RHEUMATOLOGY

Original article

Employment status and socio-economic burden in systemic sclerosis: a cross-sectional survey

Christelle Nguyen[1,2], Serge Poiraudeau[2], Caroline Mestre-Stanislas[1], François Rannou[2], Alice Bérezné[1], Agathe Papelard[2], Dominique Choudat[3], Michel Revel[2], Loïc Guillevin[1] and Luc Mouthon[1]

Abstract

Objective. To assess employment status and socio-economic burden in SSc patients.

Methods. Eighty-seven SSc patients (72 females), fulfilling the ACR or the Leroy and Medsger criteria, or both, were evaluated for employment status, socio-economic burden and handicap. Statistical analysis involved Mann–Whitney U-test and Fisher's exact test and backward stepwise regression analysis.

Results. In total, 60.9% of the SSc patients were on full-time sick leave and 35.6% were receiving a disability pension. On univariate analysis, myalgia was the only clinical manifestation more frequently encountered in sick-leave patients than others (73.6 vs 47.1%; $P = 0.012$). Karnofsky performance status (KPS) was lower in SSc patients who were on sick leave or were receiving a disability pension than others [78.5 (10.6) vs 85.8 (9.0); $P = 0.004$ and 78.1 (8.7) vs 83.1 (11.2); $P = 0.016$, respectively]. In addition, greater global, hand and mouth handicaps and depression were observed in patients on sick leave [HAQ 0.9 (0.7) vs 0.6 (0.5); $P = 0.021$; Cochin Hand Function Scale 21.7 (18.9) vs 10.7 (12.1); $P = 0.003$; mouth handicap scale 20.2 (10.8) vs 14.6 (10.0); $P = 0.014$; and depression dimension of the hospital anxiety and depression scale 7.1 (3.9) vs 4.8 (3.4); $P = 0.003$]. On multivariate analysis, factors associated with sick leave were KPS [odds ratio (OR) 0.92; 95%CI 0.88, 0.98] and myalgias (OR 3.19; 95% CI 1.19, 8.58), and the factor associated with receiving a disability pension was decreased income (OR 8.19; 95% CI 2.67, 25.12).

Conclusions. SSc patients commonly have to take full-time sick leave from work. Despite such patients receiving disability pensions, the socio-economic burden is considerable.

Key words: Systemic sclerosis, Employment status, Work, Disability, Socio-economic burden.

Introduction

SSc is a CTD characterized by excessive collagen deposition in the dermis and internal organs and by vascular hyper-reactivity and obliterative microvascular phenomena [1]. SSc is responsible for diminished life expectancy, related to skin extent and visceral involvement [2]. In addition, SSc is responsible for skin, tendon, joint and vessel damage, leading to disability, handicap and worsened quality of life [3]. Psychiatric symptoms have also been reported as a frequent consequence of disease chronicity in SSc patients, with a prevalence of depressive symptoms of 18–65% [4–12]. However, among activities of daily living (ADL) potentially affected by SSc, fitness to work and factors influencing it have rarely been studied.

Fitness to work is a major component of life, since the worker role strongly influences the ADL [13], and is commonly affected in chronic auto-immune diseases. Consequences are socio-economic burden, as well as a negative impact on the individual's well-being. Fitness to work is a multi-factorial phenomenon and depends on individual factors such as physical capacity and

psychological characteristics, as well as the requirements of work [14]. Sandqvist *et al*. [15] evaluated 44 women of working age with lcSSc in Sweden; 21 (48%) were not on sick leave, 15 (34%) were on partial sick leave and 8 (18%) were temporarily on full-time sick leave or were receiving full disability pension. Greater fitness to work was significantly associated with better capacity to perform ADL, greater satisfaction with occupation, better well-being and better health. In addition, another group recently reported a high frequency of work disability in SSc patients (56%); work disability was strongly associated with HAQ Disability Index (HAQ-DI) scores [16].

Our aim was to assess the consequences of SSc on employment status and socio-economic burden, as well as influencing factors, through a cross-sectional survey in a French cohort of SSc patients.

Patients and methods

Study design

We performed a cross-sectional survey of 38 consecutive patients who were hospitalized for at least 1 day in our Internal Medicine Department and 70 patients recruited during the annual meeting of the Association des Sclérodermiques de France (ASF), the French SSc patients association, in April 2007.

