The Relevance of Hand Mobility and Functionality Surveillance in Patients with Systemic Sclerosis

A Relevância da Vigilância da Mobilidade e da Funcionalidade das Mãos em Pacientes com Esclerose Sistêmica

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Abstract

Introduction: *Systemic sclerosis causes skin thickening, Raynaud's phenomenon, visceral damage, and musculoskeletal issues. Hand impairment, affecting about 90% of patients, limits mobility, dexterity, and grip strength, significantly impacting daily life, with few treatment options.*

This study aims to characterize hand function in patients with Systemic Sclerosis and, secondarily, to describe those undergoing rehabilitation and using assistive devices.

Material and methods*: This cross-sectional observational study included Systemic Sclerosis patients from Rheumatology service care meeting 2013 American College of Rheumatology/European League Against Rheumatism Systemic Sclerosis criteria. Sociodemographic and clinical data were collected through anonymous questionnaires.*

The exclusions were based on the inability to contact the patient, refusal to participate in the study due to transportation costs, and incompatibility with work schedules.

Data included age, gender, education, employment, disease subtype, systemic involvement, symptom duration and diagnosis duration. Hand rehabilitation and assistive device usage were assessed. Additionally, hand and fingers' skin thickness was assessed using the modified Rodnan Skin Score. Hand mobility was evaluated by the Modified Hand Mobility in Scleroderma, and Grip was measured by Jamar dynamometer. Disability status, quality of life and hand function were appraised using the Health Assessment Questionnaire, Medical Outcomes Short Form-36 and Cochin Hand Functional Scale, respectively.

The data were analyzed using the International Business Machines Corporation Statistical Package for the Social Sciences software, version 29 (International Business Machines Corporation, 2023).

We performed descriptive statistics. A linear regression for Cochin Hand Functional Scale score included variables marginally or significantly associated in univariate analysis, adjusting for various factors.

Results: *A total of 32 patients participated, predominantly female, with Limited Systemic Sclerosis. Few used assistive devices (18.8%) or received hand rehabilitation (14.3%). Cochin Hand Functional Scale median score was 5.0, with 10.5 for the third quartile, indicating low functional compromise, and only four patients had this scale score ≥ 25.*

Hamis score was significantly associated with Cochin Hand Functional Scale (adjusted R-squared = 0.80), explaining 80% variability.

Conclusion: *This study underscores the need for continuous assessment of hand mobility and function, as*

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well as the implementation of a multidisciplinary approach in the management of patients with Systemic Sclerosis.

keywords: *Scleroderma; Hand; Rehabilitation; Quality of Life; Function.*

Resumo

Introdução: A Esclerose Sistémica causa espessamento da pele, fenómeno de Raynaud, lesão visceral e alterações musculoesqueléticas. O comprometimento das mãos, que afeta cerca de 90% dos doentes, limita a mobilidade, destreza e força de preensão, impactando significativamente a vida quotidiana, com poucas opções de tratamento.

Este estudo tem como objetivo caracterizar a função das mãos em doentes com esclerose sistémica e, secundariamente, descrever aqueles que realizam reabilitação e utilizam produtos de apoio.

Material e métodos: Este estudo observacional transversal incluiu doentes com Esclerose Sistémica em acompanhamento no serviço de Reumatologia, cumprindo os critérios de Esclerose Sistémica do Colégio Americano de Reumatologia/Liga Europeia Contra o Reumatismo de 2013. Os dados sociodemográficos e clínicos foram recolhidos através de questionários anónimos.

As exclusões basearam-se na incapacidade de contactar o doente, recusa em participar no estudo devido a custos de transporte e incompatibilidade com horários de trabalho.

Os dados recolhidos incluíram idade, género, nível de escolaridade, situação profissional, subtipo da doença, envolvimento sistémico, duração dos sintomas e do diagnóstico. A realização de reabilitação da mão e a utilização de produtos de apoio foram avaliadas. Adicionalmente, a espessura da pele das mãos e dos dedos foi avaliada utilizando o *Modified Rodnan Skin Score*. A mobilidade das mãos foi avaliada através do *Modified Hand Mobility in Scleroderma*, e a força de preensão foi medida com o dinamómetro Jamar. O estado de incapacidade, a qualidade de vida e a função das mãos foram avaliados utilizando, respetivamente, o *Health Assessment Questionnaire*, o *Medical Outcomes Short Form-36* e a *Cochin Hand Functional Scale*.

Os dados foram analisados utilizando o software *International Business Machines Corporation Statistical Package for the Social Sciences*, versão 29 (*International Business Machines Corporation*, 2023).

Foram realizadas estatísticas descritivas. Uma regressão linear para o valor da *Cochin Hand Functional Scale* incluiu variáveis marginalmente ou significativamente associadas na análise univariada, ajustada para vários fatores.

