The Experience of Emotional Distress in Women with Scleroderma:

A Qualitative Study

Evan Newton, BA

Department of Psychiatry

McGill University, Montreal, Quebec

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ENGLISH ABSTRACT

Depression or emotional distress seems to be an issue for many medical patients, but there is debate as to how it should be defined, measured, and treated. The goal of this study was to better understand this issue by conducting in-depth interviews with women with scleroderma, a chronic rheumatic disease. The main objectives were to determine how participants described distress, what they believed caused it, and how they coped with it. Interview transcripts were analyzed using qualitative thematic analysis. Many participants described distress associated with the illness, but the term "depression" was reserved for a very specific, severe experience. Participants preferred more normal mood descriptors, and often described distress in terms of demoralization, or adjustment disorder. Participants listed concrete aspects of the illness that caused distress, and some added that their reaction to stress could exacerbate the progression of the disease. Participants dealt with distress by not dwelling on their circumstances, by for the most part avoiding psychologists and support groups. The support participants preferred came in the form of contact with friends and family.

FRENCH ABSTRACT

La dépression et la détresse émotionnelle représentent une difficulté pour plusieurs patients médicaux. Cependant, un débat existe autour de la façon dont celles-ci devraient être définies, mesurés et traités. Le but de ce projet était de d'aborder cette question en conduisant les entrevues avec des femmes atteintes par la sclérodermie, une maladie rhumatologique chronique. Les objectifs principaux était d'établir comment les participantes décrivaient leur détresse, ce qu'elles apercevaient comme étant la cause de celle-ci, et comment elles ont y pu faire face. Les transcrits des entrevues étaient analysés avec l'analyse qualitative thématique. Plusieurs des participantes ont décrit la détresse associée avec la maladie, mais le terme "dépression" était réservé pour une expérience spécifique et sévère. Les participantes ont préféré des descripteurs d'humeur plus banals, et ont fréquemment décrit la détresse comme étant consistant avec la définition de démoralisation. Elles ont listé des aspects concrets de leur maladie qu'elles apercevaient comme étant la cause de leur détresse, et quelques unes parmi elles ont ajouté que leur réaction au stress pourrait exacerber la progression de leur maladie. Les participantes ont gérer leur détresse en évitant de réfléchir sur leurs circonstances, et en évitant les services des psychologues et groupes de soutien pour patients. Le soutien que les participantes ont préférée étaient le contact avec leurs familles et amis.

Scleroderma is an auto-immune connective tissue disorder whose symptoms stem from too little blood flow and excessive collagen production.[1,2] The first symptoms are usually thickening of the skin on the hands and face leading to visible disfigurement, but the ultimate course of the disease varies substantially across people. In some cases, the disease may remain relatively mild for years. In others, systemic collagen production may affect internal organs including the heart, kidneys, lungs, and gastrointestinal tract. If this is the case, patients may die from ensuing lung or kidney failure. There are treatments available to control some symptoms, such as fibrosis, acid reflux, pain, circulation problems, and hypertension, but to this day there is no cure.

In terms of the epidemiology of the disease, a recent study using administrative data from the province of Quebec estimated an overall prevalence at 44.5 cases per 100,000 people.[3] The risk for women is four to five times that of men,[4] and the age of onset is highest between the ages of 30 and 50.[5,6] A recent pan-Canadian study estimated the annual cost per patient to be over $18,000 CAN, similar to the cost per patient in rheumatoid arthritis,[7] and calculated the total cost per year across North America to be 1.9 billion US dollars.[8]

Research on the impact of scleroderma on the patient has shown that it is a devastating illness. The symptoms most commonly reported by patients include pain; gastrointestinal symptoms; tightness, deformity, and loss of dexterity in joints and extremities; breathing problems; sleep difficulties; and fatigue.[9,10,11,12] Patients consistently report substantial disability and impaired

function,[10,13,14,15,16,17,18,19,20,21] including difficulties with personal care, household chores, work, leisure activities, and sexual intimacy.[22,23,24,25,26]

The severity of the disease and the chronic burden it places on patients has prompted research looking at rates of depression among scleroderma patients. A recent systematic review of studies done on depression in scleroderma using validated questionnaires found that between 36 and 65% of patients experience significant depressive symptoms, depending on the questionnaire and cut-off used.[27] These rates are comparable to or higher than rates of depressive symptoms among patients with cardiovascular disease, chronic obstructive pulmonary disease, and diabetes. However, no study has used a "gold standard" structured diagnostic interview to estimate rates of major depression, A study by Thombs et al. determined that the high rates of depressive symptoms among patients with scleroderma are not significantly inflated by the conflation of symptoms of the disease with somatic symptoms of depression, such as sleep, appetite, and energy problems,[28] although there appears to be a relationship between worse disease and higher depressive symptoms. Depressive symptoms in scleroderma are associated with more severe disease and worse scores on measures of particular symptoms, including diffuse disease, tender joints, gastrointestinal symptoms, breathing problems.[29]

Depression and emotional distress are important issues for many people living with chronic illness. There is, however, debate about how this distress should be defined, measured, and treated in the context of medical disease. The dominant system for defining and measuring emotional distress in medical

patients is with the use of depression questionnaires, whereby patients are asked to ascribe frequency or severity to a list of statements to produce a number that quantifies their experience. Those with scores exceeding a predetermined cut-off are considered to be experiencing significant depressive symptoms.

There are, however, several problems with this method. First, it is possible that questionnaires might exaggerate the problem of depression in medical patients. Horwitz and Wakefield, for instance, criticize the practice of depression screening in primary care by arguing that it generates high rates of false positives – it identifies people as "depressed" who really are not.[30] They criticize the screening tools for failing to take into account the context of someone's distress, and argue that truly disordered distress that warrants treatment occurs when there is an absence of stressors (unlikely for people who are sick). They also argue that transforming the DSM criteria into a quick and easy-to-use tool can weaken the criteria by changing subtle wording, and removing a key criterion about the impact of the symptoms on functioning.

In medical settings, there is evidence supporting Horwitz and Wakefield's argument that questionnaires might identify many patients who do not have depression, or for whom identification and labeling of their distress as depression is not helpful. Although the exact rate depends on the population screened and the diagnostic characteristics of the tool used, false positive screens among patients with medical disease are routinely over 50%.[31] In a review of depression screening in postnatal women, Mitchell and Coyne note the dismal rates of follow-up with psychological professionals by women who received both positive

screens and referral.[32] In a German study cited by Mitchell and Coyne, for instance, only 18% of mothers identified as depressed chose to seek help.[33] An important question is whether depression questionnaires correctly label the experiences of patients, given that many of those who are identified as likely depressed do not feel the need to see a psychologist, and disagree with the results of the questionnaire.