Patients

To be eligible for the study, patients had to fulfill the ACR [17] or the Leroy and Medsger [18] criteria, or both, for SSc. Patients from the ASF were assessed within 48 h during Spring 2007 (temperature 20°C). Parameters recorded were age; sex; age at disease onset; disease duration; disease form [limited SSc (lSSc), lcSSc or dcSSc]; Karnofsky Performance Status (KPS) score; mouth opening (inter-incisor distance measured in millimetres); skin involvement; telangiectasias; RP; pitting scars; digital ulcers; calcinosis; gastrointestinal tract, joint and/or muscle involvement; dyspnoea [assessed by the New York Heart Association (NYHA) 4-point scale]; interstitial lung disease; pulmonary arterial hypertension (PAH); and renal crisis. History of oesophagus, gastrointestinal, joint, muscle and/or heart involvement; interstitial lung disease; PAH; and renal crisis was obtained from clinical charts of hospitalized patients and self-reports for ASF members.

Employment status

Patients' employment status was self-reported. Parameters recorded included presence and duration of official disabled status as defined by receiving a disability pension; current full-time sick leave status (yes/no); physical job (yes/no); work-time duration (full-time or part-time); number of work-time duration changes since the SSc diagnosis; number of occupational changes since the beginning of the disease and participation in voluntary work or associations.

Health status

Health status was assessed by the KPS score, the scale ranging from 0 (dead) to 100 (normal no complaints; no evidence of disease) [19].

Health-related quality of life

Health-related quality of life was assessed by the French version of the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) [20], which is a self-administered questionnaire covering eight areas: physical function, physical role, bodily pain, general health, vitality, social function, emotional role and mental health. For each area, scores range from 0 (poorer health status) to 100 (better health status). Scores can also be summarized in two global scores: the physical component score (PCS) and the mental component score (MCS).

Disability

Global disability. Global disability was assessed by the HAQ [21], the scale ranging from 0 (no disability) to 3 (maximal disability). The HAQ includes 20 items divided into eight domains.

Patients' perceived disability. Patients' perceived disability was assessed by the McMaster Toronto Arthritis Patient Preference Disability Questionnaire (MACTAR) [22]. Patients were asked to select three situations among ADL that caused them maximal trouble [19]. Each item is scored on an 11-point semi-quantitative scale (range 0–10). The global score ranges from 0 (no disability) to 30 (maximal disability). This scale has been validated in SSc [19].

Hand disability. Hand disability was assessed by the Cochin Hand Function Scale (CHFS) [23], a questionnaire administered by the physician that contains 18 items related to ADL. Each question is scored on a scale of 0 (performed without difficulty) to 5 (impossible to do). The total score is obtained by adding the scores of all items (range 0–90). This questionnaire has been validated in SSc [24].

Mouth disability. Mouth disability was assessed by the Mouth Handicap In SSc (MHISS) scale, a questionnaire administered by the physician that contains 12 items concerning difficulties in performing ADL. Each question is scored on a scale of 0 (never) to 4 (always) [25]. The total score is obtained by adding the scores of all items (range 0–48).

Anxiety and depression

Anxiety and depression were assessed by the Hospital Anxiety and Depression scale (HAD). This scale has seven questions for the anxiety dimension (HADa) and seven for the depression dimension (HADd) [26]. Each point is scored on a scale of 0–3, the total score ranging from 0 (no depression, no anxiety) to 21 (maximal depression, maximal anxiety).

Aesthetic burden

Aesthetic burden was assessed on an 11-point semi-quantitative scale, the total score ranging from 0 (no aesthetic burden) to 10 (maximal aesthetic burden).

Statistical analysis

Data analysis involved use of Systat 9 software (SPSS, Chicago, IL, USA). Quantitative variables were described with mean (S.D.) and qualitative variables with frequencies and percentages. For univariate analysis, non-parametric tests were used because a normal distribution could not be demonstrated for all parameters studied. Comparisons between groups involved the Mann–Whitney U-test for quantitative data and Fisher's exact test for qualitative variables. For all statistical analysis, $P < 0.05$ was considered statistically significant. All CIs were calculated at the 95% level. Multivariate analysis was used to determine the variables associated with patients' sick leave or having a disability pension. A backwards stepwise regression analysis with values of 0.10 to enter and 0.10 to stay in the model was used. Variables with $P < 0.05$ on univariate analysis were entered in multivariate analysis.

