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RESEARCH ARTICLE

Consensus-based recommendations on communication and education regarding primary care physical therapy for patients with systemic sclerosis

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Abstract

Objective: This study aimed to develop recommendations for communication and postgraduate education regarding primary care physical therapy for systemic sclerosis (SSc) patients.

Methods: A virtual Nominal Group Technique was used with tasks forces for communication (n = 18) and education (n = 21). Both included rheumatologists, physical therapists (PTs) in primary, secondary or tertiary care, rheumatology nurses, advanced nurse practictioners and patient representatives. Three online meetings were organised for each task force to discuss (1) current bottlenecks; (2) potential solutions; and (3) the resulting draft recommendations. After the final adjustments, participants rated their level of agreement with each recommendation on a scale from 0 (not at all agree) to 100 (totally agree), using an online questionnaire.

Results: 19 and 34 recommendations were formulated for communication and education, respectively. For communication the main recommendations concerned the provision of an overview of primary care physical therapists with expertise in rheumatic and musculoskeletal diseases to patients and rheumatologists, the inclusion of the indication by the rheumatologist in the referral to the physical therapist and low-threshold communication with the rheumatologist in case of questions or concerns of the physical therapist. For postgraduate education three types of "on demand" educational offerings were recommended with varying levels of content and duration, to match the competencies and preferences of individual primary care physical therapists.

Conclusion: Using a systematic qualitative approach, two multi-stakeholder task forces developed practical recommendations for primary care physical therapists' communication with hospital-based care providers and postgraduate education regarding the treatment of SSc patients.

KEYWORDS
multidisciplinary care, physical therapy, primary care, professional education, systemic sclerosis

1 | INTRODUCTION

Systemic sclerosis (SSc) is a severe and rare rheumatic disease with a high clinical burden (Elhai et al., 2012). Because of the complexity and multi-organ involvement of SSc, screening and treatment of SSc often takes place in tertiary care in the Netherlands. Non-pharmacological care might contribute to preventing or decreasing the usually progressive functional disability (Liem et al., 2021a). Physical therapy (PT) is an important element of non-pharmacological care, and is used consistently by the majority of SSc patients (Belz et al., 2019; Liem et al., 2021a; Meijs et al., 2014; Stöcker et al., 2020; Willems et al., 2013). PT is generally delivered in primary rather than tertiary care (Liem et al., 2021a).

Despite the wide usage of PT in SSc, a need for improvement of its quality has been expressed by both patients and physical therapists (Liem et al., 2021a, 2021b). Apart from enhancing the current relatively weak scientific base of PT in SSc (de Oliveira et al., 2017; Liem et al., 2019; Pettersson et al., 2021), collaboration and communication between primary care physical therapists and rheumatologists and other health care professionals in the hospital setting as well as with patients is needed (Stöcker et al., 2018, 2020; Willems et al., 2013, 2015). For PT in SSc in particularly, it was found that patients expressed a need for more information on its delivery (Liem et al., 2021a). For non-pharmacological care in general, including PT, major barriers for SSc patients include accessibility of SSc-specific care and finding healthcare professionals qualified to support them (Kocher et al., 2019). In one Dutch study, about half of primary care physical therapists treating SSc patients followed postgraduate training on rheumatic and musculoskeletal diseases (RMDs), of whom 20% had received information on SSc (Liem et al., 2021b). An international study, that included 56 health professionals treating SSc patients in 17 countries, of whom 14 were physical therapists and 3 worked in primary care, showed that 39% of all participants had completed postgraduate training on SSc (Willems et al., 2015). Additionally, in both studies the majority of health professionals were confident in their capabilities in treating SSc patients (Liem et al., 2021b; Willems et al., 2015). Nonetheless, most of them expressed a need for more information and education, preferably to be provided online (Liem et al., 2021b; Willems et al., 2015). A tailored approach to organise education for physical therapists treating SSc patients is required, as only a minority of physical therapists will encounter this population.

