Content of non-pharmacological care for systemic sclerosis and educational needs of European health professionals: a EUSHNet survey

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ABSTRACT

Objective. *To describe the non-pharmacological care in systemic sclerosis (SSc) provided by European health professionals (HPs) including referrals, treatment targets, interventions, and educational needs.*

Methods. *In this observational study, European HPs working in SSc care were invited to complete an online survey through announcements by EUSTAR (European League Against Rheumatism (EULAR) Scleroderma Trials and Research) and FESCA (Federation of European Scleroderma Associations), the EULAR HPs' newsletter, websites of national patient and HP associations, and by personal invitation.*

Results. *In total, 56 HPs, from 14 different European countries and 7 different disciplines, responded to the survey. A total of 133 specific indications for referral were reported, 72% of which could be linked to the International Classification of Functioning, Disability and Health domain "body functions and structures". Of the 681 reported treatment targets 45% was related to "body functions and structures". In total, 105 different interventions were reported as being used to address these treatment targets. Almost all (98%) respondents reported having educational needs, with the topics of management of stiffness (67%), pain (60%), and impaired hand function (56%) being mentioned most frequently.*

Conclusion. *Non-pharmacological care in SSc varies in Europe with respect to the content of interventions, reasons for referral, and treatment targets. Reasons for referral to HPs are not well-aligned to HPs subsequent treatment targets in SSc care suggesting suboptimal communication between physicians and HPs. The wide variations reported indicate a need to consolidate geographically disparate expertise within countries and to develop and improve standards of non-pharmacological care in SSc.*

Introduction

Systemic sclerosis (SSc, scleroderma) is a relatively uncommon and complex autoimmune connective tissue disease of unknown origin with clinically heterogeneous manifestations (1). The disease is characterised by thickening and fibrosis of the skin and internal organs (2). Currently, there is no cure available for SSc, and medical treatment focuses primarily on minimising internal organ involvement and symptom reduction for related organ, skin, and musculoskeletal manifestations. Despite optimal pharmacological management and as a consequence of the complexity of the disease, the majority of patients with SSc experience a broad range of symptoms (3, 4) including impairments in both physical and mental health-related quality of life (HRQL) (5). Non-pharmacological treatment is often needed therefore as an adjunct to pharmacological treatment.

Research so far has shown that multiple non-physician health professionals, such as nurses, occupational therapists, physical therapists, psychologists, social workers, and dieticians can be involved in the care for patients with SSc (6-9). Two Dutch studies showed that the physiotherapist is the most frequently contacted non-physician health professional with the proportions of patients that have contact with a physiotherapist being 53 and 58%, respectively (8, 9). The variety of health professionals who can be involved in the care for patients with SSc reflects the

broad range of symptoms that the majority of patients with SSc experience (3, 4) and that can be targeted in interventions by health professionals. However, little is known about the variation in type of interventions that are actually provided by non-physician health professionals in clinical practice.

A recent systematic review (10) showed that there is a wide variety in studied non-pharmacological interventions targeting SSc and their outcomes. This might suggest that variation exists in the types of interventions patients with SSc receive and which targets are set for treatment. The EULAR Scleroderma Health Professionals Network (EUSHNet) was established in 2011 with the goal of improving the quality of non-pharmacological care in SSc by developing standards of care, reducing the variations in expertise, accessibility, and dissemination of knowledge within and among professions in Europe (11). Before standards of care can be developed, we need to know how the non-pharmacological care in SSc is regulated in clinical practice. The aim of the current study was therefore to provide an initial description of the non-pharmacological care provided by European health professionals who treat patients with SSc in terms of the content of referrals, targets of treatment, interventions, and educational needs of the health professionals.

Materials and methods

Participants and procedure

Participants were European health professionals, such as dieticians, nurses, occupational therapists, physiotherapists, podiatrists, psychologists, and social workers who are involved in the non-pharmacological care of people with SSc, and with sufficient knowledge of the English language. Health professionals working directly in clinical patient care or rehabilitation in the last five years and treating at least three patients with SSc in the last year were included in this study.

