





**BRIEF REPORT**

# Physical Therapy in Systemic Sclerosis: The Patient Perspective

Sophie I. E. Liem,<sup>1</sup>  Nina M. van Leeuwen,<sup>1</sup>  Thea P. M. Vliet Vlieland,<sup>1</sup>  Gerrie M. W. Boerrigter,<sup>1</sup> Cornelia H. M. van den Ende,<sup>2</sup> Lian A. J. de Pundert,<sup>3</sup> Marisca R. Schriemer,<sup>4</sup> Julia Spierings,<sup>5</sup>  Madelon C. Vonk,<sup>6</sup> and Jeska K. de Vries-Bouwstra<sup>1</sup>

**Objective.** To assess the use, satisfaction, needs, and preferences regarding physical therapy (PT) in patients with systemic sclerosis (SSc).

**Methods.** A total of 405 SSc patients, treated in the Leiden University Medical Center multidisciplinary care program and fulfilling American College of Rheumatology (ACR)/European Alliance of Associations for Rheumatology (EULAR) 2013 SSc criteria, received a questionnaire containing 37 questions on use and satisfaction regarding PT over a 2-year period, and their needs and preferences for future PT.

**Results.** A total of 204 SSc patients (median age 63 years, 81% female) completed the questionnaire. One hundred twenty-eight patients (63%) had used or were using PT in a primary care setting. For 39% of patients not using PT, lack of referral or lack of knowledge was the reason for not using it. The most frequently reported active treatments were muscle-strengthening ( $n = 92$  [72%]), range of motion ( $n = 77$  [60%]), and aerobic exercises ( $n = 72$  [56%]). Specific SSc hand- and mouth-opening exercises were reported by 20 (15%) and 7 (6%) patients, respectively. Manual treatment (massage or passive mobilization) was reported by 83 patients (65%). The mean  $\pm$  SD satisfaction score (range 0–10) was  $8.2 \pm 1.6$ . Regarding patients' needs, 96 patients (47%) of the total group wanted to receive more information concerning PT, and 128 (63%) wanted to continue, start, or restart PT in the near future, with 56 of the 128 patients (44%) favoring individual treatment on a continuous basis.

**Conclusion.** We observed a significant variation in the use and content of PT for SSc patients in a primary care setting. Our results suggest potential underuse of PT care, in particular for hand and oral dysfunction, and underpin the need for initiatives to improve the quality and accessibility of PT care for SSc patients.

## INTRODUCTION

Systemic sclerosis (SSc) is a rare autoimmune connective tissue disease affecting multiple organ systems (1). Patients report a wide range of symptoms, such as joint pain, skin thickening, gastrointestinal complaints, respiratory problems, fatigue, and depressive symptoms (2). All of these disease manifestations may lead to limitations in daily functioning (3,4). Consequentially, due to the clinically heterogenous character of this disease,

optimal care requires a multidisciplinary approach, with nonpharmacologic care as adjunct to pharmacologic treatment. Previously, it has been established that there are unmet health care needs regarding the delivery of nonpharmacologic care among SSc patients, including physical therapy (PT) (5). Just like in other chronic inflammatory rheumatic diseases, PT is generally considered an integral part of the management of SSc.

However, improving PT care for SSc patients remains challenging due to a lack of insight into current PT use and a lack

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<sup>1</sup>Sophie I. E. Liem, MD, Nina M. van Leeuwen, MD, Thea P. M. Vliet Vlieland, MD, PhD, Gerrie M. W. Boerrigter, PT, MSc, Jeska K. de Vries-Bouwstra MD, PhD: Leiden University Medical Center, Leiden, The Netherlands; <sup>2</sup>Cornelia H. M. van den Ende, PhD: Sint Maartenskliniek, Nijmegen and Radboud University Medical Center, Nijmegen, The Netherlands; <sup>3</sup>Lian A. J. de Pundert, PT, MSc: HagaZiekenhuis, The Netherlands; <sup>4</sup>Marisca R. Schriemer, MSc: Radboud University Medical Center, Nijmegen, The Netherlands, and NVLE,