To address these needs, improvement of communication between SSc health care professionals in SSc expert centres and primary care physical therapists and targeted postgraduate education is needed. Therefore, the current study aimed to (1) develop recommendations for communication related to PT in SSc among relevant health care providers; and (2) formulate requirements for postgraduate education on SSc for physical therapists in the primary care setting.

2 | METHODS

2.1 | Study design

This qualitative study, aiming to develop recommendations, used a consensual approach, based on the Nominal Group Technique (NGT) (McMillan et al., 2016). NGT is a common consensus method for a topic with stakeholders. It encourages idea generation and problem solving in a structured and balanced group process through face-to-face discussions in small groups (McMillan et al., 2016). Advantages of the NGT are time efficiency, cost effectiveness, and adaptability. NGT considers the views of participants equally and thus avoiding one individual dominating the group (Rankin et al., 2016). Due to restrictions to organising physical meetings during the COVID-19 pandemic, all group meetings were organised in an online format.

This study was funded by ZonMw (Project number: 10390092012220) and the patient organisation NVLE (Nationale Vereniging voor mensen met Lupus, APS, Sclerodermie en MCTD; the Dutch society for people with lupus, antiphospolidid syndrome, SSc and mixed connective tissue disease). Reporting of this study was done according to the Consolidated Criteria for REporting Qualitative Research (COREQ) (Tong et al., 2007). Ethical approval and consent to participate in this study was not required based on the Dutch Medical Research Involving Human Subjects Act (WMO). Participants gave oral consent for the recording of the online meetings and their acknowledgement in the end-reports as well as the current manuscript.

2.2 | Task forces

The study was led by a steering group of 3 members, a rheumatologist (JVB), a health professional (TVV) and an MD/PhD student (SL). Three members (CHE, LBV, WFP) were observers during the meetings. Two tasks forces, one focussing on communication and one on education, were installed. The aim of the communication task force was "to formulate recommendations on the communication between primary care physical therapists and hospital based care providers", and for the education task force "to formulate recommendations on postgraduate education on SSc for primary care physical therapists".

Both task forces consisted of rheumatologists, physical therapists working in primary, secondary and tertiary care, specialised

rheumatology nurses, advanced nurse practictioners and patient representatives. Rheumatologists, specialised rheumatology nurses, advanced nurse practictioners and physical therapists from secondary and tertiary care with known interest in SSc were invited from different hospitals in The Netherlands. Primary care physical therapists were recruited from a group participating in previous research concerning PT in SSc from a physical therapists' perspective (Liem et al., 2021b) and a professional network of physical therapists with specific expertise on RMDs (ReumaNetNL) (ReumanetNL, 2019). Patient representatives were recruited through the patient organisation NVLE and from the Patient Advisory Board of the department of Rheumatology of Leiden University Medical Center.

2.3 | Nominal group technique procedures

The original NGT consists of four steps, namely (1) silent generation of ideas in writing; (2) round-robin feedback from group members to record each idea; (3) discussion of each recorded idea for clarification and evaluation; (4) individual voting on priority ideas. As mentioned previously, face-to-face meetings were replaced by online meetings using Zoom® with password protection.

There were three online meetings for each task force between March 2021 and July 2021, led by the three steering group members. The meetings each lasted one and a half hours, were recorded and subsequently transcribed. In the transcriptions names and contact details were deleted. The recording was deleted after completing the transcriptions.

2.3.1 | First meeting: Overview of current situation and potential solutions

In accordance with the first step of NGT, participants received an explanation of the project aims and methods and a short online preparatory questionnaire (see Supplementary File) before the first meeting. These preparations aimed to facilitate their thinking about the topics to be discussed. Moreover, as part of the online questionnaire, participants were asked to think about and write down their thoughts on the aims of this project (step 1: silent generation of ideas in writing). Participants were asked to complete the online questionnaire in the week before the meeting, so that the steering group could summarise their answers.

