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Citation

Zirkzee, E. J. M., Steup-Beekman, G. M., Schouffoer, A. A., Henquet, S. M., Caljouw, M. A. A., Huizinga, T. W. J., & Vlieland, T. P. M. V. (2014). Health care in systemic lupus erythematosus (SLE): the patient's perspective. *Clinical Rheumatology*, *33*(9), 1279-1287. doi:10.1007/s10067-014-2595-1

Clin Rheumatol
DOI 10.1007/s10067-014-2595-1

ORIGINAL ARTICLE

Health care in systemic lupus erythematosus (SLE): the patient's perspective

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Received: 4 June 2013 / Revised: 8 January 2014 / Accepted: 25 March 2014

Abstract In order to provide more patient-centered care for patients suffering from systemic lupus erythematosus (SLE), we studied their current satisfaction and preferences regarding future health care delivery. We sent questionnaires to all SLE patients visiting the rheumatology outpatient clinic in Leiden, the Netherlands. The questionnaire comprised three topics: (a) health care needs using a modified version of SLE Needs Questionnaire (range 0–38), (b) satisfaction with care per provider (visual analogue scale, range 0 (not at all)–100 (very satisfied)), and (c) preferences for future healthcare (four items). One hundred and two patients (63 % response) reported an average of 16 (±6) health care needs, with all patients reporting a need in the physical domain. More needs were significantly associated with worse physical functioning and a higher educational level. The average satisfaction score was 73 (±19) with a lower overall satisfaction score being associated with younger age and an educational level higher or lower than average. Regarding preferences for future health care delivery, 75 % of patients showed interest in a yearly standardized medical assessment, 57 % in regular, specialized nurse contacts using internet, 50 % in a yearly inventory on the need for self-management support, and 36 % in an education course. The association of age, education level and physical functioning with health care needs, and/or satisfaction suggest that the delivery of care should be better tailored to the needs of subgroups of patients.

Keywords Education · Health services · Needs assessment · Patient-centered care · Patient satisfaction · Systemic lupus erythematosus

Introduction

Systemic lupus erythematosus (SLE) is a multisystem autoimmune disease which fluctuates over time and is associated with a considerable level of morbidity and mortality [1, 2]. Health care usage in patients with SLE is substantial and involves a large variety of health care services [3–5]. So far, little is known on SLE patients' experiences with this complex health care delivery. Relevant elements of the patients' perspective include their health care needs, satisfaction with care, and preferences for health care provision [6, 7].

With regards to the health care needs of patients with SLE, the SLE Needs Questionnaire (SLENQ) was employed in two studies from Australia and one from the USA [8–10]. It was found that unmet needs of patients mainly concerned the physical domain [8, 9]. Factors associated with more unmet health care needs included various sociodemographic characteristics, in particular increasing age, being single, lack of employment, and a higher educational level [8, 9].

Concerning SLE patients' satisfaction with current health care delivery, two studies using the Patient Satisfaction Questionnaire found a general satisfaction score of respectively 45 and 65 on a scale from 0 to 100 [11, 12]. In these studies, predictors of higher satisfaction were lower education, better self-reported mental and physical health status, higher

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perceived social support, and trust in as well agreement on goals with the physician [11, 13]. In addition, it was found that SLE patients were more dissatisfied with the physician's understanding about their condition than patients with rheumatoid arthritis (RA) [14]. Among several diseases, including RA, the process and structure of health care delivery were reported to have a greater influence on the patient's satisfaction than the medical outcome [15].

With respect to preferences regarding health care delivery in SLE, two qualitative studies reported that patient education should be enhanced and provided by a physician or a nurse [16]. It was also suggested that current communication between different health care providers needed improvement [17].

The aim of this study is to describe SLE patients' current satisfaction with health care delivery, their unmet needs, and their preferences for future health care provision.

Methods

Study design

The study had a cross-sectional design. This study was approved by the ethics committee of the Leiden University Medical Center and has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments http://www.wma.net/en/30publications/10policies/b3/. All participants gave written informed consent, prior to their inclusion in the study.

