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SPECIAL ARTICLE: DISABILITY AND REHABILITATION IN THE RHEUMATIC DISEASES

## Employment and Disability Issues in Systemic Lupus Erythematosus: A Review

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**Objective.** To summarize research pertaining to work disability in lupus patients, discuss challenges patients face applying for federal disability assistance in the US, and make recommendations for clinical and health policy research.

**Methods.** We searched Medline for articles on work or disability in lupus patients and gathered information from the Social Security Administration and the National Organization of Social Security Claimants' Representatives.

**Results.** We found 12 publications with employment-related data; 6 included analysis of predictors of work status. The prevalence of inability to work or cessation of work was 15–51% in these studies (3–15 years after diagnosis); 20–32% of patients received disability benefits. Lower education level, higher disease activity, higher disease damage, older age, and higher physical job strain were independent predictors of work disability or work cessation in at least 2 studies. Lupus patients may be less successful than patients with other diseases when applying for federal disability assistance, possibly because medical records may not accurately reflect functional limitations. In addition, symptoms contributing to work disability (e.g., fatigue, pain, neurocognitive dysfunction) may be difficult to assess and quantify.

**Conclusion.** Work disability in lupus patients is common. Additional research on risk factors for work disability in lupus patients and on strategies for reducing the impact of these factors on work-related activities is needed. The development of better measures and rating scales for the symptoms responsible for work disability in lupus patients and studies of factors influencing the success of obtaining federal disability benefits would also be useful.

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## INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune rheumatic disease with a significant burden on the individuals affected and their family members. Either as a consequence of the disease or of the treatments used for it, irreversible damage involving neuropsychiatric, renal, cardiovascular, and many other systems can occur (1). Although a clear improvement in the survival of SLE patients has been seen during the past 50 years (2), patients often experience long-term morbidity that can adversely affect their quality of life and ability to work, resulting in substantial direct and indirect costs to the individual and society (3). We review relevant research pertaining to measures of the prevalence and predictors of work disability or work cessation in lupus patients, drawing on studies from Europe and North America. We also review the federal disability assistance programs in the US as they pertain to lupus, highlight current data gaps, and discuss recommendations for future clinical and health policy research.

## MATERIALS AND METHODS

We searched the Medline database (last accessed July 2007) using the following search parameters: 1) lupus and disability, 2) lupus and work, 3) lupus and employment, and 4) lupus and Social Security. References within relevant reports were also reviewed. Additionally, we reviewed Web sites and personally contacted the US Social Security Administration (SSA), the National Organization of Social Security Claimants' Representatives, and several individual attorneys who represent lupus patients seeking Social Security disability benefits.

## RESULTS

**Work disability.** The available studies from Europe and the US pertaining to work status and disability in SLE patients (4–15) range in size from 15 (9) to over 4,000 patients (12), with estimates of unemployment or work disability ranging from approximately 15% to 51% an average of 3–15 years after diagnosis (Table 1). In a survival analysis of employment status, Yelin et al (15) reported that 15%, 36%, 51%, and 63% of patients stopped working after 5, 10, 15, and 20 years of disease duration, respectively. Prevalence of job loss for all reasons may be somewhat higher than the estimates based on changes in job status because of lupus or ill health. In 2 small studies, 20% (9) and 32% (13) of patients specifically reported that they were receiving disability benefits. In both studies, the majority of patients who self-reported work disability were also receiving formal benefits. Disability or work status has been associated with demographic factors, including lower levels of education (10–12,15) and older age (14,15), higher physical job demands (10,15), disease activity (10,11,14) and disease damage (13,14), and clinical features including neurologic symptoms, fatigue, and joint symptoms (4,5,13).

**Federal disability assistance.** The degree of disability related assistance for patients with SLE depends on the programs available in a state or country. Through the Social Security Act, the US Federal Government offers 2 important assistance programs: the Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program. The SSDI program is available to individuals who have worked and paid Social Security taxes for a certain number of years, depending on their age (16). The SSI program is available to individuals who have limited income and resources and who are disabled, regardless of whether they have worked in the past (17). Both programs use eligibility criteria based on diagnosis and severity of impairment. For a claim to be considered, the condition must be medically determinable by acceptable clinical and laboratory diagnostic techniques and have symptoms so severe that any type of substantial gainful work activity is not possible for at least 12 months.

The SSA publishes a Blue Book of medical conditions and guidelines for determining when each condition is severe enough to automatically qualify a person as disabled (18). The Blue Book guidelines for lupus patients are complex and can be found online at <http://www.ssa.gov/disability/professionals/bluebook/14.00-Immune-Adult.htm>. For a lupus patient to qualify as disabled, he or she must have severe involvement of at least 1 of 11 organs/body systems (joints, muscular, ocular, respiratory, cardiovascular, digestive, renal, hematologic, skin, neurologic, and mental) as defined by specific criteria. Alternatively, the patient may have lesser involvement of 2 or more systems if at least 1 of the systems is involved at a moderate level of severity and the patient has significant symptoms and signs of severe fatigue, fever, malaise, and weight loss. Supporting documentation for the Blue Book criteria may include medical history, physical examination, selected laboratory studies, appropriate medically acceptable imaging, and in some instances, tissue biopsy samples.