Dutch Patient Organization for Systemic Autoimmune Diseases, Utrecht, The Netherlands; <sup>5</sup>Julia Spierings, MD, PhD: University Medical Center Utrecht, The Netherlands; <sup>6</sup>Madelon C. Vonk, MD, PhD: Radboud University Medical Center, Nijmegen, The Netherlands

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Address correspondence to Sophie I. E. Liem, MD, Department of Rheumatology, Leiden University Medical Center, 2333ZA Leiden, The Netherlands. Email: [s.i.e.liem@lumc.nl](mailto:s.i.e.liem@lumc.nl).

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### SIGNIFICANCE & INNOVATIONS

- This study provides data on real-world use of primary care physical therapy (PT) in patients with systemic sclerosis (SSc), suggesting that both the use and content vary significantly.
- Thirty-nine percent of SSc patients who did not use PT reported that they were either not aware or not being referred.
- The findings underpin the need for initiatives to enhance the accessibility and quality of primary care PT in SSc patients.

of studies on the effectiveness and safety of PT in SSc. The few studies to date that have assessed the frequency of PT use in SSc patients have reported percentages ranging from 37% at the end of a yearly follow-up to between 53% and 58% in the last year (6–8). Only 1 study evaluated the content of PT as reported by physicians. The most often used treatment modalities were lymphatic drainage, exercise therapy, and heat therapy (8). In situations where evidence is lacking, the occurrence of practice variation and suboptimal care is likely.

To optimize PT in SSc, an evaluation of the actual content of provided PT and the identification of perceived gaps and preferences for future delivery is mandatory to formulate areas for future research. Therefore, this study aimed to assess the use and content of PT among SSc patients, including a comparison of the characteristics of PT users and nonusers. Additionally, patients' perceived benefits and satisfaction, as well as future needs and preferences, were investigated.

## PATIENTS AND METHODS

**Study design.** A cross-sectional survey study was performed among SSc patients participating in the Combined Care In Systemic Sclerosis (CCISS) (9) at the Leiden University Medical Center (LUMC) in July 2019. This study is part of a larger project evaluating PT in SSc in both patients and physical therapists. The questionnaire for physical therapists was completed anonymously (linkage to patients' questionnaires was therefore impossible) and analyzed independently from the current questionnaire for patients. The current report focuses solely on the questionnaire for SSc patients.

For the CCISS cohort, patients gave written informed consent for the use of their clinical data and annual collection of questionnaires. As the current study only involved a 1-time questionnaire, the provided informed consent was sufficient for study participation according to the Dutch law for medical research (Medical Research Involving Human Subjects Act). Therefore, an exemption for additional medical ethical review was provided by the Medical Research Ethics Committee of the LUMC (N19.054).

**Participants.** Inclusion criteria for this study were: 1) participation in the CCISS cohort at the LUMC; 2) fulfillment of the American College of Rheumatology (ACR)/European League Against Rheumatism (EULAR) 2013 criteria for SSc (10); and 3) being 18 years or older. Exclusion criteria for this study were insufficient Dutch language skills, as evaluated by the treating physician, or living abroad.

All patients in the CCISS cohort undergo an annual extensive screening for organ involvement during a care program of 1 to 2 days duration. This program includes a visit to the physical therapist, where patients perform the 6-minute walk test (9). Moreover, if patients have a problem that could potentially benefit from PT, advice is provided, and the patients are referred to a physical therapist in the primary care setting (9).