Patients

All patients with a diagnosis of SLE as established by their rheumatologist, who were treated at the Leiden University Medical Center at the time the study was conducted and who had had contact with their rheumatologist in the previous 24 months, were eligible for the study. Patients were identified by means of the hospital's central medical registration and the diagnosis was confirmed by a rheumatologist checking the medical record for the 1982 revised criteria for the classification of SLE [18, 19]. A questionnaire was sent to all patients fulfilling these criteria. The questionnaire was accompanied by an invitation letter, an information leaflet explaining the aim and methods of the study, and an informed consent form. A reminder was sent to participants who did not return the questionnaire within 1 month. Age, sex, and disease duration were recorded for all patients, irrespective of their response to the questionnaire.

Assessment methods

Health care needs

The questionnaire on needs was based on the SLENQ [20]. The original SLENQ consists of 97 items, which can be attributed to seven domains: (1) physical domain, (2) psychological (spiritual/existential) domain, (3) social domain, (4) daily living domain, (5) employment (financial) domain, (6) health services domain, and (7) health information domain. The possible answering categories include (1) not applicable, (2) already satisfied, (3) low need for help, (4) moderate need for help, and (5) high need for help. For the present study, 38 items were selected which were considered most relevant for the Dutch situation. In line with the procedure employed by the developers of the SLENQ [10], we transformed the answering categories into a dichotomous variable: categories 1 and 2 into "0=no need" and 3, 4, and 5 into "1=some need". A total need score was calculated based on the sum of all 38 items (possible range 0–38). The total health care need of a patient was classified as high total need and low total need according to the median of the total need score of all participants.

Health care usage and satisfaction regarding health care delivery

Health care providers or services included in this questionnaire were as follows: (1) general practitioner, (2) medical specialists (11 answering possibilities, e.g. rheumatologist, dermatologist, etc.), (3) health professionals (6 answering possibilities, e.g., physiotherapist, dietitian, etc.), (4) home care (2 answering possibilities, home help, and community nurse), (5) hospital admission, and (6) day patient care. In total, 20 different health care services and providers were included.

With every health care provider or service, patients were asked "Did you have contact with a … related to your SLE over the past 12 months?" (yes/no). If the answer was yes with respect to the past 12 months, patients were asked how many contacts they had had.

Satisfaction on quality of care was measured on a visual analogue scale (VAS), ranging from a minimum of 0 to a maximum appreciation of 100 for every health care provider or service that was used. For every visited health care provider or service, patients were asked "How satisfied are you with the care of……. over the past 12 months?" In case a patient had not had contact with a specific health care provider or service, patients were asked "Would you have liked to have visited the ……. in the past 12 months?"

A total satisfaction score was calculated per individual patient as the mean of all VAS scores of the different health care providers or services that the patient visited.

Satisfaction with overall health care delivery was classified as high or low satisfaction according to the median of the total satisfaction score.

Preferences on the provision of information and future health care delivery

Regarding preferences for information provision, the following options were given for health care providers: rheumatologist, other physician or general practitioner, specialized nurse, and patient organization; furthermore, the following options were given for different modes of delivery: internet, leaflets or books, contacts with other patients, and an information meeting in the hospital.

Patients were also asked on their preferences regarding four potential future services (that did not yet exist): (1) a yearly standardized medical assessment, (2) a yearly inventory on personal needs for care and counseling, (3) a group education course with (a) either patients only or (b) together with relatives and/or partners, and (4) regular contact over the internet with a specialized nurse. With every topic, the preference was scored on a five-point Likert scale: 1=disfavored, 2=not preferred, 3=indifferent, 4=preferred, and 5=highly preferred.

Sociodemographic characteristics

Sociodemographic variables included age; status of living (living with a partner yes/no); educational level (primary education (0–8 years); low secondary education (9–16 years); medium and higher vocational education/university (postsecondary; high); and paid employment (yes/no).

Disease characteristics

Disease duration (years), history of major organ involvement (including renal and neuropsychiatric manifestations), and SLE Disease Activity Index (SLEDAI) [21] at the visit closest to filling out the questionnaire were extracted from the medical record by a rheumatologist.

Physical functioning

Physical function was measured with a validated Dutch version of the Health Assessment Questionnaire (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) [22]. The HAQ was found to be a reliable outcome measure for disability in SLE [23].

