Needs and preferences regarding health care delivery as perceived by patients with systemic sclerosis

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Abstract This study aims to examine the needs and preferences regarding the delivery of health care services and information provision and their determinants in patients with systemic sclerosis (SSc). A questionnaire was sent to 77 SSc outpatients, comprising 27 items on health care needs within the domains physical, psychological, social support, employment/daily activities, or other health problems and 13 items on information needs. Moreover, the patients' preferences regarding the provision of health care services and information were listed. Additional assessments included sociodemographic characteristics, physical functioning (SSc Health Assessment Questionnaire), and quality of life (SF-36). Sixty-four patients (83%) returned the questionnaire. Twenty-six patients (41%) reported one or more unmet health care needs, with the highest proportions of patients with unmet needs seen in the physical (28%) and psychological (20%) domain. The highest percentages of patients with information needs were observed for medical subjects (20–28%). A lower mental component summary scale score and younger age were associated with the presence of at least one health care need in the psychological domain. Worse physical functioning, a diagnosis of diffuse SSc and having a partner were associated with higher information need score. A yearly, standardized multidisciplinary assessment program was most frequently mentioned as a preferred, but not yet existing health care model (59%) and the rheumatologist as a preferred source of information supply (75%). Unmet health care and information needs are common among SSc patients. To improve SSc health care, more attention should be paid to health care services for specific physical and psychological problems and medical information supply by the rheumatologist. In addition, the development of new models of care, such as a yearly, standardized multidisciplinary diagnostic program seems warranted.

Keywords Health care · Systemic sclerosis · Unmet needs

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Introduction

Systemic sclerosis (SSc) is a multisystem disease of unknown origin characterized by fibrosis of the skin and considerable morbidity [15]. Patients may suffer from dysfunction of lungs, kidneys, heart, gastrointestinal tract, and the musculoskeletal system, as well as digital ulcers,

Raynaud's phenomenon, and joint contractures. Two major subtypes are distinguished; diffuse cutaneous SSc (dcSSc) with skin thickening proximal to elbow and knees and limited cutaneous SSc (lcSSc) with involvement of the distal extremities. Given the complexity of the disease, SSc patients require multidisciplinary treatment by specialty physicians, health professionals such as physical therapists, occupational therapists, dieticians, and psychologists [3, 12, 18]. In recent years, SSc specific educational and rehabilitation programs have been developed [2, 7, 24].

Until now, little is known about how the available services relate to the health care needs of patients with SSc themselves. Rubenzik [23] found health care needs in the psychological/spiritual/existential domain in a group of 25 patients with SSc. In addition, in a Dutch study in 123 patients with SSc, the need for practical information on disease background, medication usage, and dealing with pain was identified [25]. However, in both studies it remained unclear to what extent the patients' needs were met by current health care services delivery. Moreover, the association between needs and patient characteristics has only in part been studied [23]. None of these studies evaluated the patients' preferences regarding the provision of their care, including their views on the institution of services that are not yet available.

The aim of this study was to identify unmet health care and information needs and their determinants as well as preferences for health care services delivery and information provision in patients with SSc.

Patients and methods

Study design

The study had a cross-sectional design. Ethical approval for this study was obtained from the Institutional Review Boards of the Leiden University Medical Center. All participants gave written informed consent.

Patients

Patients were recruited between May and July 2007. Inclusion criteria were: diagnosis of SSc as established by their treating rheumatologist according to ACR criteria [1], current treatment in the Leiden University Medical Center, being able to comprehend the Dutch questionnaire and age 18 years or older. A questionnaire was sent to all patients fulfilling these criteria, accompanied by an invitation letter, an information leaflet explaining the aim and the methods of the study, and a consent form. A follow-up letter was sent to participants who did not return the surveys within a month.

Assessment methods

Survey on health care and information needs and preferences.