Resultados: Participaram no estudo 32 doentes, com uma idade média de 58,0 anos, maioritariamente do sexo feminino (81,3%) e com Esclerose Sistémica Limitada (81,3%).

Poucos utilizaram produtos de apoio (18,8%) ou realizaram reabilitação da mão (14,3%). A mediana da *Cochin Hand Functional Scale* foi de 5,0, com um terceiro quartil de 10,5, indicando baixo comprometimento funcional, sendo que apenas quatro doentes apresentaram uma pontuação ≥ 25 nesta escala.

O valor do *Hamis* esteve significativamente associado à *Cochin Hand Functional Scale* (R-quadrado ajustado = 0,80), explicando 80% da variabilidade.

Conclusão: Este estudo destaca a necessidade de avaliação contínua da mobilidade e função das mãos, bem como a implementação de uma abordagem multidisciplinar na gestão dos doentes com esclerose sistémica.

Palavras chave: Esclerodermia; Mão; Reabilitação; Qualidade de Vida; Funcionalidade

Introduction

Systemic sclerosis (SSc) is an uncommon and complex autoimmune disorder marked by skin thickening, Raynaud's phenomenon (RP), visceral organ damage and musculoskeletal involvement.[1-7] This disease can affect the gastrointestinal tract, heart, lungs, kidneys, skin and/or vasculature through a complex interplay of fibrosis, inflammation and vascular damage.[2,6,7] SSc carries an unfavorable prognosis, characterized by a mortality rate exceeding 2.7 times that of individuals matched for sex and age.[5] Impaired hand function is a prevalent issue among individuals with SSc.[2]

SSc-related hand limitations encompass a range of disease manifestations, such as puffy hands and skin tightening, which still do not have an effective treatment, as well as inflammatory arthritis, tendon friction rubs, tendonitis/tendinosis, calcinosis, acro-osteolysis, RP, and digital ulcers. These diverse symptoms collectively impact the hands, causing discomfort and limited mobility for individuals affected by SSc.[2] Roughly 90% of individuals living with SSc encounter substantial functional restrictions in their hands.[4]

Understanding the diverse expressions of hand impairment is crucial given the limited availability of effective treatments.[2] This awareness is pivotal because these manifestations often lead to diminished hand mobility, decreased dexterity, and weakened handgrip strength (Grip).[2] These consequences can profoundly impact a person's ability to engage in both occupational tasks and routine daily activities.[2] Recognizing the wide range of symptoms is vital in enabling tailored interventions and support, enhancing the quality of life for individuals facing these challenges.[2,8]

Crucially, there is a notable absence of universally recognized guidelines endorsed by the European Alliance of Associations for Rheumatology (EULAR) for the non-pharmacological care of individuals afflicted with SSc.[3] Employing assistive tools and providing guidance on alternative work techniques emerge as crucial components in the rehabilitation process for individuals diagnosed with SSc. This intervention plays an essential role in alleviating the challenges faced during daily tasks, significantly enhancing the patient's ability to engage in their routine activities with greater ease and independence.[1,3]

The aim of this study was to characterize hand function in SSc patients and, secondarily, to describe those undergoing rehabilitation and using assistive devices.

Material and Methods

This was an observational, cross-sectional, and analytical study. All 50 patients who are being followed in the Rheumatology department with a diagnosis of SSc were contacted for evaluation by two physicians from the Physical and Rehabilitation Medicine service. Initially, 6 patients were unreachable, 7 patients refused to participate in the study due to transportation costs, and 3 patients declined to participate because of their work schedules.

The inclusion criteria were defined as adult patients (≥18 years) with an SSc diagnosis according to the 2013 American College of Rheumatology/EULAR (ACR/EULAR) SSc criteria.[9] Patients with another musculoskeletal or neuromuscular disorder that would result in significant hand function impairment were excluded based on expert opinion. Additionally, 2 patients who were receiving wound care for ulcers on their hand fingers were also excluded.

Firstly, a written informed consent was obtained and then an anonymous questionnaire was filled by SSc outpatients after observation at the Physical Medicine and Rehabilitation (PM&R) consultation. Patients answered the questionnaires without any clinician intervention, and clinical data were collected subsequently and independently. Data collection for patients was carried out by at least two independent investigators, and statistical analysis was conducted by independent investigators.

Variable definitions

Sociodemographic variables and clinical data

Sociodemographic (age, gender, education level, employment status, and history of occupational change due to limitations caused by SSc) and clinical data (disease subtype, systemic involvement, disability status, SSc disease duration, years since symptom onset excluding RP, and time interval between symptom onset excluding RP and medical diagnosis) were collected. The questionnaire also included questions about the practice of hand rehabilitation treatments, daily use of assistive devices, and which devices were used.

