Annals of Nutritional Disorders & Therapy

Open Access

Austin Publishing Group

Research Article

Self Reported Nutrition Concerns in Scleroderma

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Received: November 25, 2014; **Accepted:** December 11, 2014; **Published:** December 12, 2014

Abstract

Introduction: Gastrointestinal involvement is a nearly universal symptom in systemic sclerosis (SSc, scleroderma). Few studies have investigated nutrition practices in SSc. The purpose of this study was to assess dietary practices, self awareness of nutritional status, and influence of diet on symptoms of gastrointestinal involvement in SSc patients who had received the Scleroderma Foundation "Eating Well with Scleroderma" handout.

Methods: Patients were provided the "Eating Well with Scleroderma" handout from the Scleroderma Foundation. At a follow-up visit patients were asked if they had noted any weight loss, if they weigh themselves, if they had identified food that bother their stomach or gut, whether they follow a special diet, and whether they take a PPI and/or probiotic. The UCLA SCTC GIT 2.0 questionnaire, a validated instrument for evaluation of patient-reported outcomes involving the gastrointestinal tract, was administered.

Results: All patients reported that their diet influenced their gastrointestinal symptoms. BMI was similar regardless of whether weight was stable, increased or decreased over the past 6 months. Few patients (n=3) lost more than 5 pounds over the past 6 months. Patients who had a weight loss over the past 6 months, more often reported following a special diet, having moderate to severe reflux, and using probiotics than patients with stable or increasing weight. Limiting spicy, greasy and acidic foods was the most commonly reported dietary modification.

Conclusion: Patients are universally aware that diet affects gastrointestinal symptoms. This series of patients reported use of probiotics and dietary modifications, particularly those who lost weight and had moderate to severe reflux. Although patients received the "Eating Well with Scleroderma", these results highlight the need to guide nutritional interventions in SSc according to gastrointestinal symptoms.

Keywords: Scleroderma; Nutritional status; Dietary intake; Gastrointestinal symptoms

Introduction

The point prevalence of malnutrition risk in scleroderma across the globe is estimated to be between 15 and 25% [1-5]. A small corpus of literature on body composition suggests that lower lean body mass [6] with variable fat mass [7] is associated with disease outcome. Malnutrition in systemic sclerosis (SSc, scleroderma) is associated with longer duration of disease, diffuse cutaneous disease, physician assessment of disease severity, low hemoglobin, restricted oral aperture, abdominal distention and decrease in psychosocial well-being [5,7,8]. A recent report found that gastrointestinal symptoms were not associated with Body Mass Index (BMI), but was associated with decreased quality of life [9]. Unfortunately, traditional markers of nutritional status, including current weight status (BMI) and serum albumin do not seem to be good indicators of malnutrition in SSc [7,8,10].

In contrast, weight loss has long been identified as a characteristic of progression of SSc and is included in the Medsger Severity Scale [11]. However, dietary intake, nutritional counseling, and dietary modifications of patients with SSc have received little attention. A single report of dietary intake of 30 patients with SSc did not reveal differences in energy or nutrient intake [6]. However, in these SSc patients lower serum levels of nutrients and about half anthropometric measures were identified suggesting poor nutritional status. This mismatch in reported intake and physical signs of malnutrition suggests that malabsorption and, or episodic reductions in dietary intake are likely to be involved.

The import of good nutrition to the course of SSc is communicated to patients via the Scleroderma Foundation "Eating Well With Scleroderma" handout (Eating Well with Scleroderma).This is a broad guide to nutrition beginning with a description of symptoms of malnutrition in general and of protein malnutrition and general principles of good nutrition. Suggestions for many other specific issues those patients with SSc face, including the following: Dietary modifications to cope with chewing and swallowing difficulties; specific suggestions for increasing intake for individuals with large amounts of unintentional weight loss; The low Fermentable Oligosaccharides, Disaccharides, Monosaccharide's and Polyols (FODMAP) diet; reflux; inflammation; poor circulation; tight skin; and decreased gastrointestinal motility. This handout is a valued resource for SSc patients and is utilized routinely at many SSc centers to educate patients. Weight status is a common vital sign documented

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Citation: Murtaugh MA and Frech TM. Self Reported Nutrition Concerns in Scleroderma. Ann Nutr Disord & Ther. 2014;1(3): 1015.

at clinic visits. However, there is little known about dietary modifications among patients with SSc in relation to their weight change. Therefore, the purpose of this work was to ascertain dietary practices among patients with SSc concomitant with gastrointestinal symptoms and recent weight change.