Ethical considerations

This survey was conducted in compliance with the protocol Good Clinical Practices and Declaration of Helsinki principles. In accordance with French law, a formal approval from an ethics committee is not required for this kind of project. Patients gave their consent to participate after being orally informed about the study protocol.

Results

Demographic and clinical data

Overall, data for 87 patients were assessed. In total, 50 patients were recruited during the ASF annual meeting in April 2007, and the remaining 37 consecutive patients were recruited during their hospitalization in our Internal Medicine Department. All patients were Caucasian; 72 (82.8%) were female. The mean (S.D.) age at the time of evaluation was 48.6 (8.5) years, and mean disease duration 8.1 (6.4) years. A total of 30 (34.5%) patients had dcSSc, 52 (59.8%) lcSSc and 5 (5.7%) lSSc. The mean KPS was 81.3 (10.6) (range 0–100) (Table 1).

Employment status in SSc patients

Fifty-three (60.9%) patients were on full-time sick leave at the time of evaluation. Thirty-one (35.6%) patients were receiving a disability pension. Among the 34 patients not on sick leave, 24 (70.6%) of the working patients had full-time employment and 10 (29.4%) part-time employment. Approximately 40% of the full-time and part-time workers (45.8 and 40%, respectively) had to change their working-time duration at least once after the diagnosis of SSc. Overall, 31% of the patients experienced occupational changes after the diagnosis of SSc. SSc patients changed their type of occupation 0.6 (1.1) times, on average, during their working lifetime. These parameters

TABLE 1 Demographic and clinical characteristics of 87 patients with SSc

Characteristic	
Age, mean (S.D.), years	48.6 (8.5)
Sex, female	72 (82.8)
Age at disease onset, mean (S.D.), years	41.2 (8.9)
Disease duration, mean (S.D.), years	8.1 (6.4)
dcSSc	30 (34.5)
lcSSc	52 (59.8)
lSSc	5 (5.7)
KPS (0–100), mean (S.D.)	81.3 (10.6)
Inter-incisor distance, mean (S.D.), mm	38.9 (10.3)
Skin involvement	75 (86.2)
Telangiectasias	72 (82.8)
RP	84 (96.6)
Pitting scars	48 (55.2)
Digital ulcers	31 (35.6)
Calcinosis	31 (35.6)
Gastrointestinal tract involvement	78 (89.7)
Arthralgias	59 (67.8)
Myalgias	55 (63.2)
Dyspnoea, NYHA classification, mean (S.D.)	2.0 (0.8)
Interstitial lung disease	37 (42.5)
PAH	8 (9.2)
Scleroderma renal crisis	7 (8.0)

Data are given as *n* (%) unless otherwise indicated.

did not differ by sex or age category (<50 or >50 years old; Table 2).

Employment status and organ manifestations

Visceral involvement was not greater for SSc patients receiving a full disability pension or those who were on sick leave at the time of evaluation, except for more frequent myalgias for patients on sick leave (73.6 *vs* 47.1%; $P = 0.012$; Table 3).

Employment status and handicap

On univariate analysis, perceived health status, as indicated by KPS score, was lower for SSc patients on sick leave or receiving a disability pension than for others [78.5 (10.6) *vs* 85.8 (9.0); $P = 0.004$ and 78.1 (8.7) *vs* 83.1 (11.2); $P = 0.016$, respectively]. In addition, patients on sick leave showed increased scores for HAQ, CHFS, MHISS and HADd [HAQ 0.9 (0.7) *vs* 0.6 (0.5); $P = 0.021$; CHFS 21.7 (18.9) *vs* 10.7 (12.1); $P = 0.003$; MHISS scale 20.2 (10.8) *vs* 14.6 (10.0); $P = 0.014$; and HADd scale 7.1 (3.9) *vs* 4.8 (3.4); $P = 0.003$]; the MACTAR global score was greater but not significantly for these patients [16.4 (7.9) *vs* 13.1 (7.3); $P = 0.084$]. Groups did not differ in other outcome measures (SF-36, HADa and aesthetic burden), except for the physical role between patients receiving or not a disability pension (Table 4). On multivariate analysis, factors associated with sick leave were KPS [odds ratio (OR) 0.92; 95% CI 0.88, 0.98] and myalgias (OR 3.19; 95% CI 1.19, 8.57).