**Questionnaire on physical therapy.** The questionnaire was self-developed by the main authors (SIEL, NMM, TPMV, and JKdV-B). Draft versions of the questionnaire were critically revised by the SSc working group of the Arthritis Research and Collaboration Hub foundation, a nationwide effort to improve the management of systemic autoimmune disease (5). The questionnaire addressed 5 themes in PT, including use, content, perceived benefits, satisfaction, and needs and preferences. A detailed description of the questionnaire, including the complete questionnaire, is shown in Supplementary Table 1, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.24741>.

**Other assessments.** Sociodemographic data, disease characteristics, and measurements of daily functioning (6-minute walk test and Health Assessment Questionnaire [HAQ]) were obtained from the database of the CCISS cohort. For the current study, data gathered during the care program visit closest to the date of completing the questionnaire were used. A complete overview of the collected data and definitions is provided (see Supplementary Table 2, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.24741>).

**Statistical analysis.** Descriptive statistics were used to summarize patient's characteristics, the use, content, perceived benefits of PT, satisfaction of PT, and needs and preferences regarding PT. According to their distribution, continuous variables were either presented as mean  $\pm$  SD or medians with interquartile range (IQR [first–third quartiles]). Categorical variables were presented as frequencies with percentages.

All patients who completed the questionnaire were included (responders). Patients who did not complete the questionnaire are referred to as nonresponders. Based on the use of PT according to the questionnaire, patients were categorized into 2 groups: PT-group (patients who did receive PT in the past

2 years) and no PT group (patients who did not receive PT in the past 2 years). To compare the characteristics of the responders with nonresponders and the PT group with no PT group, independent *t*-tests, Mann-Whitney U tests, or chi-square tests were used, where appropriate. The following characteristics were included: age, sex, smoking habits, body mass index, duration since non-Raynaud's phenomenon, SSc subset, modified Rodnan Skin Score, presence of antitopoisomerase or centromere antibodies, forced vital capacity and diffusing capacity for carbon monoxide in percentage of predicted, interstitial lung disease, pulmonary arterial hypertension, 6-minute walk test distance, decreased ejection fraction, gastrointestinal symptoms, renal crisis, musculoskeletal involvement, current use of immunosuppression, and the HAQ.

All analyses were conducted using SPSS 25.0 software. *P* values less than 0.05 were considered statistically significant.

## RESULTS

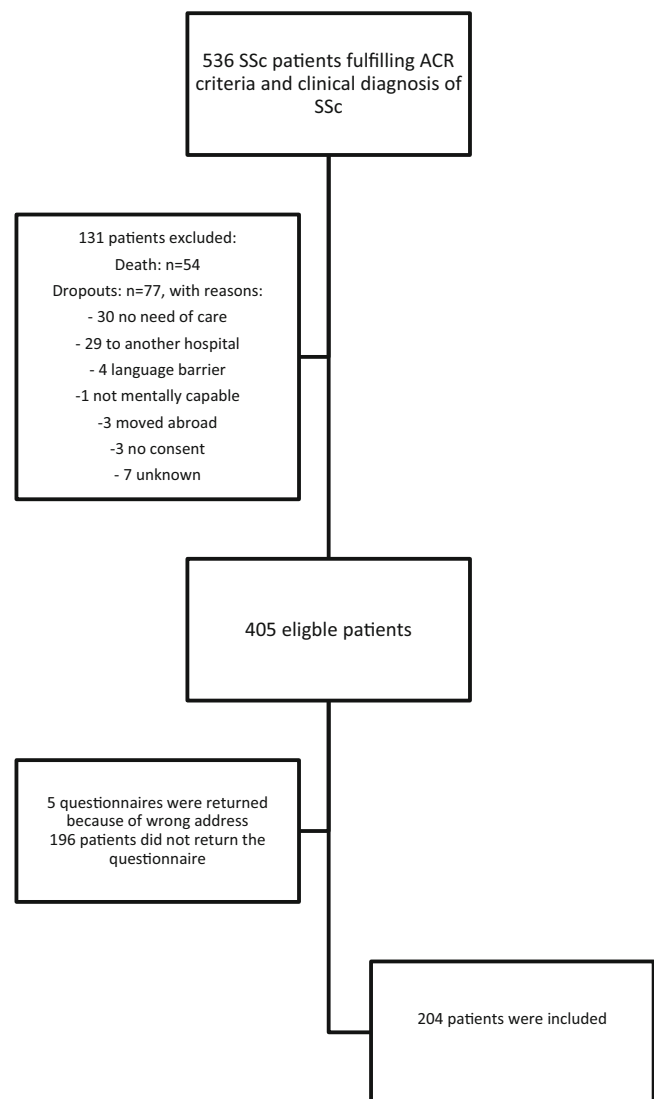
### Questionnaire response and patients' characteristics.

