

Psychosocial Aspects of Scleroderma



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KEYWORDS

- Scleroderma • Systemic sclerosis • Psychosocial • Quality of life
- Self-management

KEY POINTS

- Symptoms of systemic sclerosis (SSc), including fatigue, pain, pruritus, sleep problems, and sexual impairments, negatively influence quality of life in many patients, and may lead to emotional consequences such as depression, anxiety, and body image distress caused by appearance changes.
- Providing accessible information to patients with SSc regarding problems common to people living with the disease, as well as information regarding useful resources and services to address these problems, can help patients with SSc and can easily be implemented by health care professionals.

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- In addition to referrals for professional health care interventions, low-intensity strategies such as self-management programs and support groups may be helpful to some patients with SSc.
- Future research should focus on the development and testing of interventions designed specifically to meet the educational and psychosocial needs of patients with SSc.

INTRODUCTION

Systemic sclerosis (SSc; also called scleroderma) has far-reaching consequences for physical health, as well as emotional and social well-being.^{1–4} Because there is no known cure for the disease, SSc treatment focuses on reducing symptoms and disability, and improving health-related quality of life (HRQL). This article summarizes the impact of SSc on common patient-reported problems associated with HRQL and describes potential interventions to support coping with the consequences of the disease.

Depression

Depression involves symptoms that may include sadness, loss of interest or pleasure, feelings of guilt or low self-esteem, poor concentration, and disturbed sleep or appetite. A study of 345 patients with SSc enrolled in a Canadian registry reported that the prevalence of major depressive disorder (MDD) was 4% for the past 30 days, 11% for the past 12 months, and 23% for lifetime.⁵ A French study of 50 hospitalized patients with SSc and 50 patients with SSc who attended a patient organization meeting found that 19% had current MDD and 56% had lifetime MDD, and rates were higher in hospitalized (28% current) versus nonhospitalized (10% current) patients.⁶ Depression is substantially more common in patients with SSc than in the general population and may be more prevalent than in other rheumatic diseases.⁵ However, many patients with SSc and other chronic diseases who meet criteria for MDD at a given time point do not meet criteria consistently. In the Canadian sample, only 3 of 12 patients with SSc who had a current major depressive episode at baseline met diagnostic criteria 1 month later.⁷ Some episodes may be time limited and may resolve without targeted intervention or treatment. Others may reflect ongoing moderate symptoms that only variably meet criteria for formal diagnosis. Many patients with SSc describe ongoing emotional distress from the burden of living with the disease, but differentiate this qualitatively from what they consider clinical depression.⁸ Cross sectionally, factors associated with symptoms of depression in SSc include greater overall disease burden, which may involve degree of gastrointestinal involvement; breathing problems; skin involvement; and tender joints.^{9–11}

Anxiety and Fear

Anxiety can be a normal reaction to stress; however, it may also lead to mental health problems when experienced in excess. To date, only 1 study documented the prevalence of anxiety disorders among patients with SSc. In that study, 49% of 50 hospitalized patients and 50 patients who attended a patient meeting had at least 1 current anxiety disorder, and 64% met criteria for at least 1 anxiety disorder in their lifetimes. Social anxiety and generalized anxiety disorder were the most common.⁶ There was no difference in prevalence between hospitalized and nonhospitalized patients.

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