# Health care use and patients' perceptions on quality of care in systemic sclerosis

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# ABSTRACT

**Objectives.** To assess health care utilisation in Dutch patients with systemic sclerosis (SSc) and its associated factors. To evaluate patients' perspectives on quality of care and its association with health care use.

Methods. In a cross-sectional design, 198 Dutch patients with SSc completed an anonymous survey concerning health care utilisation, quality of care (CQ Index), and quality of life (SF-36). Results. In the last 12 months, 95% of the patients had contact with at least one medical specialist and two-thirds contacted at least one health professional (HP). The median numbers of visits to medical specialists and HPs were 7 and 7.5, respectively. Having a partner and reduced physical health status (SF-36 role-physical) were significantly associated with more visits to medical specialists and HPs. The median numbers of disciplines contacted since the onset of SSc and in the last 12 months were 8 and 4, respectively. Patients with less fatigue (SF-36 vitality) and more pain (SF-36 bodily pain) contacted more disciplines. A higher number of disciplines involved in the care was significantly associated with less satisfaction with the coordination of care (r = -0.14, p = 0.03).

**Conclusion.** Health care utilisation in Dutch patients with SSc is substantial, as is reflected in the high number of visits and the number of disciplines. Patients' rating of care coordination was lower if more disciplines were involved in their care.

# Introduction

Systemic sclerosis (SSc, scleroderma) is a rare, multisystem, autoimmune disease characterised by fibrosis of the skin. SSc often also affects internal organs such as the kidneys, lungs, heart, and gastro-intestinal tract (1). Physical functioning is impaired in most patients with SSc and disability increases over time (2). As a consequence of this complex disease, patients report impairments in their physical as well as mental health-related quality of life (HRQL) (3) and often receive treatment from a variety of health care providers (4, 5).

To date, little is known about the extent to which patients with SSc use health care services and how they evaluate the quality of care. Moreover, insight into health care utilisation in Western European countries is lacking. Research so far has been restricted to three studies (two Canadian and one Hungarian study), however those studies assessed a limited range of health care providers (4-6). Identified factors associated with more frequent visits to physicians in SSc included a higher income, more skin involvement, more comorbidities, and lower physical health status (4). The generalisability of those studies to Western European countries is limited, due to differences in health care system and the accessibility of health care services (e.g. health insurance or travel distance). In addition, disease presentation might differ among countries, since more severe SSc cases have been reported in Eastern European countries than in Western European countries (7). Therefore, it is important to assess health care utilisation by patients with SSc in Western European countries, such as the Netherlands as well.

High quality care implies that care among multiple health care providers is coordinated into a coherent whole. Recent studies strongly suggests that failures in the coordination of care are common and can cause serious quality concerns (8). The definition of care coordination is "the deliberate integration of patient care activities between two or more participants involved in a patient's care to facilitate the appropriate delivery of health care services" (9). Exchange of information and communication are basic elements of coordinated care.

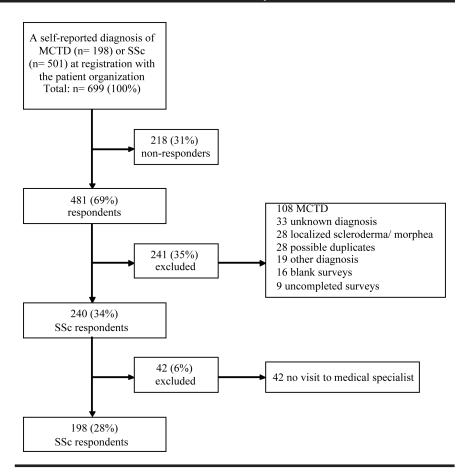
Various studies show that lack of coordination may result in inconsistent treatment plans, wasteful duplication of diagnostic testing, and contradictory advices (8, 10). Therefore, good care coordination and communication between health care providers are regarded as imperative in chronic disease management (11, 12). Since SSc is a complex disease and multiple health care providers are involved in the treatment of SSc, it might be a challenge to coordinate care. Although poor coordination of care among health care providers may have serious consequences, it has never been studied how patients with SSc perceive the coordination of their care.

