Published in final edited form as:

Am J Med Sci. 2016 May ; 351(5): 447–451. doi:10.1016/j.amjms.2016.02.021.

PerSSception: A Survey of Patients with Systemic Sclerosis and Their Perceptions of the Quality of Their Primary Care

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Abstract

Background—Among patients with systemic sclerosis (SSc), early recognition of potentially life-threatening organ involvement is critical. Because prompt recognition of early signs of organ involvement can dramatically alter a patient's outcome, it is crucial that patients and primary care providers (PCPs) recognize these symptoms. We conducted a survey of SSc patients regarding their perceptions of the quality of their primary care, and whether or not they perceive the quality of their primary care to be impaired by their scleroderma diagnosis.

Methods—A mail survey was sent to 525 patients with SSc seen at the Medical University of South Carolina. Questionnaire items addressed demographics and perceptions of their quality of their primary care.

Results—Of n=140 respondents, most (74.5%) did not feel as though their diagnosis of SSc has resulted in barriers to appropriate or satisfactory care, and most (81.3%) answered that they had not ever felt as though their medical concerns were not being addressed because they had SSc. Perceptions of barriers were significantly ($p<0.05$) associated with female gender and younger age, along with poorer overall quality of care and satisfaction with their primary care.

Conclusions—Most SSc patients value the quality of their primary care. However, some SSc patients feel that their PCPs do not adequately monitor their blood pressure, reflux symptoms, or shortness of breath. These results highlight the importance of PCPs in the overall care of SSc patients and the need for continued education regarding close monitoring of signs/symptoms suggestive of possible life-threatening internal organ involvement.

Keywords

scleroderma; systemic; primary health care; health surveys; patient satisfaction

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Introduction

Scleroderma (Systemic Sclerosis, SSc) is a rare, complex multi-organ system disease characterized by autoimmunity, vasculopathy, and fibrosis of skin and internal organs. Mortality is most often related to pulmonary, cardiac, renal or gastrointestinal involvement. Because there is currently no curative treatment for this disease, early recognition of potentially life-threatening organ involvement is critical to manage and prevent further tissue damage¹.

Many patients with scleroderma are seen in outpatient settings by rheumatologists at major tertiary care referral centers which often requires travel from surrounding states, and typically they are seen 1 or 2 times per year at the referral clinic. In between their visits with a scleroderma specialist, much of their care is provided by primary care providers (PCPs). In one study of Dutch n=64 SSc patients, 75% had visited a rheumatologist in the past 12 months, and 31% had seen a general practitioner²; in a separate Dutch study of n=198 SSc patients, 83% had visited a rheumatologist in the past 12 months, and 50% had seen a general practitioner³. Early signs of organ damage from scleroderma, therefore, may first be recognized by healthcare providers other than rheumatologists.

Early recognition of life-threatening complications of this disease can lead to quick interventions that can dramatically change patient outcomes⁴. Common signs and symptoms of organ involvement related to scleroderma include Raynaud Phenomenon with digital ischemia, shortness of breath from either interstitial lung disease or pulmonary arterial hypertension, and worsening reflux symptoms that can lead to aspiration and dysphagia. Renal involvement from scleroderma is a well-recognized complication, and close monitoring of blood pressure readings and renal function with serum creatinine and urinalysis measurements is very important. Because prompt recognition of early signs of organ involvement can dramatically alter a patient's outcome, it is crucial that patients as well as PCPs recognize these symptoms. A review of the literature uncovered several published studies regarding patients with scleroderma and their perceptions of their underlying condition⁵ and health care utilization^{2,6}, but to our knowledge there have been no studies published looking specifically at scleroderma patients' perceptions regarding the quality of their primary care.

The purpose of this study was to survey patients with SSc regarding their perceptions of the quality of their primary care, and whether or not they perceive the quality of their primary care to be impaired by their scleroderma diagnosis. To address these research questions, we conducted a mail survey of SSc patients treated by the Division of Rheumatology at the Medical University of South Carolina (MUSC).

Methods

A survey was created to address our study aims, and it included a variety of questions, including ones with responses that were ordinal (Likert-style), binary (yes/no), and open-ended. The survey was intended to be short to enhance the response rate, and drafts of the survey were reviewed by study personnel to ensure its ease of understanding and face

validity. No patient identifying information was requested in the survey. A list of all adult patients (age 18 years and older) treated at the MUSC rheumatology clinics from January 2013–October 2014 with an ICD9 diagnosis code of 710.1 (systemic sclerosis) was generated using information collected within the MUSC clinical data warehouse. A cover letter was created outlining the purpose of the study survey as well as instructions regarding optional participation and survey completion. The cover letters and surveys were mailed together with a pre-stamped return envelope to a total of 525 patients with SSc. The study was approved by the Institutional Review Board at MUSC.