Hand and fingers skin thickness, mobility and grip

Hands and fingers' skin thickness was measured by the modified Rodnan Skin Score (mRSS). The physician assigns a score to the individual anatomical area (hand and fingers) according to the most severe local involvement, classifying the skin thickness as normal (mRSS=0), mild (mRSS=1), moderate (mRSS=2), severe (mRSS=3). However, in this study, we will use the total score of only hands and fingers areas (0-12) – mRSShf.

The range of hand movement was measured using the Modified Hand Mobility in Scleroderma (HAMIS), which evaluates four hand movements (finger extension and flexion movements, finger abduction, and wrist extension), with each item being evaluated on a scale from 0 (without difficulty) to 3 (cannot do it) and a total score that varies from 0 to 12.[10]

The Grip was measured using the Jamar dynamometer (measured in kg). In the assessment of Grip and hand mobility, data from the dominant hand were considered.

Hand function, disability status and quality of life

Hand function was assessed using Cochin Hand Functional Scale (CHFS). This instrument consists of 18 questions related to the performance of daily activities in the last month to which patients respond using a Likert scale from 0 ("no difficulty") to 5 ("impossible"). Total score varies between 0 (without any functional compromise) and 90 (maximum disability) points. Its reliability and viability have been demonstrated in patients with SSc.[11]

Disability status was measured by the Health Assessment Questionnaire (HAQ) - this score classifies disability status as low disability (0 to ≤ 1), moderate disability (> 1 to ≤ 2) and high disability (> 2 to 3).[12]

The Medical Outcomes Short Form-36 (SF-36) comprises 36 questions grouped into eight domains: physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health. Each domain is scored separately and ranges from 0 to 100, with 0 indicating the worst Health-related quality of life (HRQoL) and 100 indicating the best HRQoL.[13]

Scales validated for the European Portuguese population were preferentially employed; when such versions were not available, validated Brazilian Portuguese adaptations were used. Specifically, the HAQ and the SF-36 were applied in their Portuguese versions validated for Portugal. In the absence of European Portuguese validation, as was the

case for the HAMIS test and the CHFS, the validated Brazilian Portuguese versions were adopted.[10-13]

Statistical analysis

Data was analysed with IBM® SPSS® Statistics software, version 29 (IBM® 2023). For descriptive statistics we presented means (M) and standard deviations (SD) for continuous variables with normal distribution, medians (Med) and quartiles (Q1-Q3) for continuous variables without normal distribution, frequencies, and percentages for categorical variables. Shapiro-Wilk test was used to determine normality.

Linear regression models were built to explain CHFS score based on a set of independent variables, namely age, gender, time between symptoms and diagnosis, mRSShf, Grip, HAMIS and SF-36 subscales of Physical Functioning, physical role, emotional role, energy/fatigue, emotional well-being, social functioning, pain, and general health. Assumptions of normality and independence of residuals were evaluated and confirmed using the Shapiro-Wilk test ($p > 0.05$) and Durbin-Watson test (≈2; not less than 1), respectively. Outliers were assessed by calculating standardized residuals, and no outliers were found based on the criterion ($ri > 3$ or $ri < -3$). Homoscedasticity was evaluated by analyzing the standardized residuals vs. predicted values plot. Multicollinearity was assessed by examining the values of the variance inflation factor (VIF) (<10) (Johnson & Albert, 1999). There was no evidence of multicollinearity.

The effect size was assessed using non-standardized coefficients (β) to maintain interpretability in the natural units of the predictors, and statistical significance was determined by 95% confidence intervals. These estimates were calculated using the least squares method. The proportion of variance explained by the models was evaluated using the coefficient of determination (R^2).[14-18]

Results

SSc population characteristics

A total of 32 patients were enrolled. Mean age of all participants was 58.0 years, with a SD of 10.5 years. Most of the patients were female, 81.3% (n=26). Concerning years of education, 10 (31.3%) patients had 4 years of education, 8 (25.0%) patients had 6 years of education, 4 (12.5%) patients had 9 years of education, 7 (21.9%) patients had 12 years of education and 3 (9.4%) had a higher education degree. Professional activity varied among the participants, with 50.0% being actively employed, 9.4% unemployed, 12.5% retired, and 28.1% medically retired. A total of 10 (31.3%) patients changed jobs at least once in their lifetime due to limitations caused by SSc. Type of disease was primarily classified as Limited Systemic Sclerosis (81.2%, n=26). The remaining 6 (18.8%) were diagnosed as Diffuse Cutaneous Systemic Sclerosis. Pulmonary involvement had a prevalence of 34.4% (n=11). Gastrointestinal involvement was present in 14 (43.8%) patients. Articular lesions were found in 12.5% of the patients (n=4). Mean disease duration was 16.6 years (SD=11.2). Mean time between symptoms onset and diagnosis was 5.5 years (SD=6.7). Only 6 (18.8%) patients reported the use of assistive devices. Specifically, the use of a shoe horn was present in 4 (12.5%) patients. Thick-handled cutlery was reported by 2 (6.3%) patients and shower bench or cane, by 1 (3.1%) patient each. Only 3 (14.3%) of the patients were being treated with hand rehabilitation.

