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Symptoms of disease and psychological adaptation in Brazilian scleroderma patients

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ABSTRACT

Objective: To characterize the prevalence and impact of symptoms of scleroderma in Brazilian patients and to describe their satisfaction with medical care and psychological symptoms.

Methods: One-hundred and twenty eight Brazilian scleroderma patients participated in an online survey by filling out a Portuguese version of the Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities. The mean age of participants was 38 years old (SD = 12.33), and most of the participants were females (n = 108, 88%).

Results: Hardening/tightening of skin, itchy skin and joint pain were symptoms reported as being most frequent, whereas muscle pain and difficulty climbing stairs were symptoms reported as having a higher impact. Participants reported dissatisfaction regarding the medical care. Psychological evaluations suggested that participants who scored above clinical values for depression was significantly high (90%; n = 77). In addition, 48% (n = 42) of participants fit the clinical criteria for anxiety disorder, and 40% (n = 35) of participants fit the clinical criteria of social phobia. Finally, body image disturbance was reported by 69% (n = 88) of participants.

Conclusions: The physical and psychological symptoms associated with scleroderma have a significant impact on patient quality of life. The Brazilian patients in the current sample report higher levels of dissatisfaction with medical care than patients from Canada and European countries. These Brazilian patients also report more psychopathology, particularly symptoms of depression. The current results suggest that there is a need for professionals to consider and attend to the individual problems of scleroderma patients.

Sintomas de doença e adaptação psicológica em pacientes brasileiros com esclerodermia

Palavras-chave:
Atendimento médico
Esclerodermia
Sintomas psicológicos

RESUMO

Objetivo: Caracterizar a prevalência e o impacto dos sintomas de esclerodermia em pacientes brasileiros e descrever sua satisfação com o atendimento médico e sintomas psicológicos.

Métodos: Cento e vinte e oito pacientes brasileiros com esclerodermia participaram em uma pesquisa online preenchendo a versão portuguesa do Canadian Scleroderma Patient Sur-

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vey of Health Concerns and Research Priorities. A média de idade dos participantes foi 38 anos (DP = 12,33) e a maioria dos participantes era constituída por mulheres (n = 108, 88%).
Resultados: Endurecimento/retesamento da pele, coceira na pele e dor articular foram sintomas informados como mais freqüentes, enquanto que dor muscular e dificuldade para subir escadas foram sintomas informados como tendo maior impacto. Os participantes informaram insatisfação em relação ao atendimento médico. As avaliações psicológicas sugeriram que o percentual de participantes com pontuação acima dos valores clínicos para depressão foi significativamente elevado (90%; n = 77). Além disso, 48% (n = 42) dos participantes se enquadravam nos critérios clínicos para transtorno da ansiedade e 40% (n = 35) dos participantes se enquadravam nos critérios clínicos de fobia social. Finalmente, 69% (n = 88) dos participantes informaram transtornos da imagem corporal.
Conclusões: Os sintomas físicos e psicológicos associados com esclerodermia têm impacto significativo na qualidade de vida dos pacientes. Na presente amostra, os pacientes brasileiros informam níveis mais altos de insatisfação com o atendimento médico, em comparação com pacientes do Canadá e de países europeus. Esses pacientes brasileiros também informam mais casos de psicopatologia, particularmente sintomas de depressão. Nossos resultados sugerem que há necessidade que os profissionais levem em consideração os problemas individuais dos pacientes com esclerodermia e cuidem desses problemas.

