Determinants of Work Disability in Patients with Systemic Sclerosis: A Longitudinal Study of the GENISOS Cohort

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Objectives: To determine the prevalence, correlates, and predictors of work disability (WD) in the *G*enetics versus *EN*vironment *I*n *S*cleroderma *O*utcome *S*tudy (GENISOS). We hypothesized that WD in systemic sclerosis (SSc) is a function of demographic, clinical, and psychosocial factors.

Methods: Patients enrolled in the GENISOS cohort were subdivided in 3 groups: work disabled, working, and retired or homemakers. The latter group ($n = 29$) was excluded from further analysis. We used logistic regression analysis with a forward hierarchical variable selection strategy to investigate the independent correlates of WD at enrollment. Cox regression proportional Hazard's model with a similar variable selection strategy was utilized to determine the predictors of WD in those working at enrollment.

Results: Overall, 284 patients with a mean age of 48.7 years and disease duration of 2.5 ($\pm$1.6) years were enrolled into the GENISOS cohort, consisting of 83.5% female, 46.8% white, 28.9% Hispanic, and 20.4% African American. Patients were longitudinally followed in 1438 study visits. At enrollment, 124 patients (43.7%) were work disabled, whereas 131 (46.1%) were working. Lower level of education ($P < 0.001$), higher Medsger Lung Severity Index ($P = 0.012$), higher Fatigue Severity Score ($P = 0.008$), and less social support ($P < 0.001$) correlated independently with WD. Of those working at baseline, 35 (26.7%) eventually developed WD. Nonwhite ethnicity ($P = 0.038$), lower DLCO % predicted value ($P = 0.038$), and higher Fatigue Severity Score ($P = 0.009$) at enrollment independently predicted WD on follow-up visits.

Conclusions: WD is a major problem among SSc patients and its prevalence is substantially higher than other rheumatic conditions. Demographic, clinical, and psychosocial factors correlate with WD cross-sectionally and predict WD longitudinally in these patients.

 Semin Arthritis Rheum 41:38-47

Keywords: *work disability, systemic sclerosis, Medsger Lung Severity Index, ISEL, SF-36, fatigue*

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The content of this study is solely the responsibility of authors and does not represent the official views of the funding institutions. The authors do not have any financial interests that could create a potential conflict of interest and have not received any financial support or other benefits from commercial sources for the work reported in the manuscript.

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 0049-0172/11/$-see front matter
doi:10.1016/j.semarthrit.2011.01.002

Systemic sclerosis (SSc, scleroderma) is a chronic, multisystem, connective tissue disease of unknown etiology characterized by inflammation, vasculopathy, and widespread fibrosis of skin and internal organs (1). It is associated with substantial morbidity and mortality (2,3). Advances in diagnosis and treatment have improved the prognosis of SSc in recent years (4,5). Nevertheless, this disease continues to have a detrimental impact on patients' personal and professional lives (6-12).

Previous studies by the National Arthritis Data Work Group and other investigators have shown a substantial increase in the economic impact of musculoskeletal and rheumatic conditions over the last decades in the United States. This has increased from $4 billion in 1963 (13) to $353 billion in 2005 (14), with a major proportion attributable to indirect costs of work disability (WD) and wage loss (13,14). WD continues to be a major burden on individuals affected from rheumatic conditions. This may become even more prominent in the future, as the working years and productivity lost due to WD will increase with the expected increase in the retirement age (15).

WD has been extensively studied in other rheumatic conditions such as systemic lupus erythematosus (SLE), rheumatoid arthritis (RA), and ankylosing spondylitis (16-20). Although a few studies have addressed WD and its correlates in patients with SSc in other countries (7-11,21), there are no studies investigating this issue in the United States. Moreover, there are no published prospective studies reports investigating the long-term predictors of WD in SSc patients.

In the current study, we hypothesized that WD in SSc is a function of demographic, clinical, and psychosocial factors. We investigated the prevalence of WD in a multiethnic cohort of early SSc patients and assessed the factors associated with WD, at early stages of disease. Then, we longitudinally examined the predictors of WD in the patients who were working at enrollment.

METHODS

The *G*enetics versus *EN*vironment *I*n Scleroderma *O*utcome *S*tudy (GENISOS) is a multicenter prospective study of early SSc patients. It is conducted at the 3 following sites: the University of Texas Health Science Center at Houston (UTHSC-H), the University of Texas Medical Branch at Galveston (UTMB), and the University of Texas Health Science Center at San Antonio (UTHSC-SA). Study recruitment started in January 1998 and is ongoing.

Study Subjects

Details of patient selection and recruitment have been previously described (3,22-25). Patients who fulfilled the following inclusion criteria were enrolled: (1) age ≥18 years; (2) diagnosis according to the American College of Rheumatology (formerly the American Rheumatism Association) criteria for SSc (26); (3) disease onset (defined as onset of the first non-Raynaud symptom) within 5 years of enrollment; and (4) defined ethnicity with all 4 grandparents from the same ethnic group. Patients who had SSc-like illnesses associated with environmental, ingested, or injected agents were excluded from the study. All 284 patients enrolled at the time of analysis were included in this study. The institutional review boards of all participating sites approved the study and written informed consent was obtained from all subjects.

Data Collection and Questionnaires

As previously described (3,22-25), the demographic, clinical, laboratory tests, chest radiographs, pulmonary function tests, autoantibody profile, patient-reported clinical outcomes as well as behavioral, psychosocial, and functional data were obtained at the baseline visit and then on subsequent semiannual visits.

Outcome Variable

The primary outcome was the occupational status. We have annually gathered this information in a questionnaire designed according to the definitions in the Dictionary of Occupational Titles by the United States Department of Commerce (27,28). The questionnaire collected the employment status (working full-time or part-time, unemployed, retired, disabled, student, or homemaker), job description, and the reason of the current job status if anything other than working full-time. We categorized the patients into 3 groups (Fig. 1). Group A included patients working full-time, part-time for reasons other than health problems, and full-time students. Full-time work was defined as working ≥40 hours per week. Group B were work-disabled individuals, including those who were early retired, unemployed, or part-time workers because of health problems. Furthermore, the third group of patients (group C) consisted of homemakers, retired, and unemployed individuals for reasons other than health problems. We excluded group C from further analysis as we could not determine whether their occupational status was attributable to SSc.

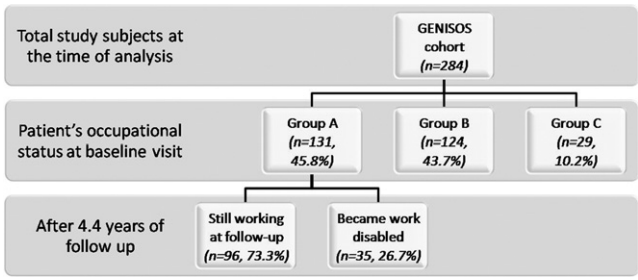

Figure 1 The employment status of the patients at enrollment and follow-up visits. (Color version of figure is available online.)