(a) Health care needs

Based on the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ) [21], we developed a questionnaire including health problems relevant for patients with SSc within the following domains: physical (twelve items), psychological (nine items), social support (three items), and daily living/employment (three items). In addition to the 12 physical items, patients were invited to report 'other physical issues' in two text fields, in case these were not covered by the previous items. With every item, patients were asked to score the presence of a problem (no/sometimes/frequently/always; range 0–3). Per domain, the number of problems per patient was computed (score ranges physical domain 0–42, psychological domain 0–27, social domain, 0–9 and daily living employment domain 0–9). In addition, a total problem score was calculated (range 0–87).

If a problem was present, patients were then asked if they had discussed it with a health care provider (yes/no) and if not, whether there was an unmet need for contact with a health care provider regarding this problem (yes/no). A total score of unmet health care needs could be computed by adding up the number of unmet needs, ranging from 0 to 29.

The internal consistency of the questionnaire and its subscales was determined by computing Cronbach's alpha for the health care problem score. In general, a Cronbach's alpha of ≥0.70 is considered acceptable. For scales with a small number of items (social support and daily living/employment) and a low Cronbach's alpha, a mean inter-item correlation was computed (optimal range recommended 0.2–0.4). Cronbach's alpha of the total health care problem questionnaire was 0.90, whereas for the subscales Cronbach's alpha was 0.79 for the physical domain, 0.89 for the psychological domain, 0.54 for the social support domain (inter-item correlation 0.34), and 0.78 for the daily living/employment domain.

As there is no gold standard for perceived health care needs, we determined the convergent validity of the questionnaire by examining the association between problem scores of the questionnaire and measures of physical and mental functioning. For this purpose, correlations were computed between the problem score of the physical domain on the one side and the Physical Component Summary Scale (PCSS) of the Short Form-36 (SF-36) and disability (HAQ

score) on the other side and between the problem score of the psychological domain and the Mental Component Summary Scale of the SF-36 (MCSS; Pearson correlation coefficients). There were significant correlations between the physical symptoms score on the one side and the PCSS ($r=-0.603$, $p<0.01$) and the HAQ ($r=-0.598$, $p<0.01$) on the other side and between the psychological symptoms score and the MCSS ($r=-0.740$, $p<0.01$).

(b) Information needs

Again based on the SLENQ [21], 13 questions assessed the need for information on the following topics: Test results, medical treatment of SSc, knowing when to see a doctor, general information on medical tests, information on SSc, physical therapy, exercise and sports, the SSc patients society, occupational therapy, dental health, dietary information, counseling services, home (nursing) care. As compared to the SLENQ, the questions about physical activities and sports, physical therapy, and home (nursing) care were added. With every topic, the information need was scored on a five-point Likert scale: 1=no need, 2=low need, 3=indifferent, 4=moderate need, and 5=high need. The scores were later dichotomized in two categories in the same manner as was done in the SLENQ: 0 'no need, low need or indifferent' and 1 'moderate or high need', so a total information need score could be computed, ranging from 0 to 13.

(c) Preferences for health care delivery specifically for patients with SSc

Patients' preferences regarding the delivery of health care in addition to regular outpatient clinic care included the following options: (1) multidisciplinary treatment if needed, (2) a yearly multidisciplinary diagnostic program with standardized measurement of disease activity and other medical assessments, (3) a yearly multidisciplinary diagnostic program with standardized measurement of disease activity and other medical assessments as well as an inventory of the patient's personal need for health professionals' care and information supply. Preferences were assessed on a five-point scale (1=no need, 2=low need, 3= indifferent, 4=moderate need, and 5=high need).

(d) Preferences regarding the provision of information

Patients were asked if they were to look for information in the next year, how they would rate their preferences for the following sources of information: internet, written information (leaflets), others coping with SSc, patient support group, information meeting in the hospital, group educational program (with or without family present), rheumatologist,

general practitioner, or nurse specialist. Preference was evaluated by a five-point scale (1=not at all preferred −5=highly preferred).

