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Work disability, lost productivity and associated risk factors in patients diagnosed with systemic lupus erythematosus

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ABSTRACT

Objective: To assess prevalence and correlates of work presenteeism, absenteeism and work disability (WD) in patients with systemic lupus erythematous (SLE) and matched controls.

Methods: Patients with SLE from six medical centres were recruited to complete a questionnaire consisting of several prevalidated survey instruments. The subject's rheumatologist completed medical history. Subjects recruited two non-SLE 'best friend' controls with matching demographics to complete a control survey. Analyses employed Student's t tests, χ^2 tests and logistic regression models.

Results: 344 subjects with SLE and 322 controls submitted completed questionnaires. Mean pain, fatigue, Brief Cognitive Symptoms Index (BCSI) scores and depressive symptoms were worse in patients with SLE with WD (all p<0.01). WD was associated with African–American race, older age (51–65 years) and less than 4-year college education (all p<0.01). High presenteeism was associated with low pain and fatigue levels, higher BCSI scores and negatively correlated with depressive symptoms (all p<0.05). Increased pain and fatigue were associated with elevated absenteeism (p<0.05). Subjects with physically and cognitively demanding work reported worse presenteeism compared with controls with similar jobs (77% vs 85%, p<0.05 and 75% vs 85%, p<0.001), respectively. Patients with most cognitively demanding jobs reported greater weekly absenteeism (mean, 5.9 h) compared with controls (mean, 6.9 overtime hours, p<0.05).

Conclusions: The questionnaire demonstrated increased WD in SLE. Highly physical and highly cognitive jobs are challenging to patients with SLE and had increased absenteeism compared with controls. Depressive symptoms were correlated with better presenteeism without major socio-demographic determinants. Employability may be enhanced by improving treatment of depressive symptoms in patients with SLE.

KEY MESSAGES

- Patients with systemic lupus erythematous (SLE) with physically and cognitively demanding work had worse presenteeism compared with controls with similar jobs and patients with the most cognitively demanding jobs reported greater weekly absenteeism compared with controls.
- Patients with SLE with work disabilities have higher pain, fatigue and depressive symptoms and worse cognitive function as assessed by validated instruments.
- Work disability in patients with SLE is higher in patients of African–American race, with older age and with less formal education.

INTRODUCTION

As survival in systemic lupus erythematosus (SLE) has improved, clinical outcomes such as work and domestic functionality have been included in the study of SLE populations.[1–3] As large numbers of individuals in gender/age groups typical of SLE are employed,[4] one socioeconomic facet of SLE that should be assessed is the ability of patients with SLE to maintain paid employment. In employed and non-employed patients with SLE, disease-related issues may impair functionality in child-rearing and household tasks as well as work function.

Loss of work and domestic function has personal and societal costs. These are considered indirect costs of SLE.[5] These include work disability (WD), absenteeism and decreased work productivity (decreased presenteeism). While work absenteeism and WD are quantifiable outcomes, variables such as presenteeism are more difficult to measure.

However, validated measures of self-reported work performance and absenteeism have been developed for general and chronic disease populations.

Increased work absenteeism and WD rates have been observed in numerous SLE studies. Reported WD rates range from 20% to 50%, and vary widely between SLE population studies.[6–11] Demographic factors associated with WD include age, low educational level, low socioeconomic status and race.[12–17] Pain, fatigue, depressive symptoms, comorbidities, disease duration, activity, damage and cognitive dysfunction have been correlated with WD.[7–10 18–25] However, studies of the association between work type at diagnosis and subsequent risk of WD have had variable results. Some studies have documented high physical demands, high cognitive demands and low job control to have higher risks of WD in SLE,[11] while other studies found no associations of global work type with WD.[21] Fewer studies have quantified work absenteeism. Yelin *et al*[1 18] found that the majority of work loss in SLE was due to WD rather than decreased work hours and that fewer subjects with SLE entered or re-entered the work force relative to general population controls. Clarke[26] found patients with SLE to have average absentee rates of only 13–16 days/year in full-time workers, while Campbell[6] found 21% of patients with SLE to have been absent due to health issues more than 15 days/year, compared with 11% in matched controls.

Work and domestic productivity, lost work and WD are clinical outcome measures, which could be followed over time in assessing clinical course and the impact of SLE therapies. We have developed a self-administered questionnaire on presenteeism, absenteeism, WD and home productivity and performed an initial cross-sectional study of functionality using this questionnaire in SLE and a matched control population. Concurrently, we measured common contributing factors to WD, including psychosocial measures, demographic data, comorbidities, work type and disease-specific factors, in order to assess determinants of work functionality as measured by this questionnaire.

METHODS

Survey overview

Patients with SLE from six medical centres in the USA were asked to complete a survey on work and domestic function, and the subject's rheumatologist completed questionnaires on the subject's medical history. Subjects were asked to recruit two non-SLE 'best friend' controls to complete a control survey.

