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Physical therapy in patients with systemic sclerosis: physical therapists' perspectives on current delivery and educational needs

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Objective: To assess the perspectives of physical therapists treating patients with systemic sclerosis (SSc) on their current practice and educational needs.
Method: In July 2019, 405 SSc patients attending a multidisciplinary SSc programme received a survey on physical therapy. Patients who indicated having received physical therapy in the past 2 years were asked to invite their treating physical therapist to complete a questionnaire including sociodemographic characteristics, referral process, content of treatment, perceived knowledge and skills, and educational needs (mostly yes/no answers).
Results: Forty-eight of 80 possibly eligible physical therapists treating SSc patients returned the questionnaire [median age 44 years (interquartile range 35–58); 52% female; median number of SSc patients currently treated: 1 (range 1–4)]. Eighty-one per cent (n = 39) of physical therapists had received a referral, with 69% (n = 27/39) judging its content as insufficient. The most often provided types of exercises were range of motion (96%), muscle-strengthening (85%), and aerobic (71%) exercises, followed by hand (42%) and mouth (10%) exercises. Concerning manual treatment, 65% performed either massage or passive mobilization. Regarding competences, 65% indicated feeling capable of treating SSc patients. Nevertheless, 85% expressed the need for an information website on physical therapy in SSc, and 77% for postgraduate education on SSc.
Conclusion: Primary care physical therapists treating patients with SSc used a wide range of treatment modalities. Although most stated that they treated very few patients, the majority felt capable of treating SSc patients. Nevertheless, the large majority expressed a need for additional information and educational activities concerning SSc.

Health professionals, such as physical therapists, play an important role in the management of people with rheumatic and musculoskeletal diseases (RMDs) (1–4). This is also the case for systemic sclerosis (SSc), a rare, chronic autoimmune disease with multiorgan involvement (5). Physical therapists are among the most frequently visited health professionals in SSc, with the proportion of SSc patients visiting a physical therapist during 1 year ranging between 37% and 58% (6–9). In the literature, SSc patients have expressed the need for improvement of non-pharmacological care, including physical therapy (10, 11). This may not be an easy task, not only because the evidence on physical therapy in SSc is scarce and treatment recommendations are lacking, but also because most patients are treated in primary care, where physical therapists have little experience with this rare disease. Thus, to develop adequate interventions, the perspective of the physical therapists concerning the delivery of care for patients with SSc must be taken into account.

In SSc, in contrast to other RMDs (12, 13), there are only a few studies assessing the perspective of health professionals on care, and none has specifically addressed physical therapists. In an international study, 56 health professionals (including 14 physical therapists) completed a questionnaire on the content of care and educational needs

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regarding SSc. This study showed that the content of non-pharmacological care in SSc varies greatly across Europe; 98% of the respondents reported SSc-related educational needs, with the topics management of stiffness, pain, and impaired hand function being most frequently mentioned (14). In addition, a Dutch study on the quality of care in SSc, using a survey (85 health professionals, 51 physical therapists) and a working conference (77 participants including six physical therapists) (10), concluded that better education of health professionals would increase the quality of care and that a network of physicians and health professionals with expertise regarding SSc is needed to share experience and knowledge (10).

Thus, to optimize the quality of physical therapy care in SSc, our first aim was to evaluate the actual provision of physical therapy in daily practice in terms of referral process, content, and perceived skills and knowledge, and our second aim was to assess physical therapists' educational needs and preferences.

Method

Study design

In this cross-sectional study, a questionnaire was used to gather information from physical therapists treating SSc patients. In July 2019, SSc patients, treated in the Combined Care In Systemic Sclerosis (CCISS) cohort (15) at the Leiden University Medical Center (LUMC) and fulfilling the American College of Rheumatology/European League Against Rheumatism (ACR/EULAR) 2013 criteria for SSc (16), received a questionnaire on physical therapy. Patients who were currently using or had used physical therapy in the past 2 years were asked to invite their treating physical therapist to complete a questionnaire, by handing over a separate envelope with the anonymous questionnaire to complete and a prestamped envelope for its return. As the survey was anonymous, we could not determine which patients had actually invited their physical therapist, or link the returned questionnaires to the patients who had invited the physical therapist. Thus, it was not known which invited physical therapists did or did not return the questionnaire.

