followup interview obtained information from 198 patients and 299 controls via a 45-minute and 15-minute telephone interview, respectively. There was little difference between the groups in participation rate (82% of patients who were alive participated compared with 84% of controls) or loss to followup (9% and 10% in patients and controls, respectively). The median time from diagnosis (reference year) to the followup interview was 4 years (range 2–6). Control interviews were significantly shorter because several sections specific to the clinical course of SLE did not apply, and because more limited information was collected in other sections.

Outcome measures: work status, amount of work, health-related absences, and reasons for job cessation. Our study includes employment information originally assessed at the baseline assessment/enrollment (1997–1999) and work status information at followup assessment conducted in 2001. In the baseline study, data were collected using a structured 60-min, in-person interview. Demographic information (date of birth, education level, ethnicity) was obtained at this time. The baseline questionnaire also included a job history for all jobs held at least 12 months from age 16 to the time of the baseline interview, including part-time and seasonal work. Information was collected on job titles, main activities or job duties, hours worked per week and months per year. This information was used to define the job held during the year preceding diagnosis year for patients and a corresponding reference year for controls; this information was used in the analysis of potential lost wages among participants with a health-related job loss at the time of the followup study.

The work history portion of the followup interviews included questions on work status (worked for pay ≥ 10 hours per week) during the year before diagnosis/reference year and during the year before followup interview. With an illness such as SLE that may have a prolonged course before a diagnosis is made, we wanted to reduce the potential for misclassifying pre-disease work status and so we chose the year before diagnosis, rather than the time of diagnosis, as the baseline period. For the comparison period, we used the year before the followup interview rather than the time of the followup interview, to standardize the period being asked about and to reduce the impact of seasonal variation in employment. These work status questions were used to classify participants into 4 groups: (1) Worked in the year before diagnosis/reference year and worked in the year preceding followup; (2) Did not work in the year before diagnosis/reference year, but did work in the year preceding followup; (3) Worked in the year before diagnosis/reference year, but did not work in the year preceding followup; and (4) Worked in neither time period.

Groups 1 and 2 were asked additional questions about months worked last year, hours worked per week last year, and time missed from work last year "because of your health," with responses given in either days, weeks, or months. Group 1 was also asked about health related work absence for a more extended period with a closed-ended question, "Since (the year before diagnosis/reference year), have you been unable to work for more than 2 months at one time because of your health?", with response categories of yes, no, and don't know. Group 3 (those who were no longer working) were asked to indicate the reason they were no longer working through a series of structured questions. The opening statement was "I am going to read some reasons why people stop working. Please tell me if any are true for you. Did you stop working because…" with 5 specified reasons ("You did not like your job, supervisor, or coworkers," "Your job ended or you were laid off," "You no longer needed to work," "You retired for reasons other than your health," and "of your health"). Participants could respond "yes" to more than one of these choices. We used an affirmative response to the "…because of your health" statement to define health-related job cessation.

Clinical covariates. Data on clinical features of SLE were collected through medical record review. We used the definitions of specific features from the 1982 (revised 1997) American College of Rheumatology SLE criteria[10,11] to classify the presence of specific features. We abstracted data pertaining to presence of malar rash, discoid rash, photosensitivity, oral or nasal ulcers, arthritis, pericarditis, pleuritis, seizures and psychosis, proteinuria, hemolytic anemia, leukopenia, lymphopenia, and thrombocytopenia. A patient was identified with having lupus nephritis based upon the results of a renal biopsy. Serum samples were collected from patients and controls at the time of study enrollment and these samples were used to assess the presence of antinuclear, anti-dsDNA, anti-Sm, anti-RNP, anti-Ro/SSA, anti-La/SSB, and anticardiolipin antibodies, as described[13].

Statistical analysis. Preliminary analysis of work status at followup and reasons one stopped working were compared by frequency of responses between patients and controls using chi-square tests. The frequency of reported health-related absence from work was also compared by using the chi-square tests. We then examined the risk of health-related job cessation, comparing patients to controls and adjusting for the matching variables (age, sex, state), ethnicity, and education.

With respect to the predictors of health-related job cessation among patients, our *a priori* interest was in arthritis because of the literature pertaining to arthritis and disability in other rheumatic diseases, and in those variables previously related to mortality risk in our study or in other recent studies (lupus nephritis, thrombocytopenia, and anti-dsDNA antibodies)[14-16]. We also examined other clinical features and autoantibody variables. With the exception of pleuritis, none of these emerged as a significant predictor of health-related job cessation in unadjusted or adjusted analyses; data for these other variables are not presented.