Methods

All procedures were approved by the University of Utah IRB project 38705. We recruited 50 consecutive patients with SSc, who were consented for nutritional and dietary assessment, and presented for a follow-up visit which was 3-6 months after their last visit where they had received the Scleroderma Foundation "Eating Well with Scleroderma" handout (Eating Well with Scleroderma). At their follow-up visit, these SSc patients were asked to respond to a brief questionnaire which was designed to determine current dietary practices, beliefs about diet and gastrointestinal symptoms, probiotic and proton pump inhibitor use, weight changes over 6 months and physical signs of malnutrition (temporal wasting). All patients also responded to the University of California, Los Angeles Scleroderma Clinical Trials Consortium Gastrointestinal Tract Questionnaire (UCLA SCTC GIT 2.0), which assesses gastrointestinal tract symptomatology.

Demographic information (age, race/ethnicity); clinical characteristics (duration of SSc from the first non-Raynaud's symptom; SSc specific antibodies); and physical exam characteristics (height and weight; modified Rodnan Skin Score (mRSS), edema, and temporal wasting) were collected at the clinic visit by the attending physician. The mRSS ranges from 0 to 51, based on assessment of skin thickness at 17 surface anatomic areas of the body. We additionally obtained information regarding presence of other gastrointestinal disease such as celiac disease, ulcerative colitis or Crohn's disease.

The UCLA SCTC GIT 2.0 questionnaire sub-scales and total scores were calculated using the method described by Khanna et al [12]. The result can be interpreted as a score or as a categorical evaluation (mild, moderate and severe) of each sub-scale and the total score.

Statistical analyses were conducted using SAS version 9.4 (SAS Inc, Carey, NC). Demographic and clinical characteristics were described using frequency for categorical variables (e.g., gender, type of special diet followed). We used mean and standard deviation to describe normally distributed continuous variables and median and inter quartile range to describe variables with skewed distributions. Differences in categorical variables or classification of gastrointestinal symptoms across levels of self-reported weight change were determined using chi-square or fishers' exact when cells included fewer than 5 observations. Differences in continuous variables across levels of weight change were ascertained using Wilcoxin ranked-sum test.

Results

The vast majority of patients were female and white (Table 1). The age range was 26 to 79 with a mean of 56.6. Disease duration ranged from 1 to 35 years with 6 years as the median duration. The median mRSS was 6 with a range from 0 to 32. Four individuals had no Scleroderma antibodies; presence of anti-centromere was the most common.

Table 1: Description of the Systemic Sclerosis Sample.

Characteristic	Mean ± SD or N (Interquartile range)
Age (years)	56.6 ±13.4*
BMI (kg/m^2)	27.7 ± 6.6*
Duration of Disease (years)	6 (3-13)**
Modified Rodnan Skin Score (mRSS, range 0-51)	6 (3-8)**
Race/Ethnicity	
White	45***
Other	5
Antibody Positive	
Centromere	27***
RNAPOLYMERASE III	7
SCL70	6
PM-SCL	2
Th/T0	1
RNP	1
None	7
Weight change	
Gain	13***
Loss	12
Stable	25
Edema	
Yes	19 ***

*Mean ± SD
**Median and Interquartile range
***Frequency

The average current BMI would be classified as overweight (Table 2). One individual was underweight, 21 were normal weight, 8 were overweight and the remaining 20 were overweight as classified by BMI. There was no pattern of weight change across BMI categories. The vast majority reported weighing themselves daily or weekly. Twenty-five individuals had no change in weight. Twelve had weight loss and 13 had a weight gain over the past 6 months. The largest weight loss was 18.2 pounds and the largest weight gain was 11.3 pounds. Only 2 of the patients had a weight loss exceeding 10 pounds;

Table 2: Current BMI, reported weight monitoring, diet modifications and medication use for gastrointestinal symptoms and weight status over 6 months.

