

Original Article

What moves the rheumatologist? Unravelling decision making in the referral of systemic sclerosis patients to health professionals: a qualitative study

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Abstract

Objectives. Well-coordinated multidisciplinary non-pharmacological care is considered to be a cornerstone in the management of patients with systemic sclerosis. However, it has been discovered that unmet information and health care needs are common in patients with SSc. In addition, referrals by rheumatologists do not always correspond with potential treatment goals as identified by health professionals. The aim of this study was to gain insight into the current referral routine of rheumatologists in SSc patients and to identify and explore factors influencing rheumatologists' decisions about referral of SSc patients to health professionals.

Methods. Qualitative semi-structured interviews were held with 13 rheumatologists specializing in SSc management from different hospitals in The Netherlands.

Results. Our study identified rheumatologists' beliefs and local policy as influencing factors for referral to health professionals and a clear need for a better referral policy. Furthermore, a lack of knowledge about and low confidence in the competence of other disciplines were identified as barriers for referral to health professionals, which may possibly lead to undertreatment.

Conclusion. In the opinion of the majority of rheumatologists, adequate referral to health professionals requires an active role for the patient and increased visibility from health professionals.

Key words: beliefs, qualitative study, referral, systemic sclerosis

Key messages

- The rheumatologists' beliefs are key themes guiding referral choices for SSc.
- Low confidence of rheumatologists in the competencies of health professionals may lead to undertreatment of SSc patients.
- A focus on pharmacological treatment may prevent a multidisciplinary approach in SSc care.

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Introduction

SSc is a complex and rare autoimmune disease with high morbidity and mortality [1, 2]. Prevalence estimates vary around 20 per 100 000 [3, 4]. The main feature of SSc is skin fibrosis, but internal organs as well as muscles, joints and tendons can be affected as well. SSc has a significant impact on daily functioning, participation and quality of life [5, 6]. A large proportion of

patients experience a wide range of physical and psychological symptoms, such as chronic fatigue, pain, stiffness of joints, reduced hand function, reduced mouth opening, depression, body image distress and uncertainty about the future [7–10]. Pharmacological treatment of SSc has modest to moderate efficacy in terms of reducing morbidity and mortality, and disease-modifying medications are scarce, if not lacking completely [11].

In The Netherlands, non-pharmacological treatment is often provided as an adjunct to pharmacological treatment. Health professionals, such as nurses, social workers, psychologists, occupational therapists, physical therapists and podiatrists, play an important role supporting patients with SSc in coping with the consequences of their disease in daily life. The majority of patients have, on average, seven or more visits yearly to one or more health professionals [10]. However, research on the efficacy of non-pharmacological interventions for this specific patient group is sparse [12]. In her systematic review on the effectiveness of non-pharmacologic interventions, Willems *et al.* [13] found 23 studies with wide variations in the content of interventions and outcome measures, but just 3 studies (randomized controlled trials) met the criteria for methodologically high quality. As a result, non-pharmacological treatments in SSc vary widely among health professionals with respect to treatment goals and content of interventions [14, 15]. Unmet information and health care needs are common among SSc patients [16]. This might be explained by the fragmented non-pharmacological care and lack of knowledge among physicians and patients about available treatment modalities for SSc. In addition, the majority of patients are dissatisfied with the coordination of care [10]. Furthermore, reasons for rheumatologists to refer SSc patients to health professionals, mainly focusing on functional impairment, do not correspond with the treatment goals of health professionals, which frequently focus on the patients' needs concerning daily activities and participation [17]. This implies that for SSc patients who receive care from multiple providers, attention should be given to the referral process, including communication among rheumatologists, SSc patients and health professionals [10].

This study is the first part of an umbrella project that aims to create transparency in the referral process of SSc patients from rheumatologists to health professionals using the view of all parties involved and to establish recommendations for improvement of the referral process. The objective of this study is to gain insight into the current referral routine of rheumatologists in patients with SSc and to identify and explore factors influencing rheumatologists' decisions about referral of SSc patients to health professionals.

Methods

We applied a qualitative study design using semi-structured interviews and inductive content analysis [18]. This methodology fits within an interpretive paradigm and

enabled us to study the perspectives of specialised rheumatologists in terms of the SSc referral process and content. In order to report explicitly and comprehensively, the COnsolidated criteria for REporting Qualitative research checklist was used [19].