Second, questionnaires confine the patient's experience to a series of supplied options. There is evidence that this is a problem; that depression questionnaires only cover a narrow range of the psychological problems important to medical patients. In a letter to the editor questioning the practical use of depression screening instruments,[34] Garssen and van der Lee point to a study at an Australian oncology center were 343 patients received the Hospital Anxiety and Depression Scale (HADS).[35] Of the patients screened, 25% met criteria for significant depressive symptoms by scoring above the cut-off of the questionnaire. Only 30% of these patients, however, actually consulted a clinical psychologist. Meanwhile, an additional 103 patients, nearly a third of the entire sample, were referred to psychologists for reasons other than a high depression score. These included issues, such as adjustment problems, relationship problems, and cancer heredity issues. Garssen and van der Lee invoke another Australian study where breast cancer patients were asked about their most pressing unfulfilled needs.[36] The top five were fears about cancer spreading, family concerns, lack of energy, uncertainty about the future, and not being able to do the things one used to. Neither anxiety nor depression was on this list. Thus, a

reasonable concern is that depression questionnaires only capture a narrow range of the psychosocial needs of medical patients.

In fact, not all research on mental health in the medically ill agrees that "depression" is the best term to capture the distress experienced by patients. A substantial amount of medical research has employed more general measures of distress, often using measures of "emotional distress," "psychologic distress," "psychosocial distress," and "mental health." Conversely, other research has tried to narrow in on more specific descriptors of distress. For example, "demoralization" has been offered as an alternative term to describe the distress of the medically ill, describing an experience qualitatively distinct from major depression. Demoralization is characterized by a loss of meaning, dysphoria, disheartenment, helplessness, and a sense of failure.[37] It differs specifically from depression in that the sufferer is not anhedonic; they can still experience the joys of normally pleasurable activities, like a visit from a loved one or the receipt of good news.[38] If further differs from major depression because it is seen as definitely arising from outside the individual as a result of chronic disappointment or failure; it has been alternately called an "adjustment disorder."[39]

Research examining the validity of demoralization in the medically ill has partly been able to distinguish between it and depression as distinct experiences. In a sample of patients with a variety of medical conditions who received a semi-structured interview for both depression and demoralization, many were diagnosed with both, but enough patients received a diagnosis of either one or the other to suggest that they are distinct syndromes.[40] A study on metastatic cancer

and motor neuron disease patients differentiated demoralization from anhedonic depression,[41] and another study on advanced cancer patients concluded that demoralization was qualitatively different than both major and minor depression.[42]

It seems emotional distress is a common problem in medical patients, but there is debate about how prevalent the problem is, how it should be defined, measured, and treated. I bring up these issues to make the argument that there is a need to seriously reconsider the experience of emotional distress of medical patients from their point of view.

A qualitative design is best suited to address this question. Qualitative methods place the patient as the expert regarding their own condition and recognize the importance of understanding the experience of the patient in guiding clinical care that addresses their needs. They also enable a critical look at language and terms by allowing the subjects to use whatever words they want to describe their experience, a necessary starting point for a study that seeks to carefully look at how emotional distress is described and labeled. Furthermore, qualitative research recognizes the importance of empathy; the recognition and understanding of another's experience by listening to their account in their own words.

To our knowledge, there are two previous qualitative studies on the patient experience in scleroderma.[43,44] The aim of these studies was general; to get an idea of the most salient symptoms, worries, and difficulties of life with the disease. Both studies used focus groups to collect data, with one adding five in-

depth individual interviews. Along with the common difficulties of fatigue, pain, and disfigurement that come along with the disease, both studies mentioned that patients brought up the emotional impact of the disease. Participants in a study by Joachim and Acorn noted their frustrations, worries, and fears of living with the disease, and Suarez-Almazor et al. concluded that general emotional distress resulting from the disease was a serious problem for many patients. However, these studies provided little detail on the nature of emotional distress in scleroderma. Thus, there is a need for a qualitative study specifically aimed at exploring this issue.

My objective was to take a critical look at the experience of emotional distress in women with scleroderma using in-depth interviews and qualitative thematic analysis. These interviews had three main objectives. The first was to better understand the nature of the emotional distress experienced by women with scleroderma; how do patients describe, understand, and attribute meaning to their experience of emotional distress? The second was to understand what they believe to cause this distress; at what stage of the disease is it at its worse? what aspects of the disease exacerbate it? The third was to understand how they cope with it.

METHODS

Participants

Study participants consisted of 16 English-speaking women with scleroderma living in the Montréal area, Québec. Ages ranged from 28 to 79, and participants presented a range of ethnic backgrounds. All were members of the Canadian Scleroderma Research Group (CSRG) patient Registry, which requires a physician diagnosis of scleroderma for eligibility. I recruited participants who were patients of the scleroderma clinic at a hospital in Montréal, at the time of their annual CSRG registry visit. The registry nurse, who is bilingual and familiar with all the patients, determined whether or not a prospective participant was fluent in English. I conducted all the interviews in English because of my limited French. A total of 20 women were approached, three of whom refused. Of the 17 women called to schedule an interview, one was unreachable after multiple attempts, resulting in a total of 16 study participants. The research ethics review boards of McGill University and the participating hospital approved the research protocol and consent forms. All participants read and signed the consent form at the time of recruitment.

Procedure

I telephoned participants in the weeks following study recruitment to set up an interview time. Of the 16 interviews, eleven took place in participants' homes, three in an interview room at the hospital, one at a place of work, and one at a restaurant. In the interviews, I used the McGill Illness Narrative Interview (MINI), a semistructured ethnographic interview schedule designed to explore

illness meaning and experience and health behavior.[45] I used sections one, three, and five of this interview. The first section invites participants to provide an initial illness narrative; what the first symptoms were, when they were experienced, what other events occurred, what helpers or healers they saw. The third section asks about perceived causes of the illness. The fifth section includes questions about how health problems have impacted their lives and changed the way they perceive themselves. I did not administer sections 2 and 4 from the schedule, which pertain to prototypes (understandings of the disease based on past personal experience or as seen in the media or experienced by others) and patients' responses to medical treatments, respectively, because of the particular focus on the emotional experience of patients.

Because of the study's specific focus on the experience of emotional distress of the participants, I added specific questions about this to supplement the initial questions of the MINI. I asked the question, "Have you experienced any emotional distress associated with scleroderma?" Depending on participants' answers, I would probe further to ask for a description; what words they use to describe it, what aspects of the disease have the biggest impact on their mood, when they experience it. If participants themselves did not bring up the word "depression," I would eventually ask if they had ever been "depressed?" Again, depending on the response, I would ask "why" or "why not" to elicit the meaning of the term "depression" to them. I asked participants how they coped with their distress, and if they've learned or gained anything from their experience with

scleroderma. I also included a question about their past use and interest in service provided by psychologists and scleroderma patient support groups.

I conducted the interviews, which lasted between 45 minutes and an hour and a half. All the names and identifying information of participants have been changed for confidentiality purposes. See the appendix for the adapted format of the MINI used in the study.