An expert panel of three rheumatologists (AAS, GSB, JMvL) and a physician/epidemiologist (TVV) was responsible for the translation and adaptation of the SLENQ and the development of additional questions concerning preferences. Pilot testing by two SSc patients resulted in a few minor adjustments of the final questionnaire.

Socio-demographic characteristics

Socio-demographic variables included age (status of living (living with a partner yes/no), educational level: primary education (0–8 years, low education level), secondary education (9–16 years, medium education level), and higher vocational education/university (post-secondary, high education level) and paid employment (yes/no)).

Disease characteristics and function

Disease duration and disease subset (dcSSc or lcSSc) [15], were derived from the medical record. Disease onset was defined as time since diagnosis by the rheumatologist in either the Leiden University Medical Center (LUMC) or if applicable in another medical center (in years). In addition, patients were asked to fill in the SSc Health Assessment Questionnaire (SSc HAQ), a 20-item questionnaire comprising eight domains of activities of daily living, with the final score ranging from 0 (no disability) to 3 (severe disability) with scleroderma symptom visual analog scales (VAS 0–100 mm) in addition to Raynaud's disease, digital ulcers, intestinal complaints, pulmonary complaints, overall complaints, and pain [4].The SSc HAQ has been found to be a reliable outcome measure for disease severity in SSc [20].

Quality of life

Quality of life was measured with the Short Form-36, which includes eight domain scores: physical functioning, role limitation due to physical problems, bodily pain, general health perception, vitality, social functioning, role limitation due to emotional problems, and mental health. The scores of the SF-36 subscales range from 0 to 100, with higher scores indicating better quality of life. The subscales can be converted into two summary scales: the physical and mental component summary scale, standardized to a score with a mean of 50 and a standard deviation of 10 in the general population. For that purpose, we used the scores from an age- and sex-matched, normative sample, drawn from a large, random, nationwide sample of adults

(n=1,742) from the general Dutch population Frequency Table and factor score coefficients [26]. The psychometric properties of this questionnaire have been found to be adequate [6].

Data analysis

Data entry was performed using Microsoft Office Access 2003. Statistical analyses were executed using SPSS 16.0 software.

Frequencies or means and standard deviations were calculated for each sociodemographic measure and disease characteristic, where appropriate. Comparisons of socio-demographic and disease characteristics of patients with limited and diffuse SSc were done with unpaired t tests, chi-square, or Fisher's exact tests, where appropriate.

Descriptive statistics were employed for the patients' needs and preferences regarding health care services and information delivery.

To determine which factors were associated with health care needs, logistic regression analysis was performed with socio-demographic and disease characteristics as independent variables and the health care need score, dichotomized into no need (0) and at least one need (≥1) as dependent variable. This analysis was repeated for each domain with the domain score dichotomized into no need (0) and at least one need (≥1) as dependent variable. To determine which factors were associated with information needs, linear regression analysis was performed, with socio-demographic and disease characteristics as independent variables and the information need score as dependent variable.
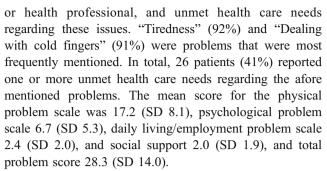
Results

Sociodemographics and disease characteristics

Of the patients, 48 of 77 responded to the initial mailing. After a reminder, another 16 returned the questionnaire, resulting in 64 responders (83%), four male and nine female non-responders. Socio-demographic and disease characteristics are presented in Table 1. In the lcSSc group, there were more females (p=0.031) and patients with lcSSc had a significantly longer disease duration than patients with diffuse SSc (p=0.019). There were no statistically significant differences in any other socio-demographic or disease characteristics between the two groups of patients.