Data analysis

Descriptive statistics were used for the patients' characteristics, health care needs, satisfaction with health care providers and services, and preferences for information provision and future health care delivery.

Comparisons between groups of responders versus nonresponders were done by Mann–Whitney and Chi-square tests where appropriate.

Logistic regression analyses were performed with the total need score (high/low) and total satisfaction score (high/low) as dependent variables and sociodemographic characteristics, duration of disease, SLEDAI, major organ involvement, and HAQ as independent variables. In the analysis of the total satisfaction score, the total need score was added as an independent variable. All variables were first included in univariate analyses; subsequently, in multivariate analyses, all univariately associated variables (entry criterion $p<0.10$) were entered, and results were adjusted for age, gender, and disease duration. Results of regression analyses are expressed in odds ratios (OR) with a 95-% confidence interval (95-% CI). *P* values below 0.05 were considered statistically significant.

Results

Patient population

The questionnaire was returned by 102 of the 161 eligible patients (63 %). The sociodemographic and disease characteristics of these patients are shown in Table 1. The 59 patients who did not respond were significantly younger ($p=0.03$) than the responders, whereas disease duration and sex did not differ significantly between these two groups.

Health care needs

Table 2 shows the prevalence of the patients' health care needs categorized per domain. In the physical domain, all patients had at least one need, whereas within the psychological domain, 93 patients (91 %) reported at least one need. Eighty-eight patients (86 %) reported at least one need in the daily living and employment domain, 84 patients (82 %) in the health services domain, 77 patients (75 %) in the health information domain, and 75 patients (74 %) in the social support domain. On average, in both the physical and psychological domains, patients reported to have "some need" for four out of the nine items. In the health information and health services domains, patients reported to have "some need" for two out of the respectively seven and four items. In the remaining

Table 1 Characteristics of 102 patients with SLE

Age, years; mean (SD)	45 (±13.7)
Duration of disease, years; mean (SD)	11 (±7.4)
Female; *N* (%)	94 (92)
Caucasian origin; *N* (%)	90 (88)
Educational level; *N* (%)	
Low	16 (16)
Medium	47 (46)
High	39 (38)
Cumulative ACR criteria at time of diagnosis, *N* (%)	
Malar rash	29 (28)
Discoid rash	17 (17)
Photosensitivity	30 (30)
Oral ulcerations	23 (23)
Arthritis	76 (75)
Serositis	33 (32)
Renal disorder	24 (24)
Neurologic disorder	2 (2)
Hematologic disorder	50 (49)
Immunologic disorder	75 (74)
Antinuclear antibody	96 (94)
SLEDAI at time of study; mean (SD)	2.2 (±2.9)
Major organ involvement at time of study; *N* (%)	52 (51)
Renal involvement	15 (15)
Neuropsychiatric involvement	17 (17)
Both	20 (19)
Paid employment; *N* (%)	56 (55)
Living alone; *N* (%)	19 (19)
HAQ; mean (SD)	0.48 (±0.60)
High health care usage; *N* (%)	39 (38)

SD standard deviation, *SLEDAI* systemic lupus erythematosus disease activity index, *HAQ* health assessment questionnaire

Table 2 Health care needs of 102 SLE patients categorized in domains as derived by SLENQ