European health professionals were invited in several ways to complete an online survey in English. First, an announcement of the survey including a hyperlink was placed in the European League Against Rheumatism (EULAR) health professionals' newsletter. Second, EUSTAR (EULAR Scleroderma Trials and Research) members were emailed about the survey including a request to forward the email to health professionals working with patients with SSc. Third, announcements were placed on a range of relevant rheumatology websites, including the Federation of European Scleroderma Associations (FESCA) website, websites of 18 national patient associations, and websites of national health professionals associations. Fourth, a systematic literature search was conducted (10) and was used to identify from authorship listings, health professionals who had published research in fields related to the effectiveness of non-pharmacological care in SSc. The corresponding author received a personal invitation by email. The snowball propagation method was also used and participants were asked to send the email about the survey to health professional colleagues. The online survey was active between June 2012 and June 2013.

Survey

The electronic survey was conducted through the NetQuestionnaires website and developed by consensus between the members of the EUSHNet Steering Group (n=9) and gathered information about: (1) participant characteristics; (2) the clinical setting, source of referral and reasons for referral to health professionals; (3) the targets of treatment; (4) interventions; and (5) educational needs. This was not an anonymous survey, since respondents could provide their name and e-mail details in case they wanted to be informed about the results. Importantly, we used a secured website and the data was only accessible with a password.

Participant characteristics assessed were: gender, country, highest academic qualification (certificate/diploma, bachelor's degree, master's degree, postgraduate research, professor), year of graduation, and type of health professional.

Questions about clinical setting and referrals consisted mainly of closed-ended items asking health professionals about their work setting (hospital, ambulatory/outpatient clinic, primary care, nursing home, home care, school/university, public health), the category of work (clinical patient care/rehabilitation, research, education, management), clinical experience (years), working in clinical practice in last five years (yes/no), and, if applicable, number of treated patients with SSc in the last year, the frequency of referrals from eight different sources, and an estimation regarding the three most common reasons for referral (open-ended question).

Targets of treatment in SSc care were assessed by providing participants with a list of 30 items of potential targets based on the concepts that were identified by Stamm *et al*. (12) and linked to the domains of the International Classification of Functioning, Disability and Health (ICF), including body functions and structures, activities and participation, and environmental and personal factors. Participants were required to tick the box(es) for those targets of treatment they felt were applicable to their own practice and they were also able to add up to two additional items per domain.

To identify types of treatment interventions that were used, a list of 69 non-pharmacological interventions was created from a literature search of reported non-pharmacological treatment modalities employed by health professionals (10, 13-19). For each intervention on the list, participants were asked how frequently they used it (never, in some patients, in most/all patients) and they had the opportunity to add additional treatment interventions to the existing list. For brevity, only interventions provided by >50% of health professionals in a profession and used in most/all patients are reported here.

Educational characteristics and needs were assessed by the following questions: post-graduate specialised training or education (yes/no), health professionals' confidence about their knowledge of current research in SSc (1 = not at all confident to 4 = very confident), usefulness of further education (1 = not at all useful to 4 = very useful), preferred mode of deliverance of education (internet/e-learning, face-to-face sessions during conferences, written ma-

terial), and a list of 22 potential topics based on the ICF for additional education (including three options to add other topics). Participants had to tick the box(es) only when they were interested in additional education on the topic.
The survey was pilot-tested by the members of the EUSHNet Steering Group, and was revised based on their feedback. A copy of the survey can be obtained from the first author.

Data analysis
Two researchers (LMW, NC) independently linked the most common reasons for referral to the ICF domains using established ICF linking rules (20). If an item could not be mapped to the ICF classification, this item was assigned as "not covered". Disagreements between the two researchers were discussed until consensus was achieved. Data were then analysed descriptively, and are presented as percentages for categorical variables. Analyses were conducted using Stata/IC 10.1 software (StataCorp LP, College Station, TX).

Results

Sample characteristics
A total of 206 people viewed the survey on the website, of whom 102 completed at least part of the survey. Duplicate response sets were identified and excluded from the analysis (n=5). Of the 97 unique response sets, 41 were excluded from the current analysis for not meeting the inclusion criteria: two (5%) did not work in Europe; 19 (46%) were not active in clinical patient care or rehabilitation in the last five years; two (5%) were medical doctors; 16 (39%) treated less than three patients with SSc in the last year; and two (5%) completed only the demographic and work setting characteristics. As a result, a total of 56 respondents were included in the analysis.
The demographic characteristics of the 56 respondents are presented in Table I. The majority of the responding health professionals were women (n=49; 88%). Occupational therapists (n=16; 29%), nurses (n=15; 27%) and physiotherapists (n=14; 25%) were the three most common professional groups represented. The majority worked in a hospital setting (n=52; 93%) and had worked more than ten years as a health professional (n=40; 71%). Three quarters of respondents reported treating more than seven patients with SSc in the past year.