Introduction

Scleroderma, or systemic sclerosis, is a connective tissue disease that causes vascular, inflammatory and fibrotic dysfunction of organ systems.[1] The etiology of this chronic disease remains unknown. The characteristics of scleroderma include microvascular damage, excessive deposition of collagen in the skin and organs, Raynaud phenomenon and hardening of the skin.[2] Scleroderma can damage the functioning of respiratory, gastrointestinal, and cardiac system, in addition to damaging renal function. Consequently, scleroderma is highly morbid and is associated with high rates of mortality.[1] Other scleroderma symptoms include musculoskeletal disorders such as joint pain, arthritis, flexion contractures of the joints and muscle weakness.[3] Because scleroderma is a rare disease with multiple symptoms, it may be difficult to diagnose and to make an accurate prognosis from the symptoms.[4]

Rheumatic diseases involve visible physical changes that correlate with the progression of the disease; however, scleroderma involves physical changes that are even more visible[5] and that tend to worsen over time.[6] In most cases, these physical disfigurements tend to localize in the face and hands. At the initial stages of the disease, physical changes include: swelling of fingers, loss of natural skin wrinkles, brightening of skin tone, hypo- or hyper-pigmentation, and facial changes, which include change in appearance of the eyes and nose, loss of flexibility in the lips, loss of ability to fully open the mouth, and difficulty in completely closing the lips.[5] Dissatisfaction with body image is more prevalent in younger patients with severe symptoms and is associated with age and disability.[7] The results from a Canadian study suggest that over three quarters of patients reported concerns about body image due to scleroderma.[6]

Regarding depressive symptoms, the same Canadian study found that approximately half of the participants reported feeling "down, depressed or hopeless" for at least several days during the previous two weeks. It is noteworthy that depressive symptoms are very common in patients with scleroderma[8] and clinical results are negatively influenced by the presence of depressive symptoms. Studies show that female patients report being dissatisfied with their body image and depression appears to be moderating this relation.[7] Anxiety symptoms are also very frequent in patients with scleroderma.[9]

Moreover, scleroderma patients have high physical and psychological morbidity and there are costs associated with regular use of healthcare with long periods of morbidity.[10] The "Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities" suggests that patients with scleroderma are more dissatisfied with healthcare than other chronically ill patients.[6]

However, until now, the frequency and impact of scleroderma symptoms and the psychological symptoms exhibited by scleroderma patients were studied only in Canada and Europe. This study intends to extend on this research by investigating the psychosocial impact on scleroderma patients living under different geographical and cultural conditions. Specifically, this study focuses on scleroderma patients living in Brazil, a country in which climatic and cultural characteristics differ significantly from European countries and Canada. For instance, evidence suggests that cold weather exacerbates scleroderma symptoms by causing Raynaud's phenomenon and pain in joints and muscles. However, it is unclear how patients in Brazil, where the climate is warm, fare relative to patients living in Canada and European countries.

Another relevant cultural difference between these countries is related to body image. Specifically, Brazilian patients may be more preoccupied with their body image because, due to the hot climate, their bodies are more exposed throughout the year. Moreover, body image is generally important in Brazil, and because the illness affects mainly women, we expect higher rates of dissatisfaction with body image in the Brazilian sample. Finally, because scleroderma is a rare disease, it can be related to specific difficulties in finding appropriate care, which may decrease patients' satisfaction with medical services and affect their global well-being. Thus, the current study aimed to explore rates of satisfaction with medical care amongst patients with scleroderma.

In light of the issues mentioned above, the objectives of the current study were as follows: (1) to characterize the main symptoms of scleroderma and their impact on scleroderma patients from Brazil; (2) to assess who made the diagnoses and how patients evaluated their satisfaction with medical care in terms of general satisfaction, technical quality, interpersonal manner, communication, financial costs, time spent with doctor, accessibility and convenience; (3) to describe the psychological symptoms, including depressive, anxiety and social phobia symptoms; (4) to assess the impact of physical appearance on social functioning; and (5) to evaluate predictors of depression, anxiety, social phobia and body image in Brazilian patients with scleroderma, controlling for education level, a variable that is known to influence psychological adjustment.