Unmet health care needs

Table 2 presents the frequencies of reported health problems in the physical, psychological, social support and daily living/employment domains, contacts with physicians and/

or health professional, and unmet health care needs regarding these issues. "Tiredness" (92%) and "Dealing with cold fingers" (91%) were problems that were most frequently mentioned. In total, 26 patients (41%) reported one or more unmet health care needs regarding the afore mentioned problems. The mean score for the physical problem scale was 17.2 (SD 8.1), psychological problem scale 6.7 (SD 5.3), daily living/employment problem scale 2.4 (SD 2.0), and social support 2.0 (SD 1.9), and total problem score 28.3 (SD 14.0).

The highest percentages of patients with an unmet need were seen within the physical domain (Table 2). The highest percentages of patients indicating at least one need was observed in the physical domain (28%), followed by the psychological (20%), social (14%), and daily living/employment (6%) domains.

Associations between sociodemographic and disease characteristics and health care needs

None of the socio-demographic and disease characteristics were significantly associated with a higher overall health care need (Table 3). Patients with at least one need in the physical domain were younger (50.3 (SD 16.1) versus 57.2 (11.5)), although the association was not significant (OR 0.96 (95%CI 0.92–1.0), p=0.69). For the psychological domain, a lower mental component summary scale score (OR 0.92; 95%CI 0.87–0.99), p=0.02 and younger age (OR 0.92; 95%CI 0.87–0.98), p=0.01 were significantly associated with a higher health care need (results not shown).

Information needs

Table 4 shows the results of the patients' needs regarding information. In the total group, the median total information need score was 6 (range 0–13). Fifty-five patients (86%) reported an information need regarding one or more of the 13 items. The topics showing the highest proportions of patients with a moderate or high information need included: test results (75%), medical tests you need (68%), medical treatment of SSc (59%), and knowing when to see a doctor (59%). A higher information need was significantly associated with dcSSc (adjusted for disease duration; beta 2.4, 95%CI 0.1–4.6, p=0.039), a lower physical component summery scale SF-36 (beta 0.09, 95% CI 0.01–0.05, p=0.048), and having a partner (beta 2.6, 95% CI 0.5–5.1, p=0.046).

Preferences regarding specific health care services additional to regular outpatient clinic care

Table 5 shows the proportion of patients interested in specific forms of the delivery of multidisciplinary services specifically for patients with SSc. Overall, 45 of 64 (70%)

Table 1 Sociodemographic and disease characteristics of 64 patients with systemic sclerosis

	Total sample, N=64	dcSSc, N=34	lcSSc, N=30
Age, years; mean (SD)	55.3 (13.2)	53.1 (10.7)	57.8 (15.5)
Female, N (%)	50 (78)[a]	23 (68%)	27 (90%)
Disease duration, years; mean (SD)	8.5 (6.4) [†]	6.4 (4.7)	10.3 (7.3)
ANA/anti-Scl70/anti-centromere/anti-RNP	55/22[a]/5/9	29/17/2/3	26/5/3/6
ESR, mm; median, mean (SD)	23.6 (16.0)	22.1 (14.7)	25.4 (17.5)
CRP, mg/dl; median, (25th–75th percentile)	4 (3–7)[a]	5 (3–9)	3 (3–7)
Creatinin, umol/l; mean (SD)	78.3 (33.7)	79.2 (26.6)	77.1 (41.0)
Interstitial lung disease, N	37[†]	24	13
Vital capacity,% expected; mean (SD)	92.0 (19.3)[a]	85.8 (18.4)	100.2 (17.6)
Pulmonary hypertension, N	2	1	1
SSc HAQ (0–3); median (25th–75th percentile)	0.63 (0.25–1.12)	0.63 (0.25–1.19)	0.63 (0.25–1.31)
VAS Raynaud's disease (0–100 mm)	28 (12–59)	21 (6–58)	30 (19–74)
VAS digital ulcers (0–100 mm)	4 (0–40)	0 (0–31)	11 (0–67)
VAS intestinal complaints (0–100 mm)	13 (0–44)	12 (0–43)	18 (0–46)
VAS pulmonary complaints (0–100 mm)	20 (0–54)	32 (0–57)	15 (0–48)
VAS overall complaints (0–100 mm)	29 (10–53)	29 (11–60)	26 (8–49)
VAS pain (0–100 mm)	23 (5–52)	24 (5–48)	19 (8–78)
SF-36; median (25th–75th percentile)			
Physical Component Summary Scale	43.8 (34.6–52.6)[b]	43.8 (33.1–54.5)	43.5 (34.6–51.7)
Mental Component Summary Scale	53.3 (43.6–63.0)	57.6 (47.9–63.8)	52.7 (41.4–59.9)
Living with partner, N (%)	46 (72)	23 (68)	23 (77)
Education level, N (%)			
Low	26 (41)	11 (32)	15 (50)
Medium	24 (38)	13 (38)	11 (37)
High	11 (17)[c]	8 (23)	3 (10)
Paid employment, N (%)	22 (34)	14 (41)[d]	8 (27)
Internet access, N (%)	50 (78)[e]	29 (85)	21 (70)