	Stable Weight N=25	Weight Gain N=13	Weight Loss N=12
Weight Change (lbs)	0	5.2 ± 2.8	-6.4 ± 5.0
Current BMI (kg/m^2)	26.8 ± 5.9	29.8 ± 6.9	27.5 ± 7.6*
BMI< 18.5	1	0	0**
BMI ≥ 18.5 and < 25	10	4	7
BMI ≥ 25 and < 30	6	1	1
BMI ≥ 30	8	8	4
Weighs self			
Almost Never	10	4	5
Daily	7	3	2
Weekly	3	4	3
Monthly	5	2	2
Uses a Proton Pump Inhibitor (yes)	20	11	12
Uses a Probiotic (yes)	18	6	11***
Follows a Special Diet(yes)	11	6	7***
Type of Special Diet			
FODMAP	0	1	1
Limit acidic, greasy or spicy foods	5	8	6
Limit Dairy Foods	3	2	1
Limit Calories, sugars, carbohydrates or fats	3	2	0
Limit Gluten	4	0	0

*Mean ±SD
** Frequency
***Difference in the distribution across weight change status, Fishers Exact p <0.05

Table 3: Gastrointestinal Symptoms and Weight Status over 6 months.

	Stable Weight N=25	Weight Gain N=13	Weight Loss N=12
GIT 2			
Mild	16	6	5
Moderate	6	4	6
Severe	3	3	1
Reflux			
Mild	19	4	4
Moderate	2	6	3
Severe	2	1	4*
Bloating			
Mild	18	8	8
Moderate	3	2	3
Severe	4	3	1
Social			
Mild	21	8	10
Moderate	3	2	1
Severe	1	3	1
Emotion			
Mild	18	7	8
Moderate	4	1	2
Severe	3	5	2
Diarrhea			
Mild	14	5	6
Moderate	9	5	4
Severe	2	3	2
Constipation			
Mild	14	8	5
Moderate	5	4	6
Severe	6	1	1
Soilage			
Mild	23	11	10
Moderate	0	0	0
Severe	2	2	2

* Fishers' Exact, $p < 0.005$

one lost between five and 10 pounds. The remaining 9 patients with weight loss lost less than 5 pounds in 6 months. Edema was present in 19 individuals and no patients had temporal wasting Table 1.

All patients reported their perception that diet is important and influences their bowel function. Nonetheless, despite being provided dietary guidelines by the Scleroderma Foundation "Eating Well with Scleroderma" only approximately half reported following a special diet. One patient had confirmed Ulcerative colitis, 3 with Celiac, one had primary biliary cirrhosis, and two had Celiac disease. In patients without celiac disease, one patient reported following a gluten-free diet, and two reported limiting their gluten intake. The most common dietary modification was limiting acidic, greasy or spicy foods. Limiting calories, carbohydrates, sugar or fats were reported by only 6 individuals. A variety of special diet restrictions including low-sodium (n=1), the renal diet (n=2), and a"Paleo" diet were also reported along with restriction of dairy foods or meat. Two individuals reported following the FODMAP diet. We detected no patterns of special diet use across severity of GI symptoms, previous endoscopy, or reported weight change.

The majority of patients had gastrointestinal symptoms classified as mild by the total score. Nine individuals had severe gastrointestinal symptoms (GIT 2.0 total score > 1.01). Sixteen had moderate symptoms (GIT 2.0 total score between 0.5 and 1.0). Patients scored as having severe emotional well-being (n=10), reflux (n=7) and distention or bloating (n=8) more often than the other sub-scales. Almost all used proton pump inhibitors (n=43), and the majority used probiotics (n=35).

BMI was similar across the recent weight change groups (stable, weight loss or weight gain). There was no difference in frequency of weighing across these self-reported weight change categories. However, probiotic use was more common among individuals who had lost weight as compared to those who were stable or had gained weight. There was no difference in frequency of proton pump inhibitor use according to weight change categories. Likewise, there were no detectable patterns in report of special diet across the reported weight loss categories. The proportion of more severe reflux was greater among those who reported weight loss over the past 6 months than among individuals who gained or did not change weight. There were no differences in the severity of other gastrointestinal symptoms or total GIT2.0 score across reported weight change groups.