The first meeting started with an introduction of the attendees and a brief presentation on the aims and working methods. Thereafter, the ideas submitted in the preparatory questionnaire were discussed, leading to a discussion on the bottlenecks in the current situation and an overview of potential solutions. Due to the online nature of the sessions, participants spoke in turns so that everybody made a contribution, following the second step of NGT (step 2: Round-robin feedback).

2.3.2 | Second meeting: Prioritising and amending potential solutions

Based on the collected statements and suggestions from the first meeting, the potential solutions were summarised by the steering group. The list of potential solutions was then sent to the participants as preparation for the second meeting. At the second meeting, these potential solutions were discussed, amended and prioritised in smaller breakout groups (3 breakout groups led by a steering group member; duration 30 min), following the third step of NGT (step 3: discussion of each recorded idea for clarification and evaluation). Afterwards, the summary of the discussion of the smaller break out groups was discussed in the whole group.

2.3.3 | Third meeting: Discussing draft recommendations

After the second meeting, draft recommendations were developed by the steering group and sent to the participants as preparation. In the third meeting, these draft recommendations were discussed and amended (step 3: discussion of each recorded idea for clarification and evaluation).

2.3.4 | Final consensus: Determining the level of agreement regarding definitive recommendations

After the final adjustments of the recommendations, each participant was asked independently to rate their level of agreement regarding each recommendation, using an pseudonymous voting procedure (step 4 of the NGT: individual voting on priority ideas). A continuous scale from 0 (total disagreement) to 100 (total agreement) was used. The mean, standard deviation (SD), median, and range of the level of agreement for each recommendation was calculated. A recommendation was approved using an arbitrary cut off of >70% of the expert group yielding a score of 70 or higher on the numeric rating scale.

3 | RESULTS

3.1 | Participants

Twenty-nine people participated in the two task forces (10 of them participated in both task forces): 3 patient representatives, 7 primary care and 5 hospital-based physical therapists, 5 specialised rheumatology nurses, 2 advanced nurse practictioners and 7 rheumatologists. Their mean age was 45 years (SD: 10), 21 (72%) were female. The mean years of (working) experience in the field of rheumatology was 15 (SD: 11) (Table 1).

3.2 | Communication

3.2.1 | Current situation and potential solutions

The issues on the process of communication were, to facilitate the discussion, categorised in three parts before the first meeting: (1) referral from hospital to primary care physical therapist: route and contents; (2) communication during the PT treatment in primary care; and (3) final report of the primary care physical therapists to the hospital.

The participants reached general consensus concerning a list of bottlenecks and facilitators regarding communication in the current situation (Table 2). In short, hospital-based care providers were found to be struggling with referring patients to specific

TABLE 1 Characteristics of participants in the task forces ($n = 29$)

	Total ($n = 29$)	Task force communication ($n = 18$)	Task force education ($n = 21$)
Age, mean (SD)	45 (10)	47 (12)	46 (11)
Female, *n* (%)	21 (72%)	12 (67%)	15 (71%)
Profession, *n* (%):			
• Patient representative	3 (10%)	2 (11%)	3 (14%)
• Physical therapist primary care	7 (14%)	4 (23%)	5 (24%)
• Physical therapists secondary/tertiary care	5 (17%)	4 (23%)	4 (16%)
• Specialised rheumatology nurses	5 (17%)	2 (11%)	4 (19%)
• Advanced nurse practictioners in rheumatology	2 (7%)	2 (11%)	2 (10%)
• Rheumatologist	7 (21%)	4 (22%)	3 (14%)
(Working) experience in rheumatology, years, mean (SD)	15 (11)	15 (10)	15 (12)

Note: Ten people participated in both task forces.
Abbreviations: *N*, number; SD, standard deviation.