In total, 204 SSc patients (50%) completed the questionnaire (Figure 1). Of the responders, 81% (*n* = 164) were female, the median age was 63 years (IQR 55–71 years), and 68% (*n* = 137) had limited cutaneous SSc (Table 1). The responders were significantly older than the nonresponders (63 versus 56 years of age; *P* < 0.001). All other clinical characteristics were comparable between these 2 groups (see Supplementary Table 2, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.24741>).

**Use of physical therapy.** Of the responders, 128 patients (63%) had used or were using PT (PT group) during the past 2 years, whereas 76 patients (37%) had not (no PT group). Patients in the PT group were older, were more often antcentromere-positive, and had more physical disabilities than patients in the no PT group (Table 1).

Of the 128 patients who used PT over the past 2 years, 79 patients (63%) were using it at the time of the questionnaire. The main reasons for not receiving PT (*n* = 77) were no need (42 of the 77 patients [55%]), no referral (16 of the 77 patients [21%]), or not aware of the possibility (13 of the 77 patients [17%]; multiple answers possible).

**Characteristics and content of physical therapy.** The majority of patients received PT for a period of >1 year (*n* = 74 [58%]); most frequently PT was less than once per week with a session duration maximum of 30 minutes (Table 2). One hundred twenty-three patients (96%) were referred to the physical therapist by a health care professional from the CCISS cohort (*n* = 78 [61%]), a rheumatologist from their peripheral hospital (*n* = 13 [10%]), or the general practitioner (*n* = 24 [18%]).



**Figure 1.** Flow diagram of the inclusion process.

A total of 108 of the 128 SSc patients (84%) receiving PT reported the use of  $\geq 1$  active treatment modalities, and in 73 of the 128 (57%) active treatment was combined with manual treatment. Ten SSc patients (8%) solely reported the use of manual treatment. The most frequently reported active treatment modalities were muscle-strengthening exercises (*n* = 92 [72%]), range-of-motion exercises (*n* = 77 [60%]), and aerobic exercises (*n* = 72 [56%]) (Table 2). Concerning manual treatment, 59 SSc patients (46%) received massage and 51 (40%) passive mobilization. Regarding SSc-specific active treatment, 20 patients (16%) performed hand exercises, and 7 (6%) mouth exercises.

**Satisfaction, perceived benefits, needs and preferences.** The care of the physical therapist was rated a mean  $\pm$  SD of  $8.20 \pm 1.6$  (of a possible score of 10) by patients receiving PT. Negative effects, such as fatigue, muscle soreness, or pain, during or after the PT were reported by 43 patients (34%).

**Table 1.** Characteristics of patients with systemic sclerosis (SSc) participating in a survey study on physical therapy (PT) (n = 204)\*