Since the physical therapists were only asked to complete an anonymous questionnaire once, this study was judged to fall outside the remit of the law for Medical Research Involving Human Subjects Act [in Dutch: Wet Medisch wetenschappelijk Onderzoek met mensen]. An exemption for medical ethical review was therefore given by the Medical Research Ethics Committee of the LUMC (N19.054).

Setting

Patients in the CCISS cohort undergo annual, comprehensive assessment in the context of the multidisciplinary SSc care pathway at the LUMC (15). Here, patients are seen by a multidisciplinary team including a rheumatologist, a pulmonologist, a specialized rheumatology nurse, a physical therapist, and if needed, a dietician, an occupational therapist, a cardiologist, a gastroenterologist, or a dermatologist. During the assessment by the physical therapist, a Six-Minute Walk Test is performed. If patients have a problem that could potentially benefit from physical therapy, advice is given or, if needed, patients can be referred to a physical therapist in primary care. Apart from referrals by the physical therapist of the multidisciplinary SSc care pathway, patients can be referred by their treating rheumatologist, other physicians, or health professionals, or start treatment on their own initiative (direct access). For this study, we refer to non-physician health professionals with the term 'health professionals'. In The Netherlands, physical therapy is fully reimbursed by the basic insurance from the first 20 sessions onwards annually. Coverage of the first 20 sessions out of the additional insurance depends on the individual insurance policy of a patient.

Questionnaire

The survey was self-developed in Dutch by the main investigators: SIEL, NVL, TPM, and JKV. Draft versions of the questionnaire were sent to the SSc working group of the Arthritis Research and Collaboration Hub (ARCH) foundation, a platform of medical expertise on systemic autoimmune diseases, for critical revision. The working group consisted of three rheumatologists, a senior researcher, one physical therapist, and one SSc patient. The survey consisted of dichotomous or multiple-choice questions, multiple-answer options, and a free text field ('other' option). The physical therapists were asked to answer the case-related questions with the last SSc patient they had treated in mind. The survey consisted of the following four parts.

First, the following characteristics of the physical therapists were asked: age, gender, work setting (primary or secondary care), work experience in years, number of SSc patients treated currently and in the past 2 years, and participation in any postgraduate education regarding RMDs (yes/no); if so, they were asked whether SSc was addressed in that course (yes/no). In addition, they were asked whether they were a member of a professional organization or network for health professionals in rheumatology (Netherlands Health Professionals in Rheumatology, other national or local networks).

Secondly, the process and content of the physical therapy for SSc were assessed, including: (i) whether a referral was made and, if so, by whom (patient self-referral, SSc care pathway, rheumatologist peripheral hospital, general practitioner), was the reason for referral specified (yes/no), and was information on SSc in

general and patient's manifestations in the referral complete (yes/no); also, physical therapists were asked whether they knew about the LUMC SSc care pathway (yes/no); and (ii) physical therapists were asked whether they performed 18 different treatment modalities, categorized into four groups as described in the national physical therapists' professional profile developed by the Royal Dutch Society of Physical Therapy (17): (a) exercises (aerobic, muscle strengthening, hand function, mouth, swallowing, balance, relaxation, hydrotherapy); (b) manual treatment (massage, passive mobilization); (c) applying physical modalities (thermotherapy, kinesiotaping, electrotherapy, ultrasound, dry needling); and (d) patient education (education on home exercises, physical activity promotion). The delivery of information on the treatment to the patient was also queried (verbally, written, both).

The third part evaluated perceived skills and knowledge of the physical therapists: feeling capable of treating SSc patients and, if not, the reason why (lack of knowledge, too little practice experience). In addition, the knowledge of the physical therapists about the different organ involvements of SSc were enquired about (yes totally/yes a bit/none). Moreover, they were asked whether they used information sources on SSc in general (yes/no), and if so, which sources were used [Google, medical literature databases, information from Dutch Arthritis Association, Dutch Patient Organization for Systemic Autoimmune Diseases (NVLE), ARCH, contacting patient, physical therapist colleagues, treating physician; multiple answers possible]. Regarding information on the health status of the patients they were treating, they were asked whether they had tried to obtain more information on the patient (yes/no, and, if so, from whom: treating physician, general practitioner, or the multidisciplinary SSc care pathway).