Table I. Sample characteristics of 56 European health professionals working with patients with systemic sclerosis (SSc).

Characteristics	n (%)
Female	49 (87.5)
Country	
Netherlands	11 (19.6)
United Kingdom	11 (19.6)
Belgium	5 (8.9)
Sweden	5 (8.9)
Switzerland	5 (8.9)
Austria	4 (7.1)
Italy	4 (7.1)
Denmark	2 (3.6)
Germany	2 (3.6)
Norway	2 (3.6)
Spain	2 (3.6)
Croatia	1 (1.8)
Hungary	1 (1.8)
Portugal	1 (1.8)
Profession	
Occupational therapist	16 (28.6)
Nurse	15 (26.8)
Physiotherapist	14 (25.0)
Podiatrist	7 (12.5)
Psychologist	2 (3.6)
Dietician	1 (1.8)
Social worker	1 (1.8)
Highest academic qualification*	
Diploma	16 (29.6)
Bachelor degree	18 (33.3)
Master degree	17 (31.5)
Postgraduate research (PhD)	1 (1.9)
Professor	2 (3.7)
Practice setting†	
Hospital	52 (92.9)
Ambulatory/ outpatient clinic	21 (37.5)
School/ university	7 (12.5)
Public health	3 (5.4)
Primary care	3 (5.4)
Home care	1 (1.8)
Category of work in last 5 years†	
Clinical patient care/ rehabilitation	56 (100)
Research	21 (37.5)
Education	19 (33.9)
Management	7 (12.5)
Other	1 (1.8)
Years worked in clinical practice as a health professional	
Less than 2 years	1 (1.8)
2-10 years	15 (26.8)
More than 10 years	40 (71.4)
Number of patients with SSc worked with in last year, more than 7 patients	43 (76.8)

*2 missings; †multiple answers possible.

Referrals
Referrals to health professionals were most frequently made by a rheumatologist (see Table II). Table III presents the reasons for referral linked to ICF codes. There were 164 reasons for referral identified and subsequently linked to 133 ICF-codes, comprising 41 unique ICF categories. Eight reasons for referral were linked to two ICF-codes and 39 reasons for referral, such as "therapy" or "advice", could not be classified and were assigned to the category "not covered". Of the 133 ICF-codes, the majority were related to "body functions and body structures"(n = 96; 72%) with "protective functions of the skin" (b810) and "functions of the joints and bones, other specified and unspecified" (b729) arising as the most frequent ICF-codes. "Carrying out daily routine"(d230) was reported by 13 health professionals and was therefore the most frequent ICF-code describing referral within the domain of "activities and participation".

Targets for treatment
Table IV shows targets on which health professionals focus during treatment in the majority of their patients with SSc. In total, health professionals reported an average of thirteen treatment targets in the care for people with SSc. The majority of the reported 681 targets of treatment were linked to the ICF domains "body functions and body structures" (n=303; 45%) with pain and stiffness mentioned by more than three quarters of the health professionals. One-third of the treatment targets are related to the ICF domain "environmental and personal factors", and a quarter to "activities and participation".

Interventions
Interventions frequently utilised in the treatment of people with SSc are detailed in Table V. In total, health professionals mentioned 36 interventions in addition to the 69 predefined interventions, resulting in a total of 105 interventions. Of these 34, were provided by >50% of health professionals in a profession and used in most/all people with SSc, including nine interventions that were provided by at least two pro-

Table II. Frequency of referrals from different sources (n=56).

	n (%)		
	Never/not applicable	Some of the patients	Most/all of the patients
General practitioners	41 (73.2)	13 (23.2)	2 (3.6)
Rheumatologists	4 (7.1)	4 (7.1)	48 (85.7)
Dermatologists	38 (67.9)	14 (25.0)	4 (7.1)
Other physician specialists	41 (73.2)	15 (26.8)	0 (0)
Non-physician health professionals	40 (71.4)	13 (23.2)	3 (5.4)
Self-referral	42 (75.0)	11 (19.6)	3 (5.4)
Other	54 (96.4)	1 (1.8)	1 (1.8)

fessional groups. The intervention "self-management" was reported by four professional groups, including occupational therapists, psychologists, one dietician, and one social worker. The 71 interventions that were not listed in Table V and used less commonly were, amongst others, enteral/parenteral tube feeding, relaxation, referrals to other health professionals, training the foot, behaviour experiments, wound care, and vocational rehabilitation (Supplementary Table I).