Data Analysis

I recorded the interviews and transcribed them with the help of two research assistants. I coded interviews deductively using several predetermined conceptual codes from the MINI. Examples of predetermined conceptual codes include *chain complexes* (contiguous events in the illness narratives), and *explanatory models* (perceived causes of their illness). Further thematic coding was done inductively through careful and multiple readings of the transcripts.

RESULTS

The section that follows presents participants descriptions of their emotional distress. In the second section, participants' perceptions about the relationship between illness and mood are presented. In the third section, the ways participants said they coped with their distress are described.

What participants said about their distress

A range of responses

I asked every participant if they had experienced any emotional distress associated with scleroderma, and then asked them to elaborate on their answer to provide a description of their distress, if appropriate. This question elicited a wide range of responses, from those who described severe distress to others who said that they had not experienced any distress associated with the disease.

Several participants described times when their moods were very severe. Participants often used the term "depression" to label these periods when their distress was at its worst. The following is a description of a severe episode that a participant at an earlier point in the interview referred to as "depression":

> I was considering taking my life. … That's how bad it was. I don't know if anybody else is the same, but that's the way I wanted to go. Like one time I told James, he was going off to work, and I said you'd be lucky to find me when you come home … 'cause I planned to take a bottle of Dilaudid and just swallow them all. … To me, there was no reason to live, when you get that low, there's no re-, I mean why am I going to go on? I'm just going to get worse in my disease; eventually it's going to take my life. Why don't I just end all my pain and suffering right now?

Others, however, said that they had not experienced significant emotional distress associated with the disease. Some said that their disease was not serious enough to warrant such a reaction:

> No, no. Not with Scleroderma, no. ‘Cause it's not that bad. It's not that bad, so, sometimes it even gives me a little break cause my mom says "okay relax, take care, I'll do it for you."

Overall, participants described a wide range of severities of distress relating to their illness.

Taking issue with the term “depression”

I asked participants about their emotional distress, and, if they did not bring up the word “depression” themselves, I eventually asked whether they believed the term fit their experience of distress. Most participants answered that they had experienced significant distress associated with the disease at some point, but many of them took issue with using “depression” as a label for it.

It is important to note that participants often used “depressing” in the everyday, colloquial sense: “scleroderma is a very depressing disease.” The term “depression,” however, was used by participants to described what they viewed as a serious, significant, and pathological experience, separate from normal suffering. One woman, who at the initial question about whether she had experienced emotional distress had answered, “yes, endless,” later qualified what she meant when asked whether the term “depressed” suited her experience:

> Yeah, I mean depressed but I don't know if it's medically depressed, you know what I mean? Just feeling down. … Yeah, feeling down, but I mean it doesn't last more than two, three days. … Yeah, like I don't need

> anti-depressants or you know I still do what I have to do and I still go to work, I still do what needs to be done but I'm feeling not so good.

Others explained that they did get "depressed," but that it was for reasons other than their scleroderma:

> Depressed? No. 'Cause of my scleroderma? No. I get depressed for other reasons, but not because of the scleroderma. Sometimes I worry about what would happen in the future if it would get worse. That worries me but it doesn't depress me. … I get upset and depressed over other things. Yeah. … Finances get me frustrated.

Other participants used terms other than "depressed" to describe their distress. One participant, who earlier in the interview mentioned being "depressed," later said, "Depressed? Not especially… I think I get more angry than depressed." Another woman, who at points cried during the interview, said "I'm not depressed, just - bored. I think so. Bored, bored." Another participant insisted she was more nervous than depressed: "It's only if someone gets me nervous … It's only when I'm nervous, most of the time I'll get depressed. So it's the nervousness that gets me depressed. I'm not depressed. Do you understand?" Another woman recognized being distressed, but minimized it to "just being frustrated. And the fear is always there, yeah, the fear is always there."

Participants endorsed being distressed at various times during their illness, and used "depressing" in the everyday sense of the word, but many maintained that "depression" was not the best term to describe their distress, and preferred defining their distress with other descriptors.

The absence of anhedonia

In terms of the specific quality of the mood experienced by participants, some described negative moods, from which they could be lifted by taking part in activities:

Quote #1

I will admit that the first year probably I had ups and downs, but never a long stretch. I'd get out there and I'd curl and I could forget it. Or go play badminton and my bridge club or whatever.

Quote #2

Participant: I just couldn't leave the house.

Interviewer: Because of your?

Participant: The mood. … I didn't feel like getting dressed. I wasn't in the mood to go out; didn't socialize, like I said. And I would only go watch my son play, only because I always enjoyed doing that. And I tried to- and the thing is once I was at the arena, and it's probably the worst place to be when you're always cold, but once I was there I felt fine. It was like, "maybe I should go out a little bit more."

The role of disposition

Several women who had experienced severe and debilitating disease said that their distress was never that serious. Elaborating on this, they attributed not getting too down to their innate, resilient disposition. The following is from a woman who said that she did not succumb to "major depression" in the face of scleroderma because of her naturally positive character:

No, no. I'm a very hopeful person (*laughs*). I'm very, very hopeful. You know, I always try to, you know, think positive. … It's just my character. … My husband's like this, you know, freaking out, and truthfully

> he worries like a hundred times more than I do. Like going out- he won't let me go out without my gloves on,[1] you know, and yeah. But, I can't take it more lightly- he looks at me like "how could you not be freaking out?" That's just my character. That's just the way I am.

Others had clearer explanations of why they were so resilient to the effects of their disease. One woman, who had been living for years with numerous chronic health problems in addition to scleroderma, explained that she had inherited her resilience from her mother, who similarly struggled with long-term, chronic health problems:

> I could have probably gone into a depression world but no, it's not my character. Like I say, my strength comes from my mother, she was a very little lady but feisty- nothing would get her down. And my mom was a sick lady through her life, went through a lot, surgeries and everything, and still came back fighting. And I guess that's where we get it from.

Another woman, who had suffered from very severe disease that had left her largely immobile and housebound for several years, insisted that her resilience to the effects of the disease had a more biological foundation:

> But I don't, I'm not down. I'm not a down person. … That's one thing I have… even with this disease, I would tell my doctor I have too many endorphins. Like, I'm always on a high. … And I'm not drugged, but that's just how I am. So yeah. I don't umm, I don't get down.

[1] Raynaud's phenomenon is exceedingly common in scleroderma. It is a hyper-reactivity of the blood vessels in the extremities, particularly the hands, to cold and emotional stress.

These examples do not mean that scleroderma is not a devastating disease. By describing their naturally resilient dispositions, these women are in fact acknowledging how threatening and difficult life with the disease can be. It is because of their strong characters, however, that they believe they have remained relatively unaffected by the disease.

The connection between illness and mood

I asked participants about what aspects of life with the disease had the biggest impact on their mood, and also sought to clarify what times in the course of the illness their distress was at its worst. The main themes that emerged were that the beginning of the disease was a particularly difficult time, worse distress was caused by worse disease, and that emotional distress could alternately worsen the disease itself.