Lastly, educational needs were assessed: the need for a website/database specifically designed for physical therapists with information on the treatment of SSc (yes/no), the need for the possibility to ask questions to a physical therapist with specific expertise on SSc (yes by telephone, yes by e-mail, no), and the need for additional postgraduate training on SSc (yes/no). If they answered 'yes', then they were asked about the preferred mode of delivery (online, face-to-face course), duration, number of accreditation points, and maximal costs.

Statistical analysis

All data obtained through the returned questionnaires were manually entered into Castor EDC (Ciwit and Castor Research, Amsterdam, The Netherlands) by the principal investigator (SIEL). Characteristics of the physical therapists, the content of physical therapy, and educational needs were evaluated descriptively. According to their distribution, continuous variables were presented as medians with interquartile range (25th–p75th percentile) or range (min–max) and categorical variables as frequencies with percentages. Analyses were conducted with SPSS version 25.0 (IBM Corp., Armonk, NY, USA).

Results

Characteristics of physical therapists

In total, 80 of the 128 SSc patients using physical therapy in the past 2 years reported that they intended to invite their physical therapist. These 80 patients were more often currently receiving physical therapy than the patients who did not intend to invite their physical therapist (86% vs 15%, $p < 0.001$) (supplementary Table S1). In total, 48 of the 80 possibly eligible physical therapists (60%) returned the questionnaire (supplementary Figure S1). The characteristics of the included physical therapists are shown in Table 1. The median age was 44 years (IQR 35–58) and 25 (52%) were female. Forty-six (96%) physical therapists

Table 1. Characteristics of 48 physical therapists treating patients with systemic sclerosis (SSc).

Sociodemographic characteristics	
Age (years), median (interquartile range)	44 (35–58)
Female	25 (52)
Work setting	
Primary care	46 (96)
Secondary care	2 (4)
Work experience	
0–10 years	14 (29)
11–20 years	10 (21)
> 20 years	24 (50)
Attended postgraduate education on RMDs*	23 (48)
Dutch Institute of Allied Health Care†	15
National congress of health professionals in rheumatology or local/regional physical therapy network	9
European League Against Rheumatism HPR online course	3
Other	5
Member of a professional organization for healthcare professionals in rheumatology*	15 (31)
Netherlands Health Professionals in Rheumatology (NPHR)	5
National network of physical therapists in rheumatology	10
Local/regional network of physical therapists in rheumatology	7
Caseload	
Total number of patients treated, median (range)	
SSc patients, currently (n = 60)	1 (1–4)
SSc patients, in past 2 years (n = 28)	1 (1–3)
Other rheumatic diseases, currently (n = 212)	4 (1–30)

Data are shown as n (%) or n, unless otherwise indicated.
RMDs, rheumatic and musculoskeletal diseases; HPR, health professionals related.
*Multiple answers possible.
†In Dutch: Nederlands Paramedisch Instituut.

worked in a primary care setting and 23 (48%) had followed a postgraduate training course on RMDs, of whom five received information on SSc during this training. The median number of SSc patients that the physical therapists were currently treating was 1 (range 1–4).

Referral process and content of physical therapy

The referral process of SSc patients is shown in Table 2. Patients gained access to the physical therapist by means of self-referral [direct access; n = 8 (17%)] or referral by a physician or health professional [n = 39 (81%); missing n = 1 (2%)]. Of the 39 referrals, 22 were from the SSc care pathway. In 37 of the 39 referrals (90%), the reason for referral was provided. In 31% of referrals, the information on SSc and specific problems of the patient was judged to be complete by the physical therapists.

Table 3 shows the reported content of the provided physical therapy. All physical therapists reported the use of active treatment modalities and 65% the use of manual treatment. The most frequently performed exercises were range of motion, muscle strengthening, and aerobic exercises, whereas hand function and mouth exercises were provided less often. Concerning manual treatment, massage was reported by 50% of the physical therapists and passive mobilization by 73%. The use of physical modalities was reported by 23%, most frequently kinesiotaping. Ninety per cent of physical therapists offered SSc patients exercises to perform at home.

Table 2. Route of referral of patients with systemic sclerosis (SSc) to physical therapists (n = 48).