Patients and methods

Participants

The sample consisted of 128 Brazilian scleroderma patients. The mean age of the participants was 38 years old (SD = 12.33), and the majority of the sample was female (n = 108, 88%) and white (n = 99, 81%). The majority of participants were married or living as married (n = 71, 60%). Only two participants lived alone. Twenty-seven percent (n = 31) of the sample were working full-time. Thirty-nine percent (n = 24) of participants had a college degree, 16% (n = 10) completed high school and 26% (n = 16) had the first level of education

The majority of participants reported being diagnosed with diffuse scleroderma (n = 51, 46%) or limited scleroderma (n = 18, 16%).

Instruments

Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities.[11] The questionnaire was distributed to us by the original authors, and we received proper authorization to translate the questionnaire. The questionnaire was translated, back-translated and validated into European Portuguese. This questionnaire evaluates the most important aspects of living with scleroderma and includes the following 11 sections: demographics, diagnosis and disease, healthcare services utilization, healthcare services reimbursement, healthcare services reimbursement needs, type of medical care, symptoms, employment, sensations, physical appearance, and commentaries. For the purpose of the current study, only a subset of these sections was analyzed. The sections are described in Table 1.

Procedure

We contacted the Brazilian Association of Patients with Systemic Sclerosis (ABRAPES), who divulgated the study to their associates. Patients were invited to complete the survey online, using Survey Monkey.

Confidentiality and anonymity were guaranteed. Participants did not provide any personal information, including name, date of birth, or telephone number. Data were collected between December 2010 and July 2011.

Statistical analysis

The data analysis was performed using the statistical software package SPSS 18 (for Windows). We ran an exploratory data analysis to verify the normality and homogeneity of the variables' distribution, however, this was not verified in our sample. Thus, we conducted parametric and non-parametric tests, and found that the results were equivalent. Finally, we choose to report the results of the parametric tests because these were more robust.[12]

We used descriptive statistics to describe the data and inferential statistics to test relations among the variables. We ran a multiple regression analysis to assess predictors of depression, anxiety, social phobia and body image. In this model, variables that showed significant correlations with the

Table 1 – Sections and aims/content of each section of the *Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities* (Taillefer SS, Bernstein J, Schieir O, Buzza R, Hudson M, Scleroderma Society of Canada, et al. Canadian Scleroderma Survey of Health Concerns and Research Priorities. 2010. Portuguese version, Leite C, Maia A, 2011. Escola de Psicologia, Universidade do Minho) as was used in the study.

Sections	Aims /content
Diagnosis and disease	To describe the medical status of participants
Medical care	To assess how scleroderma patients feel about the medical care provided to them
Satisfaction with medical care	This part is organized according to the following seven domains: general satisfaction, technical quality of care, interpersonal manner, communication, financial aspects, time spent with physician, and accessibility and convenience of care. Response options ranged from 1 (strongly agree) to 5 (strongly disagree) and items were scored so that higher scores reflected satisfaction with medical care. This section uses an existing survey: The Patient Satisfaction Questionnaire (Marshall GN, Hays RD. The patient satisfaction questionnaire short-form (PSQ-18). Santa Monica, CA: Rand Corporation; 1994).
Symptoms	The questions are based on The Scleroderma Assessment Questionnaire (SAQ) (Ostojic PS, Damjanov NS. The scleroderma assessment questionnaire (SAQ). Z Reumatol. 2006;65:168-75) and several articles, with the aim to list the frequency and impact of 69 symptoms. The response options for "symptom frequency" are as follows: never, rarely, sometimes, most of the time, and always. The response options for "symptom impact" are as follows: no impact, minimal, moderate, severe, and extremely severe
Employment	Patients' employment

(continued on next page)

Table 1 – Sections and aims/content of each section of the *Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities* (Taillefer SS, Bernstein J, Schieir O, Buzza R, Hudson M, Scleroderma Society of Canada, et al. Canadian Scleroderma Survey of Health Concerns and Research Priorities. 2010. Portuguese version, Leite C, Maia A, 2011. Escola de Psicologia, Universidade do Minho) as was used in the study. *(continued)*.