The beginning is hard

Participants mentioned experiencing distress at various points throughout the course of their illness, but the most common mention of distress was in the beginning, around the time of the diagnosis. This is a difficult time; the patient's health may be deteriorating, they may be coming to terms with the weight of the diagnosis, as well as accruing frightening information about the disease. The following is a participant's response to the initial question about whether she had experienced emotional distress associated with scleroderma:

> Especially right now because I don't know what's going on. … Otherwise it was mostly the first year or two I'm going to say. It was very hard, you don't know what's going on and the symptoms are developing, you know, you're not stabilized. So you know, it starts with the Raynaud's, then

> the acid reflux, then the skin, then it spreads. Then you get darker, then you know you're getting them all. So you're waiting for that day when you can't breathe anymore or- but it hasn't happened so that's good.

Another participant cited learning about the disease as being particularly difficult:

> But that's really when your depression starts. It's when you get that diagnosis and you go into your learning mode. … And that's the scary part. Because you start learning more and more and more and then you start reading about all these people's different life stories and you see the pictures of some people and people are on feeding tubes and ulcers…

The beginning of the illness can be a difficult time as patients struggle to adapt to both their new symptoms and the shock of the diagnosis. They often cited periods of distress occurring at this time.

Worse disease, worse mood

Many participants spoke about the relationship between the severity of disease and the severity of distress. There was a general perceived notion that more severe disease could cause worse distress. This was expressed by some of those who experienced severe disease and spoke about its impact on their mood:

> But I'm glad like, you know, those years of being in pain and the depression and the fatigue and you know, that guides your life, is gone. I have more freedom of movement now. I can come and go more on my own than what I used to be able to do. Before it was like, it was terrible.

A similar connection between disease and distress was expressed by those who considered that they had relatively mild disease, and who thought that if their health were to deteriorate, so would their emotional well-being:

> Because I'm someone who makes the best out of things. I think, you know, and what's the use? From day one that I had scleroderma till today I could've just stayed where I was- stopped studying, be depressed, stay with my parents and do nothing, you know. And no, instead, it was very, it's still very hard. But you just get over it because I'm still feeling - maybe I wouldn't be speaking like this if I were more sick- you know, if I were in a wheelchair if I couldn't do anything. But I can, so.

Another participant insisted she was not a good candidate for a study on that focussed on depression because she had more mild disease:

> … I know your thesis is more on the depressive side, maybe of the disease. And as I said in the beginning, I don't feel that I'm such a good candidate for that because I didn't get to the point in my disease where it is troubling me or bothering me enough to really feel very sad about it, and sorry for myself.

The two-way street between distress and disease

As shown above, many participants voiced the idea that worse distress accompanied worse disease. But the relationship was not always in the direction of disease influencing mood; some participants alternately added that the emotional impact of life's stressors could exacerbate the disease itself:

> But in times of stress though I noticed that it progressed a little faster. … I would notice that the little ulcers on my fingers would appear, and the thickening of the skin would be much faster - my fingers would thicken and

tighten more quickly. Like I would notice a difference in six months, you know before it was like a year, I didn't even notice anything.

In addition to the idea that stress can exacerbate the disease, a few participants added that one could control the course of the disease by staying calm and not getting too stressed-out. The following quote is from a woman who spoke at length about the need for people to calm down and slow down, and who said that it naturally made sense that hyperactive people were the ones affected by such a fast-moving disease:

> Because I, my husband also thought that this is a hyperactive disease. It's for people that are hyper. I was wired when I was younger. … It's very difficult, it attacks everything; it attacks you physically, mentally, and you just got to slow down. … Your body has this disease because it's hyper. You know it's a fast moving disease. You gotta slow it down. No, caffeine, no, cut down the sugar, you know, slow yourself down! Your body has to rest.

In addition to the notion that disease can cause distress, participants added that their reaction to life's stressors could exacerbate the disease itself.

The specific causes of distress

Participants identified several major sources of distress. Fatigue, often debilitating in scleroderma, was a common source of misery: "Well, like, no— no energy, no push, you know. You get sad, you don't go out. So you get depressed." Participants mentioned pain as another source of distress: "I had a bad night, my arms were really sore, I was crying in pain. You know. So to me, that's a big depression." Some mentioned both disfigurement, as well as the threat of

disfigurement, as being very troubling, with others attributing their current good mood to the fact that their disease was not yet visible to others. To the question about whether she had experienced emotional distress associated with the disease, one woman replied, “No, not really. No because I mean…I don't look like I have it.”

Many participants lamented the fear and uncertainty that came with the disease. The following quote illustrates this, and also adds to the aforementioned theme that the beginning of the disease is a particularly difficult time:

> At the beginning I was heartbroken. I figured I wasn’t going to live that long reading what I read. … I mean the life expectancy back when you read the articles that were written didn’t sound that promising which was quite terrifying. And I would say, you know, I did have depression then, for sure, but it didn’t last once I got over the initial prompt and realized well whatever happens you make the best of what’s out there and, uh, do it day by day and see what happens and um, that still my attitude. As I say we don’t know what’s around the corner.

The loss of autonomy

Another major source of distress for patients was losing the ability to do things they could normally do as a result of their symptoms. The following is a quote from a participant who had recently started carrying a portable oxygen tank to treat her pulmonary hypertension resulted from scleroderma having affected her lungs:

> The only part I got upset was cause I can't fly. … I mean a lot of people fly, but it costs money to- it costs money with the oxygen. And there's a lot to go through with it. I went to Acapulco last year you got to

> pay uh, for one plane to the States it was $100. Then we got on another plane it was $100. But you had to be responsible for that second plane. Which is a lot of stress right away- like where do I go, what do I do? So that's $400 for a trip, extra.

The relationship between distress and the loss of autonomy was also a perceived one. Those who maintained their basic functioning and self-sufficiency feared losing it, predicting that its effects on their mood would be drastic:

> What depresses me is, when things are not going good in my family, not being able to see my grandchildren, not being able to do things for myself. So I guess as long as I'm able to do those things, I'm not going to be affected too much. I mean I hate to think of somebody having to dress me, or feed me. I mean I think that if and when that time comes, I think I will be probably the most depressed person on the face of the earth.

In terms of causes of distress, participants listed fear and uncertainty, specific symptoms, and the loss of autonomy that accompanied them.

Ways of coping with distress

Participants stressed the importance of putting distressing thoughts out of their mind and of keeping busy as way to avoid thinking about the disease. Participants also sought new ways to stay autonomous once the disease had affected their bodies. They stressed the importance of being surrounded by friends and family, and, for the most part, expressed their disinterest in support groups and psychologists.

Putting it out of your mind

Several participants cited the importance of not thinking about their condition, of putting it out of their mind, as a way of dealing with fear and helplessness.

> You can't start thinking about it cause if you start thinking about it, then you get more depressed about it. So you've got to just do things without really thinking about it, because if you start thinking about it then that's when you start to really get yourself down and get depressed … I mean you do think about it, it does get you down, but you just try to limit it.