Referral*	
Patient self-referrals without involvement of a physician	8 (17)
Referral by physician	39 (81)
Referral by physicians, specified†	
SSc care pathway	22/39 (56)
Rheumatologist at peripheral hospital	7/39 (18)
General practitioner	8/39 (21)
Reason for referral was provided in the referral	37/39 (95)
Referral contained complete information on SSc and patient's manifestations	12/39 (31)
Being aware of SSc care pathway at Leiden University Medical Center	32 (67)

Data are shown as n (%).
*One physical therapist did not complete this question.
†Two physical therapists indicated that their patients had been transferred from other physical therapist colleagues.

Table 3. Contents of provided physical therapy, as reported by physical therapists (n = 48).

Exercises	
Aerobic exercises	34 (71)
Muscle-strengthening exercises	41 (85)
Range of motion exercises	46 (96)
Balance exercises	32 (67)
Hand function exercises	20 (42)
Mouth exercises	5 (10)
Swallowing exercises	2 (4)
Relaxation techniques	21 (44)
Hydrotherapy	3 (6)
Total: one or more types of exercise	48 (100)
Manual treatment	
Massage	24 (50)
Passive mobilization	35 (73)
Total: one or more types of manual treatment	31 (65)
Physical modalities	
Thermotherapy	2 (4)
Cold therapy	0
Kinesiotaping	8 (17)
Electrotherapy	3 (6)
Dry needling	0
Total: one or more types of physical modality	11 (23)
Patient education	
Exercises to perform at home	42 (88)
Physical activity promotion	25 (52)
Total: one or more types of patient education	43 (90)
Methods of information provision of the treatment to the patient	
Verbal information only	27 (56)
Verbal and written information	19 (40)
Written information only	2 (4)

Data are shown as n (%).
Physical therapists were asked whether they had performed or applied the above specified treatment modalities in the treatment of patients with systemic sclerosis.

Perceived skills and knowledge

Sixty-five per cent of the physical therapists stated that they felt capable of treating SSc patients (Table 4). Of the 31 physical therapists feeling capable, 20 had experienced a challenge in the treatment of SSc patients; this proportion is comparable to that among the physical therapists who did not feel capable (11/17).

Regarding the familiarity of physical therapists with possible symptoms of SSc, in particular, the distinction between different subsets of SSc and the possibility of the occurrence of a renal crisis appeared to be areas that relatively few physical therapists were acquainted with. Joint complaints, pulmonary involvement, skin involvement, and pain/fatigue were the domains most frequently reported as symptoms with which they were familiar (Table S2).

Ninety-eight per cent of physical therapists had tried to gather more information on SSc in general (Table 4). Services available on the internet (Google, PubMed) and asking the patient were the sources of information most frequently reported. Twenty-one per cent of physical therapists had tried to gather more information on the health status of their patient by contacting a physician or health professional treating the patient.

Table 4. Perceived skills, knowledge, and information sources of physical therapists treating patients with systemic sclerosis (SSc) (n = 48).

Feeling capable of treating patients with SSc	31 (65)
Experiencing a challenge in the treatment of a SSc patient*	31 (65)
Lack of knowledge	11
Finding the heterogeneous character of the disease difficult	10
Incomplete information	9
Other	5
Using sources of information on SSc in general*	47 (98)
Google	32
PubMed	19
Dutch Arthritis Association (ReumaNederland)	17
Dutch Patient Organization for Systemic Autoimmune Diseases (NVLE)	10
Arthritis Research and Collaboration Hub (ARCH)	0
Patient	25
Physical therapist colleagues	12
Treating physician	6
Other	7
Gathering more information on the health status of an individual patient	10 (21)
Contact with treating physician	4
Contact with general practitioner	5
Contact with SSc care pathway	2

Data are shown as n (%) or n.
*Multiple answers possible.
†One physical therapist contacted both the general practitioner and the hospital's physical therapist.

Educational needs and preferences

Table 5 shows the physical therapists' needs and preferences regarding information and postgraduate education. Forty-one physical therapists (85%) expressed a need for an interactive website with information on treatment of SSc patients specifically designed for physical therapists, whereas 32 (67%) desired to have access to an experienced physical therapist for advice. In addition, 37 physical therapists (77%) stated that they would like to receive additional postgraduate training on SSc, of whom 24 wanted this only if it were part of a course concerning other (systemic) rheumatic diseases as well. The physical therapists who stated no need for additional postgraduate training indicated the low number of SSc patients as the main reason.