Hand and fingers skin thickness, mobility and grip

The mRSShf showed a median of 1.5 (Q1 = 1.0, Q3 = 2.0), suggesting that skin thickness of the patients was within the normal to moderate range for most patients.

Regarding hand mobility, the HAMIS presented a median score of 3.0 (Q1 = 0.5, Q3 = 6.5), indicating that patients exhibited at least some mobility deficits.

Two types of analyses were performed: one considering the change of at least some mobility deficits (HAMIS >=1) for all movements evaluated and other considering the change of the count for all identified mobility deficits and their severity for all movements evaluated. Mobility deficits at thumb abduction was the most prevalent, with at least HAMIS score of 1 in 68.8% of the patients. Mobility deficits at supination was the second most prevalent, with at least HAMIS score of 1 in 43.8% of the patients. Mobility deficits at finger flexion and finger pronation were tied as the third most prevalent, with at least HAMIS score of 1 in 40.6% of the patients. Considering the count for all identified mobility deficits and their severity, thumb abduction was also the most prevalent with a total score of 37. Pronation had a total score of 21 and supination or finger flexion, both had observed a total score of 17 in the sample. Finger abduction problem followed closely, with a total score of 16. The remaining results can be analyzed in Fig 1. Grip, assessed with Jamar dynamometer (measured in kg) had a median score of 21.9 (Q1 = 19.4, Q3 = 26.6) suggesting that half of the patients were able to score at least 21.9 Kg of Grip.

Hand function and life quality scale

CHFS had a median score of 5.0 (Q1 = 2.5, Q3 = 10.5) and 10.5 for the third quartile, suggesting that most of the patients had low functional compromise. Only four patients had a CHFS ≥ 25. Results explained graphically in Fig 2.

General disability was evaluated through HAQ scale (Table 1). Each activity was categorized into three levels of disability: low, moderate, and high. HAQ results showed, in general, that patients had mostly low disability, with some

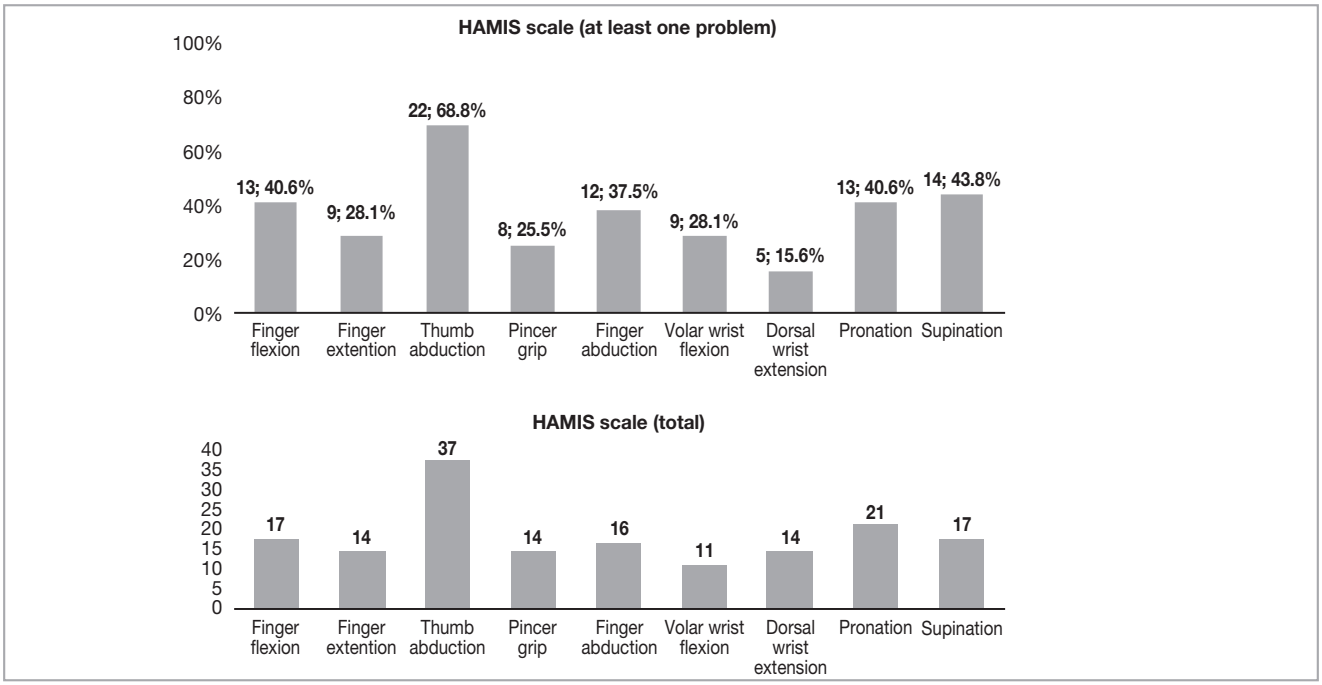


Figure 1 - HAMIS scale at least some deficit. HAMIS scale total.