TABLE 2 Bottlenecks and potential solutions in the current communication between primary care physical therapists treating patients with systemic sclerosis and hospital-based care providers

Bottlenecks	Facilitators	Possible solutions
Referral from hospital to primary care physical therapist		
• Difficulties finding primary care physical therapists with expertise on RMDs/SSc	Existence of a national network of primary care physical therapists with expertise in RMDs	Creating more awareness of a national network of primary care physical therapists with expertise in RMDs through informing rheumatologists and patient organisations
• Suboptimal contents of referral	Referral letters	Definition of the optimal contents of the referral to primary care physical therapist
• Unclear who needs to refer to primary care	Contents of referral more important than process	Definition of the optimal route of the referral to primary care physical therapists
Communication during the physical therapy treatment in primary care		
• Suboptimal communication between health care providers		Definition of the optimal timing for primary care PT to contact the referrer/rheumatologist
		Contact details of the referrer on the referral
Final report of the primary care physical therapist to the hospital		
• Lack of a final report evaluating the treatment of the primary care physical therapist to the hospital	For physical therapists, there is a standard format for a final report at the end of the treatment, issued by their professional organization	
• Language use		Fostering awareness of physical therapy specific tests/language
• Rheumatologists do not have much time	Rheumatologists think that the feedback of primary care physical therapists could be helpful and interesting	Concise reporting with emphasis on the functioning of patients

primary care physical therapists with expertise on RMDs/SSc, similarly patients reported difficulties finding such physical therapists as well. Moreover, it was perceived by both primary care physical therapists and patients that the contents of referrals is often suboptimal. Regarding the communication between the primary care physical therapist and health care providers in the hospital during the PT treatment, it was found that health care providers in hospitals were generally hard to reach. Furthermore, it was expressed that the reporting of the physical therapist at the end of the treatment was not always comprehensible and relevant for the health care providers in the hospital. A number of facilitators to improve the referral process and communication were mentioned, including the availability of a national network uniting primary care physical therapists with expertise on RMDs, and the willingness of all stakeholders to improve the current situation (Table 2).

3.2.2 | Recommendations

In total, 19 recommendations on communication were formulated, categorised in the three abovementioned parts: (1) referral from hospital to primary care physical therapist: route ($n = 4$) and contents ($n = 8$); (2) communication during the PT treatment in primary care ($n = 3$); and (3) final report of the primary care physical therapists to the hospital ($n = 4$) (Table 3). Regarding the rating of the level of

TABLE 3 Recommendations concerning communication between hospital-based health care SSc providers and primary care physical therapists ($n = 17$)

	Level of agreement (0–100), mean (SD)	Level of agreement (0–100), median (range)	Level of agreement >70, *n* (%)
Referral from hospital to primary care physical therapist: Route			
Referral to a primary care physical therapist is preferably done by a rheumatologist or in collaboration with the rheumatologist (in case of referral by another health care professional or self-referral), in order to directly transfer relevant medical information.	78 (19)	77 (69)	14 (82%)
The referral is written, and accompanied by a copy of the latest medical letter.	75 (30)	80 (95)	13 (77%)
Referral information is sent using privacy secured channels or via the patient.	94 (9)	100 (28)	17 (100%)
In all cases medical information is only exchanged when the patient has provided consent.	95 (8)	100 (25)	17 (100%)
Referral from hospital to primary care physical therapist: Contents			
The referral preferably comprises:			
• For the patient: Practical information on/contact details of primary care physical therapists with specific expertise regarding RMDs/SSc	95 (10)	100 (32)	16 (94%)
• For the physical therapist: links to easily accessible training courses on SSc	90 (11)	93 (30)	17 (100%)
The reason for referral must be clearly stated in the referral, along with the relevant medical information.	95 (9)	100 (31)	16 (94%)
The contact details of the referrer must be given clearly in the referral.	99 (2)	100 (9)	17 (100%)
For the medical part of the referral, a copy of the most recent medical letter of the treating physician (assistant) is sufficient in the majority of the cases	89 (20)	100 (81)	15 (88%)
The most recent medical letter or similar medical information must contain the following aspects: Subset of SSc, organ involvement, co-morbidity, disease course, medication, current situation, resilience of the patient and possible contra-indications for physical therapy	90 (14)	100 (50)	16 (94%)
Physician (assistants) must realise that primary care physical therapists are not familiar with certain medical terms to interpret the physical limitations of patients	91 (13)	97 (40)	15 (88%)
If the SSc patients is seen by a physical therapist in the hospital, his/her assessment could be added, depending on the reason of the referral	87 (27)	100 (100)	15 (88%)
Communication from primary care physical therapist to referrer/rheumatologist			
• The primary care physical therapist contacts the rheumatologist in case of any medical questions and/or red flags emerging from the initial assessment or during the treatment.	90 (14)	96 (50)	16 (94%)

