

Patient Perception of Disease Burden in Diffuse Cutaneous Systemic Sclerosis

Dinesh Khanna¹, Yannick Allanore², Christopher P. Denton³, Marco Matucci-Cerinic⁴, Janet E. Pope⁵, Barbara Hinzmann⁶, Siobhan Briody⁷, Janethe de Oliveira Pena⁸ and Oliver Distler⁹,
¹Division of Rheumatology, University of Michigan, Ann Arbor, MI, ²Immunogenetics, Cochin Institute, Paris, France, ³Rheumatology and Connective Tissue Diseases, University College London, London, United Kingdom, ⁴Department of Medicine, Division of Rheumatology, University of Florence, Florence, Italy, ⁵University of Western Ontario, London, ON, Canada, ⁶Bayer Pharma AG, Berlin, Germany, ⁷Blueprint Partnership, Manchester, United Kingdom, ⁸Bayer HealthCare Pharma, Whippany, NJ, ⁹Research of Systemic Autoimmune Diseases, Center of Experimental Rheumatology, University Hospital Zurich, Zurich, Switzerland

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SESSION INFORMATION

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Session Title: Epidemiology and Public Health Poster I: Comorbidities and Outcomes of Systemic Inflammatory Diseases

Session Time: 9:00AM-11:00AM

Background/Purpose:

Diffuse cutaneous SSc (dcSSc) is associated with high morbidity and mortality, and reduced quality of life. Patient priorities are rarely discussed, with physicians traditionally focusing on organ involvement rather than skin changes. Using discursive approaches and ethnography, a unique, qualitative research methodology, we evaluated the impact of dcSSc symptoms on patients' daily lives, and examined how disease burden shapes patient outlook.

Methods:

Patients were recruited via healthcare professionals (HCPs) or patient associations. In France, Italy, the UK and US, patients filmed daily short (~15-minute) video diaries about their lives over 7 days. On Days 1 and 7, patients took part in a moderator-led discussion of their experiences, and an observation session to understand the impact of living with dcSSc. In Germany and Spain, patients participated in 60-minute telephone interviews. Patients were also assigned tasks to encourage reflection on their feelings about dcSSc. Video footage and transcribed discussions were reviewed, and the data were categorized and assessed for themes, patterns, and indicators of emotion, ambivalence, and conflict.

Results:

Twenty-three patients (mean age 54; 83% women) were recruited. Of these, 17 made video diaries, and 6 took part in telephone interviews. The majority of video diaries and interviews took place in patients' homes, and on average 5.25 hours of video footage were collected per patient.

The results of the study show that time to diagnosis may be delayed, as patients trivialize their symptoms and HCPs often attribute symptoms to other causes. Patients also have a poor understanding of their diagnosis, and information to aid understanding is rarely provided. DcSSc is associated with a high treatment burden; on average this patient sample received 10 tablets of prescribed drugs per day. Importantly, while patients were aware of the seriousness of organ involvement, they reported that skin changes, pain, and fatigue have a dominant effect on daily life, impairing their ability to perform routine tasks. Skin tightening in the lower limbs and feet lead to deformity and loss of mobility, while Raynaud's phenomenon, calcinosis, and digital ulcers cause significant pain, as well as loss of function. Furthermore, skin tightening around the mouth impacts the ability to eat, and dental hygiene. Changes in esthetic appearance lead to embarrassment, loss of identity, withdrawal from social life, and depression. Patients experience dcSSc as a series of losses, including independence and self-esteem, and the unpredictability of the disease makes the patient journey and acceptance of the condition difficult. Moreover, patients tend to have small support networks and support services are not offered as part of standard care.

Conclusion:

Patients with dcSSc have high treatment and emotional burdens, with skin complications, pain, and fatigue profoundly impacting their daily lives. Patients place the most emphasis on these issues rather than the chance of organ involvement. There is an unmet need for patient information at the time of diagnosis and for emotional support services throughout their journey with dcSSc.

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