Employment and work disability in systemic lupus erythematosus: a systematic review

Kim Baker1 and Janet Pope2

Objectives. Many studies have provided information on employment and work disability (WD) rates in patients with SLE, yet are often limited by small sample sizes, poor generalizability or fail to examine the risks and outcomes of WD. Our objective was to systematically review the literature on WD in SLE to identify a more generalizable point estimate and range of WD in SLE patients.

Methods. A search was conducted using Medline, EMBase, PubMed and Cochrane databases to identify publications related to SLE and employment and/or WD. Characteristics of the study samples and employment/WD data were extracted. Descriptive statistics, a test for heterogeneity and random effects models were performed to obtain pooled estimates of employment and WD rates for all patients.

Results. Twenty-six studies with a total of 9886 SLE patients were found; however, not all patients were reviewed for WD. Larger studies demonstrated the prevalence of WD at 20–40%, and pooled estimates found that 46% (95% CI 40%, 52%) were employed with SLE and 34% (95% CI 24%, 44%) had WD. WD was related to psychosocial and disease-related factors including age, race, socioeconomic status (SES), education, disease activity and duration, pain, fatigue, anxiety and neurocognitive involvement.

Conclusions. This study provides strong evidence that costs of SLE may be very high due to job loss at a younger age in SLE patients, and identifies some risk factors associated with WD, which should be targeted by interventions aimed at preventing job loss.

Key words: Systemic lupus erythematosus, Employment, Work disability.

Introduction

SLE is a multi-system autoimmune disorder with a clinical course characterized by periods of both active disease and remission. SLE can occur at any age and in both genders, but most commonly affects young women with the first presentation in their second to fourth decade [1]. The clinical course of SLE is chronic and unpredictable, and can affect any organ, leading to common symptoms including fatigue, fever and arthritis, all of which can affect daily functioning and quality of life. Also, less common but more severe effects of SLE include organ damage, such as kidney, lung, heart and brain problems (psychosis, seizures, stroke and difficulty concentrating), which make a considerable contribution to the morbidity and mortality of SLE. SLE can cause significant and potentially irreversible morbidity, which leads to functional limitations affecting activities of daily living and ability to work [2–4]. Moreover, work disability (WD), or inability to work due to an illness, can have profound effects on both an individual and their family, stemming from financial hardship, loss of self-esteem, opportunity to socialize, loss of current earning and ability to accumulate assets for retirement, especially in an illness with such an early onset [5].

Society is also burdened by the economic impact of WD due to production loss and costs, justifying the need to examine the repercussions of WD in SLE patients on a larger population-based scale [6–9]. Due to the fact that past studies which have been carried out to examine employment and WD in SLE patients have indicated that work loss and limitation are common, it is obvious that there is a need to examine the level of WD in SLE patients and the impact that this has on their lives [2, 5–13].

Currently, the majority of the studies that provide data on SLE and employment or WD are either limited by small sample sizes, poor generalizability or merely included employment data as demographic information rather than as a variable to be examined. This article reviews previous studies that examined levels of employment and/or WD in SLE with the goal of identifying a more generalizable point estimate and range of WD in SLE patients.

Materials and methods

A search of all publications related to SLE and Disabled Persons/or Employment, Supported/or Eligibility Determination/or Disability Evaluation/or Absenteeism/or Unemployment was performed using Medline, EMBase, PubMed and the Cochrane databases from their inception (1966, 1950, 1980 and 1991, respectively) to May 2008. All studies including information on SLE and WD or employment rates were collected. Following a review of all abstracts, those which contained data pertaining to rates of WD or employment were then selected to be included in the final review (n=26 studies) [2, 4–28]. Inclusion criteria included articles published in English with SLE employment and/or WD information (prevalence, incidence) in the population examined. The authors’ definitions of WD were accepted for each study.

Description of studies

Data from each study were extracted by one investigator (K.B.). The following information was systematically extracted: (i) the country where the study was done; (ii) patient characteristics (sample size, mean ages, mean disease duration); (iii) disease measures (HAQ, SLAM, SLEDAI and/or SLICC/ACR scores); and (iv) employment and disability rates (expressed as percentage of participants).

