

Title: Determinants of happiness and quality of life in people with systemic sclerosis: a structural equation modelling approach

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Systemic sclerosis (SSc) is a chronic rheumatic disease that can lead to a substantial decrease in quality of life through physical, emotional and social impacts of the disease. Patients affected by SSc must cope with a progressive disabling condition often characterized by pain, fatigue, sexual dysfunction, body image distress and impairment in the ability to perform basic activities. Furthermore, these patients also suffer from psychological impairments, such as depression and anxiety, with further impact on their health-related quality of life (HRQoL).

There are several general and SSc-specific patient report outcomes (PROs) instruments have been developed and have evidence of validity in patients with SSc. Remarkably lacking in these outcomes is the evaluation of the overall perspective of well being, equivalent to 'happiness' or a "positive psychological dimensions". Recently, our research group demonstrated that optimization of QoL and happiness of people with rheumatoid arthritis requires not only effective control of the disease process but also improvement of the disease impact domains. In this context, personality seems to play a pivotal mediating role in these relations.

The need for further research in HRQoL in SSc has been highlighted, and particularly underexplored in SSc. The objective of the present project is to evaluate the determinants of happiness and QoL in people with SSc. Through a observational, transversal and multicenter design we expect to include ≈200 consecutive SSc adult patients registered in The Rheumatic Diseases Portuguese Registry (Reuma.pt)/Scleroderma. Physical, psychological and social dimensions will be evaluated through dedicated questionnaires and assessments. Descriptive and correlational analyses will be performed with SPSS V.23 (IBM®). A structural equation modeling (latent variable structural model) will be used to estimate the association between these variables and performed with AMOS® 24.0 (IBM® SPSS), using a maximum likelihood estimation. In order to analyse the influence of comorbidities, a multigroup analysis will be performed through a critical ratios and chi-square differences procedure. This proposal may represent an important progress towards the incorporation of PROs in the current management of SSc and, thus, in the much-needed implementation of patient-centered care.