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SSc management – In person appointments and remote therapy (SMART): A framework for management of chronic hand conditions

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ABSTRACT

The changing health care climate poses unique challenges to managing a chronic and progressive disease like systemic sclerosis (SSc). At our institution, we employ a new model for SSc management that combines “in person” appointments and “remote” therapy (SMART). This program fosters an understanding of the disease process with the goal of improving skills and confidence for self-management and empowering individuals by providing a means of daily self-assessment. Technology is utilized as a means to remotely monitor and assess progress. We present our approach as a framework for long term management of chronic hand conditions. Evidence from a variety of disciplines is cited to support the design and parameters of this model.

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Introduction

The treatment of chronic musculoskeletal conditions poses multiple challenges to health care practitioners and patients. The current health care climate compounds these challenges by providing limited reimbursement for therapy services. Treatment of these conditions is fundamentally different than an acute injury and demands long term re-assessment and treatment. Due to the chronicity, the polyarticular nature, and systemic involvement of the disease, the traditional hand therapy paradigm of short term, focused, regular sessions is neither feasible nor effective, thereby demanding a reconceptualization of rehabilitation services to optimize resources. A paradigm shift is required to move the locus of control from the clinic to the home and transfer the rehabilitation responsibility from supervised therapy to a self-monitored program.

At our institution, The Hospital for Special Surgery, we have the opportunity to treat a large number of patients with systemic sclerosis (SSc). Therapists work closely with physicians and health professionals at the Scleroderma, Myositis, and Vasculitis Center to provide both clinical care and an infrastructure for basic, translational and clinical research. We developed The SMART framework

to effectively enlist the patient as the “home therapist,” fully accountable for managing the disease and permitting the therapist to serve as consultant and coach. With fewer therapy visits invested on the front end, resources are allocated over time to allow for a long term relationship and oversight of care. This systematic approach to the therapeutic management of SSc is based on a thorough review of current evidence and best practice. SMART is a practical framework for treatment integrating traditional hand therapy “in person” appointments and “remote management” in a hybrid fashion (see Fig. 1 for a schematic representation of this approach). Both of these components are crucial to the success of the program. The “in person” component (IPc) is essential to tailoring the program to the individual needs of each patient by taking into account the wide variations and complex ranges of disease presentation. The “remote management” component (RMc) carefully monitors this individualized plan while creatively solving the problem of both decreased access to care and chronicity of illness, successfully shifting the in-person appointment experience to a self-management perspective.

The SMART framework also addresses the challenge of treatment program compliance which is particularly difficult, yet imperative in the face of chronic illness. Successful attempts to improve adherence have been studied and documented extensively.¹ Martin et al suggests three categories of contributing factors: clear and effective *communication* between the health care provider and the patient, realistic assessment of patient’s

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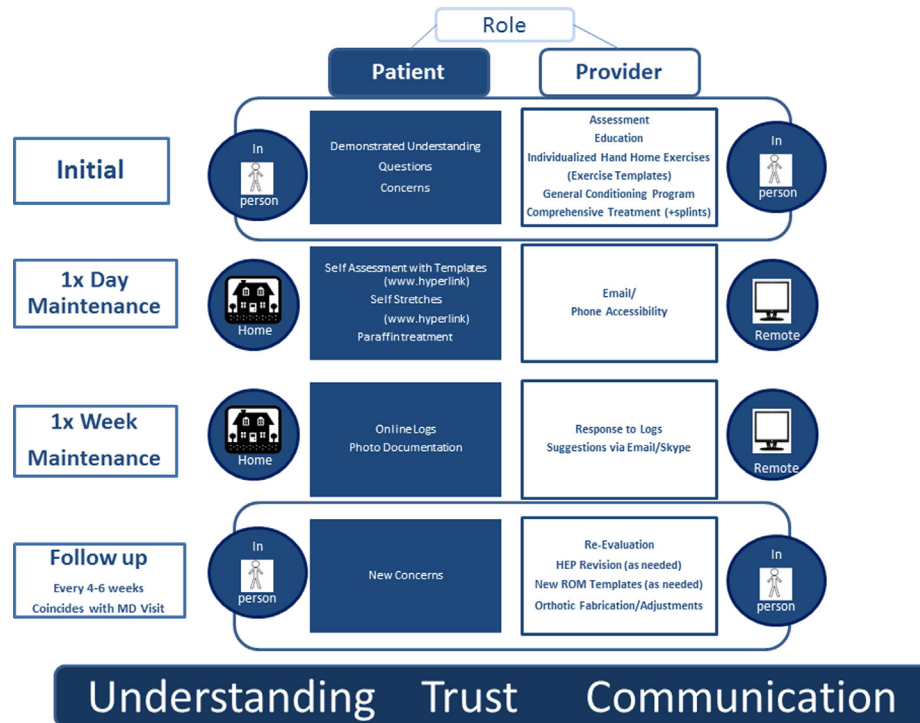