Study population

Consecutive adult ambulatory patients with SLE who fulfilled American College of Rheumatology (ACR) criteria for the classification of SLE[27] were offered enrolment in the study. Patients with a comorbid diagnosis of rheumatoid arthritis (RA) were excluded from the study. The final number of patient cases was 344.

Patients recruited their matched control (ie, 'best friend' control) without a prior diagnosis of SLE or RA. Subjects were instructed to recruit two controls that were of the same gender, approximately the same age (±5 years), did not live in the same household as the patient and resided in the USA. Based on social dynamics, we expected this method of peer-nomination of the control group to create a control group that is similar to the patient group in terms of socioeconomic status and demographics.[28 29]

The final number of controls was 321 with case–control ratio between 1:1 and 1:2. The variation in number of cases (N=344) and controls (N=321) can be confusing, and arises due to the 'best friend' control method used in this study. Patients with SLE were given two extra (control) questionnaires in stamped, preaddressed envelopes and asked to find two friends to complete the questionnaire. Their friends were to remain anonymous to the study because we could not obtain informed consent from the friends. Patients with SLE received compensation for participation, but the anonymous friends could not (due to anonymous status). Thus, either the Patients with SLE did not uniformly find two friends to agree to participate, or many of the controls may not have followed through with participation—perhaps, in part, due to lack of compensation. Thus, recruitment of the control patients by an SLE subject may vary between 0 and 2. Finally, we have nearly equal numbers of patients with SLE and controls, which was our general goal. The individual subject with SLE was not then matched to their control for analysis, but rather they were analysed in groups of SLE versus controls.

Six rheumatologists with large lupus patient populations recruited patients with lupus for this study. The six rheumatologist clinic settings were a mix of academic (n=4) and private practice (n=2), and located in diverse geographical areas (Chicago, Atlanta, Los Angeles, San Diego, San Francisco and Minneapolis).

Data collection

Data were collected between 1 October 2009 and 31 July 2010 via self-administered paper surveys. Participating subjects with SLE were provided with a 12-page patient survey, two control surveys, a letter explaining the study and postage-paid reply envelopes for each of the three surveys. Once patients were familiarised with study procedures and provided written informed consent, treating physicians completed an eight-page medical history survey, which the physician mailed back directly to a research firm tasked with managing the logistics of the study and reporting the results (Harris Interactive). Patients were asked to complete the survey within 2 weeks of their office visit and return it directly to Harris Interactive using the reply envelope. Each patient survey contained a unique identification code linking it to a

corresponding medical survey, so that patient and physician surveys could be jointly analysed. Both physicians and patients were compensated for their participation in the study, but due to the anonymity of the control survey, control subjects received no compensation.

Measures

The physician, patient and control surveys were developed in collaboration with lupus medical experts, Genentech, and Harris Interactive. The surveys consist of several pre-validated survey instruments or portions of these instruments. This questionnaire is an amalgam of portions of previously developed questionnaires, drawn together into this questionnaire. Many of the categories are adopted in part from Utset *et al*[21] and others were assembled by consensus.

Rheumatologists completed a medical survey about each recruited patient's lupus diagnosis and history. Chart audits included the following measures: date and details of SLE diagnosis (including ACR criteria), damage present in the patient using the Systemic Lupus International Collaborative Clinics/American College of Rheumatology Damage Index (SLICC/DI),[30] comorbidities using the Sangha Comorbidity Index[31 32] and specific medical treatments. Patient and control surveys were virtually identical. Patients and controls completed self-administered surveys about their life and work experiences. The control version of the survey differed from the patient version in only two ways: a question asking the year of lupus diagnosis was modified to ask controls whether or not they have been diagnosed with lupus by a doctor, and two questions specifically asking about employment status at the time of lupus diagnosis were deleted.

Patient and control surveys included the following measures: demographics (age, gender, education, income, race/ethnicity, marital status and insurance coverage), work productivity, absenteeism and presenteeism using the WHO Health and Work Performance Questionnaire (HPQ),[33] lost productivity outside of the workplace using modified questions from the HPQ and other instruments,[33 34] symptoms of fatigue using Functional Assessment of Chronic Illness Therapy (FACIT-Fatigue),[35] depression using the Center for Epidemiologic Studies Depression Scale Short Form (CES-D),[36 37] cognitive impairment using a Brief Cognitive Symptoms Index (BCSI) which was derived from the Cognitive Symptom Inventory developed by Pincus *et al*,[38 39] overall health-related quality of life (HRQoL) including both physical and mental health status using the Medical Outcomes Survey Short Form 12 (SF-12v2)[40] and comorbidities using the Sangha Comorbidity Index.[31 32]

We define absolute absenteeism as the number of hours a patient missed from work due to their health over the past 7 days. It is calculated by taking the difference between the hours expected to work in a typical 7-day week by the employer and the actual hours worked in the past 7 days. We define absolute presenteeism as the extent to which productivity has been reduced while at work due to health complaints over the past 4 weeks (adjusted for the subjects' assessments of the productivity of average coworkers). The scores range from 0% to 100%, where 100% indicates ideal performance. Low presenteeism is defined as a score of 70% or less, and high presenteeism a score of 80% or greater. The *FACIT-Fatigue scale* has expected scores ranging from 0 to 52, with higher scores indicating less fatigue. We categorise respondents into groups with scores below 15, 15–25, 26–35 and scores above 35.