Therefore, the aims of this study were 1) to assess health care use in a Dutch sample of patients with SSc and its association with demographic characteristics and HRQL, and 2) to evaluate patients' perspectives on quality of care and to examine the association between quality of care and health care use.

# Materials and methods

# Patients and procedure

Between June and August 2011, the Dutch patient organisation for patients with systemic autoimmune diseases (NVLE) invited 501 members with SSc and 198 members with mixed connective tissue disease (MCTD) to complete an anonymous online survey or a paper version on request. Invitations to members of the NVLE were based on their diagnosis at registration with the patient organisation. Because MCTD could have been evolved into SSc (13) after registration, members with MCTD at registration were invited as well. Only those patients with a self-reported current diagnosis of SSc were included in the study. Patients with a diagnosis of SSc (self-report) and age 18 years or older were included in this study. The response rate was 69% (n=481), of which 82% (n=396) answered the survey online and 18% (n=85) used the paper version (see



flowchart in Fig. 1). Based on a comparison of demographic variables, 28 questionnaires were classified as duplicates. Furthermore, 25 patients were excluded from the analyses because they failed to complete more than the demographic questions of the survey and 33 patients were excluded because they did not report a diagnosis. Only patients with systemic sclerosis were included in this study; patients with MCTD and other diseases were excluded. Of the 240 potentially eligible patients, 42 patients answered inconsistently that they had never visited a medical specialist while also reporting that a medical specialist had confirmed the diagnosis. Therefore, these patients were excluded from this study. Thus, a total of 198 SSc patients (28%) were included in the analyses. Ethical approval was obtained from the local medical ethics board (CMO 2011/203). The Dutch survey was partly based on a Canadian survey (14), which was jointly developed by a panel of Canadian Scleroderma Research Group and Scleroderma Society of Canada mem-

bers, based on the Listening to Patients Survey and the CARE III online patient survey (15) created by the Arthritis Society. The core objective of the Canadian survey was to assess a broad range of symptoms and experiences of Canadian patients with SSc, including quality of life, psychological and social aspects, employment, ability to obtain appropriate care, and interactions with health professionals. The Canadian survey was translated and adjusted for the Dutch health care system. Questions about health care utilisation relating to SSc, quality of care, and quality of life were added to the original Canadian survey. Data on health care utilisation and quality of care were used for the current study. Draft versions of the questionnaire were commented on by two patient representatives and adjusted accordingly.

## Measures

*Demographic variables* assessed were: sex, age, education, marital status, current employment status, self-reported disease subtype (limited SSc, diffuse

### Health care use in systemic sclerosis / L.M. Willems et al.

Table I. Health care utilisation by 198 patients with SSc.

Health care service	Contacted since onset SSc n (%)	Contacted in last 12 months <sup>1</sup> n (%)	Number of visits, if at least one Median (p25-p75)	
Medical specialists	198 (100)	187 (95)	$7 (4-11)^2$	
Rheumatologist	184 (93)	164 (83)	4 (2-4)	
General practitioner	177 (89)	99 (50)	3 (2-5)	
Cardiologist	143 (72)	92 (47)	1 (1-2)	
Lung specialist	139 (70)	90 (46)	1 (1-2)	
Dermatologist	115 (58)	50 (25)	2 (1-3.5)	
Internist	102 (52)	42 (21)	2 (2-4)	
Gastroenterologist	81 (41)	37 (19)	2 (1-3)	
Nephrologist	11 (6)	4 (2)	4 (1-4)	
Other medical specialists	22 (11)	26 (12)	3 (2-5)	
Health professionals	175 (88)	132 (67)	$7.5 (0-52)^2$	
Physical therapist	149 (75)	106 (53)	52 (22-55)	
Nurse specialist	89 (45)	30 (15)	1 (1-3)	
Occupational therapist	72 (36)	26 (13)	3 (1-6)	
Dietician	45 (23)	17 (9)	3 (1-4)	
Psychologist	38 (19)	14 (7)	3 (2-4)	
Social worker	35 (18)	8 (4)	4 (3-6)	
Exercise therapist	12 (6)	3 (2)	52 (5-52)	
Other health professionals	4 (2)	9 (5)	5 (3-17.5)	
Complementary therapists	60 (30)	30 (15)	$0 (0-0)^2$	
Home care	75 (38)	59 (30)	$0 (0-10)^{2}$	