In The Netherlands, the majority of SSc patients are treated by rheumatologists with special expertise in SSc, appointed at several teaching and general hospitals across the country [10]. In this study we aimed to include rheumatologists with special expertise in the management and treatment of patients with SSc. Two scleroderma expert rheumatologists (M.V., F.H.) selected colleagues with special expertise in SSc from all rheumatologists registered in The Netherlands in August 2015 ($n=361$). This resulted in a list of 24 rheumatologists. The minimum sample size for initial analysis was set at 40% ($n=10$). We applied a stopping criterion of three, implying that data saturation is achieved after three new interviews without new ideas emerging [20]. Potential participants were invited by e-mail to participate in the study. Rheumatologists were included in the study after full oral informed consent, including quotations used in the published article, was obtained. The Institutional Review Board of the Radboud University Medical Centre, Nijmegen concluded that the Medical Research Involving Human Subjects Act did not apply to this study (protocol number RR-157-678). The interviews were carried out by the first investigator (J.K.S.) at each participant's home or workplace between September 2015 and May 2016.

Data were collected during semi-structured interviews. The use of an interview guide (see [supplementary data](#), available at *Rheumatology Advances in Practice* online) ensured that the main issues were addressed. Interview questions were based on the evidence-based decision making model in order to take the view of the rheumatologist in their own context into account [21]. The semi-structured interview guide had an open-ended format. It focused on reasons for referring SSc patients to health professionals or not, factors important to rheumatologists when referring SSc patients and experiences with health professionals in daily practice.

In addition, self-reported demographic information was recorded. The interview started with open and explorative questions about factors influencing the rheumatologist's referral decisions, followed by in-depth and probing questions to extend the responses and help participants articulate their experiences. All interviews lasted between 45 and 60 min and were recorded digitally and transcribed verbatim [22].

Qualitative data analysis followed the method of inductive content analysis adapted from Nayar and Stanley [18]. Analysis followed a six-step process of coding to create established meaningful themes:

- Step 1: Transcribed interviews were read through several times by the principal investigator to obtain a sense of the whole data set.
- Step 2: Initial coding: Two investigators (J.K.S., E.C.) independently coded the first three interviews by highlighting

text fragments that appeared to capture key thoughts or concepts in relation to the research question to enhance. Subsequently J.K.S. and E.C. discussed the procedure and content of the analysis. J.K.S. continued to allocate codes to remaining transcripts.

- Step 3: Grouping codes into meaningful categories (J.K.S.).
- Step 4: The resulting categories were discussed with two members of the project group (E.C., C.H.M.E.). Minor adaptations were made by moving codes into other categories. For member checking, a short description of each category was sent to the participants and additionally to the panel of patient research partners (H.K., J.T.V., J.W.) for comment. This research triangulation enhanced the credibility of the findings [22].
- Step 5: The categories were grouped into meaningful themes. In defining the themes, the researcher paid attention to using the expressions of the participants in order not to lose the original meaning of the expression.
- Step 6: The resulting themes were discussed in the whole group of investigators until consensus was obtained. The discussion with the research team also enhanced the credibility.

Results

Study-wise data saturation was achieved at interview 13, as no new ideas had emerged after interview 10, thus the scheduling of interviews ended. None of the rheumatologists approached refused to participate or dropped out after giving informed consent. The 13 rheumatologists came from nine different centres in The Netherlands, with work experience within their specialty ranging from 3 to 30 years (Table 1).

Two major themes, beliefs and local policy and routines, were identified as influencing decision making with respect to referral of SSc patients to health professionals. We also found an additional theme reflecting the needs of the rheumatologists regarding professional multidisciplinary collaboration. The three themes, subthemes and associated categories are displayed in Table 2.

Theme 1: beliefs

Beliefs about one's own professional role

A coordinator with a helicopter view. The rheumatologist sees him/herself as a coordinator with a helicopter view, who gives the patient guidance and structure, especially at the beginning of the treatment.

P9: 'In principal, you are kind of the coordinating factor...you're almost a bit of the patient's GP...I do think, that as the rheumatologist you kind of need to keep a helicopter view of all the different aspects of what the patient is dealing with'.

They inform the SSc patient about pharmacological and non-pharmacological treatment options and in some cases about specific exercises. All rheumatologists express their intention to offer tailored care and are interested in seeing the patient from a holistic perspective. Their own continuous education and professional exchange are considered important factors for high-quality treatment, including evidence-based treatment options.