We used logistic regression to estimate the association between health-related job cessation and demographic factors (age, gender, ethnicity, education, state), practice type (university versus community-based rheumatology practices), and the selected clinical features (arthritis, pleuritis, thrombocytopenia, lupus nephritis, and anti-dsDNA antibodies). We examined each of these without adjustment for other variables, and then adjusting for the demographic factors that were potential confounders of job cessation (age, gender, ethnicity) and for the factors that remained significant after these adjustments (education, arthritis, and pleuritis). The software used was the Statistical Analysis Software, version 9.1.3 Service Pack 3 (SAS Institute, Cary, NC, USA).

RESULTS

A total of 198 SLE patients and 299 controls participated in the 2001 followup study with a mean (± SD) age at diagnosis (or corresponding reference age for controls) of 39 ± 14 years and 41 ± 14 years, respectively. As was seen in the total Carolina Lupus Study participants[17], about 90% of patients and controls in the followup study are female, 64% of patients and 32% of controls are African-American or other minorities, and education level was lower among patients (Table 1).

There was little difference in work status at baseline, with 71% of patients and 76% of controls working in the year before diagnosis or corresponding reference year, respectively (Table 2). At the followup assessment, however, the proportion of participants who were not working

Table 1. Participant characteristics. Values are number (%) unless otherwise indicated.

Characteristic	Patients, n = 198	Controls, n = 299	p
Age yrs, mean ± SD	39 ± 14	41 ± 14	0.087
[range]	[15–76]	[16–75]	
			0.9312
Male	19 (9.6)	28 (9.4)	
Female	179 (90.4)	271 (90.6)	
			< 0.0001
African-American and other minorities	126 (63.6)	97 (32.4)	
White	72 (36.4)	202 (67.6)	
College graduate			0.009
Yes	47 (23.7)	104 (34.8)	
No	151 (76.3)	195 (65.2)	
Education			0.003
Did not complete high school	36 (18.2)	26 (8.7)	
Completed high school	49 (24.8)	63 (21.0)	
Some college	66 (33.3)	106 (35.5)	
Completed college	47 (23.7)	104 (34.8)	
Clinical features†			
Arthritis	143 (73.7)	—	
Pleuritis	76 (39.6)	—	
Pericarditis	26 (13.5)	—	
Seizures/Psychosis	12 (6.2)	—	
Thrombocytopenia	22 (11.4)	—	
Lupus nephritis	47 (24.2)	—	
Anti-dsDNA antibodies	50 (26.7)	—	

† Number of missing data: 5 for arthritis, 7 for pleuritis, 6 for pericarditis, 6 for seizures/psychosis, 6 for thrombocytopenia, 5 for lupus nephritis, and 12 for anti-dsDNA antibodies. Reasons for missing data were lack of permission for use of medical record data for the clinical failures data and non-participation in the blood sample collection for the anti-dsDNA antibody data.

Table 2. Work status of SLE patients and controls in the Carolina Lupus Study, 2001 followup. Values are number (%).

	Patients, n = 198	Controls, n = 299	p
Working 10+ h week at baseline*	141 (71)	226 (76)	0.28
Work status at followup (yr preceding interview)†			
Not working	98 (50)	72 (24)	< 0.0001
Working	100 (50)	227 (76)	
Same job	49 (25)	98 (33)	
Different job	41 (21)	101 (34)	
Newly employed	10 (5)	27 (9)	0.01
Stopped working‡	51 (26)	26 (9)	
Reason(s) stopped working			
Did not like job, supervisor	0 (0)	2 (9)	
No longer needed to work	1 (2)	6 (27)	
Job ended, laid off	4 (8)	6 (27)	
Retired (other than health)	2 (4)	3 (14)	
Health	47 (92)	9 (40)	< 0.0001
Hours per week, 24 or less**	12 (12)	20 (11)	0.74
Months per year, < 9**	12 (12)	19 (10)	0.63
Days lost last year because of health, 15 or more¶	21 (21)	24 (11)	0.01
Unable to work more than 2 months since diagnosis#	25 (28)	14 (9)	< 0.001

* During the year before diagnosis or corresponding reference year, patients and controls, respectively. † "Newly employed", i.e., worked in year preceding followup interview who were not working in year before diagnosis/reference year (n = 57 patients, 73 controls). One control is missing data ("don't know") for the work status variable. ‡ Worked before diagnosis/reference year (patients and controls, respectively), but did not work in year preceding followup interview; 4 controls were missing data for these variables. ** Among participants who worked in year preceding interview (n = 100 patients, 187 controls; 40 other controls are in this group but are missing data for this question because they completed a version of the interview that did not have these questions). ¶ Among participants who worked in year preceding interview (n = 100 patients, 224 controls; 3 other controls missing data for this question). # Among participants who worked at baseline and in year preceding interview (n = 90 patients, 163 controls; 37 other controls are in this group but are missing data for this question because they completed a version of the interview that did not have this question).