The CES-D is a scale that measures depression. A score of 10 or greater suggests depression.[36 37] We classify respondents into groups with scores below 5, 5–10, 11–15, 16–20 or above 20. BCSI scores range from 0 to 100, with higher scores indicating worse functioning or greater impairment. BCSI scores are coded as 0–25, 26–50, 51–75 and 76–100. Pain is measured using a single item from the Brief Pain Inventory[41]: 'What number best describes your pain on average over the past 4 weeks (28 days)?' Responses range from 0 (no pain) to 10 (pain as bad as you can imagine). The SF-12v2 includes several subscales, measuring various aspects of HRQoL including physical, mental, social and emotional health, vitality and general health. For each subscale, scores range from 0 to 100, with higher scores indicating better functioning.[40]

Work status was determined in the year of SLE diagnosis and at time of survey for all subjects, and categorised as employed (full-time or part-time), self-employed, not employed but seeking work, not employed but not seeking work, retired, student or homemaker. Work disabled patients with SLE and controls were identified by the response 'not employed but not seeking work', while employed/employable was defined as full-time, part-time, self-employed or non-employed but seeking work. Work status was further explored by determining the duration of current work status. If subjects were not working, they were queried as to whether the non-working status was at least, in part, related to their health. Work type was classified as per USA Census Bureau, 2000,[21 42] and defined in the year of SLE diagnosis and at the time of survey completion. Socioeconomic status was assessed using educational level and household income.

Statistical analysis

All prevalidated instruments were scored according to validated scoring algorithms. Demographic, health and employment characteristics were compared for patients and controls, using Student's t tests for continuous variables and χ^2 tests for categorical variables. To examine factors influencing employment status and performance among patients, we developed logistic regression models including variables for SLE symptoms (depression, fatigue, pain, cognitive functioning), comorbidities and demographics (age, race, marital status, education). We used stepwise selection techniques to reduce the

Table 1 Baseline demographic characteristics of patients with SLE and control subjects

Population demographics	Total patients (N=344)	Total controls (N=319)	p Value*
Female gender	95%	93%	NS
Age in years, mean (SD)	(N=330)	(N=303)	
18–34	35%	34%	NS
35–49	31%	33%	NS
50–64	31%	25%	NS
65+	2%	8%	<0.05
Race/ethnicity	(N=344)	(N=321)	
African–American	45%	31%	<0.01
Caucasian	36%	45%	<0.05
Hispanic	11%	9%	NS
Asian/Pacific Island	7%	11%	NS
Other	7%	6%	NS
Marital Status	(N=341)	(N=318)	
Married/cohabitating	37%	50%	<0.01
Never married	45%	35%	<0.01
Separated/divorced	16%	12%	NS
Widowed	2%	3%	NS
#Adults in household	(N=344)	(N=321)	
Average (mean)	2.1 (SD 1)	2.1 (SD 1.4)	NS
#Children in household	(N=340)	(N=314)	
Average (mean)	0.7 (SD 1)	0.8 (SD 1.2)	NS
Education	(N=331)	(N=309)	
HS graduation or less	25%	21%	NS
Some college	41%	33%	<0.05
4 year college	17%	25%	<0.05
>4 year college	17%	21%	NS
Income (US dollars/year)	(N=324)	(N=295)	
≤34 999	51%	36%	<0.01
35 000–74 999	25%	26%	NS
≥75 000	24%	38%	<0.01

*NS=p value exceeds 0.05.
HS, high school; SLE, systemic lupus erythematous.

number of variables in the models and slight residual colinearity was assessed using ridge regression. These models were used to examine the correlates of being unemployed due to health problems and of presenteeism among patients. Statistical tests were considered to be significant at an α level of 0.05 on a two-tailed test.