SSc systemic slerosis, *N* number, *SD* standard deviation, *HAQ* Health Assessment Questionnaire, *VAS* visual analog scale, *SF-36* Short Form-36

[a] $p<0.05$ diffuse compared to limited SSc

[b] Data not available for five diffuse and four limited SSc patients

[c] Data not available for two diffuse and one limited SSc patients

[d] Data not available for nine diffuse SSc patients

[e] Data not available for one diffuse and five limited SSc patients

patients had a moderate or high need for at least one of the comprehensive services specifically for SSc patients.

Preferences regarding the provision of information

The rheumatologist was indicated as the preferred source of information in the nearby future by 75% of the patients (Table 6). Leaflets/books (63%), the Internet (61%), and group educational program in the hospital (58%) were more frequently indicated as a desired method of information delivery than information meetings organized by the Dutch Society of SSc patients, individual information provision by medical specialists other than the rheumatologist or by clinical nurse specialists (<50%).

Discussion

In this study on the needs of patients with SSc regarding the provision of health services and information, it was found that a number of patients indicated an unmet need for help regarding physical and/or mental problems. Information needs were most frequently mentioned with respect to medical issues. A substantial proportion of patients showed interest in various multidisciplinary services, and the rheumatologist was most often mentioned as the preferred provider of information.

Considering the impact of SSc on physical and psycho-social functioning and the usage of a high volume of

Table 2 Presence of health problems, current care and unmet health care needs in 64 patients with systemic sclerosis

	a. Problem present, N (%)	b. Problem has not been discussed with health care provider, N (% a)	c. Patient has not discussed the problem with health care provider, but would have liked to; unmet needs, N (% b)
Physical domain			
1. Lung problems	31 (48)	9 (29)	1 (11)
2. Digital ulcers	25 (39)	5 (20)	0
3. Gastro-intestinal complaints	39 (61)	19 (49)	6 (32)
4. Pain	49 (77)	25 (51)	7 (28)
5. Dealing with cold fingers	58 (91)	30 (52)	7 (23)
6. Impaired strength	38 (59)	21 (55)	5 (24)
7. Difficulty swallowing	26 (41)	14 (54)	2 (14)
8. Headache	24 (38)	18 (75)	4 (22)
9. Tiredness	59 (92)	43 (73)	9 (21)
10. Dry mouth	39 (61)	28 (74)	4 (14)
11. Sleeping problems	42 (66)	33 (77)	4 (12)
12. Difficulty thinking clearly	29 (45)	25 (86)	1 (4)
Other physical problems (1)	28 (43)	7 (25)	5 (71)
Other physical problems (2)	13 (20)	3 (23)	1 (33)
Number of patients ≥1 need 18 (28%)			
Psychological domain			
1. Worried about appearance	31 (48)	25 (81)	6 (25)
2. Uncertain regarding future	43 (67)	35 (81)	8 (23)
3. Fear of physical disability	45 (70)	22 (49)	7 (32)
4. Feeling lonely	24 (36)	19 (83)	4 (19)
5. Fear of disease progression	39 (61)	28 (72)	5 (18)
6. Feeling useless	26 (41)	22 (85)	3 (14)
7. Unable to do things you used to do	39 (61)	31 (79)	4 (13)
8. Feeling out of control	26 (41)	23 (88)	1 (4)
9. Feeling down/depressed	35 (55)	28 (80)	1 (4)
Number of patients ≥1 need 13 (20%)			
Social domain; difficulty with			
1. Maintaining friendship	13 (20)	10 (77)	3 (30)
2. Coping with changes in sexual relation	35 (55)	28 (80)	6 (21)
3. Support of family/friends	–[a]	21	2 (10)
Number of patients ≥1 need 9 (14%)			
Daily living/employment domain; difficulty with			
1. Maintaining job/study performance	46 (72)	32 (70)	4 (13)
2. Keeping appointments[a]	25 (39)	19 (76)	1 (5)
3. Work around the house	31 (48)	19 (61)	1 (5)
Number of patients ≥1 need 4 (6%)			
All domains			
Number of patients ≥1 need 26 (41%)			
Median number of needs 3 (1–17) (n=26)			