Sections	Aims /content
Sensations	Aims to evaluate levels of depression, anxiety and social phobia. Depression was assessed with the instrument Patient Health Questionnaire (PHQ-2) (Kroenke K, Spitzer RL. The PHQ-9, a new depression diagnostic and severity measure. Psychiatric Annals. 2002;32:1-7). The cut-off of this two-item instrument is three, higher than or equal to three means sensitivity to severe depression. The first item assesses anhedonia and the second item assesses dysphoria. The sum of the two items is a maximum of six. Anxiety was assessed with the instrument Generalized Anxiety Disorder (GAD) (Kroenke K, Spitzer RL, Williems JBW, Monahan PO, Lowe B. Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. Annals of Internal Medicine. 2007;146:317-25). Includes two items and the cut-off of this two-item instrument is three, higher than or equal to three means generalized anxiety disorder. The sum of the two items is a maximum of six. Finally, social phobia was evaluated with the instrument Mini SPIN (Social Phobia Inventory) (Connor KM, Kobak KA, Churchill LE, Katzelnick D, Davidson JRT. Mini-SPIN: a brief screening assessment for generalized social anxiety disorder. Depression and Anxiety. 2001;14:137-40). The cut-off of the items of this instrument is six. Higher than or equal to six means general social anxiety disorder. The sum of items varies between 0 and a maximum of 12.
Physical appearance	To assess concerns about body image. The three questions used in this section were taken from the instrument The Body Image Disturbance Questionnaire (Cash TF, Phillips KA, Santos MT, Hrabosky JI. Measuring "negative body image": validation of the body image disturbance questionnaire in a nonclinical population. Body Image. 2004;1:363-72).

predicted variables were entered as predictors. In all of our analyses, we set the level of significance at $P < 0.05$ and the level of marginal significance at $P < 0.1$.

Results

The frequency and impact of symptoms are summarized in Table 2. Regarding the frequency of symptoms, the five most common symptoms reported by patients were the following: joint pain (96%), hardening/tightening of skin (90%), heartburn (89%), difficulty concentrating (88%) and difficulty remembering things (88%). The five symptoms with the greatest impact were the following: muscle pain (91%), joint pain (84%), Raynaud's (84%), fatigue (83%) and difficulty sleeping (82%).

Some participants did not answer items related to how frequently they experienced symptoms, however, all participants responded to items probing the impact of these symptoms.

Most participants reported being diagnosed with scleroderma by a rheumatologist (n = 70, 65%). Only 17% (n = 18) of participants received their diagnosis from the first doctor they consulted. Finally, 27% (n = 29) of participants consulted more than 5 physicians before receiving their diagnosis.

Table 2 – Frequency and Impact (reported moderate or extremely severe) of the most reported symptoms in Brazilian scleroderma patients.