TABLE 1 Characteristics of the interviewed rheumatologists ($n = 13$)

Characteristics	Values
Female, n (%)	7 (54)
Age, median (range), years	35 (33–61)
Years in practice, n (%)	
1–10	4 (31)
11–20	7 (54)
≥ 21	2 (15)
Working in an academic hospital, n (%)	6 (46)
SSc patients in all treated patients, % (range)	35 (5–85)
Doctoral degree, n (%)	9 (69)
Involved in research, n (%)	6 (46)
Involved in SSc guidelines development (local or national), n (%)	6 (46)

Beliefs about the patient's role

Proactive patients, rheumatologist in the lead and joint decision making. Expectations regarding the patient's role in the referral process vary among rheumatologists. Some interviewees expect a very active role and feel that the patient has a responsibility to ask for a referral to care delivered by health professionals.

P1: 'The responsibility really does lie with the patient, they also need to make their own appointments, we don't do that for them'.

Several rheumatologists see themselves in the lead. They determine the policy for referral and propose this to the SSc patient. Other rheumatologists draw a picture of 'shared responsibility' based on the patient's complaint or request for assistance.

P6: 'But it's the case that I do feel it's my duty to inform that patient about everything that's available...You're sitting next to each other, you hear the story, you inform them, and together you make...I always have the feeling that we're making the decision together'.

All rheumatologists expect SSc patients to adhere to agreements made and to inform them about the progress of non-pharmacological treatments they receive. In addition, some rheumatologists mention behaviour they find conducive to good cooperation, like the expression of the patient's own opinion, informing themselves prior to the consultation or preparing a list of points to discuss.

Rheumatologists state that SSc patients often focus on problems related to the complexity of the disease and their fear of potentially harmful medical examinations. As a result, they forget or do not have the time to discuss health professional treatment options.

P11: 'If the patient has a lot of medical problems, so you have to make medication changes...and the bit about multidisciplinary or possible referral to health professionals isn't discussed if you've only got a quarter of an hour'.

Creative patients need less guidance. In several interviews, a distinction was made between 'creative' and 'passive and uncertain' SSc patients. Creative patients are able to invent their own solutions to problems. It is

TABLE 2 Themes, subthemes and categories

Themes	Subthemes	Categories
Beliefs	Beliefs about one's own professional role	A coordinator with a helicopter view
	Beliefs about patient's role	Proactive patients, rheumatologists in the lead and joint decision making Creative patients need less guidance Patients in charge
	Beliefs about the role of health professionals and rheumatology nurses	Role and effectiveness of health professionals Role of rheumatology nurse
Local policy and routines		Local policy, money and time Referral to which health professional
Needs		Need for active, visible health professionals Few large expert centres exchanging expertise with regional centres Need for regional expert networks

easier for them to grasp new knowledge and make decisions about the referral process. They require less guidance and explanation. With passive and uncertain patients, the rheumatologist is more likely to propose solutions and to determine the policy for referral.

P2: 'You sometimes need to take the patients who demonstrate helpless behaviour by the hand and actively show them the way. But in general, my impression is that the prognosis for a patient who's active, is better'.

Patients in charge. Several rheumatologists have a vision regarding the future role of the SSc patient as a partner and expect them to have an active role in the treatment process. They also have the same view with respect to their health professional and rheumatology nurse colleagues. They envisage a collaboration with four active parties.

P2: 'I think the patient should also make an active contribution to his care... So, I actually want there to be four active parties, and I prefer the responsibility to lie with the patient'.

Beliefs about the role of health professionals and rheumatology nurses

Beliefs about the role and competence of health professionals and the effectiveness of non-pharmacological treatments. Almost all rheumatologists stated that they have little or no knowledge about treatment options of health professionals. A few indicated they were familiar with the content of treatment offered by physiotherapists, occupational therapists, dieticians and hand therapists in their own centre. Outcome expectations varied widely among the rheumatologists interviewed and were based on personal experience with health professionals. Rheumatologists with a clear structure of collaboration and regular exchange with health professionals within their own work setting expressed the added value of health professional treatments.

D10: 'An incredibly important role (health professionals). Not only in self-management, but disease perception, being able to support and steer where necessary... You will not cure the disease, but I think it has a huge potential in maintaining quality of life'.

Rheumatologists with little experience with health professional colleagues within their own institution felt uncertain about the effectiveness of non-pharmacological treatments.

D4: 'I realized myself, I do not know if it helps (health professional treatments) or whether it is coincidence or not'.

Rheumatologists with little or negative experiences with a specific health professional did not believe in the clinical reasoning skills of the health professionals, describing a lack of disease-specific knowledge and poor skills regarding reporting on treatment targets, content and outcome.

D6: '...and furthermore I do not refer to these health professionals because I think they cannot do anything at all, unless there is a very apparent reason for it'.

