



SCLERODERMA AND PAIN MANAGEMENT: Don't underestimate your power to act

Pascale Marier-Deschênes,
Ph.D. Candidate at Université Laval

Dre Anne Marie Pinard
Full professor, Faculty of Medicine, Anesthesiology
Department / Laval University



WHAT IS PAIN?

Pain is: "***An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.***" ⁽¹⁾ According to this definition by the International Association for the Study of Pain (IASP), this complex experience is not solely dependent on physical factors. Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors. Depending on its duration, pain can be described as acute or chronic. The IASP defines chronic pain as "***pain that persists or recurs for more than 3 months***" ⁽²⁾.

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WE DISTINGUISH THREE TYPES OF PAIN, WHICH MAY COEXIST:

- ▶ **Nociceptive pain** arises from damage to body tissues and is the typical pain experienced following injury or caused by inflammation. It is usually described as a sharp, stabbing, or throbbing pain.
- ▶ **Neuropathic pain** results from direct damage to the nervous system itself. It is usually described as a burning or shooting pain and may cause numbness or tingling of the skin or extreme sensitivity to even the lightest touch.
- ▶ **Nociplastic pain** arises from a change in the functioning of pain-sensitive nerves rather than from direct damage to the nervous system. The sensitive nerves become more reactive (sensitized). It is similar in nature to neuropathic pain⁽³⁾.

This definition of nociplastic pain is recent and much work remains to be done to better understand its mechanisms⁽⁴⁾. However, this type of pain is a good example of neural plasticity, a concept according to which neurons have the capacity to change in response to stimulation or learning. This plasticity may lead to the chronification of pain because your brain has somehow become accustomed to sending you danger signals whenever you move or are touched, for example. Conversely, it can also be used to reverse these changes and reduce chronic pain.

WHAT ABOUT PAIN IN PEOPLE WITH SCLERODERMA?

Authors have pointed out that pain in scleroderma patients has long been underestimated and understudied^(5,6). Fortunately, several teams have recently contributed to a better understanding of the pain experience of people with scleroderma to guide assessment and management. Their findings show that more than 80% of people with systemic scleroderma experience various types of pain related to their condition^(7,8). Approximately 45% experience pain on a daily basis^(8,9), and 38% report moderate to severe pain, defined as ≥ 5 on a scale of 0 to 10⁽⁹⁾. Hand pain, associated with typical scleroderma manifestations such as ulcers, joint contractures, and impaired hand function, increases in importance with disease progression. These are common pains, present in approximately 80% of patients with systemic scleroderma^(5,8). A large number of people also report low back pain as their main pain, especially in the early stages of the disease⁽⁵⁾. Pain associated with Raynaud's phenomenon, headache, chest pain, gastrointestinal pain, and pain on swallowing are also reported⁽⁸⁾. Contrary to what might be expected, the intensity and chronicity of pain would not be associated with an increase in the disease severity⁽⁵⁾. The pain would change minimally over time, and the change that does occur in the long term suggests that overall pain tends to improve slightly, not worsen⁽⁶⁾. For localized scleroderma, 46% of participants in a European study reported experiencing mild (32%), moderate (9%) or severe (4%) pain or itching⁽¹⁰⁾.

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Consistent with the definition of pain, emotional health, perceived physical health and social support are associated with the initial experience of pain in people with scleroderma⁽⁶⁾. Social support would be of great interest in understanding the pain experience, especially since some people with scleroderma may avoid socializing because of changes in their appearance. It is important to note that it is not the number of relationships that matters, but the availability and quality of perceived social support⁽¹¹⁾.

HOW DO THESE FINDINGS GUIDE PAIN MANAGEMENT?

Regardless of the severity of scleroderma and the exact nature of the disorder, it is important to address pain, pain management and psychosocial functioning with health care professionals⁽⁶⁾. Strategies that address psychosocial factors (e.g. depression, sleep, coping skills, social network) should be considered. As previously mentioned, these factors influence perceived pain.

One approach that should be considered is to follow an adapted program of physical activity⁽¹²⁾. Regular physical activity is associated with reduced pain intensity and interference in people with scleroderma⁽¹³⁾. People with scleroderma who are physically active report lower levels of fatigue than those who are inactive. Participants in one study reported that following a combined exercise program that included aerobics and resistance training, for example, improved their physical fitness and social life, and helped them feel more energetic and stronger⁽¹⁴⁾.

Other authors suggest taking part in psychosocial follow-up⁽¹⁵⁾. Some also recommend developing skills in various areas^(6,9,11), such as:

- ▶ Mindfulness, a meditation technique that involves focusing on the present moment and being aware of one's thoughts, emotions, and bodily sensations without judging them;
- ▶ Relaxation, a technique that aims to reduce stress and anxiety through methods such as deep breathing, visualization, and muscle relaxation;
- ▶ Adaptation, the ability to adapt to life changes and face challenges in a positive way;
- ▶ Modification of maladaptive beliefs, reframing ideas or beliefs by challenging them and replacing them with more positive and realistic thoughts. In this sense, beliefs that may be false, exaggerated, irrational, or limiting can contribute to mental and emotional health problems.

It should be noted that these strategies are not specifically designed to reduce perceived pain, but rather to better manage and minimize its impact on function and quality of life.

Medication is also an option, but given its limited improvement in pain, it is a complementary option to the non-pharmacological strategies listed above.



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HOW TO SELF-MANAGE PAIN?

Pain education is the first step to better managing chronic pain. The web portal [My pain management](#) offers a wide range of expert-validated resources on the topic, as well as the pain self-management program "*Agir pour moi*" (Taking action) [in French only].

As the name suggests, self-management is an approach that emphasizes the active role we can play in managing our health condition by adopting positive behaviours. The idea is to be a key player in your own care. Self-management means developing the ability to manage symptoms, treatments, physical and psychosocial consequences, as well as the lifestyle changes associated with having a chronic disease. Compared with usual care, participation in a self-management skills program improves several measures of physical and emotional functioning in the short-to-medium term. In this sense, it is beneficial to consider both the application of certain self-management strategies in daily life and consultation with health professionals. These are two approaches that should be combined to manage pain appropriately.

The self-management strategies promoted for chronic pain are essentially the same regardless of the pain condition. Self-management programs typically include some or all of the strategies related to managing stress, energy, physical activity, thoughts and emotions, sleep, diet, and maintaining change. The program *Agir pour moi*, available at gerermadouleur.ca/agir-pour-moi/, addresses all of these strategies. We developed it using patient-centered research principles through a close partnership between a Ph.D. candidate, people living with chronic pain, health care professionals, and a graphic designer. *Agir pour moi* is completely online, free, and can be done without the assistance of a healthcare professional. Short videos of inspirational stories are interspersed throughout each lesson to support the theoretical content. The development team



wanted learners to feel understood and supported in making lifestyle changes. Input from patient partners has helped add details that normalize the experience of those in the program.

Scleroderma poses certain obstacles to the practice of physical activity, including dexterity or impaired hand function, which may or may not be related to Raynaud's phenomenon, fatigue, gastrointestinal problems, and possibly lower motivation⁽¹²⁾. Different adaptations may be considered when applying the proposed strategies. Keep in mind that you are the expert on your situation.

Although scleroderma requires you to rethink your daily life, eating habits, social relationships, work life, and plans, rethinking the way you care for yourself can slowly transform your quality of life. There are no shortcuts, but your power to take action is probably greater than you think.



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info@sclerodermie.ca