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**Original Article**

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**Scleroderma, Stress and CAM Utilization****Ka-Kit Hui, Michael Francis Johnston, Marc Brodsky, Joe Tafur and Mai Kim Ho**

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Scleroderma is an autoimmune disease influenced by interplay among genetic and environmental factors, of which one is stress. Complementary and alternative medicine (CAM) is frequently used to treat stress and those diseases in which stress has been implicated. Results are presented from a survey of patients with scleroderma. Respondents were a convenient sample of those attending a national conference in Las Vegas in 2002. Findings implicate stress in the onset, continuation and exacerbation of scleroderma. The implication is that CAM providers may be filling an important patient need in their provision of services that identify and treat stress and its related disorders.

**Keywords:** CAM use – scleroderma – stress

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**Introduction**

Scleroderma, also known as systemic sclerosis (SSc), is an autoimmune disease of unknown etiology characterized by pronounced microvascular alterations, progressive fibrosis and associated cellular and humoral immune abnormalities (1). Clinically, scleroderma encompasses a spectrum of disorders ranging from mild, limited forms of fibrosis of the skin with minimal visceral involvement to severe skin and multiple internal organ fibrosis involving the gastrointestinal tract, lungs, heart and kidneys (1). Causes of autoimmune diseases remain obscure (2).

It is argued that disease susceptibility, progression and clinical presentation are influenced by a strong interplay among genetic factors, lifecycle events, as well as natural and social environmental triggers (3). Psychological stress is thought to be associated with the onset and exacerbation of these disorders, with recent scientific evidence suggesting a relationship between stress-related brain disorders and autoimmunity rooted in a common neuroendocrine defect (2,4,5). In 2003, a study surveying a population of individuals with SSc reported that more than 50% of

patients ascribed the cause of their condition to stress (6). Despite increasing understanding of pathogenetic mechanisms of immunologically and non-immunologically induced fibrosis and the pathogenesis of scleroderma, conventional therapy remains largely empirical with limited efficacy (7). One shortcoming may be that physicians are not adequately identifying or treating stressors in the lives of their patients with scleroderma. In contrast, patients seek out complementary and alternative medicine (CAM) practitioners to identify and relieve those symptoms commonly associated with stress, such as back pain, neck pain, joint pain, anxiety and depression (8).

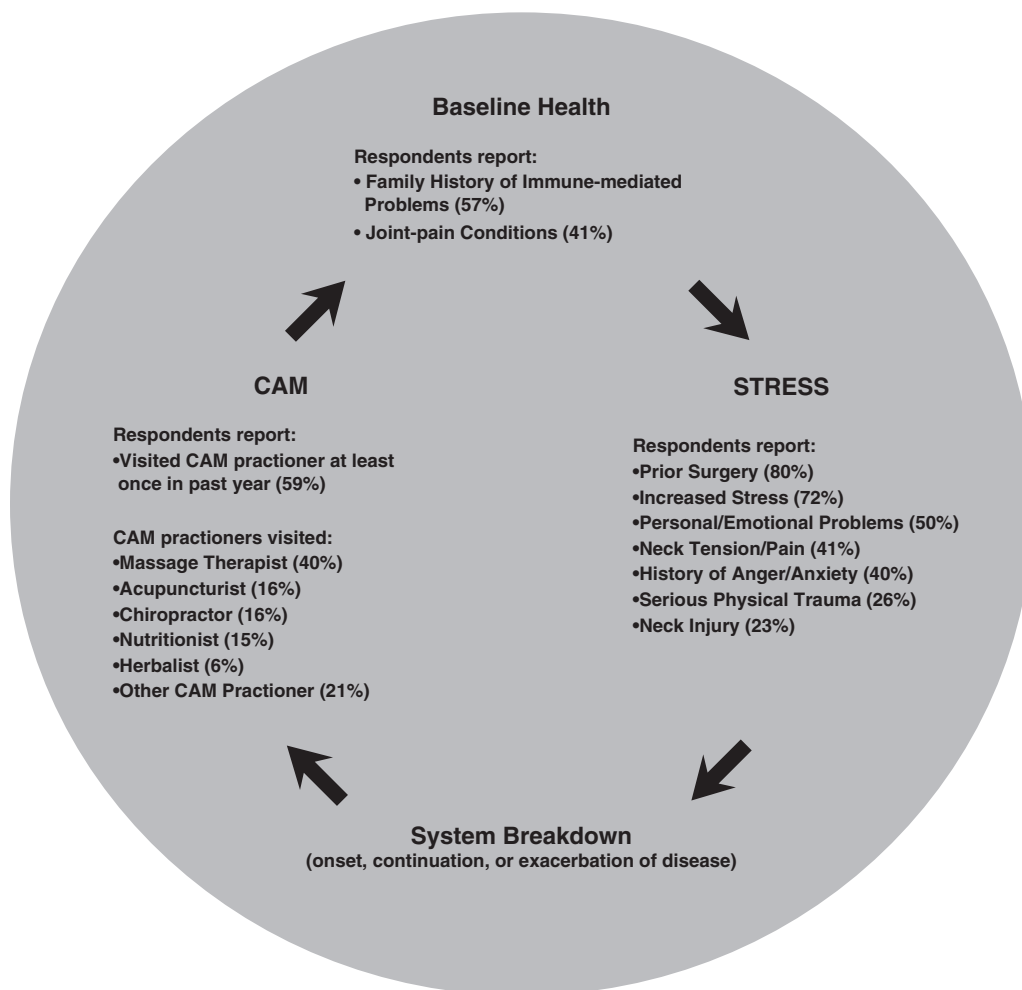
Drawing on knowledge gleaned from a search of the literature and decades of clinical experience, we designed an exploratory research project consisting of a survey distributed to a convenience sample of patients with scleroderma. We did not design the research to precisely identify the etiology of scleroderma. Nor did we seek to exhaustively catalogue the types of treatments that patients receive for scleroderma. Our purpose was to preliminarily examine two related hypotheses. The first hypothesis is that psychosocial and mechanical stress plays a role in the onset, continuation and exacerbation of scleroderma. The second hypothesis is that, for the sake of stress relief, people diagnosed with scleroderma seek out CAM providers for treatment. Our argument is that psychosocial and mechanical stress pervades the