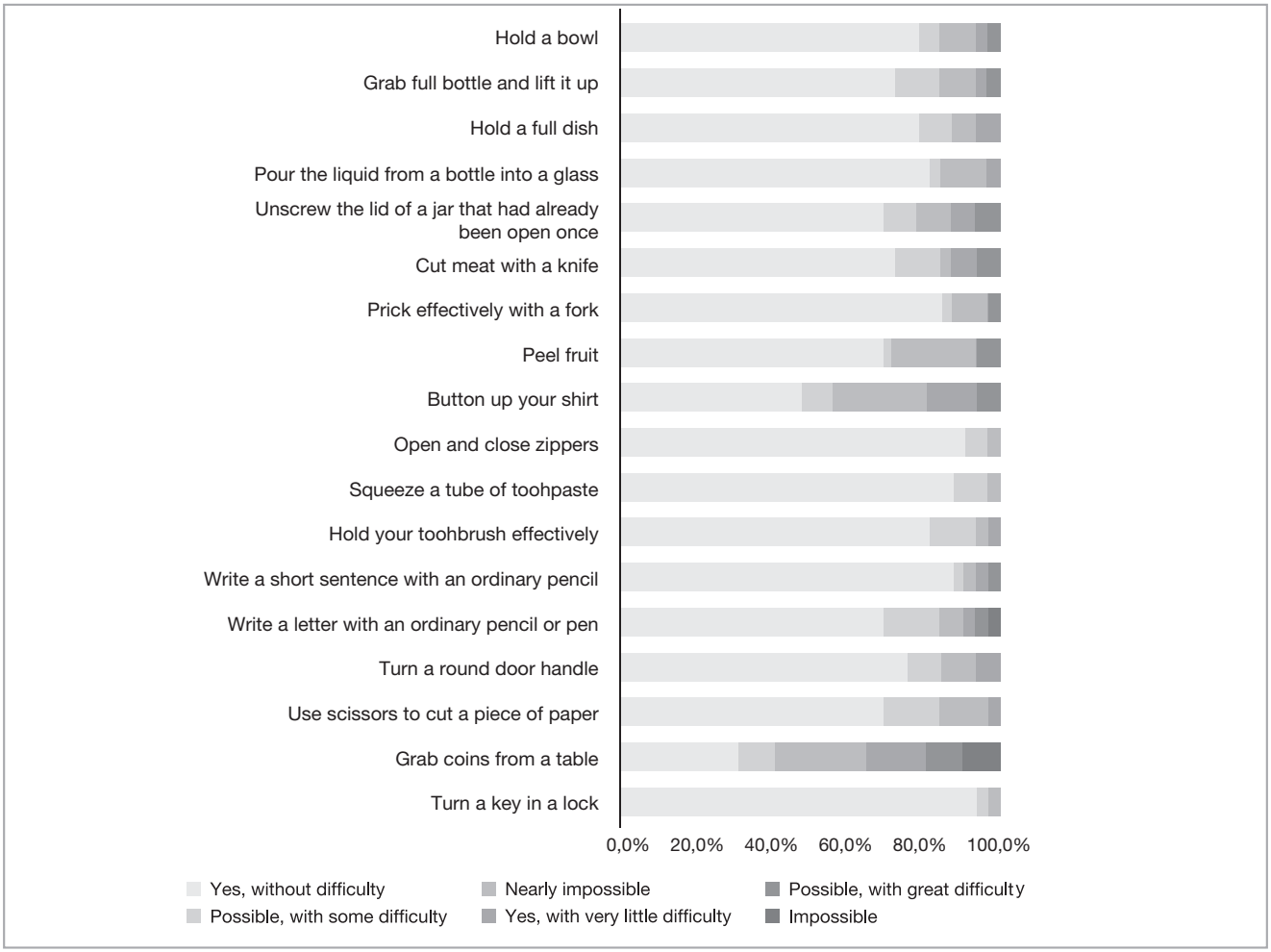


Figure 2 - Cochin Hand Functional Scale.

Table 1 - General disability was evaluated through HAQ scale. Each activity was categorized into three levels of disability: low (LD), moderate (MD), and high (HD).

