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PAPER

Health care usage in Dutch systemic lupus erythematosus patients

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As a first step in the improvement of the organization of care for patients with systemic lupus erythematosus (SLE) we studied their health care usage and its determinants. A questionnaire was sent to 161 outpatients of the rheumatology clinic of a Dutch university hospital. The questionnaire comprised questions on health care usage, quality of life and sociodemographic characteristics. Disease characteristics were extracted from the medical record. Among the 102 responders (63% response rate) the proportions of patients reporting contacts with a rheumatologist because of SLE since onset of the disease and over the past 12 months were 100% and 83%, respectively. These proportions were 93% and 68% for all other medical specialists, 88% and 44% for the general practitioner, 78% and 44% for any health professional, 29% and 9% for care at home, 48% and 17% for hospital admissions and 29% and 2% for day-patient care. Younger age, major organ involvement, the use of immunosuppressants and worse physical functioning were found to be significantly associated with greater health care use. This study demonstrated that health care usage by SLE patients is substantial and involves a variety of health care services. Further research should be directed at patients' satisfaction and patients' needs regarding the optimal organization of integrated, multidisciplinary services that are accessible for SLE patients of all ages. *Lupus* (2011) **20**, 1147–1154.

Key words: health care services; health care usage; health care utilization; SLE

Introduction

Despite a better survival due to advanced medical treatment, morbidity and mortality associated with systemic lupus erythematosus (SLE) are still considerable.^{1,2} Apart from disease activity patients suffer from the effects of accrued damage, leading to end-organ dysfunction and functional disability. Various health care providers are involved in the management of SLE patients, this may lead to a lack of cohesive health care and less experienced care providers.³

As a first step in any effort to improve care, there should be insight into current health care usage. Until now, research on the extent of health care use in SLE patients was scarce. With regard to the extent of health care use, the proportions of SLE patients who had contact with a rheumatologist

varied between 78–97% and with a general practitioner between 73–78% over 6–12 months.^{4,5} Percentages of patients having had contact with other medical specialists range from 10–33% per year.^{4,6} Over periods of six and twelve months, 6 to 22% respectively of SLE patients have had contact with a physical therapist,^{5,6} whereas the use of services provided by other health professionals, such as occupational therapists, dieticians or psychologists is largely unknown. The proportions of patients with SLE being admitted to hospital over a period of a year vary between 18–24% in literature.^{6,7} All of these data are from the United States of America, Canada and the United Kingdom.

A number of studies have examined which factors were associated with health care usage and/or health care costs in patients with SLE. Concerning sociodemographic variables, higher education,⁵ higher income,^{4,8} lower age,^{4,5,9} female sex⁴ and ethnic origin other than aboriginal or African-American⁹ were found to be associated with higher health care usage. With respect to disease characteristics, shorter disease duration,¹⁰ higher levels of creatinine,¹¹ higher levels of disease

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activity,^{5,10} more end-organ damage⁵ and worse functional status^{5,10,11} have been related to higher health care usage.

Given that data is only available on a few selected populations, and there is a lack of information on health care usage from onset of disease and the use of wider health care services, the aim of this study was to examine the use of all types of health care and its determinants among patients with SLE.

Patients and methods

Study design

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

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. In addition, patients had to be fluent in Dutch and had to be eighteen years or older. Patients were identified by means of the hospital's central medical registration and the diagnosis was confirmed by a rheumatologist (GMS-B) checking the medical record according to the 1982 revised criteria for the classification of SLE.^{12,13} A questionnaire was sent to all patients fulfilling these criteria. The questionnaire was accompanied by an invitation letter and an information leaflet explaining the aim and the methods of the study and an informed consent form. A reminder was sent to participants who did not return the questionnaire within one month. Age, sex and disease duration were recorded for all patients, irrespective of their response to the questionnaire.