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**Figure 1.** Multidimensional relation between baseline health, stress, system breakdown, and CAM use.

entire process of system breakdown—manifesting in the onset, continuation and exacerbation of scleroderma and other diseases—and that because physicians do not fully appreciate the importance of stress or provide therapeutic services that relieve stress, patients are turning to CAM providers. Figure 1 is a heuristic displaying the multi-dimensional relation between baseline health, stress, system breakdown and use of CAM.

## Methods

At the Scleroderma Foundation's 2002 National Conference 'Living Well with Scleroderma' held in Las Vegas on June 29–July 1, 2002, we collected demographic, medical and health services utilization information from a convenience sample of 113 individuals diagnosed with scleroderma. To survey these people, announcements were made at various sessions and surveys were placed in a prominent place in the conference registration for self-administration. According to Stacy Wright, executive assistant to the CEO of the Scleroderma Foundation, there were 520 attendees at the 2002 conference, of which she estimates that approximately

250 were people with scleroderma. Assuming that all were notified of the survey, the response rate would be approximately 45%. We have no systematic information about the difference between those attendees with scleroderma who did and did not fill out the survey. Further, we have no hard data about the difference between scleroderma patients who do and do not attend this conference. However, on the basis of extensive personal experience with the annual conferences, Stacy Wright notes that scleroderma attendees are extremely heterogeneous in multiple ways, including age of diagnosis, time of diagnosis, disease progression and lifestyle. Though diverse, generalizability is problematic. However, we do not consider this to be a fatal flaw, because the purpose of this preliminary research is to examine whether an insight about stress is worthy of pursuing in future, more rigorously developed research design.

Respondents were asked to identify physical, emotional and environmental insults in their lives including past surgical history, trauma/accident history, neck injuries, neck tension and pain. They were also asked about history of physical overexertion, recurrent infections,

gynecologic disorders, other rheumatological diagnoses, psychological and emotional problems, symptoms of cold extremities and sensitivity to cold weather, as well as family history of autoimmune disorders. There was not sufficient time to secure validated scales from other researchers or pretest the survey questions before the first author attended the conference. Respondents were also asked about their use of conventional medicine and CAM services. The latter was operationalized in a series of six questions that asked the respondent sequentially if they had seen a massage therapist, a chiropractor, a herbalist, an acupuncturist, a nutritionist, or any other provider of complementary/alternative therapies in the last year.

## Results

### Gender and Age

Demographically, survey respondents were almost entirely female (104 of 113). Of the female respondents, 28% had experienced endometriosis, breast pain and/or pelvic pain before the onset of their scleroderma. The average age of diagnosis for this group of patients with scleroderma was 51 years.

