Physical and Occupational Therapy Referral and Use among Systemic Sclerosis Patients with Impaired Hand Function: Results from a Canadian National Survey

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ABSTRACT

Objective: Contractures and deformities of the hand are major factors in disability and reduced health-related quality of life in systemic sclerosis (SSc). Physical (PT) and occupational therapy (OT) have been emphasized to address impaired hand function, but little is known about the extent they are employed. The objective of this study was to determine the proportion of Canadian SSc patients with hand involvement who are referred to and use PT or OT services and factors associated with referral.

Methods: Participants were respondents to the Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities who rated ≥1 of 5 hand problems (hand stiffness, difficulty making fist, difficulty holding objects, difficulty opening hand, difficulty with faucet) as occurring at least sometimes with moderate or higher impact. Patients indicated if their physicians recommended PT or OT and if they used these services. Multivariate logistic regression assessed independent predictors of PT or OT referral.

Results: Of 317 patients with hand involvement, 90 (28%) reported PT or OT referral, but only 39 (12%) reported using these services. PT or OT referral was associated with more hand problems (odds ratio [OR]=1.24, 95% confidence interval [CI] 1.02-1.51, p=0.031) younger age (OR=0.96, 95% CI 0.94-0.99, p=0.004) and not being employed (OR=0.50, 95% CI 0.26-0.97, p=.0041).

Conclusion: Few SSc patients with hand involvement are referred to PT or OT, and even fewer use these services. High-quality randomized controlled trials of PT and OT interventions to improve hand function in SSc are needed.

Keywords: Systemic Sclerosis, scleroderma, hand function, occupational therapy, physical therapy.

Contractures and deformities of the hand, consisting of decreased flexion, limited extension and reduced thumb abduction, are common in systemic sclerosis (SSc) (1-4) and are important contributors to overall disability (5-6). Physical (PT) and occupational therapy (OT) have been emphasized as rehabilitation techniques to address impaired hand functioning once contractures from SSc have developed (1). Three randomized controlled trials (RCTs) have reported that PT /OT interventions improved hand function (7-9), but none included more than 20 patients per treatment or control groups (1). The extent to which physicians recommend PT or OT services and to which SSc patients use them is unknown. Thus, the objectives of this study were to (1) determine the proportion of patients with self-reported hand impairment referred to PT or OT by their physicians, (2) the proportion using PT or OT, and (3) factors related to PT or OT referral.

SAMPLE AND METHODS

Sample

Persons with SSc completed the anonymous Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities survey between September 2008 and August 2009. The survey was advertised at an annual meeting of the Scleroderma Society of Canada, through Scleroderma Society of Canada and Sclérodermie Québec websites; in full-page magazine advertisements in McLean's and l'Actualité; by announcements in Canadian SSc-related newsletters; by contacting Canadian SSc support groups; and with materials distributed by Canadian Scleroderma Research Group physicians. Respondents completed the survey in English or French online or by requesting a paper copy. Respondents included in the present study were ≥18 years old, residents of Canada, and had physician diagnosed SSc. Signed

informed consent was not obtained as the survey was anonymous. The study was approved by the McGill University Research Ethics Board.

Measures

Survey respondents rated the frequency and impact of 69 symptoms, including 5 related to hand function. Frequency questions were worded, "How frequently have you experienced (*insert symptom*) in the past year?" with response options (*never*, *rarely*, *sometimes*, *most of the time*, *always*). Impact questions were worded, "Please specify the degree of impact that (*insert symptom*) has had on your ability to carry out everyday activities in the past year" with response options (*no impact*, *minimal*, *moderate*, *severe*, *extremely severe*). Symptom frequency and impact were recoded as dichotomous variables (frequency, *never* or *rarely* versus *sometimes*, *most of the time* or *always*; impact, *no impact* or *minimal impact* versus *moderate*, *severe or extremely severe* impact). Respondents were classified as having hand involvement if they rated ≥1 of 5 hand symptom items (hand stiffness, difficulty making fist, difficulty holding objects, difficulty opening hand, difficulty with faucet) as occurring at least sometimes with moderate or greater impact.

Survey respondents were asked to indicate from a list that included PT and OT "which treatments/therapies/tools did your physician or other health professional <u>suggest</u> that you use <u>currently</u>?" and which treatments/therapies/tools do you <u>actually</u> use <u>currently</u>?". They were classified as having been recommended PT or OT by physicians and using PT or OT if they answered yes to either PT or OT or both.