[a] Number of patients unknown due to lack of clarity in question

physician services by SSc patients [3, 10], the lack of studies on patients' needs, satisfaction, and preferences in health care is remarkable. In other rheumatic conditions, a high information need as well as a high

percentage of unmet health care needs has been demonstrated [11, 14, 16].

In our study, the highest proportion of patients with at least one unmet need was seen in the physical domain. Our

Table 3 Association between the presences of at least one healthcare need (in either the physical, psychological, social, daily living domain) and socio-demographic and disease characteristics in 64 systemic sclerosis patients

	No need	≥1 Need	OR (95% CI)
Age (years), mean (SD)	57.7 (12.0)	51.7 (14.6)	0.96 (0.92, 1.0)
Female gender (% total)	29 (76)	21 (81)	1.3 (0.38, 4.45)
Partner present (% total)	27 (71)	19 (68)	0.90 (0.30, 2.76)
Diffuse subtype SSc (% total)	21 (55)	13 (50)	0.81 (0.30, 2.20)
Disease duration (years), mean (SD)	8.8 (6.7)	7.4 (5.9)	0.97 (0.89, 1.05)
HAQ (range 0–3), mean (SD)	0.81 (0.71)	0.77 (0.69)	0.84 (0.44, 1.93)
Education, N (% total)			
Low	16 (62)	10 (39)	reference
Medium	14 (58)	10 (42)	0.75 (0.18, 3.12)
High	6 (55)	5 (46)	0.86 (0.20, 3.61)
SF-36, 0–100, mean (SD)			
PCSS	43.7 (13.2)	43.9 (9.2)	1.0 (0.96, 1.05)
MCSS	55.5 (10.8)	50.1 (11.3)	0.95 (0.91, 1.01)*

OR odds ratio, *CI* confidence interval, *SSc* systemic slerosis, *HAQ* Health Assessment Questionnaire, *SF-36* Short Form-36, *PCSS* Physical Component Summary Scale, *MCSS* Mental Component Summary Scale

*$p=0.088$

findings are difficult to compare directly with the published studies on unmet needs in SSc. Rubenzik [23] evaluated the needs of 25 SSc patients, nine diffuse, nine limited, and seven unsure subtype; but with the methodology employed in that study, questions based on a four-point scale (ranging from no need to high need), it remained unclear to what extent their indicated need for contact with a health professional was already satisfied. In patients with systemic lupus erythematosus [21], the physical domain had the highest proportion of participants with at least one unmet need. Rubenzik on the other hand, found high health care needs in nine out of ten items of the psychological/spiritual/existential domain and four out of 12 items in the physical domain, suggesting more needs in the psychological domain.