I asked participants to comment on the term "acceptance"; to answer whether they had or had not accepted life with the disease, and, if so, how they thought they had achieved this. Many participants said that they had reached some sort of acceptance of the disease. But when asked how they achieved this, the most common response was not one of having internalized the condition, of recognizing it and coming to terms with it. The overwhelming response was instead one of finally learning to live without thinking about it. In other words, for these participants, acceptance often meant another form of 'putting it out of your mind'. The following is a participant's response to the question of how she went about accepting her illness:

> I don't think about it. I just, you know, I guess you accept it without realizing, without realizing that you're accepting it. I mean, I know I need to wear gloves in September. You know, I just have to. I know I can't go skiing, because it's too cold and my legs can't hold it. So I just don't go and I find something else to do. Yeah there are many things you can do. It's like I don't know, you want an expensive car - you can't have the expensive car, you can have the less expensive car so you go for that one *(laughter)*.

Several participants stated the importance of keeping a positive attitude in the face of their illness, of not allowing themselves to think negatively about it:

> But I believe it's very important to have a positive attitude, I actually believe that. You know, with a positive attitude you can get through anything. It'll make it easier anyway to live your life.

Keeping busy

Many participants stated that keeping themselves busy and active was essential to not getting down. This is partly an extension of 'putting it out of your mind' – participants achieved this by keeping themselves occupied. The following quote is from a woman who, now retired, does work around her home farm:

> It's just like you gotta wipe it out and do something else, because if you start to sit down and you think about it- that's it, you're doomed. And it's like I don't have time. I have to go to the barn, feed the animals, and it's like they don't care how I feel, it's just like, "give me my food. Feed me." So it's like they don't have any pity.

Another woman longed for the routine and camaraderie at the job she could no longer do as the result of scleroderma:

> What I miss a lot is the camaraderie. … You get into a work environment. You see, "Hi Mandy, how are you? How was your day? Hi Steve! How are you?" Whereas at home, "Hi James…. Hi Cinnamon, Hi Billy. Hi Rusty." That's the dog and the 2 cats. Or if somebody calls you, you don't have that contact with other human beings. You know, your, your coworkers, that's what I miss. I miss not going to work. I never thought I

would ever say that. But I miss not having a daily routine. That's the hard part.

Participants coped with distress by not dwelling on the difficulties of their life with the disease. They achieved through both by forcing troubling thoughts out of their heads, and by keeping themselves occupied with some sort of routine.

Finding new ways to stay autonomous

As previously mentioned, participants cited the loss of autonomy as a source of distress. Several participants described how they had to change how they carried out certain activities and pastimes once the disease had significantly altered their bodies. Some participants found inventive ways to carry out things they had no trouble doing in the past. The following is from a woman who developed new ways to do her two favourite sports once the disease had reduced the mobility of her hands:

> Now I would say it really hasn't changed the way I live except that I had to give up my favorite sport. But I only gave it up two years ago. I persevered. … I did it for 18 years after [the disease] started. … And I guess about five years ago when the hand got extremely bad I could not do it. So I gave it up for two years but then I went back and taught myself to do it left-handed. … But badminton, I still play badminton twice a week. I taught myself to play left-handed, which I did for five years. Now I can play either hand because I have a brace I wear on the right-hand and I have my racket built up.

Others had to readjust their pace. This often meant consciously doing things slower than they had in the past to continue doing them. A woman who did paid

housework adjusted her routine after lung involvement from scleroderma had diminished her stamina:

> I told Dr. McKenzie in the beginning, "don't take everything from me, you're making a mistake. Let me do it but at my pace." I went in, I spoke to them. It's at my pace. If I get tired or I feel tired, I sit down. … I just told them that I had to go on oxygen and that while I'm working, if I get tired, I have to pace myself. – "okay, no problem." ... It gets you out. It gets you talking to other people.

Others asserted the need to simply feel autonomous. One woman challenged her diagnosis and prognosis with a bold, symbolic gesture:

> I was 34 years old. And my doctors told me that I was gonna die within a couple of years. And I just felt I wasn't gonna die. So I got up, and I went and bought a very expensive pant suit, that I didn't need, and I never wore [chuckles]. 'Cause I didn't feel like I was dying, you know…

Participants emphasized the importance of autonomy, achieving this through both concrete and more psychological means.

Support groups and psychologists

I asked participants about their past use and interest in support groups for scleroderma patients, several of which exist in and around Montreal. A few participants expressed their enthusiasm for the groups, citing the satisfaction they derived from having others around them who understood what they were going through:

> I had much support from my family, but you don't really know what it's like - the pain and the fatigue and the constant worry. So to sit with

women who sit there and say "oh, I know how you feel" and you know that they know how you really feel helped a lot.

The majority of women, however, had a negative reaction to the question of support groups. There were two common responses. The first was that seeing others with scleroderma who were visibly worse off was a frightening experience: “No. I try and it's just, it's very, very depressing. Yeah, um - I don't like to meet people with Scleroderma. I'm not part of any group. I don't go to the fundraisers. I don't do anything.” The second reason came from those who believed their disease was not yet severe enough for them to need support from other patients: “I've heard of them. I'm just not interested. I'm not at that point where I would need a support group. I'm just not there. And even if I were there I don't know if I would go.”

The overall response to the question about past use and interest in psychologists or counselors was similarly negative. One woman had sought out a psychologist to help her with marital issues. Another had received a referral for a psychologist from her nurse, but gave up after calling and finding out the waiting list was too long. Aside from these instances, the overwhelming response from participants to the possibility of talking to a psychologist in the future was one of disinterest: “Psychologists, psychiatrists, forget it. I think that if you have a good friend, that’ll do you as good. And no, I never will.”

Friends and family

Many participants expressed the importance of having friends and family around to help them feel better. This came mostly in the form of emotional

support, like talking and companionship, but also in terms of more concrete, practical support, such as having someone willing to help with housework.

First, the importance of social support was voiced by those who considered they had it:

> Probably my relationship with my husband; I mean he accepts me the way I am. He doesn't think of me as, though he says "oh you're an invalid" or when I complain about something he says "oh you're getting old," but he's very, very supportive, and just having that love, I guess he accepts me as a normal person so I feel like a normal person, I don't feel like I have a chronic condition.

Second, its importance was also expressed by those who perceived they lacked it:

> Participant: And my husband? He just-oblivious- never talks about it, nothing, never, never, never, never, never, never, never, never! He, my husband, is terrified of death. … He's no help at all- no help at all! And my kids, like I tell you, I really don't think they get it. …
>
> Interviewer: Do you wish they were more understanding of it?
>
> Participant: Um…I guess so. I guess so. It, it, because, what I wish is that they would put the blame in the right place. You know what I mean? Sort of thing. Like you're not being hard to get along with because you feel like being hard to get along with, or you feel like being crabby- it's because… *(trails off).*

Instead of seeking support from support groups and psychologists, participants preferred contact with friends and family.