<sup>1</sup>1 missing value; <sup>2</sup> number of visits including patients with no visits.

Table II. Demographic and disease characteristics of 198 patients with SSc.

Characteristics	
Female, n (%)	171 (86.4)
Age, years; mean (SD), range	58.1 (11.3), 29-85
Education level, n (%)	
0-12 years	101 (51.5)
>12 years	95 (48.5)
Living with partner, n (%)	139 (70.9)
Paid employment, n (%)	37 (18.9)
Disease subtype, n (%)	
Limited SSc	129 (65.2)
Diffuse SSc	61 (30.8)
Subtype unknown	8 (4.0)
Time since diagnosis, years; mean (SD), range	11.1 (9.5), 0-64

SSc, unknown), and the time since diagnosis.

Health care use related to SSc was assessed using a list of 26 health care providers, with the possibility to indicate other health care providers. Patients were asked whether they had had contact with a health care provider because of their SSc since the onset of the disease (yes/no) and during the last 12 months (yes/no). Health care use was classified according to four categories (Table I): medical specialists, health professionals, complementary therapists (manual therapist, touch therapist, acupuncturist, homeopathist, anthroposophist, hypnotherapist), and home care (home help, domestic help, community nurse). If patients indicated that they had contacted a health care provider during the last year, they were asked how often they had visited this health care provider during the past year.

Perceived quality of care was assessed with two subscales of the Consumer Quality Index (CQ Index), which has been found to be a reliable measure of patients' experiences with the quality of rheumatic health care (16). The subscale "cooperation and alignment" (6 items) measures patients' perspectives on how well health care providers transfer information and communicate with each other to coordinate care (*e.g.* "Were parallel treatments aligned with

one another?"). This subscale was assessed on a five-point Likert scale (never, sometimes, most of the time, always, and I don't know/ inapplica ble) except for the question "Did you make appointments with the caregivers about what to do when the disease worsens?" (yes/no). The subscale "visit to most important health care provider" (5 items) measures how patients evaluate the interaction with their most important health care provider during appointments (e.g. "Did the health care provider explain things clearly?"). The subscale was assessed on a four-point Likert scale (1 = never to 4 = always). Higher scores on the CO Index indicate higher satisfaction with the received health care. In addition, patients were asked to rate the quality of care by their most important health care provider on an 11-point scale (0 = very poor to 10 =excellent). The CQ Index showed good internal consistency in our sample, with a Cronbach's alpha of 0.87, and the subscales Cronbach's alpha was 0.80 for "cooperation and alignment" and 0.89 for "visit to most important health care provider".

The Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) is a generic questionnaire measuring HRQL (17). The questionnaire consists of 36 items that measure 8 domains of health status: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, roleemotional, and mental health. Lower scores indicate lower HRQL. The SF-36 has shown to be a valid measure of HRQL across diverse samples, including SSc (18-20). The SF-36 showed excellent internal consistency in our sample, with a Cronbach's alpha of 0.94.