As compared to the needs of SLE patients [21] (where the number of patients with a need that was already satisfied were taken into account), our study demonstrate a relatively low percentage of patients with unmet needs. This may be because of the mild functional disability as demonstrated bij SF-36 and SSc HAQ outcomes in both the diffuse and limited cSSc group.

Concerning the association between disease characteristics and health care needs, worse mental functioning was significantly associated with the presence of at least one unmet need in the psychological domain. A previous study by Rubenzik did not examine the relationship of disease characteristics and health care needs, except for subtype. In 1,193 patients with rheumatoid arthritis and ankylosing spondylitis [14], unmet health care needs were likewise associated with worse health status. The lack of association between physical functioning and health care needs in our study may be explained by the relatively mild average level of functional disability. This may partly be due to the fact

Table 4 Information needs of 64 patients with systemic sclerosis, N (%)

	No need	Low need	Indifferent	Moderate need	High Need
Test results	1 (2)	5 (8)	5 (8)	30 (47)	18 (28)
Medical treatment of SSc	4 (6)	8 (12)	10 (16)	22 (34)	16 (25)
Knowing when to see a doctor	4 (6)	8 (13)	10 (16)	23 (36)	15 (23)
Medical tests you need	2 (3)	6 (9)	9 (14)	31 (48)	13 (20)
Information on SSc,	8 (13)	10 (16)	15 (23)	17 (27)	11 (17)
Physical therapy	6 (9)	14 (22)	10 (16)	18 (28)	10 (16)
Exercise and sports	7 (11)	15 (23)	10 (16)	17 (27)	9 (14)
SSc society	15 (23)	14 (22)	10 (15)	9 (14)	7 (11)
Occupational therapist	12 (19)	11 (17)	10 (16)	20 (31)	6 (9)
Dental health	9 (14)	14 (22)	13 (20)	13 (20)	5 (8)
Dietary information	10 (16)	14 (22)	13 (20)	13 (20)	5 (8)
Counseling services	10 (16)	18 (28)	15 (23)	7 (11)	4 (6)
Home (nurse) care	12 (19)	17 (27)	15 (23)	10 (16)	4 (6)

Numbers of patients and percentages, missing numbers not listed

Table 5 Preferences for health care delivery in addition to regular outpatient clinic care of 64 patients with systemic sclerosis

	No need	Low need	Indifferent	Moderate need	High Need
Multidisciplinary treatment planned if needed, N (%)	12 (19)	2 (3)	13 (20)	19 (30)	9 (14)
Yearly program with multidisciplinary standardized medical assessment, N (%)	5 (8)	5 (8)	8 (13)	15 (23)	23 (36)
Yearly program also including an inventory of the patient's needs regarding health professionals' care, N (%)	8 (13)	4 (6)	13 (20)	15 (23)	16 (25)

Numbers of patients and percentages, missing numbers not listed

that 19 patients with diffuse systemic sclerosis had been effectively treated.

With respect to sociodemographic characteristics, in our study, a younger age was significantly associated with needs in the psychological domain. Rubenzik [23] found higher need in the social domain in patients with a rural background and a higher need in measures from the physical, psychological, daily living, and social domain in patients without a partner. In patients with rheumatoid arthritis and ankylosing spondylitis [14], no association of sex or age with health care needs was seen, whereas education was not evaluated.

Our study identified a considerable proportion of patients with a need for information, in particular on medical issues, including test results, medical treatment, and knowing when to see a doctor. These findings are in line with a Dutch study [25], where the need for information on various subjects was evaluated by a four-point Likert scale. Information on SSc (mean 2.29) had the highest score, followed by medication usage (1.77) and dealing with pain (1.77). In contrast, Rubenzik [23] concluded that there was not much need for medical information possibly because of the presumed increased publicly accessible information. Due to differences in study design, a direct comparison of the magnitude of the need for medical information between these studies is difficult. In recent years, publications on unmet information needs in other rheumatic diseases have demonstrated that patients have high desire for information [14, 19, 22]. Leung [16] found the highest unmet information need in psoriatic arthritis was advice on exercise (68%). Studies

evaluating knowledge and information need of patients with rheumatoid arthritis (RA) mainly focused on the disease and on specialist medical care [5, 9, 17]. In general, these studies report a lack in of knowledge about the disease, medical care and medication. This is partly in line with our results.