Summary

Overall, participants described a wide range of distress responses, from those who said that they had not experienced distress associated with the disease, to those who said they had experienced what they considered to be severe distress. The term "depression" was reserved for such serious experiences. Many participants, however, acknowledged experiencing distress, but preferred other descriptors. Participants often described their distress in terms demoralization; they saw it as stemming from the difficulties of life with the disease, and described moods they could be lifted out of by pleasurable activities. Participants perceived that worse disease was related to worse distress, and that the loss of autonomy that can follow symptoms was a major part of this relationship. Conversely, several participants suggested that the emotional response to life's stressors could exacerbate the disease itself.

The ways in which participants coped with their distress related to what they saw as causing it. Participants dealt with the symptoms of the disease by changing what they could control, such as making changes to the work environment and finding novel ways to keep doing formerly pursued activities. What participants could not control, they preferred not to think about: by pushing thoughts of fear and uncertainty out of their heads, by staying busy to keep their minds occupied, and by often not coming into contact with others with the disease. This desire to not dwell on their condition was further exemplified by their general dismissal of psychologists and support groups. The support participants preferred came in the form of contact with friends and family.

DISCUSSION

The Meaning of the Word "Depression"

Participants described a range of qualities and severities of distress. A few maintained the disease had not caused them significant distress, often attributing it to their resilient disposition, but for the most part participants did endorse being distressed at some point by the disease. Many participants described experiencing significant distress, sometimes all-consuming and immobilizing, but said that "depression" was not the appropriate term to describe it. These participants preferred instead terms for more "normal" emotions like "bored," "angry," "frustrated," and "nervous." It is possible that they sometimes avoided endorsing being "depressed" because of the stigma that can surround the term. I think that it is instead more likely that many did experience significant distress, but they did not use the word "depressed" because they did not see it as pathological; they saw it as a reasonable reaction to their circumstances.

Participants reserved the word "depression" for a specific experience that was severe and separate from normal suffering. They used the word to describe times when their distress was severe and unrelenting, when it had become a separate problem in itself. Furthermore, they did not use the word lightly – they had very clear conceptions about when it should be employed, usually giving a definite "yes" or "no" when asked if the word fit their experience.

The specific realm reserved for the use of the term "depression" by patients is consistent with Horwitz and Wakefield's argument that the term should be reserved as a term for abnormal sadness.[30] The authors argue that depression, true

disordered sadness, is unreasonably persistent and severe given its context. It appeared that some of these participants said they were not "depressed" because they knew exactly what caused their distress and so did not see it as an out of proportion response to their circumstances.

Demoralization

Much of how the participants described their distress fits the quality of demoralization very well. First, several participants described low moods that were alleviated by doing things they normally took pleasure from, like getting out of the house, taking part in leisure activities, or spending time with family. This is in keeping with the adjustment disorder definition, where distress is present but there is an absence of anhedonia.

Second, participants viewed their distress and their disease as being very closely linked. This adds to the demoralization hypothesis because it means they saw their distress as an adjustment to the stress of life with the disease. Participants described distress that they viewed as resulting from their illness, and provided concrete symptoms and experiences that caused distress, including fatigue, disfigurement, pain, and the loss of autonomy that resulted from these symptoms. When participants cited episodes of severe distress, they had typically occurred shortly after the diagnosis, suggesting a period of intense adjustment, but not necessarily major depression.

Third, the fact that patients mentioned being distressed but often preferred terms other than "depression" to describe these moods can also be interpreted as supporting the demoralization hypothesis. Demoralization is considered to be a

product of adjustment to difficult circumstances, and participants often viewed their distress as stemming from their illness, as a reaction, as an adjustment. They did not view it as being out of context and being a problem in its own right.

One particular theme participants described, however, could be interpreted as not adhering to the demoralization hypothesis. Jerome Frank, the initial promoter of demoralization as a distinct construct, believed that it is was the type of distress that should respond to psychotherapy *par excellence*.[41] He considered psychotherapy's main objective was to instill morale – a seemingly ideal treatment for those who are lacking it. The vast majority of participants, however, were uninterested in the possibility of speaking to a counselor or psychologist in the future, and only one had mentioned seeing a psychologist in the past. This disinterest came amidst multiple mentions of significant distress resulting from disease. If participants were truly demoralized according to the classical definition, would they not be more tempted to seek psychotherapy?

It is possible to interpret participants' disinterest in psychologists as out of keeping with the demoralization hypothesis. It is, however, also possible to consider the same phenomenon as being consistent with it. Demoralization is a form of distress that is context dependent, and it is plausible that participants had a clear idea of what was causing their distress (ie. their disease), and hence didn't see a need to psychologize what they saw as essentially an external problem. Also, someone not choosing to seek psychotherapy is not the same issue as whether or not they would respond to it if they were to seek it out. Depending on

how you interpret it, the same thing can be seen as either consistent or inconsistent with the concept of demoralization.

Therefore, some of what participants said about their distress can be seen as adhering to the demoralization hypothesis. They often described their disease and distress as closely linked, as an adjustment to symptoms and the diagnosis. The fact that they were not interested in seeking psychotherapy may suggest that the concept of demoralization tends to 'psychologise' an expression of distress that is context dependent.

Patients' Conceptions of Stress

I approached this study primarily seeking to understand how scleroderma affected people's emotional wellbeing. It was therefore surprising to hear multiple patients say that their emotional state affected the disease itself. They did this by saying that their reaction to stress exacerbated the disease.

We can think about these statements in two ways. The first is from a socio-cultural position. The term "stress" is ubiquitous in North American society, and is widely understood to mean any kind of strain our environment places on us. Some believe stress has such a prominent position in our culture that it should define the age we live in – "the Age of Stress."[46]

Much of the current popular understanding of stress springs from the work of physiologist Hans Selye, who, in the 1950's, borrowed the term "stress" from physics and applied it to medicine.[47] In his widely read book "The Stress of Life" (1956), Selye introduced the idea that environmental stress has real effects on the mammalian body, particularly on the gastrointestinal, endocrine, and immune

systems. Although he maintained that short-term reactions to stress were adaptive, he added that exposure to long-term stressors could result in tissue damage and disease. This idea, that chronic stress is bad for the body, is now widespread in our culture.[46]

The second viewpoint is a bio-medical one. The notion that stress can negatively affect the body does not exist only in mainstream culture. There is biological research that supports this notion. For example, there is evidence that psychosocial stress can precipitate rheumatologic diseases, in particular systemic lupus erythematosus,[48,49] and rheumatoid arthritis,[50] both of which, like scleroderma, are SARDs: systemic autoimmune rheumatic diseases. This process works through stress' activation of the neuroendocrine system which can affect immune function.[51]

Given both the cultural notions about and the medical research on stress, how do we interpret these patients' understandings of their disease being influenced by stress? Should we be thinking about this as a causative reality that should be further investigated biologically? Or do we think about this as a culturally-bound way of explaining a disease whose cause is not fully understood? It is likely that both are possible. The interviews conducted in this study do not help us to distinguish between the weightings of these two possibilities. What is necessary to understand is that, in many cases, patients saw their mental and physical health as closely intertwined. They saw disease as causing distress, and distress as exacerbating the disease.