Beliefs about the role of the rheumatology nurse. In all interviews, the role of the rheumatology nurse was regarded more positively compared with other health professionals. Their qualifications and skills are also highly valued. All except one rheumatologist described a close cooperation with the rheumatology nurse, ranging from an advisory role to shared responsibility. The rheumatologist often focuses on the medical aspects and has full confidence in the rheumatology nurse's ability to address the non-pharmacological and multidisciplinary aspects, to identify problems not discussed and to give advice about health professional treatment. Rheumatology nurses are often seen as a key person for referrals.

In the case of new patients, the rheumatology nurse is often involved in the intake and, later on, is the representative of the other health professionals during multidisciplinary meetings. Four of the rheumatologists

believe that, in the future, the rheumatology nurse could play a coordinating role between rheumatologists and other health professionals on a regular basis.

P9: 'In fact, I refer everybody who I diagnose with scleroderma to the rheumatology nurse. So that the nurse can give the patient more information about the clinical picture, can tell the patient about the challenges they'll face in everyday life. And I do use the nurse a bit as a guideline as to where I can further send the patient to'.

Theme 2: local policy and routines

Local policy, money and time

Local policy and, where present, care pathways have a significant impact on the intake and referral process. Some rheumatologists do not need to consider referral to health professionals, because intake and advice from all health care disciplines is part of the existing routine.

P11: 'Actually, I must say that here we're really connecting everything to the care path, so people come every year. . . So then in fact I don't need to refer them, because that happens automatically'.

Due to time constraints during follow-up consultations, referrals to health professionals initiated by the rheumatologist are mostly a result of the first consultation. Follow-up consultations are usually shorter and, due to the complexity of the disease, focus primarily on medical aspects. As a result, there is less attention given to non-pharmacological care.

P11: 'You know, if I'm really busy and my outpatient clinic runs over, that's also a factor that influences whether or not I remember to mention: "Oh yeah, maybe it might be wise for you to once go back to the occupational therapist sooner".'

Financial aspects are taken into account when deciding about referral.

P3: 'Things that I come up against? I think mainly the payment structure. And in particular for physiotherapy. For example, systemic sclerosis isn't covered in its chronic form. So I always discuss with people, look at how much is covered in the insurance. Otherwise it's really expensive for people'.

Most rheumatologists express a clear preference for certain health professionals when referring their patients. This is often driven by costs, clinical pathways and internal policies with regard to referral to either hospital-based or primary care health professionals. Another reason for referral to a preferred therapist is trust and confidence in the expertise of colleagues they know personally.

All centres use a centre-specific SSc intake list comprising medical and non-medical aspects that need to be addressed during consultation. Often there is a more comprehensive list for new patients, with additional questions about work and leisure activities as possible targets for health professional treatments.

In 11 of the 13 interviews, physical symptoms and functional limitations were the main reason for referring a patient to a health professional, while two rheumatologists base their decision on the actual or potential loss of the ability to perform everyday activities or to participate in society.

P12: 'As a rheumatologist you try to see if there are any physical limitations. If there are any, you quickly look at how you can. . . let's say, try to solve it with the help of occupational therapy or physiotherapy'.

Some rheumatologists consider non-pharmacological treatment options only after the failure of pharmacological treatment options.

Referral to which health professional?

Most rheumatologists regularly refer patients to physiotherapists and occupational therapists. Preferences for referral to either hospital-based or primary care health professionals differ. In general, physiotherapy in primary care is the first option, whereas in the case of occupational therapy, referral within the rheumatologist's own centre is common. In many places, referral to dieticians is defined by care pathways. Referrals to hand therapists, dental hygienists, podiatrists, social workers and psychologists are made on a less regular basis. Travel distance to the therapist and associated costs and effort for the patient are also determining factors.

Theme 3: needs

The needs of the rheumatologist concern their working environment, collaboration with health professionals and their vision of collaboration in the future.

Need for active, visible health professionals

Generally rheumatologists express a need for sufficient visibility of health professionals and active communication about therapy goals and treatment content. All interviewees perceived a lack of published evidence on health professional interventions.

Few large expert centres exchanging expertise with regional centres

Due to the complexity of the disease, the rheumatologists prefer that all health care take place as close as possible to the patient's home environment. They believe in the importance of establishing a satellite system of a few specialized SSc centres facilitating smaller regional centres in knowledge exchange.

P5: 'Because SSc is so rare you can actually cluster the experience and that results in the people being treated better. Although. . . you mustn't specialise it that much so that people can only reach one centre with their questions. There should at least always be a regional centre'.

