

MANagement Of patients with Systemic Sclerosis: A mixed methods study of the chronic illness management practice patterns and the development of a new model of care (MANOSS project)

Abstract

Systemic sclerosis (SSc) is a rare autoimmune disease involving fibrosis and inflammation of the skin, joints, tendons and internal organs resulting in disability, reduced quality of life and increased mortality. Like other patients with rare diseases, patients with SSc face significant health disparities concerning access to specialized health care. To improve their clinical and economic outcomes these patients are in need of coordinated illness management and patient self-management support. Therefore, a need exists to better understand chronic illness management (CIM) in SSc by engaging a range of different stakeholders.

The main purpose of the proposed study is to evaluate patient needs and contextual factors to develop a clinically feasible new model of CIM for patients living with SSc and their families to potentially improve health outcomes in this population.

A mixed methods approach will be employed to better understand real-life contextual factors and stakeholder concerns. First, we will conduct a scoping review to identify previously tested/implemented models of care for rare disease patients and in parallel we will perform a detailed review of the chronic care demands of people living with SSc. Second, a quantitative cross-sectional survey will be conducted to identify perceptions of current CIM practice patterns held by patients with SSc and healthcare providers. This data will be supplemented with qualitative interviews providing in-depth understanding of care needs to develop explanatory hypotheses on mechanisms identified in the quantitative survey results. Third, a Delphi study will be conducted with patients and professionals to model CIM process and patient outcomes for a proposed complex intervention central to the new CIM model for SSc patients.

The MANOSS study will contribute to understanding the needs of patients and families living with SSc as well as the perspectives of healthcare professionals who care for them in the Swiss healthcare system. This will serve an important evidence base for the description of a tailored and testable CIM model of care that has the potential to improve health and economic outcomes for patients with SSc.