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# Determinants of unemployment amongst Australian systemic sclerosis patients: results from a multicentre cohort study

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## ABSTRACT

**Objective.** We sought to assess employment status, risk factors for unemployment and the associations of unemployment with patients' health related quality of life (HRQoL).

**Methods.** All patients enrolled in a systemic sclerosis (SSc) longitudinal cohort study, completed an employment questionnaire on enrolment. Clinical manifestations were defined based on presence at the time of enrolment. Summary statistics, chi-square tests, univariate and multivariable logistic regression were used to determine the associations of various risk factors with employment.

**Results.** Among 1587 SSc patients, 160 (20%) were unemployed at the time of cohort enrolment excluding retired patients. Of these, 63% had limited disease subtype. Mean ( $\pm$ SD) age at enrolment was 51.9 ( $\pm$ 10.4) years; 13 years below the average retirement age in Australia. Mean ( $\pm$ SD) disease duration at recruitment was 11.1 ( $\pm$ 10.9) years. Multivariable regression analysis revealed the presence of digital amputation (OR 3.9, 95%CI 1.7-9.1,  $p=0.002$ ), diffuse disease subtype (OR 2.2, 95%CI 1.3-3.5,  $p$ -value=0.002), sicca symptoms (OR 2.7, 95%CI 1.6-4.4,  $p<0.001$ ), a physical job (OR 1.8, 95%CI 1.1-3.1,  $p=0.03$ ) and pulmonary arterial hypertension (OR 2.2, 95%CI 1.1-4.5,  $p=0.02$ ) to be associated with unemployment. Unemployed patients had consistently poorer HRQoL scores in all domains (physical, emotional and mental health) of the SF-36 form than those who were employed.

**Conclusion.** SSc is associated with substantial work disability and unemployment, which is in turn associated with poor quality of life. Raising awareness, identifying modifiable risk factors and implementing employment strategies and work place modifications are possible ways of reducing this burden.

## Introduction

The ability to work is based on multiple factors, which can be summarised as the worker's capacity to meet the physical and mental demands of a particular job. The ability to work is an important determinant of sustained employability (1) and is correlated with increased productivity and participation in the labour market (1).

The ability to work and maintain paid employment is important at an economic level, in terms of productivity loss and cost, but also for the individual worker and is associated with an individual's sense of wellbeing, satisfaction and quality of life (2). From the individual's perspective, working is one of the most important activities of daily living, providing an income, daily structure, social interaction and an opportunity to learn and develop new skills (2).

There is no standard definition of work disability (WD), and there are no validated questionnaires consistently used across studies making comparison of results difficult. Definitions used include work cessation prior to 65 years of age; work cessation prior to 65 years of age attributed to a specific condition; work cessation for at least six months' duration, receiving work disability benefits and working less than full-time. Despite the use of the various definitions, all studies examining WD show a negative effect on the individual including mental health conditions such as depression, loss of occupational identity, self-esteem, life direction and purpose (1-4). The importance of the ability to maintain employment and its consequences for patients' wellbeing has been demonstrated in both SSc (2) and rheumatoid arthritis (RA) (5). In rheumatic conditions, the cost of WD is high, generally higher than disease treatment costs (6). Quantify-

ing these economic costs is relevant to employers, insurers, health economists and policy makers. Of all the rheumatic conditions, the largest body of information is available for RA where WD occurs early with a prevalence ranging between 10–44% and increases with increasing disease duration (7–9).

Systemic sclerosis (SSc) is a chronic progressive condition, which occurs during peak working age (18–65 years). It causes impairments in bodily functions and structures, with near universal involvement of the hands. These impairments cause difficulty in participating in daily occupations, self-care and domestic chores (2, 10). Additionally, SSc causes skin thickening and an altered physical appearance contributing to psychological burden (11). Given these physical and mental consequences, SSc has the potential to cause a significant amount of WD and subsequent economic burden.