RESULTS

A total of 496 subjects with SLE were consented for the study with 344 SLE completing the questionnaire (69% response rate) and 322 controls returned the questionnaire. The average number of ACR criteria present in subjects with SLE was 6. Median disease duration was 9 years (range 1–51), and median SLICC/DI score was 1 (range 0–13). Table 1 compares the demographic data of controls with subjects with SLE. Gender was similar, but slightly more controls were >65 years old (8% vs 2%). Patients with SLE were often married, but had similar numbers of adults and children in their households compared with controls. Completion of a 4-year college and income > $75 000/year was slightly more prevalent in controls (all p<0.05). On average, patients had a total of 4.2 comorbidities compared with 1.5 in the controls (p<0.01). Controls were more often Caucasian. HRQoL in the control group approximated normal populations,[40] while all subscales of HRQoL were impaired in the SLE group compared with controls by the SF12v2 (data not shown, all p<0.01). Similarly, pain, FACIT-fatigue, depressive symptoms and BCSI score were worse in patients with SLE compared with controls (data not shown, all p<0.01) (table 1).

Patients with SLE were significantly less likely than controls to be working full time (24% vs 50%, p<0.05), although full-time employment in the year of SLE diagnosis was 49% (table 2).

The most common work status at the time of survey for subjects with SLE was WD (31% among SLE vs 4% in controls, p<0.05), defined as 'not working and not seeking work'. Confirmation of the WD variable as representative of health-related disability is illustrated by the correlation of this category with 'not working in part due to health' (88% agreement, p<0.01) and with a positive response on a question about long-term disability pension compared with working subjects (7% of employed/employable subjects vs 63% of non-working subjects were on extended sick leave or disability, p<0.01). However, a significant number of the subjects

with SLE could not characterise their work status and marked 'other' (18% in SLE vs 3% in controls, p=0.01). For WD analyses, employed/employable subjects were defined by the categories full-time or part-time work, self-employment or unemployed but seeking work. The statuses of 'retired', 'homemaker' and 'student' were not included in these comparisons and did not differ between SLE and control groups. Subjects marking 'other' work status were excluded from the WD analyses also. Among all non-working patients with SLE, subjects were much more likely than non-working controls to ascribe their working status to health problems (88% vs 15% in controls, p<0.05). Patients with SLE were more likely to report receiving a social security disability pension (overall 41% vs 4% in controls, p<0.05), and the duration of unemployment was longer in non-working subjects with SLE than controls (7.2 years vs 2.2 years, p<0.05). All parameters of work quantity and quality were lower in working subjects with compared with controls. Patients with SLE reported working fewer hours in the week prior to their survey (33.3 vs 39.1 h, p<0.05), and more sick days in the month prior (2.3 vs 0.4 sick days in controls, p<0.05). Self-assessed productivity (presenteeism, scale 0–100, 100=ideal performance) over the prior 4 weeks was worse in SLE (77% vs 85% in controls, p<0.05). Mean absentee time in the week prior was 2.7 h in SLE, while controls worked extra 4.7 h overtime, (p=0.17). Household function was worse in SLE, with 7.4 days in the month prior in which they were unable to perform household activities compared with 1.8 days in controls, (p<0.05) (table 2).

Self-reported symptoms that may impact productivity were consistently worse in the SLE population with WD, in comparison with employed/employable patients with SLE. The mean pain scale (p<0.01), fatigue scores (p<0.01), BCSI score (p<0.01) and depressive symptoms (p<0.01) were worse in patients with SLE with WD on univariate analysis (table 3).

SLICC/DI score also correlated with WD status. Among patients with SLE with WD status, 43% had a SLICC/DI score >1, compared with 26% of employed/employable patients with SLE (p<0.01). On univariate analysis, WD status was associated with classical sociodemographic parameters, including African–American race (p<0.01), older age (51–65 years) (p<0.01) and patients having less than a 4-year college education (p<0.01, data not shown), but disease duration did not differ between working and work-disabled patients with SLE (table 3). Logistic regression with stepwise elimination of the major variables found on univariate regression revealed that higher age (p=0.005), SLICC/DI score (p=0.0140), FACIT-fatigue score (p<0.001), BCSI score (p=0.017), race (p=0.003) and educational level (p<0.001) were all independently associated with WD in the SLE group (table 4).

Many of the correlations of poor self-reported work productivity (presenteeism) resembled those found in SLE with WD (tables 3 and 5).

Table 2 Patient and control employment characteristics

Characteristic	Patients with SLE (at diagnosis)	Patients with SLE (current status)	Controls (current status)	p Value*
Employment status	(N=344)	(N=344)	(N=321)	
Employed full time	49%	24%	50%	0.01
Student	25%	9%	10%	NS
Employed part time	16%	10%	12%	NS
Self-employed	3%	5%	7%	NS
Not employed, but seeking work	3%	6%	8%	NS
Homemaker	6%	9%	10%	NS
Not employed and not seeking work	9%	31%	4%	0.01
Retired	1%	6%	10%	NS
Other	4%	18%	3%	0.01
Receiving SS benefits		41%	4%	<0.01
If unemployed, how long? (year)		7.2 (SD 6.5)	2.2 (SD 2.2)	<0.01
Unemployed due to health problems		88%	15%	<0.01
Hours worked in last week (mean)		33.3 (SD 16.7)	39.1(SD 13.6)	<0.01
Sick days/months (mean)		2.3 (SD 4.9)	0.4 (SD 1.1)	<0.01
# Days not able to do full day of housework last month due to health issues		7.4 (SD 7.9)	1.8 (SD 4.9)	<0.01
Absentee time (difference between hours worked and hours expected to work in last 7 days)		2.7 h	−4.7 h	NS
Presenteeism (100%=ideal performance, in last 4 weeks)		77%	84.6%	<0.01

NS=p>0.05.
*p Value from χ^2 test for categorical variables and Student's t test for continuous variable.
SLE, systemic lupus erythematous.

