

Dorcas Kwete, Duru Favour
SYSTEMIC SCLEROSIS IN WOMEN AND SOCIAL ASPECT
Tutor PhD, associate professor Apanasovich V. G.
2nd Department of Internal Diseases
Belarusian State Medical University, Minsk

Introduction. Systemic sclerosis (SSc) is a chronic, progressive autoimmune disease with major end-organ involvement. Much attention has been focused on the management of physical and clinical manifestations; however, the effect of the disease and treatment on the patient's identity, relationships, functioning, and mental well-being are less known.

Aim: study social aspects of the life of women with systemic sclerosis.

Materials and methods. Patient data were analyzed, Thematic synthesis was used to analyze the findings.

Results and their discussion. Twenty-six articles (12 journal articles, 7 abstracts, and 7 dissertations) involving 20 patients were included. There were 20 women, and the age of participants ranged from 33 to 68 years. Subtypes of SSc were predominantly patient-reported (diffuse SS: 4; limited: 16). The disease duration since diagnosis ranged from 0 to 48 years. Data were collected using interviews (12 studies), focus groups (4 studies), phone interviews (3 studies), and an open-ended questionnaire (1 study). Women felt that they were undesirable, unattractive, and had "less to offer". Those who were single were afraid of remaining unwanted. Some had the painful experience of being told they were "no longer sexually attractive" by their husbands, or treated as if it was an embarrassment to be seen in public together. Lower libido, decreased secretions, and physical pain were barriers to sexual activity and made some women feel guilty. Patients struggled to fulfill roles as parents, grandparents, and children. In particular, women felt inadequate because they could not care for their children or perform household duties and men regretted being unable to be physically active with their children. One patient felt guilty about being unable to reciprocate the help provided by parents. Diminishing work capacity made patients feel pressured and disappointed with themselves. They reduced their work hours because of exhaustion, or sought help with fine motor tasks such as stapling, typing, and filing because of hand deformities. Some experienced discrimination by being unfairly demoted or treated as if they were "disabled".

Conclusion. Women with SS experience problems associated with social adaptation in society, due to the clinical features of the disease. Changes in facial features, Raynaud's syndrome, sclerodactyly, trophic ulcers and telangiectasia in some cases make it difficult to get married, maintain it, and have a child. In more favorable conditions are women who got married before or at the onset of the disease, when close family relationships had already developed, but not always.