Data Analyses

Survey respondents referred for PT or OT were compared to those not referred on demographic and disease variables using the χ^2 statistic for categorical variables, 2-tailed t tests for continuous variables, and the Mann-Whitney U test for ordinal variables. Among those with

hand involvement, the likelihood of PT or OT referral was assessed with multiple logistic regression. The *a priori* defined model included the number of hand symptoms for which patients reported at least moderate impairment, gender, age, education level, disease duration, work status (not working versus working full or part-time) and treating physician (rheumatologist, other physician, not receiving treatment). Whether or not patients had private insurance was included in a secondary analysis due to the large number of patients without insurance data. Discrimination and calibration of the logistic regression models were assessed with the c-index and Hosmer Lemeshow goodness-or-fit test statistic (HL), respectively (10). All analyses were conducted using SPSS version 17.0 (SPSS Inc., Chicago, IL), and all statistical tests were two-sided with a significance level of $p < 0.05$.

RESULTS

Sample Characteristics

Of 792 persons who completed all or part of the survey (not counting duplicate submissions), 157 (20%) did not specify that they had been diagnosed with SSc by a health care provider, 8 (1%) were < 18 years of age, and 71 (9%) were not from Canada. This left 556 respondents with survey data, of whom 317 (57%) had hand involvement per the study definition. Demographic and medical data of the 317 respondents included in the study are shown in Table I.

PT or OT Recommendation and Use

Only 90 respondents with hand involvement (28%) reported a PT or OT referral. Only 39 reported using PT or OT, equivalent to 43% of those recommended PT or OT, or, 12% of all patients with hand involvement. There were 287 (91%) respondents with complete predictor data who were included in the regression analysis. As shown in Table II, on an unadjusted basis, greater number of hand symptoms with at least moderate impact (odds ratio [OR]=1.26, 95%

confidence interval [CI] 1.06-1.51, *p*=0.011) and age (OR=0.97, 95% CI 0.95-0.99, *p*=0.004) were significantly associated with being PT/OT referral. In multivariate analysis, hand symptoms (OR=1.24, 95% CI 1.02-1.51, *p*=0.031), age (OR=0.96, 95% CI 0.94-0.99, *p*=0.004) and full- or part-time employment (OR=0.50, 95% CI 0.26-0.97, *p*=0.041) were independently associated with referral. The model had good discrimination (c-index=0.71) and calibration (p=0.908 for the HL statistic). Respondents with private insurance (n=108 of 197 with data) were almost twice as likely to be referred for PT/OT (OR=1.92, 95% CI 0.95- 3.90) but this was not statistically significantly (*p*=0.070) in regression analysis.

DISCUSSION

Hand function is a core determinant of overall impairment for patients with SSc. PT/OT is the primary intervention available to address impaired hand function. In this study, only 28% of Canadians with SSc with self-reported hand problems were referred to PT or OT, and only 43% of those used PT or OT (12% of all respondents with hand problems). Greater hand involvement, younger age, and not working full- or part-time were independently associated with referral. Those not working may have had greater impairment (11-12), which was not fully captured by the relatively non-specific variable used (number of hand problems). Additionally, working patients may experience logistical difficulties in accessing PT/OT.

It is not entirely surprising that physicians do not regularly refer patients for PT or OT as there is limited evidence supporting these rehabilitation treatments, and it is not known to what degree they are effective. Even in rheumatoid arthritis (RA), where there is more research, studies are not conclusive. A 2004 systematic review of hand exercise to improve function in RA determined that high-quality studies were needed to draw conclusions (13). Furthermore, physical and occupational therapists are usually trained as generalists and typically do not receive training to address the particular problems of SSc patients. Furthermore, it is unclear how

readily patients can access ongoing PT or OT, and our findings suggest that this may be related to private insurance coverage.

There are limitations to consider in interpreting the results of this study. The study used a convenience sample of survey respondents. In addition, a large portion of the survey dissemination and response was electronic (newsletters, websites and the online survey) which may have influenced respondent characteristics. The method used to determine hand involvement status was a gross measure based on simple frequency and impact ratings and may not have accurately reflected hand involvement. We did not include digital ulcers in our list of hand symptoms, which may have impacted our results as digital ulcers have been shown to increase disability among patients with SSc (14). Other limitations include the lack of precise medical information to characterize patients, due to the self-report nature of the survey and the dichotomous checklist method to assess PT and OT referral and use. As well, assessing only current referral and use did not allow us to identify patients who were previously referred or had used PT or OT services in the past. Finally, the small number of patients that used PT and OT services did not allow for assessment of factors associated with use among referred patients.