**Table 1. Studies reporting prevalence of work-related data or analysis of predictors of work status in lupus patients**

Author (ref.), country	Age, years; disease duration, years; ethnicity*	No., analysis group	Employment status	Independent predictors of employment status†	Absenteeism and job change data in working patients
No analysis of predictors of employment status Sturfelt and Nived (4), Sweden	Median 44; disease duration not reported	54 patients younger than retirement age	20% not employed during 1982 (same as population omparison rates), including 13% drawing early retirement	Not analyzed	Median 20 days annual absences (3 days in population comparison), 19% missed > 90 days
Stein et al (5), Canada‡	Mean ± SD 36 ± 12; mean ± SD 6 ± 5; 26% Native Indian, Chinese, or Japanese	102 patients with any employment history	16% retired due to lupus	Not analyzed	17% changed jobs
Clarke et al (6), Canada, UK, US	Mean ± SD 41 ± 13; mean± SD 10 ± 7; 76% white	648 female patients	30% not working due to morbidity	Not analyzed	Not analyzed
Sutcliffe et al (7), UK§	Mean ± SD 40 ±12; mean ± SD 11 ± 7; 75% white	105 consecutive patients	22% not working due to lupus, including 10% retired due to lupus	Not analyzed	Mean ± SD 8 ± 21 days (median 3) absent among all who worked
Boomsma et al (8), The Netherlands	Mean 44; median 10; 94% white	Not defined, patients employed for ≥1 year	23% resigned due to lupus	Not analyzed	Since diagnosis, 61% absent for 6 consecutive weeks, nearly 50% changed duties, 56% reduced hours
Poole et al (9), US	Mean ± SD in patients 43 ± 12; mean ± SD 8 ± 5	15 female patients from a study of spectroscopic imaging, 15 healthy female controls	27% unemployed, including 20% receiving disability (7% and 0% in controls, respectively)	Not analyzed	Not analyzed
Includes analysis of predictors of employment status Partridge et al (10), US	Mean ± SD 35 ± 10; mean 3; 53% African American, 47% white	152 patients ever employed since diagnosis (excluding 7 who chose not to work for reasons other than lupus)	40% not working due to lupus	Lower education level, higher physical job demands, higher disease activity	Since diagnosis, 27% absent for 2 consecutive months, 53% changed duties, 49% reduced hours
Sutcliffe et al (11), UK¶	Median 39; median 9; 77% white, 12% African Caribbean, 10% Asian	184 female patients	30% not working due to lupus	Lower education level, higher disease activity (Birmingham)	Not analyzed
Mau et al (12), Germany	Mean ± SD 40 ± 11; 34% ≤ 5, 38% > 10	4,603 patients in a national database	Standardized employment ratio (lupus patients compared with population) = 0.81	Lower education level, local unemployment rates, longer duration#	Not analyzed
Utset et al (13), US	Mean ± SD 41 ± 12; mean ± SD 9 ± 8; 60% African American, 26% white	50 patients in a study of neurocognitive function	48% not working due to lupus, including 32% receiving long-term or Social Security disability benefits	Neurocognitive impairment, higher damage accrual	Not analyzed
Bertoli et al (14), US	Mean ± SD 37 ± 12; mean ± SD 5 ± 3; 19% Texan Hispanic, 22% Puerto Rican Hispanic, 29% African American, 30% white	273 patients employed at enrollment	19% unable to work due to disability after 5 years' followup	Older age, male, poverty, longer duration, higher disease activity, higher damage accrual	Not analyzed
Yelin et al (15), US	Mean ± SD 45 ± 11; mean ± SD 12 ± 8; 66% white	Work cessation: 673 patients employed at diagnosis, hours worked: 878 patients ages 18–64 years with any employment history	15%, 36%, 51%, and 63% stopped working after 5, 10, 15, and 20 years of disease duration, respectively	Female, older age, lower education level, higher physical job demands, high job demand with low control, shorter duration	Little change in hours worked among those who worked continuously since diagnosis, but decreased hours/week and weeks/year among all ever employed

\* In all but 2 studies, disease duration is from the population that was analyzed for employment status. In Stein et al (5) and Boomsma et al (8), disease duration is from the total population. Total population was 120 patients in Stein et al (5) and 114 patients in Boomsma et al (8). The studies by Sturfelt and Nived (4) in Sweden, Poole et al (9) in the US, and Mau et al (12) in Germany did not report ethnicity.