Table 3 Bivariate analysis of work disability employment status in SLE

	Non-working SLE	SLE employed	p Value (bivariate)
Age (years)	43.8 (SD 12.4)	39.5 (SD 12.6)	<0.01
Disease Duration	10.7 (SD 7.6)	10.1 (SD 8.1)	0.57
SLICC/DI, score >1	43%	26%	<0.01
Pain score	6.3 (SD 2.6)	4.1 (SD 2.6)	<0.01
FACIT-Fatigue Score	20.2 (SD 11.9)	29 (SD 12.3)	<0.01
CES-D Score (>10)	71%	47%	<0.01
BCSI (≤25, 100=best function)	29%	44%	<0.01
Non-African–American race	37%	64%	<0.01

BCSI, Brief Cognitive Symptoms Index; CES-D, Center for Epidemiologic Studies Depression Scale Short Form; FACIT, Functional Assessment of Chronic Illness Therapy; SLE, systemic lupus erythematous; SLICC/DI, Systemic Lupus International Collaborative Clinics/American College of Rheumatology Damage Index.

Pain scores were worse in patients with low presenteeism than in those with high presenteeism (4.8 vs 3.5, p=0.001). Fatigue levels were worse in low presenteeism subjects (45% vs 76% with a favourable FACIT score of >25, p<0.001). High levels of depressive symptoms (CES-D index >10) were present in 69% of poor presenteeism patients, while 31% of high presenteeism patients endorsed significant depressive symptoms (p<0.001). Self-reported cognitive function was more often impaired in low presenteeism subjects (BCSI score≥26 in 52% of high presenteeism patients vs 38% of low presenteeism patients, p<0.014). However, demographic variables, age, race, education and marital status were unassociated with presenteeism. SLE duration was unassociated with presenteeism, and SLICC/DI scores did not differ between presenteeism groups.

Absenteeism reported for the week prior to interview did not vary by educational level or race/ethnicity. More severe pain level and fatigue were associated with elevated absenteeism (p=0.017 and p=0.027 respectively). Age, cognitive symptoms, depressive symptoms, summed comorbidities, marital status and disease duration also were not associated with recent work absence (table 5).

In contrast to patients with SLE, presenteeism in the *control* group did not correlate with demographic variables, education, pain, fatigue, depression or the number of comorbidities. Work type by professional category did not differ significantly between subjects with SLE and controls. Patients with SLE with physically demanding work reported worse presenteeism compared with controls with similar jobs (77% vs 85%, p<0.05), but absenteeism in SLE did not significantly differ between physically demanding jobs and other types. Patients with SLE with the most cognitively demanding jobs reported greater absenteeism (5.9 h) compared with controls (6.9 overtime hours, p<0.05) and also impaired presenteeism (75% vs 85% in controls, p<0.001). Thus, both extremes of physical and cognitive duties presented difficulty to subjects with SLE compared with controls (data not shown).

Table 4 Logistic regression of work disability employment status in SLE to obtain p values after dropping insignificant variables using STEPWISE elimination

	β coefficient	p Value (multivariate)	OR	OR 95% CI	
Intercept	1.2				
Age	0.03	0.005	1.031	1.012	1.055
Disease duration					
SLICC/DI, score >1	0.21*	0.014	1.232	1.042	1.4
Pain score					
FACIT-Fatigue Score	−0.05	<0.001	0.955	0.933	0.974
CES-D Score (>10)					
BCSI (≤25, 100=best function)	0.02*	0.017	1.015	1.003	1.029
Non-African–American race	−0.81	0.003	0.446	0.266	0.748
Education	−0.67	<0.001	0.513	0.390	0.638

ORs shown from final stepwise logistic regression model, after eliminating insignificant variables from the model. Controlled for slight multicollinearity by using ridge regression. Ridge coefficient=0.012, indicative of minimal effect on coefficients.
*SLICC, CES-D and BCSI were entered into the model as actual scoring variables and not 1/0 categories. N=254.
BCSI, Brief Cognitive Symptoms Index; CES-D, Center for Epidemiologic Studies Depression Scale Short Form; FACIT, Functional Assessment of Chronic Illness Therapy; SLE, systemic lupus erythematous; SLICC/DI, Systemic Lupus International Collaborative Clinics/American College of Rheumatology Damage Index.