Need for regional expert networks

The rheumatologists wish more interaction with health professionals and a clear communication and collaboration structure. In addition, they prefer health professionals adopt a more active role in the SSc treatment process and provide more transparency about their area of expertise and treatment content. The latter could be achieved through the establishment of local and regional networks of health professionals with disease-specific knowledge and protocols. Finally, in daily practice rheumatologists value transparent communication, direct or by telephone or e-mail, and would appreciate more structured reports.

Discussion

This study focuses on daily routines and factors influencing Dutch rheumatologists' decision about the referral of patients with SSc to health professionals. We identified two major themes: beliefs and local policy and routines. The additional theme reflecting the needs of rheumatologists regarding professional multidisciplinary collaboration is not directly related to the research question, but rather reflects the rheumatologists' perspective on future challenges. As far as we know, this is the first qualitative study focusing on the experiences of rheumatologists on this specific topic.

Initially the goal of this study was to investigate factors that influence rheumatologists in their decision to refer SSc patients to health professionals, in order to bring transparency to their decision-making process. However, during the analysis phase and comparison with existing literature, it became clear that we were not dealing with a list of distinct factors, but rather with a complex reasoning structure underlying the rheumatologist's decision-making process.

Rheumatologists expressed the considerable value they attach to evidence-based practice, as well as for the credibility of the therapy content of other disciplines. A lack of evidence for non-pharmacological treatments and a correspondingly low confidence in their competence was often mentioned. There is indeed little evidence regarding treatments that specifically focus on SSc [13]. However, since non-pharmacological treatments often do not focus on a specific disease, but rather on limitations in activities, there is evidence for a large number of non-pharmacological treatments originally intended for other rheumatic conditions [23]. Therefore, in our opinion, a transfer of knowledge about the effectiveness of non-pharmacological treatment options could improve SSc care.

In analysing rheumatologists' reasoning about decision making and referral we were able to distinguish the influence of strong local policy, financial aspects and time constraints. Our findings suggest that for referral to health professionals, in the absence of scientific evidence, rheumatologists predominantly make use of their personal experience, beliefs and local policy. This is in line with the rheumatologists' decision-making routine described by Iannello *et al.* [24]. These findings also underpin the findings of Gabbay and le May [25] regarding 'collectively constructed mindlines' that are built up as a 'bank of personalized, flexible syntheses of all the different types of theoretical and experiential knowledge' [24, p. 44], and affect professionals' reasoning and decision making.

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 of non-pharmacological treatment. A strong relationship between these two factors has also been reported by Arena *et al.* [26] and Suter *et al.* [27]. They found that a lack of knowledge about

potential benefits is an important factor in the underutilization of treatments and rehabilitation and suggest that low perception of confidence in diagnostic and treating competence influences the decision of whether or not to refer a patient. On the same note, Larme and Pugh [28] and Gallagher *et al.* [29] found that a combination of lack of knowledge and a perception of low efficacy of treatment can negatively affect the patient's empowerment in their self-management.

One strength of this study is the involvement of a panel of patient research partners, who reflected upon and advised on the execution of the different steps of our research.

Due to the fact that the majority of SSc patients in The Netherlands are treated by specialized rheumatologists working in a teaching or general hospital setting, only those rheumatologists who, in the opinion of our two expert rheumatologists (F.H., M.V.), were considered to be experts were included in the study. As a result, we may have missed rheumatologists who see themselves as an expert. Moreover, we only interviewed rheumatologists about their opinion of the referral process. Therefore the perspective of patients and health professionals is missing. This means that the picture is not yet complete. Further research will be needed to identify the perspectives of all parties involved in the referral process.

Conclusions

Our study identified rheumatologists' beliefs and local policy as influencing factors for referral of SSc patients to health professionals and the clear need for a better referral policy. Furthermore, a lack of knowledge and low confidence in the competence of other disciplines were identified as barriers for referral to health professionals, which may possibly lead to undertreatment. The low confidence level is closely linked to beliefs regarding the rheumatologist's own role as well as that of the health professionals and SSc patients. Regular mutual contact between rheumatologists and health professionals seems to be a crucial factor in increasing confidence in non-pharmacological treatment options.

In the opinion of the majority of the rheumatologists interviewed, adequate referral to health professionals requires an active role on the part of the SSc patient, greater visibility of health professionals and a coordinating role of the specialized rheumatology nurse.

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Supplementary data

Supplementary data are available at *Rheumatology Advances in Practice* online.

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