	No need *N* (%)	Some need *N* (%)
Physical	**0 (0)**	**102 (100)**
Tiredness	30 (30)	70 (70)
Sleeping problems	33 (33)	67 (67)
Pain	49 (48)	53 (52)
Dry mouth	51 (52)	47 (48)
Headaches	54 (54)	46 (46)
Digestive problems	74 (73)	28 (27)
Mouth ulcers	75 (74)	26 (26)
Shortness of breath	82 (84)	16 (16)
Skin rashes	84 (85)	15 (15)
Psychological	**9 (9)**	**93 (91)**
Feeling in control	38 (37)	64 (63)
Uncertainty regarding future	40 (39)	62 (61)
Fears physical disability	44 (43)	58 (57)
Feeling down/depressed	46 (45)	56 (55)
Fears disease flares	47 (46)	55 (54)
Unable to do what used	53 (52)	49 (48)
Feeling isolated and/or lonely	59 (58)	43 (42)
Changes in appearance	61 (61)	40 (39)
Feeling useless	64 (63)	38 (37)
Health services	**18 (18)**	**84 (82)**
Rapid test result information	29 (29)	70 (71)
Knowing when to see a doctor	39 (39)	60 (61)
Information regarding treatment effects	38 (39)	59 (61)
Guidance on the amount of exercise	58 (61)	37 (39)
Health information	**25 (25)**	**77 (75)**
Information on the tests you need	40 (40)	59 (60)
Obtaining current information on SLE	47 (49)	49 (51)
Information regarding changes to your home	73 (75)	24 (25)
Information regarding services and benefits	75 (77)	22 (23)
Dietary information	77 (19)	20 (21)
Information regarding support groups	78 (81)	18 (19)
Counseling services	81 (83)	17 (17)
Daily living	**27 (26)**	**75 (74)**
Work around home	61 (60)	41 (40)
Coping with cold	61 (60)	41 (40)
Avoiding sun exposure	62 (61)	40 (39)
Social	**30 (29)**	**72 (71)**
Ability to participate in social activity	58 (56)	44 (44)
Support from partner/children	65 (64)	37 (36)
Coping with change in your sexual relations	72 (71)	30 (29)
Maintaining relationships family/friends	80 (78)	22 (22)
Employment	**32 (31)**	**70 (69)**
Difficulty thinking clearly	44 (43)	58 (57)
Maintaining job/study performance	52 (51)	50 (49)

SLENQ systemic lupus erythematosus needs questionnaire

Items in bold indicates the total category score

domains, social support, daily living, and employment, patients reported “some need” for one health care problem on average. The average total need score was 16 (SD 6) per patient, with the minimum and maximum scores ranging from 2 to 30 (theoretical range 0–38).

Table 3 shows the univariate and multivariate regression analyses of sociodemographic and disease characteristics in patients with either a high or a low total need score. In the multivariate analysis (entry criterion $p<0.10$), a high educational level and worse physical function, as measured by the HAQ score, were significantly associated with a high total need score.

Satisfaction with health care delivery

Table 4 shows the frequency of usage and satisfaction of SLE patients per health care provider or service. Thirteen of the patients (76 % of eligible patients) who did not see a rheumatologist in the past 12 months regretted this. Regarding overall health care delivery, the average total satisfaction score for patients was 73.3 (SD 19.2). Table 5 shows univariate and multivariate regression analyses of sociodemographic and disease characteristics in patients with either a high or a low total satisfaction score. In the multivariate analysis (entry criterion $p<0.10$), a lower age and a lower as well as a higher educational level were significantly associated with a low total satisfaction score. A high total need score showed a trend for a low satisfaction with health care delivery.

Preferences on information provision and future health care delivery

Table 6 shows preferences of patients regarding information provision, showing that the highest proportion of patients wanted information provided by the rheumatologist and information delivered through the internet.

With respect to preferences on potential services, 77 (75 %) patients indicated the wish for a yearly standardized medical assessment. Fifty-eight (57 %) patients would like to be able to have regular contact with a specialized nurse over the internet. Fifty-one (50 %) patients expressed the wish for an additional yearly inventory of their personal needs for care and counseling. Thirty-seven (36 %) patients would like to visit a group education course with patients only, whereas 28 (27 %) patients preferred a group education course together with relatives and/or partners.

Discussion

In this cross-sectional study on the perspective of Dutch SLE patients on health care, we found that the majority of patients had several health care needs, especially in the physical domain. Patients with a higher educational level or worse physical functioning reported more needs. Patients' satisfaction with overall health care delivery was sufficient, with younger patients and patients with an educational level other than average reporting lower satisfaction. For future health care delivery, follow-up visits with the rheumatologist, a yearly standardized medical assessment, and information provision through the internet were the interventions preferred by the highest proportions of patients.