was much higher among patients (50%) compared with controls (24%), and 51 patients (26%) and 26 controls (9%) had stopped working since the baseline period. In addition, the frequency of entry into the workforce was lower among patients (18% and 37% of patients and controls, respectively, who were not working at baseline were newly employed at followup, p = 0.01). The biggest difference in reasons given for having stopped work was because of health, with 92% of patients compared with 40% of controls who were no longer working indicating this as a reason (p < 0.0001). A strong association was seen between SLE and likelihood of a health-related job cessation (OR = 7.9, 95% CI 3.7, 17.0, adjusting for age, sex, state, ethnicity, and education). College graduates were less likely to quit their jobs due to health compared to non-college graduates (adjusted OR = 0.27, 95% CI 0.09, 0.84) (Table 3). There was no trend across the 4 levels of education, however, with OR of 2.0, 3.4, 3.9 (and overlapping confidence intervals) for the Did not complete high school, Completed high school, and Completed some college groups, respectively, compared with the reference group of Completed college. SLE patients with arthritis were more than 3 times more likely to have left their jobs due to health reasons compared to those who didn't have arthritis (adjusted OR = 3.3, 95% CI 1.2, 8.8); an association was also seen with pleuritis (adjusted OR 2.3, 95% CI 1.1, 4.6).

We also calculated the average salary loss among patients and controls who were no longer working because of health, based on estimated 2001 salaries for the job held at the baseline period. The annual mean salary was $21,540 (SD $11,215) among the 47 patients and $24,909 (SD $9,399) among the 9 controls who had stopped working for this reason (p = 0.40). Median salary levels were also somewhat lower in the patients ($17,971, compared with $21,785 in controls). The differences between patients and controls was not statistically significant (p = 0.34) when adjusting for age, sex, ethnicity, state, and education using linear regres-

Table 3. Demographic and clinical factors associated with health-related work cessation* risk among Carolina Lupus Study patients, 2001 followup.

	n	Unadjusted OR	Unadjusted (95% CI)	Adjusted† OR	Adjusted† 95% CI
Age	198	0.98	(0.96, 1.01)	0.98	(0.95, 1.00)
Male	19	0.35	(0.08, 1.6)	0.36	(0.07, 1.8)
Female	179	1.0	(referent)	1.0	(referent)
African Americans and other minorities	126	1.9	(0.93, 4.0)	1.6	(0.71, 3.5)
White	72	1.0	(referent)	1.0	(referent)
College graduate					
Yes	47	0.31	(0.11, 0.83)	0.27	(0.09, 0.84)
No	151	1.0	(referent)	1.0	(referent)
State					
North Carolina	157	0.96	(0.43, 2.1)	1.0	(0.41, 2.4)
South Carolina	41	1.0	(referent)	1.0	(referent)
Practice type					
University	97	1.8	(0.91, 3.5)	1.7	(0.76, 3.6)
Community	101	1.0	(referent)	1.0	(referent)
Arthritis					
Present	143	2.8	(1.1, 7.1)	3.3	(1.2, 8.8)
Absent	51	1.0	(referent)	1.0	(referent)
Pleuritis					
Present	76	2.1	(1.1, 4.1)	2.3	(1.1, 4.6)
Absent	116	1.0	(referent)	1.0	(referent)
Thrombocytopenia					
Present	22	1.6	(0.62, 4.3)	2.1	(0.69, 6.3)
Absent	171	1.0	(referent)	1.0	(referent)
Lupus nephritis					
Present	47	1.2	(0.55, 2.5)	0.85	(0.34, 2.1)
Absent	147	1.0	(referent)	1.0	(referent)
Anti-dsDNA antibodies					
Present	50	1.1	(0.50, 2.3)	0.73	(0.30, 1.7)
Absent	137	1.0	(referent)	1.0	(referent)

* Work loss defined as stopping work, between year before diagnosis and followup interview, because of health (n = 47). † Adjusted for age, gender, ethnicity, education (college graduate vs non-college graduate), arthritis, and pleuritis.

sion. However, because of the greater likelihood of job loss among patients, the average salary loss, calculated for all participants at risk of job loss (i.e., 141 patients and 222 controls), was higher in patients ($5,113 and $750 per patient and control, adjusted $p < 0.0001$).

Among participants who were working, there was little difference in the amount worked (in hours per week and months per year). The median hours per week (40) and months per year (12) was the same in patients and controls, and there was also no difference when analyzed as a categorical variable (Table 2). However, reported health-related absence from work was higher among patients in the past year (median 10 and 6 days in patients and controls, respectively); with 21% of patients and 11% of controls reporting missing 15 or more days of work due to illness ($p = 0.01$). In the entire period from diagnosis (or corresponding reference year for controls), 28% of patients compared with 7% of controls were unable to work for a period of 2 or more months ($p < 0.001$).