	LD	MD	HD
Dress yourself, including tying shoelaces and doing buttons	28 (87.5%)	4 (12.5%)	0 (0.0%)
Shampoo your hair	31 (96.9%)	1 (3.1%)	0 (0.0%)
Stand up from an armless chair	31 (96.9%)	1 (3.1%)	0 (0.0%)
Get in and out of bed	30 (93.8%)	2 (6.3%)	0 (0.0%)
Cut your meat	26 (81.3%)	3 (9.4%)	3 (9.4%)
Lift a full cup or glass to your mouth	31 (96.9%)	1 (3.1%)	0 (0.0%)
Open a new carton of milk	28 (87.5%)	4 (12.5%)	0 (0.0%)
Walk outdoors on flat ground	32 (100.0%)	0 (0.0%)	0 (0.0%)
Climb up five stairs	31 (96.9%)	1 (3.1%)	0 (0.0%)
Wash and dry your entire body	31 (96.9%)	1 (3.1%)	0 (0.0%)
Take a bath	32 (100.0%)	0 (0.0%)	0 (0.0%)
Get on and off the toilet	32 (100.0%)	0 (0.0%)	0 (0.0%)
Reach and get down a 5 lb object	26 (81.3%)	2 (6.3%)	4 (12.5%)
Bend down to pick up clothing from the floor	29 (90.6%)	3 (9.4%)	0 (0.0%)
Open car doors	32 (100.0%)	0 (0.0%)	0 (0.0%)
Open jars which have been previously opened	27 (84.4%)	3 (9.4%)	2 (6.3%)
Turn taps on and off	32 (100.0%)	0 (0.0%)	0 (0.0%)
Run errands and shop	31 (96.9%)	1 (3.1%)	0 (0.0%)
Get in and out of a car	30 (93.8%)	2 (6.3%)	0 (0.0%)
Do chores such as vacuuming, housework or light gardening	30 (93.8%)	2 (6.3%)	0 (0.0%)

patients with moderate disability and very few with severe disability.

The SF-36 questionnaire assessed several dimensions of quality of life with the following results: physical functioning, median of 60.0 (Q1 = 40.0, Q3 = 85.0), physical role, median of 6.3 (Q1 = 0.0, Q3 = 21.9), emotional role, median of 25.0 (Q1 = 0.0, Q3 = 25.0), energy/fatigue, median of 50.0 (Q1 = 28.2, Q3 = 75.0), emotional well-being, median of 67.5 (Q1 = 45.0, Q3 = 80.0), social functioning, median of 75.0 (Q1 = 56.3, Q3 = 100.0), pain, median of 75.0 (Q1 = 31.3, Q3 = 100.0), and general health, median 35.0 (Q1 = 22.5, Q3 = 52.5). Patients showed lower results in physical role, emotional role and general health. For other dimensions, the median was at least 50.0.

Co-variables and hand function

Initially, we performed a univariate linear regression for explaining CHFS score and included the regression coefficients (β), standard errors (SE), 95% confidence intervals for β, and p-values. Data from the analysis performed are described in more detail in Table 2.

At last, we performed a multivariate linear regression for

Table 2 - Univariate linear regressions for explaining CHFS score - *Statistically significant (p<0.05); ‡Marginally significant.

	β	SE	95%CI for β	p-value
Age	0.30	0.25	-0.10; 0.81	0.228
Gender (male)	-6.62	6.60	-10.09; 6.86	0.324
Time between symptoms and diagnostic	-0.25	0.39	-1.05; 0.56	0.534
mRSShf	**5.71**	**1.54**	**2.57; 8.85**	**<0.001***
Grip	**-0.76**	**0.21**	**-1.19; -0.32**	**0.001***
HAMIS	**2.16**	**0.25**	**1.64; 2.67**	**<0.001***
SF-36: Physical Functioning	**-0.23**	**0.08**	**-0.40; -0.06**	**0.009***
SF-36: Role physical	-0.38	0.19	-0.77; 0.01	0.057‡
SF-36: Role emotional	**-0.67**	**0.20**	**-1.08; -0.25**	**0.003***
SF-36: Energy/Fatigue	-0.16	0.09	-0.34; 0.02	0.079‡
SF-36: Emotional well-being	**-0.26**	**0.10**	**-0.46; -0.06**	**0.012***
SF-36: Social Functioning	**-0.24**	**0.10**	**-0.44; -0.03**	**0.024***
SF-36: Pain	-0.09	0.08	-0.26; 0.08	0.307
SF-36: General Health	-0.24	0.12	-0.49; 0.01	0.058‡

Table 3 - Multivariate linear regression for explaining CHFS score - *Statistically significant (p<0.05); ‡Marginally significant.