### Genetic Factors

Our results show that genetic factors are important in that 57% of respondents reported a family history of immune-mediated problems such as allergies, eczema, or rheumatoid arthritis. Clinically, on average, respondents had been diagnosed for scleroderma 18 years before attending the 2002 conference. A high percentage (41%), also reported a history of other joint-pain conditions such as lupus, fibromyalgia, rheumatoid arthritis. As expected, another very common feature in our results is that virtually all participants (98.2%) reported having cold hands or cold feet and problems with cold weather. A high percentage (41%) reported having a past medical history of recurrent infections such as frequent flus, colds, urinary infections, yeast infections, prior to disease onset.

### Possible Role of Stress

In line with our hypothesis that stress plays a role in the onset, continuation and exacerbation of scleroderma, we find psychosocial and mechanical stress to be very prevalent in this sample. Psychologically, 72% of the respondents self-report increased stress, 50% personal/emotional problems and 40% a history of anger and anxiety before onset of scleroderma. Physically, 23% had engaged in some intense physical exercise such as weight training before the onset of scleroderma, 80% of individuals had undergone some kind of surgery, 41% had a history of neck tension and pain, 23% of respondents reported having injured their neck, 26% had experienced serious physical trauma such as that which would result from a car accident.

### Prior Treatment by CAM Practitioners

Regarding our hypothesis that people diagnosed with scleroderma seek out CAM providers, we find that 67 of the 113 respondents (59%) reported seeing at least one CAM practitioners in the past year. Among these, 27 indicated seeing a massage therapist, 11 an acupuncturist, 11 a chiropractor, 10 a nutritionist, 4 a herbalist and 14 another kind of CAM provider. Among those who had seen a CAM practitioner, 41 (61%) reported that their medical doctor knew they were seeing a complementary/alternative practitioner. When the medical doctor was aware, in only 24% of the cases (10/41), did they discuss with the patient how complications may arise due to an interaction between the CAM and conventional treatment and in only 7% of the cases (3/41) did the medical doctor discuss potential complications with the patient's CAM practitioner. Among our respondents, only four respondents reported seeing a herbalist, of which three had discussed with their doctors about possible complications and in one case the physician had spoken directly with the herbalist.

## Discussion

Our preliminary results provide a warrant for more careful investigation of the hypothesis that stress, whether resulting from psychological, mechanical overloading and/or injury, including surgery or accidents, may activate or exacerbate the pathogenetic processes in patients with scleroderma. Our findings resonate with general and specific theories in the literature. Both physiologic function and health outcomes have been shown to be directly influenced by psychosocial factors from emotional states, behavioral dispositions and psychosocial stress (9). In a study of women with Sjogren's syndrome, which is commonly associated with scleroderma, authors reported that a majority of participants considered their experience of a stressful life event 6 months–2 years before the onset of their symptoms to be highly significant (5).

We do not see our preliminary findings as contradicting arguments about the importance of genetic factors in scleroderma. Genes, one's experiences, lifestyle and stressful life experiences all help determine allostatic load, which is equivalent to the cost to a person's body to adapt to a changing environment (10). Accumulation of allostatic load with attendant overexposure to neuroendocrine and immune stress mediators can impair various organ functions, leading to disease (10).

We emphasize that a sizable number of people in this convenience sample perceived themselves to be suffering from stress of a mechanical nature, stress that results from physical overexertion, surgery, accidents, or intercurrent infections. Additionally, our survey shows that many patients perceived themselves to experience an increase in personal/emotional problems prior to the

onset of scleroderma. Astin and colleagues (9) point out that in spite of the biopsychosocial model and considerable evidence of efficacy for several mind–body therapies in stress-induced diseases, psychosocial factors continue to be underappreciated in many clinical encounters. In this article, we expand the psychosocial conceptualization of stress to include mechanical stress, which has the further implication that stress management is not limited to body–mind interventions; physical interventions such as massage and acupuncture can also play a role in stress reduction.

Our data also suggest that people diagnosed with scleroderma seek out CAM providers for assistance in relieving symptoms and conditions commonly associated with stress. Among the respondents in this sample, nearly 60% used CAM services. This also resonates with existing literature in that a high percentage of patients with rheumatologic disease conditions use CAM (11–14). Only 24% of those respondents who had notified their physicians that they were seeing a CAM provider had discussed possible complications with their physician. However, amongst those seeing a herbalist, 75% had communicated with their physician about possible complications. We agree that susceptibility, progression and clinical presentation of scleroderma are influenced by a strong interplay of several factors, of which one is psychosocial stress (2–5). Our preliminary findings further suggest that mechanical stress is involved in the onset, continuation and exacerbation of scleroderma. In that they provide services which identify and treat stress, CAM providers may be playing an important role in the management of scleroderma.

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