Assessment methods

Survey of health care usage

The questionnaire was based on a questionnaire employed in a previous study among patients with rheumatoid arthritis.¹⁴ It comprised the following categories of health care services (number of different health care professionals/services within a category) 1. rheumatologist ($n=1$); 2. medical

specialists other than rheumatologist ($n=10$); 3. general practitioner ($n=1$); 4. health professionals ($n=6$); 5. home care ($n=2$); 6. hospital admission ($n=1$); 7. day patient care ($n=1$). With every health care provider or service, patients were asked 'Did you have contact with a ... related to SLE since the onset of your disease/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 or treatment days they had had (with the exception of home care, where it was asked how many months patients received home care). Per category, a category score of 1 was applied if the answer to one or more care providers or services was yes, and a score of 0 if all answers within the category read no. The total health care usage score was the sum of six of the seven categories of care (range 0–6). Rheumatologist care was excluded from the total score as only patients who had visited the rheumatologist at least once in the past 24 months were included in this study. Health care usage was classified as high care usage and low care usage according to the median total health care usage score. Finally, patients were asked if they used complementary medicine (yes/no) and whether they had had contact with a patient association (yes/no).

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), secondary education (9–16 years; medium) and higher vocational education/university (postsecondary; high), paid employment (yes/no) and receiving a work disability pension (yes/no).

Disease characteristics

Disease duration (years) and history of major organ involvement (including renal and neuropsychiatric manifestations) were extracted from the medical record by a rheumatologist (GMS-B). In addition, the American College of Rheumatology (ACR) classification criteria at the time of diagnosis,^{12,13} SLE Disease Activity Index (SLEDAI)¹⁵ and medication use at the visit closest to filling out the questionnaire were extracted from the medical record by the principal investigator (EJMZ).

Physical functioning

Physical functioning 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).¹⁶ The HAQ was found to be a reliable outcome measure for disability in SLE.¹⁷

Quality of life

Quality of life as reflected in physical, mental and social functioning was measured with the Short Form (SF)-36, which includes eight domain scores: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. The scores of the SF-36 subscales range from 0–100, with higher scores indicating better quality of life. The subscales can be converted into two summary scales: the physical and mental component summary scores, 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 ($n=1742$) from the general Dutch population Frequency Table and factor score coefficients.¹⁸ The psychometric properties of this questionnaire have been found to be adequate.¹⁹ The SF-36 has been previously used in SLE patients and proved to have adequate construct, discriminatory and criterion validity in this patient group.²⁰

Data analysis

Descriptive statistics were used for the patients' characteristics and usage of health care services. Comparisons between groups of responders versus non-responders were done by Mann–Whitney and Chi-square tests where appropriate. To validate the question on the amount of health care use in the survey, the number of visits to the rheumatologist in the past year were retrieved from the hospital's central medical registration and compared to the number of self-reported visits by a paired *t*-test. Correlations between variables were investigated using Pearson correlation coefficients. Logistic regression models were used with sociodemographic and disease characteristics as independent variables and the high or low total health care usage score as a dependent variable, the results were expressed as odds ratios (OR) with 95% confidence interval (CI). Univariate logistic regression analyses were performed. All variables that showed univariate significance ($p < 0.05$) associated with total health care usage score were entered into multivariate analysis. The multivariate analysis was repeated by entering all variables that were univariately associated ($p < 0.10$) with the health care usage score. All analyses were adjusted for sex,

age and disease duration. *p*-values < 0.05 were considered to be statistically significant. Data entry was performed using Netquestionnaires 2005. Statistical analyses were executed using SPSS 16.0 software.

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. Their median age was 45 years (range 18–76) and their median disease duration 9 years (range 1–29). The 59 patients who did not respond had a median age of 39 years (range 19–81), which is significantly younger than the patients who did respond ($p=0.03$). In addition, in the group of non-responders the average disease duration was longer (median 13 years, range 1–29) and fewer patients were female ($n=49$, 83%), although these results did not reach statistical significance ($p=0.06$ and $p=0.13$, respectively).