TABLE 2 Employment status of 87 SSc patients by sex and age

	All patients (n = 87)	Sex			Age, years		
		Males (n = 15)	Females (n = 72)	P-value*	<50 (n = 49)	>50 (n = 38)	P-value*
Disability pension	31 (35.6)	5 (33.3)	26 (36.1)	1.000	21 (42.9)	10 (26.3)	0.121
Duration of disability pension, mean (S.D.), years	5.5 (6.9)	5.6 (4.6)	5.5 (7.3)	0.516	5.0 (4.8)	6.5 (10.1)	0.772
Sick leave	53 (60.9)	9 (60.0)	44 (61.1)	1.000	15 (30.6)	19 (50)	0.079
Physical job	25 (28.7)	4 (26.7)	21 (29.2)	1.000	10 (20.4)	15 (39.5)	0.060
Full-time employment	24 (27.6)	3 (20.0)	21 (29.2)	0.545	10 (20.4)	14 (36.8)	0.098
Changes since the beginning of the disease	11 (12.6)	1 (6.7)	10 (13.9)	0.681	6 (12.2)	5 (13.2)	1.000
Reorientation	4 (4.6)	0 (0.0)	4 (5.6)	1.000	1 (2.0)	3 (7.9)	0.314
Part-time employment	10 (11.5)	3 (20.0)	7 (9.7)	0.367	5 (10.2)	5 (13.2)	0.742
Changes since the beginning of the disease	4 (4.6)	1 (6.7)	3 (4.2)	0.542	1 (0.2)	3 (7.9)	0.317
Reorientation	2 (2.3)	1 (6.7)	1 (1.4)	0.304	1 (0.2)	0 (0.0)	0.503
Occupational changes	27 (31.0)	5 (33.3)	22 (30.6)	1.000	14 (28.6)	13 (34.2)	0.643
Occupational changes, mean (S.D.)	0.6 (1.1)	0.9 (1.4)	0.5 (1.0)	0.540	0.6 (1.3)	0.5 (0.8)	0.822
Voluntary work	18 (20.7)	1 (6.7)	17 (23.6)	0.179	9 (18.4)	9 (23.7)	0.600
Patients' associations	50 (57.5)	11 (73.3)	39 (54.2)	0.252	36 (73.5)	14 (36.8)	0.001**

Values are given as n (%) unless otherwise stated. *Non-parametric Mann–Whitney U-test for quantitative data and Fisher's exact test for qualitative data; $P < 0.05$. **Difference is significant.

TABLE 3 Demographic and clinical characteristics of 87 SSc patients by disability pension and sick leave status

	Disability pension			Sick leave status		
	Disability pension (n = 31)	No disability pension (n = 56)	P-value*	Sick leave (n = 53)	No sick leave (n = 34)	P-value*
Age, mean (S.D.), years	48.1 (6.9)	48.9 (9.3)	0.387	47.4 (9.1)	50.1 (7.0)	0.089
Sex, female, n (%)	26 (83.9)	46 (82.1)	1.000	44 (83.0)	28 (82.4)	1.000
Age at disease onset, mean (S.D.), years	40.9 (7.2)	41.4 (9.8)	0.632	39.7 (9.2)	43.5 (7.9)	0.085
Disease duration, mean (S.D.), years	7.9 (5.4)	8.2 (6.9)	0.831	8.2 (6.2)	7.8 (6.6)	0.749
dcSSc, n (%)	9 (29.0)	21 (37.5)	0.268	21 (39.6)	9 (26.5)	0.361
lcSSc, n (%)	21 (67.7)	31 (55.4)	0.252	29 (54.7)	23 (67.6)	0.486
lSSc, n (%)	1 (3.2)	4 (7.1)	1.000	3 (5.7)	2 (5.9)	0.651
Inter-incisor distance, mean (S.D.), mm	36.8 (9.2)	40.2 (10.8)	0.180	38.1 (10.5)	40.1 (9.9)	0.283
Skin involvement, n (%)	26 (83.9)	49 (87.5)	0.748	48 (90.6)	27 (79.4)	0.203
Telangiectasias, n (%)	25 (80.6)	47 (83.9)	0.770	44 (83.0)	28 (82.4)	1.000
RP, n (%)	31 (100)	53 (94.6)	0.550	51 (96.2)	33 (97.1)	1.000
Pitting scars, n (%)	13 (41.9)	35 (62.5)	0.076	29 (54.7)	19 (55.9)	1.000
Digital ulcers, n (%)	11 (35.5)	20 (35.7)	1.000	20 (37.7)	11 (32.4)	0.653
Calcinosis, n (%)	12 (38.7)	19 (33.6)	0.816	19 (35.8)	12 (35.3)	1.000
Gastrointestinal tract involvement, n (%)	30 (96.8)	48 (85.7)	0.149	47 (88.7)	31 (91.2)	1.000
Arthralgias, n (%)	21 (67.7)	38 (67.9)	1.000	35 (66.0)	24 (70.1)	0.815
Myalgia, n (%)	20 (64.5)	35 (62.5)	1.000	39 (73.6)	16 (47.1)	0.012**
Dyspnoea, NYHA classification	1.9 (0.8)	2.1 (0.8)	0.240	2.1 (0.7)	1.8 (0.8)	0.084
Interstitial lung disease, n (%)	12 (38.7)	25 (44.6)	0.652	27 (50.9)	10 (29.4)	0.075
PAH, n (%)	2 (6.5)	6 (10.7)	0.705	5 (9.4)	3 (8.8)	1.000
Scleroderma renal crisis, n (%)	4 (12.9)	3 (5.4)	0.241	4 (7.5)	3 (8.8)	1.000