† Independent predictors were statistically significant in multivariate analysis.

‡ Also reported absenteeism data and data for some employment categories in comparison with general population figures, but the terms and analytic methods were not defined.

§ Study population is a subset of the population in Clarke et al (6). Demographic data is based on the baseline data; employment status and absenteeism are based on data from the 6-month followup assessment.

¶ Study population is a subset of the population in Clarke et al (6). Patients were drawn from 2 clinics, one in London and one in Birmingham.

# These factors were associated with lower relative employment rates in univariate analyses in systemic lupus erythematosus (SLE) patients and in the multivariate analysis that included other rheumatic diseases. Results from the multivariate analysis specifically for SLE patients were not provided. The study also included patients with rheumatoid arthritis (n = 26,071), ankylosing spondylitis (n = 5,564), soriatic arthritis (n = 6,041), systemic sclerosis (n = 802), and Wegener's granulomatosis (n = 385) in the database.

After an initial review of basic eligibility requirements, the SSA sends disability benefit applications to the Disability Determination Services (DDS) office in the claimant's state (18). The DDS examines evidence from the claimant's medical records and treating sources to determine whether the person's condition meets Blue Book criteria. If that evidence is unavailable or insufficient, the DDS will arrange for a consultative examination from either the claimant's treating physician or an independent source. If the severity of the condition does not meet Blue Book criteria, the DDS then assesses the claimant's residual functional capacity, which is the remaining ability to perform basic work-related activities, including the type of work performed in the past as well as any other type of work. In addition to the medical evidence, the claimant's age, education, skills, and past work experience are all evaluated when determining residual functional capacity (16). If the claimant is judged able to perform either his or her previous work or any other type of work, the claim is denied.

Patients under retirement age who receive benefits are reevaluated at regular intervals to determine if they continue to meet the disability eligibility requirements. The frequency of these reviews can range from once every 6 months to once every 7 years, depending on the severity of the impairment and the likelihood of improvement (19). Therefore, the SSDI and the SSI programs have the potential to help patients through a difficult period caused by a disease flare or to provide long-term income support for patients who are severely and permanently incapacitated. The level of support offered by these programs is relatively low, however. In 2006, the average monthly payment for a disabled beneficiary receiving SSDI only, SSI only, or both SSDI and SSI was \$1,058, \$578, and \$699, respectively (19).

The total number of people with disabilities receiving disability benefits through the SSDI and/or SSI programs in December 2006 was 9,542,360; approximately 21% (1,979,791) of these beneficiaries fell under the broad diagnostic category of musculoskeletal system and connective tissue diseases, which includes lupus and arthritis patients (19). Data on lupus patients and arthritis patients specifically are not available. From 1996–2005, only 31% of all worker applicants were awarded Social Security benefits after the initial DDS determination (19). After consideration of appeals, the final rate of allowed claims for the same time period was 48%. The SSA does not publish data on the rate of allowed claims broken down by medical condition or diagnostic category. However, we were able to obtain unpublished data from the SSA indicating that, between 2000 and 2005, the ratio of allowed to denied claims at the initial level of review for the SSDI and the SSI programs combined was lower for diffuse diseases of connective tissue (including lupus patients) than for the categories of heart failure, arthritis, or the sums of all diseases (US Social Security Administration: unpublished data).

A common barrier to qualifying for Social Security disability benefits is incompleteness of medical records, resulting from either the patient's failure to discuss symptoms and work-related functional limitations with the physician or the physician's failure to describe the extent of these limitations in the patient's records (20–23). For SLE patients in particular, an additional difficulty in obtaining Social Security benefits may arise from the type of symptoms that can contribute to work disability such as fever, fatigue, pain, and neurocognitive dysfunction (4,5,13), which may be neither easy to assess and quantify on physical examination nor proven by laboratory or imaging methods (23,24). The Systemic Lupus International Collaborating Clinics Damage Index (1) and disease activity indices (25) do not focus on work-related functional limitations or disabling symptoms. In addition, many lupus patients experience periods of flares and periods of remission, making the assessment and consistent documentation of disability more complex. Without hard medical evidence and clear documentation, patients with lupus may fail to meet Blue Book criteria and may not be able to prove loss of residual functional capacity despite having symptoms that significantly impair their ability to work.