	β	SE	95% CI for β	p-value	VIF
mRSShf	1.43	1.70	-2.13; 4.99	0.412	2.90
Grip	-0.23	0.15	-0.55; 0.08	0.141	1.74
HAMIS	1.60	0.38	0.81; 2.39	<0.001*	3.06
SF-36: Physical Functioning	-0.02	0.06	-0.13; 0.10	0.782	1.80
SF-36: Physical Role	0.06	0.13	-0.21; 0.32	0.657	1.76
SF-36: Emotional Role	-0.11	0.17	-0.47; 0.24	0.505	2.38
SF-36: Energy/Fatigue	0.05	0.07	-0.09; 0.20	0.457	2.65
SF-36: Emotional well-being	-0.05	0.09	-0.23; 0.12	0.535	2.83
SF-36: Social Functioning	-0.11	0.08	-0.27; 0.05	0.174	2.39
SF-36: General Health	-0.11	0.08	-0.28; 0.07	0.213	1.74
Adjusted R-squared (R^2)	**Adjusted R^2=0.80**				

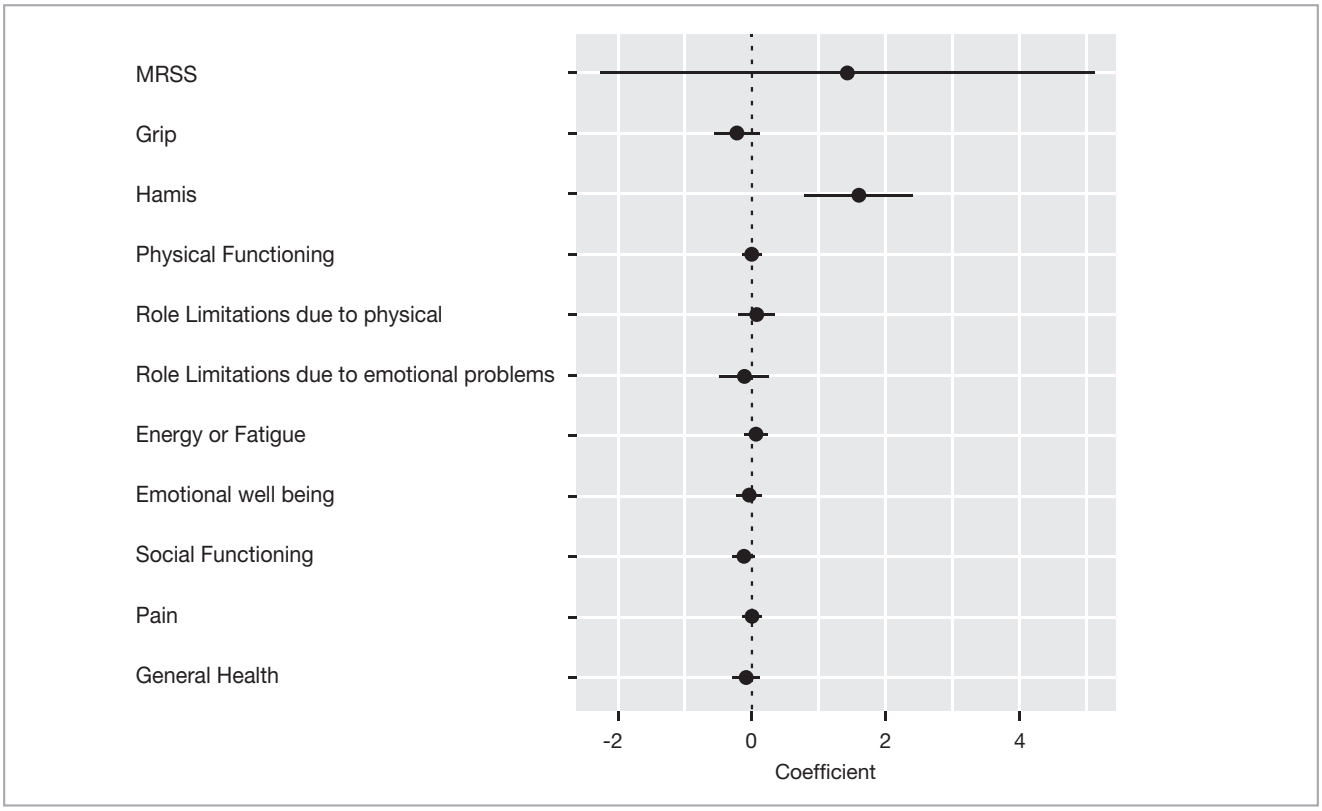


Figure 3 - Forest plot for coefficients of multivariate linear regression.

explaining CHFS score (Table 3). The explanatory variables included those that were marginally or statistically significantly associated with CHFS in the univariate analysis. Hence, the linear model was adjusted for mRSShf, Grip, HAMIS, SF-36 physical functioning, physical role, emotional role, energy/ fatigue, emotional well-being, social functioning, and general health. A single variable emerged as significantly associated with CHFS. HAMIS score was associated with CHFS, $p<0.001$, with a coefficient of 1.60, indicating 1.60 units increase in CHFS score for each unit increase in HAMIS score. Adjusted R-squared was 0.80, suggesting that 80% CHFS variability is explained by all variables included in the linear regression. When compared to univariate HAMIS R-squared (0.71), 70% of CHFS variability is explained by HAMIS, and only 9% by the other included explanatory variables. Fig 3 shows that the main reason for non-significant results are not large SE (with exception to mRSShf) but point estimates close to zero. Hence, we conclude that, in our sample, HAMIS score is, by far, the best predictor of CHFS.