There were 2 questionnaire items of primary interest: (Item #7) “Have you ever felt as though your diagnosis of scleroderma has resulted in barriers to appropriate or satisfactory care? [Yes/No] Please give an example if applicable.”, and (Item #8) “Have you ever felt as though your medical concerns were not addressed because you have scleroderma? [Yes/No] Please give an example if applicable.” We also questioned these patients regarding whether or not their primary care providers evaluate them for signs or symptoms of potentially life-threatening internal organ involvement related to their disease, such as close monitoring of blood pressure, shortness of breath, and gastrointestinal reflux. We examined whether or not their responses to these questions were associated with their demographic characteristics (age, gender, race), the type of primary care provider, frequency of visits to his or her primary care provider, duration of their primary care provider/patient relationship, as well as their overall rating of the quality of the care provided by the primary care provider.

Quantitative Analyses

Initially, survey responders were characterized using descriptive statistics (means, standard deviations, and proportions, as appropriate). Response frequencies were also tabulated for each questionnaire item.

To assess the associations between the primary questionnaire items and demographics and other item responses, cross tabulations and chi squared tests were used. Traditional chi squared tests and Fisher’s exact tests were used for categorical responses, while Mantel-Haenszel chi squared tests were used for ordinal responses. Logistic regression models were also used to determine whether any observed associations were moderated by demographic characteristics. P-values < 0.05 were considered statistically significant, and no adjustments were made for multiple comparisons, due to the fact that this was largely an exploratory study. All analyses were performed using SAS v9.4 ©.

Qualitative Analyses

Responses to open-ended questions were reviewed, and a few illustrative responses were selected and reported.

Results

Of the 525 mailed surveys, a total of n=143 (27.2%) were completed and returned. Three surveys (0.5%) were excluded from the analysis, due to them being completed by a family member of a deceased patient (n=1) or them being incorrectly identified as having SSc

(n=2). In total, n=140 completed surveys were analyzed. Twenty surveys (3.8%) were returned unopened with incorrect mailing addresses.

Of the 140 respondents included in the final analysis, the mean age (SD) was 58.9 (13.1) years and ranged from 21 to 85. A total of 85% were female. Regarding ethnicity, 77% percent of the respondents were white, and 23% identified themselves as black/other. These demographic characteristics of our participants adequately reflect the general population of patients with systemic sclerosis seen in the MUSC scleroderma clinics, where the mean age (SD) is 56.9 (13.4) years, 84% are female, and 62.4% are white.

Table 1 lists the survey questions, along with the count and frequency for each response. Almost all (94.0%) respondents receive their primary care by family medicine or internal medicine physicians, and only 1 subject reported not having a primary care provider (PCP). Almost all (88.2%) subjects reported seeing their PCP at least once per year, and almost half (49.3%) have been seeing their provider for more than 5 years. The majority of respondents (73.9%) rated the quality of their primary care as “very good” or “excellent”, and only 2 respondents (1.5%) stated their primary care providers were unaware of their diagnosis of scleroderma. Most respondents reported that their PCPs are addressing some key symptoms which could suggest possible internal organ involvement, such as hypertension (75%), reflux (57.5% of total, 67.2% of applicable patients); however, patients reported that shortness of breath was not consistently being addressed (32.4% of total, 49.5% of applicable patients). Most (67.3%) participants rated their overall satisfaction with their primary care providers as “very good” or “excellent”.

A large majority (74.5%) of respondents did not feel as though their diagnosis of scleroderma has resulted in barriers to appropriate or satisfactory care (Item 7). However, among the 35 respondents who did, some reported that their PCP does not monitor their blood pressure closely (31%), address their heartburn symptoms (40%), or address their shortness of breath (46%). Women were more likely to respond “yes” to this question about barriers than men, but this difference was not statistically significant (women: 28.7% vs. men: 10.5%, $p=0.16$). Similarly, blacks were more likely than whites to respond “yes”, but this was also not statistically significant (blacks: 36.7% vs. whites: 23.1%, $p=0.14$). Respondents who responded “yes” were significantly younger than respondents who responded “no” (“yes”: 53.5 ± 15.3 years vs. “no” 60.7 ± 11.8 years, $p=0.007$). Even after adjustment for demographic factors, feeling as though their SSc diagnosis has resulted in barriers to care was strongly associated with other questionnaire items, including a poorer overall perception of their quality of care (Item 5, $p=0.02$), PCP’s lack of understanding of SSc (Item 9, $p=0.04$), and poorer overall satisfaction (Item 12, $p=0.001$). Interestingly, patients who were referred to the SSc clinic by their PCPs were significantly less likely ($p=0.02$) to indicate that their SSc diagnosis has resulted in barriers to care than patients referred by other means (PCP referral: 9.4% reporting barriers, another rheumatologist: 22.87%, self-referral: 38.1%, other referral: 40.9%).

