

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

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Scleroderma (systemic sclerosis) is a chronic autoimmune disease that can affect several organs. Although recent advances in treatment have improved the prognosis and survival, its impact on the patient's personal and professional life remains substantial.

Work disability continues to be a major problem in individuals with rheumatic conditions. Researchers have extensively studied the work ability of patients with other rheumatic conditions such as systemic lupus erythematosus, rheumatoid arthritis, osteoarthritis and ankylosing spondylitis. Recent data by the National Arthritis Data Work Group and other researchers indicated a significant increase in the financial burden of musculoskeletal and rheumatic conditions in the United States. This has increased from \$4 billion in 1963 to \$353 billion in 2005, with a major proportion attributable to costs of work disability and wage loss.

The impact of work disability may become even more prominent in the future, as the working years and productivity lost due to work disability will increase with the expected increase in the retirement age.

We report on results of a recently published study in *Seminars in Arthritis and Rheumatism* that investigated the frequency and determinants of work disability in scleroderma. This report is the first study on frequency of scleroderma-related work disability in the U.S. This study utilized the data collected in the **Genetics versus Environment In Scleroderma Outcome Study (GENISOS)** cohort.

GENISOS is a longitudinal study of patients with scleroderma, funded by the National Institutes of Health (NIH). This study is conducted at three different sites: the University of Texas Health Science Center at Houston (Dr. Maureen Mayes and Dr. Shervin Assassi), the University of Texas Medical Branch at Galveston (Dr. Emilio Gonzalez and Dr. Brock Harper), and the University of Texas Health Science Center at San Antonio (Dr. Hilda Draeger).

The study started in January 1998 and is ongoing. It is one of the largest longitudinal cohorts of scleroderma patients in the United States. Patients in GENISOS are from different ethnic backgrounds, including a sizable portion of Caucasian, African-American and Hispanic patients. This makes the study conclusions applicable to a large segment of patients with scleroderma.

Participants in GENISOS are evaluated every six months during the first three years, and then each year. At each visit, the patients undergo a comprehensive clinical

evaluation and psychosocial assessment. Besides collection of clinical data, the patients are asked to complete standardized questionnaires about access to health care, coping with disease, fatigue severity, perceived well-being and physical limitations.

In the current study, we hypothesized that certain demographic, clinical, social and psychological factors determine work ability in patients with scleroderma.

We detected high rates of work disability in early and late stages of disease. At the first GENISOS visit, approximately 44 percent of patients were already work disabled. The average disease duration at the first visit was 2.5 years.

After average follow-up time of 4.5 years in the study, the overall disability rate increased to 62 percent. This is two to three times higher than the work disability rate in patients with other rheumatic conditions such as systemic lupus erythematosus, osteoarthritis and ankylosing spondylitis. These findings highlight the burden of disease at the individual patient and societal levels.

### **Key Findings of the Scleroderma & Work Disability Study**

- A lower education level is linked to work disability in early stages of the disease.
- Lung involvement is the most prominent predictor of work disability.
- Fatigue is an important risk factor for work disability.
- Patients with strong support systems were less likely to need work disability.

Demographic, clinical and psychosocial factors contributed to scleroderma-related work disability in GENISOS study. In particular, lower educational level, more severe fatigue and lung involvement, as well as less social support were associated with work disability in early stages of disease. Moreover, in patients who were working at the first study visit, non-Caucasians as well as those with more severe fatigue and lung involvement were at higher risk of becoming work disabled due to their health.

An educational level less than associate degree and non-Caucasian ethnicity were two demographic risk factors for becoming work disabled. This underscores the fact that more vulnerable patients and particularly minorities are at higher risk of losing their jobs due to scleroderma.

Severity of lung involvement is the most prominent clinical factor that predicts work disability among patients with scleroderma. Lung involvement is one of the most debilitating complications of scleroderma. It is the leading cause of death and one of the most common contributing factors to overall disability and physical limitation. We are currently investigating the clinical, genetic and other biologic markers that can predict the course of scleroderma lung disease in the GENISOS cohort.

Fatigue is one of the most common and prominent symptoms of patients with scleroderma. The current study showed that fatigue is an important risk factor for work disability.

Patients who had a better interpersonal support system had lower chance of developing work disability. These findings further emphasize the important impact of psychosocial factors on scleroderma and underscore the beneficial role of strong social support from family, friends and patient support groups.

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