With respect to health care needs of SLE patients, the number of patients reporting to have a need in a specific domain was very similar in our population compared to previous studies performed in Australia and the USA [8, 9]. The absolute number of needs can however not be compared among the studies due to discrepancies in the items included in the questionnaire. With respect to the determinants of health care needs, a worse physical function was significantly associated with a higher level of need. This finding is in accordance with earlier studies, both in SLE [24] and RA [25]. In addition, patients with higher education had a higher level of needs, whereas other sociodemographic characteristics showed no significant association with the number of needs. A higher educational level has previously been associated with more needs in the daily living domain in SLE patients [9]. A possible explanation might be that patients with higher

Table 3 Characteristics of patients with SLE divided into high and low total health care need score

	High 46 patients	Low 56 patients	Univariate odds ratio (95 % confidence interval)	Multivariate odds ratio (95 % confidence interval) Entry $p<0.10$
Age, years; mean (SD)	45.7 (14.1)	43.5 (±13.3)	1.01 (0.98–1.04)	1.00 (0.96–1.04)
Duration of disease; mean (SD)	10.2 (7.3)	10.7 (±7.5)	0.99 (0.94–1.05)	0.96 (0.90–1.03)
Female; *N* (%)	43 (91)	51 (91)	1.41 (0.32–6.22)	1.03 (0.19–5.66)
Caucasian origin; *N* (%)	38 (83)	52 (93)	2.74 (0.77–9.76)	
Educational level; *N* (%)				
Low	9 (20)	7 (13)	2.94 (0.91–9.47)***	2.35 (0.61–9.12)
Medium	14 (30)	32 (57)	Reference category	Reference category
High	**21 (46)**	**17 (30)**	**2.82 (1.15–6.92)****	**2.75 (1.04–7.27)****
SLEDAI; mean (SD)	2.6 (2.8)	2.0 (±3.0)	1.08 (0.94–1.24)	
Major organ involvement; *N* (%)	23 (50)	29 (52)	0.93 (0.43–2.03)	
Paid employment; *N* (%)	22 (48)	34 (61)	0.59 (0.27–1.31)	
Living alone; *N* (%)	7 (15)	12 (21)	0.66 (0.24–1.84)	
HAQ; mean (SD)	**0.67 (0.57)**	**0.31 (0.57)**	**2.99 (1.42–6.27)***	**3.01 (1.17–7.70)****
High health care usage; *N* (%)	22 (48)	17 (30)	2.10 (0.93–4.74)***	1.25 (0.47–3.32)

SD standard deviation, *SLEDAI* systemic lupus erythematosus disease activity index, *HAQ* health assessment questionnaire

*$p<0.10$; **$p<0.05$; ***$p<0.01$

Items in bold indicates significant results

Table 4 Satisfaction with health care providers in 102 patients with SLE

	Patients who visited in the past 12 months			Patients who did not visit in the past 12 months	
Service	*N* (%)	No. of visits mean (SD)	Satisfaction mean (SD)	*N* (%)	Wants to visit *N* (%)
General practitioner	45 (44)	2.8 (1.7)	65 (26.9)	57 (56)	8 (14)
Medical specialists					
Rheumatologist	85 (83)	3.2 (2.4)	79 (21.8)	17 (17)	13 (76)
Dermatologist	25 (25)	2.9 (1.7)	74 (26.7)	77 (75)	9 (12)
Nephrologist	23 (23)	4.6 (3.0)	74 (23.6)	79 (77)	8 (10)
Cardiologist	16 (16)	1.8 (1.1)	73 (21.9)	86 (84)	12 (14)
Internist	15 (15)	2.3 (1.2)	77 (26.5)	87 (85)	8 (9)
Neurologist	14 (14)	2.4 (1.0)	61 (27.4)	88 (86)	9 (10)
Pulmonologist	10 (10)	2.5 (1.6)	65 (28.3)	92 (90)	9 (10)
ENT-specialist	7 (7)	1.5 (0.6)	77 (18.9)	95 (93)	7 (7)
Psychiatrist	2 (2)	8.5 (5.0)	84 (16.3)	100 (98)	3 (3)
Health professionals					
Physiotherapist	26 (25)	43.7 (31.6)	79 (14.8)	76 (75)	11 (14)
Dietitian	14 (14)	3.3 (2.6)	67 (21.7)	88 (86)	8 (9)
Psychologist	10 (9)	6.1 (2.4)	75 (18.9)	92 (90)	6 (7)
Occupation therapist	8 (8)	2.4 (1.5)	82 (28.2)	94 (92)	8 (9)
Nurse specialist	8 (8)	2.9 (2.9)	79 (23.7)	94 (92)	9 (10)
Social worker	7 (7)	4.7 (3.4)	76 (13.1)	95 (93)	3 (3)
Care at home					
Home help	9 (9)		58 (32.3)	93 (91)	3 (3)
Community nurse	2 (2)		67 (23.3)	100 (98)	1 (1)
Hospital admission	17 (17)		80 (19.6)	85 (83)	Not relevant
Day patient care	2 (2)		65 (3.5)	100 (98)	6 (6)