*Non-parametric Mann–Whitney U-test for quantitative data and Fisher's exact test for qualitative data; $P < 0.05$. **Difference is significant.

TABLE 4 Outcome measurement scores of 87 SSc patients by disability pension and sick leave status

Outcome measures, range	All patients (n = 87)	Disability pension			Sick leave status		
		Disability pension (n = 31)	No disability pension (n = 56)	P-value*	Sick leave (n = 53)	No sick leave (n = 34)	P-value*
KPS (0–100)	81.3 (10.6)	78.1 (8.7)	83.1 (11.2)	0.016**	78.5 (10.6)	85.8 (9.0)	0.004**
SF-36 (0–100)							
Physical functioning	57.2 (26.6)	59.4 (21.9)	55.8 (29.3)	0.742	57.0 (29.0)	57.6 (23.1)	0.992
Physical role	35.9 (39.4)	50.0 (40.4)	27.1 (36.0)	0.012*	39.9 (40.0)	29.8 (38.4)	0.238
Bodily pain	43.1 (22.3)	45.6 (47.5)	44.8 (41.4)	0.991	46.5 (42.0)	43.0 (46.5)	0.674
General health perception	39.6 (18.2)	61.3 (22.8)	58.1 (20.7)	0.762	59.0 (21.1)	59.7 (22.3)	0.751
Vitality	39.2 (17.4)	42.5 (23.1)	43.5 (22.1)	0.967	45.9 (23.6)	38.9 (19.8)	0.097
Social functioning	59.3 (21.5)	57.1 (17.8)	53.9 (17.1)	0.398	57.1 (16.8)	52.1 (18.0)	0.247
Emotional role	45.1 (43.6)	37.7 (19.1)	40.1 (16.5)	0.532	41.0 (19.1)	36.5 (14.4)	0.291
Mental health	55.1 (17.3)	38.1 (20.3)	40.6 (17.0)	0.410	38.8 (18.6)	40.9 (17.9)	0.605
PCS	38.4 (12.6)	39.8 (13.5)	37.4 (12.1)	0.385	38.9 (12.8)	37.6 (12.6)	0.517
MCS	41.9 (11.8)	43.4 (13.8)	41.0 (10.3)	0.569	42.8 (11.6)	40.6 (12.1)	0.385
HAQ (0–3)	0.8 (0.7)	0.9 (0.7)	0.9 (0.6)	0.922	0.9 (0.7)	0.6 (0.5)	0.021**
MACTAR (0–30)	15.1 (7.8)	15.0 (8.0)	15.2 (7.7)	0.828	16.4 (7.9)	13.1 (7.3)	0.084
CHFS (0–90)	17.4 (17.3)	19.1 (17.7)	16.4 (17.2)	0.463	21.7 (18.9)	10.7 (12.1)	0.003**
MHISS (0–48)	18.0 (10.8)	19.3 (10.6)	17.3 (10.9)	0.359	20.2 (10.8)	14.6 (10.0)	0.014**
HADa (0–21)	9.7 (4.3)	9.6 (4.6)	9.7 (4.1)	0.742	10.0 (4.5)	9.1 (3.9)	0.392
HADd (0–21)	6.2 (3.9)	6.6 (4.7)	6.0 (3.4)	0.813	7.1 (3.9)	4.8 (3.4)	0.003**
Aesthetic burden (0–10)	4.4 (2.6)	4.0 (2.5)	4.6 (2.7)	0.274	4.6 (2.4)	3.9 (2.9)	0.214

Values are given as mean (s.d.). *Non-parametric Mann–Whitney U-test for quantitative data and Fisher's exact test for qualitative data; P < 0.05. **Difference is significant.

