Editorial

Is Work Disability Associated with Systemic Lupus Erythematosus Modifiable?

Work disability, especially premature work cessation, is a serious consequence of health conditions. For the individual, work disability reduces income and may result in loss of other employment advantages, including an active lifestyle, social networks, self-esteem, and in the US, loss of health and retirement benefits. For society, work disability means lost labor contribution and increased social program costs. Although systemic lupus erythematosus (SLE) is a relatively uncommon disease, the influence of its work disability is increased since it can extend over a long period of time, given its typical onset during young and middle-adult years.

Work disability associated with SLE has been studied less often than that of rheumatoid arthritis (RA); however, the body of literature is growing. Two articles addressing SLE work disability appear in this issue of *The Journal*[1,2]. The article by Utset, *et al*[1] examines correlates of work disability. Such information can be used to determine whether and how work disability may be modified.

Like several of the other SLE work disability studies[2-6], the sample in the Utset study is small and recruited from one rheumatology clinical site, in this case an urban setting. Thus, generalizability is an issue, an issue for the other studies as well[2-13], given that all, albeit some less than others[7,8], use clinical samples. In addition to correlates of work disability, Utset, *et al* report a work disability prevalence of 43% in their sample, which had a mean of 9 years' disease duration. This is somewhat higher than the 36% at 10 years' duration rate found by Yelin, *et al* in a large sample that best approached being population based, since subjects were recruited from the community, in addition to rheumatology practices[8]. The difference may be explained by the particular characteristics of Utset's smaller sample.

However, the SLE work disability literature[2-13] suffers from use of widely disparate methodology in addition to sample differences, so other explanations are possible. One difference, use of varying measures of work disability, is especially apt to influence study results. The measure used by Utset was "formal work disability." This is not defined, but in a prior article[5] the authors defined this as receipt of disability benefits. Subjects self-reported whether they had formal work disability currently or in the past. It is unclear if they were told what formal work disability meant. The authors report that most subjects who had formal work disability also reported their employment status as work disabled by lupus. Yelin, in contrast, examined the current employment status of subjects who were employed at disease onset, and those no longer employed were work disabled[8]. This is a more generous measure than work disability pension, or self-reported work disability due to lupus, and suggests that the difference in work disability rate between the 2 studies is more substantial than the numbers indicate.

The results of multivariate analyses assessing correlates of work disability in the Utset study differ from those of other studies[8,9,12] mainly in that work characteristics were not significant and race was significant. Three previous studies examined the role of job characteristics[3,8,9]. Subjects who had a professional or managerial type of job were less apt to be work disabled than those with other job types in one descriptive study[3], and greater job physical demand predicted work disability in multivariate analyses in the 2 studies that measured it directly[8,9]. Yelin also examined job mental demand and stressful jobs, i.e., high demand and low control, and each predicted work disability in multivariate analysis[8]. Utset assessed type of job in various ways, but none, including professional or managerial jobs versus other types, was associated with work disability. At followup, a higher portion of employed subjects held professional or managerial jobs than at baseline, suggesting a survivor effect. As the authors note, professional

See Correlates of formal work disability in an urban university SLE practice, *page 1046 and* High prevalence of unemployment in patients with SLE: Association with organ damage and HRQOL, *page 1053*

or managerial job type might have been significant in a larger sample. Another possible explanation is that, while the authors are correct in perceiving that assessment of past occupation reduces recall error in comparison to assessment of past job physical demand, it is an indirect measure and may not accurately reflect subjects' actual work.

In contrast to 3 other studies with high portions of African Americans[8,9,12], African American race was associated with work disability in the Utset study. Race did not predict work disability after adjustment for other factors in the other studies. The 4 studies differ considerably in the other characteristics of their samples and in the methods used, but the other studies all included some measure of income (poverty level in 2 studies) in their multivariate analyses. Utset used Medicaid as a poverty indicator, but it is unclear when this was assessed. As the authors note, African Americans face a number of employment disadvantages, low income, and less educational attainment, along with discrimination. Their sample is perhaps most like that of Bertoli, *et al*[12], but in addition to poverty, Bertoli, *et al* also included a measure of discrimination in their multivariate analysis.

Some measure of SLE disease severity has predicted work disability in all studies that assessed this characteristic[3,5,9,11-13]. This has usually been a disease activity score rather than damage score, but the reverse is true in Utset, *et al*. This may be because formal work disability suggests reception of disability pension, and medical criteria showing organ involvement greatly enhance disability qualification[14].

An advantage of their study is that extensive information about SLE disease characteristics was collected, including effects on specific organs, laboratory test values, medication use, and measures of fatigue and pain. Fatigue was the only specific SLE effect that correlated with work disability in the multivariate analyses, although pain was close to being significant. Only one other study mentioned fatigue[3], and in that case, subjects who had retired early due to lupus cited severe fatigue as one prominent cause. In univariate analyses, laboratory test values indicating renal involvement correlated with work disability, while other tests did not. Neurological function[3], neurocognitive dysfunction[5], impaired memory[12], or neuropsychiatric involvement[2] were associated with or predicted work disability in 4 previous studies, including one by Utset[5] and one by Bultink, *et al* in this issue of *The Journal*[2]. Clinically apparent impaired neurocognitive functioning was not associated with work disability in Utset's current study, but no testing was conducted.

Including the 2 studies in this issue, at least 13 studies now have been published with SLE work disability related data[1-13]. The study samples have not been population based, but given that SLE is relatively uncommon and difficult to diagnose, a population based study is unlikely. All studies show evidence of considerable work disability, with the largest, most representative, and most recent studies[8,11,15] showing rates at least approaching recent studies of RA work disability[15,16]. Several studies provide evidence of productivity loss due to lupus also, most clearly due to absenteeism[3,4,7,9,15]. The documentation of the extent of lupus work disability is adequate at this time, and further studies will probably not add much to the literature.

On the surface, the work disability risk factors found by Utset, *et al*[1] appear to be difficult to modify. Disease severity is not apt to become modifiable until the treatment of lupus improves. Race is not modifiable; since its impact was reduced by the addition of low income and discrimination variables in other studies, race appears to be a marker for employment disadvantage. Such disadvantages may not be easily modified. The importance of job demands, and which kinds of demands, as risk factors is not clear. In the most valid study examining the role of job demands[8], disease characteristic data were unavailable. Future studies in which a wide variety of risk factors are assessed would be useful. In addition to multivariate regression analysis, classification-tree and random-forest analyses are recommended to help identify unforeseen interactions among variables and the importance of variables[17].

Two specific effects of SLE, fatigue and neurocognitive impairment, appear to be substantial risk factors. While these effects may not be directly modifiable, intervention designed to help patients manage these effects may reduce their influence. Time management and other energy preserving strategies could help patients to better use the energy they have to accomplish essential job functions. For neurocognitive effects, Panopalis, *et al*[13] introduced the possibility that training programs developed for persons with other neurological conditions may enable patients with lupus to compensate for or restore neurocognitive impairment. Both strategies deserve to be tested. Recruiting an adequate number of employed patients with SLE for testing such interventions is challenging. However, both interventions could be useful to patients in accomplishing important family and household work and other roles[10,18], as well as employment, and this would broaden study eligibility criteria.

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