ENT ear nose and throat, *SD* standard deviation, *VAS* visual analogue scale

education set higher goals for themselves and their health care providers, since health outcomes are in fact better in higher educated patients in general as well as in patients suffering of SLE or RA [26, 27]. In previous studies, older patients and patients with a disability pension reported higher needs in specific domains [8, 9]. In agreement with this, in our population, employed patients and younger patients had a lower level of needs, although this effect did not reach statistical significance.

Concerning the patients' satisfaction with specific health care providers, no striking differences between providers were found; however, as the numbers of patients who had had contact varied largely per health care provider, comparisons are difficult to make. We found that patients who did not visit the rheumatologist in the past year regretted this specifically. The average satisfaction of patients with overall health care delivery was moderate to good. Other available data on satisfaction of SLE patients with overall health care, although measured by a different method but using a same scale, were lower or comparable to the score that we found [11, 12].

With respect to the determinants of satisfaction, educational level and age were associated with patients' satisfaction in this present study. No disease characteristic significantly determined the patients' satisfaction, although patients with a higher level of health care needs tended to be less satisfied. Younger patients were less satisfied with health care delivery. In general, being younger is described as a predictor of dissatisfaction with health care [28, 29]. Level of education has a complex impact on satisfaction with health care delivery; compared to patients with an average education, patients with a lower education are less satisfied; however, patients with higher education are also dissatisfied. Higher education has been associated with less satisfaction with health care delivery in SLE patients previously [13]. In several diseases including RA, patients with a high as well as a low educational level reported a lower satisfaction with health care. This was found to be the result of a discrepancy between patient's expectations and preferences on the one hand and received care on the other hand, with less educated patients receiving too much and highly educated patients receiving too little in-depth information and shared decision-making [30]. The expectations of patients with arthritis proved to play a significant role in satisfaction with health care [31].

Table 5 Characteristics of patients with SLE divided into high and low total satisfaction scores

	High 47 patients	Low 46 patients	Univariate odds ratio (95 % confidence interval)	Multivariate odds ratio (95 % confidence interval) entry $p<0.10$
Age, years; mean (SD)	**46.2 (13.6)**	**42.4 (14.0)**	**1.02 (0.99–1.05)**	**1.05 (1.01–1.10)****
Duration of disease; mean (SD)	10.1 (6.8)	10.5 (7.8)	0.99 (0.94–1.05)	0.98 (0.91–1.05)
Female; *N* (%)	42 (89)	43 (94)	0.59 (0.13–2.61)	1.08 (0.21–5.63)
Caucasian origin; *N* (%)	42 (89)	40 (87)	0.79 (0.22–2.81)	
Educational level; *N* (%)				
Low	**5 (11)**	**8 (17)**	**0.26 (0.07–0.95)****	**0.13 (0.03–0.64)****
Medium	29 (62)	12 (26)	Reference category	Reference category
High	**11 (23)**	**26 (57)**	**0.18 (0.07–0.46)***	**0.15 (0.05–0.45)***
SLEDAI; mean (SD)	2.32 (2.74)	2.24 (3.13)	1.01 (0.88–1.16)	
Major organ involvement; *N* (%)	23 (49)	24 (51)	0.88 (0.39–1.98)	
Paid employment; *N* (%)	24 (51)	27 (59)	0.73 (0.32–1.67)	
Living alone; *N* (%)	9 (19)	10 (22)	0.85 (0.31–2.34)	
HAQ; mean (SD)	0.49 (0.62)	0.50 (0.60)	0.96 (0.49–1.91)	
High health care usage; *N* (%)	16 (34)	23 (50)	0.52 (0.22–1.19)	
High need score; *N* (%)	17 (36)	20 (44)	0.44 (0.19–1.00)***	0.44 (0.16–1.15)***

