

<b>Principal Investigator</b>	<b>Title of Project</b>	<b>Department</b>
Cindy Mendelson (Co-I) R03	Development and Evaluation of Self- Management Program for Scleroderma	College of Nursing

Budget Start Date: 05/14/2004

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Total Award: \$225,000

### **ABSTRACT**

Scleroderma (SSc) is an autoimmune connective tissue disease with serious implications for quality of life. There is no cure for SSc; medications do little to alter its course. The disease is challenging due to the variable course and potential for disability and morbidity. Persons living outside major metropolitan areas may be emotionally and geographically isolated from support groups, knowledgeable rheumatologists and other health professionals, and disease self-management education. The purpose of this proposal is to develop and test a self-paced education and self-management program for persons with SSc. Once completed, the program will be used in a future randomized control trial to further explore self-management and quality of life in persons with SSc and the effectiveness of the program delivered via Internet. The specific aims are: develop a self-paced education and self-management program for people with SSc that includes a workbook and accompanying video/DVD/CD-ROM; and test the ability of the self-management program to change outcomes in self-efficacy, fatigue, pain, functional ability, and coping.

In Phase I, an outline for the self-management program will be prepared based on the SSc literature to include information on disease process, symptom managements, and coping skills. Focus groups will be convened to identified felt needs for such a program and essential content. Based on the focus group findings, the outlines will be updated and narratives for the workbook and a videotape/DVD/CD will be developed. Fifty individuals with SSc will be recruited into Phase II, a pre-post test design, to evaluate the effectiveness of the program to change outcomes in self-efficacy, fatigue, pain, functional ability and coping. The intervention consists of completing the self-management program. Descriptive statistics will be calculated for the demographic characteristics as well as for the outcome measures. Two sample tests will be used to compare scores on the measures before and after intervention. Debriefing interviews will be conducted to determine the ease of program use, program design, perceptions of the program, suggestions for revisions and perceived value of the program.

The proposed project will provide a comprehensive program that will educate persons with scleroderma and help them manage and cope with this chronic and disabling disease.