(Continues)

TABLE 3 (Continued)

	Level of agreement (0–100), mean (SD)	Level of agreement (0–100), median (range)	Level of agreement >70, *n* (%)
• In case of worsening of a patient's health status or lack of progression during the treatment, the primary care physical therapist contacts rheumatologist and or other health care provider in the hospital, where appropriate.	93 (11)	100 (39)	16 (94%)
• Communication is preferably done through secured e-mail, or in emergencies by telephone. Local/national privacy regulations are taken into account.	91 (14)	100 (50)	15 (88%)
Final report of the primary care physical therapists to the hospital			
• As a minimum, the final report includes the results of the initial assessment, ensuing treatment goals and the evaluation at the end of the treatment.	86 (22)	100 (79)	15 (88%)
• The final report is written and is sent using privacy secured channels or via the patient.	85 (23)	100 (55)	12 (71%)
• The reporting of the primary care physical therapist is done according to the guidelines of the professional societies of physical therapists	93 (15)	100 (50)	15 (88%)
• The final report uses terminology that is comprehensible to the patient and referrer.	85 (22)	92 (71)	14 (82%)
Recommendations not reaching the final level of agreement			
The rheumatologist or physician assistant provides the patient, along with the referral, a copy of the most recent medical letter or sends these forms. In case of referral by a hospital-based physical therapist, the physical therapist will ask the rheumatologist to provide the medical information	74 (30)	80 (94)	11 (65%)
The rheumatologist or other health care provider in the hospital refers patients to the national network ReumanetNL.nl to facilitate the identification of a primary care physical therapist with specific expertise on RMDs	76 (26)	80 (82)	11 (65%)

Note: One participant did not complete the questionnaire and is therefore missing.
Abbreviations: *n*, number; RMDs, rheumatic and musculoskeletal diseases; SSc, systemic sclerosis.

agreement with the final set of recommendations, all but one participant completed the online rating. The median score with range of the recommendations are presented in Table 3. For two recommendations less than 70% of the participants provided a median score >70 and were thus removed from the final recommendations (Table 3).

3.3 | Postgraduate education on SSc for physical therapists in the primary care setting

3.3.1 | Current situation and potential solutions

It was found that currently, the available postgraduate education on RMDs that is available to Dutch physical therapists mainly focuses on the basic knowledge of common RMDs, whereas SSc is not, or only briefly, addressed. Moreover, the absence of postgraduate education specifically focussing on non-pharmacological interventions for SSc for any health professional in primary care was mentioned. Facilitators for improvement of the situation that were mentioned included the need for and interest in extra postgraduate education on SSc among primary care physical therapists treating patients with SSc, accreditation by the professional organisation, the provision of an incentive for taking part in postgraduate education on SSc and the availability of multiple online resources to provide education (Table 4).

SSc is a rare disease and only few physical therapists treat SSc patients, often not more than once during their career. Therefore, it was suggested that the training should not be too long and/or extensive to not deter physical therapists from investing time in receiving education. Therefore, three types of education to be provided "on demand" were recommended: a concise paper, an e-learning with basic knowledge, and an e-learning with in-depth scientific background and clinical cases to foster clinical reasoning (Table 4). Moreover, the preferred language of the education was Dutch.