We found that more information needs were associated with a subtype SSc as well as worse physical functioning and having a partner. The latter is surprising; discussing SSc-related problems with a partner may generate more information needs. Rubenzik [23] found more unmet needs in the domains health services, health information, and social support in patients with less education. In patients with RA, it was demonstrated the female gender [14] and lower age [8] were predictive for the presence of information needs. A significant difference in need for information between men and women, or lower and higher education was not observed in our results.

The preferences of SSc patients regarding the provision of SSc-specific health care programs and information have never been evaluated previously. Important findings are the preference of patients for their rheumatologist as source of information supply over any other type of information gathering, and the patients' interest in a yearly daycare program with standardized assessment of the disease course in addition to regular outpatient clinic care. These findings are in line with results among patients with psoriatic arthritis, showing that a large proportion of patients are motivated to participate in various additional care programs [16].

Our study has a number of limitations. First, the study group is relatively small, although the number of

Table 6 Preferences for the provision of information in 64 patients with systemic sclerosis, N (%)

	No need	Low need	Indifferent	Moderate need	High Need
Rheumatologist	1 (2)	3 (5)	4 (6)	22 (34)	26 (41)
Internet	7 (11)	2 (3)	2 (3)	20 (31)	19 (30)
Brief lets/books	6 (9)	1 (2)	7 (11)	28 (44)	12 (19)
Other specialty physician or general practitioner	6 (9)	10 (16)	12 (19)	14 (22)	9 (14)

Numbers of patients and percentages, missing numbers not listed

participants is greater than the 25 patients studied in a previously published paper on unmet needs in systemic sclerosis [23]. Also, the cohort has relatively long disease duration, this is especially the case for the patients with dcSSc (average 6.4 years, SD 4.7). Therefore, the group of patients could probably be considered a survival cohort, which could explain the relatively mild level of functional disability as compared to other cohorts of patients with SSc [10, 13]. This selection bias could hamper the generalization of our data to patients with shorter disease duration and/or more active disease. As correlations between disease activity and stage and unmet needs may be identified by a larger study group cohort, further research is warranted.

Comparison with other patients groups may further be hampered by differences in healthcare systems and socio-economic background of patients.

Second, the questionnaire we used was based on the SLENQ, but was not yet validated in Dutch. Unfortunately, data collection was established prior to publication of the study by Rubenzik, who employed the Scleroderma Unmet Needs Index (SUNI), which was also based on the SLENQ. The items included in our questionnaire and the SUNI are largely comparable, but not identical. Finally, selection bias cannot be fully excluded since the response rate was 83%. On the other hand, a response rate of 83% is relatively high, and might probably express patients' willingness to be engaged in the optimization of health care services.

In daily practice, our results imply that SSc patients may face several physical or psychological problems that are, according to a considerable number of patients, not sufficiently addressed by rheumatologists. These include physical symptoms as pain and or Raynaud's phenomenon. The concurring need for guidance with respect to psychological issues, e.g., the uncertainty and fears patients that have to deal with, substantiates the need for a multidisciplinary approach. In our study, it was indeed demonstrated that a substantial proportion of patients showed interest in various multidisciplinary services. Another important finding in this study is the high information need in SSc patients, and the preference of the rheumatologist as information supplier. This suggests that health care in SSc should also focus on patient education. In outpatient clinic care, a rheumatologist can pay more attention to information supply. At the same time, patient education programs, involving a rheumatologist, may further improve the quality of SSc patient care.

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