	Frequency n (%)	Impact n (%)
Hardening/tightening of skin	88 (90%)	97 (76%)
Itchy skin	82 (87%)	92 (72%)
Joint pain	92 (96%)	108 (84%)
Muscle pain	83 (87%)	116 (91%)
Heartburn	89 (89%)	102 (80%)
Diarrhea	81 (84%)	88 (67%)
Fatigue	83 (86%)	106 (83%)
Difficulty sleeping	83 (80%)	105 (82%)
Difficulty concentrating	85 (88%)	93 (73%)
Difficulty remembering things	82 (88%)	100 (78%)
Raynaud's	84 (86%)	108 (84%)
Changes in skin color	81 (81%)	88 (69%)
Swollen joints	79 (81%)	104 (81%)
Numbness in feet or lower legs	78 (81%)	104 (81%)
Carpal tunnel syndrome	79 (81%)	106 (83%)
Migraine headaches	76 (79%)	96 (75%)
Difficulty climbing stairs	74 (76%)	110 (86%)
Stiffness in the hands	72 (76%)	109 (85%)
Medication side effects	73 (75%)	105 (82%)
Skin pain	72 (75%)	109 (85%)
Difficulty swallowing	73 (75%)	94 (73%)
Difficulty walking	70 (74%)	107 (84%)
Shortness of breath	70 (74%)	104 (81%)
Chest pain	73 (74%)	96 (75%)
Vaginal dryness	54 (74%)	101 (79%)
Dry mouth	71 (73%)	94 (73%)
Hypersensitivity to the sun	70 (73%)	102 (80%)
Bad taste in the mouth at night	72 (73%)	95 (74%)
Difficulty turning on a faucet	69 (73%)	104 (81%)
Nausea	69 (72%)	95 (74%)
Difficulty dressing	68 (71%)	101 (79%)
Difficulty getting in/out of a car	69 (70%)	103 (81%)
Difficulty holding objects	68 (70%)	102 (80%)
Dry eyes	67 (70%)	109 (85%)
Difficulty self-washing	66 (70%)	97 (76%)
Difficulty opening the mouth	66 (68%)	105 (82%)
Difficulty fully opening the hand	64 (66%)	97 (76%)

The results taken from the section "health care satisfaction" are summarized in Table 3. In general, participants reported negative evaluations regarding the medical care provided to them. The area where they were the least satisfied related to the financial costs of the disease.

The majority of participants (69%, n = 75) reported that scleroderma affected their ability to work. In addition, 90% (n = 77) of participants scored above the clinical criteria for depression, whereas 48% (n = 42) and 40% (n = 35) of participants scored above the clinical criteria for anxiety and social phobia, respectively. Body image disturbance was reported by 69% (n = 88) of participants, with 50% of these participants reporting that they were "very" or "extremely" concerned about the appearance of some parts of the body, which they considered to be especially unattractive due to scleroderma.

Correlation between age, education level, years since diagnosis, frequency and impact of symptoms, psychosocial variables and education level are presented in Table 4. As shown, there is a significant correlation between frequency and impact of symptoms and among the psychological variables. Education level of the participants is not correlated with others variables.

The multiple regression model that was used to test predictors of depression explained 18% of the variance related to depression symptoms ($R^2aj = 0.11$, $P < 0.05$; $F(6,69) = 2.57$, $P < 0.05$). The "impact of symptoms" ($t = 0.31$, $P < 0.05$) variable was the only significant predictor in this model (Table 5). Regarding anxiety, the current model explained 22% of variance in anxiety symptoms ($R^2aj = 0.16$, $P < 0.01$; $F(5,70) = 3.85$, $P < 0.01$). The "frequency of symptoms" ($t = -2.53$, $P < 0.05$) and "body image" ($t = 1.82$, $P < 0.1$) variables were the two significant predictors in this model. Regarding social phobia symptoms, the current model explained 34% of variance related to social phobia ($R^2aj = 0.28$, $P < 0.001$) ($F(6,69) = 5.96$, $P < 0.001$), where the "body image" ($t = 4.45$, $P < 0.001$) variable was the only significant predictor of social phobia. Finally, regarding body image, the current model explained 28% of the variance related to body image ($R^2aj = 0.23$, $P < 0.001$) ($F(4,65) = 6.19$, $P < 0.001$). In this model, "years of diagnosis" ($t = 1.82$, $P < 0.1$) and "social phobia" ($t = 3.76$, $P < 0.001$) were the two significant predictors of "body image" variability.

Discussion

In the present study we intended to assess the most frequent symptoms experienced by Brazilian scleroderma patients and the impact of these symptoms on patients' everyday life. In addition, we aimed to assess participants' level of satisfaction with their medical care and to assess participants' levels of depression, anxiety, social phobia and body image. Finally, we intended to evaluate predictors of depression, anxiety, social phobia and body image.

Table 3 – Satisfaction with medical care in Brazilian scleroderma patients.