Validation of health care usage

The mean number of visits to the rheumatologist over the past year as derived from the hospital's central medical registration was 2.8 (SD ± 1.8), which did not differ significantly from the number reported by patients themselves (mean 3.2; SD ± 2.4) ($p=0.61$).

Description of use of care

The use of health care services by patients is shown in Table 2. Patients had contact with a median of five (range 1–10) physicians since the onset of disease, with the rheumatologist, general practitioner, dermatologist, internist, neurologist and cardiologist most frequently mentioned, in this order. Ten patients had had contact with six medical specialists other than their rheumatologist since onset of disease. Seventy-eight per cent of patients had contact with one or more health professionals (median 2, range 0–6) since onset of disease, with the physiotherapist being most frequently mentioned. Complementary therapy was used by 22% of patients and 44% joined a patient association.

In last 12 months patients had contact with a median of 2 (range 0–6) medical specialists (including rheumatologists) with a mean of 11 outpatient visits. In the last twelve months 44% of patients had contact with one or more health professionals

Table 1 Sociodemographic and disease characteristics of 102 SLE patients

<i>Characteristic</i>	
Age, years; mean (SD)	45 (±13.7)
Duration of disease, years; mean (SD)	11 (±7.4)
Female; <i>N</i> (%)	94 (92)
Caucasian origin; <i>N</i> (%)	90 (88)
Educational level; <i>N</i> (%)	
Low	16 (16)
Medium	47 (46)
High	39 (38)
Paid employment; <i>N</i> (%)	56 (55)
Work disability pension; <i>N</i> (%)	32 (31)
Living alone; <i>N</i> (%)	19 (19)
No. of ACR criteria at time of diagnosis (0–11), mean (SD)	4.5 (±0.8)
Cumulative ACR manifestations at time of diagnosis, %	
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 score (0–105), mean (SD)	2.2 (±2.9)
Major organ involvement; <i>N</i> (%)	
None	50 (49)
Renal involvement	15 (15)
Neuropsychiatric involvement	17 (17)
Renal and neuropsychiatric involvement	20 (19)
Medication; <i>N</i> (%)	35 (34)
Corticosteroids	52 (51)
Antimalarials	39 (40)
Immunosuppressants	18 (18)
Warfarin	43 (42)
Antihypertensives	
SF-36 Scales (0–100); Mean (SD)	
Physical functioning	68.4 (±25.1)
Role-physical	47.5 (±41.8)
Bodily pain	68.7 (±20.8)
General health	35.5 (±19.4)
Vitality	51.2 (±17.2)
Social functioning	66.3 (±23.8)
Role-emotional	69.0 (±42.8)
Mental health	55.8 (±12.4)
Physical Component Summary	56.3 (±21.8)
Mental Component Summary	60.8 (±19.4)
Health Assessment Questionnaire score (0–3); Mean (SD)	0.48 (±0.60)

ACR: American College of Rheumatology, SD: standard deviation, SLE: systemic lupus erythematosus, SLEDAI: Systemic Lupus Erythematosus Disease Activity Index.

(median 0, range 0–5). In the total population patients had a mean of 13 visits per year to health professionals, if only counted for patients who had at least 1 contact there were 31 visits per patient per

year. Seventeen patients (16.7%) had been admitted to the hospital with a mean stay of seven days. Nine patients (8.8%) had had home help for a mean of ten months in the last twelve months. In total patients had a median use of 2 (range 0–5) different services in last 12 months.

Determinants of health care utilization

Table 3 shows univariate and multivariate (entry criterion of variables $p < 0.05$ in univariate analysis) regression analysis of sociodemographic and disease characteristics of high and low care users as classified by median of total health care usage scores in the last twelve months. In the multivariate analysis lower age, major organ involvement, the use of immunosuppressants and worse HAQ were found to be significantly associated with health care usage. Repetition of the multivariate analysis entering all variables that were associated with health care usage in the univariate analysis using a level of significance of 0.10 yielded similar results, with the following significant associations: Age, odds ratio (OR) 0.94 (95% confidence interval (CI) 0.89–0.99, $p < 0.05$); Immunosuppressants (including corticosteroids), OR 3.28 (95% CI 1.03–10.44, $p < 0.05$); SF-36 Role-emotional, OR 0.98 (95% CI 0.97–1.00, $p < 0.05$); HAQ, OR 6.51 (95% CI 1.09–38.88, $p < 0.05$).