The most frequently reported topics to address in postgraduate training on SSc included information on SSc in general, the medical treatment of SSc, and physical therapy for SSc. An online module was preferred to a face-to-face course.

Discussion

This study on the perspectives of primary care physical therapists treating SSc patients on the delivery of care, content of provided care, perceived skills and knowledge, and educational needs showed that the number of SSc patients treated by a single physical therapist is low. Most of them found the referral information incomplete. The majority used active treatment modalities and education, but overall there was considerable variation regarding the content of physical therapy. Although the majority of physical therapists felt sufficiently competent in the treatment of SSc, most of them also expressed a need for additional education on SSc. Access to expert physical therapists, online general information about SSc, and education on physical therapy for SSc with e-learning were highly desired.

With respect to the content of physical therapy, our finding that exercise therapy was one of the most frequently used treatment modalities is in line with one German study (8). Our study adds to these results with a more detailed description of the treatment modalities employed. Moreover, in our study, the physical therapists were the source of information, whereas the German study was based on physician reports. We found that half of the physical therapists performed massage, but we did not specify the type of massage. The study by Belz et al (8) only looked at one type of massage, manual lymphatic drainage, making it difficult to compare these proportions. Importantly, in our study, SSc-specific exercises, including hand and mouth exercises, were employed less frequently than aerobic or muscle strengthening exercises. The extent to which these exercises could

Table 5. Educational needs and preferences of physical therapists treating patients with systemic sclerosis (SSc) (n = 48)*.

Needs (n = 48)	
Interactive website with information on treatment of patients with SSc	41 (85)
Contacting a physical therapist with special expertise on SSc	32 (67)
By phone	11/32
By e-mail	21/32
Postgraduate training on SSc (n = 37)	
Yes	13/37
Yes, but only when it is part of a course about (systemic) rheumatic diseases	24/37
Reasons not to need an additional course (n = 11)	
No, too few patients with SSc	8/11
No, sufficient knowledge on SSc	3/11
Preferences for additional courses (n = 37)	
Mode	
Online module	17/37
Face-to-face course	9/37
Combination	11/37
Contents	
General information about SSc	25/37
Information about medical treatment of SSc	26/37
Information about physical therapy in SSc	26/37
Information about reasons for consultation with physician	24/37
Information from patients' perspective	20/37
Interactive working group with opportunity to practise	16/37
Possibility for consultation with experts after course	19/37
Possibility for consultation with fellow course member after course	12/37
Preferences for online module (n = 28)	
Mode	
Interactive e-learning	18/28
Prerecorded lecture	10/28
Duration	
Maximum 30 min	5/28
Maximum 1 h	9/28
No preference	14/28
Accreditation points, median (range)	2 (0–5)
Preferences for face-to-face course (n = 20)	
Duration	
Maximum 1 half-day	2/20
Maximum 1 working day	11/20
Maximum 2 working days	3/20
No preference	4/20

Data are shown as n (%) or n/n, unless indicated otherwise.
*For each item, the number of available answers is shown.

have been included in the home exercises given to the SSc patients remains to be explored. Yet, the current provision of hand and mouth exercises seems relatively low as, in general, approximately one-third of SSc patients experience difficulties with mouth opening, and at least half of the patients have limited hand function (18, 19). This difference could probably be explained by a combination of a lack of information in the referral, a lack of patients', physicians', and physical therapists' awareness of the possibility, and/or a lack of knowledge.

For aerobic, muscle strengthening, hand and mouth exercises, and manual treatment, clinical trials show beneficial effects on daily functioning (20–22). Regarding the effectiveness of massage, this has been evaluated as part of a larger (rehabilitation) programme for hand and/or facial involvement (23–26). These multimodal programmes show favourable results regarding hand function and facial involvement, but it is difficult to determine the magnitude of the effect of massage alone (23–26).

Sixty-nine per cent of physical therapists indicated that the referrals to them were incomplete, and lacking information on SSc in general and on patients' manifestations. Creating a standardized letter with information on SSc for the physical therapists which could be sent along with the referral could improve this issue. Furthermore, from the rheumatologists' point of view, it is important to create more awareness of the possibilities and efficacy of physical therapy. A qualitative study on daily routines and factors influencing 13 Dutch rheumatologists' decisions found that in the referral of SSc patients to health professionals, in the absence of scientific evidence, rheumatologists predominantly make use of their personal experience and beliefs, and local policy (27). A common perception among the rheumatologists was a lack of confidence in the clinical reasoning competence of health professionals and their insufficient knowledge about options for non-pharmacological treatment (27).