	Mean (SD)
General satisfaction	2.24 (1.49)
Technical quality of care	2.30 (1.40)
Interpersonal manner	2.59 (1.70)
Communication	2.40 (1.58)
Financial aspects	1.93 (1.41)
Time spent with physician	2.29 (1.56)
Accessibility and convenience	2.17 (1.45)

Regarding the frequency of symptoms, our results were similar to findings found in a Canadian sample and European samples.[6,13] Interestingly, while evidence suggest that Raynaud's phenomenon is exacerbated by cold weather, we found similar levels of prevalence of this symptom in Brazil (i.e., 86% of patients compared to 94% in a Canadian sample and 90% in a European sample[6,13]). It is worth noting that stress may worsen Raynaud's phenomenon, and there are other factors that may contribute to the current pattern of results. Relatedly, symptoms such as joint pain also tend to worsen in cold weather, however, this symptom was highly prevalent in our sample from Brazil 96% (compared to 94% in Canada and Europe[6,13]). As mentioned, this pattern of results may be due to other factors, including depression, whose contribution to the disease or the report of symptoms need to be better explored in future studies.

Scleroderma remains unknown to many health professionals and the symptoms tend to be confounded with symptoms of other diseases for a long time. This could explain why only 17% of patients were diagnosed with scleroderma by the first doctor they consulted. Relatedly, satisfaction with medical care of patients in Brazil is low and is considerably lower than levels of satisfaction reported by Canadian and European patients. For instance, on a 1 to 5 scale, which indicates "low" to "high satisfaction", respectively, Brazilian patients rated "financial aspects" at 1.93, while the European and Canadian patients rated this item at 3.2. These results were corroborated when we compared reported satisfaction with medical care in Canada, Europe and Brazil, founding that levels of satisfaction were higher in both Canada and Europe relative to Brazil. Such differences in satisfaction with medical care may arise from the distinct economic conditions of the populations, or from the organization and /or availability of access to the National Health Service in Brazil.

Finally, our results show that 90% of participants reported symptoms that are above the cut-off for depression, a finding that supports the previous evidence that depression is common amongst patients with scleroderma.[8] These results are far more robust when compared to data found in the Canadian study, in which 48%[6] of patients fit a diagnosis for depression, a difference that raises serious concerns. In the current sample, depression was associated with the variables of age, symptom "frequency" and "impact", anxiety and social phobia, suggesting that the disease is affecting more the older and the ones that have more symptoms. In this sample, the symptom "impact" was the main predictor, showing the costs in terms of mental health of the limitations in everyday life associated with symptoms.

Regarding anxiety symptoms, the results indicate that approximately half of participants (48%) reported symptoms of anxiety. This result is consistent with the idea that anxiety is very prevalent in people with some type of physical disfigurement[14] and that anxiety is common in scleroderma patients.[9] In the current sample, anxiety was associated with age, frequency of symptoms, body image, depression and so-

Table 4 – Pearson correlations among disease variables and psychosocial variables in Brazilian scleroderma patients.

Variable	1	2	3	4	5	6	7	8
1. Age								
2. Years since diagnosis	0.17[a]							
3. Frequency of symptoms	-0.15[a]	0.02						
4. Impact of symptoms	-0.16[a]	0.02	0.95[d]					
5. Body image	0.10	0.23[b]	-0.04	-0.09				
6. Depression	0.22[a]	0.17	-0.19[a]	-0.20[a]	0.42[d]			
7. Anxiety	0.24[b]	0.12	-0.27[b]	-0.27*	0.31[c]	0.63[d]		
8. Social phobia	0.25[b]	0.10	-0.28[c]	-0.32[c]	0.47[d]	0.35[c]	0.22[b]	
9. Level of education	-0.18	-0.10	-0.02	-0.04	-0.07	-0.18	0.08	-0.15

[a] $P < 0.1$.
[b] $P < 0.05$.
[c] $P < 0.01$.
[d] $P < 0.001$

Table 5 – Results of multiple regression analysis to test predictors of depression, anxiety, social phobia and body image in Brazilian scleroderma patients.

