Systemic Sclerosis and Perceptions of Quality in 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 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.

Materials and 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 sex and younger age, along with poorer overall quality of care and satisfaction with their primary care.

Conclusions: Most patients with SSc value the quality of their primary care. However, some patients with SSc 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 patients with SSc and the need for continued education regarding close monitoring of signs and symptoms suggestive of possible life-threatening internal organ involvement.

Key Indexing Terms: Scleroderma; Systemic; Primary healthcare; Health surveys; Patient satisfaction. **[Am J Med Sci 2016;351(5):447–451.]**

INTRODUCTION

Scleroderma (systemic sclerosis [SSc]) is a rare, complex multiorgan 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. As 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 damage.[1]

Many patients with scleroderma are seen in outpatient settings by rheumatologists at major tertiary care referral centers that often requires travel from surrounding states, and typically they are seen 1 or 2 times per year at the referral clinic. Inbetween their visits with a scleroderma specialist, much of their care is provided by primary care providers (PCPs). In one study of Dutch $n = 64$ patients with SSc, 75% had visited a rheumatologist in the past 12 months, and 31% had seen a general practitioner[2]; in a separate Dutch study of $n = 198$ patients with SSc, 83% had visited a rheumatologist in the past 12 months, and 50% had seen a general practitioner.[3] 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's outcomes.[4] Common signs and symptoms of organ involvement related to scleroderma include Raynaud's 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. As 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 condition[5] and healthcare utilization,[2,6] but to our knowledge there have been no studies published looking specifically at the perceptions regarding the quality of their primary care of patients with scleroderma.

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 patients with SSc treated by the Division of Rheumatology at the Medical University of South Carolina (MUSC).

MATERIALS AND 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 or 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 (aged 18 years and older) treated at the MUSC rheumatology clinics from January 2013-October 2014 with an ICD9 diagnosis code of 710.1 (SSc) 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 prestamped return envelope to a total of 525 patients with SSc. The study was approved by the Institutional Review Board at MUSC.

There were following 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 PCPs 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, sex and race), the type of PCP, frequency of visits to their PCP, duration of their PCP-patient relationship as well as their overall rating of the quality of the care provided by the PCP.

Quantitative Analyses

Initially, survey responders were characterized using descriptive statistics (means, standard deviations [SD] 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-square tests were used. Traditional chi-square tests and Fisher's exact tests were used for categorical responses, whereas Mantel-Haenszel chi-square tests were used for ordinal responses. Logistic regression models were also used to determine whether any observed associations were moderated by demographic characteristics. A $P < 0.05$ was considered statistically significant, and no adjustments were made for multiple comparisons, because of the fact that this was largely an exploratory study. All analyses were performed using SAS v9.4 (SAS Institute, Inc. Cary, NC).

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. A total of 3 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. A total of 20 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 21-85 years. A total of 85% were women. Regarding ethnicity, 77% of the respondents were white, and 23% identified themselves as black or other. These demographic characteristics of our participants adequately reflect the general population of patients with SSc seen in the MUSC scleroderma clinics, where the mean age (SD) is 56.9 (13.4) years, 84% are women, and 62.4% are white.

The Table 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 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. Most respondents (73.9%) rated the quality of their primary care as "very good" or "excellent," and only 2 respondents (1.5%) stated their PCPs were unaware of their diagnosis of scleroderma. Most respondents reported that their PCPs are addressing some key symptoms that 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 PCPs 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