Table 5 Patients with SLE: bivariate regression of absenteeism and presenteeism over the last week, by relevant covariates

Covariates	Absenteeism β coefficient	Absenteeism p Value	Presenteeism β coefficient	Presenteeism p Value
Overall mean	2.7 h	<0.05	77%	<0.01
Fatigue	−0.885	0.027	0.656	<0.001
BCSI	0.049	0.835	−0.220	0.014
CES-D	0.546	0.497	−1.359	<0.001
Pain score	4.463	0.017	−2.372	0.001
Age	0.020	0.959	0.057	0.690
Summed comorbidities	1.520	0.451	−1.616	0.030
Marital Status	−12.012	0.234	6.220	0.099
Race	4.391	0.651	0.321	0.993
Education*	N/A	NS	N/A	NS

BCSI, Fatigue, CES-D, Pain score, Summed comorbidities are on a continuous scale.
N=127. NS=p>0.05.
*Education assessed by ANOVA statistic.
ANOVA, analysis of variance; BCSI, Brief Cognitive Symptoms Index; CES-D, Center for Epidemiologic Studies Depression Scale Short Form; SLE, systemic lupus erythematous.

As sociodemographic factors and SLE-related variables have been associated with WD, a logistic regression with forward selection was performed with the dependent variable of WD. Independent variables of age, disease duration, BCSI score, SLICC/DI score, pain, fatigue, depressive symptoms, non-African–American race and education were chosen as covariates in the model based on univariate findings and literature associations. Age (β=0.04, p=0.008), SLICC/DI score (β=0.24, p=0.03), education (β=-0.75, p<0.001) and non-African–American race (β=-0.89, p=0.01) were independently associated with the outcome of WD, while BCSI score, disease duration, pain, depressive symptoms and fatigue score were not independently associated with WD (table 4). Individual comorbidities that were significant when added singly to the multivariate regression included osteoporosis (p=0.02), depression (p=0.025) and thyroid disease (p=0.05). However, these comorbidities did not materially affect the association of age, race, damage score and education with the outcome of WD and were not retained in the model. Other comorbidities including neuropathy, fibromyalgia, osteoarthritis, cancer, anaemia, liver disease, kidney disease, peptic ulcer disease, diabetes mellitus, hypertension and cerebrovascular accident did not individually associate with WD status (data not shown).

Similar forward selection multivariate regressions were used to analyse high presenteeism among employed/employable patients with SLE after dropping insignificant variables using STEPWISE method. Age, race, disease duration, education, SLICC/DI score, summed comorbidities, pain and fatigue did not correlate with the outcome of high presenteeism, while depression score (β=−0.192, p<0.0001) and being married (β=−1.237, p=0.013) did inversely correlate with high presenteeism (data not shown). Multivariate regression was not performed on absenteeism due to the paucity of correlates identified on univariate analysis.

DISCUSSION

We have developed a self-administered questionnaire based on the WHO HPQ to quantify work function, absenteeism and WD in SLE. This questionnaire successfully quantified increased WD as previously described in SLE. Thirty-one per cent of patients with SLE reported WD, and 88% of non-working patients with SLE ascribed work limitations to their health. This rate of WD was higher than controls (table 2).[9 10 19 23] Non-working patients with SLE had much longer duration of unemployment compared with controls (7.2 vs 2.2 years). Both highly physical and highly cognitive jobs represented challenges to employed patients with SLE.

On logistic regression, only age, SLICC/DI score, African–American race and education were found to correlate with WD status, similarly to what has previously been described.[9 10 19 23] Among parameters associated with WD on multivariate analysis, few are amenable to direct intervention using current treatment options to improve work outcomes. However, newer therapeutics may show effects in the future and these effects may help justify the costs of new biological therapies.

Increased absenteeism from work in SLE was documented in these questionnaires. The average deficit in SLE was 2.7 h/week, while the control subjects worked an excess of 4.7 h, when measured as a week-to-week variable. While this did not reach statistical significance due to the high variability of responses, this number is likely to be sensitive to change over time. Patients with SLE reported greater time disabled from home activities, averaging 7.4 days/month compared with 1.8 days/month in control subjects. Two previous studies quantified absenteeism on a yearly basis rather than 'absenteeism in the last week' used in this study.[6 26] Our approach of intermittently measured short-term absenteeism should be more dynamic in measuring improved function in patients with lupus. Longitudinal use of this questionnaire may be a helpful tool in tracking important aspects of health over time.