Most (81.3%) respondents answered “no” to Item 8, which asked if they ever felt as though their medical concerns were not addressed because they had scleroderma. However, among the 25 respondents who responded “yes”, many reported that their PCP does not monitor

their blood pressure closely (28%), address their heartburn symptoms (52%), or address their shortness of breath (52%). Responses to Items 7 and 8 were very strongly associated with one another ($p<0.0001$), meaning that if a subject felt as though their SSc diagnosis has resulted in barriers to care, he/she was also likely to have felt that certain medical concerns were not being addressed. Interestingly, none of the men indicated that any of their medical concerns had not been addressed, compared with 22.3% of the women ($p=0.02$). Responding “yes” to having unaddressed medical concerns was not associated with race, but it was significantly associated with age (“yes”: 53.9 ± 15.8 years vs. “no”: 60.4 ± 12.0 years, $p=0.03$). After adjustment for demographic factors, feeling as though medical concerns were not being addressed because of the SSc diagnosis was strongly associated with poorer overall satisfaction (Item 12, $p=0.02$), but not with any other questionnaire item.

When asked of examples of when they had ever felt as though their diagnosis of scleroderma has resulted in barriers to appropriate or satisfactory care, participants provided a variety of responses, including the following statement by one person: “In the ER, a nurse told another nurse that most people claiming to have scleroderma were looking for quick drugs.” One person responded, “My shortness of breath was blamed on being overweight, however I had been 65 lbs heavier just a few years earlier and never had shortness of breath and worked on my feet and ran a production floor. I resented being told it was from weight,” while another stated, “When they (doctor) don’t know what something is or what is causing something they blame it on the scleroderma.” When asked to provide examples of when they felt as though their medical concerns were not addressed because they had scleroderma, one respondent stated “My primary care doctor never discusses my scleroderma, never asks about my hands (never looks at my hands) or reflux or GI involvement,” while another said, “I am told at times to address with my rheumatologist. At times it is difficult to decide what doctor to contact.” One person mentioned that they feel “too many of [his/her] problems are not followed through because of blaming the scleroderma at times.” While these comments are obviously anecdotal in nature, it is clear that some patients feel strongly that their SSc diagnosis either results in barriers to them receiving appropriate healthcare or in their medical concerns not being addressed.

Discussion

Recent studies have estimated the prevalence of scleroderma in the United States to be 242 cases per 1 million adults⁷. Because of the rarity of this disease, many physicians (including rheumatologists) may only interact with a very limited number of scleroderma patients throughout their careers. Morbidity and mortality are often secondary to internal organ involvement, which can present as rather nonspecific symptoms such as shortness of breath or hypertension. According to the data presented, the majority of scleroderma patient participants in this study see their PCP between one and six times per year. Many patients are only seen at a major “scleroderma center” every 6–12 months. Because of this, PCPs are often the ‘first in line’ when it comes to recognizing new or concerning symptoms in scleroderma patients which could represent significant internal organ involvement from their disease. Ultimately, this recognition is crucial to the institution of early interventions and treatments that may be able to alter the course of the patients’ disease. These findings are consistent with earlier work by Willems et al. (2013), in which they surveyed Dutch SSc

patients and found that 50% had been in contact with a general practitioner in the past 12 months, and that their perceived quality of health care as assessed by the degree of “cooperation and alignment” was significantly negatively correlated with being in contact with a greater number of medical disciplines³. They also noted that only 53% perceived that their healthcare providers communicated well with one another, with 12% reporting dissatisfaction with at least one aspect of the care provided by their “most important health care provider”.

The purpose of this study was to survey patients with scleroderma regarding their perceptions of the quality of their primary care and whether or not they felt as though their diagnosis of scleroderma resulted in barriers to satisfactory care. We also wanted to assess whether or not patients felt as though key symptoms (such as hypertension, shortness of breath and gastrointestinal reflux), which could potentially represent life-threatening internal organ involvement, were being addressed by their primary care providers. Reassuringly, the majority of patients reported receiving excellent care by their PCPs and did not feel dissatisfied with the quality of their care or that their symptoms are being unaddressed. Unfortunately there still remains a subset of patients who have had negative experiences with PCPs and have felt as though the diagnosis of scleroderma has been a barrier to appropriate care.