Discussion

Within our study population, characterized by a mean disease duration of 16.6 years (SD=11.2) and a mean time lapse of 5.5 years (SD=6.7) between symptom's onset and diagnosis, predominant deficits in active range of motion (AROM) were observed. Notably, these deficits encompassed thumb abduction, supination, pronation, and finger flexion, which are consistent with findings reported by Williams et al. (2018)[19].

Our multivariate model identified a single variable significantly associated with CHFS scores. The model yielded an adjusted R-squared of 0.80, indicating that 80% of the variability in CHFS scores is explained by the variables included in the linear regression. These results highlight that AROM deficits are closely correlated with impaired hand function.

Although AROM defictis is a hallmark of SSc, current evidence regarding pharmacological and non-pharmacological interventions to prevent or restore hand mobility, remains inconsistent and of limited quality. As such, the development of compensatory and adaptive strategies becomes crucial to preserve patients' modified autonomy and participation in daily life activities. Accordingly, optimizing hand function through the prescription of task-specific assistive devices emerges as a key therapeutic approach.[20]

Therefore, examination of the CHFS scores in our population revealed a median of 5.0 (Q1 = 2.5, Q3 = 10.5), suggesting that the majority of patients experienced low functional

compromise. Nevertheless, 4 patients exhibited a CHFS score ≥ 25, indicative of substantial functional impairment in basic activities such as cutting meat with a knife, effectively using a fork, peeling fruit, unscrew the lid of a jar that had already been open once and buttoning up a shirt, as depicted in the CHFS graphic (Fig 3).

Additionally, a mere 6 patients (18.8%) reported using assistive devices, with only 2 (6.3%) utilizing thick-handled cutlery, and none of them presented a CHFS score ≥ 25. It is noteworthy that the act of eating holds socio-cultural significance, as discussed by Cipriano-Crespo (2020),[21] and disability related to the feeding process can lead to a social redefinition of food-related spaces. This blurs the line between public and private behavior, transforming the concept of "self" into "self with help." Consequently, individuals with disabilities may perceive themselves as burdens, thereby diminishing the social aspects associated with the act of eating, particularly in Mediterranean cultures where postprandial conversation is as integral as the meal itself. Despite falling outside the primary scope of our study outcomes, 2 patients reported resorting to hand-feeding during the evaluation due to their inability to use utensils of standard thickness. Notably, these individuals had never received guidance on acquiring thick-handled cutlery.

Another task that was also affected was buttoning up a shirt; however, it is considered an avoidable task, particularly when compared to essential activities such as eating, as previously discussed. Nevertheless, some interventions can be considered to help individuals adapt to their reality, such as modifications to clothing and footwear (open-back shirts, slip-on shoes, snaps, magnets, or velcro instead of buttons, zippers, etc.) and the use of assistive devices (for example, button aid). None of our patients were familiar with or used the button aid.[22]

Finally, it is important to underline that only 3 (14.3%) of the patients were being treated with hand rehabilitation. This is likely due to a deficit in the referral process to PM&R, possibly stemming from suboptimal interdepartmental communication and the absence of formal referral criteria. These gaps may also contribute to the low prescription and utilization of assistive devices observed in this sample.

This study is not without limitations. Firstly, the cross-sectional observational design limits the ability to infer causality. Secondly, our sample size is relatively small, reducing statistical power and limiting the generalizability of the findings; future studies involving larger, more diverse populations are recommended. Additionally, only self-administered questionnaires were used, which may introduce interpretation errors or biases related to literacy levels, particularly in view of the educational backgrounds reported. Furthermore, when European Portuguese validated versions of the scales were not available, Brazilian Portuguese versions were adopted, which could introduce subtle linguistic or cultural differences in the interpretation of some items. Finally, potential selection bias cannot be excluded, and the lack of longitudinal follow-up prevents any evaluation of changes in hand function over time. Future multicenter and prospective studies will be necessary to confirm these findings and to better delineate the hand function trajectory in SSc.

Conclusion

In conclusion, this study underscores the need for continuous assessment of hand mobility and function, as well as the implementation of a multidisciplinary approach in the management of patients with SSc. We suggest that patients reporting "possible with some difficulty" or worse on any CHFS item should be referred for evaluation by a PM&R physician. This would allow timely prescription of optimized assistive devices to support autonomy despite disease progression. A multidisciplinary approach focused on maintaining participation and independence may help mitigate the functional impact of SSc.

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