	Total (n = 204)	PT group (n = 128)	No PT group (n = 76)	P†
<b>Sociodemographic characteristics</b>				
Age, median (IQR) years	63 (55–71)	65 (57–71)	61 (52–70)	0.044
Female sex	164 (81)	107 (84)	57 (75)	NS
Current smoker	22 (11)	16 (13)	6 (8)	NS
Former smoker	84 (41)	57 (45)	27 (36)	NS
BMI kg/m <sup>2</sup> , mean ± SD	25 ± 5	25 ± 5	25 ± 4	NS
Time since non-Raynaud's phenomenon, median (IQR) years	9 (4–14)	9 (4–14)	9 (5–12)	NS
<b>Clinical characteristics</b>				
Type of SSc, limited	137 (68)	85 (67)	52 (69)	NS
Modified Rodnan skin thickness score, median (IQR)	3 (0–6)	2 (0–7)	3 (1–5)	NS
Antitopoisomerase antibodies	43 (21)	21 (17)	22 (29)	0.039
Anticentromere antibodies	95 (47)	67 (53)	28 (37)	0.028
FVC, mean ± SD	98 ± 17	98 ± 18	97 ± 17	NS
DLco, mean ± SD	67 ± 16	67 ± 17	66 ± 16	NS
Interstitial lung disease (HRCT and FVC < 80%)	21 (10)	14 (11)	7 (9)	NS
Pulmonary arterial hypertension	13 (6)	8 (6)	5 (7)	NS
6-minute walk test distance (meters), median (IQR)	518 (442–604)	502 (433–588)	568 (477–614)	0.012
Ejection fraction ≤ 54%	17 (9)	9 (8)	8 (11)	NS
Gastrointestinal symptoms‡	116 (57)	79 (62)	37 (49)	NS
Renal crisis	6 (3)	5 (4)	1 (1)	NS
Musculoskeletal involvement§	45 (22)	28 (22)	16 (21)	NS
Immunosuppression current	77 (38)	48 (38)	29 (38)	NS
HAQ DI, median (IQR)¶	0.64 (0.25–1.14)	0.88 (0.38–1.38)	0.58 (0.13–0.88)	0.001
Reason for not receiving PT	NA	NA		
No need	–	–	42 (55)	–
No referral	–	–	16 (21)	–
Not aware of the possibility	–	–	13 (17)	–

\* Values are the number (%) unless indicated otherwise. The PT group includes patients who had received PT in the past 2 years; the no PT group includes patients who had not received PT in the past 2 years. BMI = body mass index; DLco = diffusing capacity for carbon monoxide; FVC = forced vital capacity; HRCT = high-resolution computed tomography; IQR = interquartile range; NA = not applicable; NS = not significant.

† P values are between the PT and no PT groups.

‡ Gastrointestinal symptoms included reflux, bloating, distension, diarrhea, and fecal incontinence.

§ Musculoskeletal involvement was based on any of the following: myositis, synovitis, arthritis, proximal muscle weakness, friction rubs, or joint contractures.

¶ Health Assessment Questionnaire disability index (HAQ DI) score ranges between 0 (no difficulties/disabilities) to 3 (maximum disability).

For the needs and preferences, the findings refer to all responders regardless of PT use. One hundred sixty-one patients (85%) stated that specific knowledge on SSc and/or rheumatic diseases is necessary for physical therapists to treat SSc patients (Table 3). Moreover, 96 patients (47%) preferred to receive more information regarding PT, and 128 (63%) expressed the need to continue, start, or restart PT in the near future. Of these 128 patients, 56 (44%) preferred individual continuous therapy, and 73 of the 128 (57%) patients preferred a physical therapist close to home.

## DISCUSSION

In this cross-sectional study on the use, content, perceived benefits of PT, satisfaction of PT, and needs and preferences regarding PT from the perspective of patients with SSc, we found

a significant variation in the use and content of PT in a primary care setting during a period of 2 years. In addition, we showed a possible inadequacy of PT care for hand and oral dysfunction. Although patients who received PT care were overall satisfied, the majority of SSc patients, and also those who had not used it, expressed an unmet need for more information on PT and future PT treatment.