SD standard deviation, *SLEDAI* systemic lupus erythematosus disease activity index, *HAQ* health assessment questionnaire

*$p<0.10$; **$p<0.05$; ***$p<0.01$

Items in bold indicates significant results

Previously, we described in a study on the same population, that younger patients and patients with a worse physical function had a higher use of health care [5]; therefore, we can conclude that the amount of health care does not positively influence the determinants for health care needs or satisfaction. Regarding physical function perhaps not the amount of health care but specific attention for physical dysfunction could enhance the quality of health care for SLE patients. With respect to the influence of age, the higher usage of health care but lower satisfaction in younger patients could be partially biased since nonresponders were significantly younger. On the other hand, it could also be explained by more impact of a chronic disease or a more severe disease course or overuse of health care in the young.

Table 6 Preferences regarding information provision in 102 SLE patients

	Disfavored		Indifferent		Preferred	
	N	%	*N*	%	*N*	%
Health professional						
Rheumatologist	4	4	10	10	85	86
Other physician/GP	11	12	31	33	52	55
Specialized nurse	23	26	39	44	27	30
Patient association	46	50	28	30	19	20
Mode of delivery						
Internet	9	10	3	3	81	87
Leaflets/books	10	11	10	11	75	79
Information meeting in hospital	35	38	23	25	35	38
Contact with other patients	48	52	26	28	19	20

GP general practitioner

The preferences of SLE patients regarding health care delivery have never been evaluated previously in a similar manner. An important finding of the present study was the patients' preference for the rheumatologist and the internet as sources of information supply over any other source. In 2002, a first study on patient education via the web for SLE patients was published, which showed its feasibility as well as a positive effect on disease knowledge [32]. In several diseases, for instance in breast cancer, a good quality website enhanced information recall and patients' satisfaction after a visit with the physician [33]. Next to that of importance is the patients' interest in a yearly standardized medical assessment scheduled next to regular outpatient visits to monitor the disease course.

This study has a number of limitations. First, our cohort is a selection of patients who are under the care of a rheumatologist in a university hospital. The patient population may however be comparable to SLE patients from general hospitals, as our hospital is the only hospital offering rheumatology services in the Leiden region. Age, gender, and disease duration of patients in our study are comparable to the three populations in a study that describes patients attending various clinics in a period of 24 months [34]. Although the proportion of the responders was relatively high, certainly compared with other studies concerning patients' needs [8], it appears that younger patients were underrepresented in this study. In addition, comparison of our results with other studies may be hampered by differences in ethnic background of the patient population or the health care systems. Regarding the measurement of health care needs, alike another study, we used a selection of questions of the SLENQ [8] that were translated in Dutch; this translated questionnaire is not separately validated. The questions were selected on the basis to be appropriate and relevant to patients in our local practice; this is reflected by the high level of correspondence of the questioned items in the physical and psychological domains, domains that are more universal in patient populations in different countries than the daily living or health services domain. Therefore, we think it is suitable that in this manuscript, the internationally best comparable items of SLENQ are presented.

In conclusion, we would like to make some recommendations for health care delivery in SLE patients based on these and previous findings. Regarding the patient's need for coordination of care, it may be considered to appoint one central coordinator, e.g., the rheumatologist, to communicate with all other health care providers [17, 35]. A yearly standardized medical assessment is preferred by patients and may guarantee the provision of cohesive care and serve as an opportunity to discuss unsatisfied needs. Our study shows that patients who visit health professionals are satisfied with these visits; therefore, it may be recommended to assess whether such a consultation is needed by a yearly evaluation of physical function, for instance, by applying the HAQ. National rheumatology councils should provide good-quality websites for SLE patients. Regarding information provision, the patient's educational level is of relevance and both simple and more in-depth information could be offered on websites.

The future challenge is to provide local specialized care for SLE patients that not only addresses disease outcomes but also imbeds the patient's perspective, for patients of all ages and educational levels.

Disclosures EJ Zirkzee: none, GM Steup-Beekman: none, AA Schouffoer: none, SM Henquet: none, MA Caljouw: none, TW Huizinga: none, TP Vliet Vlieland: none.

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