3.4 | Recommendations

The 34 recommendations for postgraduate education on SSc were categorised in a general section, and subsequently worked out in more detail per education type (compact article, e-learning with basic knowledge, e-learning with in-depth knowledge), as shown in Table 5. Per education type, the recommendations specified the target group, duration, contents, format and accreditation points. For all recommendations, the final level of agreement in the questionnaire was above 80 (Table 5).

TABLE 4 Bottlenecks and potential solutions for postgraduate education on SSc for primary care physical therapists

Bottlenecks	Facilitators	Possible solutions
No specific postgraduate education on SSc for physical therapists in primary care exists	A need for extra postgraduate education on SSc has been expressed by patients and health professionals	Developing a postgraduate training on SSc, focussed on primary care physical therapy
Language	Courses in Dutch	Dutch courses
Professional organization does not cover the entire country		Developing a postgraduate training on SSc, focussed on primary care physical therapy
SSc is a rare disease	Substantial motivation from primary care physical therapists to follow postgraduate education on SSc	Postgraduate education should be provided "on demand" meaning that when a primary care physical therapist treats a SSc patients he/she can follow the education.
	Duration	Education must not be too long or extensive
	Reward after postgraduate education	Accreditation points for following postgraduate training
	Type of education	Online formats
Different levels in knowledge		Three types of education on SSc so primary care physical therapists can choose: a Concise paper, an e-learning with basic knowledge, and an e-learning with in-depth scientific background
Difficulty in finding the postgraduate education	Willingness of physical therapists to follow a postgraduate education on SSc	Using national network uniting primary care physical therapists with expertise on RMDs and patient organisations to create awareness of the postgraduate education
	Role of patients to motivate physical therapists	More awareness among patients about education possibilities

Abbreviation: SSc, Systemic sclerosis.

TABLE 5 Recommendations concerning postgraduate education on SSc for primary care physical therapists ($n = 21$)

	Level of agreement (0–100), mean (SD)	Level of agreement (0–100), median (range)	Level of agreement >70, *n* (%)
General			
Online postgraduate education on SSc is most suitable to accomplish on-demand training of primary care physical therapists; In order to suit their individual educational needs the offerings should vary with respect to duration and level (the most elementary, basic and advanced)	94 (10)	100 (30)	21 (100%)
The postgraduate education must be easily available and accessible for all physical therapists who are interested.	95 (11)	100 (45)	20 (95%)
Elementary knowledge level: Compact article			
• Target group: primary care physical therapists who treat a patient with SSc for the first time	94 (10)	100 (30)	21 (100%)
• Duration: Maximum of 45 min	84 (21)	94 (75)	17 (81%)
• Content: The most elementary knowledge to treat patients with SSc	93 (10)	100 (29)	21 (100%)
• Epidemiology: Incidence, prevalence, female/male ratio, age of onset, impact of disease on patient	89 (18)	99 (64)	19 (91%)
• Pathogenesis: Most important processes in pathogenesis	85 (22)	100 (70)	17 (81%)
• Types: Limited and diffuse cutaneous SSc and their courses	94 (12)	100 (46)	20 (95%)
• Symptoms: Possible involved organ systems and symptoms; red flags	97 (7)	100 (28)	21 (100%)
• Treatment: Most important medical treatment options and non-pharmacologic treatment with a focus on physical therapy	85 (20)	97 (68)	18 (86%)

(Continues)

TABLE 5 (Continued)