In our study, PT users were on average older and had more physical disability than patients not receiving PT. A higher level of physical disabilities in PT users is in line with an international study on the use of PT or occupational therapy (11). In 2 other studies, presence of musculoskeletal involvement was higher in SSc patients using PT (8,11), but we did not confirm this. However, clear comparisons are difficult to make, given the lack of a uniform and validated definition for musculoskeletal involvement in SSc.

**Table 2.** Use and content of physical therapy (PT) as reported by systemic sclerosis (SSc) patients receiving PT (n = 128)

Most frequently indicated reasons for PT referral	
Impaired joint mobility	92 (72)
Pain	86 (67)
Impaired muscle strength	80 (63)
Most occurring frequency and location of PT	
Total PT duration of >1 year	74 (58)
Frequency of less than once per week	64 (50)
Session duration of <30 minutes	118 (94)
PT at the practice of the physical therapist	119 (92)
Content of PT	
Exercises	
Aerobic	72 (56)
Muscle strengthening	92 (72)
Range of motion	77 (60)
Balance	55 (43)
Hand function	20 (16)
Mouth	7 (6)
Swallow	1 (1)
Relaxation techniques	10 (8)
Hydrotherapy	7 (6)
Manual treatment	
Massage	59 (46)
Passive mobilization	51 (40)
Physical modalities	
Thermotherapy	2 (2)
Cold therapy	1 (1)
Kinesiotaping	21 (16)
Electrotherapy	7 (6)
Dry needling	8 (6)
Counseling/education	
Exercises to perform at home	100 (78)
Physical activity promotion	40 (31)

\* Values are the number (%). Patients were asked whether they had performed the above-mentioned exercises (yes/no).

The definition of our study is most similar to the definition used by Belz et al (8) (with the exception of muscle atrophy, which we did not include), whereas the international study considered merely friction rubs and joint contractures (11). Although the present study revealed some differences between patients who did and did not use PT, the question whether current PT use is appropriate or not cannot be answered. For that purpose, studies on the effectiveness of PT in different subgroups of patients with SSc are needed.

Regarding the use of PT, the proportion of 63% over 2 years was somewhat higher than the percentages seen in previous studies, which reported proportions of SSc patients visiting PT during 1 year ranging from 37–58% (6–8). Firstly, our proportion covered 2 years, whereas for the previous studies (6–8) only 1 year was covered. Secondly, in our study the mean age was higher than in the previous studies (63 versus 55–58 years of age) (6–8). It could be that older SSc patients have more disabilities and, consequently, are referred more often. The study by Meijs et al (6) indeed showed higher health care use in older SSc patients. Additionally, the regulations regarding reimbursement of PT might interfere with referral. In the Netherlands, coverage of the first 20 sessions of PT depends on a patient’s additional

insurance status, but from 20 sessions onward PT is fully covered by the basic insurance for the diagnosis of SSc (not for all rheumatic diseases).

SSc-specific exercises, such as those aiming at improving hand mobility and mouth opening, were employed less frequently than aerobic or muscle-strengthening exercises. This corresponds with earlier Canadian research, which showed that a minority of SSc patients with hand problems is referred to a physical or occupational therapist (12). However, involvement of the mouth and hands is common in SSc, with 30–40% of SSc patients experiencing difficulties with mouth opening, and up to 80% of SSc patients reporting hand problems (2). We can only speculate why these exercises are not frequently addressed. Possibly, limited mouth and hand function and the effectiveness of exercises to improve hand function and mouth opening need more attention in the education of physical therapists and patients.