Depression $R^2(R^2aj)$ = 0,18 (0,11); F(6,69) = 2.57[b]		
	β	t
Age	0.11	0.96
Frequency of symptoms	0.1	0.78
Impact of symptoms	0.31	2.55b
Body image	0.11	0.84
Anxiety	0.14	1.15
Social phobia	0.02	0.12
Anxiety: $R^2(R^2aj)$ = 0,22(0,16); F(5,70) = 3.85[c]		
Age	0.16	1.45
Frequency of symptoms	-0.28	-2,.53[b]
Body image	0.23	1.82[a]
Depression	0.13	1.15
Social phobia	-0.05	-0.39
Social phobia: $R^2(R^2aj)$ = 0,34(0,28); F(6,69) = 5.96[d]		
Age	0.14	1.32
Frequency of symptoms	-0.13	-1.19
Impact of symptoms	0.15	1.34
Body image	0.46	4.45[d]
Depression	0.01	0.12
Anxiety	-0.04	-0.35
Body image: $R^2(R^2aj)$ = 0,28(0,23);F(6,69) = 6.19[d]		
Years of diagnosis	0.2	1.82[a]
Social phobia	0.41	3.76[d]

[a] $P < 0.1$.
[b] $P < 0.05$.
[c] $P < 0.01$.
[d] $P < 0.001$

cial phobia. The regression analysis showed that "frequency of symptoms" and "body image" were the most significant predictors of anxiety. Because scleroderma is characterized by a complex set of symptoms (including the ones that contribute to the change in body image), the management of them is a target that should be considered in order to reduce anxiety.

Regarding social phobia, 40% of participants reported this problem. Only part of scleroderma patients have face disfiguration, but changes in hands and other visible parts can be a challenge to the ones that are affected. Previous literature suggests that people with disfigurement tend to avoid social situations,[14] and the "body image" variable was the main predictor of social phobia in our sample, a result that can be understood in the dynamics between negative body image and avoidance of social situations.

Finally, regarding body image disturbance, 69% of participants reported such a disturbance in our sample. This finding complements the fact that scleroderma involves many physical changes on visible parts of the body.[14] However, the results in our sample are significantly higher than those found in a Canadian sample (23%).[6] This difference may be due to particular weather conditions in Brazil that require more bodily exposure throughout most of the year, and the consequent difficulty to disguise physical disfigurements.

Conclusions

The current study offers a number of challenging results, including support for a serious impact of scleroderma on the daily functioning of Brazilian patients, and a very high percentage of psychological suffering amongst these patients. The total population in Brazil is over 194 million people and scleroderma affects approximately 44 in every 100,000 people.[15] These statistics suggest that 83,600 people in Brazil may suffer from scleroderma. In light of this estimate, one main limitation of the study is the relatively small number of participants used in the sample.

A second major limitation of the study is the method by which participants were recruited. Specifically, data collection was performed through the collaboration of a patient`s association (ABRAPES) and thus this study only included patients who were somehow connected to this association. These participants may have characteristics that are not representative of Brazilian scleroderma patients in the general population. Furthermore, the fact that the questionnaire had to be filled out online may have significantly limited the range of our sample. Still, it is noteworthy that even if our sample reflects a part of the population with higher socio-economic status and higher social functioning, their reported satisfaction with medical care is still lower than that in patients from other countries and that psychological symptoms still had a negative impact on the majority of the Brazilian patients. Thus, as a whole, the current data suggest that it is necessary that health professionals are better equipped to address patients with scleroderma and that specialized support is provided to these patients. We hope that the current study may motivate further research on scleroderma patients in Brazil, calling attention to the areas of concern highlighted by our data.

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Conflicts of interest

The authors declare no conflicts of interest.

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