Outcomes of SF-36 physical functioning subscale and HAQ, both addressing physical activities, were found to be strongly correlated ($r = -0.8$, $p < 0.01$) Therefore we performed the multivariate analysis (entry criterion $p < 0.05$) with only one of the two variables at a time. When only the HAQ was entered, the OR for the HAQ score was 5.63 (95% CI 1.85–17.16, $p < 0.01$), whereas entering only the SF-36 physical functioning subscale resulted in an OR of 0.97 (95% CI 0.94–0.99, $p < 0.01$) for that variable.

Discussion

In this cross-sectional study among Dutch SLE patients, health care use was found to be substantial and included all categories of health care. Younger age, major organ involvement, the use of immunosuppressants and worse physical functioning were found to be significantly associated with greater use of health care.

With respect to the extent of health care use, the proportions of patients reporting contact with medical specialists other than a rheumatologist in our study were higher than in the literature, but the

Table 2 Health care usage of 102 patients with SLE

Health care service	Contact since onset of disease N (%)	Contact in last 12 months N (%)	Number of visits per patient in last 12 months, if at least one Mean (SD)
Rheumatologist	102 (100)	85 (83)	3.2 (±2.4)
Medical specialists ^a	95 (93)	69 (68)	7.7 (±5.6)
Internist	58 (60)	15 (15)	2.3 (±1.2)
Nephrologist	35 (34)	23 (23)	4.6 (±3.0)
Pulmonologist	36 (35)	10 (10)	2.5 (±1.6)
Cardiologist	45 (44)	16 (16)	1.8 (±1.1)
Dermatologist	62 (61)	25 (25)	2.9 (±1.7)
Neurologist	47 (46)	14 (14)	2.4 (±1.0)
Psychiatrist	18 (18)	2 (2)	8.5 (±5.0)
ENT-specialist	25 (25)	7 (7)	1.5 (±0.6)
Gynaecologist	15 (15)	10 (10)	No data
General practitioner	90 (88)	45 (44)	2.8 (±1.7)
Health professionals	79 (78)	45 (44)	31.0 (±32.8)
Physiotherapist	62 (61)	26 (26)	43.7 (±31.6)
Occupational therapist	22 (22)	8 (8)	2.4 (±1.5)
Nurse specialist	27 (27)	8 (8)	2.9 (±2.9)
Dietician	32 (31)	14 (14)	3.3 (±3.6)
Social worker	30 (29)	7 (7)	4.7 (±3.4)
Psychologist	22 (22)	10 (10)	6.1 (±2.4)
Care at home	30 (29)	9 (9)	
Home help	20 (20)	9 (9)	
Community nurse	18 (18)	2 (2)	
Hospital admission	44 (43)	17 (17)	
Day patient care	30 (29)	2 (2)	

^aOther than a rheumatologist, ENT: ear nose and throat, SD: standard deviation, SLE: systemic lupus erythematosus.

pattern of involvement of medical specialists was the same.^{4,6} The proportions of patients that reported contact with a rheumatologist also was the same.⁴ Concerning contacts with a general practitioner, the rates in our study were lower than reported in the literature.⁴ For the use of health professionals' care comparisons are difficult to make, due to lack of available data. The proportion of patients that reported contact with a physical therapist was much higher than reported in the literature.⁶ Our study demonstrated, that in addition, a considerable proportion of patients had contacts with other health professionals such as psychologists, dieticians or occupational therapists. The rate of patients being admitted in hospital was slightly lower than reported elsewhere.^{6,7} The proportion of patients in our population reporting use of complementary care was much lower than in the literature.²¹