We detected no difference in probiotic use with severity of reflux, bloating, or total GIT2.0 score.

Discussion

The gastrointestinal tract is the most common extra-cutaneous organ system involved with systemic sclerosis (SSc). Approximately 90% of patients report gastrointestinal symptoms associated with a decrease in quality of life. An improved understanding of gastrointestinal symptoms and their relation to nutritional status in SSc patients is needed. All patients with SSc identified diet as influencing their gastrointestinal symptoms and all patients had received the handout "Eating Well with Scleroderma." Our data highlight the variety of challenges for nutritional status, weight and gastrointestinal symptom management in patients with SSc.

In this present study, BMI was similar regardless of whether weight was stable, increased or decreased over the past 6 months. Others have reported that current weight is not a good indicator of potential risk for poor nutritional status [7,8,10]. Patients who lost weight intentionally were more likely to report use of both a special diet and a probiotic. In this study weight change that could be suggestive of risk for poor nutrition (> 5 lbs.) was infrequent. Importantly, none of the patients with weight loss reported restriction of calories, sugar or fat. It is notable that the majority of patients were weighing themselves daily or weekly.

Reasons that patients thought they gained weight were varied, but the most frequent reasons the patients gave for unintended gain included "stress,""not exercising,""constipation," and "fluid retention." Other patients (that were underweight) attributed weight gain to "eating healthily,""using the FODMAP diet," or "eating too much." Patient perceptions of the causes of weight loss were also varied. Healthy eating, watching portions, getting more exercise, and following a Paleo diet were reasons that imply intentional weight loss. Stress and medication changes (thyroid medication adjustments, stopping prednisone, and new gastrointestinal medication) were cited as reasons that imply unintentional weight loss.

We previously identified clinically important differences in the total GIT 2.0 score, reflux, distention/bloating, spoilage diarrhea and emotional well-being across levels of nutritional status as assessed by the subjective global assessment tool [10]. In this series, patients reported a variety of different dietary approaches, but avoidance of greasy, spicy or acidic foods was the most common. This report appears consistent with gastrointestinal symptomatology and adaptive eating behaviors. Patients who reported weight loss over the past 6 months

also reported more severe reflux than among patients who had gained weight or remained at a stable weight. A low FODMAP (fermentable oligosaccharides, disaccharides, monosaccharides, and polyols)diet is effective at reducing symptoms of IBS [13]. This approach was not commonly reported, but should be considered for management of gastrointestinal symptoms of patients with SSc. Thus, with the exception of foods that cause reflux, it was not clear whether patients used other dietary modifications or restrictions to prevent or manage severity of constipation, bloating, diarrhea, or soil age.

Limitations of the study include self-reported measures of gastrointestinal symptoms, and dietary practices. There was no measure of the extent to which patients read, comprehended or followed the "Eating Well with Scleroderma" guide. There was also no measure of how often or strictly they followed the special diets or dietary modifications that they reported. Larger and controlled study designs will be useful in further understanding the potential for dietary modifications to assist patients with preserving adequate nutritional status and coping with gastrointestinal and other SSc symptoms that impact quality of life.

Nonetheless, this study highlights that despite patients' recognition that diet significantly influences gastrointestinal tract function an improved understanding of the best diet for SSc patients is needed. Dietary handouts may not be effective for educating SSc patients on diet. Despite patients attention to their weight (ie, frequent weighing), dietary guidance for purposeful weight loss and weight gain may require individualized plans. The influence of spicy foods on reflux is well-established and supported by this study. Dietary influences on symptomatic constipation, diarrhea, and/or soilage were not clear in this study and offer an opportunity for further study.

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Ann Nutr Disord & Ther - Volume 1 Issue 3 - 2014
ISSN : 2381-8891 | www.austinpublishinggroup.com
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Citation: Murtaugh MA and Frech TM. Self Reported Nutrition Concerns in Scleroderma. Ann Nutr Disord & Ther. 2014;1(3): 1015.