



4. Focus groups to inform the development of a scleroderma emotional distress coping tool.

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Background: Scleroderma (SSc) is a rare, chronic, progressive, connective tissue disease that has negative physical and psychological implications. It is characterized by abnormal fibrotic processes and excessive collagen production, which manifests in thickening of the skin and damage to the internal organs, including the heart, lungs, and gastrointestinal tract. Treatments focus mainly on the management of medical symptoms, yet many patients experience significant emotional distress. To date, few interventions exist for patients coping with the emotional aspects of this disease. The Scleroderma Patient-centered Intervention Network (SPIN) is developing an online intervention to help individuals cope with the emotional aspects of living with SSc. Our objective was to better understand sources of emotional distress and coping strategies used by SSc patients in order to inform the development of the intervention.

Method: A total of 22 participants were recruited through the Canadian Scleroderma Research Group and the Scleroderma Society of Ontario, and 3 focus groups were conducted (Montreal French, N=11; Hamilton English #1, N=5; Hamilton English #2, N=6). Within these focus groups, participants were asked to evaluate the potential usefulness of proposed content for a SSc-specific online intervention tool. Focus group discussions were recorded, transcribed, and then coded for emerging themes using the software Atlas.ti. Thematic inductive analysis was used to identify common themes that were grouped into concepts and categories of emotional distress and common coping strategies.

Results: Core sources of emotional distress included experiencing constant pain, not understanding or knowing how to cope with depressive feelings, and attempting to improve health by experimenting with new medications and treatments. Additional areas causing distress involved maintaining roles and responsibilities within families, being unable to work, feeling constant fatigue, and being uncertain about the progression of the disease. Common coping strategies were attending support groups, maintaining a positive attitude, learning and applying strategies on how to manage symptoms of the disease effectively, and adopting a "one day at a time" mindset. The most commonly reported emotions triggered by the disease were feelings of stress, frustration, hopelessness, and anger.

Conclusion: Results from group discussions revealed sources of stress and ways of coping that were both common to living with a chronic disease and unique to SSc. This information will be used to help create a web-based intervention to support coping with the emotional aspects of living with SSc.