DISCUSSION

We examined work loss and other aspects of work status in this community-based study of SLE patients early in the course of their disease, including information on gender, ethnicity, and educational characteristics of patients and a comparison group drawn from the study area. Few longitudinal studies, even in rheumatoid arthritis, have included a community-based comparison group[18].

SLE patients had a lower rate of entry into the work force, and had a higher rate of work cessation for health related reasons compared to controls. Specific health reasons were not ascertained, but it can be presumed to be a result of conditions directly and indirectly related to lupus. Patients were 8 times more likely to have stopped working due to health reasons compared to controls, but employment rates before diagnosis were similar in these 2 groups. The differences between these groups in absences due to health were also quite strong. These statistics elucidate the toll SLE can take on patients, but it should be noted that patients who

continued to work reported levels of effort (hours worked per week and months per year) similar to the comparison group.

Our results are consistent with the LUMINA study, another cohort of patients analyzed early in the disease[19]. In the LUMINA analysis of 273 patients employed at enrollment, 19% were unable to work because of disability after a 5-year followup. Yelin, *et al* report a steadily increasing proportion of SLE patients who stopped working with increasing period of followup, from 15% at 5 years to 63% at 20 years' duration[20]. Few studies have provided comparison data from a control group. A recent longitudinal study of 957 SLE patients reported little difference in work loss compared with national employment data, but patients, particularly those between 18 and 54 years of age, were less likely to enter the workforce[21]. Sturfelt[22] reported no difference in employment rate between SLE patients and population comparison figures, but in the other studies, as in our study, unemployment rate[7] or disability rate[23] was higher among SLE patients.

In univariate and multivariate analyses among patients, job loss was associated with lower education attainment (Table 2). Our analysis replicated results reported in a multicenter study of SLE patients that identified having high school education or less in addition to receiving Medicaid or having no health insurance, having an income below the poverty level, and having greater disease activity at diagnosis, as significant factors predictive of self-reported work disability[6]. Our results are also similar to those reported by Bertoli, *et al* among work-disabled patients from the LUMINA cohort, who were poorer and less educated[19]. Patients who were referred by university practices were somewhat more apt to experience work disability compared to those referred from community practices, but this difference was not statistically significant (Table 3).

The clinical features associated with work loss in our study (arthritis and pleuritis) were not previously identified as risk factors for work loss. Most previous studies have focused on neurocognitive dysfunction, fatigue, and total damage scores or activity scores, rather than on individual clinical features[6,19,21,24,25]. Yelin, *et al* included vascular manifestations, lung manifestations, and kidney manifestations as predictive factors of work loss in a recent prospective study, but none of these factors were statistically significant[21], and a recent study by Al Dhanhani, *et al* identified a complex array of health factors to include several clinical features of SLE (i.e., avascular necrosis and fibromyalgia) to be significantly associated with work disability[26].

The loss of wages among participants who indicated health-related job cessation during the followup period (median 4 yrs since diagnosis), based on jobs held prior to diagnosis or reference year was similar for patients and controls. However, because of the greater probability of job loss among patients, the lost wages, when aggregated across all participants, were considerably higher among patients ($5,113 and $750 per patient and control, respectively, $p < 0.0001$). This estimation does not consider reduced wages that may result from other changes in employment, although there was little difference in amount worked (hours per week or months per year) among study participants in the workforce. In addition, the mean values of lost wages may be an underestimate of the actual loss of productivity due to the disproportionate number of women who are affected by SLE[27].

Several other limitations to this analysis should be noted. Some misclassification in the "pre-disease" (baseline) employment status is possible because we used a single period, that is the year before diagnosis, as the baseline period, rather than defining a patient-specific pre-illness period that would take into account the variability that is seen among patients in the length of the period between development of symptoms and diagnosis. We did not collect a complete history of all jobs held since the baseline period, but rather relied on the "snapshot" of employment in the year before the followup interview to ascertain postdisease work status. In addition, we used a much shorter interview for controls compared with patients in the followup study because we wanted to maximize participation in the former, less-motivated, group. Thus information on job title or job tasks that could be used to calculate wages for those employed at this time was not obtained.

Our study draws attention to the important economic burden expressed as work disability and work loss experienced by patients with SLE early in the course of disease (2–6 years after diagnosis). We augment the body of available research on job loss by providing additional evidence that lower education, arthritis, and pleuritis are important socioeconomic and clinical features associated with work disability. Our study population included a large representation of Whites and African-Americans; although generalizable to the southeastern United States, these results may not be as directly generalizable to other populations. Our study results are consistent with the recent review by Baker and Pope describing the prevalence of work disability among SLE patients, demographic factors associated to work disability, and the high costs of work disability[28]. Further, our results have implications for further research in occupational counseling and vocational rehabilitation[25] as a modifiable intervention aimed at reducing the economic burden of SLE.

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