This is the first study to measure presenteeism in SLE. Presenteeism represents the patients' self-reported work performance over the previous 4 weeks, adjusted for the SLE subjects' assessment of coworkers. High presenteeism was associated with low pain and low fatigue levels, good BCSI scores and negatively correlated with depressive symptoms on bivariate analysis. On multivariate regression, only lack of depressive symptoms correlated with better presenteeism. This finding may indicate that presenteeism is a unique measure without major sociodemographic determinants. Conversely, it may primarily function as a reflection of concurrent depression. This suggests that affective disorders may be a mediator of work performance and is an amenable target for therapeutic interventions. Addressing and treating affective disorders may decrease later WD. However, as longitudinal data are collected using presenteeism as an outcome measure, we may be able to determine whether presenteeism quantifies a novel dimension of function rather than reflecting depression.

The limitations in this study include the cross-sectional nature of this study, which precludes longitudinal analysis, and the lack of validation of internal consistency by repetition in individual patients. However, the associations of WD with demographic factors and absenteeism with current symptomatology give strong face validity to the accuracy of our questionnaire. An area of improvement in the next version of the questionnaire will be in the employment categorisation by including 'work disabled and not working' category on the employment descriptions.

The majority of this questionnaire characterises work activities in the last 28 days, or even in the last 7 days. Thus, recall bias should be somewhat reduced by this short interval. However, subjects who are ill may still tend to over-report some factors, such as the physical and mental demands of the job, because they may struggle at otherwise routine tasks compared with healthy controls. The short time interval covered by this questionnaire may also make this useful in a longitudinal study, to track employment issues over time on various therapies, etc.

Self-administered questionnaires exploring patient functionality in a variety of domains provide greater insight into the lives of patients with SLE, document severity of disease, and may help to measure progression or improvement in disease. The current study has determined acceptability and face validity of this questionnaire as an instrument due to high completion rate and good response rates among SLE subjects and controls and the findings are in alignment with previous research. Future research should use these measures longitudinally to determine sensitivity to change concordant with clinical disease course and/or treatment in this challenging disease.

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REFERENCES

1. Faurshou M, Dreyer L, Kamper AI, *et al*. Long-term mortality and renal outcome in a cohort of 100 patients with lupus nephritis. *Arthritis Care Res (Hoboken)* 2010;62:873–80.
2. Stratta P, Canavese C, Ciccone G, *et al*. Relative survival of patients with lupus nephritis significantly improved over time in an Italian region: comment on the article by Faurschou *et al*. *Arthritis Care Res. (Hoboken)* 2010;62:1812–3. (editorial).
3. Cervera R, Khamashta MA, Font J, *et al*. Morbidity and mortality in systemic lupus erythematosus during a 10-year period: a comparison of early and late manifestations in a cohort of 1,000 patients. Medicine *(Baltimore)* 2003;82:299–308.
4. US Department of Labor, US Bureau of Labor Statistics. Women in the dataforce: A databook. May 2002, report 985 (URL expired).
5. Panopalis P, Clarke AE, Yelin E. The economic burden of systemic lupus erythematosus. *Best Pract Res Clin Rheumatol* 2012;26:695–704.
6. Campbell R Jr, Cooper GS, Gilkeson GS. The impact of systemic lupus erythematosus on employment. *J Rheumatol* 2009;36:2470–5.
7. Panopalis P, Julian L, Yazdany J, *et al*. Impact of memory impairment on employment status in persons with systemic lupus erythematosus. *Arthritis Rheum* 2007;57:1453–60.
8. Appenzeller S, Cendes F, Costallat LT. Cognitive impairment and employment status in systemic lupus erythematosus: a prospective longitudinal study. *Arthritis Rheum* 2009;61:680–7.
9. Baker K, Pope J, Fortin P, *et al*. Work disability in systemic lupus erythematosus is prevalent and associated with socio-demographic and disease related factors. *Lupus* 2009;18:1281–8.
10. Baker K, Pope J. Employment and work disability in systemic lupus erythematosus: a systemic review. *Rheumatol* 2009;48:281–4.
11. Yelin E, Trupin L, Katz P, *et al*. Work dynamics among persons with systemic lupus erythematosus. *Arthritis Rheum* 2007;57:56–63.
12. Sturfelt G, Nived O. Clinical inconsistency, benign course and normal employment rates in unselected systemic lupus erythematosus. *Clin Exp Rheumatol* 1985;3:303–10.
13. Stein H, Walters K, Dillon A, *et al*. Systemic lupus erythematosus-a medical and social profile. *J Rheumatol* 1986;13:570–6.
14. Sutcliffe N, Clarke AE, Taylor R, *et al*. Total costs and predictors of costs in patients with systemic lupus erythematosus. Rheumatology *(Oxford)* 2001;40:37–47.
15. Boomsma MM, Bijl M, Stegeman CA, *et al*. 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.