With respect to the frequency of contacts with care providers per year, patients in our population had a number of outpatient visits to medical specialists and general practitioners comparable to literature, for instance in Canada patients had a mean of 15 and 2 visits per year, respectively.²² Also patients in our population reported contacts with a rheumatologist as often as found in the

literature.²³ Concerning health professionals the patients in our population reported many more contacts than found in the literature, for instance in Canada patients had a mean of two visits per year.²² No data on care at home or day patient care was available for comparison. Comparison of our data with that of other studies is compromised by differences in population, local differences in health insurance and logistics of care. However, patients from Canada included in the Tri-Nation Study Group seem applicable for comparison, because sociodemographic characteristics, scores on SF-36 subscales and collection of data on health care service utilization are quite comparable to our population, therefore data is shown above.

In line with available literature, the HAQ score in our study was found to be significantly associated with health care usage. Functional status is a widely recognized determinant of health care use in SLE patients.^{5,10,11} Also in line with the available literature, in our population, younger age was significantly associated with greater use of health care services, especially medical specialist care.^{4,5,9} This finding could theoretically be related to a more active disease and/or shorter disease duration in younger patients.^{24,25} However, the multivariate analyses were adjusted for disease duration and

Table 3 Characteristics of patients with SLE divided into high and low total health care usage over 12 months

	High 39 patients	Low 63 patients	Univariate Odds Ratio (95% confidence interval)	Multivariate Odds Ratio (95% confidence interval)
Characteristic				
Age, years; mean (SD)	41.9 (±13.9)	46.1 (±13.4)	0.98 (0.95–1.01)	0.95 (0.90–0.99)*
Duration of disease, years; mean (SD)	9.7 (±7.7)	11.0 (±7.2)	0.98 (0.92–1.03)	0.92 (0.84–1.01) ^γ
Female; N (%)	35 (37%)	59 (63%)	0.59 (0.14–2.52)	0.54 (0.06–4.65)
Caucasian origin; N (%)	33 (37%)	57 (63%)	0.46 (0.13–1.63)	
Educational level; N (%)				
Low	7 (44%)	9 (56%)	1.26 (0.38–4.12)	
Medium	15 (33%)	31 (67%)	Reference cat.	
High	16 (42%)	22 (58%)	1.37 (0.57–3.28)	
Paid employment; N (%)	19 (34%)	37 (66%)	0.67 (0.30–1.49)	
Work disability pension; N (%)	14 (44%)	18 (56%)	1.40 (0.60–3.28)	
Living alone; N (%)	8 (42%)	11 (58%)	1.22 (0.44–3.36)	
No. of ACR criteria at time of diagnosis; mean (SD)	4.6 (±0.7)	4.5 (±0.9)	1.24 (0.77–2.02)	
SLEDAI score; mean (SD)	3.0 (±3.5)	1.8 (±2.4)	1.15 (0.99–1.33) ^γ	
Major organ involvement; N (%)	25 (48%)	27 (52%)	2.38 (1.05–5.42)*	3.51 (1.06–11.56)*
Medication; N (%)				
Any medication	38 (40%)	58 (60%)	3.28 (0.37–29.14)	3.02 (1.02–8.93)*
Immunosuppressants (including corticosteroids)	28 (56%)	22 (44%)	4.74 (1.99–11.31) [∞]	
SF-36 Scales (0–100); mean (SD)				
Physical functioning	58.3 (±27.4)	74.8 (±21.5)	0.97 (0.96–0.99) [∞]	1.00 (0.96–1.04)
Role-physical	37.8 (±40.5)	53.6 (±41.7)	0.99 (0.98–1.00) ^γ	
Bodily pain	65.0 (±21.8)	71.0 (±20.0)	0.99 (0.97–1.01)	
General health	34.3 (±18.1)	44.6 (±22.1)	0.98 (0.96–0.97)*	0.98 (0.95–1.01)
Vitality	49.0 (±12.5)	52.6 (±19.0)	0.99 (0.97–1.01)	
Social functioning	62.2 (±21.9)	68.8 (±24.8)	0.99 (0.97–1.01)	
Role-emotional	58.1 (±46.3)	75.7 (±39.4)	0.99 (0.98–1.00)*	0.99 (0.98–1.00) ^γ
Mental health	54.0 (±12.5)	63.5 (±18.9)	0.98 (0.95–1.01)	
Physical component summary	48.9 (±21.3)	60.9 (±20.9)	0.98 (0.96–1.00) ^γ	
Mental component summary	56.3 (±19.5)	63.5 (±18.9)	0.98 (0.96–1.00) ^γ	
Health Assessment Questionnaire score (0–3); mean (SD)	0.72 (±0.70)	0.32 (±0.46)	3.23 (1.55–6.73) [∞]	5.22 (1.00–27.08)*