	Level of agreement (0–100), mean (SD)	Level of agreement (0–100), median (range)	Level of agreement >70, *n* (%)
• Physical therapy: Purpose, treatment modalities	95 (9)	100 (31)	20 (95%)
• practical tips related to physical therapy	95 (9)	100 (31)	20 (95%)
• Additional information: Reliable information sources on SSc	85 (23)	95 (90)	20 (95%)
• Fact-sheet with a summary	96 (9)	100 (38)	20 (95%)
• Accreditation points if possible	85 (24)	100 (100)	19 (91%)
Basic knowledge level: e-learning			
• Target group: primary care physical therapists who treat one or more patients with SSc for the first time and/or for a longer period	97 (6)	100 (21)	21 (100%)
• Duration: Maximum 1.5 h	90 (16)	100 (54)	19 (91%)
• Content: Basic knowledge to treat patients with SSc	95 (9)	100 (25)	21 (100%)
• Topics: Similar to elementary level,	94 (13)	100 (49)	20 (95%)
• But the e-learning is interactive with a combination of text, videos, photos and questions	97 (7)	100 (21)	21 (100%)
• Accreditation points after completing the e-learning	95 (9)	100 (27)	21 (100%)
In-depth e-learning			
• Target group: primary care physical therapists who regularly treat SSc patients or physical therapists with interest in (the scientific background of) RMDs/SSc	97 (9)	100 (30)	21 (100%)
• Duration: Maximum 1.5 h	97 (8)	100 (26)	21 (100%)
• Content: Advanced knowledge including recent scientific insights on (physical therapy) treatment in SSc and skills to apply this knowledge in clinical practice	94 (13)	100 (50)	20 (95%)
• Topics: Complementary to the offering on the basic level	95 (12)	100 (35)	20 (95%)
• Focus on the scientific background of physical therapy in SSc	90 (15)	100 (50)	19 (91%)
• Epidemiology: Incidence and prevalence in comparison to other RMDs and in people with different ethnicities	90 (15)	100 (50)	19 (91%)
• Pathogenesis: In-depth explanation of the pathogenic processes	93 (10)	100 (31)	20 (95%)
• Types: Non-cutaneous, limited cutaneous and diffuse cutaneous SSc and their courses/prognoses	96 (9)	100 (32)	20 (95%)
• Symptoms: Possible involved organ systems and symptoms; red flags	96 (9)	100 (33)	20 (95%)
• Treatment: Most recent guidelines for (non-) pharmacologic interventions in SSc	96 (8)	100 (25)	21 (100%)
• Physical therapy: Scientific evidence for physical therapy in SSc	97 (6)	100 (19)	21 (100%)
• Practical tips during physical therapy based on the available scientific evidence	98 (5)	100 (16)	21 (100%)
• Accreditation points after completing the e-learning	94 (11)	100 (37)	20 (95%)

Abbreviations: *n*, Number; SSc, Systemic sclerosis.

4 | DISCUSSION

These are the first recommendations on communication among primary care physical therapists and hospital-based health care providers involved in the management of SSc as well as the postgraduate education of primary care physical therapists. Both communication and education are essential elements in the process of optimising PT care for SSc patients. For communication the recommendations mainly concerned practical information to identify primary care physical therapists with specific expertise on RMDs for rheumatologists and patients, the inclusion of the clinical indication and relevant information on the patient's health status within referrals from rheumatologists to physical therapists, and low-threshold communication with the rheumatologist or other health care provider in the hospital in case of questions or concerns of the physical therapist. For postgraduate education three types of "on demand," mostly online, offerings were proposed to match the level of competencies and preferences of primary care physical therapists, varying in level of content and duration.

The results of the present study address the needs concerning PT in the management of SSc as expressed in two previous Dutch studies, one from the patients' and one from the physical therapists' perspective (Liem et al., 2021a, 2021b). The authors concluded on a need for more information on PT in patients and a need for better referral and more education of the physical therapists (Liem et al., 2021a, 2021b). These unmet health care needs are in line with those that have repeatedly been reported by SSc patients and their health professionals on health care delivery in general (Mouthon et al., 2017; Spierings et al., 2019; Stöcker et al., 2020).