WD in SSc has never been studied in Australia but data from other countries support this substantial aspect of disease burden. Some of these studies use specific instruments to capture work ability (workers productivity survey and work ability index) (1, 12), while others use self-composed instruments (2–4, 13). Despite the use of various instruments, all studies report substantial prevalence of WD, higher than other rheumatic conditions (13).

We sought to determine the prevalence and risk factors for unemployment in a large Australian SSc cohort.

## Methods

### *Patient cohort*

Patients enrolled in the Australian Scleroderma Cohort Study (ASCS) were included. All patients fulfilled either the American College of Rheumatology or Leroy and Medsger criteria for SSc (14, 15). The ASCS is a multi-centre study of risk and prognostic factors for cardiopulmonary and other clinically important outcomes in SSc. The ASCS comprises 13 Australian centres and has been approved by the human research ethics committees of each of the participating hospitals (St. Vincent's Hospital, Melbourne, Royal Adelaide Hospital, Monash Medi-

cal Centre, Royal Perth Hospital, The Queen Elizabeth Hospital, Sunshine Coast Rheumatology, Prince Charles Hospital, John Hunter Hospital, Royal North Shore Hospital, Royal Prince Alfred Hospital, St George Hospital, Canberra Rheumatology and the Menzies Research Institute Tasmania). All patients provide written informed consent at recruitment.

### *Inclusion and exclusion criteria*

We included all consecutive adult (>18 years) SSc patients from the ASCS recruited between December 2007 and June 2015. At enrolment, all patients complete a questionnaire regarding their current and past employment status (full-time, part-time, student, unemployed, home duties, disability preventing work or retired) and previous occupations held. Patients were categorised into three groups. Group 1 included employed patients (full-time, part-time, student), Group 2 included unemployed patients (unemployed or disabled) and Group 3 included individuals who were retired and/or doing home duties. We excluded Group 3 from the data analysis, as we could not determine whether their current occupational status was attributable to SSc. The mean ( $\pm$ SD) age of this group was 63.8 ( $\pm$ 11.2) years.

### *Data collection*

Patient demographics, clinical variables, cardiac and pulmonary assessments were obtained from the ASCS database. In addition, all patients complete the general health assessment questionnaire (HAQ) which is a validated functional assessment tool and a Medical Outcomes Study Short Form-36 (SF-36), which is a validated tool for measuring health related quality of life (HRQoL) in patients with rheumatic conditions including SSc (16). Clinical manifestations and autoantibody status were defined as present, if present at the time of enrolment. Transthoracic echocardiogram (TTE) was performed according to standardised procedures only at tertiary centres. Pulmonary involvement was assessed by pulmonary function tests (PFTs) and/or HRCT. Any patient identified as high risk of developing pulmonary

arterial hypertension (PAH) (defined as systolic pulmonary arterial pressure on TTE ( $sPAP_{TTE}$ ) of at least 40mmHg and/or Diffusing capacity of the lungs for carbon monoxide (DLCO) corrected for haemoglobin less than 50% predicted with forced vital capacity (FVC) of more than 85% predicted, without adequate explanation on high-resolution computer tomography (HRCT) lung or ventilation-perfusion (V/Q) scan of lung or both) underwent right heart catheterisation (RHC).

Interstitial lung disease (ILD) was defined based on HRCT scan demonstrating interstitial fibrosis in either an NSIP or UIP pattern. For the purposes of this study, radiographic extent of ILD was not quantified. Myocardial disease was defined on endomyocardial biopsy or as the presence of conduction deficits, arrhythmia, right ventricular or left ventricular dysfunction in the absence of other causes. Pericardial effusions were defined on echocardiogram other than a small non-significant pericardial effusion. Renal crisis was defined on a combination of any two of the following three criteria, which included new onset severe hypertension ( $\geq$ 180 mmHg systolic and/or  $\geq$ 100 mmHg) without an alternate aetiology, microangiopathic haemolytic anaemia or rising creatinine. Gastric antral vascular ectasia (GAVE), reflux oesophagitis and oesophageal stricture were defined on endoscopy. Bowel dysmotility was defined based on barium and nuclear medicine studies, antibiotic response or characteristic symptoms.