Analysis

Forest plots and scattergrams were plotted of percent employed and WD separately from the available articles. Estimates of WD by sample size were examined to determine if larger samples had less outlying estimates. Factors related to WD, such as age, education, disease duration and damage, were summarized.

CIs for study estimates were calculated using Wilson’s score method [29]. Within-study variance was estimated by

\[ \text{var}_{i} = \frac{p_{i}(1-p_{i})}{n_{i}} \]

where \( p_{i} \) is the estimate of the true proportion of patients with the condition for study \( i \) and \( n_{i} \) is the total sample size of study \( i \) [30].

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Study weights were calculated as the inverse of the within-study variance. Random effects meta-analysis was used to pool study proportion estimates while accounting for differences in study quality, study population and study design [31]. Study estimate sizes are inversely proportional to study variance. The $I^2$-statistic was used to quantify the magnitude of between-study heterogeneity [32]. An $I^2$-value represents the percentage of total variation across studies due to true difference rather than chance, with values of 0–30, 31–50 and >50% representing mild, moderate and notable heterogeneity, respectively [32].

Statistical analyses were performed using R version 2.0.1 (R Foundation for Statistical Computing, Vienna, Austria).

**Results**

**Search results**

The search process identified 135 titles (Fig. 1). During the title and abstract review process, 98 articles were excluded: 30 were duplicate citations from different databases, 59 were not specifically related to SLE and either employment or WD, and nine articles were excluded as they were not written in English. The remaining 37 unique articles were subjected to a full review, at which time an additional 11 articles were excluded: eight did not report data on employment or WD rates, and three were reviews containing no unique data to report. Thus, the final review included 26 unique titles [2, 4–28] (Table 1).

**Studies included**

Thus, 26 studies with a total of 9886 SLE patients were included in the review. Eleven studies were from the United States [2, 5, 11, 13, 14, 18, 19, 23, 24, 26, 27], three were from Canada [4, 8, 9], three were from Sweden [10, 16, 20], two were from the United Kingdom [21, 22], one was from Austria [17], one was from Canada and the United States [25], one was from Canada, the United States and the United Kingdom [6], one was from Germany [7], one was from the Netherlands [12], one was from South Africa [28] and one was from Taiwan [15]. Characteristics, sample size, disease measure scores and employment and/or WD data for the SLE patients included in the studies are represented in Table 1.

![Flow chart providing numbers of studies identified, excluded and included in the review. Of the 135 potentially relevant articles (depicted by *) that were found in MEDLINE, 54 in EMBASE, 17 in PubMed and 8 in Cochrane.](https://academic.oup.com/rheumatology/article-abstract/48/3/281/1786767)
### Table 2. Descriptive statistics for 26 articles reviewed for employment and/or WD in SLE

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Number Employed</th>
<th>Sample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yazdany et al (2008)</td>
<td>382</td>
<td>830</td>
<td></td>
</tr>
<tr>
<td>Benitha and Ticky (2007)</td>
<td>19</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>Huang et al (2007)</td>
<td>66</td>
<td>129</td>
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<tr>
<td>Jonsson et al (2007)</td>
<td>3</td>
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<td></td>
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<tr>
<td>Nived et al (2007)</td>
<td>38</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>Stamm et al (2007)</td>
<td>16</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Yein et al (2007)</td>
<td>404</td>
<td>748</td>
<td></td>
</tr>
<tr>
<td>Mau et al (2005)</td>
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<td>Tench et al (2002)</td>
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<tr>
<td>Sucitville et al (2001)</td>
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<td>Clarke et al (2000)</td>
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<tr>
<td>De Costa et al (1999)</td>
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<td>42</td>
<td></td>
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<tr>
<td>Hochberg and Sutton (1988)</td>
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<td></td>
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<tr>
<td>Loistien et al (1998)</td>
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<tr>
<td>Murphy et al (1998)</td>
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<td>Partridge et al (1997)</td>
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<td>Lacalle et al (1994)</td>
<td>68</td>
<td>150</td>
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<tr>
<td>Middletone et al (1994)</td>
<td>21</td>
<td>102</td>
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<tr>
<td>Pooled Estimate</td>
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<td>9136</td>
<td></td>
</tr>
</tbody>
</table>

Test for heterogeneity: Chi² = 599.0, df = 22 (P < 0.0001), P = 96.3%

#### Analyses/Comparisons

Descriptive statistics (minimums, maximums, medians, means and s.d.) for sample size, age (yrs), disease duration (yrs), HAQ, SLAM, SLEDAI, SLICC/ACR, percent employed (%) and percent WD (%) are displayed in Table 2. Scattergrams yield the pooled estimate and percent WD by sample size for each study (Fig. 2).