**Table 3.** Needs and preferences regarding physical therapy (PT) of patients with systemic sclerosis (SSc) who completed the questionnaire (n = 204)\*

Needs (n = 204)	
I think that specific knowledge on SSc and/or rheumatic diseases is necessary for physical therapists to treat SSc patients	161 (85)
I would like to receive more information on PT†	96 (47)
Preferred means of information provision	
Care Pathway Systemic Sclerosis, no.	77
Rheumatologist peripheral hospital, no.	26
General practitioner, no.	17
I would like to continue, start, or restart physical therapy in the near future	128 (67)
Preferences of PT in the future (n = 128)	
Maximum duration of 1 session PT	
Maximum of 30 minutes	42 (35)
30–60 minutes	50 (42)
>60 minutes	5 (4)
No preference	23 (19)
Maximum period of PT	
6 weeks	5 (4)
12 weeks	10 (8)
18 weeks	1 (1)
Unlimited	70 (57)
No preference	36 (30)
Preferred location of PT	
Close to home	73 (57)
Expertise center/hospital	13 (10)
Shared care	35 (27)
Preferred mode of PT	
Short instructions (1–3 sessions) followed by exercises at home	19 (15)
Individual sessions <12 weeks under supervision of a physical therapist	16 (13)
Individual sessions >12 weeks under supervision of a physical therapist	56 (44)
Group sessions >12 weeks under supervision of a physical therapists	19 (15)

\* Values are the number (%) unless indicated otherwise.

† Question with multiple answer options. If patients checked ≥1 of the options as yes, then the composite score of more information was yes.



The evidence for the effectiveness of exercises in patients with SSc is scanty, as concluded by multiple systematic literature reviews (13–15). Clinical trials on mouth exercises, hand exercises, aerobic and/or muscle strengthening exercises, and manual lymphatic drainage showed on average beneficial effects on daily functioning (13–15). However, the identified studies are limited by small study populations, methodologic shortcomings, and variations in the content and reporting of exercises. The scientific base for the effectiveness of PT in patients with SSc can only be strengthened by methodologically sound studies, including randomized controlled trials. To accomplish this, the availability of physical therapists with expertise on SSc in the primary care setting is required.

A considerable proportion of patients reported a lack of information and a need for future delivery of PT. Patients in this study indicated a preference for individual therapy provided by a physical therapist close to their home, preferably by a physical therapist familiar with SSc. In an ideal situation, probably all patients want their providers to be familiar with the patient's disorder. It is, therefore, important to know if treating health care professionals are sufficiently familiar with SSc. Our research group aims to solve the aforementioned problems related to quality and accessibility of PT services in primary care by conducting a project focusing on improvement of education of primary care physical therapists in SSc and development of guidelines for communication between physical therapists and the rheumatologists and non-physician health professionals in the hospital. This project has been awarded with a research grant (ZonMw: 10390092012220).

Limitations of our study are the cross-sectional research design, which implies possible recall bias of participants, and the fact that patients were recruited in a tertiary care setting. Secondly, although the response rate of 50% was relatively favorable, the results must be interpreted with care, as selection bias may have occurred. Indeed, although sex, disease duration, and subtype of SSc were similar, responders were significantly older than nonresponders. Moreover, within the group of responders, a number of differences between the characteristics of patients who did and who did not use PT were observed. However, as considerations for either or not referring patients to PT were not systematically recorded for every patient in routine care, it remains unclear to what extent these differences play a role in clinical decisions on PT referrals. Finally, our questionnaire was nonvalidated; however, it was designed and reviewed by stakeholders including patients, was detailed, and covered many domains.

To conclude, we confirm a large variability in use and practice of PT in patients with SSc. Patients who receive PT are rarely treated for hand and oral dysfunction. The majority of SSc patients expresses an unmet need regarding PT health care services. In order to optimize PT care in patients with SSc, studies to assess appropriateness of PT care, the effectiveness of specific exercises, and the perspectives of physical therapists

treating SSc patients are warranted. This study is a first step in understanding and optimizing PT use in patients with SSc.

## AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Liem had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study conception and design.** Liem, Boerrigter, van den Ende, de Pundert, Schriemer, Spierings, Vonk, de Vries-Bouwstra.

**Acquisition of data.** Liem, van Leeuwen.

**Analysis and interpretation of data.** Liem, van Leeuwen, Vliet Vlieland, de Vries-Bouwstra.

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