# Statistical analysis

Descriptive statistics were used to describe demographic characteristics and health care use. Univariate linear regression analyses were performed to examine the association of sociodemographic and disease characteristics with health care use (number of different disciplines and number of visits). The variables that showed a univariate association (p<0.20) with health care use were entered into multiple regression analyses, adjusted for sex, age, and time since diagnosis. Tolerance values were calculated to check for multicollinearity. In the final analyses, all tolerance values were between 0.39 and 0.97, indicating multicollinearity was not an issue.

Associations between perceived quality of care (including the mean scores of the CQ Index subscales and the rating of the most important health care provider), the number of different disciplines and the number of visits in the last 12 months were investigated using partial Kendall's tau, corrected for sex, age, educational level, employment status, marital status, disease subtype, and time since diagnosis. All statistical analyses were conducted using Stata/ IC 10.1 software (StataCorp LP, College Station, TX).

# Results

# Demographics and disease characteristics

Demographics and disease characteristics are displayed in Table II. In total, 27 men and 171 women were included, with a mean age of 58.1 years (SD = 11.3) and a mean time since diagnosis of 11.1 years (SD = 9.5). About half of the respondents had received higher education and most respondents were married or cohabiting. The majority of the patients (65%) had limited SSc, and 31% had diffuse SSc.

# Health care use

*Medical specialists:* Health care use is displayed in Table I. Since the onset of the disease, the majority of the patients had contacted a rheumatologist (93%), general practitioner (89%), cardiologist (72%), lung specialist (70%), dermatologist (58%) or an internist (52%). Most patients (95%) had contact with at least one medical specialist in the last 12 months. Patients reported a median of 7 visits to medical specialists in the last year. In terms of medical specialists, patients who had at least one contact most frequently visited nephrologists and rheumatologists.

*Health professionals:* Most patients (88%) had contact with at least one health professional since the onset of the disease, and 67% of the patients vis-

**Table III.** Results of univariate and multiple regression analysis of the association of sociodemographic and disease variables with the number of disciplines and the number of visits to health care providers in the last 12 months (n=197).

	Number of disciplines <sup>1</sup>		Number of visits'		
Characteristic	Univariate regression B (Beta) 95% CI for B	Multiple regression B (Beta) 95% CI for B	Univariate regression B (Beta) 95% CI for B	Multiple regression B (Beta) 95% CI for B	
Age	-0.01 (-0.06)	-0.02 (-0.07)	-0.40 (-0.09)	-0.26 (-0.06)	
	-0.04, 0.02	-0.05, 0.02	-1.08, 0.28	-1.02, 0.51	
Gender, female	-0.22 (-0.03)	-0.01 (-0.00)	0.10 (-0.00)	1.62 (0.01)	
	-1.20, 0.77	-0.99, 0.96	-21.58, 21.77	-20.07, 23.31	
>12 years education	0.51 (0.11)	0.65 (0.14)	-2.57 (-0.03)		
	-0.17, 1.19γ	-0.06, 1.36	-18.10, 12.97		
Paid employment	-0.42 (-0.07)		-0.57 (-0.00)		
	-1.28, 0.44		-20.60, 19.46		
Living with partner	-0.08 (-0.02)		12.22 (0.11)	17.97 (0.16)	
	-0.83, 0.66		-4.53, 28.98γ	0.67,35.27*	
Diffuse SSc	0.10 (0.02)		2.28 (0.02)		
	-0.62, 0.83		-14.50, 19.06		
Subtype unknown	0.25 (0.02)		4.35 (0.02)		
••	-1.44, 1.94		-34.96, 43.65		
Time since diagnosis	- 0.03 (-0.13)	-0.03 (-0.11)	-0.76 (-0.14)	-0.81 (-0.15)	
-	-0.07, 0.00γ	-0.07, 0.01	-1.58, 0.07γ	-1.66, 0.05	
SF-36 Scales					
Physical functioning	-0.06 (-0.25)	-0.04 (-0.16)	-1.11 (-0.23)	-0.90 (-0.18)	
, 0	-0.09, -0.02∞	-0.08, 0.01	-1.83, -0.40∞	-1.92, 0.13	
Role-physical	-0.07 (-0.28)	-0.06 (-0.22)	-1.80 (-0.31)	-1.81 (-0.31)	
1 2	-0.11, -0.03∞	-0.11, 0.00	-2.66, -0.94∞	-3.15, -0.46∞	
Bodily pain	-0.07 (-0.28)	-0.05 (-0.21)	-1.07 (-0.20)	-0.20 (-0.04)	
5.1	-0.10, -0.03∞	-0.10, -0.00*	-1.88, -0.25*	-1.30, 0.90	
General health	-0.04 (-0.15)	-0.02 (-0.08)	-0.72 (-0.12)	-0.05 (-0.01)	
	-0.08, -0.00*	-0.07, 0.03	-1.64, 0.21y	-1.21, 1.10	
Vitality	-0.03 (-0.11)	0.07 (0.26)	-0.85 (-0.15)	0.72 (0.12)	
,	$-0.07, 0.01\gamma$	0.01, 0.12*	-1.74, 0.03γ	-0.53, 1.97	
Social functioning	-0.04 (-0.17)	0.01 (0.06)	-0.63 (-0.13)	0.37 (0.07)	
0	-0.07, -0.01*	-0.03, 0.06	-1.37, 0.11γ	-0.64, 1.38	
Role-emotional	0.00 (0.01)		0.14 (0.04)		
	-0.02, 0.03		-0.45, 0.73		
Mental health	0.01 (0.04)		-0.39 (-0.07)		
	-0.03, 0.05		-1.23, 0.44		