The classification of patients into limited (lcSSc) and diffuse cutaneous (dcSSc) was confirmed by reviewing their peak recorded modified Rodnan skin scores.

### *Outcome variables*

The primary outcome variable was employment status at enrolment into ASCS. We sought to determine risk factors for unemployment in our SSc cohort and to compare the age of unemployment in SSc patients with age of unemployment in the general population.

### *Statistical analysis*

Data are presented as mean  $\pm$  standard deviation (SD) for continuous variables

and as number (percentage) for categorical variables. The difference in frequency was tested by using chi-square and Fisher's exact tests. Summary statistics, univariable and multivariable logistic regression, along with post-estimation diagnostics were used to determine the associations of different combinations of risk factors with unemployment. A two-tailed *p*-value of not more than 0.05 was considered statistically significant. All statistical analyses were performed using STATA 14.0 (StataCorp LP, College Station, TX, USA).

**Results**

*Patient characteristics*

Among 1587 SSc patients, we excluded 28.3% (449 patients) who were retired and 13.9% (221 patients) who reported doing home duties. Of the remaining 802 patients, 19.9% (160 patients) were unemployed and 86.6% (642 patients) were employed. The unemployed patients were similar to those in employment, being 82.5% female, 92.9% of Caucasian ethnicity and with a mean ( $\pm$ SD) age at enrolment of 51.9 ( $\pm$ 10.4) years, 13 years below the usual retirement age in Australia. Overall, patients had long disease duration, with a mean ( $\pm$ SD) disease duration since the first non-Raynaud's manifestation of 11.1 ( $\pm$ 10.9) years for the unemployed and 9.6 ( $\pm$ 9.0) years for the employed patients. Compared with those in employment, more of the unemployed patients had the limited disease subtype (lcSSc) (53.8% vs. 67.8%).

The cohort as a whole was well educated with 22.9% having completed tertiary education, 35.2% having finished secondary education and 7.2% having a trade qualification. The patients who remained in employment had consistently higher education levels than unemployed patients across all domains of education (secondary school, trade qualification, diploma and degree, *p*<0.001). In addition, employed patients had less physically active jobs than unemployed patients (*p*<0.001), with administrative and clerical work being the most common occupations of employed patients (12.5% of employed patients). Clinical manifestations more commonly found in unemployed patients

**Table I.** Univariable comparison of patients who are employed versus unemployed (n=802).

	Employed mean $\pm$ SD or %	Unemployed mean $\pm$ SD or %	<i>p</i> -value
Total patient number	642	160	
Female	538 (83.8%)	132 (82.5%)	0.69
Age at recruitment, years	50.4 $\pm$ 10.7	51.9 $\pm$ 10.4	0.13
Disease duration at recruitment*, years	9.6 $\pm$ 9.0	11.1 $\pm$ 10.9	0.09
Race			
Caucasian	568 (91.8%)	144 (92.9%)	0.12
Asian	31 (5.0%)	5 (3.2%)	
Aboriginal-Islander	7 (1.1%)	3 (1.9%)	
Hispanic	3 (0.5%)	3 (1.9%)	
Other	10 (1.6%)	0%	
Level of education			
Primary school	11 (1.7%)	18 (11.3%)	<0.001
Secondary school	201 (31.3%)	71 (44.4%)	
Trade qualification	54 (8.4%)	19 (11.9%)	
Diploma	66 (10.3%)	16 (19.5%)	
Degree	160 (24.9%)	11 (6.4%)	
Other	3 (0.5%)	1 (0.06%)	
Industry worked in prior to SSc diagnosis			
Physical work	268 (41.7%)	72 (45.0%)	<0.001
Non-physical work	166 (25.9%)	29 (18.1%)	
Disease subtype			
Limited	435 (67.8%)	86 (53.8%)	0.02
Diffuse	163 (25.4%)	61 (38.1%)	
MCTD	33 (5.1%)	11 (6.9%)	
Clinical manifestations <sup>#</sup>			
Reflux oesphagitis	270 (42.1%)	85 (53.1%)	0.01
Oesophageal dysmotility	178 (27.7%)	59 (36.9%)	0.02
Bowel dysmotility	110 (17.3%)	46 (28.8%)	0.003
Synovitis	66 (10.3%)	27 (16.9%)	0.02
Joint contractures	145 (22.6%)	53 (33.1%)	0.01
Digital gangrene / amputation	27 (4.2%)	23 (14.4%)	<0.001
Sicca symptoms	277 (43.2%)	97 (60.6%)	<0.001
PAH	49 (7.6%)	29 (18.1%)	<0.001
ILD	139 (21.6%)	35 (21.9%)	0.79
Tendon friction rubs	26 (4.1%)	14 (8.8%)	0.03
Rodnan skin score	9.2 $\pm$ 8.8	13.3 $\pm$ 12.5	0.01
WHO functional class**			
Class I	364 (61.8%)	41 (30.1%)	<0.001
Class II	182 (30.9%)	56 (41.2%)	
Class III	40 (6.8%)	30 (22.1%)	
Class IV	3 (0.5%)	9 (6.6%)	
6MWD, m	504.8 $\pm$ 109.2	406.7 $\pm$ 121.3	<0.001
Hand contracture (Finger-Palm R /L (cm))	0.8 $\pm$ 1.4	1.6 $\pm$ 1.9	<0.001