Socio-economic burden

Patients receiving a disability pension more often experienced occupational changes during their career [0.9 (1.3) vs 0.4 (0.9); P = 0.014], decreased income (71 vs 23.2%; P < 0.001), lack of advancement (71 vs 28.6%; P < 0.001) and feelings of discrimination (22.6 vs 5.4%; P = 0.030); these parameters did not differ when considering sick-leave status or physical requirement for the job (Table 5). On multivariate analysis, the only factor associated with receiving a disability pension was decreased income (OR 8.19; 95% CI 2.67, 25.12).

Discussion

In this study, 60.9% of the SSc patients, whatever the disease form, were on full-time sick leave, 35.6% were receiving a disability pension and 31% experienced occupational changes after the diagnosis of SSc. Myalgia was the only disease organ manifestation more frequently encountered in patients on sick leave than others. Factors associated with employment status were general health status; global, hand and mouth handicaps; and depression. Finally, regarding socio-economic burden, disabled patients more frequently reported decreased income, lack of advancement and feelings of discrimination.

Previous studies assessing employment status and socio-economic burden in SSc and factors influencing them have suggested a high frequency of working disability in SSc, which may be greater than in other auto-immune diseases such as RA [16]. In addition, in lcSSc, fitness to work was associated with capacity to perform ADL, satisfaction with occupation, well-being and health [15].

Consistent with previous findings, we observed a high proportion of SSc patients currently on sick leave or officially disabled. In a Swedish study of 44 women of working age with lcSSc [median age 52 (range 24–60) years], 34% were on partial sick leave and 18% were temporarily on full-time sick leave or were receiving a full disability pension [15]. In Southwestern Ontario, Canada, in a cohort of 61 patients with SSc (dcSSc and lcSSc), the proportion of patients with self-reported work disability was 56% [16], which was higher than in the study by Moser et al. [27] (36%) in a cohort of 94 patients with comparable demographic characteristics, except for mean disease duration (11 vs 8 years, respectively). Our population of patients was of working age but was younger than those in the three previous studies. Moreover, we included both male and female patients, as well as patients with one of the three types of SSc. Thus, in our study, 30 (34.5%) patients had dcSSc and 5 (5.7%) had lSSc, whereas in the Swedish study, none had dcSSc or lSSc [15], and in the Canadian study, none had lSSc [16]. In addition, the definition of work ability varies among studies and has been mainly self-reported [16, 27]. Moreover, two of the three studies on this topic did not investigate disability pensions or sick leave status [16, 27].

TABLE 5 Socio-economic burden of 87 SSc patients, by disability pension, sick-leave status and job requirement

	All patients (n = 87)	Disability pension			Sick leave status			Job requirement		
		Disability pension (n = 31)	No disability pension (n = 56)	P-value*	Sick leave (n = 53)	No sick leave (n = 34)	P-value**	Physical requirement (n = 25)	Non-physical requirement (n = 62)	P-value*
Occupational changes, mean (s.d.)	0.6 (1.1)	0.9 (1.3)	0.4 (0.9)	0.014	0.5 (0.9)	0.7 (1.3)	0.440	0.6 (0.9)	0.6 (1.1)	0.643
Decreased income, n (%)	35 (40.2)	22 (71.0)	13 (23.2)	0.000	23 (43.4)	12 (35.3)	0.507	14 (56.0)	21 (33.9)	0.090
Lack of advancement, n (%)	38 (43.7)	22 (71.0)	16 (28.6)	0.000	24 (45.3)	14 (41.2)	0.825	11 (44.0)	27 (43.5)	1.000
Feelings of discrimination, n (%)	10 (11.5)	7 (22.6)	3 (5.4)	0.030	7 (13.2)	3 (8.8)	0.734	3 (12.0)	7 (11.3)	1.000

*Difference is significant. **Non-parametric Mann–Whitney U-test for quantitative data and Fisher's exact test for qualitative data; $P < 0.05$.