In summary, hand function is an important issue that is not currently addressed for many people with SSc who report hand impairment. However, there is a lack of sufficient evidence to suggest that physicians should regularly refer SSc patients with hand problems for PT or OT services. The lack of systematic care to address disability from impaired hand function is a major care gap. The findings of this study underline the need for high-quality, adequately-powered randomized control trials to determine if PT and OT interventions would improve hand function in SSc or if early use of PT or OT could prevent contractures before they develop. In addition, they highlight the need for research to better understand how physicians attempt to manage hand problems in SSc, as well as patient access to PT and OT services.

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Table I. Characteristics of Patients with Hand Involvement (N= 317)

Variable	Total n (%)	Referred PT or OT n = 90	Not Referred n = 227	*p* value
Female gender	279 (88%)	82 (91%)	197 (87%)	0.285
Age, *mean*± *SD* (n=295)	55.5 (12.6)	52.1 (12.4)	56.9 (12.4)	0.003
Race/ethnicity (n=258) *				0.410
White	218 (84%)	62 (81%)	156 (86%)	
Other**	29 (11%)	10 (13%)	19 (10%)	
White and other**	11 (4%)	5 (6%)	6 (3%)	
Level of education				0.650
Less than high school	32 (10%)	7 (8%)	25 (11%)	
High school graduate	210 (66%)	60 (67%)	150 (66%)	
University graduate	75 (24%)	23 (25%)	52 (23%)	
Marital status				0.704
Single	27 (9%)	9 (10%)	18 (8%)	
Married	226 (71%)	65 (72%)	161 (71%)	
Separated/divorced/widowed	64 (20%)	16 (18%)	48 (21%)	
Primary spoken language				0.104
English	241 (76%)	74 (82%)	167 (74%)	
French	76 (24%)	16 (18%)	60 (26%)	
Working (full- or part-time)	87 (27%)	20 (22%)	67 (30%)	0.189
Disease Subtype				0.205
Diffuse	43 (14%)	17 (19%)	26 (11%)	

Limited/CREST	110 (35%)	28 (31%)	82 (36%)	
Not known	164 (52%)	45 (50%)	119 (52%)	
Primary SSc Care (n=311)				0.058
Rheumatologist	210 (68%)	66 (74%)	144 (65%)	
Other Physician	83 (27%)	22 (25%)	61 (27%)	
No Current Treatment	18 (6%)	1 (1%)	17 (8%)	
Years since diagnosis, *mean* ± *SD* (n=315)	11.0 (9.7)	10.3 (10.6)	11.3 (9.4)	0.412
Number of hand symptoms experienced at least sometimes				0.028
1	12 (4%)	0 (0%)	12 (5%)	
2	29 (9%)	6 (7%)	23 (10%)	
3	54 (17%)	12 (13%)	42 (19%)	
4	86 (27%)	28 (31%)	58 (26%)	
5	136 (43%)	44 (49%)	92 (41%)	
Number of hand symptoms with at least moderate impact				0.007
1	55 (17%)	12 (13%)	43 (19%)	
2	44 (14%)	9 (10%)	35 (15%)	
3	53 (17%)	12 (13%)	41 (18%)	
4	80 (25%)	24 (27%)	56 (25%)	
5	85 (27%)	33 (37%)	52 (23%)	

*Numbers do not add to 258 because patients were able to choose more than one race/ ethnicity option. **Aboriginal=10, Asian=15, Arab=3, Black=2, Latin American=2, other racial/ethnic background= 13.

Table II. Factors Associated with PT/OT Referral

Variable	Unadjusted Odds Ratio (95% CI)	*p*	Adjusted Odds Ratio (95% CI)	*p*
Hand Severity***	1.26 (1.06-1.51)	0.011	1.24 (1.02-1.51)	0.031
Male	0.64 (0.28-1.46)	0.288	0.55 (0.23-1.36)	0.197
Age	0.97 (0.95-0.99)	0.004	0.96 (0.94-0.99)	0.004
Education > High School	1.00 (0.60-1.64)	0.984	0.92 (0.52-1.62)	0.766
Disease Duration	0.99 (0.96-1.02)	0.411	0.99 (0.96-1.02)	0.519
Working full or part-time	0.68 (0.39-1.12)	0.191	0.50 (0.26-0.97)	0.041
Treating Physician				
Rheumatologist	Reference		Reference	
Other Physician	0.79 (0.45-1.39)	0.408	0.95 (0.51-1.77)	0.871
No Treatment	0.13 (0.02-0.99)	0.048	0.27 (0.03-2.15)	0.214

***Hand severity was defined as the number of hand symptoms (1-5) with moderate or greater impairment.