Fig. 1. Schematic framework for treatment.

understanding and knowledge, and a *trusting* relationship between provider and patient.¹ Based on these premises, we designed and implemented our model that rests on 3 foundational values: understanding, trust, and communication (Fig. 1). The program is designed to empower patients with knowledge and understanding, and provide them with a custom designed practical approach to manage and control hand impairment using readily available technology to facilitate the process.

Application of the SMART framework to management of SSc

Systemic sclerosis (SSc) is a chronic autoimmune condition of uncertain etiology characterized by vasculopathy and fibrosis of the skin and internal organs.² Hand impairment is a major cause of morbidity and disability in this patient population³ and is characterized by the interplay of several factors. Fibrosis of the skin and underlying tendons can lead to contracture of the fingers. Inflammatory arthritis is also frequently present, accompanied by joint pain and swelling. Additionally, vasculopathy leads to ischemic damage of the fingers with the development of digital ulceration and poor wound healing when trauma occurs. All of these factors lead to decreased range of motion and decreased function of the hand.⁴ The presence of joint pain, tendon friction rubs, and contractures predicts significantly higher disability indices.⁵ Medical treatments address specific issues in SSc, but there is presently no satisfactory disease-modifying agent to reverse the overall condition. Studies addressing individual treatment and group interventions have been reported^{5–8} as well as educational programs designed to address patient understanding and group support.^{9,10} Additionally, recent studies examine the efficacy of Internet education modules in a population with SSc.^{11,12} However, no systematic approach *encompasses* and *combines* both “in-person management” and “remote management” to meet patients’ needs by accommodating for limited health care accessibility and reimbursement as well as the chronicity of the disease.

The SMART framework is an attempt to address the global rehabilitation needs of an SSc patient. Below, we present each component of the SMART framework. These components are not sequential and often overlap. Each component is first described and then followed by evidence from a variety of disciplines to support the parameters and design. Previously reported effective treatment methods are integrated into this approach with additional novel and innovative ideas that utilize current technologic advances.

“In person” component (IPC)

The IPC consists of both an initial phase and follow up visits. The initial IPC may last anywhere from one session to 1–2 sessions weekly over a period of a month to 6 weeks. The length of the IPC will be dictated by the extent of the disease and level of impairment as well as feasibility factors such as proximity to services and health insurance coverage. Ideally, the initial IPC should be performed over several sessions, however, in individual cases one session may be all that is required or feasible. Additionally, these sessions are best performed in a quiet and undisturbed environment with enough time allotted to devote to multiple issues. The goals during the initial IPC are: 1) To provide information and understanding of the nature of the disease process and progression with particular attention to the hand. 2) To optimize the available skin and soft tissue mobility via manual therapeutic techniques. 3) To provide a simple and manageable home program that utilizes visual feedback methods for accurate self-assessment of progress.

The initial IPC is comprised of 5 components:

1. Assessment
2. Education
3. Individualized Hand Home Exercise Program – development and provision
4. General Conditioning Program – development and provision

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