16. 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.
17. Sutcliffe N, Clarke AE, Gordon C, *et al*. The association of socio-economic status, race, psychosocial factors and outcome in patients with systemic lupus erythematosus. Rheumatology *(Oxford)* 1999;38:1130–7.
18. Yelin E, Tonner C, Trupin L, *et al*. Work loss and work entry among persons with systemic lupus erythematosus: comparisons with a national matched sample. *Arthritis Rheum* 2009;61:247–58.
19. Almehed K, Carlsten H, Forsblad-d'Elia H. Health-related quality of life in systemic lupus erythematosus and its association with disease and work disability. *Scand J Rheumatol* 2010;39:58–62.
20. Bultink IE, Turkstra F, Dijkmans BA, *et al*. High prevalence of unemployment in patients with systemic lupus erythematosus: association with organ damage and health-related quality of life. *J Rheumatol* 2008;35:1053–7.
21. Utset TO, Chohan S, Booth SA, *et al*. Correlates of formal work disability in an urban university systemic lupus erythematosus practice. *J Rheumatol* 2008;35:1046–52.
22. Garris C, Oglesby A, Sulcs E, *et al*. Impact of systemic lupus erythematosus on burden of illness and work productivity in the United States. *Lupus* 2013;22:1077–86.
23. Gordon C, Isenberg D, Lerstrom K, *et al*. The substantial burden of systemic lupus erythematosus on the productivity and careers of patients: a European patient-driven online survey. Rheumatology *(Oxford)* 2013;52:2292–301.
24. Drenkard C, Bao G, Dennis G, *et al*. The burden of systemic lupus erythematosus on employment and work productivity: Data from a large cohort in the Southeastern United States. Arthritis Care Res *(Hoboken)* 2014;66:878–87.
25. 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.
26. Clarke AE, Esdaile JM, Bloch DA, *et al*. A Canadian study of the total medical costs for patients with systemic lupus erythematosus and the predictors of costs. *Arthritis Rheum* 1993;36:1548–59.
27. Hochberg MC. Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythematosus. *Arthritis Rheum* 1997;40:1725.
28. Bunin GR, Vardhanabhuti S, Lin A, *et al*. Practical and analytical aspects of using friend controls in case-control studies: experience from a case–control study of childhood cancer. *Paediatr Perinat Epidemiol* 2011;25:402–12.
29. Wacholder S, Silverman DT, McLaughlin JK, *et al*. Selection of Controls in Case–Control Studies II. *Types of Controls. Am J of Epidemiol* 1992;135:1029–41.
30. Gladman D, Ginzler E, Goldsmith C, *et al*. Systemic Lupus International Collaborative Clinics: development of a damage index in systemic lupus erythematosus. *J Rheumatol* 1992;19:1820–1.
31. Katz JN, Chang LC, Sangha O, *et al*. Can comorbidity be measured by questionnaire rather than medical record review? *Med Care* 1996;34:73–84.
32. Sangha O, Stucki G, Liang MH, *et al*. The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Rheum* 2003;49:156–63.
33. Kessler RC, Barber C, Beck A, *et al*. The World Health Organization Health and Work Performance Questionnaire (HPQ). *J Occup Environ Med* 2003;45:156–74.
34. Wang PS, Beck A, Berglund P, *et al*. Chronic medical conditions and work performance in the health and work performance questionnaire calibration surveys. *J Occup Environ Med* 2003;45:1303–11.
35. Webster K, Cella D, Yost K. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: properties, applications, and interpretation. *Health Qual Life Outcomes* 2003;1:79.
36. Andresen EM, Malmgren JA, Carter WB, *et al*. Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *Am J Prev Med* 1994;10:77–84.
37. Irwin M, Artin KH, Oxman MN. Screening for depression in the older adult: criterion validity of the 10-item Center for Epidemiological Studies Depression Scale (CES-D). *Arch Intern Med* 1999;159:1701–4.
38. Pincus TSC, Callahan LF. A self-report cognitive symptoms inventory to assess patients with rheumatic diseases: results in eosinophilia-myalgia syndrome (EMS), fibromyalgia, rheumatoid arthritis (RA), and other rheumatic diseases [abstract]. *Arthritis Rheum* 1996;39(Suppl 9):S261.
39. Yu EB, Shikiar R, Howard K, *et al*. Validation of LUP-QOL: a lupus-specific measure of health-related quality of life (HRQL) [abstract]. *Ann Rheum Dis* 2006;65(Suppl II):601.
40. Ware J Jr, Kosinski M, Keller SD. A 12-Item Short Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care* 1996;34:220–33.
41. Keller S, Bann CM, Dodd SL, *et al*. Validity of the brief pain inventory for use in documenting the outcomes of patients with noncancer pain. *Clin J Pain* 2004;20:309–18.
42. US Census Bureau. *Labor force, employment and earnings and employed civilians by occupation, sex, race, and Hispanic origin: 1983 and 1999*. Statistic Abstract of the United States: 2000: 401 and Table 660, Washington DC: US GPO, 2001 (URL expired).

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