Educational needs among health professionals

Approximately one-third of the health professionals (n=20; 39%) had participated in post-graduate specialised training, education or a course specifically about SSc. Although the majority of health professionals were either moderately confident or very confident that their knowledge of current research evidence about health professional practice in SSc care was up to date (n=44; 85%), further training would be moderately or very useful according to most participants (n=47; 90%). Specific educational needs were reported by 51 (98%) of the responding health professionals. A median of seven (interquartile range=4-9) educational needs were reported, with further education about helping patients to manage stiffness, pain, and hand function cited most frequently as priority areas (Table VI). The preferred mode of education delivery reported was a combination of internet/e-learning (n = 38; 73%), face-to-face sessions during conferences (n=33; 64%), and written material (n=31; 60%).

Table III. Reasons for referral expressed as ICF codes (n=133) mentioned by 56 health professionals.

Reasons for referral	n (%)
Body functions and structures	96 (72.2)
Mental functions	5
Sensory functions and pain	11
Functions of the cardiovascular, haematological, immunological, and respiratory systems	22
Functions of the digestive, metabolic and endocrine systems	5
Neuromusculoskeletal and movement-related functions	26
Functions of the skin and related structures	21
Other	2
Structures related to movement	4
Activities and participation	27 (20.3)
General tasks and demands	14
Mobility	5
Self-care	5
Major life areas	3
Environmental factors	10 (7.5)
Products and technology	5
Services, systems and policies	2
Other	3

Table IV. Health professionals' targets of treatment in the care for patients with systemic sclerosis (n=681) mentioned by 53 health professionals.

Targets of treatment	n (%)
Body functions and structures	303 (44.5)
Pain	47
Stiffness, cramps, calcification	41
Fatigue	35
Blood vessels functions, Raynaud's phenomenon	34
Emotional issues	32
Body image and appearance, including weight maintenance/loss	22
Skin	20
Lung function, bronchiae	19
Sleeping	19
Dry mucous membranes, dry mouth, eyes, nose	18
Ingestion functions	14
Other	2
Activities and participation	161 (23.6)
Household activities	39
Impaired hand function	37
Paid work and productive activities	36
Eating and drinking	26
Impaired foot function	17
Other	6
Environmental and personal factors	217 (31.9)
Coldness	39
Coping with the disease	37
Support from others	33
Non-pharmacological treatment	30
Experiences with healthcare institutions	23
Counselling	21
Footwear	20
Drugs and side effects	13
Other	1

Discussion

This was the first study to investigate the current non-pharmacological care in clinical practice provided by European health professionals who treat people with SSc. This study shows that non-pharmacological care in SSc is variable in Europe with respect to reasons for referral, targets of treatment, and the content of interventions. Most referrals concerned body functions and structures. There is an apparent discrepancy between the reasons for referral given by physicians and the subsequent targets of treatment set by health professionals, and it seems therefore, that expectations for non-pharmacological care are not well aligned between physicians and non-physician health professionals caring for people with SSc. We acknowledge the relatively small proportion of the total population of European health professionals completing the survey, which might reflect the fragmented expertise about non-pharmacological care for people with SSc.

Of note, there was a marked discrepancy between the reasons for referral to health professionals and the health professionals' own targets for treatment as reported in our study. Reasons for referral primarily focused on body functions and structures in referring people with SSc to health professionals, while targets of treatment were more often reported in the domain of environmental and personal factors. The finding that physicians in making referral decisions mainly focus on functions and structures might indicate a lack of knowledge regarding the range of available treatment options that health professionals can deliver for people with SSc.

Table V. Interventions used in the treatment of most/all patients with SSc by >50% of health professionals (n=53).