The Importance of Autonomy

Participants cited losing autonomy as a cause of distress, and, obversely, mentioned finding ways to feel autonomous as a means of coping with their distress. They fought to remain autonomous when the disease had impacted their bodies and limited their capabilities. They did this by seeking new ways to carry out leisure activities and by making changes to their work routine.

The importance of autonomy for mental wellbeing has been explained at length elsewhere, particularly in the context of self-determination theory. This is a theory of human motivation that states that humans have three basic needs: autonomy, competence, and relatedness.[52] Deci and Ryan, the main proponents of this theory, consider these three needs to be universal, present in people all over the world.[53] Other scholars, however, believe that autonomy is valued most in Western cultures – those originating from European societies – where there is an emphasis on independence and individualism.[54]

It follows then that the women in the study, who for the most part come from Western cultures, would value autonomy and suffer when they sensed they were losing it. This interpretation may likely apply to the loss of things that allow one to be financially independent (holding a job) or to be able to travel freely. But the most basic things that some of these women lamented losing, like being able to feed, clothe, and wash oneself, are not Western-specific values. These are the most fundamental abilities that a human can have. In other words, when these women spoke about the difficulties of losing autonomy, some of it can be interpreted as a result of our living in a western society. Some of it, however,

should be understood only as a very basic independence that is desired by people everywhere.

Coping with Distress

Beyond coping by struggling to stay autonomous in dealing with the very practical limitations of their illness, most of how the women interviewed described how they coped with their distress can be summed up in three words: don't dwell on it.

First, this came in the form of pushing troubling thoughts out of their minds. Participants repeatedly stressed the importance of this, using strong phrases like "don't think about it," and "wipe it out." When I asked participants to elaborate on the process of acceptance, most of the women said that there wasn't really a process; it was a really just a resolution to not dwell any further on the losses suffered and threats presented by the disease. Participants also asserted the importance of keeping busy. This is, in essence, a behavioural way of achieving the same distance from their predicaments. This came in the form of those who were thankful for having some sort of routine or occupation, and by those who expressed their longing for the routine they could no longer perform because of their disease.

Coping with distress by choosing to not dwell on the difficulties and threats presented by their illness was further embodied by the way the women responded to questions about the prospect of visiting psychologists and support groups. The response to both options was generally negative. Only two women had expressed past interest in seeing psychologists or counselors, and several women used strong

language insisting they would not do so in the future. Again, this reflects the participants' wish to not discuss and dwell on their situation, and their desire to seek normalcy in their lives as opposed to pathologising it even more.

Participants' general disinterest in seeing psychologists to address their emotional needs reflects some past research illustrating poor follow-up with mental health workers among post-natal women and cancer patients, as discussed in the introduction.[34,35,37] It is also in keeping with a study by Brody et al,[55] where 400 primary care patients were asked about their attitudes towards possible treatment of their emotional distress. Although 63% of their sample reported being at least somewhat interested in the possibility of having their physician try to help them with their emotional distress, only 11% of all patients (and curiously only 5% of depressed patients) desired a referral to a mental health specialist. The reluctance of participants in my study about seeing psychologists and counselors reflects these trends.

This hesitation about seeing mental health professionals cannot be wholly attributed to the lack of severity of mood among medical patients. It is likely that some people really do have severe moods that would benefit from treatment, but these people are reluctant to seek it out because of the stigma surrounding it, or maybe because of the process involved in getting in contact with a practitioner. It might also be that some people prefer to cope with distress by using their own support systems. Regardless, it would be fallacious to conclude that medical patients' seeming unwillingness to seek mental health treatment for emotional distress is wholly a result of the lack of severity of the problem.

Support groups may be a useful resource for patients of various diseases, but the setting in scleroderma is complicated by the fact that the disease is often visible. Attending support groups means seeing others with the disease, others whose disease is often more severe. Although a few patients said they benefited from talking to others with the disease, for others, coming into contact with these people served as a reminder of what may lie down the road.

Instead, the contact that participants did seek out was that which made them feel normal. Participants preferred being surrounded by understanding friends and family, evidence that they are still functioning human beings. It is likely that support groups often served the opposite function – it reminded them that they are sick.

Coping with distress by not dwelling on troubling thoughts and by seeking out normalizing situations makes sense given the nature of scleroderma. It can be disfiguring, and it can be fatal. There is no known cure. Although there are treatments for various symptoms, and there is the possibility that the disease may retreat with time, there is no chance that you can "beat" it. And, understandably, participants did not frame their coping in this way. Instead, they preferred not to confront the threat of the disease. They were not interested in working through things with psychologists, and, for the most part, avoided support groups lest they see others with the disease. They preferred things that made them feel normal, like routine and social life. This way of dealing with distress was summed up by two patients: "scleroderma is an ugly disease," one said; "if you think about it – that's it, you're doomed," another warned.

The Role of the Interviewer

Given the sensitive nature of some of the topics under discussion (body image, depression), creating a rapport with the interviewees was essential. It was for this reason that I recruited participants in person, as opposed to having the Registry nurse do the recruiting. As a consequence of having met them in person at the clinic, of having introduced myself, expressed my interest in their experience, I felt that even this bit of familiarity helped both the participant, and myself, feel more comfortable at the interview.

Creating this sense of comfort was particularly important given the sensitive nature of the topics being discussed. Although I tried to make the participants feel comfortable, I wonder if some may still have been reluctant to talk about some of the more sensitive topics. It makes sense that a middle-aged woman with scleroderma might be reluctant to discuss disfigurement with a visibly healthy young man. Would they have been more comfortable divulging such sensitive issues to a middle-aged woman or to another woman with scleroderma? For the most part I felt that the women were open with me, although there were a few participants in particular whom I felt were more reluctant than others to discuss personal issues.

Throughout the course of the study, I noticed my mindset change in a particular way. I began the project with a more positivist approach. I was concerned with the questions "are women with scleroderma distressed?", and, if yes, "what category of distress do they experience." As the study went on, however, as I conducted more interviews, my thinking became less positivist and

more interpretive. I became less concerned with what the actual mental health status of women was like, than with *how* they talked about, what they said about their experience. What did their descriptions of their distress tell us about their personal understandings of it? Also, I became less concerned with the positivist question of whether or not stress *actually* worsens the disease, than with the more interpretive question of what these statements tell us about how they viewed their bodies and how and this was influenced by the culture we live in. It is possible that this change in mindset might have altered how I conducted interviews as the study progressed, but I do not think that it significantly changed them, as I stuck to a structured list of main questions throughout.

