

Experiences, coping and support preferences of men with SSc

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Evidence suggests that men cope with stress and illness differently to women. Dr Flurey's previous research suggests men with rheumatoid arthritis, another rheumatic condition, struggle to manage and don't find support that's currently offered, delivered in a way they wish to access. Thus, men with Systemic Sclerosis (SSc) may not be receiving support suited to their needs. This project concentrates on men's experiences and needs, and will be the first to clarify the need for any specific male-oriented support structures in SSc. This project aims to find out how SSc affects the lives of male patients, how they cope with this, and what type of support male patients would like the clinical team to provide.

The project involves a comprehensive literature review of the physiological and psychosocial gender differences in (SSc). Followed by focus groups to explore impact, coping, masculinity and educational needs (content and delivery). Finding out how SSc affects male patients, and understanding how men cope with their SSc will provide a better insight into their experience, and inform the development of tailored support.

Development and evaluation of a patient decision aid for autologous hematopoietic stem cell transplantation in systemic sclerosis

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The objective of this project is to develop a decision aid for AHSCT in SSc and to collect feedback on this tool from patients with severe SSc and clinicians caring for them on the comprehensibility and perceived utility. It could also provide a model for the development of decision aids for other SSc treatments.

A five-step approach will be taken to the development of the decision aid. Knowledge users (clinicians caring for patients with SSc and patients with SSc who are candidates or have had AHSCT) will be involved throughout each step in the development process. Knowledge users will be involved throughout each step in the development process. First, a research team will be established consisting of clinicians, patients, researchers and experts in decision making (Phase 1). Phase 2 includes reviewing and synthesising the evidence on the possible harms and benefits of AHSCT versus other treatments. In phase 3, we will conduct focus group interviews to gather input on patients' decision needs. We will also conduct interviews with clinicians caring for patients with SSc to assess their views on patients' decision needs. Combining the information from phases 2 and 3 will lead to the development of an initial decision aid in phase 4. Phase 5 consists of a pilot-test during which we will collect feedback from patients with severe SSc and clinicians to assess the comprehensibility and perceived utility of the decision aid. After revising the decision aid if necessary, we will broadly disseminate the tool to patients and healthcare providers.

Development of the optimal touchscreen interface for patients with scleroderma

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Hand disability is a common consequence of scleroderma (SSc). Most SSc patients are young or middle-aged women experiencing limitations in hand function, ranging from mild impairment in early stages (Raynaud's phenomenon and puffy fingers) up to severe dysfunction in later stages (digital ulcers and sclerodactily) leading to hand deformity. Impaired hand function is a major contributor to overall disability and reduced health-related quality of life. Most personal devices (smartphones, tablets) are based on touch-screen technology, which is not easily accessible by people with hand function impairment.

Objectives and specific aims: The long term goal of this project is to improve the quality of life of SSc patients with hand dysfunction by providing them with easy-to-use touch-screen devices. To achieve this goal, the specific aims of this project are:

1. the technical design of the novel touch-screen adaptive user interface dedicated to facilitate the use by SSc patients;
2. the initial observational study to assess the improvement of quality of life perceived by SSc patients using the modified touch-screen interface
3. the innovative user centered protocol to evaluate the users satisfaction and system usability and acceptability.