Although the included physical therapists were invited by SSc patients who are annually seen at the LUMC, one-third of the physical therapists indicated that they were not aware of its existence. Moreover, the number of physical therapists who asked for additional information on the patient was low. By increasing awareness of this care pathway, we could facilitate better cooperation between the physical therapists and the LUMC centre of expertise, particularly since two-thirds of the physical therapists indicated that they would prefer access to an expert on physical therapy for SSc to enable them to ask questions.

Concerning the self-reported skills, one-third of the physical therapists reported not feeling capable in treating SSc patients. This can be explained by the low prevalence of SSc and, in line with this, little attention being given to this rare disease in educational programmes for physical therapists. Providing adequate information on general manifestations of SSc, perhaps in the form of a standardized referral letter, could lead to an improvement in the quality of care.

Regarding the educational needs of the included physical therapists, our results are generally in line with previous research among health professionals

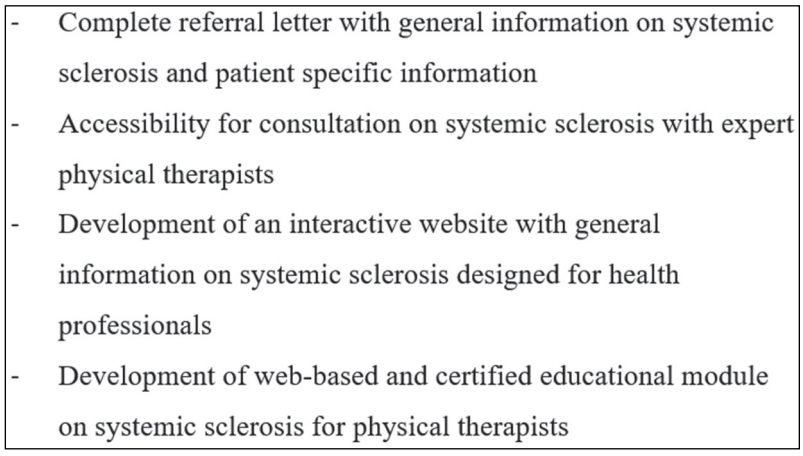

Figure 1. Box of applications in clinical practice.

in a broader context (10, 28). Similarities include the need for improvements in the referral process and the creation of a national web-based information hub and postgraduate training on SSc (Figure 1). Probably because of the rarity of the disease, the majority of the physical therapists expressed that they would like this postgraduate training on SSc to be part of more extensive training on rheumatic diseases. An online format was preferred, as this would save substantial time and costs. EULAR offers an online course for rheumatic health professionals, which has been endorsed by the Royal Dutch Society for Physical Therapy (29), and SSc has been a part of this since 2020. Moreover, in The Netherlands, Stichting ReumaNet.NL was founded in 2019 to register individual physical therapists with specific expertise on rheumatic disorders and networks in this area, to improve the quality and accessibility of their knowledge and skills (30, 31).

Our study is not without limitations. First, the data were gathered using a self-reported, non-validated questionnaire. Secondly, the regional setting in which our study was conducted could have led to selection bias, as the standardized assessment by physical therapists in the CCISS cohort could have led to more referrals or with different indications than in other settings. It should be noted that most physical therapists, including those with specific expertise regarding RMDs, will probably never see a patient with SSc. However, including this group enabled us to ask more detailed questions and thus to gather more in-depth data.

Conclusion

Our study provides new insights into the current content of physical therapy for SSc patients from the physical therapists' perspective. Our study indicates that specifically, in a rare and complex disease such as SSc, referral letters to physical therapists should contain sufficient medical and patient-related information. In addition, accessibility to expert physical therapists for consultation, and the development of an interactive website with general information on SSc and physical therapy, and a web-based and certified educational module, could contribute towards improved quality of multidisciplinary care in SSc.

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Disclosure statement

No potential conflict of interest was reported by the authors.

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Supplementary material

Supplemental data for this article can be accessed here.