GAVE: gastric antral vascular ectasia, ILD: interstitial lung disease; MCTD: mixed connective tissue disease; PAH: pulmonary arterial hypertension; SD: standard deviation; 6MWD: six-minute walk distance. \*disease duration from first non-Raynaud manifestation; <sup>#</sup> present ever from diagnosis to recruitment; \*\*higher WHO functional class denotes worse physical function.

are summarised in Table I. The dcSSc disease subtype and the presence of musculoskeletal manifestations including synovitis, joint contractures, digital amputation and hand contractures (measured by finger to palm distance) were found more commonly in unemployed patients. In addition, unemployed patients had a higher frequency of gastrointestinal involvement, sicca symptoms, PAH, WHO functional

class III or IV and a shorter six-minute walk distance (6MWD) than employed patients. There was no difference in autoantibody frequency between employment states. ILD occurred equally in both groups.

*Clinical variables associated with unemployment in SSc*

In univariable analysis (Table II), factors associated with unemployment

**Table II.** Risk factors for unemployment in univariable analysis.

Characteristic	OR (95%CI)	p-value
Tertiary education	0.29 (0.2-0.5)	<0.001
Physical job	1.54 (0.9-2.5)	0.07
Diffuse disease subtype	1.89 (1.3-2.8)	0.001
Oesophageal dysmotility	1.59 (1.1-2.3)	0.01
Bowel dysmotility	1.98 (1.3-2.9)	0.001
GORD	1.55 (1.1- 2.2)	0.01
Synovitis	1.51 (0.9-2.5)	0.12
Joint contractures	1.78 (1.2-2.6)	0.003
Digital amputation	3.87 (2.2-6.9)	<0.001
Sicca	2.15 (1.5-3.1)	<0.001
PAH	2.68 (1.6-4.4)	<0.001
ILD	1.03 (0.7-1.6)	0.89
Tendon friction rub	2.33 (1.2-4.6)	0.02
6MWD, m	0.99 (0.9-0.9)	<0.001
WHO functional class	2.69 (2.1-3.4)	<0.001
Hand contractures (Finger-Palm R or L), cm	1.29 (1.2-1.5)	<0.001

GORD: gastro-oesophageal reflux disease; ILD: interstitial lung disease; L: left; OR: odds ratio; PAH: pulmonary arterial hypertension; R: right; WHO functional class: world health organisation functional class; 6MWD: six minute walk distance; 95% CI: 95% confidence interval.

**Table III.** Risk factors associated with unemployment in multivariable analysis.

Characteristic	OR (95%CI)	p-value
Physical job	1.8 (1.1-3.1)	0.03
Diffuse disease subtype	2.2 (1.3-3.5)	0.002
PAH	2.2 (1.1-4.5)	0.02
Sicca	2.7 (1.6-4.4)	<0.001
Digital amputation	3.9 (1.7-9.1)	0.002

OR: odds ratio; PAH: pulmonary arterial hypertension; 95% CI: 95% confidence interval.