The Forest plots yielded percent employed and percent WD for each study, presenting a pooled mean estimate for each (Fig. 3). The random effects estimate of the pooled percentage of participants on WD is 34% (95% CI 24%, 44%). The pooled estimate of the percentage of employed SLE participants is 46% (95% CI 40%, 52%). The I²-statistics are 97.5% and 96.3%, respectively, indicating significant heterogeneity, meaning that the variation in study estimates is above that expected by chance and the true proportions being estimated differ by study [31].

Patient characteristics associated with WD included younger age [5], African–American race [2, 11], lower socioeconomic status (SES) and lower education [2, 5, 11, 13, 22], decreased physical functioning [2, 22], longer disease duration [2], higher disease activity [2, 11, 13, 22, 24], neurocognitive involvement [11, 20, 24], and increased pain [2, 11, 22, 27], anxiety [11] and fatigue [2, 4, 11, 24].

Work characteristics associated with WD included jobs with increased physical demands [5, 13] and increased psychosocial demands accompanied by decreased control [5]. It was also discovered that most of the decrease in work in SLE was due to total cessation rather than decreased hours [5], and that SLE patients who miss >6 weeks of work are less likely to return to work within 6 months than WG patients who miss 6 weeks of work [12].

**Fig. 2.** (A) Sample size and percent employed for 26 articles reviewed. Most of the larger studies report ~50% working. (B) Sample size and work disabled found in 26 articles reviewed. Most of the larger studies report ~30% work disabled.

**Fig. 3.** Meta-analysis of percentage of (A) SLE patients employed and (B) SLE on WD.
Discussion

In this review of 26 studies with a total of 9886 SLE patients, it was found that 32.54% of SLE patients are WD (range 5–58), which is related to a variety of psychosocial and disease-related factors including age, race, SES, education, disease activity and duration, pain, fatigue, anxiety and neurocognitive involvement [2, 4, 5, 11–13, 20, 22, 24, 27]. This is comparable with rates of WD in RA, which have been found to be 32–50% [33].

The data in this review are limited due to the variety of definitions of WD including receiving disability pensions [12, 16, 26], self-reported WD [2, 8, 13, 14, 22, 24] and aggregate data from formal WD and self-reported WD [10, 11, 17, 20]. In addition, only one study examined the rate of WD over time, reporting a 15% decline in proportion employed over a 5-yr interval [5]. Definitions of employment also varied and often lacked information on employment type or duration. Furthermore, there were diverse sets of inclusion criteria, such as age of participants and level of SLE at baseline, which makes it difficult to compare the findings between each study. Also, it cannot be determined if certain factors, such as the presence of fibromyalgia, which is very common in SLE, are correlated to the presence of WD as they were either not recorded or sample sizes were too small to allow statistical significance to be reached for the trends found. Finally, many of the studies only recruited patients from one or two centres, making the findings difficult to generalize to the entire SLE population.

In conclusion, 47.08% (s.d. 13.62) are employed with SLE and 32.54% (s.d. 16.87) are WD with SLE; thus, the direct and indirect costs of SLE may be very high due to job loss at an younger age in SLE patients. Hence, future studies are needed to further examine the risks associated with job loss in SLE patients in a large multicentred sample to determine which of these risks may be modifiable in interventions aimed at reducing indirect costs of SLE via reductions in rates of WD.

Rheumatology key messages

- A total of 47.08% (s.d. 13.62) of patients with SLE are employed and 32.54% (s.d. 16.87) are WD.
- WD related to psychosocial and disease factors.
- Need to identify modifiable risks of WD in SLE.

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References

10 Nived O, Andersson M, Lindgren M et al. Adherence with advice and prescriptions in SLE is mostly good, but better follow up is needed: a study with a questionnaire. Lupus 2007;16:701–6.