[∞]*p* < 0.01, **p* < 0.05, ^γ*p* < 0.10.

ACR: American College of Rheumatology, SD: standard deviation, SLE: systemic lupus erythematosus, SLEDAI: Systemic Lupus Erythematosus Disease Activity Index.

clinical variables including disease activity and major organ involvement but age was still significantly associated with health care usage. Major organ involvement is a known and foreseeable determinant for health care usage.⁵ The use of immunosuppressants as a determinant for health care usage was not formerly reported. In the repeated multivariate analysis (entry criterion of variables: *p* < 0.10) SF-36 Role-emotional was also significantly associated with health care usage, emphasizing the importance of emotional functioning as a determinant for health care usage in SLE patients.

This study has 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 under the care of rheumatologists in 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.²² Moreover, the distribution of ACR criteria at diagnosis in our patient population is similar to the ACR 82 cohort.¹² The number of ACR criteria is relatively low because they were counted at the time of diagnosis. Although the proportion of responders was relatively high, it appears that older, female patients with shorter disease duration were over-represented. Secondly, the amount of health care usage is a patient-reported outcome potentially leading to recall-bias. However, in our study the numbers of patient-reported and officially recorded visits to the rheumatologist in the past year were not significantly different. This finding is in line with the literature, where patients' reports were found to be as valid as providers' reports for hospital days and outpatient visits.²⁶

Another limitation is that emergency room visits were not taken into account separately. In case of emergencies related to their disease, patients usually come to the outpatient clinic and not to the emergency room. If emergency room visits had been counted, the rates would most probably be falsely low.

This study demonstrated that SLE patients make considerable use of health care, including all categories of health care services; this use was grossly comparable to other available data. Especially interesting are the substantial contacts with health professionals, not reported formerly. Lower age was the only sociodemographic variable that determined health care usage. This needs further investigation to show if there is underuse of health care in the elderly, overuse in young patients or if this difference is explained by factors related to the disease that were not accounted for in this study.

The great number of health care services involved in the care of an SLE patient has led to confusing situations³ and possibly overlap in actions. Frequent visits to health care facilities to meet with several care providers individually, may raise practical concerns and a higher disease burden for the patient. On the other hand in recent studies there are unmet needs in SLE patients.^{27,28} Therefore, it seems plausible that the extensive and complicated use of health care in SLE patients can be improved in the nearby future.

Improvements should involve patient's wishes and medical needs combined in modalities of health care services that are most financially efficient.^{29,30} This could best be done in specialized hospitals with physicians who can build experience with this complicated disease.^{31,32} Probably experience with SLE patients also improves quality in allied health care, which proved to play an important role in this population. Clarke demonstrated earlier that higher costs do not necessarily lead to better health outcomes.³³ Although the opposite, worse outcome in a managed care system trying to reduce costs, was experienced in Puerto Rico.³⁴ A future challenge lies in investigating unmet needs, satisfaction with care and health outcomes related to care in SLE patients and developing a cost efficient, multidisciplinary approach to coordinate care for SLE patients of all ages.

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Conflict of interest statement

None declared.

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