Liang et al (24) examined the agreement between the SSA determinations, physician assessments of work disability, and a standardized evaluation of work capacity in 52 patients with either arthritis or lupus who submitted new disability claims to the SSA. A breakdown of the study population by disease type was not provided. Rheumatologists' judgments of work disability (30 patients rated unable to work) agreed with SSA determinations (25 patients rated unable to work) in 67% of cases ( $k = 0.35$ ,  $P = 0.01$ ). Agreement was associated with younger age and lower socioeconomic status. The rheumatologists' evaluations were related to ratings of upper- and lower-extremity dysfunction to a greater degree than seen with the SSA ratings. SSA judgments agreed with the standardized evaluation of work capacity in 62% of cases ( $k = 0.23$ ,  $P = 0.10$ ). The authors concluded that judgments of function based on patient medical records do not accurately reflect observed performance. They also suggested that an observed performance evaluation such as the work capacity evaluation used in the study might be more useful to the SSA than chart review in certain cases.

## **DISCUSSION**

Lupus most often occurs in the young and mid-adult years, and many lupus patients can expect to live for decades with chronic disease (2). It is important to characterize the experience of these patients as they attempt to cope with long-term morbidity while living normal productive lives. The available studies, summarized in Table 1, show that work disability in patients with SLE is common, with at least 20% of patients reporting a cessation of

employment approximately 10 years after diagnosis. Several limitations can be seen in these studies: many were small, most were not prospective, many did not include productivity measures such as absenteeism, few studies included a population comparison group, and there were variable definitions of work disability. Future studies should address these limitations.

Data pertaining to the use of federal disability programs in the US are relatively limited. We found only 2 published studies with data on the prevalence of patients with SLE receiving Social Security disability benefits (9,13), and one study of lupus and rheumatoid arthritis patients that examined the process of obtaining benefits (24). The SSA data we obtained indicated a higher initial disapproval rate of applications from patients with diffuse diseases of connective tissues compared with patients with other diseases.

Given the relatively low rate of allowed claims and the low level of monthly benefits available to patients who receive assistance through the federal disability programs, efforts to help patients maintain employment would be particularly useful. Additional research on the risk factors for work disability in lupus patients and on strategies for reducing the impact of these risk factors on work-related activities is needed. Some evidence indicates that certain specific clinical factors such as neurologic symptoms, joint pain, and fatigue may be primary factors contributing to work disability or decreased work capacity in lupus patients. The impact of these factors could be lessened if we understand how they affect patients' ability to work and what aspects of work are most affected. For example, if pain is the primary cause of disability, development of a tailored pain management program could enable the patient to continue working. If a patient's job involves physical labor that aggravates joint pain, certain assistive technologies or vocational rehabilitation may be useful in allowing the person to continue to perform his or her duties. Similarly, if fatigue is the main factor contributing to work disability, exercise programs or flexible work schedules may be helpful. Studies that attempt to better characterize the reasons why disabled patients with lupus are unable to work are needed before such interventions can be developed.

It would also be useful to produce better quantitative measures of the symptoms responsible for work disability in lupus patients. Although several scales are available for some features such as fatigue (26), additional research should focus on assessing the impact of these symptoms on lupus patients' ability to perform work-related activities. These types of quantitative scales and measures would allow for more consistent and clearer documentation of work disability in patients with lupus, which may increase the success rate of disabled lupus patients applying for Social Security disability benefits. Possible templates for these kinds of measures are the standardized evaluation of work capacity used in the 1991 study by Liang et al (24), but more development and validation work is needed.

Efforts to educate both patients with lupus and physicians about work disability and the Social Security disability claims process and research on factors that may influence the success of lupus patients in obtaining disability benefits would also be useful. Physicians and patients need to work together to ensure that the nature and severity of work-related functional limitations are consistently and accurately recorded at each office visit, because this is the information used in the determination of disability eligibility. Studies of patients with lupus and patients with other rheumatic diseases applying for Social Security disability benefits could help elucidate the factors that influence whether these claims are denied or allowed. Comparative analyses of disability benefit systems in other countries as they relate to autoimmune diseases such as SLE would also provide a broader context for evaluation of the experience of patients in the US.

The economic costs associated with work disability in patients with SLE can be substantial, and indirect costs due to lost wages are greater than direct medical costs (3). Additional indirect costs associated with work disability may include loss of self-esteem, limited opportunity to socialize with others, diminished ability to support dependents and to accumulate assets for retirement, limited access to employer benefits such as health insurance and pension plans, and decreased ability to perform non-labor market activities such as housekeeping and child care (3,6,10,15). Therefore, research in work-related disability and initiatives to help reduce the incidence of work disability in lupus patients and to assist lupus patients who are truly work disabled in obtaining the financial assistance they need represent a critical need for comprehensive care of patients with this chronic disease.

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## **AUTHOR CONTRIBUTIONS**

Dr. Cooper had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study design.** Alarcón, Cooper.

**Acquisition of data.** Scofield, Alarcón, Cooper.

**Analysis and interpretation of data.** Scofield, Reinlib, Alarcón, Cooper.

**Manuscript preparation.** Scofield, Alarcón, Cooper.

**Organization of discussion and funding of workshop.** Reinlib.

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