**Table IV.** Health related quality of life (HRQoL) measured using SF-36 form.

HRQoL	Employed mean±SD	Unemployed mean±SD	p-value
SF 36 score			
Physical functioning	70.9 ± 26.4	38.7 ± 23.4	<0.001
Role – physical	65.7 ± 40.4	18.0 ± 33.4	<0.001
Bodily pain	68.5 ± 24.8	46.3 ± 26.5	<0.001
General health	52.9 ± 21.5	31.5 ± 16.6	<0.001
Vitality	53.2 ± 21.7	30.8 ± 21.7	<0.001
Social functioning	77.8 ± 23.1	54.9 ± 26.2	<0.001
Role – emotional	75.5 ± 37.3	55.0 ± 44.8	<0.001
Mental health	72.5 ± 18.1	62.8 ± 19.2	<0.001
General HAQ-DI score	0.42 ± 0.56	1.22 ± 0.74	<0.001

HAQ-D: Health assessment questionnaire disability index; SD: standard deviation.

included dcSSc ( $p=0.001$ ), tendon friction rubs ( $p=0.014$ ), gastrointestinal manifestations such as gastro-oesophageal reflux disease ( $p=0.02$ ), oesophageal ( $p=0.01$ ) and bowel dysmotility ( $p=0.001$ ), sicca symptoms ( $p<0.001$ ), PAH ( $p<0.001$ ), digital amputation ( $p<0.001$ ), joint contractures ( $p=0.003$ ) and hand contractures (measured by finger to palm distance) ( $p<0.001$ ). WHO functional class ( $p<0.001$ ) and 6MWD ( $p<0.001$ ) were also associated with

unemployment. Tertiary education was protective of unemployment ( $p<0.001$ ). Using multivariable logistic regression along with post-estimation diagnostics, we were able to determine the associations of combinations of risk factors with unemployment in SSc. These clinical variables and their associated increased odds of unemployment are presented in Table III. The dcSSc subtype was associated with a 2.2-fold increased odds of being unemployed,

physical work was associated with a 1.8 fold increased odds, the presence of PAH was associated with a 2.2-fold increased odds, sicca symptoms was associated with a 2.7-fold increased odds and digital amputation associated with a 3.9-fold increased odds of being unemployed.

*Health related quality of life (HRQoL) in SSc patients according to employment status*

Unemployed patients had significantly lower HRQoL scores across all domains of the Medical Outcomes Study Short Form-36 (SF-36), particularly in physical functioning, role-physical, general health and vitality ( $p<0.001$ ), than employed patients (Table IV). In addition, unemployed patients had significantly lower scores on their general HAQ questionnaire indicating significant functional limitation in their daily activities compared with employed patients ( $p<0.001$ ).

**Discussion**

The ability to work is a fundamental component of everyday life. Work loss is one of the most important consequences of chronic rheumatic disease impacting society through economic costs and the individual through loss of income, social and leisure activity limitations. In our cohort of Australian SSc patients, 19.9% (160 patients) were unemployed. This is likely an underestimation of unemployment as we were unable to correctly identify patients who had retired early as a consequence of their SSc and thus excluded them from the analyses. The frequency of unemployment in SSc varies geographically and between studies, but the majority report a frequency between 20% and 55% (17, 18, 3).

In our study, unemployed patients were predominantly female (82.5%) with limited disease (53.8%), which is consistent with the epidemiology of the disease itself. Of concern was the young age ( $51.9\pm 10.4$  years) of our unemployed patients. During the last census performed by the Australian Bureau of Statistics (to June 2012-13), the average age of retirement for recent retirees (those who retired in the last

five years) was 61.5years (63.3years for men and 59.6years for women). Thus, SSc contributes to a significant number of years of lost productivity. This young age of work cessation is not an uncommon finding across European (4), American (17) and Canadian (14) studies.