 $\infty$  p<0.01, \*p<0.05,  $\gamma$  p<0.20; <sup>1</sup>Medical specialists and health professionals.

ited a health professional in the last 12 months, with the physical therapist being mentioned most frequently. About half of the patients (45%) had contacted a nurse specialist at some point. In total, patients reported a median of 7.5 visits to health professionals per year, and a mean of 32 visits. If only counted for patients with at least one visit, the mean visits per patient per year was 46. In terms of health professionals, patients who had at least one contact most frequently visited physical therapists and exercise therapists.

*Complementary therapists and home care:* Besides contacts with medical specialists and health professionals since the onset of the disease, 30% of the patients had contact with at least

one complementary therapist, and home care had been used by 38% of the patients.

In total, patients visited a median of 8 different disciplines (range 0–14) since the onset of their disease, including 5 medical specialists and 2 health professionals. In the last 12 months, involvement of a median of 4 different disciplines was reported, including 3 medical specialists and 1 health professional.

### Associated factors of health care use

Univariate and multiple regression analyses are shown in Table III, both for the number of visits and the number of different disciplines in the last 12 months. The multivariate analyses show that a higher SF-36 vitality

#### Health care use in systemic sclerosis / L.M. Willems et al.

**Table IV.** Perceived quality of health care rated by patients with SSc and correlation coefficients (r) between CQ Index, number of different disciplines and number of visits (n=197)

	CQ Index	CQ Index	Number of different disciplines <sup>1</sup>	Number of visits <sup>1</sup>
	range	mean (SD)	r	r
Cooperation and alignment	1-4	2.9 (0.8)	-0.14*	-0.07
Care from your most important health care provider	1-4	3.6 (0.5)	-0.01	0.01
Score	0-10	8.4 (1.4)	-0.06	-0.03

\*p<0.05; <sup>1</sup>Kendall's tau correlation corrected for: sex, age, level of education, employment status, marital status, disease subtype, time since diagnosis.

score (Beta = 0.26, p<0.05) and lower SF-36 bodily pain score (Beta =-0.21, p<0.05) were significantly associated with the involvement of a higher number of disciplines. Thus, patients with less fatigue (SF-36 vitality) or more pain visited more different disciplines. Having a partner (Beta = 0.16, p<0.05) and lower SF-36 role-physical score (Beta = -0.31, p<0.01), meaning more problems with daily activities due to physical functioning, were found to be significantly associated with a higher number of visits.