We observed a high rate of secondary occupational change (31%) after the diagnosis of SSc. When examining specific health conditions associated with job changes, arthritis is among the health conditions most strongly related to both changing jobs and retiring over an 8-year period [28]. For example, in patients awaiting hip or knee surgery, 30% leave their original job mainly or partly because of their joint disorder. Such job loss is more common for those employed in small businesses and those whose work involves standing for >2 h/day [29]. Job-related health insurance is one of the main factors influencing employment transitions [30].

Remarkably, we found no significant association of sick leave and clinical manifestations, except for myalgias. This finding is consistent with those from Sandqvist et al. [15], who did not find evidence of any significant linear relation between working status and organ manifestations, except for skin score. In a systematic literature review assessing predictive factors of work disability in RA, biomedical variables did not consistently predict work disability [31]. These observations suggest that employment status and socio-economic burden in SSc could be related more to perceived health status and disability than to specific organ involvement.

General health status assessed by KPS score was significantly decreased for SSc patients on sick leave or receiving a disability pension. Originally developed for cancer patients, because it strongly predicts cancer outcome [32, 33], the KPS score is also used in assessing acute or chronic conditions [34–37]. As for cancer, our data support the use of the KPS score to predict outcome in SSc, because in addition to providing clinical estimates of a patient's physical state, performance and prognosis, it is also associated with the patient's social status.

Global disability, assessed by the HAQ, and location-specific hand and mouth handicaps, assessed by the CHFS and MHISS, was higher in SSc patients on sick leave than for others. This finding is fairly consistent with previous findings. In the Canadian study, HAQ-DI score was the most important independent factor associated with working disability in SSc [16]. The importance of hand function in fitness for work in SSc was previously suggested in the Swedish study, because greater fitness to work was associated with better grip force and dexterity [15]. For the first time, we provide evidence that mouth disability could also influence employment status in SSc. Because the mouth and face are frequently involved in SSc, with patients often complaining of aesthetic concerns, reduced mouth opening, altered dentition, speaking difficulties, sicca syndrome, and mouth disability may impair fitness to work. The effect of mouth disability on fitness for specific jobs, especially those requiring public contact or talking, should be further assessed.

We found increased depression scores, significantly associated with sick-leave status, in SSc patients. In a recent study of 100 SSc patients, the prevalence of current and lifetime mood disorders was 35 and 64%, respectively [38]. This prevalence is higher in SSc than

in RA patients [39] or in an elderly population without cognitive impairment [40].

Finally, SSc patients receiving a disability pension more frequently reported decreased income, lack of advancement and feelings of discrimination than did SSc patients who did not receive a disability pension. Experiences of stigmatization have been reported for other chronic health conditions such as AIDS, leprosy, tuberculosis, mental illness, epilepsy, psoriasis, cancer and obesity [41–45]. A conceptual framework commonly describes stigma as consisting of difficulties of knowledge (ignorance or misinformation), attitudes (prejudice) and behaviour (discrimination) [46]. For psoriatic patients, the feeling of being stigmatized has been shown to be associated with clinical severity of the disease and socio-demographic variables [47]. For SSc patients, disability status seems to be associated with experiencing stigmatization.

There are some limitations to our work. Our sample size was small, and information regarding employment status and socio-economic burden were derived from self-reports, which does not allow for addressing the complexity of employment or capturing details about the working environment. Also, our study was not designed to differentiate the impact of SSc on paid and unpaid work. Differentiating between paid and unpaid work could be critical for SSc patients because the disease is mostly present in women, who are more likely than men to have unpaid jobs or both paid and unpaid jobs. Education level could have been explored, because many patients may not get the education needed to move from one job to another, and flexibility may be important to remain employed. Finally, we did not address disease-related job loss in this study.

In conclusion, our study demonstrates that patients with SSc commonly have to change jobs and take full-time sick leave. Despite the availability of disability pensions, the socio-economic burden is considerable. Therefore, further development of pharmacological and non-pharmacological interventions in SSc should take into account their impact on disability and employment status. Studies comparing patients living in different countries with diverse health-care systems and work-place benefits would also be of interest.

> ### Rheumatology key messages
>
> - SSc patients commonly have to take full-time sick leave from work.
> - Global and location-specific disability is associated with sick leave.
> - Moreover, SSc patients who receive a disability pension experience stigmatization.

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