Compared with the general Australian population (19), our cohort had a lower percentage of patients finishing non school qualifications. In our cohort, only 43.6% of employed patients had a non school qualification compared with 67% of employed patients in the general population and only 37.8% of unemployed patients had a non school qualification compared with 50% of unemployed patients in the general population. Our unemployed compared with employed patients were less well educated and were more commonly involved in physical labour, which have been reported previously (17, 3). Unemployed patients were more likely to have dcSSc with higher mean Rodnan skin scores and more severe disease reflected by the presence of tendon friction rubs, PAH, poorer WHO functional class and lower 6MWD. The dcSSc subtype, worse physical function and severe disease were found to be associated with WD in a large Canadian SSc cohort (18) where WD occurred early and increased proportionally with increasing disease duration (18).

Literature specific to SSc-PAH and work ability is scarce. However, PAH in general is associated with a high frequency of depression (21-55%), anxiety (20-40%) and poor HRQoL scores (20). Additionally, the frequency of unemployment amongst PAH patients is significant ranging from 45% to 77% (20). Declining WHO functional class was identified as having a substantial impact on aspects of everyday life for the patients and their carers (20). Therefore, it is not surprising that our study found the presence of PAH, poorer WHO functional class and lower 6MWD to be significant determinants of WD.

Hand dysfunction, characterised by the presence of joint contractures and deformities, is an underappreciated entity in SSc, occurs in more than two thirds of patients and is very difficult

if not impossible to treat (21). It was foreseeable that unemployed patients had significantly worse hand function than employed patients, manifested by inability to make a fist (finger to palm distance), and the presence of synovitis, joint contractures and digital amputation. There is some evidence of improved hand function with hand occupational therapy (22) and hand surgery (23), however surgery is fraught with difficulty given the potential for poor wound healing and secondary infections (23). The best intervention is early identification of dysfunction and working with the patient and their employers to implement work environment and /or work activity to enable the patient to maintain productivity for the longest possible duration.

Sicca symptoms, due to fibrosis of the exocrine glands, are common in SSc and are significant contributors to poor health related quality of life. The association between sicca symptoms and unemployment, as demonstrated in our study, has not previously been reported. This association may be explained in part by the fact that patients with xerostomia have significant difficulty with speaking and eating (due to difficulties with swallowing) which may cause social embarrassment and reduced confidence with maintaining a working life.

Since 1984, when the World Health Organisation defined health as "a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity", quality of life issues have progressively become central to health care practice and research (24). 'Quality of life' or more specifically 'Health related quality of life' (HRQoL) refers to the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations, and perceptions (24). The literature-to-date indicates that SSc-patients experience poor HRQoL, well below that of the general population and on par or lower than other chronic conditions including other rheumatic conditions (16). Our study confirmed this low HRQoL in SSc patients and also demonstrated a signifi-

cant difference in HRQoL between employed and unemployed patients. Being aware of the main contributors to poor HRQoL in SSc may aid in identifying those at greatest risk who may benefit from adjunctive healthcare interventions such as occupational therapy, rehabilitation and counselling.

Unlike other employment studies in SSc, we did not find an increased risk with the presence of ILD (3). One possible reason may be that symptomatic ILD may be a late disease manifestation, and individuals with SSc may have work disability as a result of other disease manifestations earlier in the disease course.

We recognise that there are limitations to our study. We excluded all patients who were retired or performing home duties at the time of enrolment, as we could not accurately assess if their unemployment status was attributable to SSc. If this was indeed the case, then our results would underestimate the frequency of unemployment in our SSc cohort. In addition, our study was cross-sectional in nature and undertaken in a predominantly 'prevalent' SSc cohort. Future studies evaluating work ability over time from disease onset would be highly informative. We were unable to determine absenteeism, workers productivity or work transition and quantification of these areas is becoming increasingly important in terms of estimating the societal cost associated with work disability in SSc.

## Conclusion

SSc is associated with substantial work disability and poor health related quality of life. Raising awareness, identifying modifiable risk factors and implementing employment strategies and modifications to work place environments are possible ways of reducing this burden.

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