Limitations

The first thing to address is the fact that I interviewed only women for this study. During study planning, I recognized that men and women might provide very different accounts of life with the disease and experience of distress. Not enough English-speaking men, however, attend the local clinic to have recruited an adequate number to study. I therefore decided to focus on the experience of women, who comprise approximately 80% of those affected by the disease. Athough the study focuses on the sex that is more afflicted by the disease, it is limited by the fact that it does not address the specific experience of men with scleroderma.

Second is the fact that scleroderma is a very heterogeneous disease - no two people have exactly the same manifestations. Some of the participants had lived through severe, life-threatening disease, while others had stayed relatively

unscathed. Is it then valid to group the illness experience of all these people because they share the same diagnosis? Despite these differences, I will argue that there are some things that most, if not all, of these participants faced. These include some degree of disfigurement, fatigue, and Raynaud's phenomenon, as well as the threat that their disease may worsen with time.

Third, the sensitive nature of some of the topics might have made participants reticent to discuss them. Although I tried to make participants feel comfortable, there is still stigma surrounding the topic of depression, and to reveal having been depressed can come with a sense of vulnerability, of weakness. While many participants spoke at length about their distress, I am curious as to how much they did not divulge to me for fear of being perceived as overly sensitive or weak.

Fourth, I conducted only one interview per participant. Although this is not necessarily a limitation, I am curious as to how the results of the study would have changed if I had had several meetings with each participant. Would another day's mood color their story? Would they have been more willing to divulge personal details if we had spent more time together? A design with multiple interviews per participant would have surely yielded more complex and rich results.

Another limitation is that most participants had long-standing disease. That is, most were not in the throes of grappling with a new diagnosis, and had been living with and successfully managing their symptoms for some time. It is possible that this might have colored their narratives of distress more favorably.

(The participants did, however, often retrospectively describe periods of distress at the beginning of their illness.) This is an unavoidable pitfall of much research on scleroderma – because the disease is rare it is hard to find significant numbers of those who have been recently diagnosed.

Implications

I am not going to make any direct clinical recommendations based on this single study. Instead I will reflect on what these participants said in relation to available treatment possibilities.

Many of these participants described more "normal" experiences of distress that they did not see as out of keeping with their circumstances. Also, they listed very concrete aspects of the illness that caused distress. And, besides coping with the practical limitations of the disease, they dealt with the threat of their illness by not dwelling on it, by not confronting it, and, for the most part, by eschewing psychologists and support groups. The normal, illness-driven way in which they viewed their distress suggests that scleroderma patients might benefit more from practical support, such as disease self-management programs or occupational therapists.

Patients' fears about attending support groups could be dealt with by instead providing the practical information they might gain from these groups in the form of scleroderma patient-resource books. Several of such books exist for scleroderma, written by both patients and doctors.[56,57] and there are also self-management programs geared for general chronic disease sufferers.[58] Family members might also benefit from these books, since participants cited

understanding family members as being a great support. Physicians could recommend these books to patients and their families.

Can we generalize this thinking to other diseases? Scleroderma shares much in common with other rheumatologic diseases, most of which are incurable, severe, and to some extent disfiguring. It is likely that sufferers of these diseases, like lupus and rheumatoid arthritis, would frame their distress in similar ways and would benefit through similar interventions.

Conclusions

Increasingly, efforts to provide psychosocial support in order to improve the quality of life among medical patients focus on the diagnosis and treatment of depression, a psychiatric disorder. The interviews we conducted with women living with scleroderma suggest that, in this environment, normal sadness might be misconstrued for something it is not (i.e. pathological). This misconstrual may occur when health professionals fail to take into account the context of distress, fail to fully understand the quality of distress, and believe significant distress requires mental health treatment.

The majority of the women we interviewed experienced significant distress associated with their illness. But after careful examination, the overwhelming narrative was that this distress was normal. Many participants had problems with using the label "depression" for their distress, and instead preferred more normal mood descriptors. Participants didn't see their distress as being a problem in its own right; they viewed it as being closely connected to their illness,

as an adjustment to symptoms and diagnosis. Also, these participants overwhelmingly did not want treatment specifically for their distress.

There is no doubt that some medical patients experience severe moods that would benefit from psychological or psychiatric treatment. We should, however, be careful not to pathologize distress that the sufferer considers normal, for which they do not want treatment, and have the desire and resources to cope with on their own.

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Appendix

McGill Illness Narrative Interview (MINI)

Generic Version for Disease, Illness or Symptom

Danielle Groleau, Allan Young, & Laurence J. Kirmayer ©2006

Section 1. INITIAL ILLNESS NARRATIVE

1. When did you experience your health problem or difficulties (HP) for the first time? [*Substitute respondent's terms for 'HP' in this and subsequent questions.*] [*Let the narrative go on as long as possible, with only simple prompting by asking*, 'What happened then? And then?']

2. We would like to know more about your experience. Could you tell us when you realized you had this (HP)?

3. Can you tell us what happened when you had your (HP)?

4. Did something else happen? [*Repeat as needed to draw out contiguous experiences and events.*]

5. If you went to see a helper or healer of any kind, tell us about your visit and what happened afterwards.

6. If you went to see a doctor, tell us about your visit to the doctor/hospitalization and about what happened afterwards.

6.1 Did you have any tests or treatments for your (HP)? [*The relevance of this question depends on the type of health problem.*]

Section 3. EXPLANATORY MODEL NARRATIVE

15. Do you have another term or expression that describes your (HP)?

16. According to you, what caused your (HP)? [List primary cause(s).]

16.1 Are there any other causes that you think played a role? [List secondary causes.]

17. Why did your (HP) start when it did?

18. What happened inside your body that could explain your (HP)?

19. Is there something happening in your family, at work or in your social life that could explain your health problem?

[If answer to #19 is Yes, then ask Q.20]

20. Can you tell me how that explains your health problem?

21. Have you considered that you might have *[INTRODUCE POPULAR SYMPTOM OR ILLNESS LABEL]*?

22. What does *[POPULAR LABEL]* mean to you?

23. What usually happens to people who have *[POPULAR LABEL]?*

24. What is the best treatment for people who have *[POPULAR LABEL]?*

25. How do other people react to someone who has *[POPULAR LABEL]?*

26. Who do you know who has had *[POPULAR LABEL]*?

27. In what ways is your (HP) similar to or different from that person's health problem?

28. Is your (HP) somehow linked or related to specific events that occurred in your life?

29. Can you tell me more about those events and how they are linked to your (HP)?

Section 5. IMPACT ON LIFE

39. How has your (HP) changed the way you live?

40. How has your (HP) changed the way you feel or think about yourself?

41. How has your (HP) changed the way you look at life in general?

42. How has your (HP) changed the way that others look at you?

43. What has helped you through this period in your life?

44. How have your family or friends helped you through this difficult period of your life?

45. How has your spiritual life, faith or religious practice helped you go through this difficult period of your life?

46. Is there any thing else you would like to add?