	PT n=14	Nurse n=14	OT n=14	Podiatrist n=7	PSY n=2	Dietician n=1	SW n=1
Assessment of body functions/ structures/activities	X		X	X			
Physical activity promotion	X						
Posture training	X						
Manual therapy	X						
Training of upper extremity	X		X				
Training of the hand	X		X				
Training of the trunk	X						
Skin elasticity mouth	X						
Skin elasticity hand	X		X				
Training of household activities			X				
Training of personal care activities			X				
Training of eating activities			X				
Training of leisure activities			X				
Training of work-related activities			X				
Thermotherapy			X				
Advice lifestyle	X	X					
Advice illness and treatment	X	X					
Advice physical activity	X	X		X			
Advice medication adherence		X					
Advice nutritional						X	
Advice energy conservation			X				
Advice joint protection	X		X				
Advice splints				X			
Advice foot-care				X			
Advice footwear				X			
Advice assistive devices			X				
Advice environment modifications				X			
Self-management			X		X	X	X
Cognitive restructuring					X		
Motivational Interviewing					X		
Support patient/family							X
Supplement fluid						X	
Monitor nutritional status						X	
Health promotion	X	X		X			

PT: physiotherapist; OT: occupational therapist; PSY: psychologist; SW: social worker.

Table VI. Educational needs of 52 European health professionals (HPs) working in systemic sclerosis care (n=52).

Areas of educational need	n (%) of HPs	Areas of educational need	n (%) of HPs
Understanding stiffness	35 (67.3)	Respiratory function	19 (36.5)
Pain	31 (59.6)	Digestive functions	16 (30.8)
Hand function	29 (55.8)	Physical modalities	15 (28.9)
Fatigue	24 (46.2)	Sexual function	15 (28.9)
Circulatory problems	24 (46.2)	Functions and structures of cardiovascular system	14 (26.9)
Foot problems	24 (46.2)	Dry mucous membranes	14 (26.9)
Face problems	23 (44.2)	Ingestion functions	13 (25.0)
Emotional functions	23 (44.2)	Nutrition intervention	11 (21.2)
Psychosocial functions	22 (42.3)	Sleep	11 (21.2)
Physical functions	21 (40.4)	Other	6 (11.5)

This is likely to be due to suboptimal communication between physicians and health professionals. A tool that screens limitations in activities, participation problems, and the patient-need for advice or therapy that can be addressed by a health professional, can help guide and optimise referrals for patients, such as the Perceived Limitations in Activities and Needs Questionnaire (21). Referrals can also be optimised by allowing health professionals to refer the patients to each other or making health professionals aware that referring patients is a possibility. This will make non-pharmacological interventions in SSc more accessible but also less transparent. A case manager, such as a medical specialist or a nurse, could be a solution to increase transparency of the provided care.

In our study we found that health professionals use a wide variety of non-pharmacological interventions in treating people with SSc. In addition, we found some overlap in the interventions provided across the different professions. It is not uncommon that roles of health professionals partly overlap (22) and this can lead to both synergy and complimentary input for patients as well as to contradictory advice and conflicting treatment plans (23). Considering the diversity in interventions, the number of disciplines potentially involved, and the limited evidence for the effectiveness of many non-pharmacological interventions in SSc (10), practice-based recommendations based on a broad consensus are highly warranted to improve the accessibility and inequity of care for people with SSc and to ensure consistency in approach between different professions. International consensus on a limited number of treatment targets and the content of a limited number of non-pharmacological interventions could provide a focus for both clinical practice and research. Agreement on core elements of non-pharmacological care could increase transparency and enhance communication among different professional groups. Furthermore, a clear focus could facilitate international collaborative efforts to initiate randomised controlled trials with sufficient power to contribute meaningfully to the body of knowledge. These are important steps in establishing standards of non-pharmacological care for SSc.

Nearly all health professionals reported educational needs, although one-third of the health professionals in our study participated in post-graduate specialised training or education specifically about SSc and the majority of the health professionals were confident that their knowledge about current research in SSc was up to date. These educational needs were broadly in line with the

Supplementary Table I. List of 71 interventions not presented in Table V named by at least one health professional (n=53).

