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Psychological adaptation to a rare, disfiguring disease: European study with patients suffering scleroderma

Ângela Maia & Catarina Leite

CIPSI, Escola de Psicologia, Universidade do Minho

angelam@psi.uminho.pt

catarinaleite@portugalmail.pt

Background: Scleroderma is a chronic disorder, characterized by thickening and fibrosis of the skin and disruption of internal organs that affects global functioning and quality of life. Facial skin alterations have an impact on self-esteem and interfere with social interactions, with an association to psychological symptoms, especially depression. The aim of this study, in collaboration with a Canadian team and European Associations, intended to characterize the symptoms and the psychological problems in European patients with scleroderma.

Methods: 563 participants from 13 European Countries; 484 (89%) female; 59 (11%) male; mean age: 49 ($SD= 14.8$); 93% caucasian; 68% married; 32% higher education filled out the Patient Survey of Health Concerns and Research Priorities. (Scleroderma Society of Canada (SSC) and Canadian Scleroderma Research Group). The questionnaire has 11 Sections (Demographics, Diagnosis and Disease; Healthcare Services Utilization; Healthcare Services Reimbursement; Healthcare Services Reimbursement Needs; Medical Care; Symptoms; Employment; Sensations; Physical Appearance; Commentaries).

Results: the symptoms most commonly reported by patients are: joint pain, fatigue, Raynaud's symptoms, muscle pain, hardening/tightening of the skin, difficulty sleeping, difficulty remember things and heartburn. 74% of participants reported that they show little interest or pleasure in performing tasks several days, more than half of the days or nearly every day. 72% feels down, depressed or hopeless, several days, more than half of the days or nearly every day. 72% Feel's nervous, anxious, or on edge, more than half of the days or nearly every day. 40% reported the avoidance of activities because they feel that they will fail due to scleroderma related problems. 43% of participants have been diagnosed with diffuse scleroderma and 21% with CREST. 77% reported other medical conditions, the most frequent being Esophageal dysfunction (56%). 100% of participants reported concern regarding the appearance of parts of their bodies, which they consider especially unattractive due to scleroderma. 64% of participants reported that scleroderma affects their ability to work, very much or extremely.

Discussion and Conclusions: The results concerning the frequency and impact of symptoms were approximate to the results obtained in Canada. There was however some marked differences in psychological variables. The results of the European participants reached higher levels on issues of depression and anxiety. The results of this study indicate that all participants are concerned about the physical appearance due to scleroderma. These results emphasize the need of psychological intervention in patients with scleroderma in Europe. These results should be taken into consideration by the teams who follow these patients.