# Perceived quality of care

Table IV shows the perceived quality of care and its correlations with health care use. The mean scores for the subscales "cooperation and alignment" and "visit to most important health care provider" were 2.9 (SD = 0.8) and 3.6 (SD = 0.5), respectively. On aver-

age, patients gave their most important health care provider an 8.4 (SD = 1.4) on a scale of 0 to 10. More than 90% of the patients reported that the most important health care provider took him/her seriously, listened carefully, explained things clearly, and spent enough time during appointments, and were satisfied about the opportunity to ask questions (Fig. 2). Approximately 60% of the patients reported that treatments and advices were aligned with one another, and 53% felt that health care providers communicated well with each other. 12% of the patients reported to be dissatisfied with at least one aspect of the care provided by their most important health care provider, and 64% of the patients were dissatisfied about at least one aspect of care coordination. Scores on the subscale "cooperation and alignment" correlated significantly with the number of different health care providers (r = -0.14, p=0.03), but not with number of visits.

# Discussion

Our findings demonstrate that health care use in Dutch patients with SSc is substantial and involves multiple care providers. Physical health status and having a partner were found to be the most important factors associated with health care utilisation. In addition, our results show that two-thirds of the patients was dissatisfied with at least one aspect of care coordination.

To date, there are few studies that have assessed the use of health care services in SSc. and none of these studies was conducted in a West-European country. In our study, Dutch patients with SSc reported many visits to health care providers. In concordance with the existing literature (5, 6), the rheumatologist and general practitioner were the most frequently visited physicians. The reported number of visits to medical specialists was similar to that in a Canadian study of patients with SSc (4) and a Dutch study of patients with systemic lupus erythematosus (SLE) (21), another chronic systemic autoimmune disease. However, the number of visits in the last 12 months to health professionals in our study was considerably higher than that reported in the study of Dutch SLE patients, with an average of 32 for patients with SSc versus 13 visits for SLE visits (21).

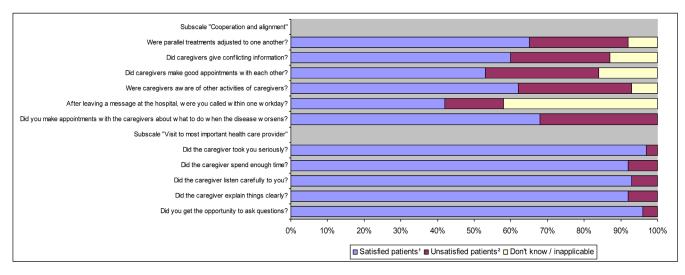


Fig. 2. Satisfaction with quality of care (CQ Index).

<sup>1</sup> Satisfied patients = "most of the time" and "always" <sup>2</sup> Unsatisfied patients = "never" and "sometimes"

Among health professionals, physical therapists are visited most frequently by patients with SSc. This finding suggests that physical therapists have a prominent role in the management of SSc. Problems may be jointly addressed in combined rehabilitation programs (22-25) and some evidence exist on their effectiveness. However, studies so far involve only small numbers of patients. The lack of accessible evidence-based non-pharmacological interventions is an important gap in care for patients with SSc, and there is a need to establish recommendations for these interventions and to reduce variability in the management of SSc (26). To address this gap, Scleroderma Patient-centred Intervention Network (SPIN) was recently established to develop, test, and disseminate a set of accessible psychosocial rehabilitation interventions, designed to complement standard medical care in SSc (27).