Interventions	Health professional(s) involved
Acceptance therapy	PT
Activity-based counselling to prevent Raynaud's phenomenon	OT
Advice warming equipment	Nurse
Advice calcinosis	Podo
Advice hand warmers	OT
Advice statutory services	PT, Nurse, Podo, PSY, SW, OT
Aerobic capacity training	PT, Nurse, OT
Balance/ coordination training	PT, Nurse, Podo, OT
Behaviour experiments	PT, Nurse, PSY, SW, OT
Care of mucosa	Nurse
Client centred interventions	PSY
Communication skills	Dietician, PT, Nurse, PSY, SW, OT
Connective tissue massage	PT, Nurse, Podo, OT
Cycling training	PT
Dental care	Nurse
Design/adapt orthotic devices	PT, Nurse, Podo, OT
Drug monitoring	Nurse, Podo
Electrotherapy	PT, Nurse
Enteral tube feeding	Dietician, Nurse
Eye care	Nurse
Fascia stretch training	PT
Group education	Nurse
Hand assessment	Nurse
Hydrotherapy/ spa therapy	PT, Nurse
Insole therapy	Podo
Laser therapy	PT, Nurse
Massage	PT, OT
Mindfulness	PT, Nurse, Podo, PSY, OT
Moistening measures	Nurse
Myofascial release technique	PT
Nail care	Podo
Nutrition assessment	Nurse
Osteopathy	PT
Padding	PT, Nurse, Podo
Paraffin/wax treatment	PT, Nurse, OT
Parenteral tube feeding	Dietician, Nurse
Podiatric surgery	PT, Nurse, Podo
Prescribe medication	Nurse, Podo
Problem-solving training	Dietician, PT, Nurse, PSY, SW, OT
Professional foot care	Nurse
Referrals	PT, Nurse, Podo, PSY, OT
Relapse prevention	PT, Nurse, PSY, OT
Relaxation	PT, Nurse, PSY, OT
Removal of callosities	Podo
Scalpel debridement of corns	Podo
Sicca screening	Nurse
Skin care	Nurse, OT
Splinting	OT
Stimulation therapy	PT
Strapping	PT, Nurse, Podo
Stress management	OT
Stretching diaphragm and oesophagus	PT
Stretching ears	Nurse
Stretching legs	PT
Stretching shoulders	PT
Stretching trunk	PT
Supplement pill	PT, Nurse
Supplement powder	Dietician, PT, Nurse
Supply medication	Nurse, Podo
TENS	PT, Nurse
Therapy regarding appearance related changes	Nurse
Therapy with vibration	OT
Training foot	PT, Nurse, Podo, OT
Training lower extremity	PT, Nurse, Podo, OT
Training of dexterity	PT, Nurse, OT
Training of walking	PT, Nurse, Podo, OT
Training temporomandibular joint	PT, Nurse, OT
Ulcer management	Podo
Ultrasound therapy	PT, Nurse
Vocational rehabilitation	PT, Nurse, PSY, SW, OT
Wound care	PT, Nurse, Podo, OT

PT: Physiotherapist; Podo: podiatrist; PSY: psychologist; SW: social worker; OT: occupational therapist.

most common symptoms experienced by patients with SSc (3, 4), *i.e.* education in helping patients to manage stiffness, pain, and impaired hand function. This survey represents the first step in understanding variation in practice and in patient-need across Europe to enable prioritisation of the most important research questions. Using this knowledge, the European network of health professionals working in SSc care, EUSHNet, will also be able to take a lead in combining the existing expertise among health professionals, provide a platform to exchange knowledge, and develop educational courses and education material. For this purpose the Framework for Action on Interprofessional Education and Collaborative Practice could be used to generate ideas on how to implement interprofessional education and collaborative practice (24).

Our study has limitations that must be acknowledged. We noted previously that the sample reflects only a small proportion of the health professionals in the EULAR countries, especially in Eastern European countries. Furthermore, only half the health professionals that viewed the survey and read the explanatory notes on the website went on to complete the survey. This suggests that the health professionals who did not start filling in the survey may not have been confident about their expertise regarding the care for people with SSc. Alternatively, the relatively low number of respondents might also be explained by a lack of interest or the difficulty in responding using English language.

In conclusion, the complexity of SSc is reflected in the wide variety of targets for treatment and the breadth of interventions that health professionals use in the treatment of SSc. The reasons for referral by medical colleagues and subsequent treatment targets are not well aligned in SSc care, suggesting suboptimal communication between physicians and health professionals. Educational needs were identified in nearly every health professional responding. The self-reported expertise among health professionals in the non-pharmacological care of SSc appears varied and a first step towards develop-

ing and improving standards of care in SSc may be to provide guidance and a framework for standardisation in education and practice through EULAR or similar organisations.

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