Since SSc is a chronic disease with impact on functional ability, well-coordinated multidisciplinary non-pharmacological care is a cornerstone in the management of SSc patients (Rausch Osthoff et al., 2018). Studies have, therefore, recommended to increase awareness of non-pharmacological support, evidence-based guidelines for non-pharmacological care, and education for health professionals to optimise care (Smith et al., 2018; Spierings et al., 2019). Probably due to the rarity, complexity and heterogeneity of SSc, and the limited evidence of pharmacological and non-pharmacological treatment options (Becetti et al., 2019; Khanna et al., 2020; Nakayama et al., 2016), this is not an easy task and even more precision is needed due to the heterogeneous nature of the disease. Indeed, patients present with a variety of reasons to PT and essential contents of PT in SSc vary greatly between patients (Liem et al., 2021a). Moreover, in some patients with severe cardiopulmonary involvement cardiopulmonary exercises need to be monitored closely. In addition, it can be challenging to distinguish non-SSc related PT problems to SSc-related PT problems. Communication and education are therefore essential in order to ensure quality and efficacy of PT care in SSc.

This study adds to the needs established within previous studies as it offers the first practical steps towards improving the communication and education for primary care PT in SSc, which are two essential elements in the process of improvement of the accessibility and quality of PT in SSc as a whole. Regarding communication, it was striking that a lack of practical contact information was found to be a bottleneck by both primary care physical therapists, health care providers in the hospital and patients. Thus, some of the recommendations were very practical by nature, and pertained for example, to the inclusion of the rheumatologist's contact details in the referral or the better dissemination of the availability of a national network of primary care physical therapists with expertise in RMDs that already exists since 2019 (ReumanetNL, 2019).

Regarding education, online courses were found to be the optimal solution to train primary care physical therapists. By having different options, varying in level and duration, the different educational needs can be met. Their uptake could be facilitated by providing accreditation by the professional organisation. Moreover, the language would preferably be Dutch, as English is a language barrier, as identified in previous research on health professionals' educational needs (Vliet Vlieland et al., 2016). Despite the availability of international training courses on SSc (EMEUNET), their uptake by primary care physical therapists is likely to be limited, not only due to the language barrier but also because such a course might be too elaborate and not focused on delivery of care by primary care health professionals.

The next step we foresee is to implement and disseminate the recommendations of communication and education. To enable this, we believe that it is key to collaborate with organisations in the field representing all stakeholders: patient organisations, physical therapists and physicians, and to get financial support, for example, to develop high-quality e-learnings.

Strengths of the methodology employed in the present study were its systematic approach, following a specific qualitative research method, that is, the NGT, as well as the intensive and sustained participation of the task force members. Apart from the dedicated health care providers, the patient representatives played an important role in the whole process and the relevance, credibility and implement ability of the end products. In that sense, their participation in the project is an excellent example of effective patient participation in research (de Wit & Adebajo, 2019).

Some limitations should be taken into account. The sample size is small, but purposeful chosen to include all relevant perspectives. Even though the focus groups consisted of many different health professionals, we cannot rule out that we might have missed the target group, for example, the primary care physical therapists who have never seen an SSc patient before.

5 | CONCLUSION

In conclusion, we developed practical recommendations for communication between primary care physical therapists and hospital-based care providers treating SSc patients and education of primary care physical therapists regarding the management of SSc patients. These recommendations contribute to improvement of the quality of physical therapy in patients with systemic sclerosis.

AUTHOR CONTRIBUTIONS

Sophie I. E. Liem, Theodora P. M. Vliet Vlieland and Jeska K. de Vries-Bouwstra were responsible for the design of the study. All authors were involved in preparing and conducting the focus groups. Sophie I. E. Liem performed the analysis. Sophie I. E. Liem, Jeska K. de Vries-Bouwstra and Theodora P. M. Vliet Vlieland wrote the manuscript. All authors reviewed the manuscript critically and approved the final version.

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CONFLICT OF INTEREST

The authors declare no conflict of interest for this manuscript.

DATA AVAILABILITY STATEMENT

Data are available upon reasonable request from the authors.

ETHICS STATEMENT

none.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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