There are several limitations of this survey. First and foremost, this was a survey strictly assessing the patient’s perception and may not accurately reflect the true content of patient-provider encounters. We did not assess these issues through the PCP’s perspective or medical records, and thus we cannot be certain as to whether or not symptoms have truly been unaddressed. Second, our response rate was only 27.2%; thus, it is possible that some of our proportion estimates may not appropriately reflect the perceptions of all SSc patients; however, we believe that regardless of this limitation, our findings do shed light on potential deficits in the care of some SSc patients. Because some of the questions contained in this survey required only a “yes” or “no” answer, we were not able to further assess more specifically what the patients perceived the barriers to satisfactory care might be.

Conclusion

This survey highlights the importance of PCPs in the overall care of patients with scleroderma, and the need for continued education to all providers regarding close monitoring of signs/symptoms suggestive of possible life-threatening internal organ involvement. It also serves to emphasize the importance of communication amongst specialists and primary care providers in order to achieve the best and safest outcomes for patients with scleroderma. Moving forward, our goals include creating an informational pamphlet for both our scleroderma patients and their PCPs highlighting several important features of scleroderma and key symptoms that require close monitoring. We also hope to create data templates within our electronic medical record progress notes, so that all key elements could be easily incorporated into letters that are sent to our scleroderma patients’ outside providers, again outlining key symptoms to monitor closely and instructions on initial management of such symptoms.

Acknowledgments

This project was supported by grants from the National Institutes of Health (National Center for Advancing Translational Sciences, grant number UL1TR000062, and the National Institute for Arthritis and Musculoskeletal and Skin Diseases, grant number P60AR062755). The funding agencies had no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

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Table 1

Survey questionnaire items and response frequencies

Questionnaire Item	Response (n)*	Percent (%)
1. Do you have a primary care provider?	Yes (139)	99.3
	No (1)	0.7
2. If yes, how often do you see your primary care provider?	Once a year or less (16)	11.8
	1–2 times per year (59)	43.4
	3–6 times per year (48)	35.3
	More than 6 times per year (13)	9.5
3. What kind of health care professional is your primary care provider?	Family Medicine (75)	56.0
	Internal Medicine (51)	38.0
	Obstetrics/Gynecology (1)	0.8
	Physician's Assistant (2)	1.5
	Nurse Practitioner (0)	0.0
	Other (5)	3.7
4. How long have you been seeing your current primary care provider?	1 year or less (25)	18.1
	1 to 3 years (27)	19.6
	3 to 5 years (18)	13.0
	More than 5 years (68)	49.3
5. How would you rate the quality of the care you receive by your primary care provider?	Poor (2)	1.5
	Fair (8)	5.8
	Good (26)	18.8
	Very Good (36)	26.1
	Excellent (66)	47.8
6. Does your primary care provider know about your diagnosis of scleroderma?	Yes (136)	98.6
	No (2)	1.4
7. Have you ever felt as though your diagnosis of scleroderma has resulted in barriers to appropriate or satisfactory care?	Yes (35)	25.6
	No (102)	74.5
8. Have you ever felt as though your medical concerns were not addressed because you have scleroderma?	Yes (25)	18.7
	No (109)	81.3
9. How confident are you in your primary care provider's understanding of scleroderma?	1 Not confident (8)	6.0
	2 (14)	10.5
	3 Somewhat confident (39)	29.3
	4 (34)	35.6
	5 Confident (38)	28.6
10. Who referred you to the MUSC Scleroderma Clinic?	Primary Care Provider (32)	23.9
	Another Rheumatologist (58)	43.3
	Self-referral (21)	15.7

Questionnaire Item	Response (n) [*]	Percent (%)
	Other (23)	17.1
11. Does your primary care provider:		
A. Monitor your blood pressure closely?	Yes (100)	74.6
	No (34)	25.4
B. Address your reflux or heartburn symptoms?	Yes (80)	57.6
	No (39)	28.0
	Not applicable (20)	14.4
C. Address your shortness of breath?	Yes (45)	32.4
	No (46)	33.1
	Not applicable (48)	34.5
12. What is your overall satisfaction with your primary care provider?	Poor (4)	3.0
	Fair (17)	12.6
	Good (23)	17.0
	Very Good (41)	30.4
	Excellent (50)	37.0

^{*} Although there were n=140 surveys included in the analyses, there were some questionnaires with missing responses; thus not all individual item response frequencies total 140.