Less than half of the participants in our study reported ever having visited a nurse specialist in secondary care, and only one out of six patients had contact with a nurse specialist during the last year. This is not concordant with the European League Against Rheumatism (EULAR) recommendations on the role of the nurse in the management of rheumatic diseases, which states that all patients should have access to a nurse specialist throughout the course of the disease (28). This result may to some extent be due to underreporting of visits, because visits to a nurse specialist are usually planned in conjunction with a visit to a rheumatologist. Therefore, this could be regarded by patients as being part of a visit to a second care unit instead of a separate visit. Despite the good accessibility of health professionals like psychologists, occupational therapists, and social workers, who are skilled to target psychological well-being and physical functioning, patients reported relatively few visits to those health professionals. This might suggest that the provided care is not yet properly tuned to the patients' needs. In concordance with results from studies conducted in the UK (29) and Germany (30), patients in our sample were satisfied with their most important

health care provider. However, patients were not very satisfied with the coordination of care, as about two-thirds of the patients were dissatisfied with at least one aspect of the coordination of care. In addition, we found that a greater number of health care providers involved in the care was associated with more dissatisfaction with coordination of care. These findings underline the need for further improvement in the coordination of care in the complex disease SSc. Our research findings warrant further research like qualitative studies to identify barriers in the coordination of care from health care providers' and patients' perspectives in order to obtain starting points to improve coordination of care in SSc.

An interesting finding in our study was that having a partner was correlated with more visits to health care providers, even after controlling for demographic and disease-related characteristics. A possible explanation for this finding is that married individuals are more likely to be subject to healthrelated social control than unmarried individuals (31) and receive more encouragement from their partners to visit a health care provider. Existing literature is, however, inconclusive regarding the association between marital status and health care use (32). Although the majority of the published studies found that marital status had no impact on health care utilisation (32), other studies found that being unmarried or living alone is associated with greater health care utilisation. Possibly, in rare diseases like SSc, the encouragement and involvement of partners might have an influence on health care use, since information about the disease and its treatment is not readily available (33).

Another unexpected finding was that higher levels of fatigue (SF-36 vitality) were significantly associated with the involvement of fewer different disciplines in the patient's care. This indicates that tired patients are less likely to seek treatment from various care providers less often, even though treatment might be more necessary. This finding suggests that health care use might not yet be properly attuned to the patients' needs in SSc. Possibly, fatigue may prevent certain patients from seeking the treatments they need for their SSc symptoms. Since fatigue has been found to be one of the main symptoms of SSc (14), our findings warrant specific attention to the impact of fatigue on visits to health care providers.

This study has certain limitations that should be taken into account when interpreting the results. First, the level of health care use was based on a patientreported outcome, potentially leading to recall bias. According to the literature (34, 35), self-reported physician visits in the last year are less precise than computerised provider records and are inaccurate due to underreporting, which is likely to increase as the number of visits increases. Thus, health care use in SSc might be even higher than described in this study. Furthermore, due to the use of patient-reported outcomes and the anonymous nature of the survey, it was not possible to verify the patient-reported diagnosis. However, previous data show that patients with rheumatic diseases rarely report a diagnosis that is incompatible with their clinical diagnosis (36). A potential limitation of the generalisability of our results is selection bias. Characteristics of the non-responders in this study are unknown and the sample in this study included only members of the patient organisation. However, with regard to demographic and disease characteristics, the patients in our study were comparable to another large and welldescribed Dutch sample of patients with SSc (37).

A strength of the present study was the inclusion of a relatively large number of patients from all regions of the Netherlands, thereby avoiding geographical differences such as access to care influencing our results. In addition, a broad range of health care providers was included, providing a detailed and comprehensive insight into health care utilisation in SSc.

In conclusion, health care use in SSc in the Netherlands is substantial and involves a range of care providers. The involvement of a greater number of different disciplines in the care of SSc was associated with less patient satisfac-

# Health care use in systemic sclerosis / L.M. Willems et al.

tion in terms of communication among health care providers and care coordination. This implies that, for patients with a complex disease who receive care from multiple providers, attention should be given to the coordination of care, including communication among health care providers and synchronisation of treatments.

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